



# Planning for the Future Project

*Initiating 'End of Life' Discussions  
for People with Dementia*

**St. Vincent's Hospital, Athy, Co. Kildare  
St. Brigid's Hospice, The Curragh, Co. Kildare**

*Funded by the Irish Hospice Foundation*



Final Report Phase I  
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# FOREWORD

## **Planning for the Future**

This project set out with a clear and commendable vision that the views and wishes of people with dementia with regard to their end of life needs are heard and communicated. Opportunities to introduce mechanisms to support the future care planning for people with dementia were identified, piloted and successfully introduced within the ten bedded dedicated dementia unit, which is situated within St Vincent's Hospital in Athy. This was achieved by delivering education, and developing support and guidance tools for staff to facilitate conversations and care planning in matters relating to their end of life care with residents in Le Cheile.

The collaboration between the specialist palliative care team from St Brigid's Hospice in Co Kildare, and St Vincent's in Athy, enabled by this quality improvement project, has resulted in stronger relationships between these services, which in turn has assisted in the delivery of better end of life care for all residents in St Vincents.

I look forward to hearing how the outcomes and outputs from this project are sustained and transferred across other sites and settings, enabling more people with dementia and their families receive the timely advice and opportunity to discuss the care they would like to receive as they enter the last phase of their life.

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# INTRODUCTION

The term **dementia** is used to describe a collection of symptoms including a decline in memory, communication skills, reasoning and gradual loss of skills needed to carry out daily activities (NICE guidelines 2007). A person with dementia may demonstrate acute sensitivity to his or her social environment and a high level of stress. Dementia is a life-limiting condition and the person will, in general, undergo a gradual and progressive deterioration in their symptoms. In Ireland there are currently over 41,000 people living with dementia, and this number is projected to increase to over 140,580 by 2041 (Cahill et al., 2012). It is estimated that at least 40% of people with dementia are currently in residential care in Ireland and 18% of acute medical beds are occupied by people with dementia (O'Shea, 2007).

Palliative care is concerned with "the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement" (WHO, 2007). The need to provide high quality end-of-life care is essential. The needs of dying people may include, but are not limited to, knowing when death is coming, understanding what can be expected, being able to maintain a sense of control, giving preference to their wishes, having access to information, spiritual and emotional support as required (Palliative Care for All, 2008). People must have the opportunity to discuss their wishes and choices regarding end of life care. Where decisions on such matters cannot be made due to diminished or absence of capacity, his/her representative should be consulted (HIQA 2009). Obstacles to quality end-of-life care have also been identified in the literature and may include failure to recognise treatment futility, lack of communication among decision makers, no agreement on a course for end-of-life care, and failure to implement a timely end-of-life care plan (Travis et al. 2002).

Although traditionally palliative care services have centred on people with cancer, the principle that people with diseases other than cancer should have their palliative care needs met has been adopted in Irish policy since the publication of the *Report of the National Advisory Committee on Palliative Care* in 2001. While a great deal of work has been done to develop specialist palliative care services in Ireland, the need to develop services for people with non-malignant lifelimiting conditions was acknowledged in the joint HSE and IHF report *Palliative Care for All* (2008). This report highlighted the particular need to further develop palliative care services in the areas of chronic obstructive airway disease (COPD), dementia and heart failure.

Providing high quality palliative care for people with dementia presents unique challenges due to the person's inability to verbally express preferences for their care as the illness progresses, and the fact that the end of life phase may be long and difficult to identify. It must be recognised that the process of dying is complex, and the separation of end-of-life into a defined period when palliative care services can be mobilised and administered is not possible (Palliative Care for All, 2008). In order to overcome these challenges it is necessary that the principles of palliative care be embedded within the disease management framework, allowing for non-specialist palliative care needs to be considered and addressed by the staff who are delivering the on-going care to people with dementia. The McCarron et al study in 2008 suggests that the principles of person-centred dementia care mirror the broad principles of palliative care.

# PROJECT BACKGROUND

This is a joint project between St. Vincent's Hospital, Athy, Co. Kildare and St. Brigid's Hospice, The Curragh, Co. Kildare. St. Vincent's Hospital, Athy is a residential care facility for older people in HSE Dublin Mid-Leinster, which includes a ten bedded dedicated dementia unit – Le Chéile. St. Brigid's Hospice is a specialist palliative care inpatient unit.

The principal motivator for this project was the recognition of the need to capture spontaneous communications from residents with dementia regarding end of life care, referred to as 'Special Moments'. Anecdotal evidence highlighted how residents, some of whom were at an advanced stage of their condition, clearly and coherently expressed their wishes about their own end of life care. These included issues regarding pain, their wish to stay in the care home, and their readiness for death. It was felt that in order to ensure that each of these communications were recognised and appropriately captured in the care plan, all staff would need to be sensitive to and aware of their importance. Within Le Chéile there was a recognition that while initiating discussions around end of life care enhances the end of life experience for people with dementia and their families, there was a number of potential barriers for staff in initiating and having these discussions.

In order to explore and begin to meet these needs, a consultative project group was established in 2009 (Appendix A). Funding was sought and received from the Irish Hospice Foundation. A smaller working group was then established (Appendix B) to develop a project plan designed to explore potential challenges staff face around end of life care discussions, and to implement changes to overcome these barriers and support staff in their role.



## **AIM**

**To develop a framework to support staff with initiating discussions around end of life care issues with residents/families in Le Chéile dementia specific unit, adapting aspects from the Gold Standard Framework.**

## **PHILOSOPHY**

The focus of this project places communication at the heart of its aim and acknowledges that the ability to communicate is not totally lost as the dementia condition progresses, but rather requires increasingly sensitive perception by the carer. The project aspires to combine person centered and palliative care approaches to the care of people in the later stages of dementia living in Le Chéile.

An open approach has been adopted which accepts that dementia is lifelimiting. For those people who reach the end stages of dementia symptom management and comfort measures may be more appropriate than invasive interventions. Care is ideally based on previously discussed wishes and preferences. The project team wish to emphasize that respectful and inclusive care at all stages of the condition can be achieved when the true essence of person centred care is adopted.

The importance placed on introducing discussions on end of life preferences and wishes early on was guided by best practice recommendations from the Gold Standards Framework (GSF). This advance care planning tool in particular emphasises that “to be able to provide the best care possible for all residents and their families...we need to know more about what is important to them and what are their needs and preferences for the future” (Gold Standard Framework, 2012).

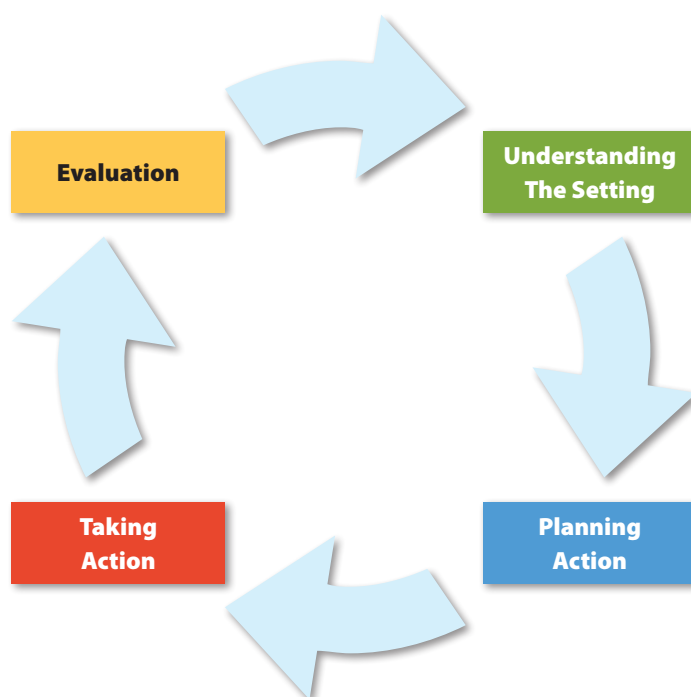
# ACTION RESEARCH CYCLE

Though no formal change model was used, the project followed the structure of an action research process, i.e. 'learning by doing' (O'Brien, R. 1998). Action research involves a group of people coming together, identifying a problem, planning and implementing action to address that problem, evaluating whether the action was successful, and if needed implementing additional action. Therefore it is a constant process of learning, taking action and review.

For clarity the findings of the project are presented within the framework of the Action Research Cycle (ARC), though this model is being used retrospectively for reporting results, rather than being the change model used at the time.

Action research is a style of research which looks at a problem and tries to find a solution to it. It is a cyclical process that involves understanding the setting, planning and taking action with reflection and evaluation. The four stages of the action research cycle are illustrated below in Figure 1 below.

**Figure 1: Action Research Cycle**

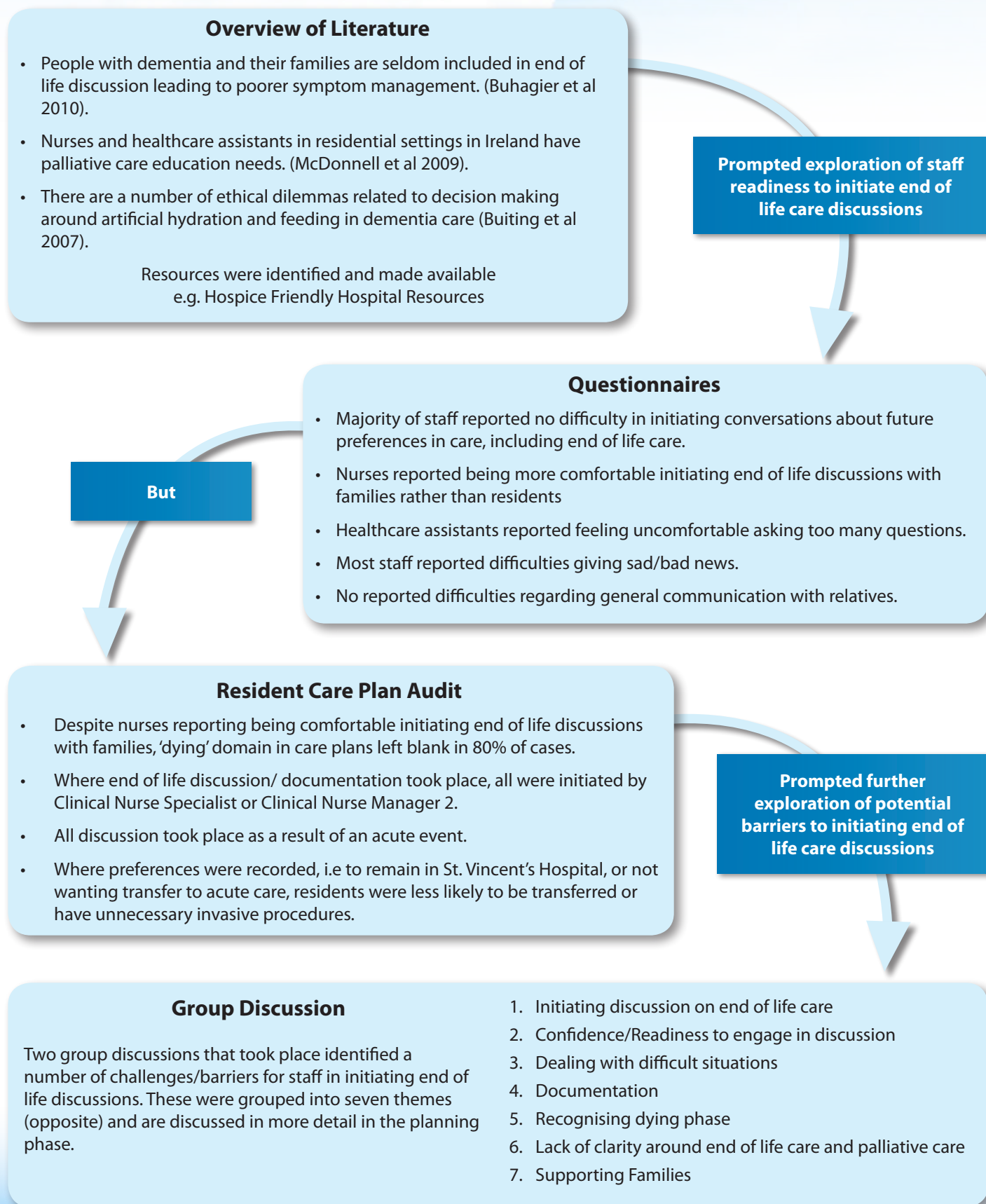


To begin, stakeholders work together to identify what the main issues are. It is accepted that not all issues will be identified at this stage, as additional insight will be gained throughout the ARC. Once the issues have been identified, action planning focuses on the first steps which need to be taken to rectify identified issues. These plans are then implemented in the taking action stage. Finally, the plans implemented are evaluated to determine what impact they have had on the issues identified. This in turn leads into the next phase of the ARC, that of understanding and identifying new issues that may have arisen throughout the process of the previous cycle.



# PROCESS

This flow chart summarises the steps taken during the project. These are further elaborated in the next few pages.



# FINDINGS

The project team carried out four exercises in order to gather information on dementia and palliative care locally, nationally and internationally, and to explore relevant issues within St. Vincent's Hospital, Athy. The four exercises carried out in the understanding phase of the project were:

## Overview of Current Literature

A review of current literature was undertaken in order to gather the evidence pertinent to the remit of the project.

Throughout the course of the project, additional literature and best practice guidelines were continually reviewed as they became available. Through this process additional resources were identified and integrated into the project and have been referred to in this report.

## Staff Questionnaire

A questionnaire was adapted from the Hospice Friendly Hospitals Staff Questionnaire to explore any challenges staff face during discussions and communications with residents and family members regarding end of life care. The questionnaire was distributed to the 17 staff members in the Le Chéile unit, 13 of which were returned giving a response rate of 76%.

## Resident Care Plan Audit

An audit of ten residents' dying domain page care plans and medical charts from Le Chéile was carried out to determine the range and level of information recorded pertaining to the residents' wishes and preferences regarding palliative and end of life care. Dying domain refers to one of the 12 activities of daily living in Roper, Logan and Tierney model of nursing (1990).

## Group Discussions with Staff

Building on the findings from the staff questionnaires, a number of informal group discussions that included all nursing and health care assistant staff took place. These were planned in order to explore, more fully, some of the challenges and difficulties staff reported in discussing and documenting end of life care issues.

These discussions were tape recorded and hand-written verbatim and thematic analysis used to identify themes, including:

1. Initiating discussion on end of life care
2. Confidence/readiness to engage in discussion
3. Dealing with difficult situations
4. Documentation
5. Recognising the dying phase
6. Lack of clarity around end of life care and palliative care
7. Supporting families

# PLANNING

In order to clearly link the planning phase with the findings from exercises carried out during the process phase, a brief account of each of the challenges identified by staff is presented, along with the actions planned by the smaller working group to address each of these challenges/ barriers.

## 1. CHALLENGE

### Initiating discussion on end of life care

Some staff had difficulty with how best to initiate discussions around end of life care, including: what language to use; how to meaningfully engage the person with dementia in the discussion; and how to introduce the topic sensitively, without the implication that the person is entering the 'active dying' phase.

### PLANNED ACTIONS

#### 1. Updating 'dying domain' in care plan

Completing care plans was identified as a most useful prompt for initiating end of life discussions. Therefore care plans were updated to allow for easier introduction of the topic, guided by resources available from the Gold Standards Framework (2012), and the 'dying domain' page was replaced by 'planning for end of life care' page.

#### 2. Development of visual prompts

To address staff concerns regarding how best to initiate discussions, especially where residents may have diminishing communication skills, it was decided to develop a series of visual prompt cards by adapting methods of communications used with people with learning difficulties. (Appendix A).



## 2. CHALLENGE

### Confidence/Readiness to engage in discussion

Staff recognised that residents sometimes introduced the topic (special moments) e.g. 'I think I'm dying'. Staff missed these opportunities to explore this further as they felt they didn't have the skills to maintain the momentum of the conversation in a sensitive and supportive way. When the topic of end of life care was introduced by residents or family members, many staff were not sure if they were saying the 'right thing'. Concerns included the following:

- **Use of appropriate vocabulary**
- **Giving the correct information**
- **Answering difficult questions e.g. eating and drinking at end of life.**
- **Finally some healthcare assistants expressed uncertainty about whether it was their role to engage in such conversations.**

## PLANNED ACTIONS

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### 3. Staff Education

To develop/source suitable education programmes to

- Empower staff by ensuring they have the skills to allow them to engage confidently with end of life discussions.
- ensure staff have information on end of life issues such as the advantages/disadvantages of artificial hydration/nutrition.

### 4. Staff awareness

To create an open culture of awareness among all staff to help them recognise 'moments' when residents may express, verbally or non-verbally, their wishes and preferences regarding end of life care. This will be achieved through staff education, open discussion at ward level and updating care plans.

### 5. Empowering Staff

In order to ensure that all discussions around end of life care are captured accurately, health care assistants will be empowered to carry out these discussions and report them to nursing staff. These discussions will be documented in the residents end of life domain in the care plan (see planned action 8).



## 3. CHALLENGE

### Dealing with difficult situations

Staff spoke about difficult situations they had encountered, examples included family members getting upset when end of life care issues discussed and the appropriateness of breaking bad news over the phone. Another challenge that was presented related to the provision of further guidance to ensure healthcare staff could competently address the management of end of life symptoms. Staff were also aware of how end of life care discussions can trigger emotions they may have regarding their own mortality or death experiences in their past.

## PLANNED ACTION

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### 6. Staff Education

To develop/source education/training programmes to

- give staff the skills and competencies to deal with difficult situations.
- provide the opportunity for staff to explore their own feelings and attitudes towards death and dying.

### 7. Development of Guidelines

Guidelines to be developed around symptom management to ensure continuity and quality of care at end of life for people with dementia.



## 4. CHALLENGE

### Documentation

There were discrepancies where staff reported being happy to initiate conversations around end of life care but care plan audits showed very few entries on the 'dying' domain page. Even where something was recorded, it did not capture resident's wishes and preferences regarding end of life care.

### PLANNED ACTION

#### 8. Updating 'Dying' Domain in Care Plan

A new care plan page to be developed and a new heading changed from "dying domain" to "End of Life domain". Care plans to be updated to include additional prompts regarding exploration of each resident's wishes around end of life care.



## 5. CHALLENGE

### Recognising dying phase

While some staff felt competent in being able to recognise when residents were entering an 'active dying' phase, others felt they were incompetent or inexperienced. All staff stressed the importance of knowing the resident well in order to be able to see changes in the resident's condition. Conversely when staff are very close to residents, they may not recognise a gradual decline in the persons' condition. Therefore, there is a need to be involved closely with each resident's care, while maintaining a certain objectivity to allow for accurate assessment. Health Information and Quality Authority (HIQA) requires a review and reassessment of residents every 3 months or sooner if a resident's condition should change.

### PLANNED ACTIONS

#### 9. Use of prognostic indicators from Gold Standard Framework

Staff to be educated in the use of prognostic indicators to support them in recognising, acknowledging and acting when residents enter the 'active dying phase'.

#### 10. Development of symptom management guidelines

Guidelines to be developed to support staff to recognise and anticipate the need for appropriate pharmacological interventions for symptom management that may occur at end of life. Staff education in training and palliative care helps to differentiate between residents whose symptoms can be appropriately controlled by staff in Le Chéile and residents who need the support of the specialist palliative care team.

#### 11. Introduction of PAL and 'This is me' documents in care plan

The introduction of Pool Activity Level (PAL) (Pool, 2002) and 'This is me' (2010) documents to support new staff in getting to know the resident, and to facilitate continued person-centred care when the resident is transferred to another care facility.



## 6. CHALLENGE

### Lack of clarity around end of life care and palliative care

Staff identified confusion around definition of the terms end of life care and palliative care, and the issues pertinent to dementia. Some staff found it difficult to accept that dementia is a life limiting condition. Therefore additional education is needed around these issues, including the physical and emotional aspects of dying to ensure that the appropriate level of importance is placed on end of life care.

### PLANNED ACTIONS

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#### 12. Staff awareness/culture

Introduce a cultural change in how end of life care is approached for people with dementia. This will be achieved through staff education, open discussion at ward level and updating care plans.

#### 13. Introduction of hospice friendly hospital resources

Introduction of resources such as the ward Altar and spiral symbol. Continuous engagement with the Hospice Friendly Hospitals programme (2012)



## 7. CHALLENGE

### Supporting families

Where the person with dementia needs support in expressing their preferences/wishes regarding end of life, family members/relatives often act as their advocate. Staff felt that they needed a common language that would be simple to use and understand in order to have discussions with families regarding their expectation for the resident's illness trajectory. Staff voiced concerns that sometimes families felt they were solely responsible for making the decision to adopt a palliative care approach, leading to feelings of guilt around the decision. While it is important to include families in discussion they also need reassurance that staff are competent to provide good quality end of life care. Some staff voiced concerns about the impact on families and residents on the practice of transferring residents out of the unit when they came close to end of life. Finally, staff commented on the need for additional bereavement support for families after their loved one had passed away.

### PLANNED ACTIONS

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#### 14. Staff education

To source/develop education workshops to give staff the language and skills necessary to discuss families' expectations for residents illness trajectory.

#### 15. Developing information booklet for families

To develop/adapt an information booklet on end of life care for people with dementia.

#### 16. Updating 'dying' domain in care plan

The 'dying' domain page to be changed to reflect the role of family members and medical staff. While families are to be involved in discussions around end of life care as advocates, the final decision rests with the medical officer and will be in the residents best interest.



# TAKING ACTION

The following changes have been made in line with the planned actions outlined in the previous section.

## Development/Adaptation of Care Plans

- The 'dying' domain has been changed to 'planning for end of life care'. The language in this domain has been developed and changed to allow for easier introduction of the topic and to facilitate all nursing staff to discuss/initiate discussion around end of life care. Further questions/ prompts have been added to ensure all aspects of end of life care are discussed and recorded. The page also highlights that while any decisions regarding medical care are made in consultation with the person/their family, the final decision rests with the medical officer.
- The topic of end of life care has now been introduced as part of the normal three monthly review. The discussion with the resident and families referred to as 'best interest' meetings allows the resident's preferences and wishes to be reviewed.
- Both the Pool Activity Level (PAL) document and the 'This is me' (2010) document have been introduced into the care plan, to allow new staff to get to know the resident more quickly, and for continuity when residents are transferred to acute care or other care areas.

**Ask me what I want**

It's really important to us that you are cared for as you want. We want make sure that any decisions about your end of life care or treatment now and in future are based on your wishes and preferences

We always want to know that we're doing what you want in relation to your care... We will discuss this every 3 mths or sooner if your condition changes

Do you have any worries or wishes about your future care?

Have you ever thought about what you might want if you became very unwell...?

What do you think is most important to you as you near end of life.. Who? Where?

## **Staff Education**

The need for staff education was identified in a variety of different areas. Therefore, a number of different education and workshops days have been sourced and developed to meet all the needs and concerns highlighted by staff during the understanding phase. All Le Chéile staff, across all grades attended training sessions together.

- The three day National Dementia Education Programme has been rolled out. This person centred programme is designed to educate and raise participants' awareness around issues relating to dementia. It also includes a module on palliative care, which covers legal and ethical issues and the Gold Standard Framework prognostic indicator guidance.
- Final journeys training day 1 & 2 has been rolled out to all Le Chéile staff and other staff in St. Vincent's Hospital. This training is designed to raise awareness of end of life issues and enhance communication skills. Staff also had the opportunity to reflect upon and discuss their own preferences and concerns regarding end of life.
- A one day workshop with Specialist Palliative Care (SPC) staff was developed and delivered. This workshop gave staff relevant information and provided them with an opportunity to practice discussions around end of life care using the new end of life care plan domain. Staff had the opportunity to make suggested changes to the document at this time.
- A number of additional resources and materials on end of life and dementia have been added to the library which is to be accessible by all staff.
- Two staff members completed an on-line End of Life and Dementia Education Module with Bradford University.
- Three staff members completed a three day summer school programme entitled 'Fostering a Culture of Effectiveness in Care at End of Life through Practice Development'.

## **Visual Prompt Cards**

As the dementia illness progresses verbal communication skills often decline. Promoting the use of other senses, e.g. vision, the level of engagement and communication between staff and residents can increase. In addition to the extensive staff education/training and changes to the residents care plans, visual prompt cards have been developed and are currently being piloted with staff in Le Chéile as an additional resource for initiating discussions and include residents to ascertain their preferences and wishes around end of life care (Appendix C).

## **Staff Awareness/Culture**

As a step towards creating an open culture of awareness regarding end of life care in Le Chéile and St. Vincent's Hospital, the policy document on end of life care has been revised and updated to reflect current best practice around end of life care. In addition, the changes made during the project e.g. education and improved documentation, have prompted both formal and informal discussions among staff helping to ensure that end of life care is given the same attention and regard as all other domains of care.



## **Empowering Staff**

Healthcare Assistants and Nursing staff were included in all education programmes in order to give them the skills and confidence to engage in end of life care discussions when these were initiated by residents. This helps ensure that those 'special moments' where residents express preferences around end of life care are captured appropriately, as these moments tend to be short transient moments with the person with dementia. Nurses then have a responsibility to write preferences captured in the care plan, while healthcare staff have responsibility to report on these moments so that they can be included in the care plan. This information can then be used to guide discussion around the care pathway for the resident.

## **Development of Symptom Management Guidelines**

Best practice around symptom management and end of life care was gathered from the current literature. These guidelines were adapted by the staff of St. Vincent's in conjunction with staff from St. Brigid's from the Peterborough Palliative Care Dementia Group (2005). Education and training of staff is necessary and the ongoing use of the guidelines will be subject to clinical audit. These guidelines support staff to recognise and anticipate the need for appropriate pharmacological interventions for symptom management that may occur at end of life. It is not intended that these guidelines would be used prescriptively; rather they have been developed as a guide only. The guidelines state that all medication doses derived using the information below should be checked and prescribed by an experienced practitioner.

## **Introduction of Hospice Friendly Hospital Resources**

Hospice Friendly Hospice programme works to ensure end of life care is central to the mission and everyday business of the hospital, providing a quality service for all at the end of life, whether their death is expected or unexpected. They have designed resources to enhance the care of dying or deceased patients e.g. Multi-denominational Ward altar (Waltar), end of life drape for coffin and end of life symbol to create awareness a death has occurred. A sympathy card is sent to the next of kin of each deceased resident from the Director of Nursing Office within a month of his/her death.

# EVALUATION AND FUTURE ACTIONS

In order to evaluate the impact of the project, the 'end of life' domain in the residents care plans were re-audited 6 months after the introduction of the updated 'end of life' domain.

## Resident Care Plan Re-Audit

Residents care plans were re-audited to determine the impact of the actions taken to date. The audit found 100% entry on the 'end of life' domain, with individualised preferences and wishes documented. It was found that end of life discussions are now part of each residents regular three monthly review. No residents had been transferred to acute care, except for treatment post falls, and all returned to Le Chéile on the same day. Only two nursing staff had not written in the 'end of life' domain notes, and these were the two staff members who had not taken part in the education programmes. During this audit it was noted that while resident care plans had documentation on end of life care, these discussions were not always recorded in the medical notes.

In order to extend the philosophy of the project to the rest of St. Vincent's Hospital, an audit of resident care plans was proposed in order to collect baseline information. Building on findings from the evaluation of the first phase of the project, the audit was extended to include both residents nursing care plans and medical notes, thus continuing the process of the action research cycle.

## Audit of Care Plans/Medical Notes in Rest of Hospital

The audit revealed that 76% of care plans had no information on preferences and wishes regarding end of life care documented. 46% of those had noted 'resident unable/not discussed'. There was no evidence of families invited to get involved.

In addition it was found that there was no designated space for recording end of life care wishes in the medical notes, making an audit of same very difficult. No entries on end of life treatment decisions were found in the medical notes.

## Future Action Plans

Getting communication right from the beginning fundamentally impacts on the experience of residents/patients and families at end of life. We need to continue improving outcomes, through discussion, for people with dementia to have their end of life care need met.

- 1) Extending the project throughout the rest of the hospital by introducing planning for end of life care. Sharing the learned experiences will improve the care for all residents who have dementia by enabling them to have the opportunity to discuss and express their wishes about end of life care and have it documented accordingly.
- 2) Form an End of Life Committee to maintain and improve current policy and guidelines around end of life care practices, underpinned by a person centered approach to care. This committee will evaluate end of life practices in a comprehensive and integrated way.

- 3) Continued engagement with Hospice Friendly Hospital Programme to improve the culture of the care environment, incorporating the four components of integrated care; communication, design, dignity and patient autonomy.
- 4) Documents developed as part of the project will be available on the Dementia page of the Irish Hospice Foundation website - **[www.thehospicefoundation.ie](http://www.thehospicefoundation.ie)**
- 5) Information around end of life care to be included in the hospital information booklet. This will introduce residents and relatives to the topic of end of life and afford them the opportunity to discuss relevant information about end of life care in an understanding, supportive environment.
- 6) Discrepancies between nursing and medical documentation was identified as part of the project. These discrepancies will be examined and efforts made to develop a more cohesive approach to end of life care for residents with dementia. A designated page in medical notes to be developed and implemented where discussions around end of life care can be documented.
- 7) To maintain continuity of care, the resident's end of life preferences and wishes are communicated to staff if the resident with dementia is transferred to an acute care setting. The aim is to aid compliance with the resident's preferences and wishes and to prevent inappropriate investigations or interventions.
- 8) Palliative care medication management to be incorporated in mandatory education management updated every two years.
- 9) In line with best practice an audit tool will be developed to evaluate the introduction of Symptom management guidelines. This audit tool will be available on Irish Hospice Foundation website with other documents developed as part of this project.

# ACKNOWLEDGEMENTS

We would like to acknowledge and thank the following for all their support and guidance:

Residents and their families and all staff in Le Cheile

Anna de Suin for preparing the project report

Finally, our printers Data Print for advise, patience and recommendation in finalising report.

## APPENDIX A

### Members of the Consultative Project Group

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## APPENDIX B

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# APPENDIX C



Baile Átha Cliath & Lár Laighin - Dublin Mid-Leinster  
St. Vincent's Hospital, Athy, Co. Kildare.

Affix Addressograph here

## Planning for End of Life Care

Ward/Unit: \_\_\_\_\_

**It is really important to us that we care for you in the way that you want to be cared for. We want to make sure that any decisions about your end of life care or treatment both now and in the future are based on your values, wishes and preferences.**

We want you to remain as well as possible for as long as possible but have you ever thought about what would be most important to you if **you became seriously ill while you are in St Vincent's?**

.....  
.....  
.....

**If the doctor and staff felt that acute treatment in a general hospital would not be of benefit to you at that particular time, what would you prefer to do?**

Remain in St Vincent's hospital for treatment and symptom management.  
**Yes**  **No**

Transfer for more advanced acute medical treatment to Accident and Emergency department.  
**Yes**  **No**

ALL DECISIONS ABOUT YOUR ONGOING MEDICAL CARE WILL BE MADE IN CONSULTATION WITH YOU AND YOUR DOCTOR, AND IN YOUR BEST INTEREST.

**You might find discussing end of life care difficult, in which case could I ask you to think about your wishes and preferences around future end of life care and I will come back to you again on**

.....  
Nurse's Signature .....

Date .....

Are there any documents we should be aware of in relation to your end of life care e.g. Enduring Power of Attorney (EPA)/ Ward of Court?

.....  
.....

**Ensure relevant information is documented and updated in resident's medical notes**

Can you tell me what you understand about your illness and this particular stage of it?

.....  
.....  
.....

What do you think would be most important to you when **you are nearing end of life? E.g.** Have you ever thought of where you would like to be? Who would you like to have with you?

.....  
.....  
.....

Would you like to talk about any worries or fears that you may have about death and dying?

.....  
.....  
.....

Any preferences/wishes for after death?

.....  
.....

Wish to be Cremated: **Yes**  **No**

Have you shared any of this information with your family, friend or any other person?  
**Yes**  **No**

**With** .....  
**Relationship** .....

Would you like to share this information with your other relatives?

**Yes**  **No**

**We will give you the opportunity every three months (or sooner if there is any change in your condition), to revisit these discussions. This will allow you to add to, or change any preferences and wishes already discussed.**

Information obtained from  
.....

Relationship .....

Care Plan Commenced: **No**  **Yes**  Date.....

Palliative Care Plan: **No**  **Yes**  Date.....

**Nurse's Signature** \_\_\_\_\_ **Date** \_\_\_\_\_



**Feidhmeannacht na Seirbhíse Sláinte**  
Health Service Executive  
Baile Átha Cliath & Lár Laighin - Dublin Mid-Leinster  
St. Vincent's Hospital, Athy, Co. Kildare.

Affix Addressograph here

## Planning for End of Life Care

Ward/Unit: \_\_\_\_\_

When we spoke previously about your end of life preferences and wishes you expressed..... (Review conversation with resident about previous preferences and wishes).  
Is there any change since that conversation or would you like to add anything else?

Date		Signature

## APPENDIX D

### Visual Prompt Cards

#### SIGNIFICANT SHIFT IN TREATMENT FOCUS



#### TRANSFER TO ACCIDENT AND EMERGENCY





## APPENDIX E

### Symptom Management Cards

# Planning for the Future Project

## A Guide to Symptom Control at End of Life in Advanced Dementia

**St. Vincent's Hospital, Athy, Co. Kildare**  
**St. Brigid's Hospice, The Curragh, Co. Kildare**

*Funded by the Irish Hospice Foundation*



Updates are available on

[http://www.olh.ie/upload/departments/files/1352996847\\_OLHandCS\\_Opioid\\_Conversion\\_Chart.pdf](http://www.olh.ie/upload/departments/files/1352996847_OLHandCS_Opioid_Conversion_Chart.pdf)

This chart is subject to regular review and it is up to each individual user to avail of current updated copy.

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# Planning for the Future Project

*Initiating 'End of Life' Discussions for People with Dementia*