

**“At the end of the day we're kind of motoring along on our own”:**

**Investigating the views of people with aphasia, their family, and speech and language therapists on the need, value, and challenges of providing family therapy after stroke.**

Jessica Tessa Henihan

A thesis submitted to Trinity College Dublin, the University of Dublin in fulfilment of the requirements for the degree of

Master of Science by Research

2024

## Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and it is entirely my own work.

I agree to deposit this thesis in the University's open access institutional repository or allow the Library to do so on my behalf, subject to Irish Copyright Legislation and Trinity College Library conditions of use and acknowledgement.

I consent to the examiner retaining a copy of the thesis beyond the examining period, should they so wish (EU GDPR May 2018).

Signed:



---

Jessica Tessa Henihan

## Summary

Stroke significantly impacts the lives of both the person who sustained the stroke and their entire family unit (Dawes et al., 2022), often profoundly changing the roles and dynamics within families (Klonoff, 2014). Where communication disabilities, such as aphasia, occur as a result of stroke the changes within a family are exacerbated (Kitzmüller et al., 2012), with both people with aphasia (PwA) and their families experiencing social isolation, loneliness, and depression (Kauhanen et al., 2000; Kutlubaev & Hackett, 2014). When compared to families of stroke survivors who do not have aphasia, families with aphasia experience a significantly higher burden of care and will experience more negative stroke related outcomes (Bakas et al., 2006). Although family therapy can help to address the changes and support family members during the readjustment process, there is a lack of research on the use of family therapy when one person has aphasia (Henihan et al., 2024). The unique challenges that aphasia causes, may necessitate the involvement of speech and language therapists (SLTs) in the provision of family therapy for people with aphasia and their family, but there is a dearth of research on how SLTs support families of PwA to negotiate role changes in the family.

This study aimed to address the following question: What are the experiences and perceptions of PwA, their family members and SLTs on the need, value, and challenges of providing family therapy in contexts where one member of the family has aphasia? This research was of a qualitative design utilising an exploratory-experiential approach, applying reflexive thematic analysis (Braun & Clarke, 2021b) to systematically code data and create themes, in order to explore patterns across the data from multiple stakeholder perspectives. Eight individual interviews were conducted with PwA and their

family members. Two focus group discussions were held with seven SLTs. Data was collected using semi-structured in-depth communication-supported interviews with PwA and their family members to understand the perception and experiences of participants who are personally invested in this topic, providing rich and detailed responses (Braun & Clarke, 2013). Focus groups were utilised for SLTs as they allowed rich information to be obtained around the views of SLTs and identify where and why participants agree or disagree with certain issues in this area (Goodman & Evans, 2015).

Five themes were generated through the analysis process: (1) That's it. You're on your own; (2) Psychosocial challenges faced by PwA – diverse solutions for a diverse disability; (3) The cautious boundaries of SLTs working with families; (4) Doing my best and imagining what's possible: SLT roles in family therapy; and (5) "There is just so much going on" - The luxury of time and timing. Theme 1 focuses on the intense period of change that occurs after stroke, especially when people are discharged from acute care. Theme 2 centres on some of the reasons why there are limited supports available to families where one person has aphasia. Theme 3 highlights the perspective of SLTs and their role in supporting PwA and their families after stroke. Theme 4 identifies the resources SLTs need to support PwA and their families to negotiate familial changes. Theme 5 represents how both families and SLTs lack the time to support changes in familial relationships and identified when might be the 'right time' for family therapy to occur, and in what context.

This study provides evidence that there is a need for accessible family therapy services for PwA and their families after stroke. Systemic change is needed within the healthcare system to address the lack of support for these families. Better coordination

and integration between healthcare services in the context of family therapy could provide an opportunity for joint working between SLTs and family therapists.

## **Acknowledgements**

I would like to sincerely thank my research supervisor, Dr. Caroline Jagoe, who provided invaluable advice, guidance, and support at each stage of this project. I am immensely grateful for your encouragement to undertake this research and for taking me on as your student for a second time!

I cannot begin to express my thanks to all of the participants in this study who gave their time, energy, and support to this research. I want to express my gratitude in particular to the families who participated in this study. It was a privilege to listen to your stories and share my own experiences with you all. It is my deepest hope that the findings of this thesis contribute positively in some way to supporting families who experience stroke and aphasia in the future.

I would like to dedicate this work to my parents, Rebecca and Rory. Our lived experience of stroke and aphasia has been the entire motivation to undertake this research. Without your words of encouragement, love, reassurance, and support this project would not have been possible. Lastly, I would like to thank Oscar, my dog, who has provided unconditional love and cuddles every step of the way.

## Table of Contents

Declaration .....	ii
Summary.....	iii
Acknowledgements .....	vi
Table of Contents .....	vii
List of Tables .....	x
List of Figures.....	xi
List of Appendices.....	xii
List of Abbreviations.....	xiii

### Section 1: Literature Review

Chapter 1. The impact of stroke and aphasia on the family system .....	2
1.1 Family functioning and the centrality of communication processes .....	3
1.2 Family functioning following stroke .....	4
1.3 Aphasia .....	5
1.3.1 Impact of aphasia on the person with aphasia and their participation in family life .....	6
1.4 Impact of aphasia on the family .....	9
1.4.1 Relationship changes between the PwA and their significant other .....	10
1.4.2 Parenting and aphasia .....	14
1.4.3 Impact of aphasia on children within the family unit .....	16
1.4.4 Lack of support from healthcare providers to address family dynamics after stroke-related aphasia.....	18
1.5 Living successfully with aphasia as a family .....	18
1.6 Role of speech and language therapists in providing holistic support to PwA .....	20
1.7 Clinical guidelines and policies for stroke rehabilitation in Ireland .....	21
Chapter 2. Family Therapy .....	23
2.1 An overview of family therapy .....	23
2.2 Family therapy after stroke .....	24
2.2.1 Family therapy .....	25
2.2.2 Family therapy adapted for people with acquired brain injury .....	25
2.2.3 Psychoeducation .....	26
2.2.4 Psychosocial therapy .....	26
2.2.5 Inclusion of people with communication disabilities in family therapy research ...	26
2.2.6 Professionals involved in delivering family therapy.....	27
2.3 Situating the thesis and research question .....	28

## **Section 2: Methodology**

Chapter 3. Methodology .....	31
3.1 Research design .....	31
3.1.1 The 'Big Q' qualitative framework .....	32
3.1.2 Constructivist ontology and subjectivist epistemology .....	32
3.1.3 Phenomenological hermeneutic approach .....	34
3.1.4 Reflexive thematic analysis and its credibility .....	34
3.1.5 Positionality statement .....	36
3.2 Ethical considerations .....	37
3.2.1 Recruitment and consent of PwA and family members .....	38
3.2.2 Speech and Language Therapists .....	41
3.2.3 Family Therapists .....	42
3.2.4 Sample Size .....	42
3.2.5 Participant characteristics .....	43
3.3 Data collection tools and processes .....	46
3.3.1 PwA and family members .....	47
3.3.2 Speech and Language Therapists .....	50
3.3.3 Family Therapists .....	51
3.3.4 Recording and transcription of interviews and focus groups .....	51
3.4 Analysis .....	52
3.4.1 Familiarisation .....	55
3.4.2 Data coding .....	56
3.4.3 Generating initial themes .....	57
3.4.4 Developing and reviewing themes .....	58
3.4.5 Refining, defining, and naming themes .....	59
3.4.6 Write up .....	60
3.5 Summary .....	60

## **Section 3: Findings**

Chapter 4. Findings .....	62
4.1 Introduction .....	62
4.2 Overview of themes .....	62
4.3 Theme 1: That's it. You're on your own. ....	65
4.3.1 Aphasia - it's a shock to the family system .....	66
4.3.2 Reality and isolation set in at home.....	71
4.3.3 We needed help, but it wasn't there .....	74



4.4 Theme 2: Psychosocial challenges faced by PwA – diverse solutions for a diverse disability. ....	76
4.4.1 Help can come in all shapes and sizes.....	78
4.4.2 Aphasia excluding people from services: “his own little pigeonhole” .....	81
4.4.3 The needs of PwA are “just so individual” .....	88
4.4.4 Family therapy – helping everyone get “on the same page at the same time” .....	90
4.5 Theme 3: The cautious boundaries of SLTs working with families .....	93
4.5.1 Working with families are SLTs’ bread and butter .....	95
4.5.2 "Cautiousness about opening up all that emotion" .....	98
4.6 Theme 4: Doing my best and imagining what’s possible: SLT roles in family therapy... ..	101
4.6.1 SLTs want to know more to help more .....	102
4.6.2 It takes two professionals to tango .....	104
4.7 Theme 5: “There is just so much going on” - The luxury of time and timing.....	107
4.7.1 Time is a luxury that is dependent on the setting.....	109
4.7.2 Families are already juggling so much.....	110
4.7.3 The timing of family therapy should be made “on a case-by-case basis” .....	112
4.8 Summary of findings.....	116
<b>Section 4: Discussion</b>	
Chapter 5. Situating the findings in the context of existing research .....	120
5.1 Summary of findings.....	120
5.2 The needs of families after stroke.....	122
5.3 The value of receiving familial support after stroke .....	126
5.4 Challenges of providing family therapy.....	130
5.4.1 Misconceptions of healthcare professionals and counselling services about PwA.....	130
5.4.2 Family therapists may lack the skills to support PwA .....	131
5.4.3 Lack of clarity/Skill development around the role of SLT in family therapy .....	132
5.4.4 Responding to challenges: What is the role of SLTs in family therapy?.....	138
Chapter 6. Towards accessible family therapy in Ireland .....	141
6.1 Limitations .....	141
6.2 Towards accessible family therapy in Ireland: Suggestions for future research.....	142
6.3 Final thoughts.....	143
References.....	145
Appendices .....	172

### **List of Tables**

Table 1	Inclusion and exclusion criteria for in-depth supported interviews of PwA	p. 39
Table 2	Inclusion and exclusion criteria for in-depth supported interviews of family members of PwA	p. 39
Table 3	Inclusion and exclusion criteria for focus group with SLTs	p. 41
Table 4	Inclusion and exclusion criteria for focus group with family therapists	p. 42
Table 5	Participant characteristics of PwA	p. 45
Table 6	Participant characteristics of family members	p. 46
Table 7	Participant characteristics of SLTs	p. 47
Table 8	Components of the interview guide for data collection with PwA and their family	p. 49
Table 9	Focus group discussion guide used with SLTs	p. 52
Table 10	Excerpts from my reflexive journal	p. 55

## List of Figures

Figure 1	The wall question from the Assessment for Living with Aphasia (Kagan et al., 2013)	p. 44
Figure 2	Diagram of the iterative process of thematic analysis based on Braun and Clarke (2006; 2021b)	p. 53
Figure 3	Example of codes generated in Quirkos	p. 57
Figure 4	Overview of developing themes on paper	p. 59
Figure 5	Overview of themes and subthemes	p. 64
Figure 6	Overview of subthemes under main theme: That's it. You're on your own.	p. 65
Figure 7	Overview of subthemes under main theme: Psychosocial challenges faced by PwA – diverse solutions for a diverse disability.	p. 77
Figure 8	Overview of subthemes under main theme: The cautious boundaries of SLTs working with families.	p. 94
Figure 9	Overview of subthemes under main theme: Doing my best and imagining what's possible: SLT roles in family therapy.	p. 102
Figure 10	Overview of subthemes under main theme: "There is just so much going on" - The luxury of time and timing	p. 108

## List of Appendices

<b>Appendix A</b>	A1 - Initial ethical approval letter	p. 172
	A2 - Ethical approval letter after amendments	p. 173
<b>Appendix B</b>	B1 - Aphasia friendly letter	p. 174
	B2 - Participant information leaflet for people with aphasia	p. 175
	B3 - Participant information leaflet for adult family members	p. 182
	B4 - Participant information leaflet for children under 18 years of age.	p. 187
<b>Appendix C</b>	C1 - Consent form for people with aphasia	p. 193
	C2 - Consent form for adult family members	p. 194
	C3 - Parental consent form for family members under the age of 18	p. 196
	C4 - Assent form for family members under the age of 18	p. 198
<b>Appendix D</b>	D1 – Participant letter for SLTs	p. 199
	D2 – Participant information leaflet for SLTs	p. 200
<b>Appendix E</b>	E1 – Participant letter to Family Therapists	p. 205
	E2 – Participant information leaflet for Family Therapists	p. 206
<b>Appendix F</b>	F1 - Sample picture supports	p. 211
	F2 - Interview guide for people with aphasia	p. 212
	F3 - Interview guide for adult family members	p. 213
	F4 - Interview guide for family members under 18 years of age	p. 214
<b>Appendix G</b>	G1 - Focus group topic guide for SLTs	p. 215
	G2 - Focus group topic guide for family therapists	p. 216
<b>Appendix H</b>	H1 – Interview with Alan, man with aphasia	p. 218
	H2 – Interview with Debora, wife of PwA	p. 241
	H3 – SLT Focus Group 2	p. 269

## List of Abbreviations

ALA	Assessment for Living with Aphasia
CPT	Communication Partner Training
ESD	Early Supported Discharge
FTAI	Family Therapy Association of Ireland
GDPR	General Data Protection Regulations
IASLT	Irish Association of Speech and Language Therapists
ICP	Irish Council for Psychotherapy
PIL	Participant information leaflet
PwA	Person with Aphasia
SEA	Supporting Emotions with Aphasia
SFBT	Solution Focused Brief Therapy
SLT	Speech and Language Therapist



## **Section 1: Literature Review**

## **Chapter 1. The impact of stroke and aphasia on the family system**

Stroke significantly impacts the lives of both the person who sustained the stroke and their entire family unit (Dawes et al., 2022), often profoundly changing the roles and dynamics within families (Klonoff, 2014). Where communication disabilities, such as aphasia, occur as a result of stroke the changes within a family are exacerbated (Kitzmüller et al., 2012).

The suddenness of stroke, in addition to the communication disabilities prevalent in this population, significantly alters family dynamics. However, there is a lack of research on how best to ameliorate this disruption or whether family therapy may be beneficial and if so, how best it could be provided. The small amount of research which has been conducted on family therapy in cases of acquired brain injury has mostly excluded people with communication disabilities (Henihan et al., 2024). Furthermore, there has been no exploration to my knowledge, on the needs of families where one person has aphasia and how to negotiate changes within the family as a result of aphasia. Additionally, the role of speech and language therapists (SLTs) in supporting the negotiation of familial roles has not received attention, based on a recent scoping review of the literature published in English (Henihan et al., 2024). There is little research to guide practice in this area, including in an Irish context where the introduction of Sláintecare<sup>1</sup> provides an opportunity to reimagine services.

This chapter will begin by considering the nature of family functioning. Secondly, the aetiology and impact of stroke is outlined. Thirdly, the impact of aphasia on the

---

<sup>1</sup> Sláintecare is a proposed reform of the healthcare system of Ireland. The aim of this policy is to provide timely and accessible universal healthcare services to every Irish citizen.



person with aphasia (PwA), spouses, and children is discussed, followed by consideration of the role of SLTs in providing psychosocial support to families where one person has aphasia. Finally, I have provided an overview of national policies which impact the provision of stroke care in acute and rehabilitation settings in Ireland.

### **1.1 Family functioning and the centrality of communication processes**

Family life is created and maintained through the provision of care, assistance, socialisation and maintenance of relationships with each member within the unit (Galvin et al., 2015). Each person has a unique role and hierarchical place within the family, with each member relying on one another to carry out their role to maintain a state of equilibrium (Larøi, 2003). When the equilibrium is disrupted, and roles within the family are altered, a shift in the dynamics of a family can occur, throwing the family into a state of dysfunction (Walker & Akister, 2004).

Communication is at the core of family life and healthy family functioning is based on the successful communication of roles, responsibilities, requests, and emotions (Olson & Gorall, 2003). Communication, with a high demand on spoken language, forms the foundations of relationships between family members allowing for collaboration within the family to resolve potential problems (Boxer, 2002; Kagan, 1995; Pound et al., 2018; Simmons-Mackie & Damico, 1995). The hierarchical structure of family is dependent on effective communication processes within the family system (Olson, 2000). For example, when children are present within the family system, there is asymmetrical authority with the parent assuming a higher level of authority in parent-child interactions (Killmer, 2023). In this instance, parenting is based on successfully communicating the rules associated with the foundational structures to their children.

Using their superior linguistic repertoire (Kent, 2012), parents must negotiate and deal with the resistance by children of parental requests through counterarguments (Goodwin, 2006). An inability to access the linguistic skills to negotiate with children changes the power dynamics in the parent-child relationship (Killmer, 2023). When communication within the family is disrupted, such as when one member of the family has aphasia, family functioning can be thrown into disarray with catastrophic consequences (Berg et al., 2020).

## **1.2 Family functioning following stroke**

When one member of a family experiences the sudden onset of disability or illness, family dynamics can be dramatically affected (Golics et al., 2013). Stroke, or cerebrovascular accident is one cause of sudden disability – a sudden loss of oxygen in brain cells due to a blockage or rupture of an artery which results in damage to that area of the brain and usually an acquired disability and chronic health conditions (Phipps & Cronin, 2020).

Stroke can substantially affect family dynamics with significant shifts in family roles and relationships (Galvin et al., 2015), impacting both immediate and extended family members, with significant consequences for the emotional and mental health of the family (Carnes & Quinn, 2005). Substantial shifts in family roles and relationships have been described as one of the most traumatic consequences of stroke (McDermott & McDonnell, 2014), although only a limited number of studies in the existing literature have attended to the unique challenges faced where the person experiences post-stroke aphasia. Consequently, a few seminal studies in this area have been drawn upon to

provide an overview of the prominent issues families where one person has aphasia face.

Currently, the number of people living with the effects of stroke is estimated to be 101 million people worldwide, with working age adults (people between 18-65 years of age) representing nearly 25% of the stroke population (Feigin et al., 2022). In Ireland, stroke is the largest cause of acquired disability with 30,000 people living with the effects of stroke. Every year, approximately 6000 people will have a stroke, with 25% of these occurring in working age adults (National Office of Clinical Audit, 2020). The effects of stroke can include substantial changes in a person's cognition, motor and sensory abilities, and communication. Communication disabilities are common after stroke and include aphasia, dysarthria, and cognitive communication difficulties (Rispoli et al., 2010). Aphasia, the communication disability which this thesis focuses on, affects approximately 30% of the stroke population (Flowers et al., 2016). Changes within familial roles after stroke is widely reported across the literature with aphasia causing significant and life altering changes to the family (Nätterlund, 2010).

### **1.3 Aphasia**

An international consensus study provided a definition of aphasia as follows (Berg et al., 2020, p.391):

*Aphasia is a communication disability due to an acquired impairment of language modalities caused by focal brain damage. Aphasia may affect participation and quality of life of the person with aphasia as well as their family and friends. Aphasia masks competence and affects functioning across relationships, life roles and activities, thereby influencing social inclusion, social connectedness, access to*

*information and services, equal rights, and wellbeing in family, community and culture.*

This consensus study deliberately expanded the definition to emphasise and encompass the wide-ranging communicative consequences that aphasia causes (Berg et al., 2020). However, aphasia affects both PwA and their family members, with families experiencing social isolation, loneliness, and depression (Kauhanen et al., 2000; Kutlubaev & Hackett, 2014). Aphasia not only impacts the individuals within a family unit, but also their relationships - significant disruption to roles within the existing family unit and changed dynamics within the family have been documented, with such changes making it difficult to come to terms with a new reality (Kitzmüller et al., 2012). Third-party disability is defined as the impact that a chronic health condition such as aphasia has on all members of the family unit (World Health Organization, 2001), and this concept has been applied to aphasia, in recognition that aphasia affects the entire family unit (Grawburg et al., 2013).

Healthy family functioning is reliant on the successful two-way nature of communication but within the context of a communication disability such as aphasia, this may not be possible, with psychosocial factors considerably impacting both the person with a communication disability and their significant other (Code et al., 1999; Code & Herrmann, 2003). Given that family functioning is based on the negotiation of roles and relationships through communication, aphasia impacts how the family 'works' as a unit. The impact is a complex interplay between the effect of aphasia on the individual themselves, and their interaction with family members. Understanding the

impact of aphasia on the PwA is therefore important to understanding the disruption to the family unit.

### **1.3.1 Impact of aphasia on the person with aphasia and their participation in family life**

Aphasia produces distinct psychosocial barriers which are frequently not experienced in the same way as stroke survivors without aphasia (Hilari, 2011; Northcott et al., 2015). Kutlubaev & Hackett (2014), have demonstrated the deleterious impact of communication disability on the lives of PwA, identifying aphasia as a prominent factor in the development of post stroke depression, with the incidence of depression in PwA one-year post-stroke estimated to be roughly 60% (Kauhanen et al., 2000). While there is no clear research demonstrating an association between aphasia subtype and psychological outcomes, research has demonstrated that aphasia severity correlates with an increase in depression in PwA (Zanella, et al., 2023). In addition to depression, PwA often experience social isolation (Kutlubaev & Hackett, 2014), anxiety (Morris et al., 2017), and adjustments in how they view their identity (Shadden & Agan, 2004). In a study conducted by Hilari (2011), on the presence of psychological distress three months post stroke, a significantly higher amount of PwA (93%) presented with distress when compared to participants who did not have aphasia (50%) (Hilari, 2011), with psychological distress often persisting for at least 6 months post-stroke (Thomas & Lincoln, 2008). The communication changes that aphasia causes are often one of the main stressors for PwA, with this population more likely to experience higher levels of cortisol during linguistic tasks when compared to participants without aphasia (Laures-Gore & Buchanan, 2015) – levels of stress which are likely therefore also experienced

during the 'linguistic task' of conversation. The mental health difficulties experienced by stroke survivors has been found to increase the distress levels within the family and worsen family functioning (Carnes & Quinn, 2005).

A study conducted by Fotiadou et al. (2014) which examined blogs written by PwA reported that PwA identified and expressed changes within the dynamics of their family, and described how these changes occurred as a direct consequence of their stroke and aphasia. The changes that PwA experience within their family include a loss of autonomy and independence, change in identity, changes in roles within the family, and inability to participate in family activities (Dowswell et al., 2000; Manning et al., 2021; Parr et al., 1997). Furthermore, changes in parental roles for the parent with aphasia caused diminished parent-child interactions (Fotiadou et al., 2014). With regards to financial roles within a family, the loss of jobs or the inability to return to work as a direct result of aphasia exacerbated feelings of dependence on others (Manning et al., 2021) while also putting a strain on other family members to take on the financial burden (Nätterlund, 2010). Family members of PwA described the impact of aphasia on their family member with aphasia emphasising how the PwA had become dejected, unhappy, and resentful, and found living with aphasia overwhelming. Additionally, relatives identified that PwA became reclusive, socially isolated and ultimately depressed as a result of being unable to keep up with conversations going on around them (Nätterlund, 2010). While all of these studies indicate that changes in family dynamics occur when one person has aphasia, there is a specific lack of research on how families can be supported to navigate these changes.

PwA often identify their own goals around the importance of maintaining family relationships (Worrall et al., 2011), with partners of PwA wanting to be actively involved in aphasia rehabilitation (Howe et al., 2012). Goals most closely aligned to family functioning that were identified by PwA and their spouses include: (1) being able to effectively communicate to maintain their relationships (both with their partners and with extended family) (Howe et al., 2012; Worrall et al., 2011); (2) cope with new responsibilities (Howe et al., 2012); and (3) provision of information about aphasia to family to support their understanding of aphasia (Howe et al., 2012). These goals signal the importance of addressing family functioning after stroke.

#### **1.4 Impact of aphasia on the family**

Regardless of the severity of aphasia, its impact on quality of life is felt by the entire family unit (Cavanaugh & Haley, 2020). The sudden onset of an acquired communication disability causes substantial changes within familial roles and relationships, impacting the mental well-being of the entire family (Cumming et al., 2008; Hinckley, 2006; Dorze & Brassard, 1995; Parr et al., 1997). Significant distress related to loss of roles and independence is experienced by all family members (Ch'Ng et al., 2008; Dowswell et al., 2000). These disruptions are a direct result of acquired communication disabilities, as the nature of communication disabilities impacts a family's ability to have discussions about the negotiation of roles or shifts in the family dynamics (Parr et al., 1997). The changes within the family system are immediately apparent upon returning home from acute or rehabilitation services with significant deterioration within the family function noted in several studies (Clark & Smith, 1999; Dowswell et al., 2000; King et al., 2002). Partners of PwA often express feelings of

frustration, irritation, loneliness, and sadness, and are at high risk for developing depression themselves (Grawburg et al., 2013).

Aphasia has an immediate effect on family relatives through their relationships, daily interactions and common environment with the person with the communication disability (Grawburg et al., 2014). An increase in life demands experienced by family members has been documented, with PWA often becoming more dependent on the family (Grawburg et al., 2014), requiring each member of the family to take on new responsibilities (Kitzmüller et al., 2012). Such responsibilities may include relatives taking on a substantial amount of tasks such as supporting the PWA to communicate in different daily activities (Gillespie & Murphy, 2010; Le Dorze & Signori, 2010), and providing care to family members in the context of dramatic changes to their relationship with the PWA (Bakas et al., 2006; Le Dorze & Signori, 2010). When compared to families of stroke survivors who do not have aphasia, families with aphasia experience a significantly higher burden of care and will experience more negative stroke related outcomes (Bakas et al., 2006). Aphasia not only changes the relationships between the PWA and their family members, but it also changes family members' relationships with each other and the wider community (Grawburg et al., 2014). Consequently, families have to find a new way of being, often without the support of healthcare providers (Nätterlund, 2010).

#### **1.4.1 Relationship changes between the PWA and their significant other**

Changes in a family member's role in the family has a particular impact when the PWA is a significant other, such as a spouse or life partner (Nätterlund, 2010; Winkler et al., 2014). In marital or long-term relationships between a PWA and their partner, there is often a struggle for the PWA to maintain their autonomy in the relationship while also



receiving emotional and physical care from their partner. This loss of independence may cause PwA to become irritable and angry at the lack of equality in the relationship (Kitzmüller et al., 2012). Traditional roles between the PwA and their significant other have been documented to shift after stroke. In a study by Winkler et al (2014), domestic roles that were usually carried out by the PwA before stroke were now taken on by their partner (Winkler et al., 2014) such as making meals, cleaning, gardening, DIY and shopping (Grawburg et al., 2014). In addition to domestic tasks, significant others also had to take on caring tasks such as supporting PwA to complete activities of daily living, managing appointments, and helping the PwA practice and carry out therapy 'homework' (Winkler et al., 2014). Financially, major changes to household income are common in families after stroke for a number of reasons. Firstly, PwA are often unable to return to work after stroke (Graham et al., 2011) and when the PwA was the primary earner within the family, the effects of reduced income are further exacerbated. Secondly, the significant other of the PwA may need to reduce their working hours in order to carry out caregiving duties to the PwA, further reducing the household income. Additionally, significant others often report diminished personal spending to cover the associated costs of aphasia (Grawburg et al., 2014). In some cases, the loss of finance impacts on families so greatly that they need to move house (Nätterlund, 2010). PwA often reported feelings of shame in being unable to provide for their family (Kitzmüller et al., 2012). When PwA were able to continue working, their job often left them exhausted and occasionally caused health problems (Nätterlund, 2010). Consequently, they were unable to parent their children or carry out household tasks, personal leisure activities, and rehabilitation therapy. Family members often describe pressure to be employed and contribute financially while also spending time and providing emotional

support to other members of the family including the PwA and children (Nätterlund, 2010). This frequently leads to the significant other becoming socially isolated, exhausted (Manders et al., 2011), experiencing loneliness, and feeling emotionally unsupported (Nätterlund, 2010).

Regarding the health of family members who primarily care for the PwA, caregivers often describe health related problems such as anxiety, mental health difficulties, depression, hypertension (Grawburg et al., 2014), loneliness, and isolation (Winkler et al., 2014). Relatives of the PwA also experience a range of cognitive difficulties including impaired memory, exhaustion, fatigue, stress, burnout, and emotional lability (Winkler et al., 2014). These symptoms are attributed to experiencing overwhelming stress and pressure from changes that transpire because of aphasia. Consequently, these changes and the resulting symptoms lead to family members not having sufficient time or energy to participate in personal or recreational activities causing tensions to arise between PwA and their family (Grawburg et al., 2014).

Spouses often experience feelings of grief, specifically grieving for the loss of the way their partner was before their stroke (Winkler et al., 2014). Emotional and physical intimacy declines after stroke because traditional roles where both partners are 'equal' within the relationship significantly change, with one person becoming the carer and the other becoming the receiver of care (Waterhouse & Metcalfe, 1991). This decline in emotional and physical intimacy greatly affects relationship satisfaction levels (Grenier-Genest et al., 2017; Palmer & Palmer, 2011). Partners of PwA report a multitude of changes in communication between them and their partner including changes to the manor and content of the communication, a decline in conversational abilities, and

partners having to make decisions on behalf of the PwA which causes tension within their relationship (Grawburg et al., 2014; Hemsley et al., 2013; Howe et al., 2012).

Significant others of PwA miss both the physical and emotional intimacy in their relationship, identifying how aphasia impacts their ability to have in-depth conversations to increase emotional intimacy (Lemieux et al., 2001). Partners miss the emotional support that they used to receive from the PwA – especially feeling listened to and heard during conversations (Winkler et al., 2014). While PwA and their partners want to experience a reconnection within the relationship through emotional and physical intimacy, aphasia acutely impacts the ability to reconnect, as communication plays a key role in regaining intimacy within the relationship (Grenier-Genest et al., 2017; Palmer & Palmer, 2011; Pierce & Summers, 2015; Steinke et al., 2013). Furthermore, spouses take on a new role of emotionally supporting the PwA through motivating and reassuring them and demonstrating empathy (Winkler et al., 2014). In cases where PwA require emotional support, the emotional loneliness of the family member providing the support is deepened (Nätterlund, 2010). Significant others of PwA often use communication techniques to support their conversation with their partner with aphasia and with other people both within and outside the family (Nätterlund, 2010). Partners frequently describe that continuously supporting conversations is an exhausting task which can lead to communication breakdowns, tension, and negative feelings between the communication partner and the PwA (Winkler et al., 2014). Some family members describe a lack of energy to support conversations all the time, in addition to working and completing household chores (Nätterlund, 2010). These negative effects of aphasia on the carer results in a lack of time to spend with family members (Bakas et al., 2006).

Moreover, role changes in the relationships are not addressed by healthcare providers, worsening frustration within the relationship (Boles, 2006).

Lower levels of relationship satisfaction have been described by PwA and their partners (Łapkiewicz et al., 2008; Williams, 1993). Within the area of activity and participation in the international classification of functioning framework, carers of PwA report that their partner's loss of communicative effectiveness and efficiency results in an inability to continue participating in shared social activities and also results in a loss of friends within their social network (Grawburg et al., 2013a; Howe et al., 2012; Kitzmüller et al., 2012). When couples want to do an activity together, it has to be planned in advance of the event, removing spontaneity from the equation in the relationship, with both PwA and their partners lamenting this change (Kitzmüller et al., 2012). In one study, stroke survivors reported that romantic relationships lasting less than five years ended by the first anniversary of the stroke with disability cited as the main reason for the cessation of the relationship. When probed further about why the relationship ended, stroke survivors described how some partners were unable to accept role changes and were unsupportive of their partner during rehabilitation. The ending of relationships caused stroke survivors to feel abandoned and further isolated which worsened their mental health (Kitzmüller et al., 2012).

#### **1.4.2 Parenting and aphasia**

PwA regularly experience alterations to their role as a parent, with several studies identifying the role of parenting as heavily reliant on successful parent-child communication (Cava et al., 2014; Levin et al., 2012; Romero-Abrio et al., 2019). Successful parent-child communication throughout life is linked to enhanced life satisfaction and mental wellbeing for the entire family unit (Levin et al., 2012) and

therefore disruptions to this relationship are significant, and warrant attention in a population where parent-child communication is at risk.

In one study by Kitzmüller et al. (2012), stroke survivors and their partners recounted that both the acute and rehabilitation stages of stroke recovery took up a huge amount of their time and energy, leaving them exhausted by the time they returned home. With the limited free time that parents did have at home, they were often too tired to spend time with their children and fulfil their parenting obligations. Consequently, parents often experienced feelings of guilt, regretted not being present for their children, and were unable to meet their children's social and emotional needs (Kitzmüller et al., 2012).

When aphasia was present, family members expressed concern with how their children would react to one parent having aphasia (Nätterlund, 2010). Parents with aphasia have described a role reversal when parenting younger children. In this case, their child takes on the role of 'parent', for example through the child telling the parent with aphasia what to do instead of the parent guiding the child. These alterations in roles are further exacerbated by the PwA struggling to reassert their role due to the communication demands exceeding capacity (Manning et al., 2021). Furthermore, in families where one person had aphasia, the parent without aphasia frequently took on a sole parent role, further exacerbating the exhaustion and tensions in the family dynamic (Kitzmüller et al., 2012).

As children progress through the developmental stages, so do the communicative demands they place on parents, which can overwhelm the PwA (Parr, 2001). Ultimately, children start to seek support solely from the other parent, further

straining the relationship with the parent with aphasia (Fotiadou et al., 2014), with PwA feeling a loss of their 'parental' identity (Parr, 2001). Frequently, PwA identified being unable to regain their role as a parent (Fotiadou et al., 2014; Matos et al., 2014; Parr, 2001).

#### **1.4.3 Impact of aphasia on children within the family unit**

Children of parents who have had a stroke have expressed heightened feelings of grief and loss, with one study reporting that children are at risk of suffering from mental health difficulties (Charles et al., 2007). A study conducted on children of stroke survivors aged 4-18 years found that 54% experienced behavioural problems within the first year after stroke. After one year, this rate dropped to 29%. Behavioural problems were found to be caused by depression and the child's concern about the marital relationship (Visser-Meily et al., 2005). In the acute stages of stroke, children describe feelings of fear and worry that their parent might die. In the rehabilitation stages and when the parent returned home, some children were witness to their parent going through a medical emergency such as seizures (Kitzmüller et al., 2012).

Some children have been documented to take on new self-imposed roles or responsibilities while others were forced to take on new tasks within the family such as carrying out household duties or minding siblings (Charles et al., 2007), resulting in a lack of freedom and perfectionism in carrying out new tasks. Consequently, children identify feelings of loneliness and isolation with a lack of support from family or friends causing tension between the child and their parents (Kitzmüller et al., 2012). Children try to resolve conflicts between their parents by caring for the disabled parent in an attempt to ease the burden on the other parent (Kitzmüller et al., 2012). Parents describe how

disability and changes resulting from the disability are not openly talked about within the family, with children echoing the same observations. Children express the need to discuss these changes, but do not feel like they can with their family members, and express a desire to talk to someone outside the family such as a healthcare professional (Kitzmüller et al., 2012). Similar findings were also described in a case study on the narratives of a single mother with aphasia and close family. The PwA's child felt he was unable to discuss his concerns around the impact of aphasia with any close relative and while outwardly appearing fine, he was struggling with coming to terms with the change in his mother (Barrow, 2008).

Aphasia can act as a substantial barrier between children and their parents, with parents with aphasia finding it difficult to communicate love and affection to their children (Kitzmüller et al., 2012). Furthermore, some children find it difficult to come to terms with or accept the communication changes that occur when one parent has aphasia, with rifts appearing in the parent-child relationship. Consequently, children can withdraw from the relationship with their parent, with some children leaving home as soon as legally allowed, much to the dismay of their parent (Kitzmüller et al., 2012). Conversely, some relationships between other family members, such as siblings, are seen to have strengthened, with aphasia bringing family members together (Grawburg et al., 2014).

Regardless of the age of a child, when a parent has a stroke and acquires aphasia, their relationship with that person can change significantly. Hallé et al., (2011), conducted a study on the relationship between adult children and their parent with aphasia, with aphasia affecting every part of their relationship and significant changes in

familial roles occurring (Hallé et al., 2011). Similarly, PwA are often unable to participate in significant life events with their adult children (Parr, 2001). There is huge importance in maintaining the roles of a PwA within their family, with the maintenance of parental roles allowing the PwA to live successfully with aphasia (Brown et al., 2010).

#### **1.4.4 Lack of support from healthcare providers to address family dynamics after stroke-related aphasia**

A fundamental insufficiency and inconsistency of support services after stroke has resulted in families being unequipped to come to terms with changes in the family dynamic after stroke (Dawes et al., 2022; Nyström, 2011). Research shows that both PwA and their partners agree that aphasia is experienced as the ‘worst’ disability after stroke, with aphasia causing feelings of grief and anger when communication breaks down (Kitzmüller et al., 2012). Partners of PwA feel isolated in their grief with no support from healthcare providers on how to deal with communication breakdowns within the relationship (Kitzmüller et al., 2012). Families have stressed that emotional support for families should be a fundamental part of services offered principally in the first-year post stroke (Bellon et al., 2015). There is a notable gap in literature pertaining to interventions to address family dynamics when one member has aphasia, and the literature on family-related needs is also minimal in comparison to that addressing the impact of aphasia on individuals.

#### **1.5 Living successfully with aphasia as a family**

In research conducted by Kitzmüller et al. (2012), healthy family relationships were valued as a crucial component in living successfully with aphasia. PwA described their gratitude to their spouses for supporting them through the acute and rehabilitative



stages of stroke, ensuring that they received optimal care. Additionally, some participants described that successful family functioning encouraged them to keep going with therapy, even when they no longer wanted to carry on. Some spouses reported receiving emotional and practical support from extended family members, allowing the spouse to maintain a work life balance in addition to their caregiving responsibilities (Kitzmüller et al., 2012).

A number of key elements of living successfully with aphasia have been outlined, many of which rest on family relationships either directly or indirectly. Firstly, establishing a reliable way for the PwA to communicate with the family and *vice versa* (Brown et al., 2010). Secondly, the PwA having good mental health (Holland, 2006) and when this is not the case, the need for specific and individual emotional support for the PwA including psychotherapy, counselling, and support groups (Brown et al., 2011a). Family members also highlighted the need for their own access to support, including emotional and practical support (Brown et al., 2011a). Thirdly, the importance of maintaining autonomy and independence, with adaptations to family roles preferred over complete removal of that role, allowing the PwA to continue carrying out a certain function or role within the family and maintain their identity and autonomy. Furthermore, becoming involved in the community and contributing to society positively influences the lives of PwA and their family members. Additionally, having access to healthcare professionals who have prior knowledge of aphasia and use supported conversation techniques allows PwA to maintain independence and feel empowered in medical situations (Manning et al., 2019). Finally, an emphasis on celebrating improvements both of the PwA and improvements in family life is an important part of living successfully with aphasia (Brown et al., 2011a). This further highlights the need to

address the impact of aphasia on the family system and identify supports that can address these needs.

### **1.6 Role of speech and language therapists in providing holistic support to PwA**

In order to live well with aphasia and improve quality of life, psychosocial features of mental well-being must be addressed by healthcare professionals (Simmons-Mackie & Cherney, 2018), but this should not be limited to the wellbeing of *individuals* at the expense of the relational *dynamics*. SLTs have a core role in addressing the impact of psychosocial difficulties experienced by PwA, either by supporting their clients where appropriate or referring their clients to a mental health professional when more severe symptoms unrelated to aphasia are present (Kneebone & Dunmore, 2000; Sandberg et al., 2021). Approaches that SLTs can use to support PwA include a stepped model of psychological care. This model comprises of five increasing levels of support for people with mental health difficulties, with care being provided in the first two tiers by allied health professionals (Kneebone, 2016). Counselling and providing support to PwA and their family is within the remit and scope of practice of SLTs (IASLT, 2023) and SLTs can utilise tools and strategies such as active listening and collaborative goal setting (Sandberg et al., 2021). Furthermore, recent research has focused on a variety of psychological tools such as solution focused brief therapy (Northcott et al., 2021) and behavioural therapy (Thomas et al., 2013).

While there are numerous tools, resources, and interventions available for SLTs, and it is within the remit of SLTs to provide this type of care, there is a specific lack of provision of psychological support for the family unit itself. Furthermore, additional barriers exist when more severe mental health difficulties are present. The existing

psychological care system is unable to support the family unit of PWA, as there is a lack of mental health professionals who can deliver an adapted therapy which involves supported conversation (Santo Pietro et al., 2019; Strong & Randolph, 2021).

A number of surveys on the perspectives and practices of SLTs on the provision of psychological support to PwA has been conducted in the United States of America (Hayashi et al., 2023), South Africa (Nash et al., 2022), United Kingdom (Northcott et al., 2017), Australia (Sekhon et al., 2015), and New Zealand (Gibson & Purdy, 2014). Despite the majority of SLTs agreeing that providing psychological support was within their role and was an important part of aphasia therapy, many did not provide this support for a number of reasons. These reasons included a specific lack of training to carry out this support, case load pressures leading to a lack of time to implement psychological support, and lack of access to a mental health professional to support these sessions (Hayashi et al., 2023; Northcott et al., 2017). Within an Irish context, a survey conducted on 95 SLTs identified a lack of access to mental health services and community support services for PwA and their family members (Manning, Cuskelly, et al., 2020).

### **1.7 Clinical guidelines and policies for stroke rehabilitation in Ireland**

The development of stroke rehabilitation services has remained a low priority on government agendas worldwide, resulting in inadequately designed and poorly managed services. The low prioritisation of rehabilitation service development has been attributed to policymakers' lack of expertise or understanding about stroke rehabilitation services (World Health Organization, 2017). In the Irish context, accessing specialist stroke rehabilitation services is challenging regardless of socioeconomic background, as

in many cases these services are non-existent, with people relying on the support of charities to navigate life after stroke (Muldoon et al., 2017).

The National Stroke Strategy 2022 – 2027 has also “*acknowledged that rehabilitation services are under-developed in Ireland*” (Health Service Executive, 2022, p. 44). With regards to accessing psychological care, the National Stroke Strategy 2022-2027 highlights the lack of and the need for universal access to psychology services for PwA following stroke specifically stating that:

*Every effort should be made to ensure those with communication issues post stroke are able to access supports such as psychology. How this can be achieved will need to be considered going forward in collaboration with SLT services.*

(Health Service Executive, 2022, p. 58)

While funding for stroke services was promised by the Irish government in line with the National Stroke Strategy 2022-2027, the funding allocated to 2024 will not be provided, putting a huge strain on the already weak stroke rehabilitation infrastructure in Ireland (Irish Heart Foundation, 2023). In the context of these limitations, it is essential to understand the existing needs of key stakeholder groups in order to inform how future services are designed and delivered in a way that recognises that the needs of the person receiving care are situated within a wider family system.

## **Chapter 2. Family Therapy**

As described in the previous chapter the impact of a sudden event such as stroke can significantly shift roles and relationships, substantially disrupting family functioning (Larøi, 2003). Aphasia presents a unique challenge for families, as the tool used to negotiate and come to terms with change, communication, is substantially altered (Walker & Akister, 2004). Therefore, families where one person has aphasia require a unique solution to help support them to negotiate these changes and re-establish equilibrium in the family.

This chapter provides an overview of the prominent theories and types of family therapy interventions, with specific reference to family therapy for people post stroke and their family members, the inclusion of people with acquired communication disabilities in family therapy research, professionals involved in the provision of family therapy, and family therapy in an Irish context.

### **2.1 An overview of family therapy**

Family therapy is based on the systems theory, where family is defined as a complex system made up of individuals who undertake roles and collaboratively work together towards common goals that cannot be achieved individually (Smith-Acuña, 2010). Systemic family therapy focuses on the interconnectedness of a family and how a change in one person in the family, affects the functioning of the entire system (Larøi, 2003). The goals of this type of therapy are to: (1) assess the functioning of the family system; (2) address the changes within the family system; (3) support family members to establish new roles or reclaim existing roles while maintaining the same hierarchical structure in the system; and (4) improve the overall communication within the family system (Walker & Akister, 2004). As described in the previous chapter, stroke and

aphasia affect familial roles and responsibilities causing dysfunction within the family system (Larøi, 2003). In the context of stroke and aphasia, family therapy could be useful in addressing the changes within the family and supporting the family to regain a sense of homeostasis. Techniques or intervention types used to attain systemic family therapy goals vary greatly but primarily address family functioning using the systems theory. Family therapists working within this framework support the family to redefine their roles and strengthen how each individual communicates with one another (Carr, 2012). This process is carried out through observations of the family in their natural environment and slowly implementing changes within the family (Walker & Akister, 2004). These observations allow families to create a new positive environment in which family life can continue and create a supportive plan that will enable family members to respond to issues that may arise within the family system (Carr, 2012).

Systemic family therapy can take place in a range of formats including group therapy where multiple families attend; couples therapy; individual counselling for all family members; and family therapy where all members of the family are present (Florian & Katz, 1991; Klonoff & Koberstein, 2010; Kreutzer et al., 2002; Rosenthal & Young, 1988). The format for therapy is determined by specific factors within each family such as the types of relationships present in the family, prior familial dysfunction, the ages of family members, and family members willingness to take part in therapy (Walker & Akister, 2004).

## **2.2 Family therapy after stroke**

In a scoping review on the use of family therapy after acquired brain injury (Henihan et al., 2024), twenty-four articles were identified over five multidisciplinary

databases, with four distinct categories of interventions addressing family therapy in an acquired brain injury population. These categories included family therapy, family therapy adapted for people with acquired brain injury, psychoeducation, and psychosocial interventions. All of these interventions are based on systemic family therapy (Henihan et al., 2024). While these studies predominantly focus on stroke as the primary cause of brain injury, some studies do include other aetiologies (i.e. beyond exclusive stroke related injuries). A summary of the main findings is provided here.

### ***2.2.1 Family therapy***

These interventions centred on providing familial education on the effects of acquired brain injury, identifying and redefining familial roles and responsibilities, providing skills to explore shifts in relationships and tools to cope with the changes (Borenstein et al., 1987; Butera-Prinzi et al., 2014; Dausch & Saliman, 2009; Maitz & Sachs, 1995; Nichols et al., 1996; Perlesz & O'Loughlan, 1998; Todd & Satz, 1980; Yeates et al., 2010).

### ***2.2.2 Family therapy adapted for people with acquired brain injury***

This type of therapy provided family therapy that was specifically adapted for people with acquired brain injury, through individual and group counselling to all members of the family. There was a specific focus on building empowerment and agency within families, in addition to supporting adjustments and expectations in roles and responsibilities. The outcomes of this type of intervention included reduced caregiver burden and familial conflict (Butera-Prinzi et al., 2016; Collins & Kennedy, 2008; Couchman et al., 2014; Davis & Tadros, 2019; Kreutzer et al., 2010; Perlick et al.,

2013; Söderström et al., 1992; Straits-Troster et al., 2013; Watzlawick & Coyne, 1980; Zarski et al., 1988).

### **2.2.3 Psychoeducation**

Interventions utilising this category of therapy supplied families with information on the nature and trajectory of acquired brain injury, with a specific focus on emotionally supporting families to cope with an adjustment in family dynamics and improve the functioning of the family (Blom Johansson et al., 2013; Clark et al., 2003; Lauer-Listhaus, 1991; Turnblom & Myers, 1952).

### **2.2.4 Psychosocial therapy**

Interventions based on psychosocial therapy utilised community support services for the individual with acquired brain injury and their family members. These services helped families reintegrate back into the community and learn to live in a new way. Families participating in these studies reported improvements in family cohesion (Glass et al., 2000; Hibbard et al., 2002).

### **2.2.5 Inclusion of people with communication disabilities in family therapy research**

Out of the twenty-four studies included in the scoping review on family therapy after acquired brain injury (Henihan et al., 2024), twelve included people with communication disabilities (Blom Johansson et al., 2013; Borenstein et al., 1987; Butera-Prinzi et al., 2016; Collins & Kennedy, 2008; Davis & Tadros, 2019; Lauer-Listhaus, 1991; Nichols et al., 1996; Söderström et al., 1992; Todd & Satz, 1980; Turnblom & Myers, 1952; Watzlawick & Coyne, 1980; Zarski et al., 1988), two explicitly excluded communication disabilities (Clark et al., 2003; Glass et al., 2000), and ten implicitly



excluded this population due to the communication demands of the study (Butera-Prinzi et al., 2014; Couchman et al., 2014; Dausch & Saliman, 2009; Hibbard et al., 2002; Kreutzer et al., 2010; Maitz & Sachs, 1995; Perlesz & O’Loughlan, 1998; Perlick et al., 2013; Straits-Troster et al., 2013; Yeates et al., 2010).

### ***2.2.6 Professionals involved in delivering family therapy***

Primarily, family therapy is provided and delivered independently by family therapists (Klonoff & Koberstein, 2010) who in Ireland, would have primary degrees in social work, nursing, and psychology, with postgraduate specialisation in family therapy. However, the use of family therapy interventions and techniques to support the readjustment of roles does also fall within the scope of practice of other healthcare professionals (Hodgson et al., 2014; Marlowe, 2013; Rolland & Walsh, 2005; Tyndall et al., 2012). Research on the use of family therapy for people with stroke has utilised several different types of healthcare providers such as psychiatrists, psychologists, social workers, and SLTs (Henihan et al., 2024). When post-stroke aphasia is present in families, the involvement of SLTs in family therapy may be particularly useful, especially when the communication disability affects a family’s ability to actively participate in the typical delivery of therapy. Prior research on how SLTs address psychosocial wellbeing with PwA has highlighted positive experiences of SLTs working jointly with mental health professionals (Northcott et al., 2017). Furthermore, exploratory research by Strong and Randolph (2021), on the experiences of mental health professionals providing psychological services to PwA has identified that these professionals valued the input of SLTs. Mental health professionals within that study highlighted the essential role SLTs have in creating a successful therapy interaction when one person has aphasia (Strong &

Randolph, 2021). As family therapists having similar training to other mental health professionals, there is a possibility that joint working between SLTs and family therapists could successfully work to support PwA and their families.

In Ireland, family therapy is a small discipline, with approximately 300 family therapists registered across the island of Ireland with the Family Therapy Association of Ireland (FTAI, 2023). The concept and practice of family therapy was first introduced in Ireland in 1975 and since then has primarily focused on delivering services to children and young people with mental health disorders. Additionally, the majority of registered family therapists in Ireland provide family therapy as part of their main professional role such as nurses, social workers, psychiatrists, and psychologists (Carr, 2013). There is limited research on the provision of family therapy services in Ireland which might be attributed to the limited number of registered family therapists and the more recent introduction of family therapy in Ireland.

### **2.3 Situating the thesis and research question**

The limited research on the use of family therapy after stroke has demonstrated positive outcomes with its use, such as improving family functioning, increasing empowerment within families, supporting the negotiation of roles and relationships, and diminishing the burden of care on family members. Aphasia greatly affects family functioning when compared to stroke survivors without aphasia, however, there is a specific lack of research on the use of family therapy when one person has aphasia. The unique challenges that aphasia causes may necessitate the involvement of SLTs in the provision of family therapy for PwA and their family, but there is a dearth of research on how SLTs support families of PwA to negotiate role changes in the family. Furthermore,

there is a specific lack of research addressing family therapy and stroke in Ireland, even though stroke is the leading cause of acquired disability.

In addition to the literature outlining the effects of aphasia and stroke on the family system, one of the primary reasons for conducting this research is my own familial experiences with aphasia. When I was 11 years old, my mother had a stroke and has receptive aphasia as a result of this. We experienced significant changes as a family because of aphasia and were not offered any help in navigating these changes. Ultimately, these experiences have led me to study speech and language therapy for my undergraduate degree, and completing further research in this area, as I want to provide support and guidance to families in similar situations.

This study addresses the question *what are the experiences and perceptions of different stakeholder groups on the need, value, and challenges of providing family therapy for PwA and their family members?*

## **Section 2: Methodology**

## **Chapter 3. Methodology**

Through analysis of qualitative data from the key stakeholder groups, this study aimed to address the following question: What are the experiences and perceptions of different stakeholder groups on the need, value, and challenges of providing family therapy for PwA and their family members?

This chapter will begin by discussing the research design including the credibility of reflexive thematic analysis in Section 3.1, before addressing the ethical considerations in Section 3.2. Section 3.3 details the data collection tools and processes and presents an overview of the study participants. The chapter ends with a discussion of the data analysis procedures.

### **3.1 Research design**

This research was of a qualitative design utilising an exploratory-experiential approach – an iterative process used to comprehend or explore meaning and the processes through which people construct meaning (Braun & Clarke, 2013). This design allowed me to systematically collect, arrange, and interpret the experiences and perceptions as shared by individuals and groups of people – centring on their story (Grossoehme, 2014). The use of a qualitative research approach, specifically reflexive thematic analysis, was employed as it allowed me to attain a depth of awareness and insight into the experiences and perspectives of key stakeholder groups (Palinkas, 2014). Below I outline my paradigmatic, ontological, epistemological, and phenomenological hermeneutic approach to this research. These are outlined to enhance the transparency with regards to the theories which underpin their study (Braun & Clarke, 2013), and thereby optimise the credibility and reliability of this qualitative research (Braun & Clarke, 2021b).

### **3.1.1 The 'Big Q' qualitative framework**

The central question of this research relates to the experiences and perceptions of key stakeholder groups on the value and need of family therapy after stroke. Therefore, it was appropriate to situate the study within a framework that explicitly values and focuses on the understanding of experiences. Qualitative research affords an opportunity to investigate and describe people's experiences and perception in great depth. Researchers and participants are impacted by the interactions that take place during qualitative investigations, and our understanding of the human condition is impacted by the knowledge generated during qualitative research (Brinkmann & Kvale, 2017).

One framework which supports these values is a 'Big Q' qualitative framework, which is centred around the "*situated nature of meaning*", recognising that there is no single answer or truth, and that people's perceptions and experiences are situated within a certain context (Braun & Clarke, 2021b, p. 228). Additionally, this framework involves reflecting on my own perceptions and experiences in relation to the topic, influenced as they are by my personal and professional experiences (see Section 3.1.5 for a positionality reflective statement) and situating these assumptions in the context of this research (Braun & Clarke, 2013). This framework was operationalised using a range of qualitative tools within a qualitative paradigm (semi-structured interviews and focus groups) and qualitative methods (reflexive thematic analysis) to explore the perspectives and experiences of key stakeholder groups.

### **3.1.2 Constructivist ontology and subjectivist epistemology**

This research was ontologically situated in a constructivist worldview, reflecting on my beliefs that there are truths which can be uncovered, that individuals' personal

perceptions of an experience or phenomena are true, and that people's understanding of the world is shaped by their experiences and perspectives . Furthermore, this constructivist framing afforded me an opportunity to understand the underlying factors that influence the need for family support when one person has aphasia (Schwandt, 2014). As the research used an exploratory-experiential approach, it was appropriate to situate the study within this ontological positioning. Additionally, the reporting of my ontological beliefs affords readers an understanding of how these beliefs influence the research from conceptualisation of a research topic through to the method used to collect and analyse this information (Braun & Clarke, 2013).

Epistemologically, I adopted a subjectivist approach, reflecting on my beliefs that there is not one objective truth that can be uncovered. Rather, there is a collection of truths (no single one better than another) that are inescapably influenced and shaped by the environment in which they are discussed, and that this specific environment cannot be separated from reality (Lincoln & Guba, 1985). Additionally, this approach values my own subjectivity and its use as a tool throughout data collection and analysis (Braun & Clarke, 2013; Crotty, 1998). Furthermore, the use of writing in the first person throughout aligns with a subjectivist approach and affords readers an opportunity to get a sense of the reflexive and subjective nature of qualitative research (Langdridge, 2007). These approaches also align with the Big Q qualitative framework that this research is situated in, rejecting ideas of neutrality and objective truths (Braun & Clarke, 2021b). Both my ontological and epistemological assumptions reflect the nature of the research question relating to the experience and perceptions of key stakeholder groups.

### ***3.1.3 Phenomenological hermeneutic approach***

This study was also influenced by my phenomenological philosophical beliefs – the idea that people’s lived experience is a research topic in its own right and that these experiences are co-constructed and interpreted by the researcher. It also reflects the idea that researcher subjectivity is inherent to the research process and should not be separated or removed from the process (Langdrige, 2007). Additionally, hermeneutics of empathy, a philosophical approach to research focusing on making sense of experiences, was adopted (Braun & Clarke, 2021b). This approach reflects on bringing my own viewpoints and beliefs into the research process and using them as a tool (Langdrige, 2007).

### ***3.1.4 Reflexive thematic analysis and its credibility***

A broad discussion of thematic analysis and the chosen method within thematic analysis is discussed here including the rationale for the specific use of reflexive TA.

Thematic analysis is a group of methods with a wide variety of characteristics, fundamental research values (ranging from coding reliability to the subjectivity of data analysis), and analytic processes (Braun & Clarke, 2021a). Consequently, it was important to consider a range of methods before proceeding with data collection to ensure consistency between the method and my ontological, epistemological, and hermeneutic positions. It was important to ensure that the research designs and methods supported the research question and that my approach to the data, including my personal world views, were provided to the readers. The consideration of all the above methods allowed me to make an informed decision on which method was most appropriate to address the central research question, increasing the integrity and credibility of this piece of qualitative research (Levitt et al., 2017).



Some methods within thematic analysis focus on coding reliability and topic summaries rather than developing themes directly from codes. Researcher subjectivity is viewed as 'bias', which could jeopardize the trustworthiness of the coding. Multiple coders are used to negate the bias, and the final coding is decided by consensus between coders and that a high level of agreement equates to reliable coding (Braun & Clarke, 2021b). Such approaches were not considered consistent with the nature of the study, the Big Q qualitative framework that the study was situated within, in addition to my ontological, epistemological, and phenomenological hermeneutic approach as described above. As described earlier, I was not seeking one objective truth or attempting to identify and analyse data in a bias-free void. Instead, I wanted to use my own experiences and perceptions as tools to create and interpret the lived experience of PwA and their family members, and the professional experience of SLTs. Reflexive thematic analysis allowed me to generate themes through repeated interaction with the data, recognising that themes cannot exist without the researcher. While subjective in nature, I acknowledged my own assumptions by engaging on continuous reflection throughout the entire research process (Braun & Clarke, 2021b).

As the aim of this research was to develop, analyse, and understand patterns across qualitative data from multiple stakeholder groups, the use of reflexive thematic analysis was deemed the most appropriate method of analysis as it involves systematic data coding to create themes (Braun & Clarke, 2021b). As this study centred on the views, experiences, and perspectives of three main stakeholder groups, the use of reflexive thematic analysis allowed me to keep the stories of participants as the central concerns, and address patterns within and across the stakeholder groups. To ensure the credibility of the research is maintained, it was important to fully report the

methodology so that it could be replicated. Additionally, the use of reflexivity was employed as it allowed me to critically reflect on my role within the research, both as a member of the SLT stakeholder group and as a family member of a PwA (Braun & Clarke, 2013).

### ***3.1.5 Positionality statement***

Within qualitative research, it is important to reflect on your position within the research and to use this position as a tool to analyse the data.

With both lived experience as a family member of a PwA in addition to working experience with PwA, this was a topic that was personally and professionally important to me. I have experience being a child of a parent with aphasia associated with stroke. When I was 11 years old, my mother had a stroke and has receptive aphasia as a result of this. We experienced significant changes as a family because of aphasia, with each member experiencing these changes in a unique way. There were no resources offered at the time to assist our family in navigating these changes, leaving us to come to terms with these effects on our own. In making sense of my own experience of family life after stroke, I wanted to support people in similar situations, ultimately leading to my choice of studying speech and language therapy for my undergraduate degree. As part of my undergraduate thesis, I chose to focus on the area of family therapy after acquired brain injury, identify the extent to which people with acquired communication disabilities were included in family therapy research.

From a professional point of view, I am also approaching this research from the perspective of a clinician who actively provides therapy or support to people and have experience using supported communication, including communication partner training at an undergraduate level. While this provides me with the skills to support the

communication of PwA, it was at times challenging to step back from the clinician role during data collection. It is with these experiences that I have a unique perspective and interest in these areas.

### **3.2 Ethical considerations**

Ethical approval was granted for this study by the School of Linguistic, Speech and Communication Sciences Research Ethics Committee, Trinity College Dublin on November 4<sup>th</sup>, 2022 (see Appendix A1). An amendment to this application was sought and approved by the School of Linguistic, Speech and Communication Sciences Research Ethics Committee, Trinity College Dublin on February 15<sup>th</sup>, 2023 (see Appendix A2). This amendment included the recruitment of PwA and their family members and family therapists through social media in addition to the already approved recruitment mechanisms.

A range of ethical issues must be considered especially when researching private lives and publishing them in the public domain. Therefore, it was important to consider a range of ethical procedures to minimise harm and risk to participants and the researcher (Brinkmann & Kvale, 2017). These considerations are discussed below.

As this research aimed to involve populations who are at risk of vulnerability, including people with a communication disabilities and children under 18 years of age, specific measures were taken to ensure that participants were fully informed. Particular care was given over provision of information through accessible methods specifically regarding the voluntary nature of participation, their right to withdraw at any stage, and the details on how their personal data would be processed. Recruitment and participation of people considered at risk of vulnerability was considered as an integral part of this study, to ensure that the results of this study are both relevant and

meaningful to the families who have lived through these experiences (Hersh et al., 2021). The use of pseudonyms was employed for PwA and their family members to protect their identity and the sensitive nature of the information they provided. After consulting the literature on referencing of participants in qualitative research, I utilised pseudonyms rather than participant codes, as they allow the reader to engage empathetically with the participants without depersonalising the information they provided (Heaton, 2022; Saunders et al., 2015). Each group of participants are discussed below, including the measures relating to recruitment and informed consent.

### ***3.2.1 Recruitment and consent of PwA and family members***

PwA and their family members were recruited for the study using convenience sampling. This participant group was recruited through the Dublin Conversation Partner Scheme - 'Connect'<sup>2</sup> in Trinity College Dublin and through social media. PwA who participated in Connect in 2021 and 2022 who consented to be contacted for future research purposes were contacted by a gatekeeper in the Department of Clinical Speech and Language Studies. An aphasia friendly letter and participant information leaflet (PIL; see appendix B) was created. These were sent to 30 potential participants via post and email by the gatekeeper. Participants signalled interest in participating in the study by emailing me directly (as the named researcher) or contacting the gatekeeper. A fortnight after posting and emailing the information, the gatekeeper called potential participants to alert them of the PIL and remind them of the opportunity to make contact. The use of snowball sampling where PwA could nominate family members to participate was also

---

<sup>2</sup> First year undergraduate SLT students are matched with and visit people with aphasia living in Dublin to engage in supported conversation. This scheme helps students to learn how to use supported communication techniques while also giving people with aphasia opportunity for conversations and reduce social isolation.

utilised. PwA were included in the study if they had a diagnosis of aphasia post stroke regardless of type or severity, were over 18 years of age, and resident in Ireland (Table 1). Family members were included in the study if they identified as family members of a PwA, were over 8 years of age, and resident in Ireland (Table 2).

**Table 1**

*Inclusion and exclusion criteria for in-depth supported interviews of PwA*

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
People who have a diagnosis of aphasia after stroke.	Has a diagnosis of primary progressive aphasia or has a severe cognitive impairment.
PwA over 18 years of age.	PwA under 18 years of age.
People who have any type of severity of aphasia after stroke.	People with a diagnosis of a progressive neurological condition.
PwA resident on the island of Ireland (Republic of Ireland or Northern Ireland).	PwA not resident on the island of Ireland (Republic of Ireland or Northern Ireland).

**Table 2**

*Inclusion and exclusion criteria for in-depth supported interviews of family members of PwA*

*PwA*

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
People who identify as family members of PwA (this includes spouses, children, parents, grandparents, and extended family).	People who do not identify as family members of PwA (this includes friends, carers, and healthcare providers).
Family members over 8 years of age.	Family members under 8 years of age.
Family members who are resident on the island of Ireland (Republic of Ireland or Northern Ireland).	Family members who are not resident on the island of Ireland (Republic of Ireland or Northern Ireland).

When obtaining the consent of PwA throughout the research process, it was important to consider that obtaining explicit informed consent may require

communication support for PWA (Pearl & Cruice, 2017), and a fundamental requirement under General Data Protection Regulations (GDPR). PwA have been regularly excluded from stroke related research due to their perceived inability to give consent (Pearl & Cruice, 2017) but as described earlier the recruitment and participation of PwA was inherent to

this study to ensure that the results of this study are both relevant and meaningful to the families who have lived through these experiences (Hersh et al., 2021). The use of several communication accessible methods in this study to recruit and obtain consent from PwA was employed. When participants contacted me to signal interest in participating in the research, a five-day reflection period was used before scheduling an interview to ensure the participant had time to consider all aspects of participating in the research. An aphasia-friendly consent form was used before the start of the interview (see appendix C1), following a brief re-discussion of the PIL. If any participant was unable to give written consent, verbal or gestural consent was obtained and recorded. The consent procedures were also completed with family members (see appendix C2).

While this study was intended to facilitate the recruitment of children under the age of 18 and procedures were put in place to accommodate children to participate, no persons under the age of 18 participated in the study. Procedures that were put in place included obtaining consent using a parental consent form (see appendix C3) signed by the participant's parent or guardian after a five-day reflection period. This consent form clearly explained how their child's data will be used, processed, and stored, and that the study is voluntary. It also explained that they could withdraw their child from the study at any time. As part of the consent process, written or verbal assent from each

participant under 18 years of age would have before obtained before starting the interview (see appendix C4).

### **3.2.2 Speech and Language Therapists**

This participant group was recruited for the study using purposive and snowball sampling through the Irish Association of Speech and Language Therapists (IASLT) and social media. Participants received a prepared letter with the PIL by email from the gatekeeper of the organisation of which they are a member (see appendix D). This was also shared on the social media pages of the IASLT (Facebook, Twitter, and Instagram). In the case of social media recruitment, the participants were invited to click on a link which brought them to the PIL. The PIL provided them with details of the study and data protection. The participants then contacted me to express interest in the study. Consent was obtained through an online consent form filled out before the focus group. SLT participants were included in the study if they were registered with IASLT, ordinarily practiced speech and language therapy in Ireland and had worked with people with post stroke aphasia at some stage in their career (Table 3).

**Table 3**

*Inclusion and exclusion criteria for focus group with SLTs*

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
SLTs who are registered with IASLT.	SLTs who are not registered with IASLT.
SLTs who ordinarily practice in Ireland.	SLTs who do not ordinarily practice in Ireland.
SLTs who have worked with people with post stroke aphasia at some stage in their career.	SLTs who have not worked with people with post stroke aphasia at some stage in their career.

*Note.* IASLT = Irish Association of Speech and Language Therapists

### 3.2.3 Family Therapists

Recruitment of this participant group was attempted using purposive sampling through the Family Therapy Association of Ireland (FTAI) and the Irish Council for Psychotherapy (ICP). Numerous attempts were made to recruit participants through circulation of a prepared letter with the PIL by email from the gatekeeper of the organisations (see appendix E). The PIL provided details of the study and data protection. Table 4 outlines the intended inclusion and exclusion criteria. Despite multiple invitations, no responses were received from family therapists and the project proceeded with the two core stakeholder groups.

**Table 4**

*Inclusion and exclusion criteria for focus group with family therapists*

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Family therapists who are registered with Family Therapy Association of Ireland or the Irish Council for Psychotherapy.	Family therapists who are not registered with Family Therapy Association of Ireland or the Irish Council for Psychotherapy.
Family therapists who ordinarily practice family therapy in Ireland.	Family therapists who do not ordinarily practice family therapy in Ireland.
Family therapists who have or who have not worked with PwA.	

### 3.2.4 Sample Size

The issue of sample size rationales and ‘data saturation’ are contentious topics in qualitative methodology research. Braun and Clarke (2013) do have guidelines which recommend that 6-10 interviews or 2-4 focus groups is sufficient for reflexive thematic analysis. These guidelines were followed for this project, but both individual interviews and focus group discussions were used, yielding a total of ten hours of recording.



There is mixed information about data saturation, including its definition and its role in qualitative research. Reflexive thematic analysis is based on the idea that meaning is not inherent or self-evident in data and instead lies at the intersection of the data and the researcher's contextual and theoretical beliefs and practices (Braun & Clarke, 2021c). As described by Braun and Clarke (2021c), aiming to predict the point of data saturation is not plainly linked to the amount of focus groups or interviews which are conducted and what themes are constructed from those interviews as themes do not exist in isolation from one another. Moreover, the process of analysis is never complete and does not have a discoverable end point. In contrast, the researcher chooses when to stop coding and move to the next phase of the analysis using their own interpretative judgement (Braun & Clarke, 2021c).

### ***3.2.5 Participant characteristics***

Eight individual interviews were conducted, involving four men with aphasia and four family members who were all female spouses (see Tables 5 & 6). Two focus group discussions were held with seven SLTs (Table 7). Participants with aphasia all have pseudonyms beginning with the letter 'A' and family members have pseudonyms beginning with the letter 'D'.

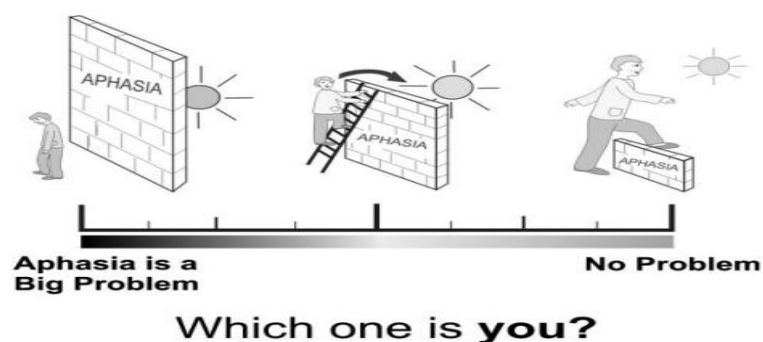
The ages of participants with aphasia ranged from 49 to 77 years with the time since onset of aphasia ranging from three to 11 years. All participants with aphasia nominated their spouse to participate in the familial interview.

With regards to immediate familial structures, Alan had one young child aged 5 years at the time of the interview, Arnold and Arthur had adult children and grandchildren, and Arron had no children. Information about the type of aphasia that participants had was obtained by contacting their SLT and asking for their diagnosis

based on formal and informal assessments. For Arron, I was unable to receive contact from his previous SLT despite multiple attempts to contact them. The “wall question” from the Assessment for Living with Aphasia (ALA) (Kagan et al., 2013) was used to interpret the self-reported impact of aphasia on family life during the acute stage of recovery and at the time of the interview. Previous research has adapted and utilised this particular question in conjunction with semi-structured interviews to document the impact of aphasia in specific situations (e.g. Baier et al., 2018). The *wall question* depicts a man standing at three different walls with varying heights. "Aphasia" is written on each wall. Beneath the images, there is a scale which ranges from "aphasia is a big problem" to "no problem" (see Figure 1). Participants were presented with the picture and asked how aphasia impacted family life when they were in hospital and were then asked how aphasia impacted family life currently. The *wall question* was scored from zero to four with a score of zero meaning that aphasia impacted significantly on their life and a score of four meaning that aphasia had relatively little impact on their life. Most participants identified that aphasia impacted their family more at the time of the interview when compared to the acute stage. The characteristics are presented in Table 5.

**Figure 1**

*The wall question from the Assessment for Living with Aphasia (Kagan et al., 2013)*



**Table 5***Participant characteristics of PwA*

<b>Name (Pseudonym)</b>	Alan	Arron*	Arnold	Arthur*
<b>Gender</b>	Male	Male	Male	Male
<b>Age</b>	52	49	68	77
<b>Time since onset of aphasia (years)</b>	11	5	3	8
<b>Aphasia characteristics</b>	Severe expressive and moderate receptive aphasia	No details available	Moderate expressive and moderate receptive aphasia	Moderate expressive aphasia and moderate dysarthria
<b>Familial Role</b>	Husband and father to young child	Husband	Husband and father to adult children, grandfather	Husband and father to adult children, grandfather
<b>ALA Wall Question - Acute Stage **</b>	4	3	0	2
<b>ALA Wall Question – Time of interview **</b>	4	2	2	0

*Note.* ALA = Assessment for Living with Aphasia. \*PwA were given the option of having their family member present for their interview to support the conversation. Arron and Arthur asked for their wives to be present during the interview. \*\* ALA wall question scores range from 0 to 4 with lower scores equating to higher self-reported impact of aphasia.

Four family members participated in the interviews with one husband with aphasia – Arnold opting to be present for his wife’s interview. The age of family members participating in the interviews ranged from 43 to 67 years with all participants representing the familial role of wife. Family members were also presented with the *wall question* picture (Figure 1) and asked the same questions as their partner with aphasia.

Half of the participants identified that aphasia impacted their family more at the time of the interview when compared to the acute stage. The characteristics are presented in Table 6.

**Table 6**

*Participant characteristics of family members*

<b>Name (Pseudonym)</b>	Daisy	Debora	Deirdre	Diana
<b>Gender</b>	Female	Female	Female	Female
<b>Age</b>	43	51	66	67
<b>Familial Role</b>	Wife	Wife	Wife	Wife
<b>ALA Wall Question - Acute Stage **</b>	4	4	0	0
<b>ALA Wall Question – Time of interview **</b>	1	2	3	3

*Note.* ALA = Assessment for Living with Aphasia. \* Lower ALA scores equate to higher self-reported impact of aphasia.

Seven SLTs in total participated in focus group discussions with four SLTs present in focus group one and three SLTs attended focus group two. SLTs described a number of working areas including acute hospitals, early supported discharge, rehabilitation hospitals, and primary care centres. Codes were used as identifiers for SLTs who took part in the focus group as the information they were describing was of a professional nature rather than a personal nature (Heaton, 2022; Saunders et al., 2015). The characteristics are presented in Table 7.

### **3.3 Data collection tools and processes**

Data was collected through the use of interviews (for PwA and their family members) and focus group discussions (for SLTs). All data was audio-recorded and

transcribed verbatim. A description and rationale for the use of these methods is discussed below.

**Table 7**

*Participant characteristics of SLTs*

<b>Code</b>	<b>Focus Group</b>	<b>Area currently working</b>	<b>Length of time working as an SLT</b>
SLT01	Group 1	Acute hospital and early supported discharge	11 years
SLT02	Group 1	Rehabilitation hospital	1 year
SLT03	Group 1	Primary care	27 years
SLT04	Group 1	Rehabilitation hospital	1 year
SLT05	Group 2	Acute hospital and early supported discharge	8 years
SLT06	Group 2	Acute hospital	15 years
SLT07	Group 2	Primary care	18 years

**3.3.1 PwA and family members**

Data was collected using semi-structured in-depth communication-supported interviews with PwA and their family members. Interviews were utilised to understand the perception and experiences of participants who are personally invested in a topic, providing rich and detailed responses (Braun & Clarke, 2013). Furthermore, semi-structured and communication-supported interviews have been regularly used in aphasia research and widely appraised as a valuable tool in qualitative aphasia research (Luck & Rose, 2007).

I devised a preliminary interview guide (Table 8), initially focusing on areas relevant to the research question and previous gaps in the research area identified in preliminary research (Henihan et al., 2024) (e.g., the exclusion of people with

communication difficulties in family therapy research, research on the relationships between PwA and their significant others and children). These questions were then trialled with a co-researcher (R.H.) who has aphasia. The inclusion of a researcher with living experience of stroke and aphasia ensures that the research being conducted is both relevant and meaningful to those whom this research is centred on (Hersh et al., 2021). Following these trials and based on feedback from the co-researcher, adaptations to the questions were made. These included clarifying questions, simplifying the language used throughout the interview, and removing questions which were not deemed to be relevant to potential participants.

In order to support PwA to communicate their answers, I gathered information about communicative strategies which helped the PwA at the beginning of the interview (Luck & Rose, 2007). This included information about what helps them understand questions, and how to repair any communication breakdowns which may occur throughout the interview. Additionally, techniques such as gesture, writing, drawing, and photos relevant to the questions asked during the interview (see appendix F1) were used to support communication throughout the interview to ensure the opinions and views of PwA were captured in their entirety (Luck & Rose, 2007). The use of supported conversation techniques throughout the interviews meant that in some cases, the interviews required the use of closed questions. While closed questions are not typically considered best practice in semi-structured interviewing, it enables persons with moderate to severe aphasia to participate (Luck & Rose, 2007). As an SLT with experience using supported conversation techniques, I drew on all of these techniques in any instances where participants understanding of the questions was unclear. My

experience of participating in these conversations suggest that all participants were adequately engaged.

**Table 8**

*Components of the interview guide for data collection with PwA and their family*

<b>Topic Area</b>	<b>Main Questions</b>
Family structure	Tell me a little bit about you and your family.
Impact of aphasia on family	<p>What was it like for you and your family after stroke? - Has any of that changed and how/why?</p> <p>Can you talk to me about what is has been like for you and your family since you have had aphasia?</p> <p>How has aphasia impacted how you are with your family and how your family is with you?</p>
Involvement in healthcare sessions	<p>Were there any times where your family was involved in any of your therapies?</p> <p>Can you tell me about a time when they were involved in the session?</p>
Access to services	<p>How have you and your family been supported since your stroke?</p> <p>What support did your family need?</p> <p>Is there any time when you or your family really needed support? When was that?</p> <p>Were there times when you or your family tried to get help but could not?</p> <p>What has helped you adjust to this new way of being as a family?</p>
Family therapy	<p>Family therapy is a type of counselling that helps improve relationships in families especially when a big change happens.</p> <p>Thinking about your stroke journey, would family therapy have been useful?</p>

In order to gather rich, in-depth accounts that are relevant to the research question, it was important that I could build trust quickly, and support communication appropriately. Additionally, the interviews focused on potentially sensitive topics for the participants (e.g., discussing time spent in hospital, familial relationships), therefore it was important to establish trust early in the interview (Braun & Clarke, 2013). I used opening questions that allowed the participant to ease themselves into the interview (e.g., Can you tell me a bit about you and your family?). Closing questions allowed the participant to raise any unaddressed or significant topics that had not been covered already. This allowed participants to provide a unique insight into previously unidentified needs or wants (Braun & Clarke, 2013) (see appendix F2 – F4). Each interview was conducted in either the participant's home or in a private clinic room in Trinity College Dublin. Interviews lasted between 30 minutes and 70 minutes.

### ***3.3.2 Speech and Language Therapists***

Focus groups were utilised for SLTs as they are a beneficial tool for investigating the collective perspectives, experiences, and attitudes towards a particular issue, in this case, family therapy for PwA. The use of focus groups allowed me to obtain rich information around the views of SLTs on the use of family therapy and identify where and why participants agree or disagree with certain issues in this area (Goodman & Evans, 2015). An online format for focus groups was used as it provided the greatest degree of flexibility for clinicians across different clinical sites. Focus group topics were created for SLTs. These topics focused on areas such as working with PwA and their families, providing support to PwA, and PwA and family therapy (see Table 9 and appendix G1 for more details). Seven participants agreed to participate in the focus groups. The participants were split up into two online focus groups consisting of 3-4



participants in each group. Consent was obtained prior to the focus group discussion through individual online forms. Focus groups lasted 45 minutes.

### **3.3.3 Family therapists**

Despite multiple attempts at recruitment, through several different routes and formats, no family therapists responded to the invitation to participate in the study. However, in designing the study, I had intended to run focus group discussion similar to what is described above for SLTs. The topic guide for family therapists is available in appendix G2 but remains unused.

### **3.3.4 Recording and transcription of interviews and focus groups**

Interviews were recorded using a Zoom H1 handy recorder (audio) and a canon camera recorder (video and backup audio). The video recording was used to capture both speech and non-speech communication. Online focus groups were recorded using Zoom's inbuilt recording application. After recording, the video and audio files were uploaded to a secure OneDrive file. All recorded data was transcribed using an orthographic transcription of verbal utterances (Braun & Clarke, 2006). Member checking can be a consideration in qualitative research however, as Braun and Clarke (2023) have identified "*the use of member checking is infused with assumptions about reality and knowledge production that sit (conceptually) uncomfortably with reflexive TA*" (p. 4). Given both the time constraints of the thesis and the methodology of using thematic analysis, member checking was not done.

Once the interviews and focused groups were transcribed, filler words that did not add meaning to the sentences were removed for ease of reading (Flick, 2013). For PwA, the transcribed interviews also included notes within the dialogue detailing any gestures, writing, pictures, or other types of communication used throughout the

interview. For focus groups, zooms inbuilt transcription feature was used to generate the initial transcripts after which the recording was reviewed, and corrections made to the transcript. A sample of three transcripts (interview with PwA – appendix H1, interview with a family member -appendix H2, focus group with SLTs – appendix H3) are referenced in the appendix.

**Table 9**

*Focus group discussion guide used with SLTs*

<b>Topic Area</b>	<b>Focus group questions for SLTs</b>
Demographic Information	Each participant to introduce themselves to the group.
Working with adults with aphasia and their families	Tell me about your experience working with families of adults with aphasia? Is this something you do routinely?
Providing support to PWA	In your education as an SLT, have you ever received training in counselling?
PWA and Family Therapy	Family therapy is a type of counselling that helps improve relationships in families especially when a big change happens.  Have you ever received any training in Family Therapy?  Do you think family therapy would be useful for people with aphasia and their family members?
Role of SLT in family therapy	Do you think SLTs have a role in family therapy and what would make that possible?

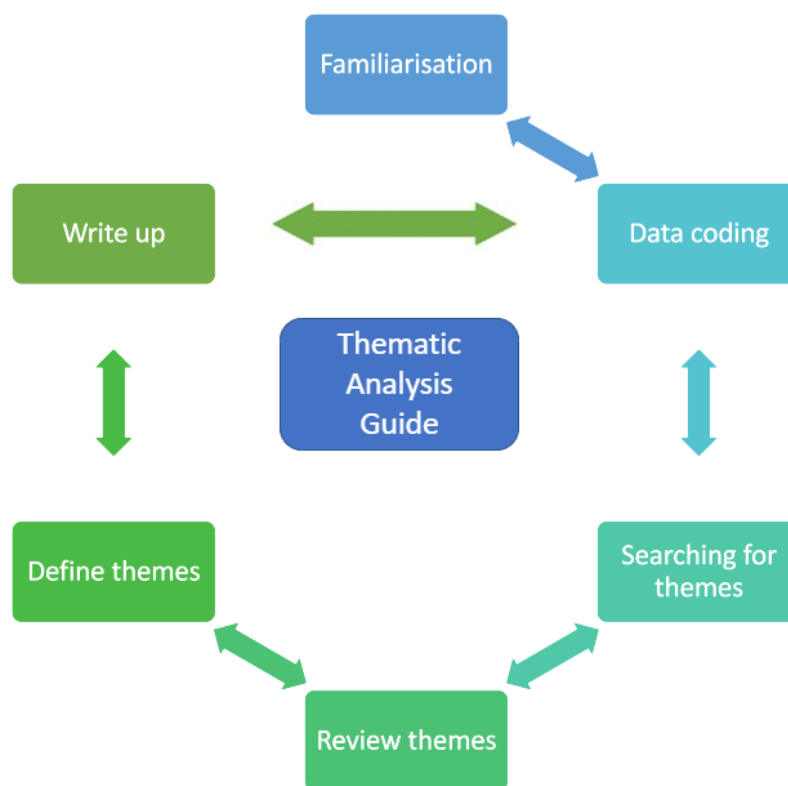
### **3.4 Analysis**

The method of analysis used for interviews and focus groups was reflexive thematic analysis. The analysis was completed over six phases involving dataset

familiarisation, data coding, initial them generation, theme development and review, theme refining, defining, and naming, and writing up (Figure 2).

**Figure 2**

*Diagram of the iterative process of thematic analysis based on Braun and Clarke (2006; 2021b)*



As described by Braun and Clarke (2021b), the process of thematic analysis is not linear, it is an iterative process which allows the researcher to move and return to different phases as many times as necessary. This helps to create a rich and thick analysis of the data (Braun & Clarke, 2006).

Throughout the data collection and analysis stage I practiced reflection, an essential aspect of reflexive thematic analysis, by keeping a reflexive journal (Braun & Clarke, 2006, 2021b). The journal allowed me to keep track and document my thoughts and reflections on experiences throughout the research process. Throughout the entire research process, I scheduled time to engage in active reflection and recording these reflections. During my data collection, I only scheduled one family interview or focus group per day and left time afterwards to note my initial thoughts or feelings towards topics. Scheduled time for reflection was especially important when completing family interviews, as I often felt a sense of camaraderie and related the most with this group. I have provided two excerpts from my reflexive journal below from two different stages of the research process – data collection and writing the analysis (see Table 10).

Data transcription was carried out as soon as practical after interviews, affording me an opportunity to reflect on the way I phrased questions, how I followed up on people's thoughts or opinions and topics and I reflected on how I could adapt these questions to ensure that the responses I was obtaining elicited rich and detailed information. During familiarisation, I made sure to take note of any initial ideas or feelings towards the data. When creating themes, I made sure to accurately document how I identified themes, ensuring it was an inductive process. At times, as this topic was of a personal and emotional nature, I took time and space away from the data to process my own feelings towards this, before returning to the data with a refreshed approach.

**Table 10**

*Excerpts from my reflexive journal*

**22/2/23 – Reflecting on my second focus group with SLTs**

Yesterday I had my second focus group with SLTs. For the first focus group, I felt very anxious beforehand. I was worried about the questions I was asking and about the group dynamics. I felt so relieved at their open and honest responses that I was more relaxed with the second group and to me it felt more like a chat with colleagues rather than “researcher” and “participants”.

The participants in this group took a both a pragmatic and realistic approach in supporting families where one person has aphasia. I was surprised at the openness that this group had towards the role of SLTs in supporting people with aphasia and their families. The idea that particularly stood out to me was that of SLTs wanting to work with family therapists, that they were not only open to the idea, but recognised the value of joint working. I really feel this was reiterated by all participants and I am interested to look at this idea across both focus groups. These two focus groups have made me feel hopeful that there is a possibility of change within a healthcare system. That SLTs see the struggles that families face and that they do want to help these families. I am looking forward to listening to this focus group again and see what other ideas stand out to me.

**3/7/23 – Reflections on the findings chapter**

The findings chapter has been much more difficult to write than I anticipated. I often find myself reflecting on the time and energy that these participants have given during the interviews and focus groups. They have given raw and honest accounts of their personal and professional experiences. I have found it easier to write sections focusing on SLTs and perhaps that is because their views are professional. I am representing a professional narrative rather than a personal one. When it comes to people with aphasia and their family members, I feel stuck. I am almost paralysed because I want to ensure I am representing their views as clearly as possible, and I am constantly reviewing every sentence I am writing. I think it is time to just write now and edit later.

**3.4.1 Familiarisation**

Familiarisation involved developing a thorough and intimate understanding of the dataset. This phase began during the data collection process and continued to the transcription stage which informed the earlier stages of analysis, allowing me to become familiar with the data prior to starting the analysis and any initial ideas or feelings towards the data were noted and reflected upon (Braun & Clarke, 2006). To build on this

initial familiarisation, I listened to and read the interview and focus group transcripts at least four times in an active way where meanings and patterns were identified and noted.

### **3.4.2 Data coding**

Data coding allowed me to identify features of the data which appeared interesting or noteworthy, and I organised the data into meaningful groups. This phase of thematic analysis involved reading each transcript closely and labelling all parts of the script where there was any meaning that might be pertinent to the research question (Braun & Clarke, 2021b). I employed the use of the coding software, Quirkos (Quirkos, 2023), as this software allowed me to easily move back and forth between transcripts when I was creating the initial codes (Figure 3). As the themes tended to be 'data driven' an inductive approach was utilised, where coding and theme development were shaped by and grounded within the data, to capture the stakeholders' experiences of family life after stroke. Applying an inductive lens to the analytic process, reflected the fact that this area of research is relatively new and an exploratory approach was therefore most appropriate (Braun & Clarke, 2021b). Consequently, when working with the data, the focus of the coding evolved reflecting the iterative and reflexive nature of thematic analysis. For example, what was initially coded as "valuable to work with families" became "working with families is a valuable and integral part of SLT". Additionally, the process of coding was fuelled by my own interpretation and subjectivity, but it is important to note that this type of qualitative analysis is about meaning making rather than focusing on truth-seeking (Braun & Clarke, 2021b). After all of the data was systematically and rigorously coded, a list of 60 codes remained and were used in the following phase of analysis.

**Figure 3**

*Example of codes generated in Quirkos*



### 3.4.3 Generating initial themes

The next three phases of reflexive thematic analysis began with generating initial themes – shared ideas across data (Braun & Clarke, 2021b). To enable me to track and record the initial generation of themes, I continued to use Quirkos to provide a visual framework when mapping the themes. This phase of analysis involved first listing all of the codes across the dataset.

From here, I identified broad concepts from codes that could be grouped together (Braun & Clarke, 2021b). For example, I initially grouped together codes developed from both families and SLTs about the impact of the acute phase of stroke on families, before teasing out the similar meanings identified by both groups and narrowing this down further. Using this method, the themes identified initially were

more semantic. Once I identified codes which could be grouped together, I considered these codes alongside my research question (Braun & Clarke, 2021b). These themes were classed as provisional, and it was important to evaluate each theme on its own. This evaluation involved considering how each theme will tell the story of the dataset, whether the theme represents something meaningful, and if the theme was coherent (Braun & Clarke, 2021b). The theme “Psychosocial challenges faced by PwA – diverse solutions for a diverse disability” was initially called “a pill won’t fix it all” but after some consideration, the meaning behind the theme was less about the use of antidepressant medication as a one stop shop to solve depression in aphasia and more about an underlying misconception that PwA would be unable to participate in traditional talking therapy. It was important for me to continuously reflect on the themes I was creating to make sure I was capturing a broad variety of data that was connected by a shared meaning. As described by Braun and Clarke (2021b), it can be easy to fall into a pattern of creating topic summaries (summaries of what participants say about a particular topic) rather than themes as patterns of meaning. To counteract this, after a few hours of theme construction, I reflected on the themes I had identified and asked myself if I had summarised what participants had said about a particular topic or had I identified shared meaning across the dataset. I also discussed my initial thoughts or concerns about themes with my supervisor.

#### ***3.4.4 Developing and reviewing themes***

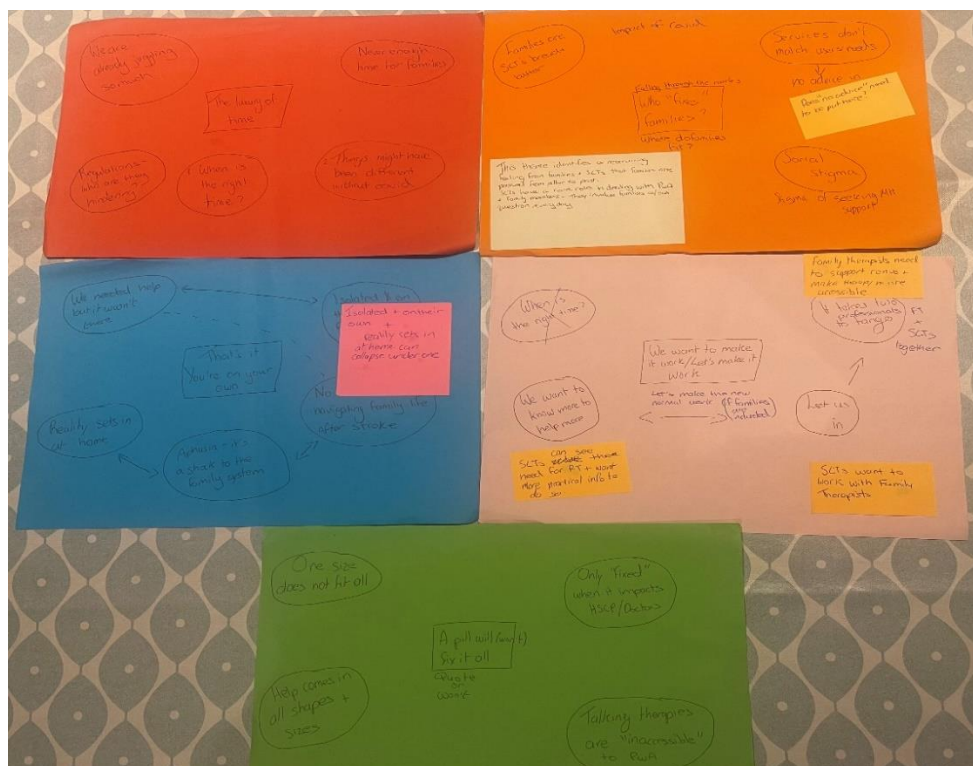
This process involved my reengagement with the coded extracts and the entire dataset to examine the feasibility of the initial grouping of data and evaluate whether these initial groupings could be improved or reorganised. Reviewing themes helped to foster richer development of themes which more accurately addressed the research



question (Braun & Clarke, 2021b). This phase allowed me to redefine, adjust and clarify central organising ideas. During this time, I moved from using the online software Quirkos to using paper as I felt this gave me fresh ideas and the ability to see all the themes and subthemes at once, helping me identify the broader picture – more specifically, helping me ‘see the wood from the trees’ (Figure 4).

**Figure 4**

*Overview of developing themes on paper*



*Note.* Provisional themes are presented in rectangular boxes and provisional subthemes are presented in circles.

### **3.4.5 Refining, defining, and naming themes**

Following completion of phase 4, five themes had been identified, at which stage I moved on to defining and naming themes. When I was defining themes, I ensured that I included what the theme was about, its boundaries, its uniqueness when compared to other themes and its contribution to the whole analysis. During refinement, I went back

to the audio recordings to ensure that the response analysed was genuine and not misrepresented. When naming the themes, I ensured that I represented its meaning and analytic direction as described by Braun and Clarke (2021b).

#### **3.4.6 Write up**

This stage of reflexive thematic analysis involved the write up of the entire thesis including the literature review and methodology chapter, and the analysis and discussion chapters which follow this. While the literature and methodology were written prior to the analysis, changes and adjustments were made after the analysis section was written, reflecting the iterative process of reflexive thematic analysis (Braun & Clarke, 2021b).

#### **3.5 Summary**

This chapter presented a description of the methodology I utilised in this study, including the research design with a rationale for the methodology where I identified my ontological and epistemological beliefs, ethical consideration and approval, data collection tools and processes, and an overview of the process of analysis. The aim of this study was to explore the perspectives and experiences of three groups of key stakeholders on the need, value, and challenges of providing family therapy in the context of aphasia. The reflexive thematic analysis of the interviews and focus group is presented in Chapter 4.

## **Section 3: Findings**

## Chapter 4. Findings

### 4.1 Introduction

This study aims to investigate the experiences and perceptions of PwA, their family members, and SLTs, with regards to the need, value, and challenges of providing family therapy to PwA and their family members. These perspectives were obtained through the use of semi-structured, communication-supported interviews with PwA and their family members and focus groups with SLTs. This chapter presents the findings of this analysis, beginning with a brief overview of the themes created from the data, followed by an in-depth description of each theme and subtheme using illustrative quotes from across the dataset.

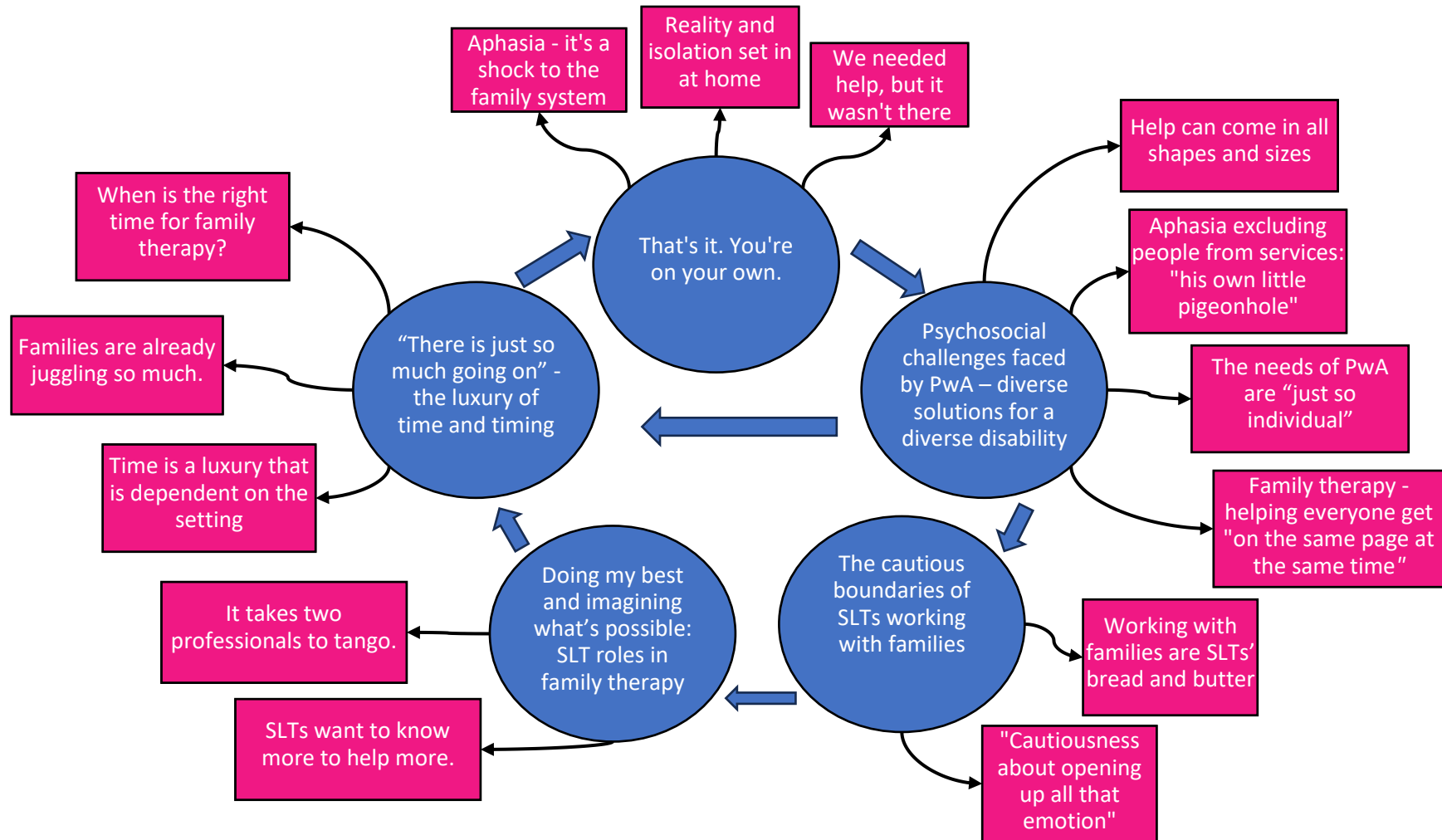
### 4.2 Overview of themes

Five themes were generated through the analysis process: (1) That's it. You're on your own; (2) Psychosocial challenges faced by PwA – diverse solutions for a diverse disability; (3) The cautious boundaries of SLTs working with families; (4) Doing my best and imagining what's possible: SLT roles in family therapy; and (5) "There is just so much going on" - The luxury of time and timing. These themes are presented in the figure below. While each theme is distinct and discussed separately the links between these themes conveys the overall story of the data in a cyclical relationship over time. This cyclical relationship describes the experiences and perceptions of PwA, their family, and SLTs over several stages of a person's stroke journey. The diagram represents how these themes interact with each other and demonstrate how each element of the cycle feeds into the next (Figure 5). Theme 1 focuses on the intense period of change that occurs when PwA are discharged from acute care, with families describing the effects that

changes in family dynamics have on their mental health. A lack of available services to help negotiate these changes, perpetuates feelings of isolation within the family unit. Theme 2 centres on the reasons why available support services for people living with stroke after acute care are not meeting the needs of these families and that any service targeted towards PwA and their family's needs to provide unique and multifaceted support. Theme 3 highlights that SLTs view working with families as a core part of their profession, however, they expressed a cautiousness when supporting families. This cautiousness was attributed to a lack of skills, confidence, and experience in using counselling techniques to support families. Theme 4 identifies the resources SLTs need to support PwA and their families to negotiate familial changes, including; (1) practical training and resources; and (2) open communication and interdisciplinary working between family therapists and SLTs. Finally, theme 5 represents the importance of when family therapy may occur in a person's stroke journey, in addition to the lack of time that SLTs have to spend with PwA and their family in acute care. The lack of time SLTs have to spend with families, perpetuates and feeds into the isolation that families experience upon discharge from acute care representing the cycle displayed in the figure on the next page. Themes are presented in a blue circle and subthemes are presented in a pink box (Figure 5).

Figure 5

Overview of themes and subthemes

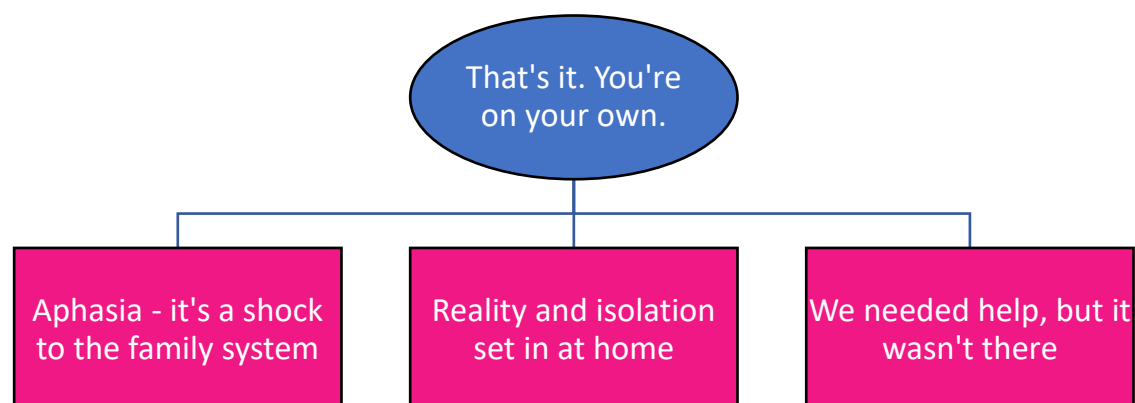


### 4.3 Theme 1: That's it. You're on your own.

The first theme, *that's it, you're on your own*, focuses on the experiences of PwA and their family members as feeling cut off and isolated from support once they are discharged from the acute healthcare system. Families (both PwA and their family) identified that the support they received while in hospital (i.e., acute hospital or rehabilitation unit), did not prepare them for the reality of living with aphasia. Both family members and SLTs identified that PwA and families require more long-term support to help adjust to role and relationship changes after stroke. The three subthemes that informed the theme were: (1) Aphasia – it's a shock to the family system; (2) Reality and isolation set in at home; and (3) We needed help, but it wasn't there (Figure 6). Each subtheme is discussed in more detail below.

**Figure 6**

*Overview of subthemes under main theme: That's it. You're on your own.*



#### **4.3.1 Aphasia - it's a shock to the family system**

The sudden onset of stroke means that families were often “*a bit shell shocked*” (SLT06, lines 22) when a member of their family sustained a stroke, with the significant others of PwA describing feelings of disbelief as a result of the sudden changes that stroke brings to the entire family unit. Deirdre, a wife of a man with aphasia, described her surprise when her husband sustained a stroke:

*It was a big surprise because there was no alarm bells ringing beforehand. It literally just happened on the night and that was it. For somebody who was active, fit, and lead, basically a pretty good life. And it was hard to believe that it landed on his doorstep.*

(Deirdre, lines 19 - 20)

The sudden onset of aphasia meant that families often found it difficult to come to terms with significant changes with SLTs describing how “*aphasia changes relationships hugely*” (SLT01, lines 261). Attempting to address relationship changes can be seen as “*confronting for families*” (SLT02, lines 109) and “*it can seem like an acceptance that there may not necessarily be an impairment-based improvement*” (SLT02, lines 109 - 110).

The sudden onset of aphasia also came as a shock to Arnold, a man with aphasia. Here Arnold describes his determination to improve his communication, but often felt sad at the changes in his communication.

**Interviewer:** *And how did you feel?*

**Arnold:** *(..) Nothing. But oh my [undistinguishable] (Arnold pointing to his head) was back off.*

**Interviewer:** *Your head was kind of- it was off?*

**Arnold:** *Yeah. Lot of work in hospital. I'd be authoring in two act of them trying to get it better.*

**Interviewer:** *Yeah. So you were doing a lot of work to try and get better?*

**Arnold:** *Yeah. (...)*



**Interviewer:** *How did it make you feel? (...) (Interviewer puts pictures of different emotions on the table). (...)*

**Arnold:** *A little bit sad (Arnold points to the sad picture).  
(Arnold, lines 121 - 144)*

As a result of the sudden event, several families expressed during the acute stages that they were in “*survival mode*” (Daisy, line 134), focused on the present and “*just getting through every day*” (Daisy, line 135), not initially understanding the long-term impact of stroke and aphasia on their loved one and the family system itself. Daisy described that in her situation, while healthcare professionals “*try to do the long road*” and explain what life in the future might look like, she felt that she had “*no concept*” of the long-term implications of stroke (Daisy, lines 134 - 136). Similarly, Diana, a wife of a man with aphasia, was also focused on the present during the acute stage “*praying that he wouldn't die, initially*” before realising about a month into the acute phase “*what are we going to do if he doesn't die*” (Diana, lines 9 – 10).

Extended family also had difficulty coming to terms with aphasia during the acute stage. Diana described how her adult sons were shocked about an incident that happened during the earlier stage of stroke recovery. Their lack of understanding of stroke, aphasia, and its prognosis, meant that her sons no longer wanted to be involved in helping their father.

*The whole thing was really stressful, right at the start for everybody. Very stressful. Because Arthur, like Arthur went out one day, he was only out of the hospital a week or so. And he went off one day on the bus. And he went into [XXX] and he was in a pub. And like at this stage he could hardly- barely, barely express himself. (...) And we couldn't get him to come home. And, you know, the lads were, were looking at me going 'This is a total nightmare'. And it was a total nightmare. But it was an acute stage. Do you know what I mean?  
(Diana, lines 146 - 150)*

Even through the initial shock of these sudden changes, Diana maintained hopefulness and positivity, feeling relieved by the fact that her husband sustained a stroke, and it was not a condition that was going to deteriorate over time: *“It's not like dementia. It's not like you're looking into the future and things are going to be worse (...) There's a prospect of things being better”* (Diana, lines 34 - 36).

SLTs recognised that families can be overwhelmed with information in the acute stage, finding it difficult to process information about aphasia and changes in communication. Instead, acute SLTs attempted to help family members *“get their head around the fact that communication can be affected after a stroke and what is an aphasia”* by providing them with *“some basic resources”* (SLT05, lines 302 - 303).

Across the interviews, families and SLTs identified that the rehabilitation priorities of PwA and their family members, with regards to stroke recovery, changed over the first year of stroke. Some examples of initial goals identified included *“[being] able to walk”* (SLT07, line 156), and *“[get] back driving”* (Daisy, line 60). These goals changed over time with Diana describing how her sons needed someone to *“have explained things [aphasia] to them in a non-medical context”* (Diana, line 97).

Participants noted that these changes in goals occurred when they had a better understanding of the long-term implications of stroke and aphasia. These priorities were reported by participants to have become more obvious after PwA had been discharged from rehabilitation services and they experienced these changes in the context of real-life situations. Daisy described how the reality of the severity of aphasia was something she did not realise until her husband came home, explaining how:

*It's really the speech and language now is the worst part of his injury. Probably for me. (...) Really the speech and language is, on a day-to-day basis, for like me as a family and for [Daughter], is the most difficult thing.*  
(Daisy, lines 86-89)

The changes in rehabilitation priorities described by family members were also reflected by SLTs. These changes in priorities were most noticeable when people returned home as issues that were not obvious in the context of a rehabilitation unit are now present at home and are experienced in the context of real-life difficulties in functional activities or participation.

*Then what happens is the person gets home, and they realize, okay, there's this whole other change in roles within the family now, and different dynamics, and the way that the partner communicates with their husband or wife has changed the way that they're able to access information. And you know that's got a knock-on effect for financial management or reading the bills that come in, and all of that.*  
(SLT07, lines 176 - 179)

Furthermore, an SLT working in primary care described how families return to SLTs for further support after spending time at home, recognizing the impact that aphasia has on the family system.

*And it's when they come back (...) they now realise the person's walking, but actually it's the communication impairment is the piece that they're most concerned about and the changes.*  
(SLT07, lines 323 - 324)

Both PwA and their partners noted that extended family (such as adult children, adult siblings, and parents) reacted in different ways to the news of stroke and aphasia. One partner described how her sister-in-law “*was devastated*” after seeing her brother after his stroke, as he was “*her baby brother*” and she “*still looks at him through those eyes*” (Debora, lines 241 - 245).

In the experience of Alan, extended family did not always understand the impact of aphasia on the PwA and on the immediate family, leading to a breakdown in familial relationships. Alan described how his brothers found coping with his stroke difficult, so they stopped visiting and contacting him:

*No the eh [Brother1] eh. The stroke is difficult and eh and eh. [Brother2], [Brother1], thank you very much (Alan points to the door and sighs). (...) End of story.*

(Alan, lines 227 - 228)

One SLT recognised that people outside of immediate family do not see or understand the changes which happen after stroke. In SLT07's encounters with people who have sustained less severe strokes:

*There's a sense that the wider community, maybe, are saying, 'God aren't you glad that he's home', or 'that he survived', or and maybe the nuances of those changing roles, even if it's a high-level [mild] aphasia don't get seen by the wider community.*

(SLT07, lines 184 - 186)

This recognition was mirrored in the reports of partners, who reported that extended families did not understand aphasia, with the PwA masking their difficulties and putting on a front when family came to visit. This led to partners feeling isolated and on their own when supporting the PwA. In Debora's experience of family members visiting her husband:

*One family member ehm gave him a newspaper one day to read in [Acute Hospital F] and was saying oh you know, he read everything because he was laughing right. And I was like, oh right, but then I was like there's not a chance not a chance he can. Do you know what I mean?*

(Debora, lines 188 - 190)

Diana described how her adult sons' lack of understanding of stroke, aphasia, and its prognosis, meant that her sons no longer wanted to be involved in helping their father. Diana described how her adult sons "*just can't get their heads around it [aphasia]*" but she felt that "*it's not actually their problem*" (Diana, lines 21 - 23). As a result of their lack of understanding of stroke, aphasia and its prognosis, her sons no longer wanted to be involved in their father's life "*because they were afraid [...of] what it was going to be like*" (Diana, lines 151).

#### **4.3.2 Reality and isolation set in at home**

Upon returning home, families described having to come to terms with and facing the true reality of living with aphasia. At this time, families reported an absence of support from healthcare professionals, leaving both PwA and their families isolated and navigating a new life on their own. Participants described how they were cut off from help and were unsure of what services were available, or who to even ask for help.

Three participants with aphasia (Alan, Arron, and Arthur) reported being cut off from services once they got home even though they identified a need for psychological support. Arthur described how he previously had psychological support from his SLT in the community and highly valued this support. When this SLT left their post, Arthur was discharged from the service and no longer received support, despite expressing that he still needed it.

**Interviewer:** *Is there any time do you think between when you had your stroke to now where you really needed the kind of emotional support, but you didn't? There wasn't any.*

**Arthur:** *Well eh (Arthur points to [SLT] on page). [SLT]. (Arthur points to [SLT] and then points away)*

**Interviewer:** *When [SLT] moved?*

**Arthur:** *Yeah.*

**Interviewer:** And then after that, there's not been

**Arthur:** (Arthur puts his hands together as if he is praying and then looks up to the ceiling) Please God.

**Interviewer:** Yeah you really want it.

**Arthur:** Yeah, yeah.

(Arthur, lines 226 - 234)

Similarly, Arron also described how he felt cut off from services after leaving a rehabilitation unit, emphasising the need for more support when people return home.

**Interviewer:** Was there any support that maybe you and Debora needed together?

**Arron:** No. No, no, no, (Arron shakes his head "no" and points to Debora who is laughing).

**Interviewer:** No okay. So you both you felt that you were both? Okay.

**Arron:** No ehm eh (Arron points at [Rehab Hospital A]).

**Interviewer:** So [Rehab Hospital A].

**Arron:** Yeah. Fucking hell.

**Debora:** Yeah. Like when you came home, they were kind of finished with you.

**Arron:** Yeah. Yeah. And fucking hell. Yeah! (Arron points to his arm and then gestures "more").

**Debora:** Yeah, I think you wanted more Arron didn't you?

**Arron:** Yeah. Fucking hell.

(Arron, lines 1005 - 1014)

Arthur discussed the strained relationship with his adult sons after his stroke, identifying that his sons did not understand his communication difficulties, and this impacted on his relationship with them and his grandchildren, increasing feelings of isolation.

**Interviewer:** And you're- because you have difficulty with speaking (Arthur nod his head "yes") Had that impacted? or I suppose has that kind of affected how you are with your family?

**Arthur:** Yeah. Yeah. Yeah.

**Interviewer:** And do you think your family understand?

**Arthur:** No. (...)

**Interviewer:** And do you get on well with your grandchildren?

**Arthur:** No, no. (Arthur laughs) (...) No. (Arthur laughs) I don't- I don't see them. I don't see them.

**Interviewer:** You don't see them?

**Arthur: No. No.**  
(Arthur, lines 154 - 166)

Alongside PwA, family members also reported feeling isolated, with no support from healthcare services or extended family. Deirdre explained how *“we do feel kind of we're on our own all the time if you know what I mean? There's nothing there.”* (Deirdre, line 97). Diana emphasised her need to discuss the impact of aphasia on her life with friends and extended family but that they simply could not comprehend aphasia's impact on their relationship. Consequently, Diana felt isolated and on her own, with no one to support her in navigating these challenges.

*Well, you see, you don't have anybody to talk to. And I suppose that's, that's the core of your research isn't it? Other people don't get [living with aphasia]? And, you know, most of the time, you don't want other people to get it [living with aphasia].*  
(Diana, lines 102 - 103)

Debora, when describing her experience of returning home with her husband after his stroke, explained how her sister had died after a short illness. Two significant events had occurred in Debora's life at the same time and the emotions surrounding the death of her sister and the significant changes that her husband had sustained was not fully realised until her husband was discharged home from hospital. It was only then, when Debora was on her own, that she acknowledged the intense impact these events had on her life: *“Ehm but I remember at one stage I was like, I think I'm falling apart here. You know that kind of way?”* (Debora, lines 82 - 83).

Families and SLTs also described the change in roles within the family as further exacerbating feelings of isolation with all the responsibility of family life now falling on one person's shoulders. Daisy had notable concerns that if something happened to her,

she did not know who would look after her daughter, as she felt her husband (PwA) would be unable to manage. Daisy described the extra familial responsibility that she had taken on:

*Yeah, like, everything falls on me even now. (...) like, when [Daughter] was like, small, like, smaller and stuff like that, like even, yeah, like simple things, like say, we'd be going somewhere, like going down the west or something like that and we'd stop somewhere to get McDonald's or something. I can't even say to him, like, look, I'm just gonna bring her to toilet. Can you order the food? Like, nothing like that? Like, everything has to wait for for me and like that. Like, that's really when it started to kick in.*  
(Daisy, lines 51-55)

#### **4.3.3 We needed help, but it wasn't there**

Participants, specifically PwA and family members, reported an intense period of change after the stroke and the need for support once they returned home. For some PwA and their family members, there was no support available once home. Deirdre recognised the need for support for both her and her husband once they returned home. She described her experience of seeking support from charities and stroke support services that were advised to her by healthcare professionals but was met with barriers surrounding the age of her partner.

*When we did touch base with [Charity B]. And they said that because of Arnold's age, he wasn't, he would, they wouldn't be able to help him because he's over 65. So we kind of felt that there was a lot of doors closed, even though they- we were told that they were open.*  
(Deirdre, lines 50 - 52)

While Arron described receiving some support when attending rehabilitation services, when asked if Arron would have liked more emotional support at home, Arron explicitly stated his need for more support:



**Interviewer:** *When you got home. Do you? Did you feel like you needed support? (...)*

**Arron:** *Oh, yeah fucking hell (Arron nodding head “yes” and has a worried expression on his face).  
(Arron, lines 556 - 558)*

Daisy described that while her family needed support, there was a lack of clarity on what services were available for her family and navigating the healthcare system was “a mammoth” task:

*Like, I've never been involved in the healthcare system before like, never. And it's a mammoth like (Daisy laughs). Like, it really is. And I just didn't, it's like, it's like a duck out of water. I didn't have a clue.  
(Daisy, lines 125 - 127)*

SLTs described their attempts to provide support for families in areas such as “coming to terms with (...) changes to roles” (SLT03, line 25), “talking about communication style changing [and] the aphasia impacting the relationship” (SLT05, lines 190 -191), and how “the communication deficit changes the roles and changes the dynamic and changes how that person communicates with the world and the people around them” (SLT07, lines 275 - 276). This support was provided by SLTs during the acute or rehabilitation stage of a person’s recovery, but SLTs identified that this support may be more appropriate once PwA and their families are back home.

*If you were to ask someone about the change of role in in those immediate first few days and weeks after, but in rehab it does have more of a place like at home, but there is still nearly an unknown to how that's gonna happen until the person gets home.  
(SLT05, lines 186 -188)*

During the focus groups, SLTs also highlighted the issues of a lack of support or services for families when returning home. SLT06 emphasised a lack of primary care

services in her area to support PwA when discharged from hospital, describing how: *“they're discharged to no service anywhere (...) [and] I find that challenging”* (SLT06, lines 107 - 108).

A potential barrier in accessing psychological services was identified by SLT07, who works in primary care services. SLT07 described how PwA and their partners spend time during sessions *“giving me the whole narrative”* of the effects of aphasia on their family but that there is a *“stoicness”* coming from family members insisting *“No, we’re fine”* when psychological support is offered (lines 236 – 237). SLT07, also identified that this *“stoicness”* may originate from an underlying *“stigma attached to attending counselling or psychology supports”* that is occasionally present in some clients and families who attend SLT services. Furthermore, SLT07 surmised that clients and their families *“build up a rapport and a certain dependency on us [SLTs] or a certain team member and the thought of starting over somebody else is a barrier for them”* in addition to underlying stigma *“that [the] older generation may have towards psychological supports”* (SLT07, lines 235 -240).

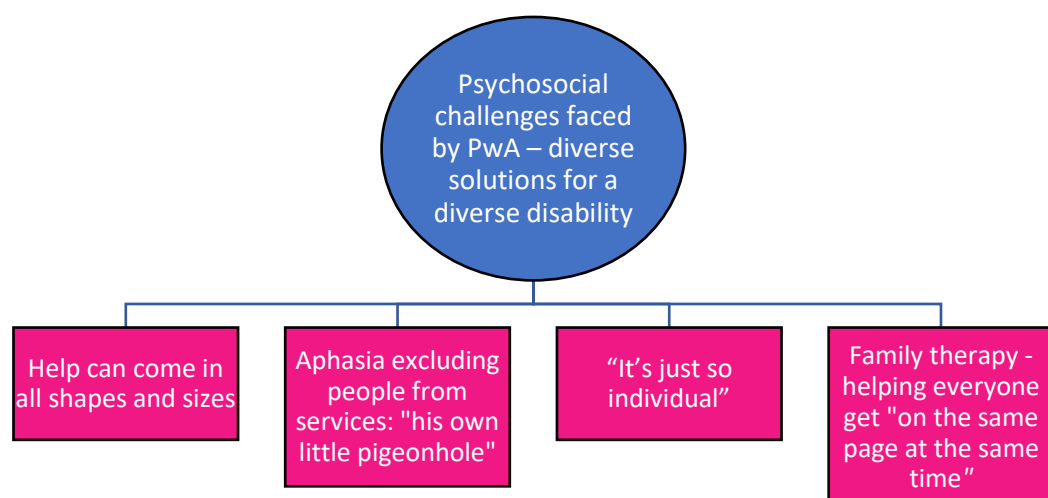
#### **4.4 Theme 2: Psychosocial challenges faced by PwA – diverse solutions for a diverse disability**

As established in the previous theme, PwA and their family members experience an intense period of change after stroke, with aphasia affecting the family roles and dynamics. Both PwA and their spouses described how this change in relationships affected their mental health, and a lack of available supports to help negotiate these changes.

The second theme, *psychosocial challenges faced by PwA – diverse solutions for a diverse disability*, centres around a reoccurring perspective from PwA, family members, and SLTs that many healthcare providers have an underlying misconception that PwA are unable to participate in traditional psychological therapies as a direct result of their communication disability. Furthermore, the role of SLT's within the context of identifying and supporting the psychological needs of PwA, is not recognised by the wider medical team. Within this theme, family members and PwA identified benefits and limitations to support which they did receive after stroke. The four subthemes that informed the theme were: (1) Help comes in all shapes and sizes; (2) Aphasia excluding people from services: "his own little pigeonhole"; (3) The needs of PwA are "just so individual"; and (4) Family therapy - helping everyone get "on the same page at the same time". Each subtheme is discussed in more detail below (Figure 7).

**Figure 7**

*Overview of subthemes under main theme: Psychosocial challenges faced by PwA – diverse solutions for a diverse disability.*



#### 4.4.1 Help can come in all shapes and sizes

With limited experience of family therapy or communication accessible counselling services, PwA and family members spoke of a range of other types of support that was experienced as helpful. This included support from health and social care professionals, carers, counselling supports, charities, and the local community.

PwA identified health and social care professionals as key persons who provided critical psychosocial support to both them and their families. Several times during the interview with Arron, he identified his occupational therapist as supportive during his transition home.

**Arron:** *Okay, okay. Now. (Arron points to “occupational therapist” written on page). Okay, now. Okay. Yeah. Now.*

**Debora:** *So the occupational therapist.*

**Arron:** *Yeah. Yeah. Fucking hell.*

**Debora:** *She was brilliant.*

**Interviewer:** *And was great. Back to this word support.*

**Arron:** *Fucking hell.*

(Arron, lines 881-891)

Similarly to Arron, Arnold stressed that his SLT provided a friendly and open environment to discuss his concerns.

**Interviewer:** *What do you like from the speech therapy?*

**Arnold:** *(Arnold looks to the page and points). This line. Nice to think because we got pictures because I'm talking to the nice and friendly. And they get good day.*

**Interviewer:** *Okay, so it helps. And they're friendly.*

**Arnold:** *Yes.*

**Interviewer:** *Friendly. That's good. And it helps you talk better?*

**Arnold:** *Yes.*

(Arnold, lines 425 - 431)

In Arthur's reflection of support obtained, he also felt that his primary care SLT greatly supported him emotionally and was the only person that he could talk to, who would actually listen to him.

**Interviewer:** So you found [SLT] really good-

**Arthur:** Yes, yeah.

**Interviewer:** At giving you kind of, would you say emotional support a little bit?

**Arthur:** Yes. Yeah.

**Interviewer:** So, so language was one- a bit of it. But she also gave you emotional support.

**Arthur:** Yeah (Arthur gives a thumbs up) (...)

**Interviewer:** Did anyone else give you any emotional support?

**Arthur:** Ah. No, no.

**Interviewer:** No. Not really?

**Arthur:** No

**Interviewer:** And- But would you have liked more?

**Arthur:** Oh, yes. Yeah, yes. I don't know. Everyday!

**Interviewer:** Everyday.

**Arthur:** Oh Jesus yeah.

(Arthur, lines 201 - 221)

Support from carers at home was highly valued by PwA and their family members, with Arron and Deborah explaining that, in their circumstances, having a carer gives Arron independence in their relationship.

**Interviewer:** Was there anything that helped you? Or you and Debora to kind of get back to some sort of routine?

**Arron:** Yeah, fucking hell yeah (Arron looks to Debora).

**Debora:** Well we had- we had [carer]. [carer] the carer.

**Arron:** Yeah fucking hell.

**Debora:** He's your care assistant isn't he?

**Arron:** Yeah.

**Debora:** And you've had him since, I think Arron

**Arron:** One, two, three, four (Arron counts out 4 on his fingers). (...)

**Debora:** So you kind of that was one of your supports wasn't it Arron? And you still have [carer] who's he's great, isn't he in fairness? (Arron nods his head "yes"). Do you know what I mean? You rub along great and he is very good. Like every day when he comes in he always checks that you're okay.

(Arron, lines 2144 - 2193)

Diana described how the healthcare professionals in rehabilitation settings focused on “*practical help*” which addressed activities of daily living, in addition to Diana’s own concerns around changes to daily life.

*It wasn't about he can get up out of bed, he can dress himself, he can wash himself, now he can go home. Do you know what I mean? It was all about what's his rehabilitation goals, what, you know, what can you reasonably expect? What can we think about? Are there any specific things specific urgent needs? Do you know that sort of stuff? And you know what, like, when you're thinking about having somebody in the house, who, who's different, you know, they're not the same person? There's no two ways about it. That's actually what you need. You need a bit of practical help.*

(Diana, lines 51 - 55)

Counselling was highlighted as a key support service which was highly valued by two significant others (Debora and Deirdre). This type of support helped participants to come to terms with stroke and aphasia and adapt to a new way of living. Notably, it was significant others who were offered this support, rather than the entire family unit.

*They were very supportive, and they offered me, counselling. So I've got six sessions of counselling with them. And I have to say, she put me back together. (Laughs) And got me going again, do you know, that kind of way she kind of helped with that stumbling block that was in my head, (...) She helped to put that to the side so that we could you know because I was kind of doing everything through guilt, you know, and we just had to find a different way of like (...) So you had to find a way to be, a different way to be. You know?*

(Debora, lines 72-86)

Deirdre highly valued her access to counselling services and accessing these services “*helped me deal with different situations*” (Deirdre, line 215). However, these services were only available for a short period of time, not fully fulfilling all her current needs.

*I actually had the services of a psychologist in [Day Hospital A]. And I found that really, really beneficial. Then [psychologist] changed role and moved. And I was of*

*the- I understood that I was going to- somebody else will be appointed. And whatever happened and I did have the conversation with the psychiatrist. And seemingly, no, I wasn't getting that service.*  
(Deirdre, lines 209 - 212)

Arron reflected on support received in the form of a key worker from a brain injury support charity. Within a supported conversation, Debora and Arron discuss how the support from key workers gave Arron more independence.

**Debora:** *Well you were you had [Charity A] then. (Arron nods his head "yes") Do you remember? [Charity A] came on board.*

**Arron:** *Yep.*

**Debora:** *And you did a two-year program with them, and you had a key worker. Do you remember you had [Key Worker 1]?*

**Arron:** *Yep*

**Debora:** *And she was fantastic. So she was a great support. And for me, I thought she was great support for me as well. Do you know what I mean? Em so that was one support you had wasn't it.*

(Arron, lines 2015-2024)

Finally, Daisy identified how support from the community after her husband's stroke was essential, describing that spending time in the community has increased social opportunities for both her and her husband.

*And that's something that I've seen really is key as well, I think, for everybody to be involved in the community and not isolate yourself or separate yourself out. And it used to concern me because I could see him getting very isolated and separated out. And but he's great, now. Like, I think walking the dog has been brilliant for him, because he gets to talk to so many people. But for myself, definitely being involved in the community and friends, you know, through the church and school and things like that. It's been brilliant.*  
(Daisy, lines 134-140)

#### **4.4.2 Aphasia excluding people from services: "his own little pigeonhole"**

With the limited services available for PwA and their families, participants spoke of services which were often not equipped to support PwA. As Deirdre described "Like

*we have support services. Don't get me wrong. But they find that difficult. Supporting us. If you know what I mean?"* (Deirdre, lines 97 - 98).

Arron and Arnold, who both attended stroke support groups with their partners (Debora and Deirdre) identified that these groups were not geared towards working-age stroke with Debora describing *"There was a support group for stroke survivors but it was a lot of elderly people. (...) But I think possibly to have something young do you know what I mean?"* (Debora, lines 447). Furthermore, stroke support groups did not meet their needs for advice regarding living with aphasia.

*I did go on the support group for the with the [Charity C] in relation to strokes, and, and found it very helpful. But I cancelled out of the calls (...) the people I was talking to were fully geared for stroke patients who had a physicality (...) but none of them were able to deal with aphasia.*  
(Deirdre, lines 52 - 55)

Arnold was referred by his SLT to attend a day hospital, so Deirdre could have some time for herself during the day, but Deirdre reported that *"Nobody there had aphasia. Nobody knew how to deal with aphasia. So Arnold was flying solo"* (Deirdre, lines 65 - 66).

When Arnold and Deirdre did attend an online support group specifically for aphasia, they identified that while the support group was beneficial, it was geared towards primary progressive aphasia.

*We went on to the support group with [Charity D]. And that was very helpful. (...) But in saying that [Charity D] were dealing with an awful lot of cases where the aphasia was as a result of dementia. So it meant that Arnold was yet again on his own, in his own little pigeonhole (...). At the end of the day we're kind of motoring along on our own.*  
(Deirdre, lines 55 - 60)



In Debora's case, she was offered support via a support group for carers of stroke survivors but did not attend the group as she expressed feelings of guilt as a result of leaving her husband on his own:

*It [support group] used to be on a Saturday and I never went because I-I was like, I'm gone. Monday to Friday. (...) And then I'm like "Well, I'm off" (...) And you're Arron sitting here for another couple of hours on your own on Saturday, so I never went to it.*

(Debora, lines 465 - 475)

Lastly, while carers were highly valued by PwA and their family members in helping families adjust to a new normal, carers often were unaware of aphasia and did not have the skills to support communication for the PwA. Deirdre described how carers coming in to provide care to her husband, Arnold, did not know how to support conversations with him.

*Because this is the whole thing. We have carers coming in and unfortunately, but it's not their fault, either. They're not trained enough to know about Arnold [aphasia], now, they all they all go on a learning curve (...) but yeah, we do feel kind of very much left on our own.*

(Deirdre, lines 75 - 78)

Participants reported a lack of accessibility, specifically for PwA, in terms of accessing traditional psychological talking therapies. SLTs attributed this inaccessibility to a number of reasons: (1) pre-existing attitudes of multidisciplinary teams to treat psychological distress with medication; (2) misconceptions that PwA were unable to participate in talking therapies because of the aphasia; (3) aphasia is a language barrier in accessing talking therapies; (4) psychologists/family therapists do not have the tools to maximise communicative success with PwA; and (5) mental health difficulties are only treated when it impacts on the person's ability to participate in intervention plans. The

lack of accessibility in psychology services is worsened by the long waiting lists to receive psychological care.

This inaccessibility was described by SLTs in multiple ways such as the pre-existing attitudes of multidisciplinary teams *“It's maybe as well the attitudes of existing teams (...) So you know mood? Give them some antidepressants and send them on their way.”* (SLT06, lines 303-304). SLT05 described the severity of aphasia as a barrier to accessing the language needed to participate in talking therapies:

*The severity of communication impairment being the primary one (...). The services offering the pure therapy are used to people who can access language. Like talking therapy is a primary is like one of the primary forms of therapy in the community. So, if people can't access that there's already like a challenge there. So, if someone has a more mild aphasia they will have more access or they will have more success in accessing traditional therapy approaches. (...) So yeah, I think the primary barrier is the severity of communication impairment.*  
(SLT05, lines 286-292)

SLTs also identified that psychologists do not have the tools to maximise communicative success with PwA, further complicating the matter of access to talking therapies:

*In terms of I suppose the psychological follow up. You know that potentially any of the care that someone's going to give eh especially if someone has a severe expressive difficulty that a psychologist would find it so hard to support them as well.*  
(SLT05, lines 146-148)

As described earlier, both Deirdre and Debora highly valued and benefitted from receiving psychological support in the form of counselling after their partner's stroke. Consequently, both Debora and Deirdre felt that counselling support for their partners would be very beneficial, but neither PwA was offered this type of support.

*Ehm and I always say, I got offered counselling. Arron didn't. He saw like a social worker, he saw ehm a psychiatrist, probably out in the [Rehab Hospital A]. If it was mood, and, but, he hasn't had [counselling] and I think [Key Worker 1] saw he had a bit of eh cause Arron dipped with his [mood]- understandably, do you know what I mean? (...) Ehm but I think there should be some form of counselling (...) For someone like Arron that has lost [his] speech.  
(Debora, lines 755-794)*

Similarly, Deirdre expressed how her partner would benefit from counselling and explicitly sought psychological support for her husband Arnold, describing to a psychiatrist that her partner needed support, but was told that as a result of his aphasia, he would not be able to access this service.

*Well you see I did ask the question (...) for Arnold to have a psychologist. We felt that there-he might open up in some way and be able to explain how he's feeling but the psychiatrist said that this wasn't going to happen because of the aphasia. There wouldn't- Arnold wouldn't be able to engage in conversation with a psychologist. So I was speechless and couldn't say anything other than. All I said was that that does not make one jot of sense to me. (...) I think that the psychiatrist isn't right in what she was saying. I can't say she's wrong. She probably does know best but I do feel that there should have been a psychologist's support for Arnold.  
(Deirdre, lines 226 - 232)*

This lack of support left Deirdre frustrated as she and her son did not have the skills to psychologically support her husband. Deirdre explained how psychologists are the professionals “*who understand how people are feeling. I am not professional enough to deal with that and neither is my son. So it's not there for him.*” (Deirdre, lines 234 – 235).

In Diana and Arthur's experience, Arthur was referred to a counselling service, but to date, has received no response from them.

**Diana:** *They [SLT and Occupational therapist] put a referral in for Arthur to have counselling. That's six years ago.*

**Interviewer:** *And you've heard nothing since?*

**Diana:** *Nothing. Zero.*

(Diana, lines 80 - 83)

In making sense of how PwA can be supported after stroke, SLTs described how members of the multidisciplinary team in which they worked, did not always value the role of SLTs and in fact SLTs were sometimes seen as “*slowing things down*” (SLT06, line 289). SLT06 specifically identified how she felt she was perceived by the multidisciplinary team in the context of an acute hospital:

*Because I find just in in a busy environment what happens is, you know you. I do my initial assessment. I convey to the team. Okay, they have problems with this and that. And then, you know, a doctor just goes to the patient. The patient nods along, and they're like “Oh, we have that sorted.” Like “Why are you slowing things down?” (...). If I was thinking about what would help me it would be to ehm-I suppose to be recognised as you know, the-the value I can bring rather than [...]. I feel sometimes there's a perception on the surface that I'm slowing things down rather than helping in terms of people's pathway through us through our acute service. (SLT05 nodding « yes » in response to SLT06's statement.) (SLT06, lines 285 - 290)*

This sentiment was also mirrored by SLT05 who had recently changed jobs from a rehabilitation unit to an acute setting, she described how there is a shift in priorities of healthcare workers “*I'm adjusting to that shift. I've had rehab now here for the last 3 years, and I'm like right we gotta keep things flowing*” (SLT05, lines 291 - 292).

SLT participants, when talking about the psychosocial changes faced by PwA in the acute phase and the acute impact it can have on the PwA's mental health, described how the team takes a more reactive rather than proactive approach to support PwA. SLT06 described how mental health difficulties are only seen when it impacts the intervention plans of the multidisciplinary team:

*I just have envisaged the NHS, or you know, other services might have more of an attitude of kind of early intervention, and you know, providing support before it's even needed. I don't think we have that ethos at all. I think we're reactive, and we deal with mood and counselling when it becomes a barrier to participating in impairment based and physical based therapies. And that's when we address it.*  
(SLT06, lines 244 - 246)

Additionally, SLT's highlighted how their role, within the context of identifying and supporting the psychological needs of PwA, was not recognised by the wider team, adding to the notion that multidisciplinary teams are reacting to mental health difficulties faced by PwA rather than trying to prevent them.

*This is not to blame other people but I'm not sure that the MDT around me, or, you know, would-would even recognize that that [counselling] would be something that I'm doing, or you know, to kind of look to me for that. I-I would find with-with the patients that we see here with aphasia. Sometimes I find myself in a role of I am nearly being like I'm counselling about everything because you are the person who's most in contact with the family to try and get resources, get photos, you know, get-get background.*  
(SLT06, lines 96 - 99)

During the focus groups, while no SLTs had experience of referring PwA and their families to family therapy, discussions were had more generally about how psychological services such as family therapy could be made more accessible. SLTs identified themselves as having an integral role in supporting both PwA and their families in accessing these services. SLT07 described how the “overall role” of SLTs is to support “communication participation” and that accessing family therapy requires SLTs to support “communication participation” (SLT07, line 340). Furthermore, SLT07 emphasised that if PwA are “accessing a service that they're not able to access from a

*communication point of view then that's part of what we should be doing is supporting that access for them"* (SLT07, lines 342-343).

While SLTs described that working with family therapists was possible, they had some concerns around family therapists' comfort levels in supporting PwA, recognising this discomfort as a barrier in providing family therapy to PwA and their families. SLT07 reflected on her previous experience of joint working with counselling services describing that *"I don't think other colleagues within the psychology and counselling profession feel comfortable working with clients with communication disabilities"* (SLT07, lines 217 - 218). SLT02 felt that if PwA and their families are accessing family therapy, and the family therapist is *"unable to support communication from that perspective"* (SLT02, lines 268), then PwA are at "risk" of not being able to fully engage and benefit from this therapy. SLT05 described how this would significantly impact PwA *"especially if someone has a severe expressive difficulty that a psychologist would find it so hard to support them as well"* (SLT05, lines 118 - 119).

#### **4.4.3 The needs of PwA are "just so individual"**

The range of supports experienced by PwA were mirrored by the recognition of the diversity of aphasia. SLTs' emphasised the individuality of PwA *"because everyone's aphasia will be so different"* (SLT01, lines 237) and the effects it has on the family system vary between families. Therefore, support provided to family needs to be tailored and specific to each scenario that it is required. As described by SLT01:

*Their needs will be so specific and individual because you could have somebody very high level with kind of very mild really linguistics deficits. But who wouldn't necessarily require any kind of concrete supports let's say but just time. And it's different, it's just so individual to the person it's hard to know.*  
(SLT01, lines 231 - 233)

Within the PwA and their family members' accounts of support that PwA received after stroke, support groups were talked about in a more negative frame. For example, when asked about any support that he might have received, Alan described his experience of a support group, where he went to one session and did not return.

**Alan:** *Eh no, this is the table the table and absolutely for get out of here like. Get out of here. (...) Stroke a stroke and stroke.*

**Interviewer:** *So, it was a support group?*

**Alan:** *Yes.*

**Interviewer:** *Okay. And you didn't like that?*

**Alan:** *No. Where they were coffee and biscuits over here. Like, come on, like. (...) One and no more.*

(Alan, lines 511-528)

When provided with an alternative to support groups, Alan felt one-to-one support would better suit his needs.

**Interviewer:** *You didn't like the stroke support group with all of the people sitting round.*

**Alan:** *No, no, no, no.*

**Interviewer:** *(...) you think that maybe if you and Daisy went to one person that might be-*

**Alan:** *Yeah, yeah getting them all.*

**Interviewer:** *(...) so if you and Daisy were to go to that one person what would you like from that?*

**Alan:** *A group no and a woman yes. (...) That's really good like.*

(Alan, lines 698-714)

Similarly to Alan, Arthur also expressed his disdain for support groups and his preference for individual support.

**Interviewer:** *Would you have liked to go to a support group with other people or?*

**Arthur:** *No, no, no.*

**Interviewer:** *No, you'd prefer one on one?*

**Arthur:** *Yeah, yeah.*

**Interviewer:** *That'd be better.*

**Arthur:** Yeah.

**Diana:** *You did go at one stage right at the start. [SLT] put you in touch with the [Charity D]?*

**Arthur:** *Ah yeah, yeah, yeah.*

**Interviewer:** *And did you like that or?*

**Arthur:** *No! No, no, no.*

**Interviewer:** *No, it wasn't your cup of tea?*

**Arthur:** *No, no.*

(Arthur, lines 494-504)

The averseness to group support was also mirrored in the accounts of family members with Debora describing how her husband avoids groups as a result of his aphasia, explaining that Arron: *“Did not like group work and does not like group work. (...) He's just no no no no. (...) I think he does be a bit lost in it. You know, so he kind of avoids that.”* (Debora, lines 380-385).

Debora felt that peer support such as a *“buddy up system”* would better support the psychosocial needs of her husband in addition to benefitting the peer supporter.

**Debora:** *Or eh not a buddy up system. But you know the way they do a buddy up system at school. (...) Where they (...) try link in with someone like Arron with someone like Arron (...) Do you know what I mean?*

**Interviewer:** *Yeah, and that you could kind of meet up and and you know talk about-*

**Debora:** *Yes yeah.*

(Debora, lines 836 – 848)

#### **4.4.4 Family therapy – helping everyone get “on the same page at the same time”**

The fourth and final subtheme under the theme ‘Psychosocial challenges faced by PwA – diverse solutions for a diverse disability’ is centred on the idea that aphasia affects every person differently, therefore, supports offered need to represent the diverseness of aphasia. As described above, families and SLTs have identified a disparity in support offered when PwA return home. While no families or SLTs had direct experience of family therapy, when asked about its potential value after stroke, families



agreed that it would have been beneficial, with Diana explaining “*there's no two ways about it. That's [family therapy is] actually what you need*” (Diana, lines 54 - 55). Families and SLTs identified a number of reasons of how family therapy could help their family. These goals included; (1) addressing changes in roles and identity that happen as a result of aphasia; (2) navigating family life after stroke; (3) adjusting to a new way of living; (4) explaining changes in family life in a non-medical context; (5) the social reality of aphasia; (6) therapy and practical support .

SLTs participating in the focus groups described family therapy as “*really useful*” (SLT01, line 192) with SLT07 specifically addressing the need for family support in primary care:

*If there's a counselling that addresses the change in roles and change in identity, then absolutely because that's at the core of what's happening for our clients with the aphasia, and especially I would see that now in primary care.*  
(SLT07, lines 173 -175)

In the context of needing support to navigate family life after stroke, PwA agreed that it would have been useful for them and their family.

**Interviewer:** *Is that [family therapy] something that you think kind of at any stage over your time since you've had your stroke might have been useful?*

**Arron:** *Ehm eh. Maybe, maybe, yeah.*

**Interviewer:** *So maybe it might have been. (Interviewer writes down Family Therapy). So you think family therapy, it may be it might have been useful, or do you think Oh, definitely, we really needed it or not? Definitely we didn't need it. Or it might have been useful but.*

**Arron:** *Ah yeah. Yeah fucking hell. Yeah*  
(Arron, lines 1176 - 1181)

When prompted, Arthur described how he and his family needed support daily to adjust to a new way of living.

**Interviewer:** *And- But would you have liked more [family support]?*  
**Arthur:** *Oh, yes. Yeah, yes. I don't know. Everyday! (...) Oh Jesus yeah.*  
**Interviewer:** *Because every day is difficult and*  
**Arthur:** *Oh yes, yeah.*  
**Interviewer:** *And you're learning to kind of live in a new way again.*  
**Arthur:** *Yes, yeah.*  
(Arthur, lines 218 - 225)

When asking family members about the value of family therapy after stroke, family members felt that *"there should be some form of counselling"* (Debora, line 428), or therapy that allowed the family *"to think about different ways of dealing with it [changes after stroke]"* (Diana, line 99), a resource to explain changes *"in a non-medical context"* (Diana, line 97) and focus on *"the social reality of it all"* (Diana, line 98). Furthermore, Debora highlighted the fact that her family needed *"Therapy along with practical-practical advice and support. (...) in hindsight, yeah, it [family therapy] would have been a good thing"* (Debora, line 149).

Debora explained that in her situation, family therapy *"would be brilliant"* and *"would help everybody feel that they're doing alright"* (Debora, lines 286; 367). Additionally, Debora identified how her husband does not always understand the effect that stroke has had on her, and that family therapy would be useful to explore conversations with Arron about this.

*Sometimes I think Arron, is, I thought this, he's empathetic. Don't get me wrong. (..) But he has to survive. And (...) he's dealing with [something that] is 100 times worse than it is for the rest of us to know what I mean (...) So sometimes I think an odd time I might have to say to him, about me. Arron I'm sorry but you're gonna have to wait for a few minutes? Sounds awful. (...) But like, you have to wait for a few minutes? I'll do it when I'm ready. You know?*  
(Debora, lines 288 - 295)

Some family members reflected on the idea that family therapy would have helped to discuss issues that arose in the more acute stages of stroke which has now been brushed over and left unaddressed. Diana described the potential usefulness of family therapy in her family explaining:

*I think it would have been useful- in our case, right? We're not. We're not a family that kind of talks about kind of deep things. Do you know what I mean? Ehm I think it would have been helpful. Maybe one or two sessions? For sure. Just to let people have a space to say stuff. That can't be said now because we've moved on.*  
(Diana, lines 141 - 143)

Daisy highlighted how in her situation, she felt uncomfortable discussing certain topics with family or friends and needed another person to talk to.

*God it would have been so helpful to have somebody to talk to even to because sure there's a lot of stuff you can't talk to close family or friends, and you just don't want to or whatever.*  
(Daisy, lines 124 - 125)

Debora explained how family therapy would allow everyone to:

**Debora:** *family therapy would be fantastic thing just to get everyone in a room (...) And I think it would just help for everyone to be on the same page at the same time. And to know this is what Arron needs or this is what someone else needs. (...) To have that space where this is where we're gonna help Arron. Arron this where you could possibly do, you know. And this is how we're going to? Yeah, definitely.*

**Interviewer:** *Everyone's voice is heard within that.*

**Debora:** *Yes. Yeah*

(Debora, lines 338 - 403)

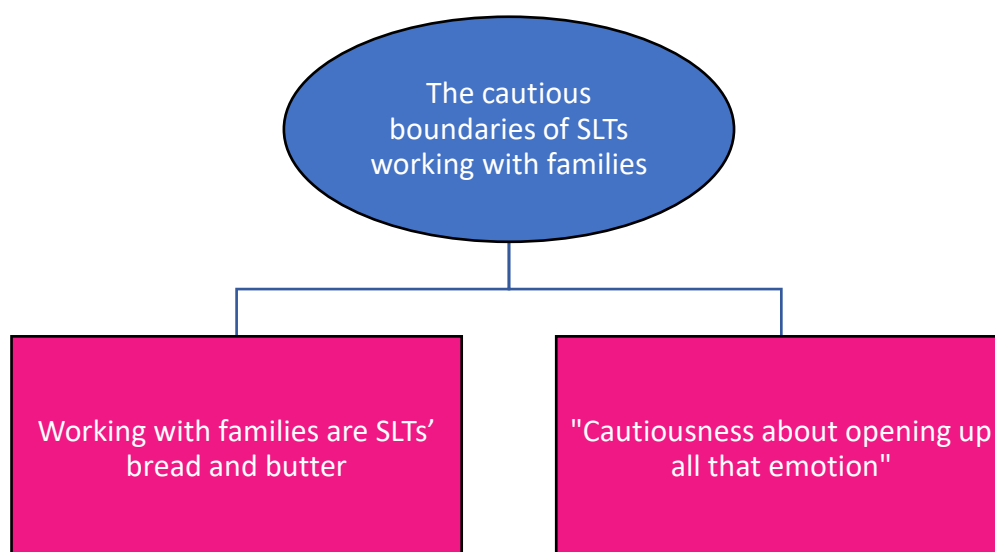
#### **4.5 Theme 3: The cautious boundaries of SLTs working with families**

In the context of unmet psychological needs of the family, as discussed in theme two, the SLT participants in this study addressed the issue of their professional role in supporting PwA and their families after stroke. While SLTs identified that working with

families is a core part of their profession, the primary method of involving family members was often through the use of communication partner training (CPT), focusing specifically on communication success rather than on the family roles and dynamics. SLTs expressed supporting families with cautiousness as they often were unsure of where to direct them for support. Furthermore, SLTs communicated that they felt they lacked the skills, confidence, and experience to use counselling techniques to support families. This was exacerbated by a lack of psychology presence to support SLTs on multidisciplinary teams. Consequently, SLTs expressed feelings of guilt, knowing that these families would be left with no help. The third theme, *the cautious boundaries of SLTs working with families*, represents these perspectives. The two subthemes that informed the theme, *the cautious boundaries of SLTs working with families*, were: (1) Working with families are SLTs' bread and butter; and (2) "Cautiousness about opening up all that emotion". Each subtheme is discussed in more detail below (Figure 8).

**Figure 8**

*Overview of subthemes under main theme: The cautious boundaries of SLTs working with families.*



#### **4.5.1 Working with families are SLTs' bread and butter**

In the wider context of the role of SLT in supporting families, SLTs commonly agreed that working with families was a *“key part of the work that I do”* (SLT03, line 33), *“it’s what I do every single day”* (SLT03, line 32), and that working with families is *“critical to (...) a continuum of care and creating a positive environment at home”* (SLT02, lines 66-68).

SLTs described providing familial support across a wide range of settings with the type of support offered changing dependent on the stage of rehabilitation.

In more acute stages of recovery SLTs described providing *“family education”* (SLT04, line 44), which included helping families *“get their head around the fact that communication can be affected after a stroke”* (SLT05, lines 365), understanding *“aphasia and presentation that [the] particular person has”* (SLT04, line 45), and providing *“basic resources”* (SLT05, lines 366). SLTs worked on helping families support communication by discussing *“the communication deficits and strength of the clients and we did a lot of work around communication passports.”* (SLT07, lines 35 – 37). With SLT05 sending family members a video which explains aphasia at a *“very just basic level, I think at the moment is the acute priority here”* (SLT05, lines 368 – 371).

Within the rehabilitation stage of recovery, SLTs described a range of supports which differed from that offered in the acute stage, summarising that the support they provided was a *“counselling supportive role”* (SLT01, line 52). At this stage of recovery, the main support offered by SLTs to families was CPT with SLTs valuing the *“large*

*psychosocial element*” (SLT02) that comes with using this training. SLTs valued the use of CPT with families to help support the *“transition home”* (SLT05, line). While the use of CPT was described as a counselling technique with psychological elements by one SLT, they specifically focus on conversation, rather than considering the wider psychological impact of aphasia.

*There's a huge element of counselling skills in that in terms of videoing or identifying something that's going well. Leaving space for self-exploration and the person themselves to identify what helps in the conversation or not.*  
(SLT05, lines 74 - 75)

Another tool utilised by SLTs in the rehabilitation stage was peer support groups for family members. These groups focused on providing education around aphasia and its effect on communication and helped families with *“coming to terms (...) [with] changes to roles”* (SLT03, line 37). Family members involved in these sessions ranged from *“groups for children, groups for teens (...) and groups of kind of peer support groups for partners and family education days”* (SLT01, lines 63-64).

SLT03 described her experience of working with grandchildren *“where the grandchildren were very important you know part of the person's life”* with a specific focus on the communication between grandchildren and their grandparents (SLT03, line 61).

*I would've kind of been observing first off, cause often the person with aphasia might say or their family member might say the communication is much stronger with the grandkids. So I'd kind of observe and try and kind of I suppose let the adults family members kind of see how easy the communication can be when certain conditions are there. (...) And explaining [aphasia] to kids.*  
(SLT03, lines 65 – 67)

SLTs who worked in early supported discharge (ESD), or primary care centres reflected on the inclusion of families in the provision of their services often citing that it was easier to include family as sessions took place “*in the family home*” (SLT01, line 49). SLT01 described the manner in which they work with families as part of ESD, focusing on the fact that therapy will be more family focused because family members are present during sessions.

*I noticed a contrast when I'm on ESD rotation, and I mean I'm in the family home and so the family is kind of very eh integral to the rehab, and it really is kind of more family oriented because you're in their home, and you probably have to be involved, and they've invited you in.*

(SLT01, lines 49-51)

SLT05 identified that while family members want to be involved in sessions and it is easier for them to be involved, it is important that the PwA is at the centre of the session and is prioritised.

*It was a lot easier to get families involved, you're in the home, family members are present. They're interested. They want to sit in on sessions, but again guided by the person with the aphasia, guided by their severity, and what they want to work on.*

(SLT05, lines 53 – 56)

Family members of PwA also identified benefits from being involved in speech and language therapy sessions. Daisy described how participating in sessions with her husband allowed them to reconnect by doing a shared activity:

*It [speech and language therapy] helped us bond again as well, because you almost have to re-bond as a couple after something like this happens. It was because you both change. Changes everybody, like in a family, I think. So yeah, definitely found that helpful.*

(Daisy, lines 100 - 102)

Debora discussed the importance of attending speech and language therapy sessions to help improve communication between her and her husband.

*Because you want to see what they were doing what was happening, and try and pick up some tips, you know, that you could carry on. Back even the simplest things of piece of pen of paper and pen, yeah, and figuring out. And we used to do a lot of that. (...) Writing the key words, I always found that speech and language therapists started doing that and that was helpful.*  
(Debora, lines 104 - 107)

#### **4.5.2 "Cautiousness about opening up all that emotion"**

Within the context of supporting PwA and their families, SLTs often felt like they were unable to support their patients' psychosocial needs to the extent that was required with SLT06 stating *"I would always like to do more"* (SLT06, line 30). Feelings of restraint around supporting the psychosocial needs of PwA and their families was described by SLT07 as *"a kind of a cautiousness about opening up all of that emotion"* (SLT07, lines 184).

SLTs who described these feelings of cautiousness and restraint often cited a lack of skills, confidence, and experience in using counselling techniques. SLT06 described their hesitation around addressing the psychological aspects of aphasia with their clients due to a fear of being unable to manage any situations which arise as a result of these conversations.

*And I just feel like if I was to even say anything, I'm afraid that that it would cause upset that I'm not sure I have the skills to manage. (...) I just have that fear of it, you know. If I go, there is everything going to fall apart and I won't know what to do with it then?*  
(SLT06, lines 152 - 155)



SLT05 discussed their experiences of using CPT and feeling uncomfortable with even addressing communication changes that have occurred as a result of aphasia with family members.

*[Counselling is] something (...) I'd want more confidence with. It is challenging. (...) Even I suppose even conversation partner training. There's a huge element of counselling skills in that in terms of videoing or identifying something that's going well. (...) [I felt] really uncomfortable talking about or challenging a family members communication style, and what they can improve.*

(SLT05, lines 73 - 78)

SLT07 reflected on a specific situation where one client with aphasia had a young child, and she was unsure of how to address changes within the family, as this was her first experience of working with a family who had young children.

*I'm very aware that I haven't involved her [the child] ever in therapy, and I sometimes check in with myself, and think, should I? And is that appropriate? And she doesn't know any different. And if I do, how would I? Even she doesn't know Dad any other way. What would I do? What would that look like if I just I haven't gone there at all. (...) I've never had a client as young as this particular client and with a young child, I think, on my part, it's-it's purely inexperience.*

(SLT07, lines 136 – 143 )

SLTs also highlighted that PwA and their family members are sometimes not ready to discuss topics around emotions and feelings of changes after stroke where PwA are just “*trying to have a brave face for their family and try to keep it together*” (SLT06, line 152). Furthermore, barriers within the broader context of the healthcare system, such as services available to PwA after discharge from acute care, impacts on how they navigate conversations about psychological wellbeing with SLT06 expressing “*Then where do you direct them for supports?*” (SLT06, lines 184 – 185). In one instance, SLT06 appeared to feel constrained in how much she was able to engage with clients about

their emotions and feelings about aphasia, because of the limited services available to this cohort in the context of the wider healthcare system.

*So I find that part particularly difficult with counselling as well because we don't have psychology [services], we don't have neuropsychology [services]. It's a hard place to get into with people because I'm always conscious you know you're trying to explore feelings and recovery, not knowing if the person can access anything once they leave the hospital.*

(SLT06, lines 102 - 105)

Additional barriers identified by SLTs included the lack of psychologists on multidisciplinary teams impacting on how they approach conversations around psychological support.

*Alone as a speech and language therapist it was, it was hard to do that work alone like it would have been. I'd have liked a colleague and then I'm thinking maybe neuropsychological support, or someone psychotherapy. Someone.*

(SLT05, lines 192 - 194)

While SLT07 was aware of services, citing “*I'm quite comfortable having those conversations and knowing where to sign post in terms of additional psychological supports*” (lines 84 – 85), she identified that psychology services often do not accept people with communication disabilities, mirroring the discussion in the previous theme around misperceptions of PwA abilities to participate in counselling sessions.

*We're also running into some barriers in terms of psychology accepting them for CIPC [Counselling in Primary Care] the community counselling service. And I'm finding that not just with the aphasia clients but that client's kind of with communication difficulties they're sort of being banded around a little bit between services. And I don't know what's driving that and I'm always saying on the referral forms “Has communication disability. Link with me and I will help facilitate for a first session and link in.”. And there isn't that same mutual way of working and some of that is just historic.*

(SLT07, lines 213 - 217)

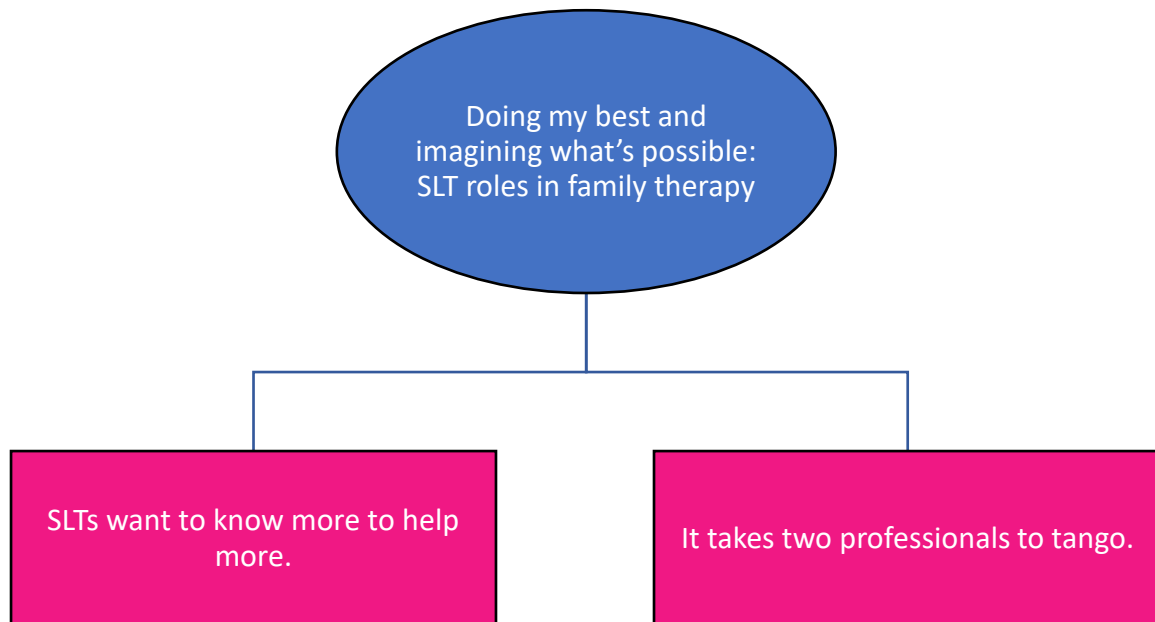
Consequently, SLTs recognised that families don't always "*have a place to discuss that [changes]*" (SLT07, line 180) and were often isolated once they were discharged. Moreover, SLT06 described her reluctance and guilt around not addressing these psychosocial challenges as a result of aphasia citing how "*not knowing if the person can access anything once they leave the hospital*" can make her "*start to feel responsible if I nearly say too much because yeah, you're afraid that that then you're setting them up to be disappointed*" (SLT06, lines 104 -106). While SLT05 was aware of charities such as Aphasia Ireland, and referred clients to those services, she had "*no personal experience of engaging with them*" and had no "*feedback from clients*" about the services but hoped that it was "*something good*" (SLT05, lines 114 - 115).

#### **4.6 Theme 4: Doing my best and imagining what's possible: SLT roles in family therapy**

The fourth theme, *doing my best and imagining what's possible: SLT roles in family therapy*, centres on the perspective that while SLTs want to support PwA and their family, they require more practical training and resources to do so. Furthermore, SLTs identified the need for open communication and interdisciplinary working between family therapists and SLTs to make family therapy work. This interdisciplinary work involves SLTs supporting family therapists' communication with PwA including communication supports. Additionally, SLTs want family therapists to help them in supporting PwA dealing with changes in roles as a direct result of communication disability. The two subthemes that informed this theme, *doing my best and imagining what's possible: SLT roles in family therapy*, were: (1) SLTs want to know more to help more and (2) It takes two professionals to tango (Figure 9).

**Figure 9**

*Overview of subthemes under main theme: Doing my best and imagining what's possible: SLT roles in family therapy.*



#### **4.6.1 SLTs want to know more to help more**

In this wider context of supporting PwA and their family, SLTs commonly argued that while they did have a *“module in counselling”* during college *“nothing kind of prepared you for it [supporting PwA and their families in the context of psychosocial changes]”* (SLT03, lines 129 - 130). SLTs recounted how counselling modules were *“theory based”* (SLT04, line 127) and lacked *“specifics around supporting someone with maybe more visual aids or techniques to support their expression”* (SLT05, lines 69 - 70). With one SLT explaining how the module they had received *“didn't leave that much of an impact”* (SLT01, lines 135 - 136) and another stating that she *“never had formal training”* (SLT06, line 96). As a result, SLTs reported that *“the hardest coming into my career as a speech therapist is that family kind of counselling education”* (SLT04, lines

127 - 128). With SLT04 suggesting *“more practical education (...) would be definitely worthwhile and beneficial.”* (SLT04, line 128).

To counteract the lack of practical training in supporting PwA and their family, SLTs described how they sought additional training outside of college. A range of training programs were described. These included *“a week’s intensive course in counselling people with communication difficulties”* (SLT03, lines 130 - 131), the *“supporting emotions with aphasia series”* (SLT02, line 149), *“motivational interviewing”* (SLT03, line 132), and *“solution focused brief therapy”* (SLT01, line 138). SLT01 participated in a course on the use of solution focused brief therapy with PwA and utilised a family case. SLT01 benefitted from the use of a family case in this conference as:

*Families do want solutions and kind of it, can help to move away from maybe that not negative focus, but that focus, that everything is wrong. And how can it be fixed? So it was a good approach.*  
(SLT01, lines 143 - 144)

Additionally, while SLTs identified some materials which are available to support PwA in talking about their emotions such as *“Talking Mats training and the Better Conversations [training] and communication partner training”* (SLT06, lines 255 - 256), *“blob trees”* (SLT05, line 72), and the *“VASES [visual analogue self-esteem scale]”* (SLT05, line 72), SLTs expressed a need for *“more tangible resources”* (SLT07, line 93). SLT07 described the lack of *“resources for this particular cohort can be challenging”*, resulting in her *“making things up as I go”* (SLT07, lines 85 - 87).

While SLT05 had access to resources to assess a component of wellbeing, specifically self-esteem, she did not appear to feel confident in taking action on the

findings, leaving her feeling that it was *“A really cruel thing to put someone through”*

(SLT05, lines 120 - 121). In her experience of using this assessment SLT07 described how:

*The pictures are so un-expressive. The words are really hard, and it's a really again, if you're asking people questions and they're rating, and you're not offering anything (...) if you're bringing the VASES to someone, and it's like, yeah, if you feel anxious and you feel depressed and you feel like X, Y, and Z, and you're just sitting with that, I suppose rather than having a solution focused approach then after. It's hard.*

(SLT05, lines 121 - 125)

SLTs recognised that within sessions *“you are balancing different family relationships and personalities and all that”* (SLT04, line 271). Consequently, SLTs want to learn more about *“the principles or background or processes [of family therapy]”* citing that it *“could be helpful in the part that we do”* (SLT01, line 262 - 263) and *“just knowing kind of techniques to navigate through that could only be helpful as well.”* (SLT04, lines 271 - 272). SLT02 identified that understanding *“the full extent of services that are available”* would be valuable in helping to *“flag very early on if you think this [family therapy] might be something someone would be of benefit.”* (SLT02, lines 264 - 265). Finally, SLT07 suggested that having a toolkit to support PwA and families that was *“aimed at speech and language therapists to use that would be ideal”* (SLT07, line 90).

#### **4.6.2 It takes two professionals to tango**

As part of the focus groups, SLTs were asked to reflect on how they can support PwA and their families in negotiating family changes because of aphasia. SLTs established that there *“definitely is a role”* (SLT02, line 269) for SLTs within family therapy for this specific population. SLT07 explained that because *“the communication deficit changes the roles and changes the dynamic and changes how that person*

*communicates with the world and the people around them*” then SLTs *“definitely have a role in being able to support the emotions that come from that as well”* (SLT07, lines 275 - 277). SLTs also recognised that while they have a core role in supporting the emotions around communication changes and its impact on role changes, they are not *“equipped to do it [support families] by ourselves”* (SLT07, line 278). Throughout the focus groups, there was agreement that there is a need for *“joint piece of working, linking in with our colleagues [family therapists]”* (SLT07, lines 278 - 279), with SLT05 commenting that if SLTs are *“putting ourselves out there that they [family therapists] come and join us, and that we work together”* (SLT05, line 311).

In the absence of experience in working with family therapists, SLTs were asked to imagine what could make family therapy accessible for PwA and their families. SLTs drew on previous experiences of joint working with healthcare professionals in supporting PwA to access services. In identifying ways in which joint working could occur, SLTs came up with a number of methods. Firstly, SLTs identified their role in providing more general advice around supported communication to family therapists *“making sure that the family therapist is a good communicator and understands how to support conversations”* (SLT03, lines 221 - 222) with PwA. Secondly, SLT03 established that open communication between SLTs and family therapists about the needs of a specific PwA including *“what works best”* was essential in supporting PwA to access this therapy (SLT03, line 230). SLT07 specifically described how she would support family therapists in relation to a specific client *“so I mean even for the therapist working with him to know that he needs more time or the picture support”* (SLT07, lines 251 - 252). Thirdly, SLTs highlighted the importance of making sure that PwA *“can access it [family therapy] and that they don't feel more alienated and isolated in a session that all the*

*other communicators are at higher level*" (SLT05, lines 267 - 268). To ensure that PwA feel equal within family therapy sessions, SLT05 explained how sessions should not be *"so language heavy"* and *"ensuring that no matter what, the family therapy is (...) at their [PwA] level [of comprehension and expression]"* (SLT05, lines 260 – 264). Lastly, SLT01 discussed how she would approach the topic with a PwA explaining how *"if you're aware, (...) that they're (PwA) going to these therapy sessions, it'd be something that you'd help them prepare for just like you'd be helping them prepare for other ADL's [activities of daily living]"* (SLT01, lines 242 - 244).

Throughout the focus groups, SLTs reflected on their experiences of working in individual therapy in tandem with a psychologist, recognising that these skills in joint working are transferable to support joint working with family therapists. These skills included: (1) SLTs demonstrating supported conversation during psychology sessions; (2) SLTs helping to reliably establish how a PwA is feeling; (3) psychologists observing SLT sessions; and (4) psychology drop-in clinics where SLTs could receive support from psychologists about adjustments to life after brain injury. While SLTs established that they had a core role in supporting PwA and their families, they emphasised that this work cannot be completed independently, and they need family therapists to work with them to make family therapy work.

Within psychology sessions for PwA, SLTs discussed their role in these sessions as *"demonstrating the kind of supported conversation bit"* (SLT03, line 176) and *"allow that conversation [about psychological health] to happen"* (SLT04, lines 165). In an acute setting, SLT01 described joint working with the stroke team psychologist around *"mood concerns"* of PwA, with the psychologist including SLT01 in sessions where it *"would be*



*beneficial in establishing reliably where or how they're [PwA is] feeling"* (SLT01, lines 168 - 169). In the rehabilitation setting where SLT02 works, there were psychologists who have been trained in using supported communication techniques. When a PwA was referred to psychology for concerns around mood, the *"psychologist would always jump in on our [SLT] sessions"* to observe the communicative ability of the PwA, allowing the psychologist to establish *"that they'd be able to support a talking therapy approach or whether I may need to jump into some of their direct sessions, as well to support the patient from a communication perspective"* (SLT02, lines 155 - 158). SLT02 felt that a *"mixed approach"* as described above could work with a family therapist (SLT02, line 160). SLT05 had experience working as part of a community team (primary care) as an SLT in the U.K. where there was a weekly *"neuropsych drop-in clinic"* (SLT05, line 196). In this clinic, SLTs could discuss concerns if they felt their client needed *"counselling support"* for a number of reasons such as *"an adjustment to brain injury, adjustment to diagnosis, adjustment to life at home, [or] relationship changes"* (SLT05, lines 197 -198). The neuropsychologists would then provide *"strategies and advice"* to support their clients or *"get input [therapy]"* from a neuropsychologist on the team (SLT05, lines 198 - 199). The *"opportunity to discuss those cases with someone with counselling and psychological training"* allowed SLT05 to support her clients independently (SLT05, line 202). This section demonstrates that SLTs want to work with family therapists to support PwA and their families to live in a new way after stroke and aphasia.

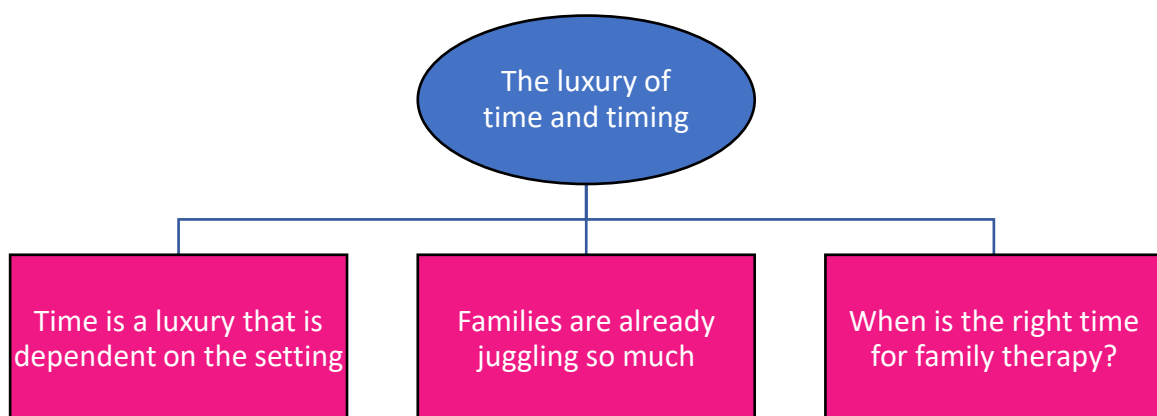
#### **4.7 Theme 5: "There is just so much going on" - The luxury of time and timing**

The final theme, *"There is just so much going on" - the luxury of time and timing*, represents a two-fold perspective on the concept of time. From the perspective of SLTs,

they identified that they had a lack of time to spend with PwA and their family as a result of staffing constraints and competing priorities. Family members of PwA identified that during the acute and rehabilitation stages of stroke, they often have to juggle newfound responsibilities in addition to supporting their partner and attending therapy sessions. Therefore, support to help navigate the changes in roles and responsibilities needs to not add to the stress felt by family members. Finally, SLTs, PwA, and family members, identified when might be the 'right time' for family therapy to occur, and in what context. The three subthemes that informed this theme, *"There is just so much going on"* - *the luxury of time and timing*, were: (1) time is a luxury that is dependent on the setting; (2) families are already juggling so much; and (3) when is the right time for family therapy? (Figure 10).

**Figure 10**

*Overview of subthemes under main theme: "There is just so much going on" - the luxury of time and timing.*



#### **4.7.1 Time is a luxury that is dependent on the setting**

SLTs highly valued having ample time to spend with both PwA and their family members and that spending more time with families “*would be lovely*” and they “*would always like to do more [with families]*” but SLTs recognised that they often do not have “*enough time to work with families*” in addition to a lack of “*resources to engage with that [families]*” (SLT06, lines 242; 20; 47; 242-243).

In particular, a lack of time was felt by SLTs most in the acute stage of a person’s stroke journey as “*there is just so much going on*” (SLT04, line 206) during this time. SLTs within the focus groups discussed their struggles to allocate enough time to provide, at a basic level, language interventions to their patients with aphasia, let alone family members, as in the acute stage “*priority is given to dysphagia*” (SLT06, line 21). SLT06 specifically identified how valuable it would be for her to have more “*time and the availability to get to know the person [with aphasia]*” as “*aphasia and the communication effectiveness can change*” it would improve her “*confidence around [supporting] family [in negotiating role changes]*” by having a better understanding of the family dynamics (SLT06, lines 281 - 283). Similarly, SLT01 explained how a lack of time in the acute phase means that she does not have “*a lot of time to do intervention with families*”, instead giving families a “*quick bedside update when you meet them on the ward or giving them a phone call more so now since Covid*” (SLT01, lines 33 - 34). SLT06 reported that because of “*staffing and time constraints (...) families tend to kind of get pushed to the back a little bit*” (SLT06, lines 21 - 22).

While SLTs emphasised that a lack of time and staffing constraints meant that they cannot always support families, SLT01 expressed that family members may not

always want this support immediately. Instead, family members may want to prioritise the communication rehabilitation of the PwA in the acute phase saying that they *“should be getting all of the therapy now [and] this is the intensive part”* (SLT01, line 112).

Therefore, SLT01 felt that it would be difficult *“to justify the spend of the session on the family (...) it would be hard to sell that”* (SLT01, lines 111 - 113).

Time pressures on SLTs change as a person moves through their rehabilitative journey and in the context of rehabilitation units and primary care, SLT02 described how SLTs have *“the luxury of a little bit more time”* to spend with PwA and their families (SLT02, line 40). The time available in these settings allows SLTs to focus on educating family members and providing them with resources to support changes in communication. SLTs described how they could work with a multitude of family members including close and extended family, with SLT03 describing her work *“spouses, adults, children and (...) a good bit of a grandkids actually. Where the grandchildren were very important you know part of the person's life”* (SLT03, lines 60 - 61). SLT02 described how working with family members *“really varies”* and is *“more responsive as opposed to something that we always actively have as an ongoing”* (SLT02, lines 56 - 59).

#### **4.7.2 Families are already juggling so much**

Family members reported that they benefitted from involvement in therapy sessions with their partner and *“really felt it was very important to be there, like, as much as I could”* (Daisy, line 100) (as discussed in the subtheme of theme 3, *working with families are SLTs' bread and butter*). Although they valued attending sessions with their partner, the newfound roles and responsibilities of the primary caregiver often

meant it was difficult for spouses to juggle attending sessions and while also carrying out their additional responsibilities.

PWA often have a multitude of appointments to attend upon discharge from acute care with significant others often having to organise getting their partner to these appointments while juggling additional household activities. Debora explained that even now, five years after her husband's stroke, her days revolve around scheduling appointments with "*[Charity A], [Charity B], physiotherapist, speech and language, occupational, going out to [Primary Care C] appointments (...) going for Botox, going for medical appointments, and making phone calls dealing with emails*" (Debora, lines 71 - 73). In Debora's situation, she had no other family to share the responsibilities with so "*everything falls to you (...) especially at the beginning [after discharge from acute care]*" (Debora, line 70) with Daisy explaining how organising and getting to appointments "*was really stressful (...) the more appointments you have, the more stress it's adding to you as well*" (Daisy, lines 165 - 166). Diana also experienced feeling overwhelmed with being involved in sessions and "*trying to work as well*" (Diana, line 70). Diana emphasised in the later stages of her husband's rehabilitation, she took a step back from attending sessions with him to focus on herself as "*body and soul have to be kept together*" (Diana, line 71).

SLT01 emphasised that in her clinical experience, family members attending therapy sessions acts as a "*demand that people have on their time*" (SLT01, line 193) especially when the spouse is "*working to kind of be the breadwinner if the other person is out of work, or minding the kids*" (SLT01, line 192). Daisy, now acting as the sole financial provider for her family, described attending sessions with her husband as

*“stressful trying to manage, like work and to be there at the sessions as well”* (line 99) and it was difficult trying to balance all of her new responsibilities. Debora also agreed that it was difficult to *“fit all that [sessions] in around your work”* (Debora, line 72). Daisy explained that while family therapy would be beneficial, you have to *“balance between getting help, the actual getting help adding more stress on to you because you have to try and make time somewhere”* (Daisy, lines 166 - 167).

Debora constantly focused on her husband’s recovery and tried to *“always put him [Arron] first”* and *“explain to Arron [about] different things that were happening”* (Debora, lines 76 - 77). The lack of time and additional responsibilities led to Debora feeling *“on empty”*, in addition to working a full-time job (line 57). Debora experienced both mental and physical exhaustion describing her experience coming home from work:

*Then you have to come home and you have to do the housey things, and the food, and Arron is there and you're asking things, and sometimes you're very tired.*

(Debora, lines 57 -58)

#### **4.7.3 The timing of family therapy should be made *“on a case-by-case basis”***

Across interviews with PwA, their families, and SLTs identified *“a time and a place”* (SLT05, line 292) during stroke recovery, where they felt that family therapy would have helped the most or been most appropriate. There was great variation in the periods of time suggested both between stakeholder groups and within stakeholder groups, suggesting that the need for family therapy is individual, and every family will need individualised therapy with SLT01 summarising that *“it might depend on where the person is at in terms of their own priorities”* (SLT01, line 190 - 191).

Diana and Arthur reflected on their feelings about the timing of family therapy would be most useful for them. Both Diana and Arthur agreed that family therapy would have been useful during the acute phase of their journey as this is when their family struggled to adjust to changes the most.

**Interviewer:** *And would you have liked the emotional support a bit sooner? So maybe in [Acute Hospital G] or [Charity E]?*

**Arthur:** *Yes, yeah, yes.*

**Interviewer:** *Definitely. Yes. And, so you think in [Acute Hospital G], you would have liked that?*

**Arthur:** *Yes*

(Arthur, lines 207 - 210)

Diana felt that family therapy would have been useful “*early on*” in the stroke journey as “*the whole thing [situation] was really stressful, right at the start, for everybody*”. Diana emphasised that receiving familial support at this stage would have allowed her sons to understand the rehabilitative process better “*so something at that stage would have really helped*” (Diana, lines 146 - 152).

In contrast to Arthur and Diana, SLTs hypothesised that family therapy would “*certainly not [be appropriate] in the acute [stage]*” (SLT03, line 201) and would be “*uncomfortable, or it’s [family therapy] not the most biggest priority*” (SLT05, lines 186) at that time. From the perspective of SLT05, “*if you were to ask someone about the change of role in in those immediate first few days and weeks*” (SLT05, lines 186 - 187) that these answers would change overtime, implying that it would be better to address these changes later on in the rehabilitation process. SLT07 postulated that family therapy would not be “*effective at that point in the hospital. (...) because they’re just so overwhelmed with information at the time in the hospital*” (SLT07, lines 313 - 315) and not be able to take on board recommendations to support the adjustment in roles.

Most participants felt that family therapy has “*more of a place like at home*” because role changes tend not to materialise “*until the person gets home*” (SLT05, lines 187 - 188). SLT07 expressed that family therapy would work best “*when the person's come home and the dynamics have kind of settled into a new routine at home*” (SLT07, lines 317 - 318). When asked about when family therapy would have been most useful, Arron felt that having that support immediately upon returning home from an in-patient rehabilitation setting would have benefitted him greatly:

**Interviewer:** *Or home?*

**Arron:** *Home. (Arron nods head yes)*

**Interviewer:** *Definitely, that would have been when it was most useful.*

**Arron:** *Yeah. (...)*

**Interviewer:** *Do you think you needed it straight away? As soon as you got home?*

**Arron:** *Yeah, fucking hell, yeah.*

**Interviewer:** *Straightaway?*

**Arron:** *Yeah, yeah*

**Interviewer:** *Yeah. So you didn't think actually we were okay when we got home but a couple of months later, we. (Arron shakes his head “no”). No it was straightaway.*

**Arron:** *Yeah*

(Arron, lines 1222 - 1229)

In Daisy's situation, it was less of a case of being mentally ready to engage in family therapy, rather it was that it would have been most effective “*when you've come back home*” as she had an opportunity to take “*three months off*” work which meant that she “*would have had the time then*” (Daisy, lines 163 - 164).

*So yeah, probably when he first came home, maybe after the first like couple of weeks. To have, like, yeah, a few sessions then or something would have been probably the best time.*

(Daisy, lines 167 - 168)



SLTs participating in the focus groups agreed that the timing of family therapy during a family's stroke journey is important as referral to therapy might be "quite confronting" (SLT03, line 197), there may be "competing demands (...) [and] depends on the phase that you're in post stroke (...) [and] it might depend on where the person is at in terms of their own priorities" (SLT01, lines 190 – 192). SLTs focused more on families being mentally prepared to address changes. SLTs working in acute settings felt that addressing role changes was "uncomfortable" and "not the most biggest priority" explaining how family therapy would "have more of a place at home (...) [because] there is still nearly an unknown to how that's [family changes] gonna happen until the person gets home" (SLT05, lines 187 - 188). When asked about when family therapy would be most useful, SLTs postulated that a "9 to 12 [months] block [post stroke] does sound most appropriate" (SLT04, line 206) but that it was difficult to "put a concrete time frame on something that is so individual" and should be assessed "on a case by case basis" (SLT02, lines 214 - 217). Furthermore, SLT03 felt that family therapy was not a "service that is accessible" and would be dependent on "where you would live and access and cost" (SLT03, lines 196 - 197). SLTs agreed that a more concrete timeframe for delivering family therapy would be a "sweet spot (...) of 9 to 12 months" (SLT03, lines 201) would "sound most appropriate" (SLT04, lines 206). Arthur agreed that family therapy would have been useful in a similar timeframe to that described by SLTs:

**Interviewer:** Yeah. And when do you think it would have been useful? Maybe if you were in [Acute Hospital G], kind of [Charity E] or in [Primary Care C] with [SLT].

**Arthur:** Eh [Primary Care C]

**Interviewer:** [Primary Care C] with [SLT]?

**Arthur:** Yeah, yeah.

**Interviewer:** So maybe kind of six months after your stroke? That would've been the best time to get that help.

**Arthur:** Yeah.

(Arthur, lines 302 - 308)

SLT01 and SLT02 felt that it would be too difficult to pin down a specific point in time where family therapy would be most appropriate for PwA and their family members. Instead, SLT01 felt family therapy would be most beneficial *“when there’s an idea of what the kind of long-term impairments are likely to be”* as when people are *“in a phase of rapid improvement (...) things could be changing between one family session to the next so finding solutions to live with one way, and then things are changing”* therefore when *“the impairment profile has settled a little bit (...) it’s probably easier to see what life with aphasia is going to look like (...) and it’s probably easier to plan for a life with aphasia”* (SLT01, lines 207 - 212). SLT02 agreed explaining that with the nature of aphasia and the individuality of family dynamics that the time for family therapy should be decided *“on a case-by-case basis, and I don't know if you could put it like, if you were to put a time frame on it”* (SLT02, lines 214 -215).

#### **4.8 Summary of findings**

This chapter presented an overview of the findings from this study including, the reflexive thematic analysis of the interviews and focus groups. Five central themes with fourteen subthemes were outlined, representing the experiences and perceptions of key stakeholder groups on the need, value, and challenges of providing family therapy where one person has aphasia. Theme 1 focused on the intense period of change that occurs after stroke, especially when people are discharged from acute care. The effects of aphasia on family roles and dynamics are not fully realised until people return home and experience these changes in the context of real-life barriers. Families describe the effects of changes in familial relationships on their mental health, and a lack of available

services to help negotiate these changes. Theme 2 centred on some of the reasons why there are limited supports available to families where one person has aphasia. These reasons include an underlying misconception from healthcare professionals that PwA are unable to participate in traditional psychological therapies as a direct result of their communication disability. Theme 3 highlighted the perspective of SLTs and their role in supporting PwA and their families after stroke. SLTs identified that working with families is a core part of their profession, however, they expressed a cautiousness when supporting families. SLTs attributed this cautiousness to a lack of skills, confidence, and experience in using counselling techniques to support families. Theme 4 identified the resources SLTs need to support PwA and their families to negotiate familial changes. These areas include: (1) practical training and resources; (2) open communication and interdisciplinary working between family therapists and SLTs. Theme 5 represented how both families and SLTs lack the time to support changes in familial relationships and identified when might be the 'right time' for family therapy to occur, and in what context. The first referred to the luxury of time, with SLTs wanting more time to spend with PwA and their families but recognising that more time is not currently possible due to staffing constraints and competing priorities. This lack of time feeds into the first theme where PwA and their family feel isolated and on their own after discharge from acute healthcare. The second element refers to SLTs, PwA, and family members, identifying the time at which addressing family role changes and relationships would be most appropriate.

The aim of this study was to explore the perspectives and experiences of three groups of key stakeholders on the need, value, and challenges of providing family

therapy in the context of aphasia. A discussion of the findings in the context of existing research is presented in Chapter 5 and 6.

## **Section 4: Discussion**

## **Chapter 5. Situating the findings in the context of existing research**

The aim of this study was to obtain an in-depth understanding of the experiences and perceptions of PwA, their family members, and SLTs on the use of family therapy after stroke. The analysis of interviews and focus groups conducted with these key stakeholder groups has provided valuable insight into the need, value, and challenges of providing family therapy for PwA and their family members.

This chapter provides a discussion of the findings presented in the previous chapter. Section 5.1 provides a summary of the findings in relation to their themes, section 5.2 will discuss the findings in the context of the existing literature on the needs of families after stroke, section 5.3 will discuss the value of family therapy as described by participants in this study and situating their responses in relation to existing literature on family therapy after stroke, finally section 5.4 will focus on the challenges to providing family therapy.

### **5.1 Summary of findings**

The findings were presented with reference to five overarching themes that were generated during the analysis of the data, namely: (1) That's it. You're on your own; (2) Psychosocial challenges faced by PwA – diverse solutions for a diverse disability; (3) The cautious boundaries of SLTs working with families; (4) Doing my best and imagining what's possible: SLT roles in family therapy; and (5) "There is just so much going on" - the luxury of time and timing.

As discussed in theme one, PwA, family members, and SLTs recognised and highlighted that families experience a sudden and intense period of change after stroke, with aphasia significantly affecting family roles and dynamics. In acute stages of stroke and aphasia, families described being unable to come to terms with the changes that

occurred in their loved one, which in some cases caused extended families to distance themselves. SLTs attributed a breakdown in familial relationships to a lack of understanding of aphasia, especially in cases where the communication disability was more subtle. Theme two encapsulated the perpetuation of a lack of understanding when PwA attempted to mask their communication difficulties when with extended family or friends. A lack of psychological support for PwA and their families was attributed to an underlying misconception that PwA are unable to participate in traditional psychological therapies as a direct result of their communication disability. This misconception was further exacerbated due to the medical team misunderstanding the role of SLT's within the context of identifying and supporting the psychological needs of PwA. PwA, their family members, and SLTs identified that this cohort require more long-term support surrounding adjustment of role and relationship changes after stroke and that this support would need to be diverse, to represent the heterogeneity of aphasia. Theme three centred on SLTs identifying their role when working with families, emphasising that this work is a core part of their role in all settings, primarily using communication partner training (CPT) to support families where one person has aphasia. However, there was a feeling of cautiousness and trepidation when supporting families as SLTs expressed how they often were unsure of where to direct families for further support. Moreover, SLTs communicated that they felt they lacked the skills, confidence, and experience to use counselling techniques to support families. This lack of confidence was exacerbated by a lack of psychology presence to support SLTs on multidisciplinary teams. In theme four, SLTs identified what their role in family therapy might look like. SLTs highlighted that in order to better support PwA and their family in the negotiation of roles and relationships, SLTs require more practical training, resources, and open

communication with interdisciplinary working between family therapists and SLTs. This interdisciplinary work involves both SLTs supporting family therapists' communication with PwA including communication supports and family therapists providing information to SLTs specifically around supporting PwA dealing with changes in roles as a direct result of communication disability. While participants emphasised the significant value they felt family therapy could provide, theme five addressed important areas of when family may be most appropriate to address changes in family roles and dynamics was different between and in stakeholder groups. A number of factors were identified with regards to the timing of family therapy which included ensuring that the family therapy did not add stress to the newfound responsibilities that families had after stroke. SLTs highlighted that the use of family therapy techniques as part of their role would be difficult due to staffing constraints and competing priorities during different stages of aphasia rehabilitation. Consequently, the timing of the implementation of family therapy must be carefully considered and recognised as unique for each family during this time. These themes encapsulated the lived experiences of PwA and their families in addition to the working experiences of SLTs providing a unique insight into the challenges faced by these stakeholder groups.

## **5.2 The needs of families after stroke**

PwA and family members described an absence of both psychosocial and psychological support from healthcare professionals both during and after acute care with regards to negotiating family life after stroke and aphasia. This lack of support left families isolated and navigating this unique and challenging period on their own, with varying success. Previous research conducted by Nätterlund (2010) has identified similar findings, where family members described a lack of support from healthcare



professionals around the provision of information about aphasia and coping with the adjustment to life with aphasia (Nätterlund, 2010). Building upon prior research, it is apparent that families where one person have aphasia need psychological support to adjust to a new way of being, with the National Clinical Guidelines for Stroke for the UK and Ireland (hereon referred to as the National Clinical Guidelines for Stroke) stating that *“psychological care should be provided by stroke services across acute and community settings”* (Intercollegiate Stroke Working Party, 2023, p. 26). However, audits of psychological services available in the UK and Ireland *“continue to highlight inadequate service provision, and surveys of the long term needs of people with stroke echo the need for service improvement”* (Intercollegiate Stroke Working Party, 2023, p. 26). Furthermore, the National Stroke Strategy 2022 – 2027 has also *“acknowledged that rehabilitation services are under-developed in Ireland”* (Health Service Executive, 2022, p. 44), mirroring the descriptions of a lack of psychological care from PwA and their family members in this study.

The National Institute for Health and Care Excellence stroke rehabilitation in adults’ guidelines also recognise the need to address psycho-emotional adjustment. Since 2013 these guidelines have set out that healthcare professionals working in the area of stroke should *“Support and educate people and their families and carers to help them make an emotional adjustment after stroke, recognising that their psychological needs may change over time and in different settings”* (National Institute for Health and Care Excellence, 2023, sec. 1.6.3). SLTs, in addition to their allied healthcare colleagues, are responsible for identifying and addressing the psychological well-being of their clients (Kneebone, 2015). However, participants in this study described a lack of support in this manner.

With regards to accessing psychological care, the National Stroke Strategy 2022-2027 highlights the lack of and the need for universal access to psychology services for PwA following stroke specifically stating that:

*Every effort should be made to ensure those with communication issues post stroke are able to access supports such as psychology. How this can be achieved will need to be considered going forward in collaboration with SLT services.*

(Health Service Executive, 2022, p. 58)

PwA and their family members highlighted the significant and sudden changes that stroke and aphasia caused, both on a personal and a familial level throughout the interviews. Frequently, participants reported that the impact of aphasia on family life was most obvious when PwA were discharged home and aphasia acted as a barrier in negotiating roles and responsibilities. Indeed, research on discharge after stroke suggests that the transition home may initially be marked by relief, however adjusting to a new way of living and sense of self is often challenging and perpetuated by uncertainty around recovery (Connolly & Mahoney, 2018; Gustafsson & Bootle, 2013; Lin et al., 2022). Less research is available on the family experience, but the findings of this study suggest that adjusting to life after stroke and living with aphasia affects the entire family system.

Family members and SLTs who participated in this study discussed the reality of changes to every role within the family system, often with the significant other taking on additional responsibilities. It was then that families felt a significant need for a service, like family therapy, which would provide advice on how to navigate this new life, help them to learn how to live in a new way, and ultimately help everyone come to terms

with aphasia. A scoping review of family therapy after stroke by Henihan et al. (2024), has identified that interventions to support families are beneficial with positive outcomes noted across the 24 included studies. Improvements were noted in quality of life, family cohesion, understanding, negotiation, and restoration of family roles and responsibilities, family empowerment, and reduced familial conflict (Henihan et al., 2024).

Additionally, the isolation experienced by PwA and their immediate family, was exacerbated by a lack of understanding of the effects of aphasia on the family system by friends and extended family members. There is a lack of awareness about aphasia and the impact it has on the individual in society (Brown et al., 2012), causing PwA and their immediate family to encounter negative communicative experiences in communal settings (Nätterlund, 2010; Wray & Clarke, 2017). Research has also shown that this lack of knowledge can cause friends and extended family to avoid interactions with the PwA (Cruice et al., 2006; Northcott & Hilari, 2011). A survey conducted in the west of Ireland identified that 19.7% of surveyed participants had heard of aphasia, while only 5.5% of respondents had sufficient knowledge of aphasia, indicating that public awareness of aphasia in Ireland is low (McMenamin et al., 2021). Therefore, it is perhaps unsurprising that in the initial stages of living with aphasia, a lack of understanding on the part of the extended family may impact on their ability to empathise with the PwA and more immediate family members. PwA and their families consider access to information and awareness about the disability crucial for leading fulfilling lives with aphasia achieving success (Brown et al., 2012; Grohn et al., 2012; Manning et al., 2017; Manning, MacFarlane, et al., 2020). Furthermore, a solid understanding of aphasia and the ability to articulate it to others seem crucial for fostering confidence and enriching social

involvement for the PwA (Manning, MacFarlane, et al., 2020; Worrall et al., 2011), with the provision of information on aphasia to family members positively influencing relationships (Hilton et al., 2014).

Within this study, families were unsure of what services currently exist to support PwA and family life after stroke. Stroke aftercare services in Ireland are mostly front-loaded with limited access to post-stroke support for PwA and their family, and are dependent on location, with more opportunities for services in cities versus rural areas (Walsh et al., 2013). Furthermore, families in this study highlighted that existing stroke support services do not cater to the specific and unique challenges that PwA and their families experience. In a survey conducted by Manning et al. (2020), on how SLTs support PwA to live well, SLTs identified that support for families, where one person has aphasia, was limited and mainly came from charity services with only 4% (n=3) of families having access to some form of psychological support (Manning, MacFarlane, et al., 2020).

### **5.3 The value of receiving familial support after stroke**

When specifically asked about family therapy, PwA, family members, and SLTs, expressed that this type of intervention would be valuable. Families identified a number of reasons of how family therapy could help their family. Similar findings have been found in literature on living successfully with aphasia. Brown et al. (2012), conducted a review of qualitative studies on the concept of living well with aphasia utilising the perceptions of SLTs, PwA, and family members. Seven overarching themes were identified in how to live successfully with aphasia and the goals identified in the Brown et al. (2012) study have similarities with the goals identified in this thesis. The similar

goals include: (1) meaningful relationships (Brown et al., 2012) and addressing changes in roles and identity that happen as a result of aphasia (this study); (2) living successfully with aphasia as a journey over time (Brown et al., 2012) and adjust to a new way of living (this study); and (3) support (Brown et al., 2012) and therapy and practical support (this study).

With limited experience of family therapy or communication accessible counselling services, participants reflected on other services they received that were deemed as valuable in relation to adjustment to family life after stroke. Health and social care professionals and carers were identified by both PwA and their family members as critical for providing psychosocial support. Additionally, partners of PwA valued being included in SLT sessions as they helped people reconnect to their partner through communication. Previous research has identified that families want to take part in rehabilitation sessions and identify themselves as a key part of the multidisciplinary team (Avent et al., 2005; Brown et al., 2011b; Howe et al., 2012; Michallet et al., 2001; Worrall et al., 2010). Furthermore, SLTs play a pivotal role in reconnecting PwA to their family through communication supports (Elman, 2007).

Family members who had access to counselling services highlighted counselling as a key support service, allowing them to come to terms with stroke and aphasia and adapt to a new way of living. Notably, it was significant others who were offered this support rather than the entire family unit. It is not known whether this situation is unique to post-stroke aphasia, or whether those without communication disability after stroke receive therapy in a family context. These results show how PwA and their families value receiving psychosocial support but need greater support in navigating family life after stroke. Access to psychological services for PwA remains limited, despite

research outlining the deleterious effects of aphasia on psychological wellbeing (Baker et al., 2021; Clarke, 2013; Moss et al., 2021). While existing research where PwA are involved in psychological therapy has reported benefits of psychological interventions (Manning, MacFarlane, et al., 2020; Moss et al., 2021), SLTs have reported barriers in referring PwA to psychological services with even more difficulty reported when the aphasia was described as more severe (Manning, Cuskelly, et al., 2020; Wray et al., 2020), a finding echoed in this study.

While there is a current lack of services available to address the psychological impact of aphasia on the family system, more recent research emerging from the United Kingdom has focused on creating interventions which centre on supporting the psychosocial and psychological impacts of aphasia on the PwA. These interventions are based on models such as collaborative care, matched care and the stepped model of psychological care, and biopsychosocial models (World Health Organization, 2001). These models are recommended for use in the provision of psychological care for people post stroke in Ireland (Intercollegiate Stroke Working Party, 2023).

One example of an innovative solution whereby PwA can access psychological interventions is the use of solution-focused brief therapy (SFBT) with PwA (Northcott et al., 2018), with PwA significantly benefitting from the use of this therapy to come to terms with changes as a result of aphasia (Northcott et al., 2021). SFBT centres on a person's knowledge and available resources to help them to successfully live with a health condition, with a specific focus on hopes for the future rather than concentrating on deficits. SFTB supports a person to identify current areas of success and what helps make this area successful, using these tools as a foundation to help the person with future progress (K. Burns, 2016). Northcott et al. (2021) has modified SFTB so that it is

communicatively accessible for the PwA, with a specific focus on aphasia specific challenges that these people face. Traditionally, SFBT is a short intervention lasting three to five sessions, however this adapted form of SFTB provides extended sessions (up to six sessions over a three-month period) for PwA to ensure that sufficient time can be given to cover topics discussed in SFBT. This trial of SFTB was delivered by SLTs with further training in this intervention, in addition to receiving supervision and support. The results of this study indicated that both PwA and SLTs perceived the intervention as valuable and acceptable with any type of severity of aphasia (Northcott et al., 2021). Examining this study and its innovative adaptations provides evidence that adapting psychological interventions to be communicatively accessible is possible, enabling PwA regardless of severity, to engage in these psychological therapy approaches. Furthermore, it makes way for consideration, what adaptations could be made to family therapy as an intervention or practice to make it communicatively accessible for families where one person has aphasia.

A case study from Australia has described the use of family therapy where one family member has a communication disability. The intervention was provided to this family in 20 sessions over a two-year period and was delivered by family therapists and social workers. The intervention was shown to be effective, and reduced familial conflict, caregiver burden, and social isolation (Butera-Prinzi et al., 2016).

In Ireland, a new project “Supporting Emotions in Aphasia” (SEA) was established to address the current lack of an interdisciplinary community for aphasia psychological care. This project is focused on addressing the need for interdisciplinary working, training, learning, and improved access to aphasia psychological care in Ireland.

The community is comprised of SLTs, neuropsychologists, occupational therapists, and clinical psychologists. SEA provides a number of webinars and training sessions around the provision of aphasia psychological care (Manning et al., 2023). However, this group specifically focuses on the individual rather than the wider family system.

#### **5.4 Challenges of providing family therapy**

While no families or SLTs had experience of family therapy in the context of aphasia, these groups reflected on their experiences of psychological services in general, including community primary care, psychologists on stroke multidisciplinary teams, and outpatient psychiatry. Families and SLTs discussed potential barriers that PwA and their family members may face when attempting to access psychological support, including family therapy.

##### ***5.4.1 Misconceptions of healthcare professionals and counselling services about PwA***

Participants reported a significant lack of accessibility in terms of accessing traditional psychological talking therapies for PwA, which would include family therapy as a systems approach to psychological support a family unit. SLTs and families identified through their experiences, that healthcare professionals (not including SLTs) have underlying misconceptions that PwA are unable to participate in psychological talking therapies because of their communication disability. SLTs highlighted their concerns that these misconceptions may also exist in family therapy services. PwA have also reported similar misconceptions with research identifying that healthcare professionals are reluctant to adjust their communication style or make assumptions about their cognitive abilities (M. Burns et al., 2015). Past research in countries such as the UK (Northcott et al., 2017, 2018) and Australia (Ryan et al., 2019) have described similar findings when



SLTs attempt to refer PwA to mental health services. SLTs in these studies have reported rejected referrals where the person has a communication disability due to the assumption that the person will be unable to participate in traditional psychological talking therapies. Psychological services have also rejected SLT input for these sessions (Northcott et al., 2017, 2018; Ryan et al., 2019). When SLTs are involved in joint mental health sessions, they described feeling undervalued by their colleague, with frequent misunderstandings and disagreements in how a session should be conducted (Northcott et al., 2018). Research carried out in the US on the experiences of mental health professionals working with PwA have identified similar barriers which may prevent PwA from accessing mental health services. These barriers included insufficient understanding of aphasia and communicative supports (Strong & Randolph, 2021), suggesting that this issue is prevalent across a range of countries.

#### ***5.4.2 Family therapists may lack the skills to support PwA***

SLTs postulated that family therapists may not be equipped to support PwA from a supported communication approach, leaving PwA at risk of being unable to participate fully in therapy sessions. SLTs shared their concerns that this may worsen family divides as PwA may feel alienated and further isolated during sessions. While there is no direct research about the numbers of family therapists working with PwA, comparisons can be drawn from the general mental health professional literature. Healthcare professionals, especially those addressing psychological wellbeing may lack the necessary supported communication skills to support conversations with PwA (Ryan et al., 2019; Sekhon et al., 2015) and may underestimate the skills needed to support conversations (Northcott et al., 2017). Similar research has identified that non SLT professionals working in stroke

care lack the supported communication skills needed to have successful interactions with PwA (Baker et al., 2021; Carragher et al., 2021; van Rijssen et al., 2022), with these professionals feeling inadequately prepared to evaluate mood challenges and offer emotional assistance (Baker et al., 2021; Northcott et al., 2017; Sekhon et al., 2015; van Ewijk et al., 2021). A study of healthcare professionals in the Netherlands perceived communication disabilities as hindering therapy activities, with participants reporting communication breakdowns and a lack of skills to repair these breakdowns (van Rijssen et al., 2022). PwA have reported poor experiences with healthcare professionals who regularly do not adapt clinical interventions to suit the communication strengths of PwA (M. Burns et al., 2015).

Part of the SLT role is to increase public awareness of aphasia, in addition to providing supported communication training to their non SLT colleagues (Sandberg et al., 2021). However, recent research has established that less than 50% of the SLTs are engaged in offering communication partner training to their non SLT colleagues (Manning, Cuskelly, et al., 2020). Ryan et al (2019) has highlighted that there is a specific lack of research on the efficacy of supported conversation techniques for PwA in psychology settings (Ryan et al., 2019).

#### **5.4.3 Lack of clarity/Skill development around the role of SLT in family therapy**

Overall, SLTs expressed that they had a specific role in family therapy for PwA as communication disability affects how families communicate with aphasia changing family dynamics, roles, and relationships. Furthermore, SLTs defined their role in supporting PwA and their family members to access family therapy services with SLTs citing that their overall role is to support “*communication participation*” and that

includes participation in therapy services. However, greater support is needed to achieve this role.

Similar findings suggest that SLTs do recognise and acknowledge the challenges that PwA and their families experience when coming to terms with the impact that aphasia has on their lives and recognise that addressing these changes is an integral part of their professional responsibilities (Hilari, 2011; Northcott et al., 2017, 2018; Sekhon et al., 2015; van Ewijk et al., 2021; Wray et al., 2020). However, research by Northcott et al. (2018) on the views of SLTs providing psychosocial support has found that SLTs disagree on the scope of their role in providing this support.

Given that the role of an SLT is to support communication, SLTs are frequently the first profession to identify when PwA are experiencing decreased mental wellbeing (Baker et al., 2021), making them likely to identify decreased family cohesion. SLTs within this study highlighted that their role in identifying and supporting the psychological needs of PwA is not recognised by the wider multidisciplinary team, with concerns raised that this lack of understanding would also occur when SLTs identify the psychological needs of the entire family. Comparable findings have also been identified in a survey conducted by Cruice and Ten Kate (2019) on how SLTs assess quality of life in PwA. Participants reported that a lack of clarity on the role and scope of SLTs in their assessment and provision of psychosocial support was impacting on the multidisciplinary teams understanding of the contributions SLTs make in the area of improving quality of life for PwA (Cruice & Ten Kate, 2019). A lack of clearly defined roles and scope of practice for SLTs in the assessment and provision of psychosocial support is resulting in a lack of support being provided to PwA and their families and resonates with other

findings. SLTs continue to describe their concerns when addressing psychosocial wellbeing in PwA, with 40% of SLTs feeling unprepared and unsure of where their professional boundaries lie (Northcott et al., 2017). The lack of clearly defined boundaries for SLTs is perpetuated by a lack of joint working between SLTs and mental health professionals, in addition to the limited access to mental health services that PwA experience (Northcott et al., 2017). Similarly, other SLT disciplines have experienced a misunderstanding of their role in different settings including joint working between educational psychologists and SLTs (Dunsmuir et al., 2006), SLTs working in palliative care (Hawksley et al., 2017), and SLTs working with people with dementia (Dooley & Walshe, 2020), indicating that a number of SLT disciplines are affected by this issue.

However, exploratory research by Strong and Randolph (2021), on the experiences of mental health professionals providing psychological services to PwA has identified that these professionals valued the input of SLTs. Mental health professionals within that study highlighted the essential role SLTs have in creating a successful therapy interaction when one person has aphasia (Strong & Randolph, 2021). SLTs have the potential to have the same role in family therapy, but the availability of family therapist and the development of professional alliances would be required for this potential to be realised.

Although SLTs in this study have identified that they would like to offer psychological help to PwA and their families, they frequently describe a feeling of unpreparedness, a lack of skills, and a lack of support to do so. These feelings of unpreparedness and lack of skills has also been identified in past research pertaining to psychologically supporting PwA (Northcott et al., 2017, 2018; Sekhon et al., 2015; van

Ewijk et al., 2021). While the National Clinical Stroke Guidelines have identified that each professional on a stroke multidisciplinary team should have adequate training to support people post stroke with psychological problems (Intercollegiate Stroke Working Party, 2023), the SLTs in this study have identified that they are insufficiently trained to address these issues.

When discussing how they support families, SLTs identified techniques they used such as providing families with basic information resources such as videos and communication passports, educating families about aphasia, and defining the communication strengths and deficits of the PwA. Previous research has highlighted SLT involvement in providing emotional support during SLT sessions, frequently utilising counselling approaches such as active listening or motivational interviewing (Hunting Pompon, 2021; Rose et al., 2014). However, SLTs in this study have highlighted a lack of confidence in supporting families, even when using well established techniques specifically within their scope of practice, such as communication partner training (CPT). CPT has many benefits such as improving communication participation and well-being for PwA and their communication partners (Simmons-Mackie et al., 2016), and has a high-quality level of evidence as a background for its use (Shrubsole et al., 2017). Furthermore, SLTs understand the multifaceted benefits that CPT can provide (Sirman et al., 2017) and want to deliver more regular and comprehensive CPT (Rose et al., 2014). However, the implementation of CPT in clinical practice is inconsistent (Shrubsole et al., 2023). SLTs in this study expressed providing a counselling supportive role using CPT with specific reference to the psychosocial elements it contains. However, when probed further, they felt uncomfortable addressing communication changes that have occurred as a result of aphasia with family members. The findings of this study are consistent with

previous research which indicates that SLTs perceive a lack of competence and confidence when implementing CPT programs (Chang et al., 2018; Sirman et al., 2017), with a lack of clear guidelines and methodologies in research studies around the administration of CPT acting as a barrier for its implementation in clinical settings (Cruice et al., 2018). Furthermore, SLTs identified a lack of skills to address the wider psychological impact of aphasia, expressing that they were unable to support their patients' psychosocial needs to the extent that was required and were cautious when discussing emotional issues with PwA. Similarly, a study conducted by Ryan et al. (2019) has identified that some SLTs encounter uncertainty when it comes to defining their responsibilities in dealing with psychological distress in PwA.

SLTs attributed a lack of confidence in using counselling skills to a lack of practical skills provided in counselling modules in college. SLTs reported that counselling modules for SLTs in college did not prepare them for supporting PwA and their families through psychosocial changes after stroke. The modules were theory based and lacked specifics around supporting people with less reliance on language. Previous research has identified SLTs' desire to have additional training which would equip them with the skills to address psychological concerns (Sekhon et al., 2019; Wray et al., 2020).

In this study, SLTs who had sought additional training in counselling techniques outside of college, namely SFBT and motivational interviewing, highly valued this training and felt that their clients benefitted from its use during session. This finding is consistent with prior research on SLTs who received training in counselling strategies, with these SLTs reporting that both they and their clients significantly benefit from this training. SLTs describe their approach to sessions as more client-centred and having

space within a session to discuss emotions that arise (Northcott et al., 2018; Sekhon et al., 2019). SLTs within this study have suggested that more practical teaching is needed to help them in this area. Although there have been request for additional training in psychological and counselling skills throughout their pre-qualification training (Sandberg et al., 2021), Sekhon et al. (2019) has reported a lack of consistency in the provision of counselling training for SLT students.

The broader context of the health system itself (lack of psychologist on multidisciplinary teams, Counselling in Primary Care not accepting referrals for PwA, access to mental health services etc...) is impacting on how SLTs navigate conversations about the psychological impact of aphasia on the family system. A lack of confidence in using counselling techniques was further exacerbated by a lack of psychologists on stroke rehabilitation multidisciplinary teams where SLTs could discuss patient concerns. The National Clinical Stroke Guidelines have emphasised the importance of having psychologists who are stroke-skilled on a stroke multidisciplinary team, to provide advice and support to colleagues, in addition to carrying out psychological assessments and interventions to people after stroke (Intercollegiate Stroke Working Party, 2023). However, as of 2020, out of the 24 acute hospitals across Ireland, no hospitals had the recommended level of stroke psychologists within the hospitals with 14 hospitals having no access to a stroke psychologist (Health Service Executive, 2022).

Furthermore, SLTs were unsure of where to direct PwA for further psychological supports, so consequently did not have any conversations around psychosocial wellbeing with their clients. Similar findings have been reported of referrals to mental health services being rejected as mental health professionals felt PwA were unable to

participate and benefit from therapy, in addition to refusing the help of SLTs to facilitate sessions (Northcott et al., 2017, 2018; Ryan et al., 2019). When SLTs were aware of community psychological services, these services did not accept people with communication disabilities. Consequently, SLTs felt guilty knowing that families cannot access any services to support family life.

SLTs highly valued having time to spend with families but cited that they often do not have enough time to work with families. This lack of time was particularly prominent with SLTs working in acute hospitals, describing how staffing and time constraints significantly impacted on their ability to provide updates about the PwA to family members, with greatly reduced time to discuss aphasia in an in-depth manner. Research has demonstrated that the large caseloads and the structure of sessions impacts on SLTs ability to provide comprehensive therapy and psychosocial support to PwA and their family (Manning, Cuskelly, et al., 2020; Manning et al., 2023; Wray et al., 2020). Measures implemented in Ireland during the Covid-19 pandemic have perpetuated time pressure issues by significantly increasing SLT caseloads (Müller et al., 2023). Similar reports around time pressures acting as a barrier to addressing psychosocial needs of PwA and their families has been reported by Northcott et al. (2017).

#### **5.4.4. Responding to challenges: What is the role of SLTs in family therapy?**

SLTs identified a number of ideas that could facilitate the provision of family therapy for PwA and their family members. SLTs highlighted that having training in the principles of family therapy would be helpful to incorporate into SLT sessions with specific resources aimed at SLTs. Prior research has identified that SLTs benefit from



training in psychological techniques such as SFBT or motivational interviewing and have implemented these skills in their everyday practice (Northcott et al., 2018).

While SLTs established that they have a core role in supporting PwA and their families, they emphasised that this work cannot be completed independently, and they need family therapists to work with them to make family therapy work. SLTs identified the possibility of open communication and joint working between SLTs and family therapists. This joint working was described as SLTs supporting family therapists in relation to specific clients and *vice versa*. Prior research on how SLTs address psychosocial wellbeing with PwA has highlighted positive experiences of SLTs working jointly with mental health professionals (Northcott et al., 2017). As family therapists having similar training to psychologists, there is a possibility that joint working between SLTs and family therapists could successfully work to support PwA and their families.

CPT could be provided to family therapists by SLTs, ensuring that PwA can access family therapy at a communication level that is at their current ability. In areas where CPT has been provided to healthcare professionals working with PwA, positive effects such as increased confidence in working with PwA, more successful communicative interactions have been described (Cameron et al., 2018; Forsgren et al., 2017; Isaksen et al., 2023; van Rijssen et al., 2022, 2023). A number have studies have highlighted the benefits of providing training to medical students (Baylor et al., 2019; Burns et al., 2017) and social work students (Rowland & McDonald, 2009) around the use of supported conversation techniques with people with communication disabilities. This research demonstrates that it is possible for both qualified family therapists and student family therapist to be provided with CPT and implement these tools and techniques in sessions

with PwA and their family members. Therefore, supporting the wider availability of family therapy for PwA and their families.

## **Chapter 6. Towards accessible family therapy in Ireland**

This chapter will address the findings in relation to their limitations, discussing what accessible family therapy might look like in Ireland, providing recommendations for future research, and providing my final thoughts.

### **6.1 Limitations**

Despite receiving ethics approval to recruit family therapists to participate in this research, in addition to contacting the Family Therapy Association of Ireland and the Irish Council for Psychotherapy who disseminated the participant information leaflets, no family therapists participated in this research. While it is disappointing that their views are not represented in this study, it is perhaps not surprising that it was difficult to recruit participants from this stakeholder group to participate in focus groups. It is postulated that the reason behind a lack of family therapists was due to a number of factors. Firstly, there is only a small population of family therapists working across Ireland (FTAI, 2023). Secondly, the majority of research on family therapy within the Irish context has focused on delivering services to children and young people with mental health disorders (Carr, 2013), meaning that family therapists may not understand the needs of PwA and their family members. However, this research has demonstrated that families where one person has aphasia need access to family support, and without the right support, the effects of aphasia on the family system can have detrimental consequences on individuals within the family.

The focus groups and interviews were conducted in a semi-structured manner, affording participants an opportunity to concentrate and discuss topics within this area that they deemed were important to them and relevant to family life with aphasia. This

approach meant that no two data collection sessions referred to identical issues, resulting in some themes while significant to some participants, were not highlighted by others. However, it did allow for unique and relevant topics outside of the interview guides to be discussed. With regards to the participants included, a limitation of the study was that all PwA were male, and all family members were female spouses. The inclusion of a larger number of participants and wider variety could have identified not only further unique perspectives, but also reinforced some of the points that were raised by the sample that did participate. SLTs agreed to participate in the focus group on their own initiative, meaning that there is a possibility of selection bias. Participating SLTs may have felt they had relevant insights or opinions on family therapy for PwA and their family.

## **6.2 Towards accessible family therapy in Ireland: Suggestions for future research**

It is clear that families experience a range of changes within their system after stroke, with aphasia impacting these changes even further. Families want and need additional support to navigate these changes, but the existing stroke rehabilitation and mental health services in Ireland are failing to address the psychological needs of families where one person has aphasia. The National Stroke Strategy for 2022 – 2027 recognises the need for SLTs to be involved in supporting access to mental health services for PwA (Health Service Executive, 2022), but provides no guidance on how this co-working can be achieved.

Future research should address possible solutions for the provision of family therapy services to families where one person has aphasia. One such solution is to provide a stepped model of psychological care. This model of care encompasses a

structured progression throughout a tiered program where support can be provided by a range of stroke professionals. Individuals are matched to an appropriate tier based on their level of need. Previous research has demonstrated that this model can be successfully adapted for PwA with mood disorders (Kneebone, 2016). This model could be adapted for use with family therapy interventions, where more lower levels of familial distress can be addressed by allied healthcare professionals and higher levels of familial distress can be addressed by family therapists with training to support communication where a communication disability is present. Future research could address the feasibility and acceptability of a family therapy programme for PwA and their family members.

Secondly, SLTs cannot solely support families in adjusting to changes after stroke. Research on the experiences and perspectives of family therapists need to be conducted in order to create a service which is accessible and beneficial for PwA and their family.

### **6.3 Final thoughts**

Families where one person has aphasia face unique challenges in navigating familial life *after* stroke and learning to live life *with* aphasia. Without the necessary supports such as family therapy, families will continue to navigate through the sudden and intense changes that aphasia brings on their own, with significant consequences such as familial breakdown and poor mental wellbeing for each individual. Systemic change in our healthcare system is needed to address a lack of psychological support for families and to ensure that every family has an opportunity to live family life successfully with aphasia. Sláintecare provides an opportunity to reimagine services, with the aim of this policy centred on providing universal and equitable access to healthcare for all

citizens of Ireland, ensuring that people receive the right support, in the right setting, at the appropriate time (Burke et al., 2018). An element of the Sláintecare policy is to have better coordination and integration between healthcare services and in the context of family therapy, it could provide an opportunity for joint working between SLTs and family therapists. Without the support of family therapists, these families and those affected by stroke and aphasia in the future will continue to navigate life with aphasia on their own.

## References

- Avent, J., Glista, S., Wallace, S., Jackson, J., Nishioka, J., & Yip, W. (2005). Family information needs about aphasia. *Aphasiology*, *19*(3–5), 365–375.  
<https://doi.org/10.1080/02687030444000813>
- Baier, C. K., Hoepner, J. K., & Sather, T. W. (2018). Exploring Snapchat as a dynamic capture tool for social networking in persons with aphasia. *Aphasiology*, *32*(11), 1336–1359.  
<https://doi.org/10.1080/02687038.2017.1409870>
- Bakas, T., Kroenke, K., Plue, L. D., Perkins, S. M., & Williams, L. S. (2006). Outcomes among family caregivers of aphasic versus nonaphasic stroke survivors. *Rehabilitation Nursing: The Official Journal of the Association of Rehabilitation Nurses*, *31*(1), 33–42.  
<https://doi.org/10.1002/j.2048-7940.2006.tb00008.x>
- Baker, C., Worrall, L., Rose, M., & Ryan, B. (2021). Stroke health professionals' management of depression after post-stroke aphasia: A qualitative study. *Disability and Rehabilitation*, *43*(2), 217–228. <https://doi.org/10.1080/09638288.2019.1621394>
- Barrow, R. (2008). Listening to the voice of living life with aphasia: Anne's story. *International Journal of Language & Communication Disorders*, *43* Suppl 1, 30–46.  
<https://doi.org/10.1080/13682820701697947>
- Baylor, C., Burns, M., McDonough, K., Mach, H., & Yorkston, K. (2019). Teaching Medical Students Skills for Effective Communication With Patients Who Have Communication Disorders. *American journal of speech-language pathology*, *28*(1), 155–164.  
[https://doi.org/10.1044/2018\\_AJSLP-18-0130](https://doi.org/10.1044/2018_AJSLP-18-0130)
- Bellon, M., Crocker, R., Farnden, J., Gardner, J., Sando, S., & Peterson, C. (2015). Family Support Needs Following Acquired Brain Injury Across Metropolitan and Regional/Remote South Australia. *Brain Impairment*, *16*(2), 131–144. <https://doi.org/10.1017/Brlmp.2015.17>

- Berg, K., Isaksen, J., Wallace, S. J., Cruice, M., Simmons-Mackie, N., & Worrall, L. (2020). Establishing consensus on a definition of aphasia: An e-delphi study of international aphasia researchers. *Aphasiology*. <https://doi.org/10.1080/02687038.2020.1852003>
- Blom Johansson, M., Carlsson, M., Östberg, P., & Sonnander, K. (2013). A multiple-case study of a family-oriented intervention practice in the early rehabilitation phase of persons with aphasia. *Aphasiology*, 27(2), 201–226. <https://doi.org/10.1080/02687038.2012.744808>
- Boles, L. (2006). Success stories in aphasia. *Topics in Stroke Rehabilitation*, 13(1), 37–43. <https://doi.org/10.1310/29WX-32LE-A21H-3JQJ>
- Borenstein, P., Linell, S., & Währborg, P. (1987). An innovative therapeutic program for aphasia patients and their relatives. *Scandinavian Journal of Rehabilitation Medicine*, 19(2), 51–56.
- Boxer, D. (2002). *Applying Sociolinguistics: Domains and face-to-face interaction*. John Benjamins Publishing.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. SAGE Publications Ltd.
- Braun, V., & Clarke, V. (2021a). Can I use TA? Should I use TA? Should I *not* use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, 21(1), 37–47. <https://doi.org/10.1002/capr.12360>
- Braun, V., & Clarke, V. (2021b). *Thematic Analysis: A Practical Guide*. SAGE Publications Ltd.
- Braun, V., & Clarke, V. (2021c). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 13(2), 201–216. <https://doi.org/10.1080/2159676X.2019.1704846>



- Braun, V., & Clarke, V. (2023). Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher. *International Journal of Transgender Health, 24*(1), 1–6. <https://doi.org/10.1080/26895269.2022.2129597>
- Brinkmann, S., & Kvale, S. (2017). Ethics in Qualitative Psychological Research. In C. Willig & W. S. Rogers, *The SAGE Handbook of Qualitative Research in Psychology* (pp. 259–273). SAGE Publications Ltd. <https://doi.org/10.4135/9781526405555.n15>
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010). Snapshots of success: An insider perspective on living successfully with aphasia. *Aphasiology, 24*(10), 1267–1295. <https://doi.org/10.1080/02687031003755429>
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011a). Living successfully with aphasia: Family members share their views. *Topics in Stroke Rehabilitation, 18*(5), 536–548. <https://doi.org/10.1310/tsr1805-536>
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011b). Living successfully with aphasia: Family members share their views. *Topics in Stroke Rehabilitation, 18*(5), 536–548. <https://doi.org/10.1310/tsr1805-536>
- Brown, K., Worrall, L. E., Davidson, B., & Howe, T. (2012). Living successfully with aphasia: A qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *International Journal of Speech-Language Pathology, 14*(2), 141–155. <https://doi.org/10.3109/17549507.2011.632026>
- Burke, S., Barry, S., Siersbaek, R., Johnston, B., Ní Fhallúin, M., & Thomas, S. (2018). Sláintecare – A ten-year plan to achieve universal healthcare in Ireland. *Health Policy, 122*(12), 1278–1282. <https://doi.org/10.1016/j.healthpol.2018.05.006>
- Burns, K. (2016). *Focus on Solutions: A Health Professional's Guide*. Solutions Books.
- Burns, M., Baylor, C., Dudgeon, B. J., Starks, H., & Yorkston, K. (2015). Asking the Stakeholders: Perspectives of Individuals With Aphasia, Their Family Members, and Physicians

- Regarding Communication in Medical Interactions. *American Journal of Speech-Language Pathology*, 24(3), 341–357. [https://doi.org/10.1044/2015\\_AJSLP-14-0051](https://doi.org/10.1044/2015_AJSLP-14-0051)
- Burns, M., Baylor, C., & Yorkston, K. (2017). Patient-Provider Communication Training for Dysarthria: Lessons Learned from Student Trainees. *Seminars in speech and language*, 38(3), 229–238. <https://doi.org/10.1055/s-0037-1602842>
- Butera-Prinzi, F., Charles, N., & Story, K. (2014). Narrative Family Therapy and Group Work for Families Living with Acquired Brain Injury. *Australian and New Zealand Journal of Family Therapy*, 35(1), 81–99. <https://doi.org/10.1002/anzf.1046>
- Butera-Prinzi, F., Charles, N., & Story, K. (2016). Holding Resilience in Trust: Working Systemically With Families Following an Acquired Brain Injury. *Journal of Social Work in Disability & Rehabilitation*, 15(3–4), 285–304. <https://doi.org/10.1080/1536710X.2016.1220882>
- Cameron, A., Hudson, K., Finch, E., Fleming, J., Lethlean, J., & McPhail, S. (2018). ‘I’ve got to get something out of it. And so do they’: Experiences of people with aphasia and university students participating in a communication partner training programme for healthcare professionals. *International Journal of Language & Communication Disorders*, 53(5), 919–928. <https://doi.org/10.1111/1460-6984.12402>
- Carnes, S. L., & Quinn, W. H. (2005). Family Adaptation to Brain Injury: Coping and Psychological Distress. *Families, Systems, & Health*, 23(2), 186–203. <https://doi.org/10.1037/1091-7527.23.2.186>
- Carr, A. (2012). *Family Therapy: Concepts, Process and Practice*. John Wiley & Sons.
- Carr, A. (2013). Development of Family Therapy in Ireland. *Contemporary Family Therapy*, 35(2), 179–199.
- Carragher, M., Steel, G., O’Halloran, R., Torabi, T., Johnson, H., Taylor, N. F., & Rose, M. (2021). Aphasia disrupts usual care: The stroke team’s perceptions of delivering healthcare to patients with aphasia. *Disability and Rehabilitation*, 43(21), 3003–3014. <https://doi.org/10.1080/09638288.2020.1722264>

- Cava, M.-J., Buelga, S., & Musitu, G. (2014). Parental Communication and Life Satisfaction in Adolescence. *The Spanish Journal of Psychology*, *17*, E98.  
<https://doi.org/10.1017/sjp.2014.107>
- Cavanaugh, R., & Haley, K. L. (2020). Subjective Communication Difficulties in Very Mild Aphasia. *American Journal of Speech-Language Pathology*, *29*(1S), 437–448.  
[https://doi.org/10.1044/2019\\_AJSLP-CAC48-18-0222](https://doi.org/10.1044/2019_AJSLP-CAC48-18-0222)
- Chang, H. F., Power, E., O'Halloran, R., & Foster, A. (2018). Stroke communication partner training: A national survey of 122 clinicians on current practice patterns and perceived implementation barriers and facilitators. *International Journal of Language & Communication Disorders*, *53*(6), 1094–1109. <https://doi.org/10.1111/1460-6984.12421>
- Charles, N., Butera-Prinzi, F., & Perlesz, A. (2007). Families living with acquired brain injury: A multiple family group experience. *NeuroRehabilitation*, *22*(1), 61–76.  
<https://doi.org/10.3233/NRE-2007-22107>
- Ch'Ng, A. M., French, D., & Mclean, N. (2008). Coping with the Challenges of Recovery from Stroke: Long Term Perspectives of Stroke Support Group Members. *Journal of Health Psychology*, *13*(8), 1136–1146. <https://doi.org/10.1177/1359105308095967>
- Clark, M. S., Rubenach, S., & Winsor, A. (2003). A randomized controlled trial of an education and counselling intervention for families after stroke. *Clinical Rehabilitation*, *17*(7), 703–712. <https://doi.org/10.1191/0269215503cr681oa>
- Clark, M. S., & Smith, D. S. (1999). Changes in family functioning for stroke rehabilitation patients and their families. *International Journal of Rehabilitation Research*, *22*(3), 171.
- Clarke, D. J. (2013). The role of multidisciplinary team care in stroke rehabilitation. *Progress in Neurology and Psychiatry*, *17*(4), 5–8. <https://doi.org/10.1002/pnp.288>
- Code, C., Hemsley, G., & Herrmann, M. (1999). The Emotional Impact of Aphasia. *Seminars in Speech and Language*, *20*(01), 19–31. <https://doi.org/10.1055/s-2008-1064006>

- Code, C., & Herrmann, M. (2003). The relevance of emotional and psychosocial factors in aphasia to rehabilitation. *Neuropsychological Rehabilitation, 13*(1–2), 109–132.  
<https://doi.org/10.1080/09602010244000291>
- Collins, R. C., & Kennedy, M. C. (2008). Serving families who have served: Providing family therapy and support in interdisciplinary polytrauma rehabilitation. *Journal of Clinical Psychology, 64*(8), 993–1003. <https://doi.org/10.1002/jclp.20515>
- Connolly, T., & Mahoney, E. (2018). Stroke survivors' experiences transitioning from hospital to home. *Journal of Clinical Nursing, 27*(21–22), 3979–3987.  
<https://doi.org/10.1111/jocn.14563>
- Couchman, G., McMahon, G., Kelly, A., & Ponsford, J. (2014). A new kind of normal: Qualitative accounts of Multifamily Group Therapy for acquired brain injury. *Neuropsychological Rehabilitation, 24*(6), 809–832. <https://doi.org/10.1080/09602011.2014.912957>
- Crotty, M. (1998). *The Foundations of Social Research: Meaning and Perspective in the Research Process*. SAGE Publications.
- Cruice, M., Blom Johansson, M., Isaksen, J., & Horton, S. (2018). Reporting interventions in communication partner training: A critical review and narrative synthesis of the literature. *Aphasiology, 32*(10), 1234–1265.  
<https://doi.org/10.1080/02687038.2018.1482406>
- Cruice, M., & Ten Kate, O. (2019). Clinicians' views and practices in quality of life in aphasia rehabilitation: A preliminary study. *Aphasiology, 33*(11), 1293–1318.  
<https://doi.org/10.1080/02687038.2019.1632787>
- Cruice, M., Worrall, L., & Hickson, L. (2006). Perspectives of quality of life by people with aphasia and their family: Suggestions for successful living. *Topics in Stroke Rehabilitation, 13*(1), 14–24. <https://doi.org/10.1310/4JW5-7VG8-G6X3-1QVJ>

- Cumming, T. B., Cadilhac, D. A., Rubin, G., Crafti, N., & Pearce, D. C. (2008). Psychological Distress and Social Support in Informal Caregivers of Stroke Survivors. *Brain Impairment*, 9(2), 152–160. <https://doi.org/10.1375/brim.9.2.152>
- Dausch, B. M., & Saliman, S. (2009). Use of family focused therapy in rehabilitation for veterans with traumatic brain injury. *Rehabilitation Psychology*, 54(3), 279–287. <https://doi.org/10.1037/a0016809>
- Davis, J., & Tadros, E. (2019). Using Medical Family Therapy with Parents of an Adult Child with Traumatic Brain Injury. *The American Journal of Family Therapy*, 47(4), 261–274. <https://doi.org/10.1080/01926187.2019.1640652>
- Dawes, K., Carlino, A., van den Berg, M., & Killington, M. (2022). Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions. *Disability and Rehabilitation*, 44(2), 282–290. <https://doi.org/10.1080/09638288.2020.1766582>
- Dooley, S., & Walshe, M. (2020). *Management of Cognitive Communication Difficulties in Dementia: A Cross Sectional Survey of Speech and Language Therapists*. <http://www.tara.tcd.ie/handle/2262/95642>
- Dorze, G. L., & Brassard, C. (1995). A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases. *Aphasiology*, 9(3), 239–255. <https://doi.org/10.1080/02687039508248198>
- Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., & Hearn, J. (2000). Investigating recovery from stroke: A qualitative study. *Journal of Clinical Nursing*, 9(4), 507–515. <https://doi.org/10.1046/j.1365-2702.2000.00411.x>
- Dunsmuir, S., Clifford, V., & Took, S. (2006). Collaboration Between Educational Psychologists and Speech and Language Therapists: Barriers and opportunities. *Educational Psychology in Practice*, 22(2), 125–140. <https://doi.org/10.1080/02667360600668246>

- Elman, R. J. (2007). The importance of aphasia group treatment for rebuilding community and health. *Topics in Language Disorders, 27*(4), 300–308.  
<https://doi.org/10.1097/01.TLD.0000299884.31864.99>
- Emmel, N., Greenhalgh, J., Manzano, A., Monaghan, M., & Dalkin, S. (2018). *Doing Realist Research*. SAGE Publications Ltd. <https://doi.org/10.4135/9781526451729>
- Feigin, V. L., Brainin, M., Norrving, B., Martins, S., Sacco, R. L., Hacke, W., Fisher, M., Pandian, J., & Lindsay, P. (2022). World Stroke Organization (WSO): Global Stroke Fact Sheet 2022. *International Journal of Stroke, 17*(1), 18–29.  
<https://doi.org/10.1177/17474930211065917>
- Flick, U. (2013). *The SAGE Handbook of Qualitative Data Analysis*. SAGE.
- Florian, V., & Katz, S. (1991). The other victims of traumatic brain injury: Consequences for family members. *Neuropsychology, 5*(4), 267–279. <https://doi.org/10.1037/0894-4105.5.4.267>
- Flowers, H. L., Skoretz, S. A., Silver, F. L., Rochon, E., Fang, J., Flamand-Roze, C., & Martino, R. (2016). Poststroke Aphasia Frequency, Recovery, and Outcomes: A Systematic Review and Meta-Analysis. *Archives of Physical Medicine and Rehabilitation, 97*(12), 2188-2201.e8. <https://doi.org/10.1016/j.apmr.2016.03.006>
- Forsgren, E., Hartelius, L., & Saldert, C. (2017). Improving medical students' knowledge and skill in communicating with people with acquired communication disorders. *International Journal of Speech-Language Pathology, 19*(6), 541–550.  
<https://doi.org/10.1080/17549507.2016.1216602>
- Fotiadou, D., Northcott, S., Chatzidaki, A., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person's social relationships? *Aphasiology, 28*(11), 1281–1300.  
<https://doi.org/10.1080/02687038.2014.928664>
- FTAI. (2023, June 11). *Family Therapy Association of Ireland*. Family Therapy Association of Ireland. <http://www.familytherapyireland.com/>

- Galvin, K. M., Braithwaite, D. O., & Bylund, C. L. (2015). *Family Communication: Cohesion and Change*. Routledge.
- Gibson, R., & Purdy, S. C. (2014). How do speech language therapists in New Zealand perceive the psychological impact of communication difficulties? *Speech, Language and Hearing, 17*(2), 116–122. <https://doi.org/10.1179/2050572813Y.0000000026>
- Gillespie, A., & Murphy, J. (2010). Divergences of perspective between people with aphasia and their family caregivers. *Aphasiology, 24*, 1559–1575.  
<https://doi.org/10.1080/02687038.2010.500810>
- Glass, T. A., Dym, B., Greenberg, S., Rintell, D., Roesch, C., & Berkman, L. F. (2000). Psychosocial intervention in stroke: Families in Recovery from Stroke Trial (FIRST). *The American Journal of Orthopsychiatry, 70*(2), 169–181. <https://doi.org/10.1037/h0087746>
- Golics, C. J., Basra, M. K. A., Finlay, A. Y., & Salek, S. (2013). The impact of disease on family members: A critical aspect of medical care. *Journal of the Royal Society of Medicine, 106*(10), 399–407. <https://doi.org/10.1177/0141076812472616>
- Goodman, C., & Evans, C. (2015). Focus Groups. In K. Gerrish & J. Lathlean (Eds.), *The Research Process in Nursing, 7th Edition | Wiley*. Wiley Blackwell. <https://www.wiley.com/en-ie/The+Research+Process+in+Nursing%2C+7th+Edition-p-9781118522585>
- Goodwin, M. H. (2006). *Participation, affect, and trajectory in family directive/response sequences*. *26*(4–5), 515–543. <https://doi.org/10.1515/TEXT.2006.021>
- Graham, J. R., Pereira, S., & Teasell, R. (2011). Aphasia and return to work in younger stroke survivors. *Aphasiology, 25*(8), 952–960. <https://doi.org/10.1080/02687038.2011.563861>
- Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013a). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology, 27*(7), 828–848.  
<https://doi.org/10.1080/02687038.2013.768330>

- Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013b). Third-party disability in family members of people with aphasia: A systematic review. *Disability and Rehabilitation*, 35(16), 1324–1341. <https://doi.org/10.3109/09638288.2012.735341>
- Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2014). Describing the impact of aphasia on close family members using the ICF framework. *Disability and Rehabilitation*, 36(14), 1184–1195. <https://doi.org/10.3109/09638288.2013.834984>
- Grenier-Genest, A., Gérard, M., & Courtois, F. (2017). Stroke and sexual functioning: A literature review. *NeuroRehabilitation*, 41(2), 293–315. <https://doi.org/10.3233/NRE-001481>
- Grohn, B., Worrall, L. E., Simmons-Mackie, N., & Brown, K. (2012). The first 3-months post-stroke: What facilitates successfully living with aphasia? *International Journal of Speech-Language Pathology*, 14(4), 390–400. <https://doi.org/10.3109/17549507.2012.692813>
- Grossoehme, D. H. (2014). Overview of Qualitative Research. *Journal of Health Care Chaplaincy*, 20(3), 109–122. <https://doi.org/10.1080/08854726.2014.925660>
- Gustafsson, L., & Bootle, K. (2013). Client and carer experience of transition home from inpatient stroke rehabilitation. *Disability and Rehabilitation*, 35(16), 1380–1386. <https://doi.org/10.3109/09638288.2012.740134>
- Hallé, M.-C., Duhamel, F., & Le Dorze, G. (2011). The daughter-mother relationship in the presence of aphasia: How daughters view changes over the first year poststroke. *Qualitative Health Research*, 21(4), 549–562. <https://doi.org/10.1177/1049732310391274>
- Hawksley, R., Ludlow, F., Buttimer, H., & Bloch, S. (2017). Communication disorders in palliative care: Investigating the views, attitudes and beliefs of speech and language therapists. *International Journal of Palliative Nursing*, 23(11), 543–551. <https://doi.org/10.12968/ijpn.2017.23.11.543>
- Hayashi, H., Gravier, M., Gustavson, K., & Bernstein-Ellis, E. (2023). Perspectives of U.S. speech-language pathologists on supporting the psychosocial health of individuals with aphasia.



- Journal of Communication Disorders*, 105, 106365.  
<https://doi.org/10.1016/j.jcomdis.2023.106365>
- Health Service Executive. (2022). *National Stroke Strategy 2022-2027*. Health Service Executive.
- Heaton, J. (2022). “\*Pseudonyms Are Used Throughout”: A Footnote, Unpacked. *Qualitative Inquiry*, 28(1), 123–132. <https://doi.org/10.1177/10778004211048379>
- Hemsley, B., Werninck, M., & Worrall, L. (2013). “That really shouldn’t have happened”: People with aphasia and their spouses narrate adverse events in hospital. *Aphasiology*, 27(6), 706–722. <https://doi.org/10.1080/02687038.2012.748181>
- Henihan, J., Henihan, R., & Jagoe, C. (2024). Family Therapy as an Intervention for Adults With Aphasia and Other Communication Disabilities After Acquired Brain Injury: A Scoping Review. *Rehabilitation Counseling Bulletin*, 0(0).  
<https://doi.org/10.1177/00343552241236859>
- Hersh, D., Israel, M., & Shiggins, C. (2021). The ethics of patient and public involvement across the research process: Towards partnership with people with aphasia. *Aphasiology*, 1–26.  
<https://doi.org/10.1080/02687038.2021.1896870>
- Hibbard, M. R., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., Ireland-Knight, L., Gordon, W., Avner, J., & Gartner, A. (2002). Peer Support in the Community: Initial Findings of a Mentoring Program for Individuals with Traumatic Brain Injury and Their Families. *The Journal of Head Trauma Rehabilitation*, 17(2), 112.
- Hilari, K. (2011). The impact of stroke: Are people with aphasia different to those without? *Disability and Rehabilitation*, 33(3), 211–218.  
<https://doi.org/10.3109/09638288.2010.508829>
- Hilton, R., Leenhouts, S., Webster, J., & Morris, J. (2014). Information, support and training needs of relatives of people with aphasia: Evidence from the literature. *Aphasiology*, 28(7), 797–822. <https://doi.org/10.1080/02687038.2014.906562>

- Hinckley, J. J. (2006). Finding Messages in Bottles: Living Successfully with Stroke and Aphasia. *Topics in Stroke Rehabilitation*, 13(1), 25–36. <https://doi.org/10.1310/FLJ3-04DQ-MG8W-89EU>
- Hodgson, J., Lamson, A., Mendenhall, T., & Tyndall, L. (2014). Introduction to Medical Family Therapy: Advanced Applications. In J. Hodgson, A. Lamson, T. Mendenhall, & D. R. Crane (Eds.), *Medical Family Therapy: Advanced Applications* (pp. 1–9). Springer International Publishing. [https://doi.org/10.1007/978-3-319-03482-9\\_1](https://doi.org/10.1007/978-3-319-03482-9_1)
- Holland, A. L. (2006). Living successfully with aphasia: Three variations on the theme. *Topics in Stroke Rehabilitation*, 13(1), 44–51. <https://doi.org/10.1310/13D7-R31R-8A0D-Y74G>
- Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). ‘You needed to rehab ... families as well’: Family members’ own goals for aphasia rehabilitation. *International Journal of Language & Communication Disorders*, 47(5), 511–521. <https://doi.org/10.1111/j.1460-6984.2012.00159.x>
- Hunting Pompon, R. (2021). Basic Counseling Skills: Working With People With Aphasia and Their Families. *Perspectives of the ASHA Special Interest Groups*, 6(5), 1003–1014. [https://doi.org/10.1044/2021\\_PERSP-20-00298](https://doi.org/10.1044/2021_PERSP-20-00298)
- IASLT. (2023). *IASLT Scope of Practice*.
- Intercollegiate Stroke Working Party. (2023). *National Clinical Guideline for Stroke for the UK and Ireland*. [www.strokeguideline.org](http://www.strokeguideline.org).
- Irish Heart Foundation. (2023, October 29). *National Stroke Strategy at risk due to funding*. Irish Heart Foundation. <https://irishheart.ie/news/national-stroke-strategy-at-risk-due-to-funding/>
- Isaksen, J., Beeke, S., Pais, A., Efstratiadou, E.-A., Pauranik, A., Revkin, S. K., Vandana, V. P., Valencia, F., Vuksanović, J., & Jagoe, C. (2023). Communication partner training for healthcare workers engaging with people with aphasia: Enacting Sustainable Development Goal 17 in Austria, Egypt, Greece, India and Serbia. *International Journal of*

*Speech-Language Pathology*, 25(1), 172–177.

<https://doi.org/10.1080/17549507.2022.2145355>

Kagan, A. (1995). Revealing the competence of aphasic adults through conversation: A challenge to health professionals. *Topics in Stroke Rehabilitation*, 2(1), 15–28.

<https://doi.org/10.1080/10749357.1995.11754051>

Kagan, A., Simmons-Mackie, N., Victor, J. C., Carling-Rowland, A., Hoch, J., & Huijbregts, M.

(2013). Assessment for Living With Aphasia. *APA PsycTests*.

<https://doi.org/10.1037/t65936-000>

Kauhanen, M. L., Korpelainen, J. T., Hiltunen, P., Määttä, R., Mononen, H., Brusin, E., Sotaniemi,

K. A., & Myllylä, V. V. (2000). Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovascular Diseases (Basel, Switzerland)*, 10(6), 455–461.

<https://doi.org/10.1159/000016107>

Kent, A. (2012). Responding to Directives: What can Children do when a Parent Tells them what to do? In S. Danby & M. Theobald (Eds.), *Disputes in Everyday Life: Social and Moral*

*Orders of Children and Young People* (Vol. 15, pp. 57–84). Emerald Group Publishing

Limited. [https://doi.org/10.1108/S1537-4661\(2012\)0000015007](https://doi.org/10.1108/S1537-4661(2012)0000015007)

Killmer, H. (2023). How parents with aphasia deal with children's resistance to requests. *Clinical*

*Linguistics & Phonetics*, 1–21. <https://doi.org/10.1080/02699206.2023.2226303>

King, R. B., Shade-Zeldow, Y., Carlson, C. E., Feldman, J. L., & Philip, M. (2002). Adaptation to

Stroke: A Longitudinal Study of Depressive Symptoms, Physical Health, and Coping

Process. *Topics in Stroke Rehabilitation*, 9(1), 46–66. [https://doi.org/10.1310/KDTA-](https://doi.org/10.1310/KDTA-WELC-T2WR-X51W)

[WELC-T2WR-X51W](https://doi.org/10.1310/KDTA-WELC-T2WR-X51W)

Kitzmüller, G., Asplund, K., & Häggström, T. (2012). The Long-Term Experience of Family Life

After Stroke. *The Journal of Neuroscience Nursing : Journal of the American Association*

*of Neuroscience Nurses*, 44, E1-13. <https://doi.org/10.1097/JNN.0b013e31823ae4a1>

Klonoff, P. S. (2014). *Psychotherapy for Families after Brain Injury*. Springer Science & Business.

- Klonoff, P. S., & Koberstein, E. J. (2010). Family Life. In *Psychotherapy after brain injury: Principles and techniques* (pp. 150–170). Guilford Press.
- Kneebone, I. I. (2016). Stepped psychological care after stroke. *Disability and Rehabilitation*, *38*(18), 1836–1843. <https://doi.org/10.3109/09638288.2015.1107764>
- Kneebone, I. I., & Dunmore, E. (2000). Psychological management of post-stroke depression. *British Journal of Clinical Psychology*, *39*(1), 53–65.  
<https://doi.org/10.1348/014466500163103>
- Kreutzer, J. S., Kolakowsky-Hayner, S. A., Demm, S. R., & Meade, M. A. (2002). A Structured Approach to Family Intervention After Brain Injury. *The Journal of Head Trauma Rehabilitation*, *17*(4), 349.
- Kreutzer, J. S., Stejskal, T. M., Godwin, E. E., Powell, V. D., & Arango-Lasprilla, J. C. (2010). A mixed methods evaluation of the Brain Injury Family Intervention. *NeuroRehabilitation*, *27*(1), 19–29. <https://doi.org/10.3233/NRE-2010-0578>
- Kutlubaev, M. A., & Hackett, M. L. (2014). Part II: Predictors of depression after stroke and impact of depression on stroke outcome: an updated systematic review of observational studies. *International Journal of Stroke: Official Journal of the International Stroke Society*, *9*(8), 1026–1036. <https://doi.org/10.1111/ijs.12356>
- Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. Pearson Education.
- Łapkiewicz, E., Grochmal-Bach, B., Pufal, A., & Tlokinski, W. (2008). Aphasia and changes in the quality of marital relations. *Acta Neuropsychologica*, *6*, 237–246.
- Larøi, F. (2003). The family systems approach to treating families of persons with brain injury: A potential collaboration between family therapist and brain injury professional. *Brain Injury*, *17*(2), 175–187. <https://doi.org/10.1080/0269905021000010140>

- Lauer-Listhaus, B. (1991). Group psychotherapy for families of head injured adults: A psychoeducational approach. *Counselling Psychology Quarterly*, 4(4), 351–354.  
<https://doi.org/10.1080/09515079108254443>
- Laures-Gore, J. S., & Buchanan, T. W. (2015). Aphasia and the neuropsychobiology of stress. *Journal of Clinical and Experimental Neuropsychology*, 37(7), 688–700.  
<https://doi.org/10.1080/13803395.2015.1042839>
- Le Dorze, G., & Signori, F.-H. (2010). Needs, barriers and facilitators experienced by spouses of people with aphasia. *Disability and Rehabilitation*, 32(13), 1073–1087.  
<https://doi.org/10.3109/09638280903374121>
- Lemieux, L., Cohen-Schneider, R., & Holzapfel, S. (2001). Aphasia and Sexuality. *Sexuality and Disability*, 19(4), 253–266. <https://doi.org/10.1023/A:1017953308761>
- Levin, K. A., Dallago, L., & Currie, C. (2012). The Association Between Adolescent Life Satisfaction, Family Structure, Family Affluence and Gender Differences in Parent–Child Communication. *Social Indicators Research*, 106(2), 287–305.  
<https://doi.org/10.1007/s11205-011-9804-y>
- Levitt, H. M., Motulsky, S. L., Wertz, F. J., Morrow, S. L., & Ponterotto, J. G. (2017). Recommendations for designing and reviewing qualitative research in psychology: Promoting methodological integrity. *Qualitative Psychology*, 4(1), 2–22.  
<https://doi.org/10.1037/qup0000082>
- Lin, S., Wang, C., Wang, Q., Xie, S., Tu, Q., Zhang, H., Peng, M., Zhou, J., & Redfern, J. (2022). The experience of stroke survivors and caregivers during hospital-to-home transitional care: A qualitative longitudinal study. *International Journal of Nursing Studies*, 130, 104213.  
<https://doi.org/10.1016/j.ijnurstu.2022.104213>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. SAGE.

- Luck, A. M., & Rose, M. L. (2007). Interviewing people with aphasia: Insights into method adjustments from a pilot study. *Aphasiology*, *21*(2), 208–224.  
<https://doi.org/10.1080/02687030601065470>
- Maitz, E. A., & Sachs, P. R. (1995). Treating families of individuals with traumatic brain injury from a family systems perspective. *The Journal of Head Trauma Rehabilitation*, *10*(2), 1.
- Manders, E., Mariën, A., & Janssen, V. (2011). Informing and supporting partners and children of persons with aphasia: A comparison of supply and demand. *Logopedics, Phoniatrics, Vocology*, *36*(4), 139–144. <https://doi.org/10.3109/14015439.2011.562534>
- Manning, M., Cleary, C., & McCaughey, C. (2023). How do speech and language therapists enact aphasia psychosocial support in Ireland? A cross-sectional online survey informed by normalization process theory. *International Journal of Language & Communication Disorders*. <https://doi.org/10.1111/1460-6984.12959>
- Manning, M., Cuskelly, C., Russ, E., & Franklin, S. (2020). Supporting people with post-stroke aphasia to live well: A cross-sectional survey of Speech & Language Therapists in Ireland. *Health & Social Care in the Community*, *28*(6), 2105–2116.  
<https://doi.org/10.1111/hsc.13021>
- Manning, M., Hickey, A., MacFarlane, A., & Franklin, S. (2017). *Perspectives of people with aphasia post-stroke towards recovery & living successfully. A systematic review and qualitative evidence synthesis* (5). *17*(5), Article 5. <https://doi.org/10.5334/ijic.3906>
- Manning, M., MacFarlane, A., Hickey, A., & Franklin, S. (2019). Perspectives of people with aphasia post-stroke towards personal recovery and living successfully: A systematic review and thematic synthesis. *PLoS One*, *14*(3), e0214200.  
<https://doi.org/10.1371/journal.pone.0214200>
- Manning, M., MacFarlane, A., Hickey, A., Galvin, R., & Franklin, S. (2020). The relevance of stroke care for living well with post-stroke aphasia: A qualitative interview study with working-

- aged adults. *Disability & Rehabilitation*, 44(14), 3440–3452.  
<https://doi.org/10.1080/09638288.2020.1863483>
- Manning, M., MacFarlane, A., Hickey, A., Galvin, R., & Franklin, S. (2021). 'I hated being ghosted' - The relevance of social participation for living well with post-stroke aphasia: Qualitative interviews with working aged adults. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 24(4), 1504–1515.  
<https://doi.org/10.1111/hex.13291>
- Marlowe, D. (2013). Bridging Conversations: Discussing the Intra-professional Relationship between Medical Family Therapy and Family Therapy. *Journal of Family Therapy*, 35(2), 119–138. <https://doi.org/10.1111/j.1467-6427.2011.00553.x>
- Matos, M. da A., Jesus, L., & Cruice, M. (2014). Consequences of stroke and aphasia according to the ICF domains: Views of Portuguese people with aphasia, family members and professionals. *Aphasiology*, 28, 771–796.  
<https://doi.org/10.1080/02687038.2014.906561>
- McDermott, G. L., & McDonnell, A. M. (2014). Acquired brain injury services in the Republic of Ireland: Experiences and perceptions of families and professionals. *Brain Injury*, 28(1), 81–91. <https://doi.org/10.3109/02699052.2013.857790>
- McMenamin, R., Faherty, K., Larkin, M., & Loftus, L. (2021). An investigation of public awareness and knowledge of aphasia in the West of Ireland. *Aphasiology*, 35(11), 1415–1431.  
<https://doi.org/10.1080/02687038.2020.1812047>
- Michallet, B., Le Dorze, G., & Tétrault, S. (2001). The needs of spouses caring for severely aphasic persons. *Aphasiology*, 15(8), 731–747.  
<https://doi.org/10.1080/02687040143000087>
- Morris, R., Eccles, A., Ryan, B., & Kneebone, I. I. (2017). Prevalence of anxiety in people with aphasia after stroke. *Aphasiology*, 31(12), 1410–1415.  
<https://doi.org/10.1080/02687038.2017.1304633>

- Moss, B., Northcott, S., Behn, N., Monnelly, K., Marshall, J., Thomas, S., Simpson, A., Goldsmith, K., McVicker, S., Flood, C., & Hilari, K. (2021). 'Emotion is of the essence. ... Number one priority': A nested qualitative study exploring psychosocial adjustment to stroke and aphasia. *International Journal of Language & Communication Disorders*, *56*(3), 594–608. <https://doi.org/10.1111/1460-6984.12616>
- Muldoon, O., Walsh, S., Curtin, M., & Kinsella, E. (2017). *Getting my life reset. The lived experience of brain injury: The Irish experience*. University of Limerick, Acquired Brain Injury Ireland.
- Müller, N., Lyons, R., Devlin, A. M., Antonijevic-Elliott, S., & Kirkpatrick, V. (2023). The impact of the COVID-19 pandemic on speech and language therapy services in Ireland: A mixed-methods survey at two time points during the pandemic. *International Journal of Language & Communication Disorders*. <https://doi.org/10.1111/1460-6984.12971>
- Nash, J., Krüger, E., Vorster, C., Graham, M. A., & Pillay, B. S. (2022). Psychosocial care of people with aphasia: Practices of speech-language pathologists in South Africa. *International Journal of Speech-Language Pathology*, *24*(3), 330–340. <https://doi.org/10.1080/17549507.2021.1987521>
- National Institute for Health and Care Excellence. (2023). *Stroke rehabilitation in adults (NG236)*. <https://nice.org.uk/guidance/ng236>
- National Office of Clinical Audit. (2020). *IRISH NATIONAL AUDIT OF STROKE NATIONAL REPORT*. <https://www.noca.ie/documents/irish-national-audit-of-stroke-national-report-2020>
- Nätterlund, B. S. (2010). Being a close relative of a person with aphasia. *Scandinavian Journal of Occupational Therapy*, *17*(1), 18–28. <https://doi.org/10.3109/11038120902833218>
- Nichols, F., Varchevker, A., & Pring, T. (1996). Working with people with aphasia and their families: An exploration of the use of family therapy techniques. *Aphasiology*, *10*(8), 767–781. <https://doi.org/10.1080/02687039608248449>



- Northcott, S., Burns, K., Simpson, A., & Hilari, K. (2015). 'Living with Aphasia the Best Way I Can': A Feasibility Study Exploring Solution-Focused Brief Therapy for People with Aphasia. *Folia Phoniatica et Logopaedica : Official Organ of the International Association of Logopedics and Phoniatics (IALP)*, 67(3), 156–167. <https://doi.org/10.1159/000439217>
- Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke? *International Journal of Language & Communication Disorders*, 46(5), 524–534. <https://doi.org/10.1111/j.1460-6984.2011.00079.x>
- Northcott, S., Simpson, A., Moss, B., Ahmed, N., & Hilari, K. (2017). How do speech-and-language therapists address the psychosocial well-being of people with aphasia? Results of a UK online survey. *International Journal of Language & Communication Disorders*, 52(3), 356–373. <https://doi.org/10.1111/1460-6984.12278>
- Northcott, S., Simpson, A., Moss, B., Ahmed, N., & Hilari, K. (2018). Supporting people with aphasia to 'settle into a new way to be': Speech and language therapists' views on providing psychosocial support. *International Journal of Language & Communication Disorders*, 53(1), 16–29. <https://doi.org/10.1111/1460-6984.12323>
- Northcott, S., Simpson, A., Thomas, S., Barnard, R., Burns, K., Hirani, S. P., & Hilari, K. (2021). 'Now I Am Myself': Exploring How People With Poststroke Aphasia Experienced Solution-Focused Brief Therapy Within the SOFIA Trial. *Qualitative Health Research*, 31(11), 2041–2055. <https://doi.org/10.1177/10497323211020290>
- Nyström, M. (2011). A bridge between a lonely soul and the surrounding world: A study on existential consequences of being closely related to a person with aphasia. *International Journal of Qualitative Studies on Health and Well-Being*, 6(4), 10.3402/qhw.v6i4.7911. <https://doi.org/10.3402/qhw.v6i4.7911>
- Olson, D. H. (2000). Circumplex Model of Marital and Family Systems. *Journal of Family Therapy*, 22(2), 144–167. <https://doi.org/10.1111/1467-6427.00144>

- Olson, D. H., & Gorall, D. M. (2003). Circumplex model of marital and family systems. In F. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (pp. 514–548). The Guilford Press.
- Palinkas, L. A. (2014). Qualitative and Mixed Methods in Mental Health Services and Implementation Research. *Journal of Clinical Child & Adolescent Psychology, 43*(6), 851–861. <https://doi.org/10.1080/15374416.2014.910791>
- Palmer, S., & Palmer, J. B. (2011). *When Your Spouse Has a Stroke: Caring for Your Partner, Yourself, and Your Relationship*. JHU Press.
- Parr, S. (2001). Psychosocial aspects of aphasia: Whose perspectives? *Folia Phoniatrica et Logopaedica : Official Organ of the International Association of Logopedics and Phoniatrics (IALP), 53*(5), 266–288. <https://doi.org/10.1159/000052681>
- Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about Aphasia: Living with Loss of Language After Stroke*. Open University Press.
- Pearl, G., & Cruice, M. (2017). Facilitating the Involvement of People with Aphasia in Stroke Research by Developing Communicatively Accessible Research Resources. *Topics in Language Disorders, 37*(1), 67–84. <https://doi.org/10.1097/TLD.0000000000000112>
- Perlesz, A., & O'Loughlan, M. (1998). Changes in stress and burden in families seeking therapy following traumatic brain injury: A follow-up study. *International Journal of Rehabilitation Research, 21*(4), 339.
- Perlick, D. A., Straits-Troster, K., Strauss, J. L., Norell, D., Tupler, L. A., Levine, B., Luo, X., Holman, C., Marcus, T., Dixon, L. B., & Dyck, D. G. (2013). Implementation of Multifamily Group Treatment for Veterans With Traumatic Brain Injury. *Psychiatric Services, 64*(6), 534–540. <https://doi.org/10.1176/appi.ps.001622012>
- Phipps, M. S., & Cronin, C. A. (2020). Management of acute ischemic stroke. *BMJ, l6983*. <https://doi.org/10.1136/bmj.l6983>

- Pierce, L. L., & Summers, D. (2015). Stroke. In C. Lehman (Ed.), *The specialty practice of rehabilitation nursing. A core curriculum*. (7th ed., pp. 471–510). Association of Rehabilitation Nurses.
- Pound, C., Parr, S., Lindsay, J., & Woolf, C. (2018). *Beyond Aphasia: Therapies For Living With Communication Disability*. Routledge.
- Quirkos. (2023). *Quirkos* (2.5.3) [Computer software]. <https://www.quirkos.com/>
- Rispoli, M. J., Machalicek, W., & Lang, R. (2010). Communication interventions for individuals with acquired brain injury. *Developmental Neurorehabilitation*, *13*(2), 141–151. <https://doi.org/10.3109/17518420903468464>
- Rolland, J. S., & Walsh, F. (2005). Systemic Training for Healthcare Professionals: The Chicago Center for Family Health Approach. *Family Process*, *44*(3), 283–301. <https://doi.org/10.1111/j.1545-5300.2005.00060.x>
- Romero-Abrio, A., León-Moreno, C., Musitu-Ferrer, D., & Villarreal-González, M. E. (2019). Family Functioning, Self-Concept and Cybervictimization: An Analysis Based on Gender. *Social Sciences*, *8*(2), Article 2. <https://doi.org/10.3390/socsci8020069>
- Rose, M., Ferguson, A., Power, E., Togher, L., & Worrall, L. (2014). Aphasia rehabilitation in Australia: Current practices, challenges and future directions. *International Journal of Speech-Language Pathology*, *16*(2), 169–180. <https://doi.org/10.3109/17549507.2013.794474>
- Rosenthal, M., & Young, T. (1988). Effective family intervention after traumatic brain injury: Theory and practice. *The Journal of Head Trauma Rehabilitation*, *3*(4), 42–50. <https://doi.org/10.1097/00001199-198812000-00007>
- Rowland, A., & McDonald, L. (2009). Evaluation of Social Work Communication Skills to Allow People with Aphasia to be Part of the Decision Making Process in Healthcare. *Social Work Education*, *28*(2), 128–144. <https://doi.org/10.1080/02615470802029965>

- Ryan, B., Bohan, J., & Kneebone, I. (2019). Help-seeking and people with aphasia who have mood problems after stroke: Perspectives of speech–language pathologists. *International Journal of Language & Communication Disorders*, 54(5), 779–793.  
<https://doi.org/10.1111/1460-6984.12476>
- Sandberg, C. W., Nadermann, K., Parker, L., Kubat, A. M., & Conyers, L. M. (2021). Counseling in Aphasia: Information and Strategies for Speech-Language Pathologists. *American Journal of Speech-Language Pathology*, 30(6), 2337–2349. [https://doi.org/10.1044/2021\\_AJSLP-20-00312](https://doi.org/10.1044/2021_AJSLP-20-00312)
- Santo Pietro, M. J., Marks, D. R., & Mullen, A. (2019). When Words Fail: Providing Effective Psychological Treatment for Depression in Persons with Aphasia. *Journal of Clinical Psychology in Medical Settings*, 26(4), 483–494. <https://doi.org/10.1007/s10880-019-09608-4>
- Saunders, B., Kitzinger, J., & Kitzinger, C. (2015). Anonymising interview data: Challenges and compromise in practice. *Qualitative Research*, 15(5), 616–632.  
<https://doi.org/10.1177/1468794114550439>
- Schwandt, T. A. (2014). *The SAGE Dictionary of Qualitative Inquiry*. SAGE Publications.
- Sekhon, J. K., Douglas, J., & Rose, M. L. (2015). Current Australian speech-language pathology practice in addressing psychological well-being in people with aphasia after stroke. *International Journal of Speech-Language Pathology*, 17(3), 252–262.  
<https://doi.org/10.3109/17549507.2015.1024170>
- Sekhon, J. K., Oates, J., Kneebone, I., & Rose, M. (2019). Counselling training for speech–language therapists working with people affected by post-stroke aphasia: A systematic review. *International Journal of Language & Communication Disorders*, 54(3), 321–346.  
<https://doi.org/10.1111/1460-6984.12455>

- Shadden, B. B., & Agan, J. P. (2004). Renegotiation of Identity: The Social Context of Aphasia Support Groups. *Topics in Language Disorders, 24*(3), 174–186.  
<https://doi.org/10.1097/00011363-200407000-00005>
- Shrubsole, K., Power, E., & Hallé, M. (2023). Communication partner training with familiar partners of people with aphasia: A systematic review and synthesis of barriers and facilitators to implementation. *International Journal of Language & Communication Disorders, 58*(2), 601–628. <https://doi.org/10.1111/1460-6984.12805>
- Shrubsole, K., Worrall, L., Power, E., & O'Connor, D. A. (2017). Recommendations for post-stroke aphasia rehabilitation: An updated systematic review and evaluation of clinical practice guidelines. *Aphasiology, 31*(1), 1–24. <https://doi.org/10.1080/02687038.2016.1143083>
- Simmons-Mackie, N., & Cherney, L. R. (2018). Aphasia in North America: Highlights of a White Paper. *Archives of Physical Medicine and Rehabilitation, 99*(10), e117.  
<https://doi.org/10.1016/j.apmr.2018.07.417>
- Simmons-Mackie, N., & Damico, J. (1995). Communicative competence in aphasia: Evidence from compensatory strategies. In M. Lemme (Ed.), *Clinical aphasiology* (pp. 95–105). Proed.
- Simmons-Mackie, N., Raymer, A., & Cherney, L. R. (2016). Communication Partner Training in Aphasia: An Updated Systematic Review. *Archives of Physical Medicine and Rehabilitation, 97*(12), 2202–2221.e8. <https://doi.org/10.1016/j.apmr.2016.03.023>
- Sirman, N., Beeke, S., & Cruice, M. (2017). Professionals' perspectives on delivering conversation therapy in clinical practice. *Aphasiology, 31*(4), 465–494.  
<https://doi.org/10.1080/02687038.2017.1278739>
- Smith-Acuña, S. (2010). *Systems Theory in Action: Applications to Individual, Couple, and Family Therapy*. John Wiley & Sons.
- Söderström, S., Fogelsjö, A., Fugl-Meyer, K. S., & Stenson, S. (1992). Traumatic brain injury crisis intervention and family therapy—Management and outcome. *Brain Injury Treatment*

and Research Group. *Scandinavian Journal of Rehabilitation Medicine. Supplement*, 26, 132–141.

Steinke, E. E., Jaarsma, T., Barnason, S. A., Byrne, M., Doherty, S., Dougherty, C. M., Fridlund, B., Kautz, D. D., Mårtensson, J., Mosack, V., Moser, D. K., & Council on Cardiovascular and Stroke Nursing of the American Heart Association and the ESC Council on Cardiovascular Nursing and Allied Professions (CCNAP). (2013). Sexual counselling for individuals with cardiovascular disease and their partners: A consensus document from the American Heart Association and the ESC Council on Cardiovascular Nursing and Allied Professions (CCNAP). *European Heart Journal*, 34(41), 3217–3235.

<https://doi.org/10.1093/eurheartj/eh270>

Straits-Troster, K., Gierisch, J. M., Strauss, J. L., Dyck, D. G., Dixon, L. B., Norell, D., & Perlick, D. A. (2013). Multifamily Group Treatment for Veterans With Traumatic Brain Injury: What Is the Value to Participants? *Psychiatric Services*, 64(6), 541–546.

<https://doi.org/10.1176/appi.ps.001632012>

Strong, K. A., & Randolph, J. (2021). How Do You Do Talk Therapy With Someone Who Can't Talk? Perspectives From Mental Health Providers on Delivering Services to Individuals With Aphasia. *American Journal of Speech-Language Pathology*, 30(6), 2681–2692.

[https://doi.org/10.1044/2021\\_AJSLP-21-00040](https://doi.org/10.1044/2021_AJSLP-21-00040)

Thomas, S. A., & Lincoln, N. B. (2008). Predictors of emotional distress after stroke. *Stroke*, 39(4), 1240–1245. <https://doi.org/10.1161/STROKEAHA.107.498279>

Thomas, S. A., Russell, C., Seed, R., Worthington, E., Walker, M. F., Macniven, J. A., & Lincoln, N. B. (2013). An evaluation of treatment integrity in a randomized trial of behavioural therapy for low mood in stroke patients with aphasia. *Clinical Rehabilitation*, 27(12), 1097–1106. <https://doi.org/10.1177/0269215513489579>

- Todd, J., & Satz, P. (1980). The Effects of Long-Term Verbal Memory Deficits: A Case Study of an Adolescent and His Family. *Journal of Marital and Family Therapy*, 6(4), 431–438.  
<https://doi.org/10.1111/j.1752-0606.1980.tb01336.x>
- Turnblom, M., & Myers, J. S. (1952). A Group Discussion Program With The Families Of Aphasic Patients. *Journal of Speech and Hearing Disorders*, 17(4), 393–396.  
<https://doi.org/10.1044/jshd.1704.393>
- Tyndall, L. E., Hodgson, J. L., Lamson, A. L., White, M., & Knight, S. M. (2012). Medical Family Therapy: Charting a Course in Competencies. *Contemporary Family Therapy*, 34(2), 171–186. <https://doi.org/10.1007/s10591-012-9191-9>
- van Ewijk, L., Bootsma, T. M. C., van Rijssen, M., & Ter Wal, N. (2021). Speech language therapists' experiences with subjective well-being in people with aphasia. *International Journal of Language & Communication Disorders*, 56(3), 473–484.  
<https://doi.org/10.1111/1460-6984.12596>
- van Rijssen, M., Isaksen, J., Vandenborre, D., Veldkamp, M., Bryon, E., Remijn, L., Visser-Meily, A., Gerrits, E., & van Ewijk, L. (2023). Ways to improve communication and support in healthcare centres according to people with aphasia and their relatives: A Dutch perspective. *Aphasiology*, 37(1), 69–82.  
<https://doi.org/10.1080/02687038.2021.1988505>
- van Rijssen, M., Veldkamp, M., Bryon, E., Remijn, L., Visser-Meily, J. M. A., Gerrits, E., & van Ewijk, L. (2022). How do healthcare professionals experience communication with people with aphasia and what content should communication partner training entail? *Disability and Rehabilitation*, 44(14), 3671–3678.  
<https://doi.org/10.1080/09638288.2021.1878561>
- Visser-Meily, A., Post, M., Meijer, A. M., van de Port, I., Maas, C., & Lindeman, E. (2005). When a parent has a stroke: Clinical course and prediction of mood, behavior problems, and

health status of their young children. *Stroke*, 36(11), 2436–2440.

<https://doi.org/10.1161/01.STR.0000185681.33790.0a>

Walker, S., & Akister, J. (2004). *Applying Family Therapy: A Guide for Caring Professionals in the Community*. Russell House.

Walsh, M., Galvin, R., Macey, C., McCormack, C., & Horgan, F. (2013). *National survey of stroke survivors: Documenting the experiences and levels of self-reported long-term need in stroke survivors in the first 5 years. systematic review: factors associated with community re-integration in the first 12 months post stroke: a qualitative synthesis*. [Report]. Royal College of Surgeons in Ireland.

<https://doi.org/10.25419/rcsi.10798769.v3>

Waterhouse, J., & Metcalfe, M. (1991). Attitudes toward nurses discussing sexual concerns with patients. *Journal of Advanced Nursing*, 16(9), 1048–1054.

<https://doi.org/10.1111/j.1365-2648.1991.tb03365.x>

Watzlawick, P., & Coyne, J. C. (1980). Depression Following Stroke: Brief, Problem-Focused Family Treatment. *Family Process*, 19(1), 13–18. <https://doi.org/10.1111/j.1545-5300.1980.00013.x>

Williams, S. E. (1993). The impact of aphasia on marital satisfaction. *Archives of Physical Medicine and Rehabilitation*, 74(4), 361–367.

Winkler, M., Bedford, V., Northcott, S., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect the carer and their relationship with the person with aphasia? *Aphasiology*, 28(11), 1301–1319. <https://doi.org/10.1080/02687038.2014.928665>

World Health Organization. (2001). *International classification of functioning, disability and health, ICF*. Geneva.

World Health Organization. (2017). *Rehabilitation in health systems*.



- Worrall, L., Brown, K., Cruice, M., Davidson, B., Hersh, D., Howe, T., & Sherratt, S. (2010). The evidence for a life-coaching approach to aphasia. *Aphasiology*, *24*(4), 497–514. <https://doi.org/10.1080/02687030802698152>
- Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, *25*(3), 309–322. <https://doi.org/10.1080/02687038.2010.508530>
- Wray, F., & Clarke, D. (2017). Longer-term needs of stroke survivors with communication difficulties living in the community: A systematic review and thematic synthesis of qualitative studies. *BMJ Open*, *7*(10), e017944. <https://doi.org/10.1136/bmjopen-2017-017944>
- Wray, F., Clarke, D., & Forster, A. (2020). “Guiding them to take responsibility”: Exploring UK speech and language therapists’ views of supporting self-management of aphasia. *Aphasiology*, *34*(4), 411–430. <https://doi.org/10.1080/02687038.2019.1697865>
- Yeates, G. N., Luckie, M., De Beer, Z., & Khela, P. (2010). Elucidating the psychosocial context of ‘post-concussion syndrome’ (PCS): A case study from post-Milan systemic family therapy. *Journal of Family Therapy*, *32*(2), 186–202. <https://doi.org/10.1111/j.1467-6427.2010.00493.x>
- Zanella, C., Laures-Gore, J., Dotson, V. M., & Belagaje, S. R. (2023). Incidence of post-stroke depression symptoms and potential risk factors in adults with aphasia in a comprehensive stroke center. *Topics in Stroke Rehabilitation*, *30*(5), 448–458. <https://doi.org/10.1080/10749357.2022.2070363>
- Zarski, J. J., West, J. D., De Pompei, R., & Hall, D. E. (1988). Chronic Illness: Stressors, the Adjustment Process, and Family-Focused Interventions. *Journal of Mental Health Counseling*, *10*(2), 145–158.

## Appendix A

### A1 - Initial ethical approval letter



**Trinity College Dublin**

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

<b>Application</b>	Academic Year 2022/23
<b>Applicant Code</b>	MT1
<b>Applicant/Supervisor Name</b>	Jessica Henihan / Dr Caroline Jagoe
<b>Title of Research</b>	Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.
<b>Date of this letter</b>	04/11/2022

---

Dear Jessica,

Your amended submission (dated 03/11/2022) for ethical approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin and has been approved in full.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one electronic copy (to [slscs@tcd.ie](mailto:slscs@tcd.ie) )
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

A handwritten signature in cursive script that reads "Ciarán Kenny".

**Dr Ciarán Kenny**

Chair, Research Ethics Committee

School of Linguistic, Speech and Communication Sciences

## Appendix A

### A2 - Ethical approval letter after amendments



**Trinity College Dublin**

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

<b>Application</b>	Academic Year 2022/23
<b>Applicant Code</b>	MT1
<b>Applicant/Supervisor Name</b>	Jessica Henihan / Dr Caroline Jagoe
<b>Title of Research</b>	Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.
<b>Date of this letter</b>	15/02/2023

---

Dear Jessica,

Your amended submission (dated 07/02/2023) for ethical approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin and has been approved in full.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one electronic copy (to [slscs@tcd.ie](mailto:slscs@tcd.ie) )
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

A handwritten signature in cursive script, reading "Ciarán Kenny".

**Dr Ciarán Kenny**

Chair, Research Ethics Committee

School of Linguistic, Speech and Communication Sciences

## Appendix B

### B1 - Aphasia friendly letter



To whom it may concern,

Jessica Henihan is a Speech and Language Therapist and a MSc student in the Department of Clinical Speech and Language Studies in Trinity College Dublin in Ireland.

As part of her MSc, she is conducting a research study that will investigate the views of Speech and Language Therapists, Family Therapists, and people with aphasia and their family members on the use of family therapy after acquired brain injury.



Aphasia is a disorder that affects how a person communicates. It can affect how a person uses and understands spoken and written language. It can have a big impact on everyone in a family. A Speech and Language Therapist is the healthcare professional that is responsible for diagnosing and treating this condition.



This research will be carried out in the form of interviews. The reason for conducting this study is that there is very little research in this area especially on the experiences and perceptions of people with aphasia and their family. Therefore, people with aphasia and their family may not be receiving the right healthcare or support.



In order to do this research, Jessica is asking people with aphasia and their family members to participate in interviews. Family members must be aged 8 years or older to participate. If you are interested, please see the attached Participant Information Leaflet.



If you have any questions you can contact Jessica via email ([henihanj@tcd.ie](mailto:henihanj@tcd.ie)), or



Contact Brendan McFadden (Executive Officer in Department of Clinical Speech and Language Studies, Trinity College Dublin) by phone: 01 896 1496

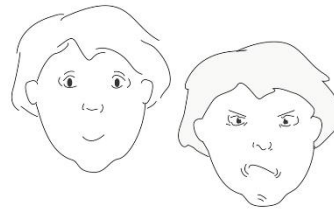
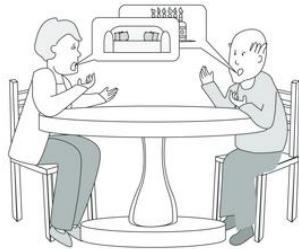
## Appendix B

B2 - Participant information leaflet for people with aphasia

# Participant Information Leaflet

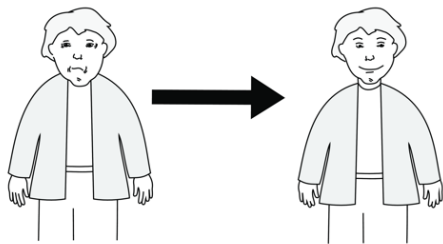
<b>Project:</b>	Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.
<b>Researchers:</b>	Jessica Henihan (Speech and Language Therapist)  &  Dr Caroline Jagoe (Speech & Language Therapist)

We want to find out:



How **you** and your **family** **feel** about aphasia

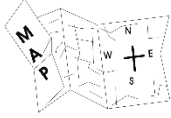
**Changes** in your family



What **has helped** you adjust to this new way of being a family.

What **would help** you and your **family**.

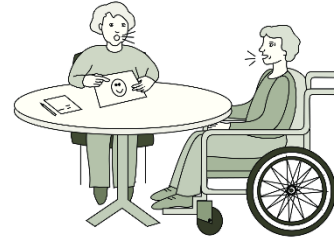
Participating in this research involves **both** the person with aphasia and their family members.

<p><b>Where?</b></p> 	<p>The research will happen:</p> <p>In your <b>home</b>                      <b>OR</b>                      <b>online</b></p>  	
<p><b>What?</b></p> 	<p>You will participate in an interview for <b>1 hour</b>.</p>	
<p><b>When?</b></p> 	<p><b>Dates and times</b> will be confirmed.</p> <p>The research will start in <b>November 2022</b>.</p>	

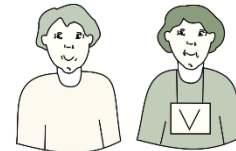
## What will happen during the interview with the person with aphasia?

1. **Interview** with the person with aphasia.

These will be done by a speech & language therapist.



2. The interviews will be **videotaped** so the researcher can write about the information later.



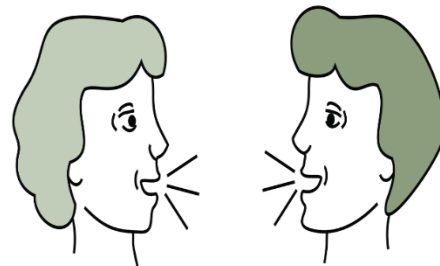
The interview will last for about **1 hour**.  
The time will be confirmed with you.



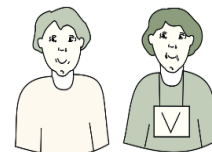
## What will happen during the interview with family members?

1. **Interview** with family members.

These will be done by a speech & language therapist.



2. The interviews will be **videotaped** so the researcher can write about the information later.





The interview will last for about **1 hour**.  
**The time will be confirmed with you.**



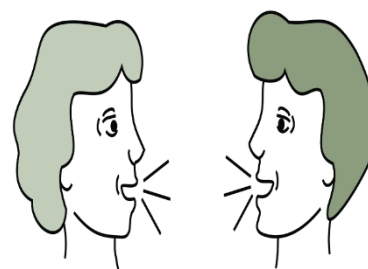
### **Potential benefits:**

- ✓ This will help research
- ✓ This could help other families with aphasia



### **What will happen after the interview?**

If you consent, the researcher will contact your Speech and Language therapist and ask them details about your last assessment.



### **Right to withdraw**

You can **stop** at any time

It is **your choice**

It is **okay if either the person with aphasia or the family member** decides to stop participating



## Potential risks

There are some risks.

1. You might **feel upset or uncomfortable**.

You can **stop** at any time.

You can **not answer** a question.

2. You might get **tired**.

You can **stop** at any time.

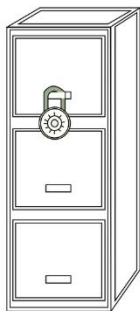


The interview will last 1 hour.

This may be inconvenient.

## What will happen to the information gathered?

Your participation is **confidential**.



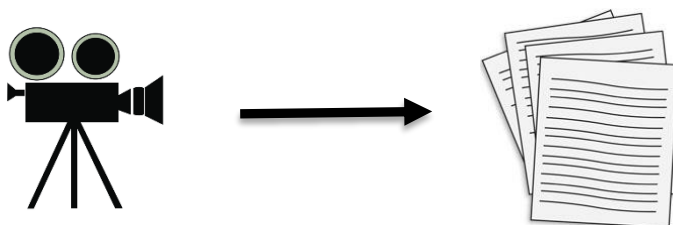
Information will **only be accessed by the research team.**

Your **name will not appear** on any notes.



The **video recording will be securely stored** on a password-protected computer.

The video recordings will be **transcribed**. Your name and anything that could identify you will be coded.



You may **request a copy of the transcript** if you wish to do so.

If you **wish to participate** please contact **Jessica Henihan** and provide your name and contact details.



**Jessica Henihan**

[henihanj@tcd.ie](mailto:henihanj@tcd.ie)

**OR** you can contact **Brendan** from Trinity College Dublin



01 896 1496

## Appendix B

### B3 - Participant information leaflet for adult family members

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

## Participant Information Leaflet for adult family members

Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.

<b>Site</b>	Trinity College Dublin
<b>Principal Investigator(s) and Co-Investigator(s)</b> <i>(insert names, titles and contact details. Where relevant, give the name of academic supervisor)</i>	Jessica Henihan (Principal Investigator) <a href="mailto:henihanj@tcd.ie">henihanj@tcd.ie</a> Dr Caroline Jagoe (Co-investigator & academic supervisor) <a href="mailto:cjagoe@tcd.ie">cjagoe@tcd.ie</a>
<b>Data Controllers</b>	Trinity College Dublin (for research data)
<b>Data Protection Officer</b>	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 <a href="mailto:dataprotection@tcd.ie">dataprotection@tcd.ie</a>

You are being invited to take part in a research study that is being done by Jessica Henihan at Trinity College Dublin.

Before you decide whether or not you wish to take part, please read this information sheet carefully. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with others. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

This leaflet has four main parts:

- Part 1 – Information about the Study
- Part 2 – Information on how your data will be used and stored
- Part 3 – Information about Costs, Funding and Approval
- Part 4 – Further Information

### Part 1 – The Study

#### Why is this study being done?

You are being asked to be part of a project. This project is about families where one person has aphasia.

- Aphasia is a disorder that affects how a person communicates.
- It can affect how a person uses and understands spoken and written language.

- It can have a big impact on everyone in a family.
- We want to see how aphasia impacts you and your family.
- We want to see how we can support families like you.

Right now, there is not a lot of research in this area. We hope that this study will help families like yours in the future.

#### **Why have I been invited to take part?**

You have been invited to take part because your family member has aphasia.

We aim to have 10-15 families involved in this study.

#### **Do I have to take part? Can I withdraw?**

You don't have to take part in this study. *It is up to you to decide whether or not to take part.*

You can change your mind about taking part in the study and opt out at any time even if the study has started. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact *Jessica Henihan* at [henihanj@tcd.ie](mailto:henihanj@tcd.ie) who will be able to organise this for you.

#### **What happens if I change my mind?**

You can change your mind at any time by contacting Jessica Henihan at [henihnaj@tcd.ie](mailto:henihnaj@tcd.ie). If you wish, you can ask for your data to be destroyed. If you request this, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in research studies prior to this time.

#### **What will happen to me if I decide to take part? What will I need to do?**

If you decide to participate you will be interviewed by the researcher (Jessica Henihan).

- The study will take place in your home or online via zoom for 1 hour.
- If you decide to participate you can contact the researcher who will provide you with the participant information leaflet. After 5 days, the researcher will send you a consent form which you can sign and send back.
- Once the consent form is signed and returned by email, the researcher will contact you and arrange a suitable date, time, and place for the interview.

#### **Online Interviews - Zoom**

- If the interview is scheduled online via zoom, on the day of the interview the researcher will email you a link to the zoom meeting.
- You will join the meeting at the designated time in a location of your convenience, where you will meet the researcher.
- The researcher will answer any questions you might have and ask if you want to continue with the study.
- During the interview, the researcher will ask you about how aphasia has affected your life and your relationship with your family member who has aphasia. They will also ask you about any support that you have received or would like to receive.
- The interview will last for no longer than 60 minutes. When the interview is over, you can

leave the meeting.

### **Interviews in person**

- If the interview is scheduled in person, on the day of the interview the researcher will email you to confirm the interview.
- The researcher will meet you and your parents at the time for the interview.
- The researcher will answer any questions you might have and ask if you want to continue with the study.
- During the interview, the researcher will ask you about how aphasia has affected your life and your relationship with your family member who has aphasia. They will also ask you about any support that you have received or would like to receive.
- The interview will last for no longer than 60 minutes.

#### **Are there any benefits to taking part in this research?**

Taking part in this study will not directly benefit you. However, research using your data and information may help us to better understand how to help families where one person has aphasia. This is a long-term research project, so the benefits of the research may not be seen for several years.

#### **Are there any risks to me or others if I take part? What will happen if something goes wrong?**

There is a risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.

There is a risk that this interview may make you feel uncomfortable, anxious, upset, or embarrassed because of what we are talking about. You do not have to talk about anything that may make you feel uncomfortable, anxious, upset, or embarrassed. You do not have to answer certain questions if you do not want to.

If you become emotional, you can stop the interview and you can talk to your parents or your parents' speech and language therapist who can provide information about local supports.

## **Part 2 – Data Protection**

### **How will my data be used?**

Data from this research project may be published in future in medical journals. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The original recording and all copies will be available only to the present investigators: Jessica Henihan and Dr Caroline Jagoe.

### **What information about me (personal data) will be used as part of this study? Will my medical records be accessed?**

The following information will be used as part of the study:

- Your name
- Your email address
- Your signature (consent form)
- A recording of the interview which contains audio and video. This is so the researcher can transcribe the interview afterwards.

**No medical records will be accessed.**

**Who will have access my personal data? What will happen to my personal data?**

*All the personal data that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team: Jessica Henihan & Dr Caroline Jagoe. All of your personal data will be stored in Ireland. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly request this.*

Data that can identify you will be kept for seven years as this is the Data Controller's policy. Anonymised or coded data will be kept for seven years as this is the Data Controller's policy. All data is stored on a password protected cloud-based storage approved by the Data Controller. After this time period your personal data will be erased by the researcher supervisor

**Will my personal data be kept confidential? How will my data be kept safe?**

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we do this:

Any information or data which is obtained during this research which identifies you will be treated confidentially. All the data collected will be stored on the researcher's laptop in an encrypted and password protected file. The data will then be made anonymous so as to hide your identity. All original files will be encrypted and transferred to a secure folder in the Trinity College Dublin computer network. Any files containing identifiable information will then be deleted off the laptop, so that only anonymous data remains. All files will accessible only by Jessica Henihan and Dr Caroline Jagoe.

All individual researchers involved in this project have been trained in data protection law and are bound by professional code to maintain confidentiality.

A risk assessment and a data protection impact assessment has been carried out, indicating a low risk level.

If something did go wrong, we would:

- Notify you, the participant
- Notify The Trinity College Data Protection Officer, who would notify the Trinity College Data Protection Commissioner within 72 hours
- Every effort would be made to minimise the data breach.

**What is the lawful basis to use my personal data?**

*According to data protection legislation<sup>1</sup>, we are required to inform you of the legal basis for using your personal data. The tasks we are performing are considered to be in the public interest<sup>2</sup>*

*Some data that is defined as more sensitive (information about racial/ethnic origin & health status), is being used for scientific purposes<sup>3</sup>*

**What are my rights?**

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to have your data transferred to another organisation or 'data controller'
- The right to restrict or object to processing of your data

- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to request deletion of your data

*By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Jessica Henihan at [henihanj@tcd.ie](mailto:henihanj@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).*

## Part 3 – Costs, Funding and Approval

### Has this study been approved by a research ethics committee?

*Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 4/11/22.*

### Who is organising and funding this study?

No funding has been obtained for this study.

### Is there any payment for taking part? Will it cost me anything if I agree to take part?

*No, we are not paying participants to take part in the study.*

## Part 4 – Further Information

### Who should I contact for information or complaints?

*If you have any concerns or questions, you can contact:*

- *Principal Investigator: Jessica Henihan. Email: [henihanj@tcd.ie](mailto:henihanj@tcd.ie)*
- *Research Supervisor: Dr. Caroline Jagoe. Email: [cjagoe@tcd.ie](mailto:cjagoe@tcd.ie)*
- *Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).*

*Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: [www.dataprotection.ie](http://www.dataprotection.ie).*

### Will I be contacted again?

*If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep. If you consent, we will contact you to arrange a time to conduct the interview.*



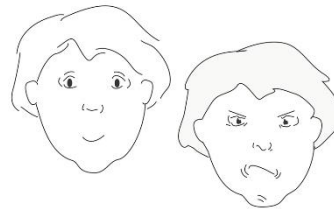
Appendix B

B4 - Participant information leaflet for children under 18 years of age

## Participant Information Leaflet for children under 18 years.

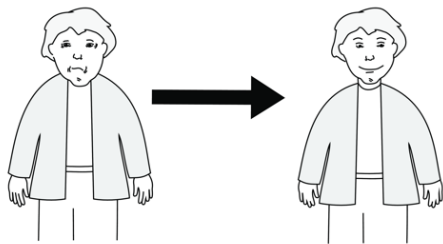
<b>Project:</b>	Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.
<b>Researchers:</b>	Jessica Henihan (Speech and Language Therapist)  & Dr Caroline Jagoe (Speech & Language Therapist)

We want to find out:



How **you** and your **family** **feel** about aphasia

**Changes** in your family

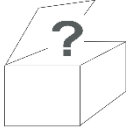




What **has helped** you adjust to this new way of being a family.

What **would help** you and your **family**.

Participating in this research involves **both** the person with aphasia and their family members.

<p><b>Where?</b></p> 	<p>The research will happen:</p> <p>In your <b>home</b>                      <b>OR</b>                      <b>online</b></p>  
--	---

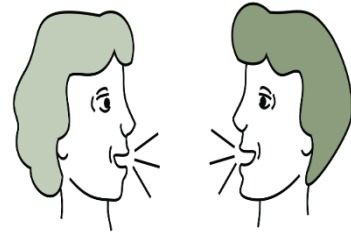
<p><b>What?</b></p> 	<p>You will participate in an interview for <b>1 hour</b>.</p>  <p>Your family can also participate in an interview for <b>1 hour</b>.</p>
---	--

<p><b>When?</b></p> 	<p><b>Dates</b> and <b>times</b> will be confirmed.</p> <p>The research will start in <b>November 2022</b>.</p>
---	---

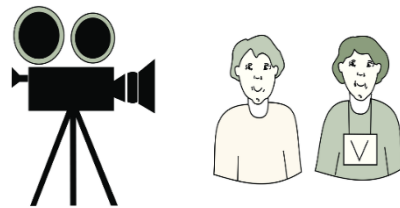
## What will happen during the interview with family members?

1. **Interview** with family members.

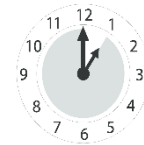
These will be done by a speech & language therapist.



2. The interviews will be **videotaped** so the researcher can write about the information later.



The interview will last for about **1 hour**.  
**The time will be confirmed with your parents.**



### Potential benefits:

- This will help research
- This could help other families with aphasia



### Right to withdraw

You can **stop** at any time  
It is **your choice**



## Potential risks

There are some risks.

1. You might **feel upset or uncomfortable**.

You can **stop** at any time.

You do **not have to answer** the question.

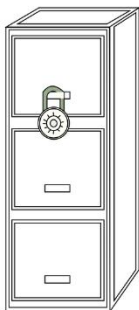
The interview will last 1 hour.

This may be inconvenient.



## What will happen to the information gathered?

Your participation is **confidential**.



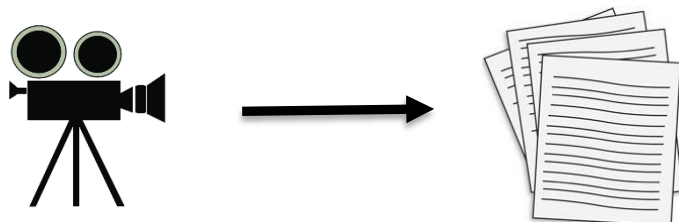
Information will **only be accessed by the research team**.

Your **name will not appear** on any notes.



The **video recording will be securely stored** on a password-protected computer.

The video recordings will be **transcribed**. Your name and anything that could identify you will be coded.



You may **request a copy of the transcript** if you wish to do so.

If you **wish to participate** your parents can contact **Jessica Henihan** and provide your name and contact details.



**Jessica Henihan**

[henihanj@tcd.ie](mailto:henihanj@tcd.ie)

**OR** your parents can contact **Brendan** from Trinity College Dublin



01 896 1496

Appendix C

C1 - Consent form for people with aphasia

**Consent Form for people with aphasia**

1. This study has been explained to me by:

---

2. I would like to take part in this study

**YES**



**NO X**

3. I allow the researcher to ask my Speech and Language Therapist about my most recent assessment.

**YES**



**NO X**

4. I understand that my details will be kept securely.

I want my details to be kept to allow me to participate in the research study. (These details will be kept for **7 years only**).

Signature:

\_\_\_\_\_

Witness signature:

\_\_\_\_\_

Researcher name: Jessica Henihan

Title and qualifications: Speech and Language Therapist. SL057185.

Signature and Date: \_\_\_\_\_

## Appendix C

### C2 - Consent form for adult family members

TRINITY COLLEGE DUBLIN  
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

## Consent Form for adult family members

Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.

Participant code for study: \_\_\_\_\_

There are **2 sections** in this form. Each section has a statement and asks you to initial if you agree. The end of this form is for the researchers to complete.

Please ask any questions you may have when reading each of the statements.

Thank you for participating.

Please tick the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General	Tick box
I confirm I have read and understood the <b>Information Leaflet</b> for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	<input type="checkbox"/>
I understand that this study is <b>entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason.</b>	<input type="checkbox"/>
I understand that all information will be kept private and confidential and that my name will not be disclosed.	<input type="checkbox"/>
I understand that I <b>will not be paid for taking part in this study.</b>	<input type="checkbox"/>
I know how to contact the research team if I need to.	<input type="checkbox"/>
I agree to take part in this research study having been fully informed of the <b>risks, benefits and alternatives</b> which are set out in full in the information leaflet which I have been provided with.	<input type="checkbox"/>
I agree to being contacted by researchers by email as part of this research study.	<input type="checkbox"/>

Data processing	Tick box
I understand that personal information about me, including the transfer of this personal information about me outside of the EU, will be protected in accordance with the General Data Protection Regulation.	<input type="checkbox"/>
I understand that there are <b>no direct benefits to me</b> from participating in this study.	<input type="checkbox"/>
I understand that I <b>can stop taking part in this study</b> at any time without giving a reason.	<input type="checkbox"/>





## Appendix C

### C3 - Parental consent form for family members under the age of 18

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

## Consent Form for participants under 18 years of age

Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.

Participant code for study: \_\_\_\_\_

There are **2 sections** in this form. Each section has a statement and asks you to initial if you agree. The end of this form is for the researchers to complete.

Please ask any questions you may have when reading each of the statements.

Thank you for participating.

Please tick the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General	Tick box
I confirm I have read and understood the <b>Information Leaflet</b> for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study is <b>entirely voluntary, and if I decide that I do not want to my child to take part, they can stop taking part in this study at any time without giving a reason.</b>	
I understand that all information will be kept private and confidential and that my name or my child's name will not be disclosed.	
I understand that my child <b>will not be paid for taking part in this study.</b>	
I know how to contact the research team if I need to.	
I agree that my child can take part in this research study having been fully informed of the <b>risks, benefits and alternatives</b> which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researchers by email as part of this research study.	

Data processing	Tick box
I understand that personal information about me or my child, including the transfer of this personal information about me or my child outside of the EU, will be protected in accordance with the General Data Protection Regulation.	
I understand that there are <b>no direct benefits to me or my child</b> from participating in this study.	
I understand that my child <b>can stop taking part in this study</b> at any time without giving a reason.	

-----  
Participant Name (Block Capitals)      Participant Signature      Date

-----  
Parent/Guardian Name (Block Capitals)      Parent/Guardian Signature      Date

**To be completed by the Principal Investigator.**

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team

Researcher name  
Title and qualifications  
Signature  
Date

\_\_\_\_\_  
**2 OR 3 copies to be made: 1 for participant, 1 for PI and 1 for clinical records if relevant.**

## Appendix C

### C4 - Assent form for family members under the age of 18

#### Assent Form

You are being asked to be part of a project. This project is about families where one person has aphasia.

- Aphasia is a disorder that affects how a person communicates.
- It can affect how a person uses and understands spoken and written language.
- It can have a big impact on everyone in a family.
- We want to see how aphasia impacts you and your family.
- We want to see how we can support families like you.

Right now, there is not a lot of research in this area. We hope that this study will help families like yours in the future. This is a long-term project, so the benefits of the research may not be seen for a few years.

Your parents have already been told about the project. Please read this form and ask the researcher any questions you have. It is your choice to be part of the project or not.

#### Why have I been invited to take part?

You have been invited to take part because your Mum or Dad has aphasia. We aim to have 10-15 families involved in this study.

#### Do I have to take part?

You don't have to take part in this study. *It is up to you to decide whether or not to take part.* If you decide not to take part, it won't affect you in any way. Even if your parents gave their permission, you can still decide not to be in the project or to stop at any time. The researchers will respect your decision.

#### Privacy

- The information from this project will be kept private. No names will be included in any reports written about the project.
- Your parents will not see the information you give.
- Your information will be kept for 7 years. After this, the data will be destroyed.

#### Questions

The researchers conducting this project are Jessica Henihan and Dr Caroline Jagoe from Trinity College Dublin.

You can ask questions before you take part in the project.

#### Please complete the form below if you want to be part of the project.

I want to be part of this project:

Name (Please Print): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix D

### D1 – Participant letter for SLTs



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

To whom it may concern,

Jessica Henihan is a Speech and Language Therapist and a MSc student in the Department of Clinical Speech and Language Studies in Trinity College Dublin in Ireland. As part of her MSc, she is conducting a research study that will investigate the views of Speech and Language Therapists, Family Therapists, and people with aphasia and their family members on the use of family therapy after acquired brain injury.

This research will be carried out in the form of online focus groups. The reason for conducting this study is that there is very little research in this area especially on the experiences and perceptions of different stakeholder groups. Therefore, people with aphasia and their family members may not be receiving the appropriate healthcare or support.

In order to conduct this research, Jessica is recruiting Speech and Language Therapists who work (or have previously worked) with people with aphasia and their family members, to participate in a focus group. If you are interested, please see the attached Participant Information Leaflet. If you have any queries, you can contact Jessica via email ([henihanj@tcd.ie](mailto:henihanj@tcd.ie)), or you can contact her Academic Supervisor, Dr Caroline Jagoe ([cjagoe@tcd.ie](mailto:cjagoe@tcd.ie)).

## Appendix D

### D2 – Participant information leaflet for SLTs

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

# Participant Information Leaflet for Speech and Language Therapists

Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.

<b>Site</b>	Trinity College Dublin
<b>Principal Investigator(s) and Co-Investigator(s)</b> <i>(insert names, titles and contact details. Where relevant, give the name of academic supervisor)</i>	Jessica Henihan (Principal Investigator) <a href="mailto:henihanj@tcd.ie">henihanj@tcd.ie</a> Dr Caroline Jagoe (Co-investigator & academic supervisor) <a href="mailto:cjagoe@tcd.ie">cjagoe@tcd.ie</a>
<b>Data Controllers</b>	Trinity College Dublin (for research data)
<b>Data Protection Officer</b>	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 <a href="mailto:dataprotection@tcd.ie">dataprotection@tcd.ie</a>

You are being invited to take part in a research study that is being done by Jessica Henihan at Trinity College Dublin.

Before you decide whether or not you wish to take part, please read this information sheet carefully. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with others. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

This leaflet has four main parts:

- Part 1 – Information about the Study
- Part 2 – Information on how your data will be used and stored
- Part 3 – Information about Costs, Funding and Approval
- Part 4 – Further Information

## Part 1 – The Study

### Why is this study being done?

Communication is one of the main parts of family life. When communication is disrupted (for example, when a person has aphasia), it changes how people interact with each other and can cause a breakdown within the family. We are doing this study to look at the use of family therapy

for people with aphasia and their family members. This project is being carried out as part of Jessica Henihan's MSc thesis. It is hoped that this study will provide a new insight into the experiences and perceptions of speech and language therapists on the need for family therapy. Currently, there is very little research in this area and the lack of knowledge about the role of SLTs may result in poorer service provision to people with aphasia and their families.

**Why have I been invited to take part?**

You have been invited to take part because you are a qualified Speech and Language Therapist, working in Ireland, registered with the Irish Association of Speech and Language Therapists (IASLT), and have worked with or currently work with people with aphasia.

We aim to have 20-30 people involved in this study.

**Do I have to take part? Can I withdraw?**

You don't have to take part in this study. *It is up to you to decide whether or not to take part.* You can change your mind about taking part in the study and opt out at any time even if the study has started. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Jessica Henihan (Principal Investigator) at [henihanj@tcd.ie](mailto:henihanj@tcd.ie) who will be able to organise this for you.

**What happens if I change my mind?**

You can change your mind at any time by contacting Jessica Henihan (Principal Investigator) at [henihanj@tcd.ie](mailto:henihanj@tcd.ie). If you wish, you can ask for your data to be destroyed. If you request this, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in research studies prior to this time.

**What will happen to me if I decide to take part? What will I need to do?**

The study will take place online via zoom focus group. It will last for no longer than one hour. If you decide to participate you will be contacted by the researcher and asked to fill in an online consent form before the focus group. Once you have filled in the online consent form, you will be contacted by the researcher again where they will arrange a suitable date and time for the focus group to take place. On the day of the focus group, the researcher will email you a link to a zoom meeting. You will join the meeting at the designated time in a location of your convenience, where you will meet the researcher and other focus group participants. The researcher will answer any questions you might have and ask for your consent to continue. In the focus group, the researcher will ask you about your experiences of working with or providing support to people with aphasia and their families and your perceptions of the role of speech and language therapists in this area. The focus group will last for no longer than 60 minutes. When the focus group is over, you can leave the meeting.

**Are there any benefits to taking part in this research?**

Taking part in this study will not directly benefit you. However, research using your data and information may help us to better understand the role of speech and language therapists in helping people with aphasia and their families adapt to changes because of aphasia and may result in improved care for this population. This is a long-term research project, so the benefits of the research may not be seen for several years.

**Are there any risks to me or others if I take part? What will happen if something goes wrong?**

There is a risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.

There is also the time inconvenience of the focus group. However, as stated previously, the focus group will last for no longer than 60 minutes.

## Part 2 – Data Protection

### How will my data be used?

Data from this research project may be published in future in medical journals. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The original recording and all copies will be available only to the present investigators: Jessica Henihan and Dr Caroline Jagoe.

If you agree to your data being used in future research, or in teaching your consent form will be held until the data is no longer in use.

### What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

The following information will be used as part of the study:

- Your name
- Your email address
- Your signature (consent form)
- A recording of the focus group which contains audio and video. Audio and video recording will take place to help the researcher transcribe the focus group and use video to record non-verbal communication.

### Who will have access my personal data? What will happen to my personal data?

*All the personal data that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team: Jessica Henihan & Dr Caroline Jagoe. All of your personal data will be stored in Ireland. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly request this.*

Data that can identify you will be kept for seven years as this is the Data Controller's policy. Anonymised or coded data will be kept for seven years as this is the Data Controller's policy. All data is stored on a password protected cloud-based storage approved by the Data Controller. After this time period your personal data will be erased by the researcher supervisor.

### Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we do this:

Any information or data which is obtained during this research which identifies you will be treated confidentially. All the data collected will be stored on the researcher's laptop in an encrypted and password protected file. The data will then be made anonymous so as to hide your identity. All original files will be encrypted and transferred to a secure folder in the Trinity College Dublin computer network. Any files containing identifiable information will then be deleted off the



laptop, so that only anonymous data remains. All files will be accessible only by Jessica Henihan and Dr Caroline Jagoe.

All individual researchers involved in this project have been trained in data protection law and are bound by professional code to maintain confidentiality.

A risk assessment and a data protection impact assessment has been carried out, indicating a low risk level.

If something did go wrong, we would:

- Notify you, the participant
- Notify The Trinity College Data Protection Officer, who would notify the Trinity College Data Protection Commissioner within 72 hours
- Every effort would be made to minimise the data breach.

#### **What is the lawful basis to use my personal data?**

*According to data protection legislation<sup>3</sup>, we are required to inform you of the legal basis for using your personal data. The tasks we are performing are considered to be in the public interest<sup>4</sup> Some data that is defined as more sensitive (information about racial/ethnic origin & health status), is being used for scientific purposes<sup>5</sup>*

#### **What are my rights?**

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to have your data transferred to another organisation or 'data controller'
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to request deletion of your data

*By law you can exercise these rights in relation to your personal data unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Jessica Henihan at [henihanj@tcd.ie](mailto:henihanj@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).*

## **Part 3 – Costs, Funding and Approval**

#### **Has this study been approved by a research ethics committee?**

*Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 4/11/2022.*

#### **Who is organising and funding this study?**

No funding has been obtained for this study.

#### **Is there any payment for taking part? Will it cost me anything if I agree to take part?**

*No, we are not paying participants to take part in the study.*

<sup>3</sup> The European General Data Protection Regulation (GDPR)

<sup>3</sup>Article 6(1)(e)

<sup>5</sup> Article 9(2) (j))

## Part 4 – Further Information

### Who should I contact for information or complaints?

*If you have any concerns or questions, you can contact:*

- *Principal Investigator: Jessica Henihan. Email: [henihanj@tcd.ie](mailto:henihanj@tcd.ie)*
- *Research Supervisor: Dr. Caroline Jagoe. Email: [cjagoe@tcd.ie](mailto:cjagoe@tcd.ie)*
- *Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).*

*Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: [www.dataprotection.ie](http://www.dataprotection.ie).*

### Will I be contacted again?

*If you would like to take part in this study, you will be asked to complete online Microsoft Form consent form. You will be given a copy of this information leaflet and the completed Consent Form to keep. If you consent, we will contact you to arrange a time to conduct the focus group.*

## Appendix E

### E1 – Participant letter to Family Therapists



To whom it may concern,

Jessica Henihan is a Speech and Language Therapist and a MSc student in the Department of Clinical Speech and Language Studies in Trinity College Dublin in Ireland. As part of her MSc, she is conducting a research study that will investigate the views of Speech and Language Therapists, Family Therapists, and people with aphasia and their family members on the use of family therapy after acquired brain injury.

Aphasia is a disorder that affects how a person communicates. It can affect how a person uses and understands spoken and written language. It can have a significant impact on everyone in a family. A Speech and Language Therapist is the healthcare professional that is responsible for diagnosing and treating this condition.

This research will be carried out in the form of online focus groups. The reason for conducting this study is that there is very little research in this area especially on the experiences and perceptions of different stakeholder groups. Therefore, people with aphasia and their family members may not be receiving the appropriate healthcare or support.

In order to conduct this research, Jessica is recruiting Family Therapists (whether they have worked with people with aphasia or not) to participate in an online focus group.

If you are interested, please see the attached Participant Information Leaflet. If you have any queries, you can contact Jessica via email ([henihanj@tcd.ie](mailto:henihanj@tcd.ie)), or you can contact her Academic Supervisor, Dr Caroline Jagoe ([cjagoe@tcd.ie](mailto:cjagoe@tcd.ie)).

## Appendix E

### E2 – Participant information leaflet for Family Therapists

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

## Participant Information Leaflet for Family Therapists

Investigating the views of SLTs, family therapists, and people with aphasia and their family on the use of family therapy after acquired brain injury: A qualitative study.

<b>Site</b>	<b>Trinity College Dublin</b>
<b>Principal Investigator(s) and Co-Investigator(s)</b> <i>(insert names, titles and contact details. Where relevant, give the name of academic supervisor)</i>	Jessica Henihan (Principal Investigator) <a href="mailto:henihanj@tcd.ie">henihanj@tcd.ie</a> Dr Caroline Jagoe (Co-investigator & academic supervisor) <a href="mailto:cjagoe@tcd.ie">cjagoe@tcd.ie</a>
<b>Data Controllers</b>	<b>Trinity College Dublin (for research data)</b>
<b>Data Protection Officer</b>	<b>Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 <a href="mailto:dataprotection@tcd.ie">dataprotection@tcd.ie</a></b>

*You are being invited to take part in a research study that is being done by Jessica Henihan at Trinity College Dublin.*

*Before you decide whether or not you wish to take part, please read this information sheet carefully. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with others. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.*

This leaflet has four main parts:

- Part 1 – Information about the Study
- Part 2 – Information on how your data will be used and stored
- Part 3 – Information about Costs, Funding and Approval
- Part 4 – Further Information

### Part 1 – The Study

#### Why is this study being done?

Aphasia is a disorder that affects how a person communicates. Aphasia can be caused by an acquired brain injury. It can affect how a person uses and understands spoken and written language. It can have a significant impact on a person's interactions, relationships, and quality of

life. Communication is one of the main parts of family life. When communication is disrupted (for example, when a person has aphasia), it changes how people interact with each other and can cause a breakdown within the family. We are doing this study to look at the use of family therapy for people with aphasia and their family members. This project is being carried out as part of Jessica Henihan's MSc thesis. It is hoped that this study will provide a new insight into the views of family therapists on their role in helping people with aphasia and their families adapt to changes because of aphasia. Currently, there is very little research in this area and the lack of knowledge about the role of family therapists may result in poorer service provision to people with aphasia and their families.

**Why have I been invited to take part?**

You have been invited to take part because you are a qualified Family Therapist, working in Ireland and are registered with the Family Therapy Association of Ireland or the Irish Council for Psychotherapy.

We aim to have 20-30 people involved in this study.

**Do I have to take part? Can I withdraw?**

You don't have to take part in this study. *It is up to you to decide whether or not to take part.* You can change your mind about taking part in the study and opt out at any time even if the study has started. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Jessica Henihan (Principal Investigator) at [henihanj@tcd.ie](mailto:henihanj@tcd.ie) who will be able to organise this for you.

**What happens if I change my mind?**

You can change your mind at any time by contacting Jessica Henihan (Principal Investigator) at [henihanj@tcd.ie](mailto:henihanj@tcd.ie). If you wish, you can ask for your data to be destroyed. If you request this, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in research studies prior to this time.

**What will happen to me if I decide to take part? What will I need to do?**

The study will take place online via zoom focus group. It will last for no longer than one hour. If you decide to participate you will be contacted by the researcher and asked to fill in an online consent form before the focus group. Once you have filled in the online consent form, you will be contacted by the researcher again where they will arrange a suitable date and time for the focus group to take place. On the day of the focus group, the researcher will email you a link to a zoom meeting. You will join the meeting at the designated time in a location of your convenience, where you will meet the researcher and other focus group participants. The researcher will answer any questions you might have and ask for your consent to continue. In the focus group, the researcher will ask you about your experiences of working with or providing support to people with aphasia and their families and your perceptions of the role of speech and language therapists in this area. The focus group will last for no longer than 60 minutes. When the focus group is over, you can leave the meeting.

**Are there any benefits to taking part in this research?**

Taking part in this study will not directly benefit you. However, research using your data and information may help us to better understand the role of family therapists in helping people with aphasia and their families adapt to changes because of aphasia and may result in improved care for this population. This is a long-term research project, so the benefits of the research may not be seen for several years.

**Are there any risks to me or others if I take part? What will happen if something goes wrong?**

There is a risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.

There is also the time inconvenience of the focus group. However, as stated previously, the focus group will last for no longer than 60 minutes.

## Part 2 – Data Protection

**How will my data be used?**

Data from this research project may be published in future in medical journals. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The original recording and all copies will be available only to the present investigators: Jessica Henihan and Dr Caroline Jagoe.

If you agree to your data being used in future research, or in teaching your consent form will be held until the data is no longer in use.

**What information about me (personal data) will be used as part of this study? Will my medical records be accessed?**

The following information will be used as part of the study:

- Your name
- Your email address
- Your signature (consent form)
- A recording of the focus group which contains audio and video. Audio and video recording will take place to help the researcher transcribe the focus group and use video to record non-verbal communication.

**Who will have access my personal data? What will happen to my personal data?**

*All the personal data that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team: Jessica Henihan & Dr Caroline Jagoe. All of your personal data will be stored in Ireland. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly request this.*

Data that can identify you will be kept for seven years as this is the Data Controller's policy. Anonymised or coded data will be kept for seven years as this is the Data Controller's policy. All data is stored on a password protected cloud-based storage approved by the Data Controller. After this time period your personal data will be erased by the researcher supervisor.

**Will my personal data be kept confidential? How will my data be kept safe?**

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we do this:

Any information or data which is obtained during this research which identifies you will be treated confidentially. All the data collected will be stored on the researcher's laptop in an encrypted and password protected file. The data will then be made anonymous so as to hide your identity. All original files will be encrypted and transferred to a secure folder in the Trinity College Dublin

computer network. Any files containing identifiable information will then be deleted off the laptop, so that only anonymous data remains. All files will be accessible only by Jessica Henihan and Dr Caroline Jagoe.

All individual researchers involved in this project have been trained in data protection law and are bound by professional code to maintain confidentiality.

A risk assessment and a data protection impact assessment has been carried out, indicating a low risk level.

If something did go wrong, we would:

Notify you, the participant

Notify The Trinity College Data Protection Officer, who would notify the Trinity College Data Protection Commissioner within 72 hours

Every effort would be made to minimise the data breach.

#### **What is the lawful basis to use my personal data?**

*According to data protection legislation<sup>1</sup>, we are required to inform you of the legal basis for using your personal data. The tasks we are performing are considered to be in the public interest<sup>2</sup>*

*Some data that is defined as more sensitive (information about racial/ethnic origin & health status), is being used for scientific purposes<sup>3</sup>*

#### **What are my rights?**

You are entitled to:

The right to access to your data and receive a copy of it

The right to have your data transferred to another organisation or 'data controller'

The right to restrict or object to processing of your data

The right to object to any further processing of the information we hold about you (except where it is de-identified)

The right to have inaccurate information about you corrected or deleted

The right to request deletion of your data

*By law you can exercise these rights in relation to your personal data unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Jessica Henihan at [henihanj@tcd.ie](mailto:henihanj@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).*

## **Part 3 – Costs, Funding and Approval**

#### **Has this study been approved by a research ethics committee?**

*Yes, this study has been approved by the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences on 4/11/2022.*

#### **Who is organising and funding this study?**

No funding has been obtained for this study.

#### **Is there any payment for taking part? Will it cost me anything if I agree to take part?**

*No, we are not paying participants to take part in the study.*

## Part 4 – Further Information

### Who should I contact for information or complaints?

*If you have any concerns or questions, you can contact:*

- *Principal Investigator: Jessica Henihan. Email: [henihanj@tcd.ie](mailto:henihanj@tcd.ie)*
- *Research Supervisor: Dr. Caroline Jagoe. Email: [cjagoe@tcd.ie](mailto:cjagoe@tcd.ie)*
- *Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).*

*Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: [www.dataprotection.ie](http://www.dataprotection.ie).*

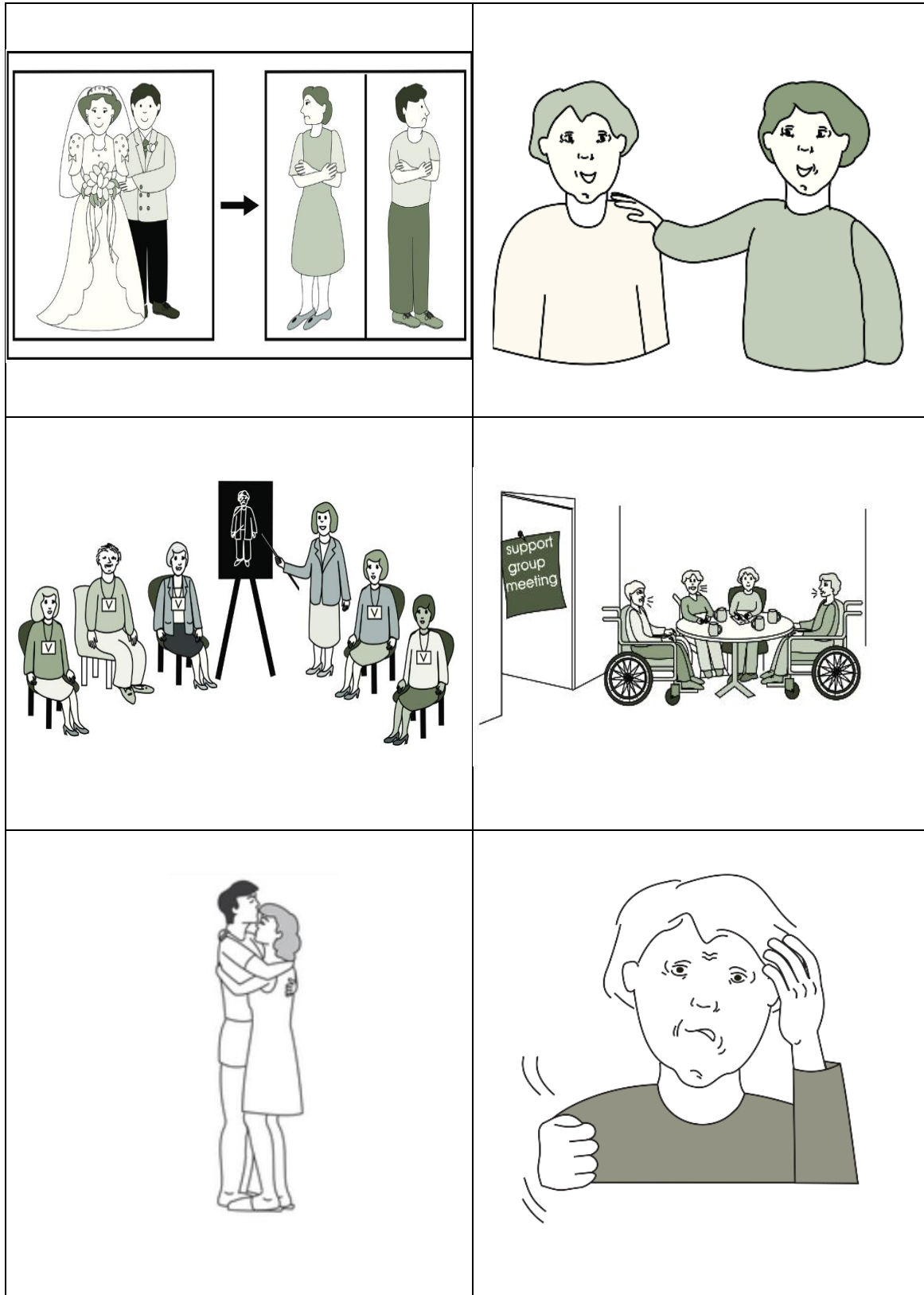
### Will I be contacted again?

*If you would like to take part in this study, you will be asked to complete online Microsoft Form consent form. You will be given a copy of this information leaflet and the completed Consent Form to keep. If you consent, we will contact you to arrange a time to conduct the focus group.*



Appendix F

F1 – Sample picture supports



## Appendix F

### F2 – Interview guide for people with aphasia

Topic Area	Main Questions	Prompts
<b>Family structure</b>	Tell me a little bit about you and your family.	
<b>Impact of aphasia on family</b>	<p>What was it like for you and your family after stroke? - Has any of that changed and how/why?</p> <p>Can you talk to me about what is has been like for you and your family since you have had aphasia?</p> <p>How has aphasia impacted how you are with your family and how your family is with you?</p>	What has been easy or difficult for you and your family?
<b>Involvement in healthcare sessions</b>	<p>Were there any times where your family was involved in any of your therapies?</p> <p>Can you tell me about a time when they were involved in the session?</p>	Would you have liked your family to be involved in the sessions?
<b>Access to services</b>	<p>How have you and your family been supported since your stroke?</p> <ul style="list-style-type: none"> <li>• What support did your family need?</li> </ul> <p>Is there any time when you or your family really needed support? When was that?</p> <p>Were there times when you or your family tried to get help but could not?</p> <ul style="list-style-type: none"> <li>• Why was this?</li> </ul> <p>What has helped you adjust to this new way of being as a family?</p>	What would help you and your family?
<b>Family therapy</b>	<p>Family therapy is a type of counselling that helps improve relationships in families especially when a big change happens.</p> <p>Thinking about your stroke journey, would family therapy have been useful?</p>	<p>Is this a therapy you have had before?</p> <p>Tell me more.</p> <p>Why/Why not?</p>
<b>Background information</b>	<p>Collect:</p> <ul style="list-style-type: none"> <li>• Age</li> <li>• Gender</li> <li>• Languages spoken</li> <li>• Time since onset of aphasia</li> <li>• Wall question – now and at the start of their time with aphasia</li> </ul>	

## Appendix F

### F3 – Interview guide for adult family members

Topic Area	Main Questions	Prompts
<b>Family structure</b>	Tell me a little bit about you and your family.	
<b>Impact of aphasia on family</b>	<p>What was it like for you and your family after X's stroke? -Has any of that changed and how/why?</p> <p>Can you talk to me about what is has been like for you and your family since X has had aphasia?</p> <p>How has aphasia impacted the family?</p>	What has been easy or difficult for you and your family?
<b>Involvement in healthcare sessions.</b>	<p>Were there any times where you were involved in any of your partners therapies?</p> <p>Can you tell me about a time when you were involved in the session?</p>	<p>Would you have liked to be involved in your partners sessions?</p> <p>Would that have been useful?</p>
<b>Access to services</b>	<p>How have you and your family been supported since your partner's stroke?</p> <ul style="list-style-type: none"> <li>- What support did your family need?</li> </ul> <p>Is there any time when you or your family really needed support? When was that?</p> <p>Were there times when you or your family tried to get help but could not?</p> <ul style="list-style-type: none"> <li>- Why was this?</li> </ul> <p>What has helped you adjust to this new way of being as a family?</p>	What would help you and your family?
<b>Family therapy</b>	<p>Family therapy is a type of counselling that helps improve relationships in families especially when a big change happens.</p> <p>Thinking about your family's stroke journey, would family therapy have been useful?</p>	<p>Is this a therapy you have had before? - Tell me more</p> <p>If not, do you think this is something that would help you now?</p>
<b>Background information</b>	<p>Collect:</p> <ul style="list-style-type: none"> <li>- Age</li> <li>- Gender</li> <li>- Languages Spoken</li> <li>- Wall question now and at the start of the journey</li> </ul>	

## Appendix F

### F4 - Interview guide for family members under 18 years of age

Topic Area	Main Questions	Prompts
<b>Family structure</b>	Tell me a little bit about you and your family.	
<b>Impact of aphasia on family</b>	Tell me what it has been like for you and your family since your Mum/Dad's talking has changed.	What has been easy or difficult for you and your family?
<b>Involvement in healthcare sessions</b>	Were there any times where you were involved in any of your Mum/Dad's therapies	What was that like? Would you have liked to be involved in your Mum/Dad's sessions?
<b>Access to services</b>	<p>What has helped you get used to this new way of being as a family?</p> <ul style="list-style-type: none"> <li>- Was there anyone who helped you and your family?</li> </ul> <p>Sometimes, it can be hard for families to get used to this new way of being. What do you think would help make it easier or better?</p>	
<b>Family therapy</b>	<p>Family therapy is a way of helping families make their relationships better, especially when a big change happens.</p> <p>Is this something you think might have helped you and your family?</p>	
<b>Background information</b>	<p>Collect:</p> <ul style="list-style-type: none"> <li>- Age</li> <li>- Gender</li> <li>- Languages Spoken</li> <li>- Wall question now and at the start of the journey</li> </ul>	

## Appendix G

### G1 - Focus group topic guide for SLTs

Welcome group and introduce self. Check that they understand confidentiality policy. Reiterate the length of time the focus group will take.

Topic Area	Focus group questions for SLTs	Prompts
<b>Demographic Information</b>	Each participant to introduce themselves to the group.	<ul style="list-style-type: none"> <li>• Length of time working as an SLT</li> <li>• Length of time working with adults with aphasia</li> <li>• What setting are they currently working in.</li> </ul>
<b>Working with adults with aphasia and their families</b>	Tell me about your experience working with families of adults with aphasia? Is this something you do routinely?	<ul style="list-style-type: none"> <li>• What situations do you work with family members?</li> <li>• What are the main goals when you work with families of people with aphasia?</li> <li>• Describe how you work with family members.</li> </ul>
<b>Providing support to PWA</b>	In your education as an SLT, have you ever received training in counselling?	<ul style="list-style-type: none"> <li>• Can you tell me more about the type of counselling or the focus of the training?</li> <li>• How have you used this training or why you have not used this training?</li> </ul>
<b>PWA and Family Therapy</b>	<p>Family therapy is a type of counselling that helps improve relationships in families especially when a big change happens</p> <p>Have you ever received any training in Family Therapy?</p> <p>Do you think family therapy would be useful for people with aphasia and their family members?</p>	<ul style="list-style-type: none"> <li>• In your view, do you see any challenges for these clients in accessing family therapy?</li> <li>• Do you think these clients require further communication supports to access family therapy?</li> </ul>
<b>Role of SLT in Family Therapy</b>	Do you think that SLTs have a role in family therapy and what would make that possible?	<ul style="list-style-type: none"> <li>• What supports could be put in place for SLTs to provide family therapy for people with aphasia and their families?</li> <li>• Do you think the service of family therapy lies elsewhere?</li> <li>• Do you see this being a multidisciplinary session?</li> </ul>

End the discussion by summarizing the main points. If there is time, invite participants to reflect on the main ideas, and ask if they have any additional thoughts to share

## Appendix G

### G2 - Focus group guide for Family Therapists

Welcome group and introduce self. Check that they understand confidentiality policy. Reiterate the length of time the focus group will take.

<b>Topic Area</b>	<b>Focus group questions for Family Therapists</b>	<b>Prompts</b>
<b>Demographic Information</b>	Each participant to introduce themselves to the group.	<ul style="list-style-type: none"> <li>• Length of time working as a FT</li> <li>• Main Client Group</li> <li>• Setting</li> </ul>
<b>Introduce aphasia</b>	To ensure that we are all on the same page in this conversation, I'm going to take a moment to describe a communication disability called aphasia. Aphasia usually occurring after a brain injury.....	
<b>Working with adults with aphasia and their families</b>	What are your experiences of working with adults with aphasia and their family?	<ul style="list-style-type: none"> <li>• What are the benefits or challenges?</li> </ul>
<b>Case Vignette</b>	<p>Have you ever worked with a family where the reason for them attending is precipitated by a diagnosis of a significant health condition in one of the family members?</p> <p>Keeping that family in mind I would like you to imagine that one member of the family had received a diagnosis of aphasia following a stroke. This means that they have difficulty understanding language and they have difficulty using verbal language including reading and writing. This family has been referred to you for support.</p>	<p>Describe how you would work with this family?</p> <p>What would you find challenging when working with these families?</p>

<b>Role of Family Therapists</b>	As a Family Therapist, do you see a role in helping people with aphasia and their families and what would make that possible?	<ul style="list-style-type: none"><li>• What supports could be put in place for Family Therapists?</li><li>• Do you see this being an MDT session?</li><li>• Do you think these clients require further communication supports to access family therapy?</li></ul>
----------------------------------	---	--

## Appendix H

### H1 – Interview with Alan, man with aphasia

1 **Interviewer:** Okay. So, could you maybe tell me a little bit about you and your family? So, kind of who's in your family?

2 **Alan:** Eh [Sister1], [Brother1], [Brother2], [Sister2], and me. And Mum and Dad, well die now.

3 **Interviewer:** Okay. Yeah. (Interviewer writes family names down) Okay, so Daisy, that's your wife.

4 **Alan:** Yeah.

5 **Interviewer:** And then is [Brother1]. Is?

6 **Alan:** (Alan takes pen) Eh the eh the eh the [Brother2] no eh [Brother1]? Brothers.

7 **Interviewer:** Brothers, they're your brothers.

8 **Alan:** Brothers, brothers, brothers (Alan points to [Brother1] and [Brother2])

9 **Interviewer:** Okay. So, [Brother1] and [Brother2] are your brothers.

10 **Alan:** Yeah.

11 **Interviewer:** Okay. And is

12 **Alan:** [Sister2].

13 **Interviewer:** [Sister2] is your sister?

14 **Alan:** Sister. And then [Sister1].



15 **Interviewer:** Okay.

16 **Alan:** [Sister1] [Sister1]. Yeah.

17 **Interviewer:** Okay. Okay, and then there's you.

18 **Alan:** Yeah

19 **Interviewer:** And do you have any children?

20 **Alan:** One.

21 **Interviewer:** One. Yeah?

22 **Alan:** Oh yeah. Oh yeah. Cheeky.

23 **Interviewer:** Is she or he?

24 **Alan:** The brains? [Daughter] the brains

25 **Interviewer:** [Daughter], is it?

26 **Alan:** Oh Yeah.

27 **Interviewer:** Yeah. And how old is [Daughter]? (Alan gestures 5) Five.

28 **Alan:** Yeah.

29 **Interviewer:** So, you've got a lot coming up.

30 **Alan:** Don't I know. The discos. The [Daughter] the discos. Smaller.

31 **Interviewer:** Yeah. You'll be worried.

32 **Alan:** Boys and girls (Alan nods his head and then raises his eyebrows).

33 **Interviewer:** Exactly. I know. So, you've got two brothers and two sisters.

34 **Alan:** Yeah.

35 **Interviewer:** And your wife Daisy.

36 **Alan:** Yeah

37 **Interviewer:** And one child [Daughter].

38 **Alan:** Yeah.

39 **Interviewer:** Okay. So, what was it like for you and your family after your stroke?

40 **Alan:** Hard. Hard and eh. The boss (gestures to himself) okay. And eh a stroke like. And eh [Acute Hospital E], [Rehab Hospital A], and eh  
41 other one eh. [Acute Hospital E].

42 **Interviewer:** [Acute Hospital E] you were in [Acute Hospital E]

43 **Alan:** Yeah

44 **Interviewer:** Yeah

45 **Alan:** [Acute Hospital E]

46 **Interviewer:** and then [Rehab Hospital A]

47 **Alan:** [Rehab Hospital A] and another one

48 **Interviewer:** And another one.

49 **Alan:** And yeah, one year, one year yeah,

50 **Interviewer:** For one year. So, it was this was all in one year.

51 **Alan:** Oh yeah

52 **Interviewer:** Yeah. So, were you- How long were you in [Acute Hospital E] do you think? A while?

53 **Alan:** On the tablets strong?

54 **Interviewer:** Yeah. Okay.

55 **Alan:** Strong.

56 **Interviewer:** I know what you mean.

57 **Alan:** On that week and that then eh grand? Yeah.

58 **Interviewer:** Yeah. So, this was all one year. And for you, what was that like for you?

59 **Alan:** Desperate like. Desperate (Alan shakes his head). So, like trying yeah. And eh slowly slowly getting there getting there. Yeah. Slowly  
60 slowly

61 **Interviewer:** Yeah

62 **Alan:** I know the golf and the bike and the walk and [Dog]. Yeah grand. The maintenance. Yeah. Slowly slowly. Getting there, Getting there.

63 **Interviewer:** And then, during this time, what was it like for Daisy, do you think?

64 **Alan:** Yeah, this and strong. And eh Daisy is strong. Strong, strong. And [Daughter] is the same. Daddy, daddy. What what? Close the door.  
65 Okay (laughs). Me uh no fucking quiet-quiet.

66 **Interviewer:** It was difficult for you.

67 **Alan:** Yeah. Yeah. [Daughter] and Daisy is magnificent, magnificent. Yeah.

68 **Interviewer:** Yeah. And then were your brothers or sisters involved at all during that year?

69 **Alan:** (Alan shakes hand in a "kind of" motion) Mum? Okay. And [Sister2]. Okay. And eh [Brother1], once and twice. [Sister1] once and eh.  
70 Once. Yeah.

71 **Interviewer:** Yeah. And what do you think it was like for your siblings did it have a big impact on them.

72 **Alan:** Oh no, no.

73 **Interviewer:** Okay, so it's mainly you,

74 **Alan:** [Daughter] and Daisy. and more. Yeah.

75 **Interviewer:** Okay. Since this, so after your- Since you've got home. What has it been like for you at home?

76 **Alan:** Yeah, and eh. The the [Rehab Hospital A] right [Rehab Hospital A] and "ah" the fall over boom. And since [indistinguishable] fall over  
77 again. And fall again. And falling again. Done and the tablets. One tablet? Yeah. Thank God.

78 **Interviewer:** Yeah. So, it was it was difficult to come from [Rehab Hospital A]?

79 **Alan:** Oh yeah oh yeah yeah. And then the this eh stretching eh. The stretching like. A woman and stretching. (Alan stretches out his arm)  
80 Okay. And yeah. Eh The woman is friendly and eh. Friendly and friendly.

81 **Interviewer:** Yeah

82 **Alan:** Friendly. Friendly. And the papers, the papers.

83 **Interviewer:** The papers?

84 **Alan:** The papers, make the papers the picture of me and [Daughter]. And eh papers [Newspaper1]!

85 **Interviewer:** So, it was in the papers?

86 **Alan:** [Newspaper1], [Newspaper2] and [Newspaper3]-whatever. The papers.

87 **Interviewer:** So, there's a picture of you and Daisy in the papers. (Alan nods head "yes") Yeah. And is that about you being in [Rehab  
88 Hospital A]?

89 **Alan:** Yeah, [Rehab Hospital A] and eh and eh winners as it is like. I know the. Yeah. Horrible. Anyway.

90 **Interviewer:** Yeah. And if we talk a little bit about aphasia, so the difficulty that you have with speaking, how has that been for you?

91 **Alan:** Like, spelling is excellent-? No eh. 10 out of 10. Right. The spellings "eh - eh eh eh" (Alan indicates spelling is bad). Yeah.

92 **Interviewer:** Okay. And how does that make you feel?

93 **Alan:** Okay. Okay. (Alan puts his head in his hands indicating what happens when he gets frustrated with spelling) Calm down. Calm down  
94 now.

95 **Interviewer:** That's okay.

96 **Alan:** No, no, no. To calm down. And slowly, slowly. Yeah. Yeah.

97 **Interviewer:** So, do you think it's slowly-slowly going a little bit better?

98 **Alan:** Yeah. The spelling is? Okay. The readings Okay and eh the eh the [Daughter] and me do it (Alan points to a spelling book)

99 **Interviewer:** Yeah, you do that together.

100 **Alan:** Yes, yes, yes. Yes.

101 **Interviewer:** Yeah. And then with the spelling and getting stuck with words. How does that make you feel? Maybe sad or happy or

102 **Alan:** Oh, no, that's not nice. Yes. Me concentrate like, come on. Come on slowly, slowly. Getting there. Concentration. And slowly slowly  
103 and eh the woman (SLT) has brilliant, like, brilliant. Yeah.

104 **Interviewer:** So, you kind of feel determined.

105 **Alan:** Oh, yeah, definitely. Definitely. Definitely!

106 **Interviewer:** Yeah. And then when you're speaking to other people-

107 **Alan:** Slowly, slowly. And the words. Slow, yeah slow.

108 **Interviewer:** Slow and when you're at home with Daisy and [Daughter], do-. Are there any times where you think, oh, I really want to be  
109 able to say this, but I can't.

110 **Alan:** Yeah, yeah. The word is perfect. Spelling of bleuh bleuh bleuh (bad). Can't say it like can't say it.

111 **Interviewer:** And when you're talking maybe to Daisy, and you can't spell something out. How does- How do you feel?

112 **Alan:** Kind of the. Sign language sign language so that's not sign language. The sign languages.

113 **Interviewer:** Yeah.

114 **Alan:** Sign language eh eh eh (points to picture book). Oh, the dryer, and the dishwasher washer. So, words the word words.

115 **Interviewer:** The words. And you use this book?

116 **Alan:** Yeah.

117 **Interviewer:** Yeah. And that makes it

118 **Alan:** And eh and eh the coffee and tea on the apple, the footballs on boiled eh boiled egg, fruit, and a sandwich.

119 **Interviewer:** Yeah. So, this helps?

120 **Alan:** Ah brilliant yeah.

121 **Interviewer:** Yeah, and would you use that with eh [Daughter]?

122 **Alan:** No, no, no. No. I use it just in case. Just in case. Just in case.

123 **Interviewer:** And then thinking back to maybe when you're in [Rehab Hospital A]. You know, when you go for your- the different therapy  
124 session, so you might go to physio

125 **Alan:** Yes.

126 **Interviewer:** You might go to speech and language therapy.

127 **Alan:** Yes.

128 **Interviewer:** Were your family. Was Daisy involved in therapy?

129 **Alan:** Yes, yeah. A woman and me and you the swimming, Daisy swimming. And teach and eh the the [pool]. The swimming me the  
130 swimming the swim and exercise. The stretching. And the the, the (Alan imitates swimming on his back) exercise? And eh one and eh one  
131 hour, one hour. Okay, the wash the wash. That's. So he's and eh the pants and? Yeah,

132 **Interviewer:** Yeah.

133 **Alan:** Driving, so yeah.

134 **Interviewer:** So was that that was you and Daisy

135 **Alan:** No the- and eh. Daisy is Daisyis on eh. "Come on now". "No, no, no," "come on now". "Okay, okay". Oh, no. Yeah.

136 **Interviewer:** So, Daisy motivates you a lot.

137 **Alan:** Oh yeah and strong.

138 **Interviewer:** And she's strong. Yeah. Yeah. So, when you were doing your swimming, and practicing the stretches. That was with was that  
139 with the therapist a physio.

140 **Alan:** No eh. I know the swimming and exercise and stretches and woman and Daisy and me.

141 **Interviewer:** Yeah. So, there was three people?

142 **Alan:** Yes.

143 **Interviewer:** Okay. And did you like that Daisy was there?

144 **Alan:** No. Like, no, no, no way. No way. And slowly, slowly.

145 **Interviewer:** Yeah. And why did you not like that she was there? You didn't want it?

146 **Alan:** I know the one year to me, one year, two years, three years, four years, five years, six years. Okay. Now one year. No, no, no way I  
147 know to swim. No. And slowly, slowly.

148 **Interviewer:** Yeah.

149 **Alan:** The bike okay. And then slowly, slowly.



150 **Interviewer:** Yeah, yeah. So, when you you said so you were swimming and I'm just gonna put down (Interviewer writes down the names)  
151 so the woman okay, who was helping you? [Alan] and Daisy.

152 **Alan:** The word and eh Daisy.

153 **Interviewer:** So, Daisy here,

154 **Alan:** Daisy and eh.

155 **Interviewer:** And this-this woman.

156 **Alan:** Yeah, the memory is gone.

157 **Interviewer:** That's okay. That's fine. We'll just put-

158 **Alan:** Daisy okay. and [Daughter] okay and, me. [Brother1]. Okay. This one? (laughs and points to an SLT letter)

159 **Interviewer:** Oh, [SLT]?

160 **Alan:** [SLT] [SLT]. Okay, [SLT] gone and eh. I know that. Yeah. The memory is gone like.

161 **Interviewer:** Yeah. And that that does happen. You know. But if we go back to the swimming bit of it. So, you were all together, but you  
162 said sometimes you didn't want Daisy there.

163 **Alan:** Oh, I know. No way. No. Way.

164 **Interviewer:** And why? Why if we said no, to Daisy. Why?

165 **Alan:** No. Therapy and Daisy. "No way, no" "come on like". And then the fucking lift. The lift. And slowly, slowly, yeah, getting there. And  
166 Daisy brilliant and the woman's brilliant.

167 **Interviewer:** Yeah. So having Daisy there was good. In the end?

168 **Alan:** Strong.

169 **Interviewer:** Yes. Strong. So, in the beginning, maybe no.

170 **Alan:** No. Oh, yeah.

171 **Interviewer:** But by the end.

172 **Alan:** Oh yeah

173 **Interviewer:** Okay. And then thinking about your speech and language therapy.

174 **Alan:** Brilliant, brilliant.

175 **Interviewer:** So, with [SLT]. Okay, so let's see you find that really good.

176 **Alan:** And eh and eh the woman is slow. Perfect like perfect.

177 **Interviewer:** Yeah. So was [SLT]. Or sorry, not [SLT]. was Daisy. With you?

178 **Alan:** Oh, one once and twice? Once and twice.

179 **Interviewer:** Okay. Okay, would you have liked more? Would you like to Daisy to be there more?

180 **Alan:** Mon eh Monday, Tuesday, Wednesday, Wednesday, Wednesday, Wednesday, Wednesday.

181 **Interviewer:** Every Wednesday?

182 **Alan:** Yes.

183 **Interviewer:** Yeah. Yeah. And

184 **Alan:** One hour and tired.

185 **Interviewer:** Yeah, yeah. And would you have liked- so you were saying it was mainly. It was you and [SLT]? Yeah. Most of the time. Yeah.

186 Yeah. And then sometimes Daisy was there

187 **Alan:** Once or twice?

188 **Interviewer:** Yeah. And was it good when Daisy was there?

189 **Alan:** Oh, definitely yeah

190 **Interviewer:** Yeah. Did you find it more helpful when Daisy was there?

191 **Alan:** No. The woman and me. That's all. That's the Daisy and the woman and me. Panic and the woman and me. That's all.

192 **Interviewer:** That's all. Do you think that was better? With you and [SLT]?

193 **Alan:** Yes.

194 **Interviewer:** Yeah. Yeah. Okay. And then. Well, when Daisy was there, so it was Daisy, [Alan] and [SLT].

195 **Alan:** Yes. [SLT].

196 **Interviewer:** Was Was that good?

197 **Alan:** No, it's but Daisy once and twice and go and I know that you and [SLT]-[SLT]?

198 **Interviewer:** Yeah.

199 **Alan:** Yeah. On hour Monday, Tuesday, Wednesday, Wednesday, Wednesday. Yeah.

200 **Interviewer:** Yeah. So, was it- After the session so when you came home? Yeah. Was Daisy

201 **Alan:** Sit down and eating? And the spelling and

202 **Interviewer:** And the spelling. And would Daisy, do the spelling with you?

203 **Alan:** No

204 **Interviewer:** No, you do it.

205 **Alan:** And-and [Daughter]. And-and eh [Daughter], and me that's all. It's brilliant.

206 **Interviewer:** [Daughter] and you. And [Daughter] likes helping her Dad?

207 **Alan:** Oh brilliant. Yeah.

208 **Interviewer:** Is she good at spelling?

209 **Alan:** Spelling. Yeah.

210 **Interviewer:** Yeah. And that's good that you can do that together.

211 **Alan:** Yeah, yeah yeah, definitely.

212 **Interviewer:** Yeah. And you both like that.

213 **Alan:** Yeah. Yeah. Yeah.

214 **Interviewer:** Okay. Then if we think about when you had your stroke, okay, so [Acute Hospital E] when you had your stroke. Then in

215 [Rehab Hospital A] when you were trying to get better, and then home. Any of those times do you think your family needed help?

216 **Alan:** Sad and happy.

217 **Interviewer:** Sad and happy

218 **Alan:** And angry

219 **Interviewer:** and angry?

220 **Alan:** Sad and angry

221 **Interviewer:** And your family? So, if we think [Alan], Daisy and [Daughter].

222 **Alan:** Yeah.

223 **Interviewer:** Okay.

224 **Alan:** [Sister2]? Yeah.

225 **Interviewer:** If we think

226 **Alan:** Check-up. Check-up.

227 **Interviewer:** Yeah. So if we think [Alan], Daisy and [Daughter] just those people. So you Daisy and [Daughter], did you all need help?

228 **Alan:** No the eh [Brother1] eh. The stroke is difficult and eh and eh. [Brother2], [Brother1], thank you very much (Alan points to the door  
229 and sighs).

230 **Interviewer:** Yeah.

231 **Alan:** End of story.

232 **Interviewer:** Yeah. That must be difficult for you.

233 **Alan:** Yeah. Yeah. The tablet is strong. Hadn't got a fucking clue like.

234 **Interviewer:** yeah, yeah. And then, do you think [Daughter] was upset?

235 **Alan:** No, she, no. I know, the sit down and [Daughter] and Daisy, slowly to arm that's grand. And I know that [Daughter] and Daisy, and eh  
236 slowly. Stroke is difficult. Blah, blah, blah. And get there. Yeah. Yeah. Yeah.

237 **Interviewer:** That's really good. Do you think that there were people there to help, Daisy? [Daughter]? Yeah.

238 **Alan:** Yeah definitely.

239 **Interviewer:** Yeah. Who were they?

240 **Alan:** A man. No, a woman, a woman. A woman. And friendly. Friendly.

241 **Interviewer:** Yeah. And was that in the hospital?

242 **Alan:** [Acute Hospital E]? No eh [Rehab Hospital A].

243 **Interviewer:** It was in [Rehab Hospital A]. And they they helped Daisy and [Daughter].

244 **Alan:** Definitely-definitely.

245 **Interviewer:** Okay. So, they were helped as well in [Rehab Hospital A]. And then, after at home did Daisy and [Daughter] get help?

246 **Alan:** No, no eh. No.

247 **Interviewer:** Do you think they needed help?

248 **Alan:** No, the angry upset and don't touch things shut the door and blah blah. Yeah, and ah [SLT] and a woman was brilliant. Like so brilliant  
249 like.

250 **Interviewer:** Yeah, so you find the service really?

251 **Alan:** Brilliant oh Yeah

252 **Interviewer:** So, when. Stroke is a big change

253 **Alan:** Oh yeah definitely

254 **Interviewer:** And everything kinda changes in work at home.

255 **Alan:** On eh [Acute Hospital E] and the gone existence like. Weak (Alan lifts up right arm). This one weak. Weak (Alan points to right leg).

256 **Interviewer:** And then did your family so Daisy and [Daughter]. Were there changes there did anything change?

257 **Alan:** The brain the brain the brain is no more. A stroke. Yeah, yeah.

258 **Interviewer:** Yeah. Okay. And then because of all these changes So you said Oh [SLT] the speech and language therapist. That was really  
259 good.

260 **Alan:** Ah brilliant, brilliant.

261 **Interviewer:** And you liked the swimming? With the woman and Daisy together and that was really good as well.

262 **Alan:** Yeah, yeah.

263 **Interviewer:** Was there anything else that you didn't get but you would have liked?

264 **Alan:** Eh No, this is the table the table and absolutely for get out of here like. Get out of here.

265 **Interviewer:** Yeah, was the said the people around the table were they

266 **Alan:** A stroke?

267 **Interviewer:** A stroke okay.

268 **Alan:** Stroke a stroke and stroke.

269 **Interviewer:** So, it was a support group.

270 **Alan:** Yes.

271 **Interviewer:** Okay. And you didn't like that?

272 **Alan:** No. Where they were coffee and biscuits over here. Like, come on, like.

273 **Interviewer:** Yeah. Okay.

274 **Alan:** One and no more.

275 **Interviewer:** No more. You didn't like it?

276 **Alan:** No.

277 **Interviewer:** Um, and was that? So, there was people who'd had a stroke.

278 **Alan:** Yes, yes, yes.

279 **Interviewer:** And then was there a person one person who was in charge?

280 **Alan:** Yes.

281 **Interviewer:** And do you know, like, what type of person they were with?

282 **Alan:** A woman?

283 **Interviewer:** A woman? Was she



284 **Alan:** The woman and the woman? That's all.

285 **Interviewer:** Yeah. And do you think were they volunteers? Or maybe a speech and language therapist.

286 **Alan:** I don't know.

287 **Interviewer:** You don't know. Yeah.

288 **Alan:** And eh Yeah no.

289 **Interviewer:** And was that in [Location]?

290 **Alan:** No, the rugby the. Oh the rugby the [Location].

291 **Interviewer:** [Location].

292 **Alan:** Over there over there. The river. The river and eh.

293 **Interviewer:** So, is this in [Location]?

294 **Alan:** Yes.

295 **Interviewer:** Okay. Is it the [Location]?

296 **Alan:** Slightly (Alan motions towards himself)

297 **Interviewer:** Back from that a little bit.

298 **Alan:** Yeah.

299 **Interviewer:** Oh I'm trying to think. Was it was it-

300 **Alan:** The pub?

301 **Interviewer:** Was it [Location]?

302 **Alan:** No, the new one. Brand new one, [Location], or whatever. Yeah.

303 **Interviewer:** Yeah. Okay. So that that was in a rugby club?

304 **Alan:** Yeah. No. Over the road. One minute and stay the group and.

305 **Interviewer:** Okay. Yeah. Yeah. And you didn't like that?

306 **Alan:** No,

307 **Interviewer:** That wasn't for you?

308 **Alan:** No.

309 **Interviewer:** Do you think it would have been better to talk to someone like we are now?

310 **Alan:** Definitely definitely definitely.

311 **Interviewer:** One person. Rather than a group.

312 **Alan:** Group? Yeah.

313 **Interviewer:** So, one person is better. Okay. So, family therapy is a type of therapy that helps when a big change happens? Like a stroke?

314 **Alan:** Yes.

315 **Interviewer:** Okay. Because we know a stroke is a really big change. And it can help all people in the family. And it's just one therapist. They  
316 can see you or they can see Daisy or [Daughter], or they can see all of you together. Do you think that's something?

317 **Alan:** No eh [Daughter]? To Daisy and me want to and [Daughter] Stay there.

318 **Interviewer:** Stay there. Yeah. So, you think [Daughter] is okay?

319 **Alan:** Yeah, yeah, yes. Yes. Yeah.

320 **Interviewer:** She's young. She's five.

321 **Alan:** Yeah, yeah. Yeah.

322 **Interviewer:** But you think it would be good for you and Daisy?

323 **Alan:** Yes.

324 **Interviewer:** To help.

325 **Alan:** Yes.

326 **Interviewer:** Okay. And at any stage, so in [Acute Hospital E] when you had your stroke, or in [Rehab Hospital A]. Did anything like that?

327 Where it was for you and Daisy? Did that happen?

328 **Alan:** No. Anger. Anger me anger. And eh slowly, slowly, slowly. Getting there and eh and their work. That's work to shed. And me the

329 working away I can. One hour. Asleep and the next day one hour of building? And one hand.

330 **Interviewer:** Yeah. Well, that's very impressive. Yeah. And I think it's, it's, it's good, you know, that I think you say, oh, it was very difficult,

331 and you said you're angry. But it's slowly getting

332 **Alan:** Getting there getting there

333 **Interviewer:** A little bit better.

334 **Alan:** And ehm. Okay, one day the wood and the wood (mimics chopping wood). And eh clamp and a clamp easy. Clamp and a clamp.

335 **Interviewer:** Yeah.

336 **Alan:** And the clamp. Easy. Clamp the clamp.

337 **Interviewer:** Clamp you can hold it then. It won't move. It won't move

338 **Alan:** Yes

339 **Interviewer:** Yeah. I don't know too much about woodwork but I do know the clamps.

340 **Alan:** No no no

341 **Interviewer:** And that's something that makes you feel good or happy?

342 **Alan:** The radio

343 **Interviewer:** The radio

344 **Alan:** And eh and eh the radio. Sit down and and eh Rosenstock. Funny funny. Rosenstock. Eh the man.

345 **Interviewer:** Mario Rosenstock.

346 **Alan:** Oh my god the laughs.

347 **Interviewer:** Yeah, he's great. He's really funny.

348 **Alan:** The Taoiseach and the oh my god. Funny.

349 **Interviewer:** He's brilliant. Yeah. So those kinds of things are you like doing.

350 **Alan:** I know he just. And funny oh my god. Oh Rosenstock number 1.

351 **Interviewer:** So we kind of talked a little bit about you and your family. And your daughter [Daughter].

352 **Alan:** Oh Yeah

353 **Interviewer:** And a little bit about when you had your stroke. And from [Acute Hospital E] to [Rehab Hospital A] to home. We talked a little  
354 bit about the swimming

355 **Alan:** That's right.

356 **Interviewer:** And [SLT].

357 **Alan:** Yeah

358 **Interviewer:** The speech and language therapist. And that you didn't like the stroke support group with all of the people sitting round.

359 **Alan:** No, no, no, no.

360 **Interviewer:** No that wasn't for you. Okay but you think that maybe if you and Daisy went to one person that might be.

361 **Alan:** Yeah, yeah getting them all.

362 **Interviewer:** And what would you so if you and Daisy were to go to that one person what would you like from that?

363 **Alan:** A group no and a woman yes. One hour and spelling is well slow and the yeah.

364 **Interviewer:** Well that's that's.

365 **Alan:** That's really good like.

366 **Interviewer:** It is. It is. And you're and I think doing things with [Daughter] is really nice. You both sit down together. Ehm so is there  
367 anything else, thinking back on your stroke journey. So from beginning to now is there anything that you would have liked that you didn't  
368 get.

369 **Alan:** Oh everything oh no yeah.

370 **Interviewer:** Lots of things?

371 **Alan:** Like crying, falling and slowly, slowly determination.

372 **Interviewer:** Yeah determination. And would you have liked more help?

373 **Alan:** No.

374 **Interviewer:** No, you're happy with that.

375 **Alan:** Happy. And the woman eh and [Rehab Hospital A] that's all like (thumbs up)

## Appendix H

### H2– Interview with Debora, wife of PwA

1 **Interviewer:** So if you tell me a little bit about you, who's living at home as well with a little bit about your own kind of family support.

2 **Debora:** So it's just myself and Arron at home and the dog [Dog]. And then my family. I have eh em three brothers and eh two sisters and  
3 one passed. Em so they live in the close area. And yeah. I'd be quite close to friends and eh Arron's family. and the girls. Yeah. Her husband  
4 would be great support. Yeah.

5 **Interviewer:** So there's a lot of people kind of around you, you know,

6 **Debora:** Yes.

7 **Interviewer:** Yeah. A lot of family. Ehm so what was that like for you kind of after Arron stroke,

8 **Debora:** Ehm I had a lot of guilt? And ehm it was just, I suppose, because we were kind of only realizing how serious it was. Ehm and it was  
9 just kind of dealing with all of that.

10 **Interviewer:** Yeah.

11 **Debora:** All in the one go and just seeing Arron the way he was.

12 **Interviewer:** Yes,

13 **Debora:** He couldn't walk, couldn't talk, couldn't do anything really do you know so?

14 **Interviewer:** Yeah

15 **Debora:** Yeah its quite overwhelming and eh yeah

16 **Interviewer:** Yeah. And, you know, since his stroke, kind of, how have the two of you been, you know, together? Like, has there been any  
17 changes within your relationship? Or, you know, if that's? Yeah. Has there been that? I suppose any changes in your relationship since  
18 then?

19 **Debora:** Yeah, more or less? Because Arron's on the receiving end of me not being in charge but having to do you know what I mean? And  
20 if I go at a slower pace I've to ring someone he wants it done 10 minutes ago? I'm like, yeah. You know, I've X, Y, and Z to do. To do. Yeah.  
21 So things like that. That's where all the, you know, where he'd be quite Before a stroke. He was, a real you know, and want independence.

22 **Interviewer:** Yeah.

23 **Debora:** And, you know, he was great at what he did, and things like that. I felt bad for him being on the receiving end, even apart from  
24 losing everything else that would have been driving him mad you know that kind of way the the loss of power.

25 **Interviewer:** Yeah.

26 **Debora:** Or autonomy. He's relying on everyone else to do things for him.

27 **Interviewer:** Yeah. Yeah. Yeah. And I know, you'd said that you kind of felt a little bit guilty. And maybe could you tell me a little bit more  
28 about that, where you don't have to, by the way, we can move on.

29 **Debora:** Yeah it was just because Arron was at home on his own when it happened. And he was there for quite a while. I was in work. So I  
30 couldn't reach him. But I didn't think too much of it.

31 **Interviewer:** Yeah

32 **Debora:** Until he kind of got later on going hmm.

33 **Interviewer:** Yeah, yes.

34 **Debora:** So when I saw him kind of when he got home and seen him struggling through everything. Yeah, like guilt was quite. Because I'm  
35 saying if I'd gotten him a little while longer, he might have more speech or our lives mightn't have been impacted it has been, you know?



36 **Interviewer:** Yeah. And, you know, since maybe, since the initial bit, you know, like now how do you feel about kind of the stroke and the  
37 changes like now.

38 **Debora:** Ehm

39 **Interviewer:** Compared to maybe what had happened

40 **Debora:** When that happened? I kind of [Charity A], when we linked in with [Charity A]. They were very supportive, and they offered me,  
41 counselling. So I've got six sessions of counselling with them. And I have to say, she put me back together. (Laughs) And got me going again,  
42 do you know, that kind of way she kind of helped with that stumbling block that was in my head,

43 **Interviewer:** Yeah

44 **Debora:** She helped to put that to the side so that we could you know because I was kind of doing everything through guilt, you know, and  
45 we just had to find a different way of like, when Arron came home from hospital, and saw the house, he didn't recognize, like, he was  
46 opening all the presses going "oh", you know, he'd forgotten where everything was, and his clothes and what things look like.

47 **Interviewer:** Yeah,

48 **Debora:** Do you know that kind of way. So you had to find a way to be. A different way to be. You know? Yeah

49 **Interviewer:** Yeah. And, you know, speaking a bit about his difficulty with talking, how has that kind of impacted your relationship or, you  
50 know, the family's relationship in general, or has it actually kind of been?

51 **Debora:** Yeah, it's been a huge impact, because ehm as you can see from the interview, even trying to do you know for Arron like, trying to  
52 figure out what he needs what he's trying to say. I'm always quite careful about. To give him the time, it's very difficult because sometimes  
53 you don't want to jump in because you're stifling then. Or you look like you're taking over. And then you want to give him the chance to try  
54 and get it on himself. But then, you know, sometimes he doesn't understand certain questions, and we go down rabbit holes, they call  
55 them. Do you know that kind of way, it could be something simple. And suddenly we're veered off. And we've completely lost what we  
56 were starting to speak about in the first place, because we've gone down somewhere else. Ehm And I'd find that very difficult. And

57 sometimes just the tiredness because I work as well. Yeah. So I'm an SNA, and full on work. And then when you come home, that sounds  
58 awful. But it's the truth. And you come home, and you're nearly on empty already. But then you have to come home and you have to do  
59 the housey things and the food and Arron is there and you're asking things, and sometimes you're very tired. And like that you don't.  
60 Sometimes I'm like something that could be quite simple. Because I've worn out. I don't get it straight away. And sometimes,  
61 understandably, he can get frustrated. And I get frustrated as well.

62 **Interviewer:** Yes.

63 **Debora:** Sometimes I feel like,

64 **Interviewer:** yeah,

65 **Debora:** because I'm not getting to know or should be more in tune or,

66 **Interviewer:** yeah,

67 **Debora:** Do you know, the kind of, like, gets in the way sometimes. And you're just getting through as best you can. Yeah, you know.

68 **Interviewer:** Yeah. And, you know, so you find that it has, it has had like quite an impact in some aspects, you know, and especially with  
69 kind of working as well, and coming home and doing all of that the housework, and looking after everything. And then, you know, trying to  
70 be there for Arron as well. And support him. It can be very tiring.

71 **Debora:** Yeah, yeah. Because everything kind of like everything falls to you, because you have to, especially at the very beginning, because  
72 this is we were dealing with this [Charity A], [Charity B], physiotherapist, speech and language, occupational, going out to [Primary Care C]  
73 appointments, and trying to fit all that in around your work, going for Botox going, for medical appointments, and making phone calls  
74 dealing with emails. And it was like, at some stage, I was like, I think I'm gonna have a breakdown because it was do you know what I mean  
75 you were kind of left stumbling around the place. You know.

76 **Interviewer:** Trying to pull everything together.

77 **Debora:** And trying to, yeah, and then trying to explain to Arron, different things that were happening and just trying to juggle, you know,  
78 your appointments and just trying to ehm always put him first.

79 **Interviewer:** Yeah.

80 **Debora:** But you know,

81 **Interviewer:** Where do you come in that?

82 **Debora:** You know like it wasn't. It was just kind of, to make sure his needs were met. And then ehm I don't know, it was just very difficult.  
83 It was very, it's got a bit easier. I have to say. Ehm but I remember at one stage I was like, I think I'm falling apart here. You know that kind  
84 of way.

85 **Interviewer:** Yeah, And I know we talked about this with Arron but you were saying there were so many kind of different like physical  
86 occupational and speech and language. And were there times you were involved in those in you know, those kinds of sessions.

87 **Debora:** The ones in hospital?

88 **Interviewer:** Yeah.

89 **Debora:** They were very good. [Acute Hospital F] were brilliant I have to say if I was because I would always be visiting Arron I'd go in the  
90 afternoon, back in the evening, then ehm and then if I was there, they'd always say come on down, you know, and that they wanted, I  
91 think they wanted Arron to have that support of look how well Arron is doing. Do you know that kind of way?

92 **Interviewer:** Yeah. yeah.

93 **Debora:** To bring him on and that ehm Arron as I said was, I think he liked me being there. But if I wasn't there, he'd get on with it he'd just  
94 focused to, you know, he wanted to he was in the wheelchair first and then he was progressing to standing up and do you know that kind  
95 of thing. But they were really good. Ehm The girl from speech and language eh used to come to Arron's room and she'd have the cards you  
96 know the categories and that and you know be sitting in on that. And ehm sometimes she'd give me a little bit of work Arron used to come  
97 home at weekends. Yeah, so that was kind of a bit scary as well because he'd come home in a wheelchair taxi and taxi man put him in the

98 room we'd only a small house still have and I'd be they're going (sigh) how I'm gonna juggle this. do you know what I mean, the bathroom  
99 was upstairs you know it I was just you know, so yeah, that was. I think I forget. What was I on again?

100 **Interviewer:** That's okay I was just asking about you taking part in like the different sessions.

101 **Debora:** Oh, yes. Yeah.

102 **Interviewer:** Like was did you? Was that something you found useful or?

103 **Debora:** No, it was?

104 **Interviewer:** Yeah.

105 **Debora:** Because you want to see what they were doing what was happening, and try and pick up some tips, you know, that you could  
106 carry on. Back even the simplest things of piece of pen of paper and pen, yeah, and figuring out. And we used to do a lot of that.

107 **Interviewer:** Yeah

108 **Debora:** Writing the key words, I always found that speech and language therapists started doing that and that was helpful.

109 **Interviewer:** Yeah.

110 **Debora:** Do you know what I mean

111 **Interviewer:** Yeah.

112 **Debora:** But the thing was, I had mentioned it before with the the yes and no. And that's why Arron would get so because we'd be  
113 completely on different page, he might of being saying yes to something where he might have meant no, you know, and, and sometimes  
114 other family members would? I don't think they were they understood?

115 **Interviewer:** Yeah,

116 **Debora:** How serious it was for him. And so I had to kind of bite back sometimes do you know, because there were like, oh he's doing great  
117 and I was Like, he's not really do you know, like being pessimistic or, you know, there's always, you know, and I'd be like, we have to be  
118 realistic.

119 **Interviewer:** Yeah,

120 **Debora:** We're here. You know, so I found that difficult to tell to be honest.

121 **Interviewer:** Yeah. Yeah. And maybe, you know, Were there times where there was something that you weren't involved in, like some  
122 source of care towards Arron that you actually thought oh I would have liked to have been there? You know? Or if I could have you know?

123 **Debora:** Ehm. I don't think so. Because I went to, like we have is involved in the physio to be there to see it. And in the [Rehab Hospital A],  
124 they asked me to come in on a couple of times to show different exercises. Yeah, speech and language. Ehm in [Acute Hospital F], they  
125 were really good. They let me sit in or go to the office, when they've started moving Arron down out the room, I'd be able to go to that. Eh  
126 the same in the [Rehab Hospital A], ah, the girl out there. We had a couple of private interviews about Arron and how he was getting on  
127 and how the future was looking for him and that. Eh And, and but she differed, the girl in [Acute Hospital F] that would give me little bits  
128 of work to do with Arron. The speech and language therapist in the [Rehab Hospital A], she had a completely different outlook. She said,  
129 you're his wife, you're not there to, you know,

130 **Interviewer:** Yeah

131 **Debora:** I think that time should be.

132 **Interviewer:** Yeah,

133 **Debora:** Because some patients will say, she's me wife, or me husband,

134 **Interviewer:** Yeah

135 **Debora:** You know, and they might feel

136 **Interviewer:** Yeah,

137 **Debora:** And Arron would always veer anyway, understandably, towards the professionals,

138 **Interviewer:** yeah

139 **Debora:** where you'd be like, do you know, that kind of way.

140 **Interviewer:** Yeah.

141 **Debora:** It's like, the stakes are changed. And

142 **Interviewer:** yeah,

143 **Debora:** and I think she was trying to say don't,

144 **Interviewer:** yeah, don't worry about that bit of it

145 **Debora:** don't have it. Yes. I was like, that kind of took a bit pressure of then

146 **Interviewer:** Yeah,

147 **Debora:** do you know that kind of way.

148 **Interviewer:** And that was better for you.

149 **Debora:** I think so. I didn't want to be looking like school teacher coming in. And I do you know that kind of way

150 **Interviewer:** Yeah, yeah.

151 **Debora:** Because we had to. We were married we are married.

152 **Interviewer:** Yeah,

153 **Debora:** everything else that changed. That would have been another thing.

154 **Interviewer:** Yeah. Yes.

155 **Debora:** See, Arron's quite headstrong? (Laughs) Do you know what I mean?

156 **Interviewer:** Definitely, yeah.

157 **Debora:** And it has stood to him God it has, do you know what I mean?

158 **Interviewer:** Yeah.

159 **Debora:** So and the other thing is, from a relationship point of view, like, sometimes you have to bight back because you can't. We do have  
160 arguments.

161 **Interviewer:** Yeah.

162 **Debora:** And because we're still I can't I won't treat work like wrap him in cotton wool like, I can't

163 **Interviewer:** Yeah yeah

164 **Debora:** Because hes, a man and he needs to be mask-. Do you know? Yeah. And we so we do have Spats like, do you know, but that  
165 sometimes it's, it's difficult because it feels like I can voice my opinion.

166 **Interviewer:** Yeah.

167 **Debora:** And he can't.

168 **Interviewer:** Yeah, yeah,

169 **Debora:** he can't articulate he might be able to show me he can show me he's annoyed or.

170 **Interviewer:** Yeah,

171 **Debora:** Pissed off with me. Well like, he can't articulate. This is why you did to really annoy me today.

172 **Interviewer:** Yeah

173 **Debora:** Whereas I can say Arron. I've been w- do you know I've been working I'm not going to trying to be patient.

174 **Interviewer:** Yeah,

175 **Debora:** He cant articulate that. So you always feel that like that you have him one up over him and nothing like that.

176 **Interviewer:** Yeah,

177 **Debora:** It's the opposite. It's like you can't,

178 **Interviewer:** Yeah. Yeah.

179 **Debora:** Go full force Do you know?

180 **Interviewer:** Yeah, you don't want to

181 **Debora:** No because I feel like I have an advantage on him.

182 **Interviewer:** Yeah,

183 **Debora:** Cuz I can speak.

184 **Interviewer:** Yeah.



185 **Debora:** That's horrible.

186 **Interviewer:** And is that like that kind of aspect of your relationship? Is that something that actually you would have liked someone to  
187 maybe talk to you about or kind of talk you through? Or give you advice on?

188 **Debora:** Quite possibly Yes. Because in [Acute Hospital F] as I thought, that wasn't. I knew more about Arron's eh diagnosis and what the  
189 future held like I found that I was hoping to ask certain questions about Arron, because I'm saying can he like, one family member ehm  
190 gave him a newspaper one day to read in [Acute Hospital F] and was saying oh you know, he read everything because he was laughing  
191 right. And I was like, oh right, but then I was like there's not a chance not a chance he can. Do you know what I mean?

192 **Interviewer:** Yeah.

193 **Debora:** And I think Arron would've masked a lot.

194 **Interviewer:** Yeah,

195 **Debora:** The speech and language therapist picked up on that. She said Arron reads a room, he can walk in and go. And I know even the  
196 certain times when I'm sitting there, and Arron has. I just know that he's pretended

197 **Interviewer:** Yeah

198 **Debora:** Do you know what I mean that he's like, God, yeah.

199 **Interviewer:** Yeah,

200 **Debora:** Like he's understanding everything. And sometimes, I kinda go did you understand and he'll go. Or sometimes if he was on the  
201 phone to his sister. She'd be yapping away. And I knew y him. He'd be like this with me. Dunno what she's on about. Do you know but he'd  
202 go? Yeah. yeah yeah yeah yeah You know?

203 **Interviewer:** Yeah.

204 **Debora:** And that was given her a false image of what was going on? Yeah.

205 **Interviewer:** Yeah. Yeah. And, you know, I mean, how like, have you, Arron and even his siblings or your family? Have you been supported?  
206 Maybe since the stroke at all? I know, you're talking about the [Charity A] services.

207 **Debora:** Yeah

208 **Interviewer:** and was there. You know, how, what were what was that like? I know you'd said you had counselling and that? You know.

209 **Debora:** Yeah, I'd got counselling with them, which was brilliant. came at the right time. Definitely. Ehm they were just he had a key  
210 worker, she was really good. She used to ring. Or she'd come up with ideas for Arron. Eh like the Dublin bus training, and he did that  
211 recently. I can't remember. I can't remember chronological anymore. (laughs)

212 **Interviewer:** Time has gone

213 **Debora:** Because it's just, do ya know,

214 **Interviewer:** Yeah

215 **Debora:** People say like, when was that. I haven't got a clue when this happened, ehm so they would come up with things like that he used  
216 to go to [Charity A] and I think he went a couple of days a week if there was different activities, did not like group work, and does not like  
217 group work.

218 **Interviewer:** Yeah

219 **Debora:** He's just no no no no.

220 **Interviewer:** Yeah

221 **Debora:** I think he does be a bit lost.

222 **Interviewer:** Yeah

223 **Debora:** In it. You know, so he kind of avoid that.

224 **Interviewer:** Yeah.

225 **Debora:** And that's why I was asking about the within the organization for say, [Charity B] and [Charity A], was there a program that they  
226 would consider running for someone like Arron or their clients come along, that have kind of background to give them a bit of self-esteem  
227 back

228 **Interviewer:** Yeah

229 **Debora:** Do you know what I mean?

230 **Interviewer:** Feel like they're contributing. You know?

231 **Debora:** Yeah Because he definitely needs that he needs something of his own?

232 **Interviewer:** Yeah, yeah.

233 **Debora:** He definitely does. You know,

234 **Interviewer:** Yeah. And, you know, is there I think you said, [Charity A] came at the right time,

235 **Debora:** Yeah

236 **Interviewer:** And I suppose. Is there any time where you, and you and Arron or his family kind of felt like, Oh Okay, this is when we really  
237 need support, now is the time more than anything, you know?

238 **Debora:** Ehm. I think his family kind of were like, [Sister1] would have been the main and still is the main person and she'd be more of eh.  
239 She'd be trying to get him out. You know, I don't I didn't haven't talked to [Sister1] about her.

240 **Interviewer:** Yeah

241 **Debora:** Not she was- she was devastated.

242 **Interviewer:** Yeah

243 **Debora:** She was devastated because that's her. her baby brother,

244 **Interviewer:** Yeah

245 **Debora:** Do you know what I mean she still looks at him through those eyes, that's that's her do you know?

246 **Interviewer:** Yeah

247 **Debora:** She was devastated. Ehm I don't know if she would have I told her about today. If she'd like to be involved, like so. She you know

248 **Interviewer:** Yeah

249 **Debora:** Ehm so support wise for us. I don't know because we had the carer coming in and we were going to the appointments. For physio,  
250 eh Arron had started going [Primary Care C]. And I used to go to as many as them as I could and the girls were lovely.

251 **Interviewer:** Yeah

252 **Debora:** So you'd get a bit spoilt do you know what I mean.

253 **Interviewer:** Yeah

254 **Debora:** The speech and language therapist ehm, I remember the first time she she Arron went to her for an assessment. I could see she  
255 was quite shocked.

256 **Interviewer:** Yeah,

257 **Debora:** I could see him and she was because he couldn't literally could get nothing else.

258 **Interviewer:** Yeah.

259 **Debora:** And I remember she said, Okay Arron. (Whispers next bit) And she said to me, would you like to stay back for a chat? and I said no,  
260 because I at the time. I didn't want to look like I was behind his back. Yeah. Do you know what I mean?

261 **Interviewer:** Yes.

262 **Debora:** I've been in so many of them, as well, because he was there. I didn't want to do you know?

263 **Interviewer:** Yeah

264 **Debora:** So they were the people who I kind of got a bit of support from

265 **Interviewer:** Yeah,

266 **Debora:** Could I have done with more? I think so.

267 **Interviewer:** Yeah

268 **Debora:** Because sometimes they were coming at me thick and fast. Do you know what I mean? With emails and appointments and all  
269 that. And I was just like, okay

270 **Interviewer:** Yeah.

271 **Debora:** Do you know? And I felt like I had, I had to do everything, and possibly. It's only recently I've been kind of tried to dole out. Can  
272 you go to this appointment with Arron? Because I can't,

273 **Interviewer:** Yeah

274 **Debora:** You know, I'd be asking. [Sister1], but you'd be kind of you want it to look like you are coping

275 **Interviewer:** Yeah.

276 **Debora:** Do you know? Do you know what I'm saying?

277 **Interviewer:** Yeah, yeah.

278 **Debora:** Eh So, um, because sometimes there's a lot of appointments. I'm like, I can't be asking me job all the time (laughs). So I'm just  
279 gonna have to be ballsy and ask.

280 **Interviewer:** Yeah.

281 **Debora:** You know?

282 **Interviewer:** Yeah yeah yeah

283 **Debora:** So yeah, I suppose that way I might have needed a bit more. You know?

284 **Interviewer:** Yeah. An-and, was there anything? Either that, like support that someone gave you or anything that you kind of found that  
285 helped you to kind of adjust to this new way of being, you know,

286 **Debora:** Ehm? I suppose the counsellor?

287 **Interviewer:** Yeah.

288 **Debora:** And when you brought up that family therapy, I think that would be brilliant.

289 **Interviewer:** Yeah.

290 **Debora:** Because sometimes I think Arron, is, I thought this, he's empathetic. Don't get me wrong.

291 **Interviewer:** Yeah

292 **Debora:** But he has to survive. And he's to, he's dealing with is 100 times worse than it is for the rest of us to know what I mean.

293 **Interviewer:** Yeah.

294 **Debora:** So sometimes I think an odd time I might have to say to him, about me. Arron I'm sorry. but you're gonna have to wait for a few  
295 minutes? Sounds awful.

296 **Interviewer:** No. Not at all

297 **Debora:** But like, you have to wait for a few minutes? I'll I'll do it when I'm ready. You know? It's like (oh my god)

298 **Interviewer:** Yeah,

299 **Debora:** That has I've had to roll that back a bit where I'm going it's okay for him to know that somebody else needs.

300 **Interviewer:** Yeah.

301 **Debora:** You know,

302 **Interviewer:** Needs supporting, you know,

303 **Debora:** Yes, yeah.

304 **Interviewer:** Yeah. And do you think so a little bit on the family therapy? So that's something you definitely you've said there? You'd find  
305 useful.

306 **Debora:** Yeah definitely.

307 **Interviewer:** And do you think that would have been useful kind of, kind of immediately in the beginning. Like when he had the stroke and  
308 he was in [Acute Hospital F] or in [Rehab Hospital A], or [Rehab Hospital C], or actually when he got home? You know.

309 **Debora:** Let me think now,

310 **Interviewer:** Or it can be throughout all of it. It, you know,

311 **Debora:** I know that when we were out in [Rehab Hospital A] we had that big meeting,

312 **Interviewer:** Yeah

313 **Debora:** You know, where everybody's involved.

314 **Interviewer:** Yeah.

315 **Debora:** And they're telling you Arron is there as well and? They're giving all the feedback. And I- And sometimes when you're hearing  
316 things, it's, do you know, you're kind of you can't even

317 **Interviewer:** Process yeah

318 **Debora:** process what's happening. Like my sister. Ehm when Arron had his stroke, my sister was in hospital

319 **Interviewer:** Okay

320 **Debora:** in hospital.

321 **Interviewer:** Yeah

322 **Debora:** And she was dying of cancer.

323 **Interviewer:** Okay.



324 **Debora:** So she passed away in the April.

325 **Interviewer:** Yeah

326 **Debora:** So I had to put all that eh grief

327 **Interviewer:** Yeah

328 **Debora:** to the side,

329 **Interviewer:** Yeah

330 **Debora:** Do you know what I mean?

331 **Interviewer:** Yeah

332 **Debora:** And sometimes. it's only coming up

333 **Interviewer:** Yeah,

334 **Debora:** recently.

335 **Interviewer:** Recently

336 **Debora:** Yes,

337 **Interviewer:** And now's when you need

338 **Debora:** So family. You don't like every family has stuff going on? And then when that big explosion happens?

339 **Interviewer:** Yeah,

340 **Debora:** I think family therapy would be fantastic thing just to get everyone in a room and do you know what I mean.

341 **Interviewer:** And talk through it

342 **Debora:** Because it's not just that that's happened. It's

343 **Interviewer:** Yeah.

344 **Debora:** Someone has other things everybody has other things going on? Yeah. And You're kind of dealing with do you know.

345 **Interviewer:** Yeah. Yeah.

346 **Debora:** And you can't be like eh you're trying to be there. 100% It's not possible.

347 **Interviewer:** Yeah. Yeah.

348 **Debora:** Especially when you have so many things going on. You know?

349 **Interviewer:** Yeah yeah

350 **Debora:** And so many things to try and juggle and process.

351 **Interviewer:** Yeah.

352 **Debora:** And the other thing is the, like, sounds awful. But I'll be truthful, it's. Sometimes it's the time it takes to work out the simplest of  
353 things that Arron is trying to tell you.

354 **Interviewer:** Yeah.

355 **Debora:** And because you're tired or, like, I'm going through the menopause (laughs). Give it all to you

356 **Interviewer:** Yeah yeah

357 **Debora:** So my memory and brain fog.

358 **Interviewer:** Yeah

359 **Debora:** You know, you saw. We were sitting here. He spent ages trying to tell us one thing, and eventually it clicked. This is what he's  
360 talking about.

361 **Interviewer:** yeah

362 **Debora:** Do you know so it's the simplest of things. That take Sometimes it takes a big amount of time. And you're like, sometimes we sit  
363 there we'll laugh because we're like this after we're exhausted.

364 **Interviewer:** Yeah,

365 **Debora:** Trying to figuring out one thing.

366 **Interviewer:** Yeah.

367 **Debora:** Do you know? So

368 **Interviewer:** Yeah.

369 **Debora:** So I think ehm for family support, it's just I think it would help everybody feel that they're doing alright?

370 **Interviewer:** Yeah.

371 **Debora:** Do you know what I mean?

372 **Interviewer:** Yeah

373 **Debora:** We're not gonna get it right 100% of the time for Arron. It's going to be times where it's tough.

374 **Interviewer:** Yeah,

375 **Debora:** Sometimes I feel like I don't help the situations

376 **Interviewer:** Yeah

377 **Debora:** As well. You know what I mean?

378 **Interviewer:** Yeah

379 **Debora:** Because it's sometimes it can be impatient.

380 **Interviewer:** Yeah,

381 **Debora:** I'm just at the end of the rope. You know,

382 **Interviewer:** Yeah yeah.

383 **Debora:** My bathroom has been the saviour. I go in there and, and then I come back out again. And I go right Okay. Carry on.

384 **Interviewer:** Yeah, yeah.

385 **Debora:** So I think the family support would be a great thing.

386 **Interviewer:** Yeah.

387 **Debora:** And I think it would just help for everyone to be on the same page at the same time. And to know this is what Arron needs or this  
388 is what someone else needs. and do you know.

389 **Interviewer:** Yeah. Yeah

390 **Debora:** You know. Because the most, one of the most hardest things was as well, is that you had to relay all the information to so and so.  
391 And then so and so wanted to know, and so and so wanted to know, and like do you ever get phone exhaustion,

392 **Interviewer:** Yeah

393 **Debora:** Where you're like, I can't, go over this anymore.

394 **Interviewer:** Yeah

395 **Debora:** And say the same story again and again, for the updates or.

396 **Interviewer:** Yeah.

397 **Debora:** You know? So

398 **Interviewer:** Yeah,

399 **Debora:** To have that space where this is where we're gonna help Arron. Arron this where you could possibly do, you know,

400 **Interviewer:** Yeah.

401 **Debora:** And this is how we're going to?

402 **Interviewer:** Yeah

403 **Debora:** Yeah, definitely.

404 **Interviewer:** Everyone's voice is heard within that.

405 **Debora:** Yes. Yeah

406 **Interviewer:** Yeah. And is there anything else maybe that we haven't talked about, but that you think would have been useful or would be  
407 useful right now for you? You know.

408 **Debora:** Ehm I always say that [Charity A] offered me, counselling. Arron saw, he's linked in with, [Charity B]. And he had a lovely girl called  
409 [Key Worker 1], she came to the house twice a week. And she did great work with Arron. And he has another eh key worker now.

410 **Interviewer:** Yeah

411 **Debora:** Ehm [Key Worker 2] ehm and I always say, I got offered counselling Arron didn't. He saw like a social worker, he saw ehm a  
412 psychiatrist, probably out in the [Rehab Hospital A]. If it was mood, and, but, he hasn't had and I think [Key Worker 1] saw he had a bit of  
413 eh cause Arron dipped with his- understandably, do you know what I mean.

414 **Interviewer:** Yeah

415 **Debora:** And that's why I want him to do a bit of, voluntary work to have something to give him back a-a piece of him

416 **Interviewer:** Yeah yeah

417 **Debora:** and not to be the one on the receiving end of it all the time,

418 **Interviewer:** Exactly

419 **Debora:** Do you know?.Ehm And I think when [Key Worker 1] saw his mood had dipped at one stage, they have a psychiatrist out there,  
420 and she did an interview on Arron, and did a questionnaire

421 **Interviewer:** Yeah

422 **Debora:** Just checking for depression and all that

423 **Interviewer:** Yeah

424 **Debora:** and said he was just a little bit low.

425 **Interviewer:** Yeah

426 **Debora:** And they gave him like a program to do

427 **Interviewer:** Yeah

428 **Debora:** Daily activities to bring them up again.

429 **Interviewer:** Yeah

430 **Debora:** Ehm but I think there should be some form of counselling

431 **Interviewer:** Yeah

432 **Debora:** For someone like Arron that has lost a speech. I think they should be loads of images.

433 **Interviewer:** Yeah.

434 **Debora:** Do you know what I mean.

435 **Interviewer:** Yeah.

436 **Debora:** For him to try and

437 **Interviewer:** Yeah

438 **Debora:** Get out

439 **Interviewer:** Extract himself

440 **Debora:** Cause I think he banks down and awful lot.

441 **Interviewer:** Yeah

442 **Debora:** And then it comes out, every so often, which it has to

443 **Interviewer:** Yeah

444 **Debora:** But there should be definitely,

445 **Interviewer:** Yeah,

446 **Debora:** You know,

447 **Interviewer:** Definitely. Anything else? Anything other than counselling or anything else that you could think of that you think actually even  
448 it might be a service that doesn't actually exist? That you think oh, you know, if I could

449 **Debora:** Ehm I know the the eh there was a support group for stroke survivors but it was a lot of elderly people.

450 **Interviewer:** Yeah.

451 **Debora:** Ehm And I know someone was trying to I tried to link Arron in and I don't know what happened. But I think possibly to have  
452 something young do you know what I mean.

453 **Interviewer:** Yeah yeah

454 **Debora:** Or eh not a buddy up system. But you know the way they do a buddy up system at school.

455 **Interviewer:** Yeah

456 **Debora:** Where they. Do You know what I mean to try link in with someone like Arron with someone like Arron



457 **Interviewer:** Yeah, yeah

458 **Debora:** Do you know what I mean?

459 **Interviewer:** Yeah, and that you could kind of meet up and and you know talk about

460 **Debora:** Yes yeah.

461 **Interviewer:** Yeah. And you think maybe something like that for you would have been useful as in for people like you who are saying  
462 situation to have a partner to talk to or?

463 **Debora:** Now the the [Charity A] offers they do ehm family counselling eh.

464 **Interviewer:** Kind of like a

465 **Debora:** Carers

466 **Interviewer:** Carers group kind of thing

467 **Debora:** But it it used to be on a Saturday and I never went because I-I was like, I'm gone. Monday to Friday.

468 **Interviewer:** Monday to Friday

469 **Debora:** and I was there. And then I'm like, Well, I'm off my.

470 **Interviewer:** yeah

471 **Debora:** You know, my support.

472 **Interviewer:** Yeah.

473 **Debora:** And you're sitting here for another

474 **Interviewer:** yeah

475 **Debora:** couple of hours on your own on Saturday,

476 **Interviewer:** yeah

477 **Debora:** so I never went to it.

478 **Interviewer:** Do you think maybe if they had like an online one so that your were you could do it maybe from home for like half an hour?

479 **Debora:** Yeah, I think they were doing that but it just said

480 **Interviewer:** They were doing that but it just

481 **Debora:** Yes,

482 **Interviewer:** You wanted to spend time with Arron because you hadn't or

483 **Debora:** Because I hadn't yeah,

484 **Interviewer:** or you know you were working you know

485 **Debora:** Yeah, yeah

486 **Interviewer:** Yeah definitely. And is there anything else that you'd like to add or?

487 **Debora:** Ehm I don't think so. No.

## Appendix H

### H3 – SLT Focus Group 2

1 **Interviewer:** So what we'll do is, I'm just going to start off and ask each person to kind of introduce yourself. How long you've been working  
2 as a speech and language therapist. So maybe what setting you're working in at the moment. So anyone can jump in and answer this.

3 **SLT05:** I'll jump in. My name is SLT05. I'm working as speech therapist for 8 years, I think now. I'm currently working in inpatient stroke in  
4 [Acute Hospital B], started in inpatients 2 weeks ago. Before that I was ESD for stroke, rehab in an over 65s offsite rehab (Rehab Hospital  
5 B). I was in the UK before that. Community Rehab, inpatient rehab and acute as well.

6 **Interviewer:** Brilliant. Thanks SLT05 and if anyone else wants to jump in there.

7 **SLT06:** Grand, I'll jump in. SLT05 I can't believe you've been working for 8 years. (laughs)

8 **SLT05:** I know! How are you SLT06? Practice educator, what? 9 years ago then. (laughs)

9 **SLT06:** Oh Jesus. Okay. So my name is SLT06 and I work in currently working in the hospital in [Acute Hospital C]. I've been here for the past  
10 couple of years. Just started actually with the stroke team here formally, and but I've worked kind of with them here for a good while. I  
11 would have worked in other all my experiences pretty much acute settings. I did a little stint with ESD. But yeah, that's me. I'm working  
12 awhile.

13 **Interviewer:** Brilliant. Thanks SLT06.

14 **SLT07:** I'm SLT07 and I've been working for 18 years as a speech and language therapist. Firstly, primary care mixed paed and adults  
15 caseloads, and then 7 years in [Acute Hospital D], still working with stroke inpatient and outpatient there. And then 18 months ago I  
16 transitioned to a new post setting up an adult service within the primary care team in [Primary Care B]. So I have been doing that for the  
17 past 18 months.

18 **Interviewer:** That's fantastic. So obviously there's a wide range of experience here as well in different settings. So it'd be really nice to hear  
19 of your experiences, both now and in the past, as well in your different roles. So I suppose if you could tell me a little bit about your  
20 experience working with families of adults with aphasia. Maybe is this something you do routinely?

21 **SLT06:** I would think I don't do- I would always like to do more. I think I'm generally meeting people immediately post-stroke presenting  
22 with aphasia. Families are a bit shell shocked by everything and unfortunately kind of priority is given to dysphagia. So just within staffing  
23 and time constraints, I find that families tend to kind of get pushed to the back a little bit. I don't know if other people feel that as well. But  
24 that's kind of what I've had going on.

25 **SLT07:** Certainly when I was inpatients we did a lot, or I did a lot with the families in terms of I suppose the education piece. I would bring  
26 them in and talk to them about the communication deficits and strength of the clients. And we did a lot of work around communication  
27 passports in the hospital. They would have been very involved there in terms of giving us photographs for that and information about the  
28 client's interest, and just be able to personalise not just the speech rehab, but the other HSCP we have. And then linking in with them a lot,  
29 I found just naturally my role in terms of communication support around care planning meetings as well. So I would often be sitting in the  
30 care planning meetings with a white board, sort of translating for want of a better word for the client in the meetings. But that then  
31 transitions to then sort of being sort of almost key worker for the families as well and being able to simplify the medical terms and explain  
32 things. So that was in the inpatient setting in terms of really how we managed it. And then in primary care a lot of it is around the  
33 conversation partner training. So some of our clients would have aphasia, but they might have a cognitive overlay as well. And then the  
34 shifts move maybe less from impairment based in rehab of the client but into supporting the communication partner.

35 **SLT05:** I suppose even my experience in acute for the last 2 weeks has been quite similar to SLT06's and I think the families aren't actually  
36 on the ward as much as they were. Say I was covering neurosurgery 3 years ago, and there was families present a lot more during the day.  
37 But I think since Covid that we've been really strict with visiting times. So families are only coming in for meetings. So other than phone  
38 calls, the only face to face work I've got to do hands on with families in the last 2 weeks has been when people came in for CPMs (care  
39 planning meetings). My experience in the Rehab unit, I really maximized the use of tele health for kind of like, even just education piece  
40 with family members when they were presented with an aphasia, and they were in the Rehab unit for a month or 2. Again, no visiting. So it  
41 was really kinda had to go get special circumstances to get family members in for conversation partner work which was I suppose they  
42 were flexible with that even more so than other things and to help transition home. ESD. It's it was a lot easier to get families involved,  
43 you're in the home, family members are present. They're interested. They want to sit in on sessions, but again guided by the person with  
44 the aphasia, guided by their severity, and what they want to work on. ESD can be quite early days, it can be more impairment based at the  
45 start. And but again, depending on the severity.

46 **SLT06:** I find, in that acute phase that I'm involved in it's working with families. There's an awful lot about like it's quite a hopeful time, in a  
47 lot of the cases like there's you know you're trying to explain, in my experience. Don't have enough time for it, so maybe it's a symptom of  
48 not having enough time to work with families. But you know you're trying to explain that the person is finding it difficult. And I find that

49 you know families are coming back with, you know, “Oh, but they said this to me”. And you know I like they recognise this person you  
50 know so it's very much like. Oh, you need to see what I see, and I think they're getting better. And so yeah, that's what I find in in the acute  
51 phase. And there's kind of hope and recovery would be the main things that I'm encountering.

52 **SLT05:** Hmm.

53 **Interviewer:** Yeah. And I think it would be SLT07 like you're working in kind of after that acute phase now. You know, would you still see  
54 that same kind of families coming in with a lot of hope? Or would that maybe have changed?

55 **SLT07:** I mean it's been interesting because it's a new service so there historically wasn't a primary care service for adults in the [XX] area.  
56 So initially I was getting a lot of referral for people 10 plus years post their stroke. Who would have heard about the story, who are coming  
57 back in, and I guess you could say that that's hope. I'd say it's hope tinged with sort of exasperation as well. That they were like, you know  
58 we got some therapy at the time, but then nothing. And we read about your new service, and we are just trying. And I'm always very  
59 measured in terms of how I would pitch what I can offer in that case. But I definitely find that what I'm noticing with those particular  
60 clients is impairment wise, I don't feel we're making any change to the client's communication, but I think confidence wise and  
61 participation wise. The families are saying the person's grown in confidence communicating and they're contributing more to conversations  
62 at home. So for them that's a very functional outcome that's achieved.

63 **Interviewer:** So, I suppose kind of thinking of those areas seem to be kind of communication partner training and you know providing that  
64 education and support. I suppose, in those early days or even at the stage where they're starting to come into like a primary care service,  
65 you know I suppose there may be times where you need to use kind of more counselling skills.

66 **SLT06:** Sorry. (Beeping goes off in background from SLT06's video.)

67 **Interviewer:** That's okay don't worry. There are times where you may need to use more kind of counselling skills to support people with  
68 aphasia and their family members through this kind of time. In your education as a speech and language therapist, or through kind of  
69 continuous professional development, would you have ever received training in counselling or counselling techniques?

70 **SLT05:** We did like we had a module in counselling in [college]. So yeah it was covered. But I suppose the specifics around supporting  
71 someone with maybe more visual aids or techniques to support their expression less. Not specific to aphasia. I know that group with  
72 supporting emotions in aphasia has started up in Limerick. Or how long that's been running? And that they've been offering some  
73 resources to speech and language therapists. I accessed one of those. I remember them talking about blob trees and VASES (visual

74 analogue self-esteem scale) and things like that. But I don't. Yeah, it's something I'd want more confidence with. It is challenging. Just and  
75 even I suppose even conversation partner training. There's a huge element of counselling skills in that in terms of videoing or identifying  
76 something that's going well. Leaving space for self-exploration and the person themselves to identify what helps in the conversation or not.  
77 It's definitely- it's so different to impairment-based therapy. And it definitely when I started off as a new grad, was terrified of conversation  
78 partner training. I remember going through the whole website of better conversations with aphasia to try and be really like equipped in  
79 knowing how to do this, and really uncomfortable talking about or challenging a family members communication style, and what they can  
80 improve. And so yeah, sorry I've gone off on a tangent but.

81 **Interviewer:** Yeah and how about anyone else, you know, I suppose with that counselling element is that something you would have had in  
82 college or gone and sought you know CPD in or?

83 **SLT07:** I mean, I feel I'm long out of college at this stage it's hard to remember, but I do recall us having I don't know if it's a module, but  
84 sessions in counselling. I think just on a personal level, the way that I work is very therapeutic in that way, and I'd be a very a very strong  
85 advocate of supporting clients, not just the aphasia clients. So I'm, I'm quite comfortable having those conversations and knowing where to  
86 sign post in terms of additional psychological supports. I think like SLT05 says, just in terms of sometimes having the resources for this  
87 particular cohort can be challenging. And I know again, in the context of being a new service and trying to order equipment and resources. I  
88 don't have a huge amount in the clinic, so I find I'm sort of making things up as I go, maybe writing out lots of single words that the person  
89 can point to, or using mood charts, or I've got a deck now of photographs, and I lay them out and the person tries to point to what one  
90 symbolises their mood so trying to try to find ways. But I don't feel like I have an actual toolkit that I can pull on and feel confident using at  
91 the moment. I'm sure that will come but it's something that if there was a resource aimed at speech and language therapists to use that  
92 would be ideal. I sort of feel like I'm fishing around a little bit and pulling from different areas. And similar to SLT05, I'm aware of the SEA  
93 lecture series and workshops that were on but I've only been able to attend one of them. I think they are recorded and it's sort of on my  
94 list to try to access other ones. Yeah. So I'm aware of that resource, I think that's fantastic but potentially more tangible resources in the  
95 context of the busy clinic would be great.

96 **SLT06:** Yeah, my experience I don't remember counselling modules in college. It's been a while. I've never had, I suppose. Yeah, it was. I've  
97 never had formal training, or I'm not sure that I don't really feel that this is not to blame other people but I'm not sure that the MDT  
98 around me, or, you know, would even recognize that that would be something that I'm doing, or you know, to kind of look to me for that. I  
99 would find with the patients that we see here with aphasia. Sometimes I find myself in a role of I am nearly being like I'm counselling about  
100 everything because you are the person who's most in contact with the family to try and get resources, get photos, you know, get  
101 background. And then you're drawn into that kind of as SLT07 mentioned, like a key worker role which is difficult when maybe there's

102 especially over the past few years during Covid when communication and families getting information was quite difficult. Suddenly you're  
103 the one getting phone calls and emails about like "What have other therapists done?" "Do you know what a medical team we can't get a  
104 doctor.". So I find that part particularly difficult with counselling as well because we don't have psychology, we don't have  
105 neuropsychology. It's a hard place to get into with people because I'm always conscious you know you're trying to explore feelings and  
106 recovery, not knowing if the person can access anything once they leave the hospital. And it just yeah, you feel I start to feel responsible if I  
107 nearly say too much because yeah. You're afraid that that then you're setting them up to be disappointed. When you say, oh, well, you  
108 know you could do this. You could. We could access communication partner training, and then they're discharged 2 days later, and it hasn't  
109 it hasn't happened, and they're discharged to no service anywhere or something like that. So I find that challenging.

110 **Interviewer:** I think that's such an interesting point you know that you feel a kind of responsibility. You know, if you're mentioning these  
111 things that hopefully, there is something out there but there's not always. You know, I wonder if you know SLT05 or SLT07, is that  
112 something that you would have found yourselves or?

113 **SLT05:** Yeah, like I sometimes even find myself recommending the aphasia charity. What's their name again? The

114 **Interviewer:** Aphasia Ireland?

115 **SLT05:** Aphasia Ireland. But I've never engaged in those services. So if do feel like sometimes that's the I have no personal experience of  
116 engaging with them myself, or feedback from clients. I don't know how an official it is, or how that. I know they do conversation partner  
117 training for free on a on a Saturday, or like that linking people with CONNECT or anything else is like bolsters. But I do always have a little  
118 bit of a guilt like I've never actually checked that out. I hope it's something good. But you know they're offering the service for people but  
119 there's. In terms of I suppose the psychological follow up. You know that potentially any of the care that someone's going to give especially  
120 if someone has a severe expressive difficulty that a psychologist would find it so hard to support them as well. I mean just thinking there  
121 you were mentioning about the tools and counselling. The VASES, I always think, is like an assessment that we hear so much about. But I  
122 think it's a really cruel thing to put someone through any experience of that any time I've actually used it. The pictures are so un-  
123 expressive. The words are really hard, and it's a really again, if you're asking people questions and they're rating, and you're not offering  
124 anything. Like support like that again. I really agree with SLT06, and that that if you're opening up, if you're bringing the VASES to someone,  
125 and it's like, yeah, if you feel anxious and you feel depressed and you feel like X, Y, and Z, and you're just sitting with that, I suppose rather  
126 than having a solution focused approach then after. It's hard.

127 **Interviewer:** Definitely, you know, and I, I can see like it's a kind of common theme that that does keep coming up, as you know. What can  
128 we offer these people afterwards? You know. I suppose speaking a little bit about families and kind of on the topic of offering support to  
129 people. Family therapy is a type of counselling that helps improve relationships in families, especially when a big change happens. As we  
130 know, people who are having strokes are getting are younger and younger, and often have families, whether it's grandparents who have  
131 grandchildren, and they've had a stroke, or if it's parents or adult children of people as well, you know family therapy is a way for people to  
132 kind of get through these changes together. I'm just wondering. Have any of you ever received any training in in family therapy or in that  
133 sort of area.

134 **SLT05:** No.

135 **SLT07:** No, not at all. No.

136 **Interviewer:** Yeah.

137 **SL07:** And it's interesting Jessica. Like I'm thinking of a client that I have now, who's 10 years post-stroke, and he's young, and since having  
138 had his stroke, he and his wife went on to have a child together, and they have a 5-year-old daughter. And I'm very aware that I haven't  
139 involved her ever in therapy, and I I sometimes check in with myself, and think, should I? And is that appropriate? And she doesn't know  
140 any different. And if I do, how would I? Even she doesn't know Dad any other way. What would I do? What would that look like if I just I  
141 haven't gone there at all.

142 **Interviewer:** And is there a kind of like particular reason that you kind of feel? You know that you haven't gone there, or?

143 **SLT07:** I think I much. I think it's inexperience. So I think the clients that I would have worked with in the hospital were all 70 and 80 plus, so  
144 they I would be talking with adult children, and maybe some teenage grandchildren, I've never had a client as young as this particular client  
145 and with a young child, I think, on my part, it's purely inexperience. Yeah.

146 **Interviewer:** And how about anyone else? Has anyone else had any experience in that area or kind of a similar experience to SLT07's.

147 **SLT05:** It's again. It's more grandchildren. There's a really good YouTube video about it. It's a treasure. So it's a treasure chest, and how  
148 Grandad lost his words. And the kids are gone on a pirate hunt to find their words, and explains, aphasia really beautifully. So my main like  
149 this, that's the only thing I just would send on the parents to send this for their young kids to understand why Grandad or Granny has is  
150 slightly different, but no direct work. But that little bit of indirect is the is the most of it.



151 **SLT06:** I would find. Yeah, I was curious, Jessica, to see how kind of you define family therapy because I think the perception of it that is  
152 well that you know. What I've done is impairment-based therapy with family present is kind of the extent of it. I suppose the barriers to  
153 maybe exploring how people are working through it, and changes in relationships I would find is like emotion. I'm not sure. There's patients  
154 I've worked with where I know from them that they're trying to have a brave face for their family and try to keep it together. And I just feel  
155 like if I was to even say anything, I'm afraid that that it would cause upset that I'm not sure I have the skills to manage. And also trying to  
156 judge, you know, are they ready for that? Are they like? I just have that fear of it, you know. If I go, there is everything going to fall apart  
157 and I won't know what to do with it then?

158 **Interviewer:** Yeah, definitely. And I would say, you know again, it seems very similar to what other people are saying. It's you know the  
159 kind of experience you know. Again going back to that, you know, after care of the services that are available that you can even send  
160 someone to.

161 **SLT05:** Yeah.

162 **Interviewer:** So I suppose kind of thinking back on the clients that you seen. So maybe, SLT07, for you would be that family. you know. Do  
163 you think family therapy would be useful for people with aphasia and their family members, you know going through this time.

164 **SLT07:** And, Jessica, you. I lost the connection there for a second when you're explaining family therapy is family therapy? Is it like family  
165 systems therapy? Like a type of counselling, or what do you mean by it?

166 **Interviewer:** Yeah, it would be a type of counselling that helps improve relationships within families, especially if you change happens so  
167 like a struggle.

168 **SLT07:** Okay.

169 **Interviewer:** But it the family as well, is very loosely defined, and I mean like family, can be just, you know, a husband and wife or partners.  
170 It doesn't necessarily mean there have to be children or grandchildren, or anything like that. But it's. Do you think this might be something  
171 that might be useful for those for people with aphasia and their family members?

172 **SLT07:** I mean, not knowing about the type of kind thing I don't know about particularly that type. But if there's a counselling that  
173 addresses the change in roles and change in identity, then absolutely because that's at the core of what's happening for our clients with  
174 the aphasia, and especially I would see that now in primary care. So while in the acute care the focus is very much on getting better, and

175 oftentimes that looks like mobilizing, you know. Be able to walk and then get home. I think. Then what happens is the person gets home,  
176 and they realize, okay, there's this whole other change in roles within the family now, and different dynamics, and the way that the partner  
177 communicates with their husband or wife has changed the way that they're able to access information. And you know that's got a knock-  
178 on effect for financial management or reading the bills that come in, and all of that. So yeah, I'm sure I it hasn't something that's really  
179 come up for me in primary care yet, because the clients that I see are so long since the stroke just being a new service. And then the new  
180 strokes I'm still trying to figure out where they're going from the acute care hospital. I think they're staying within their early supported  
181 discharge teams or so. I don't know if that work is being done there. But from working before in the acute care and following them as  
182 outpatients, the role in changing identities is a big adjustment. Yeah. And I don't know if I don't know that we. Not we but health care  
183 professionals ever, maybe ask about that, or whether the families have a place to discuss that. And I think from knowing people who've  
184 had high-level strokes. There's a sense that the wider community, maybe, are saying, God aren't you glad that he's home, or that he  
185 survived, or and maybe the nuances of those changing roles, even if it's a high-level aphasia don't get seen by the wider community. And  
186 that it's, it's the care partner who is left day to day, and so I do feel strongly that you know whether it's us or the physio or somebody that  
187 we should be asking and giving space for the person to discuss that. But I get what you're saying SLT06 that there's a kind of a cautiousness  
188 about opening up all of that emotion. And then where do you direct them for supports?

189 **SLT05:** Hmm. I suppose, in the acute setting it's nearly uncomfortable, or it's not the most biggest priority. If you were to ask someone  
190 about the change of role in in those immediate first few days and weeks after, but in rehab it does have more of a place like at home, but  
191 there is still nearly an unknown to how that's gonna happen until the person gets home. I'm thinking about someone that I worked with in  
192 ESD that maybe we did go there with a relationship change. A gentlemen in his forties. And the safety net there was that they were going  
193 to the [Rehab Hospital A]. So I was even just reflecting on that now. About why? How? Why was that different? And there was a lot more  
194 kind of talking about communication style changing, the aphasia impacting the relationship, the importance of the neuropsychological  
195 support that they were going to get me in the [Rehab Hospital A] and around that as well. But alone as a speech and language therapist it  
196 was, it was hard to do that work alone like it would have been. I'd have liked a colleague and then I'm thinking maybe neuropsychological  
197 support, or someone psychotherapy someone. I would have had that team in the UK. But it was. It was different to explore that without it.

198 **SLT06:** Can I be nosy and ask you SLT05 is it is it different in the NHS? Is it, you know. Is there?

199 **SLT05:** Yeah so like my community team in the NHS had em. We had a neuropsych drop-in clinic every Tuesday that you could. You had 15  
200 minutes to present the client you think had like neuro- if you wanted like a neuropsych assessment or counselling support. So if it was an  
201 adjustment to brain injury, adjustment to diagnosis, adjustment to life at home, relationship changes you could, you could present. Either  
202 get strategies and advice or get input from whatever was gonna help with the goal. In neurorehab we had a psychotherapist and a

203 psychology team so there was a lot of support. But then again, sometimes they would just kind of support in the background, and you still  
204 would do the hands-on conversation partner training. But it was yeah, it was. Again I think you have- I'd a fear of this like "Am I doing the  
205 right thing?". So when you had the opportunity to discuss those cases with someone with counselling and psychological training, and they  
206 either give you the language to use, or like a kind of mantras kind of that definitely helped. Or we used to do a bit of scripting role play  
207 sometimes even in those sessions that they say you know "When they say x, you could say Y.". It was this. Yeah, you had a lot more  
208 support. Well you think you'd carry on all those skills but it's actually different when it's, those people aren't there, to bounce it off people.  
209 people are so different.

210 **Interviewer:** I suppose even like opening that up to the whole group there, I mean, that sounds like something that you really benefited  
211 from at the time, and that your patients did as well. Is that something that you know you think would be useful to have here, you know,  
212 SLT07 or SLT06? Is that some- that kind of support there, is that something that you would like?

213 **SLT06:** Yeah.

214 **SLT07:** Yeah I had a

215 **SLT06:** Oh, no, you go ahead. I was just saying that I'd love it.

216 **SLT07:** Yeah, we've no access to neuropsychology and I'm having to try to signpost those people privately. yeah, I'm trying to create ways  
217 of kind of getting that piece done. We're also running into some barriers in terms of psychology accepting them for CIPC (Counselling In  
218 Primary Care) the community counselling service. And I'm finding that not just with the aphasia clients but that clients kind of with  
219 communication difficulties they're sort of being banded around a little bit between services. And I don't know what's driving that and I'm  
220 always saying on the referral forms "Has communication disability. Link with me and I will help facilitate for a first session and link in.". And  
221 there isn't that same mutual way of working and some of that is just historic. I think, in primary care that people work quite unidisciplinary.  
222 But I don't think other colleagues within the psychology and counselling profession feel comfortable working with clients with  
223 communication disabilities. There is definitely a role for us there and supporting them as well as them supporting us to have the language  
224 and the concepts.

225 **Interviewer:** Yeah, and I suppose SLT07 you've offered there like you know, on the referral forms that you're happy, you know, to be  
226 contacted about it. Has anyone actually contacted you like with regards to that? No. (SLT07 shakes head "no" in response to question.)

227 **SLT07:** No, and but none of them have actually made it into the room yet. So I'm still working on it with a couple of clients. And with that  
228 client's stroke and one of his things is just social participation, and there's a new social prescribing service, and I referred him to there. And  
229 the plan is that, yeah, I will go and meet for the first session. But some of it is just you know we're not located in the same building, we're  
230 playing phone tag with each other, and things are dragging on. It's the usual structural barriers that are kicking in there.

231 **Interviewer:** Yeah, it wasn't even staying on that kind of topic of barriers or challenges, you know. And this is this is for everyone. You  
232 know. What challenges do you see for these clients in trying to access, you know, family therapy or therapy in general?

233 **SLT05:** The severity of communication impairment being the primary one so like exactly what SLT07 said. The services offering the pure  
234 therapy are used to people who can access language. Like talking therapy is a primary is like one of the primary forms of therapy in the  
235 community. So if people can't access that there's already like a challenge there. So if someone has a more mild aphasia they or they will  
236 have more, they will have more access or they will have more success in accessing traditional therapy approaches. Like I know there's. You  
237 know, when you hear about art therapy and music therapy and other forms of visual therapies you don't, I've never heard or seen of them  
238 really in practice other than again [Rehab Hospital A] has some music therapy. So yeah, I think the primary barrier is the severity of  
239 communication impairment.

240 **SLT07:** Yeah. And another thing I'm noticing in communities is still a lot of stigma attached to attending counselling or psychology supports  
241 and maybe not coming from the client themselves, but from the partners. And sometimes there's a stoicness of "No, no, we're fine" or  
242 they say "No. I don't think I need counselling". But and then they're just, you know, giving me the whole narrative and talking. And inside  
243 my head I'm thinking "This is why I would be recommending counselling for you". And maybe they build up a rapport and a certain  
244 dependency on us or a certain team member and the thought of starting over somebody else is a barrier for them alongside that stigma  
245 that that older generation maybe have towards psychological supports.

246 **SLT06:** I find just to add to that. It's maybe as well the attitudes of existing teams, possibly myself, included, so it's not to say it's others but.  
247 This kind of sense of you know well, that's that would be lovely but you know we don't have, we don't have time and resources to engage  
248 with that. So you know mood? Give them some antidepressants and send them on their way. And you know that's better placed  
249 somewhere else instead of maybe. I just have envisaged the NHS, or you know, other services might have more of an attitude of kind of  
250 early intervention, and you know, providing support before it's even needed. I don't think we have that ethos at all. I think we're reactive,  
251 and we deal with mood and counselling when it becomes a barrier to participating in impairment based and physical based therapies. And  
252 that's when we address it.

253 **Interviewer:** Yeah, I think there's been some really interesting points, and it seems the kind of same sort of issues are coming up each time.  
254 I suppose, sticking with the kind of the communication part of it, you know. Do you think you know these clients require further  
255 communication supports to access family therapy? You know. And what might that look like?

256 **SLT07:** Yeah, I mean, I'm thinking about my client, the younger man and he's single words and masks his comprehensive difficulties quite  
257 well, and he would find accessing a talking therapy very difficult without additional support. So I mean even for the therapist working with  
258 him to know that he needs more time or the picture support. So he's got some single words, written comprehension. I'm such an advocate  
259 of joint working in in joint sessions. So I definitely would love to do that sort of work together with another team member. So yeah, I do  
260 think there's scope for that.

261 **SLT06:** I think there's I think there's materials as well like, I know. I've my attempts at trying to upskill, you know doing talking mats  
262 training, and the better conversations and communication partner training. And I think all of that helps but yeah, it's a hard one.

263 **SLT05:** Sorry, Jessica. What was that specific question again?

264 **Interviewer:** So do you think these clients require kind of further communication supports to access family therapy? And what might that  
265 look like?

266 **SLT05:** Yeah, absolutely as SLT06 said. Things like talking mats, just visuals. Not things being so, language heavy. Again, I think from  
267 experience with conversation partner training as my like this whole style of family therapy. Sometimes, if the group got too big, so if there  
268 was like 3 daughters that were clambering over who was going to do the therapy, and they all wanted to be involved. Sometimes, if person  
269 had a severe aphasia again they'd lose access to the conversation. Things might be happening too fast even to get their voice. So it's about  
270 ensuring that no matter what the family therapy is that they that it's at their level. And that might I don't know it's interesting to think  
271 about that, and think about then you know, even sometimes, like a family meeting in a hospital might not be the most appropriate place  
272 for the person with aphasia to attend. If the meeting is going to pass them out. So I might have like a chat with the MDT. Sit there and  
273 make that meeting accessible to the patient before they join, so like. What would that look like for family therapy again? So it's just from it  
274 being at the level that they can access it and that they don't feel more alienated and isolated in a session that all the other communicators  
275 are at higher level.

276 **Interviewer:** Yeah, I suppose kind of touching a little bit on our role within this. You know, SLT07, you kind of mentioned about doing joint  
277 sessions, you know. But this is open to everyone. Do you think that SLTs have a role in family therapy and kind of what would make that  
278 possible? Do you feel?

279 **SLT07:** I think it goes back to our overall role and our role is communication participation and that's how I view it as supporting community  
280 participation. So to work around person communication with family members in the house, or if they are working around that. So if they're  
281 accessing a service that they're not able to access from a communication point of view then that's part of what we should be doing is  
282 supporting that access for them. So on a very basic level like that? Yes. And then I think secondly because the communication deficit  
283 changes the roles and changes the dynamic and changes how that person communicates with the world and the people around them.  
284 Then we definitely have a role in being able to support the emotions that come from that as well. So for those two reasons I feel very  
285 strongly that we do. But I don't feel that we're equipped to do it by ourselves. I think it comes back down to that joint piece of working,  
286 linking in with our colleagues of psychology or councillors.

287 **SLT06:** I'm not sure how I'm going to articulate this but. I think that I think that if I was thinking about how to improve the quality and  
288 improve my confidence around family therapy, that I would really value, number one having more time with the patient because  
289 sometimes I feel like, I suppose there there's also the aphasia, but the aphasia and the communication effectiveness can change. And I feel  
290 if I could- if I had the time and the availability to get to know the person really well, then I would feel much more comfortable, you know,  
291 and by getting to know them well, it would be, you know, having opportunities to observe sessions with other clinicians. You know, having  
292 the opportunity to be available to the medical team to support conversation. Because I find just in in a busy environment what happens is,  
293 you know you. I do my initial assessment. I convey to the team. Okay, they have problems with this and that. And then, you know, a doctor  
294 just goes to the patient. The patient nods along, and they're like "Oh, we have that sorted." Like "Why are you slowing things down?".  
295 "Why?" you know "We don't need to revisit that we've talked to X, Y, and Z person". So if I was thinking about what would help me it  
296 would be to I suppose to be recognised as you know, the value I can bring rather than I. I feel sometimes there's a perception on the  
297 surface that I I'm slowing things down rather than helping in terms of people's pathway through us through our acute service. (SLT05  
298 nodding « yes » in response to SLT06's statement.)

299 **SLT05:** Hmm. And SLT06 it's so interesting to hear you say that cause I'm adjusting to that shift. I've had rehab now here for the last 3  
300 years, and I'm like right we gotta keep things flowing. And I think with that point though, I think there's a time and a place for the type of  
301 work, and that family therapy, that conversation partner training, that adjustment work probably happens closer to the being at home or  
302 the rehab stage than the acute stage. Like at the moment I'm like right let's get their head around the fact that communication can be  
303 affected after a stroke. And what is an aphasia. Here are some basic resources. We have a video we brought out last year with aphasia

304 awareness week from [Acute Hospital B] that has two examples of someone who recovered and now has mild aphasia and someone who  
305 has a serious aphasia still after rehab. So maybe, sending that link and very just basic level, I think at the moment is the acute priority here.  
306 That's what I'm telling myself and the phone call updates, and then the again try to support them on the start of their journey. And I've  
307 been, I've been, I'm still thinking about the that whole piece that you mentioned at the start. And offering kind of realism and maintaining  
308 hope. It's been something that I'm really considering now as well, having worked at kind of all levels of the pathway too.

309 **Interviewer:** I definitely think there's been some really interesting points brought up throughout this, you know, and I think it is definitely a  
310 fine balance between realism and keeping hope at the same time. So I suppose, just before we finish up, we've kind of I'm going to just run  
311 through the kind of areas we've talked about, which was you know, your experiences working with adults with aphasia and their family  
312 members, your kind of training and counselling, what you might have done kind of CPD as well. You know we've talked a bit about family  
313 therapy, and whether that would be useful for people with aphasia and their family members, you know, and how you know, how can they  
314 access those services? And then our role as SLTs, you know, in in family therapy. What would it look like and what makes it possible? And  
315 so, before we finish up? If there's anything that we didn't discuss but you feel is kind of important feel free to bring it up now.

316 **SLT05:** I think that key point that we need support with something like family therapy. That we can't like be spearheading it just ourselves,  
317 unless, again we have the additional training, additional support. That our huge benefit would be having more counselling, more neuro  
318 psychology on neurological teams and hospital and in the community. That we can do more joint working and then that we get that kinda  
319 as SLT07 was saying. Gosh! Like we're putting ourselves out there that they come and join us, and that we work together.

320 **SLT07:** And I think it's just the timing of that along that patient's, I hate that word: journey. But the patients experience I having worked in  
321 hospitals like I can't necessarily see it being as effective at that point in the hospital. Like I often find clients come to me in the community,  
322 and I'm thinking God were they given any information about aphasia? But it's because they're just so overwhelmed with information at the  
323 time in the hospital. And it's when they come back, and they've lost the leaflets and they have forgotten. Or they now realise the person's  
324 walking, but actually it's the communication impairment is the piece that they're most concerned about and the changes. So I think I can't  
325 imagine it working as optimally as it possibly could at that time later on, when the person's come home and the dynamics have kind of  
326 settled into a new routine at home.

327 **SLT06:** Just one thing that occurred to me there, just as a facilitator as well. I suppose, in those scenarios where I felt that things have gone  
328 better when working with family has been when I've had like OT's supporting as well just around trying to tease out that cognitive versus  
329 language piece, because so many patients will have elements of varying degrees of cognitive impairment, and trying to tease that one out  
330 so that would be another kind of big facilitator for me. Yeah that was the only other thing I thought of.