Who Can Ever Understand?

Talking about your cancer
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This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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Introduction

This booklet has been written to help you find ways to talk about your cancer and to ask for the help and support you need. It can be very difficult to come to terms with the fact that you have cancer. You may find it hard to talk about what’s happening to you and how you feel. You may feel awkward talking to family and friends, or to the nurses, doctors and other professionals looking after you.

In the booklet you will find some simple guidelines that will make it easier for you to talk about your cancer with friends, family, doctors, nurses and other people looking after you. The guidelines can help you to ask for what you want and need. The tips in this booklet can also help you to talk about what you are feeling and to understand common reactions to being told you have cancer. The booklet will also help you to understand how your friends and family may be feeling and why they may find it hard to talk to you.

Talking about your cancer

Why it’s difficult to talk about cancer

The moment when you are told you have cancer is almost always a moment of deep distress. In fact, most people say that they have never faced a bigger and more daunting challenge.

Many people have to cope with various crises such as marital problems, financial problems or problems with family members. However, most of those will seem far less serious than facing a diagnosis of cancer.

You may feel almost paralysed mentally by the news. It can help to spend a moment or two thinking about why that can happen. Understanding a feeling is the first step in dealing with it.

Your feelings

‘When I heard that word ‘cancer’, my mind went completely blank. I don’t think I heard a single word the doctor said after that.’

Shock and disbelief

When you first hear that you have cancer, however positive the future might be, you can experience very strong feelings of shock and disbelief. This is a normal way to feel. The fact of cancer, as something that is happening to you, is something most of us are unprepared for. Even if you have feared that your problem is cancer, the moment at which that fear is confirmed is still very distressing.

There are many aspects to this feeling of shock. Most people think of cancer as a serious and perhaps fatal disease. You may fear the possibility of unpleasant treatment or that the cancer will cause you pain. You may worry about becoming a burden to your family, not being able to work and so on.

Denial

In quite a lot of people the feeling of disbelief is accompanied by a desire to shut out and deny the news. Most people use denial as a
valuable method of dealing with very threatening news when they first hear it.

Denial is a normal human coping strategy. It allows you to take serious news on board without having it swamp you totally. It is only when denial is prolonged – going on for many weeks or months – that it becomes a problem. Denial may cause a breakdown in communications between you and your family (or healthcare team). You may come to realise that you are using denial, or someone close to you may point it out to you. Do not blame yourself or feel that you must hurry to overcome it. It may well be a normal reaction, which in time will allow you to accept the news and deal constructively with it.

Coping with feelings of shock, disbelief and denial can make it difficult for you to talk about your situation. You may not be used to talking about deeply personal and intimate matters. If that has been your pattern in the past, then you are going to find it difficult if you want or need to talk about your feelings. Again, being aware of this will help you a bit. The rest of this booklet will help you even more. You can also call the National Cancer Helpline 1800 200 700 or visit a Daffodil Centre for a copy of the free booklet, Understanding the Emotional Effects of Cancer. You can also download this booklet from our website, www.cancer.ie

Other feelings
There are other feelings that may make you want to withdraw and not to communicate with the people around you. You may feel guilty and think that in some way you have brought this on yourself. This is a very common feeling. You may be unsure and embarrassed about how you will react when you talk to other people. You may be afraid that you will cry. You should not worry about this, as crying is often a good thing because it allows easier communication.

You may be worried about how your friends or family will react. Will they withdraw from you? Will they judge or condemn you? Will they blame you? Or you may be worried that talking about the disease might quicken its progress. For example, if you openly discuss your concern that the treatment might not work, then it won’t. Of course that is nothing more than superstition, but it still worries quite a lot of people.

Talking about needs and wants
You may find it difficult to talk about your needs and wants. Once you are diagnosed with cancer, there are people around who want to help you. It is much better for you if you can say what it is that you need or want. You’ll be surprised how many people are really quite glad to hear clearly from you what your needs are.

Other people’s attitudes
You may worry that the people you want to talk to will feel uncomfortable talking about these things, and you are probably right. In our society serious subjects such as cancer are not openly discussed. Nobody feels very comfortable talking about cancer. It’s not the fault of your friends or family – and it’s certainly not your fault – it’s just the way things are at the moment. But there are signs that things are changing. Society is slowly getting more accustomed to talking about serious personal subjects, particularly if they involve health.

The people around you may have no idea what to say. To make it worse they may feel that they ought to know what to say. They want to help you but do not want to upset you further by saying the wrong thing. So rather than face you without that imagined magic formula, they may tend to avoid you altogether. There are people who have never had a serious or threatening illness themselves or known anyone else with one. They may be unsure of what you want, and not know how to ask you. They may also be worried about how you’ll react. Your relatives and friends may think they won’t know what to do if you cry and so on.

Again, this booklet will show you how you can help them overcome these anxieties. Another booklet in this series, Lost for Words: How to Talk to Someone with Cancer, is specifically written for them. If you would like a copy call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre, or download it from our website, www.cancer.ie
The benefits of talking

So, if it’s so difficult, why bother? Why is it worth talking about what’s going on if it makes you and your friends feel uncomfortable? Talking openly will do a great deal to help you through any difficulties that may lie ahead.

★★★★ Talking openly will do a great deal to help you through any difficulties that may lie ahead.

How talking can give you support

Most people seem to get comfort from talking to each other. Fears or concerns, which are voiced, are somehow put into perspective by talking about them. That’s probably the basis of the old proverb ‘a sorrow shared is a sorrow halved’.

There are probably things that you have been thinking about, and about which you can’t make up your mind. You’ll often find that you have already decided on the answer without being aware of it. You may only realise the answer when you phrase the question. In other words, talking about something often teaches you how you feel about it.

★★★★ Talking about something often teaches you how you feel about it.

If your listener hears your fears or concerns, and then simply stays with you, that also changes your attitude to what you had been thinking or worrying about. It makes you feel that your fears or worries are normal. If your friend can hear about them and not run away, then perhaps these fears are not as bizarre or strange or ugly as you feared. Talking about a fear or a worry often stops it growing in your mind. Very often when you are thinking a lot about something that is worrying you, the fear or concern seems to get bigger. It seems to grow in size in your imagination until it becomes very threatening, even overwhelming. Once the fear or concern is out in the open and is being discussed, it often does not sound as bad.

Conversation around something we feel deeply about can produce a special closeness. Talking about something important or personal produces a bond between the participants, which is valuable in itself. You may not feel like talking about your cancer, and getting on with your normal activities may help you to cope, but be alert to how you are feeling and try not to bottle up your emotions.

How to feel more in control of your situation

Very often, when the diagnosis is cancer, you may feel as if you have little or no control over the disease or its treatment. There is often one treatment plan, which offers a chance of improvement, and no real alternative. Certainly you can always decide not to have any treatment. Sometimes that’s the right decision, but often it isn’t. That feeling of ‘I haven’t got a choice really’ is very common. It’s also very unpleasant. It may lead to feelings of powerlessness and resentment.

You will feel more in control if you find out as much as you can about your cancer and its treatment. Ask your doctor about what side-effects you can expect before starting treatment. The more information you have about your situation and the better you become at talking about it, the more you will feel involved in your own care. If you and your family understand your illness and its treatment, you will be better able to cope.

To sum up

- Understanding a feeling is the first step in dealing with it.
- Denial can be a normal coping strategy, which in time will allow you to accept and deal with your cancer.
- Do not be afraid to cry, as it often makes communication easier.
- Saying what you need or want can help you.
- Talking openly can help you through any difficulties that lie ahead.
- Finding out more about your cancer and treatment can help you feel more in control.
Who should you talk to?

If you want to talk, who is the best person to talk to? Well, the first part of the answer is: who did you speak to about your biggest worries before this? If there is someone in whom you’ve always confided your most serious worries or problems, then of course that person should be on the top of your list now. Not everyone has a soulmate. Ask yourself this question: Who is the person that I could imagine would make me feel most comfortable talking about difficult problems? It might be anyone. For example, your spouse or partner, your closest friend, your mother, sister, brother or religious leader. It may even be somebody you quite like but haven’t until now been on close terms with.

In fact, you may find it difficult to talk to someone close to you about your cancer. You may find it easier to speak to someone else such as a business partner or an acquaintance. If you can’t think of anyone you would like to talk to, discuss this issue with your doctor or nurse. There may be counsellors or social workers that can help you identify the most suitable person in your circle. You may also find it useful to talk to a nurse in confidence on the National Cancer Helpline: 1800 200 700.

Support groups

There are many groups that have been set up to support people with specific cancers. There are also support groups for people of all age groups who share common problems when a diagnosis of cancer is made. The National Cancer Helpline nurses can advise you about the different support groups that are available.

Some people find support groups very helpful. They may form bonds with other members that are deeper and more significant than almost anything in their past. But other people get embarrassed or uncomfortable talking about personal issues with strangers. If groups are not your style, don’t worry.

You and your partner

You or your partner might find that your emotions are overwhelming and it is stopping you from carrying on a normal life. It might also be a sign that you are becoming depressed. In this situation, it can help to talk to your GP, a counsellor, psychiatrist or in group therapy.

Talking with a trained counsellor in a more focused way can help you sort out your feelings and find ways to cope with them. This can be very useful, especially if you cannot discuss your feelings and emotions with people close to you. You and your partner are likely to find your own best way of dealing with your emotions. Do remember that all feelings and thoughts pass and you will feel better at some time in the future.

Often partners try to protect each other by not being completely open about their fears and concerns. It is important to talk openly with your partner. This can help you both to understand each other and may bring you closer together.

Some people find that it helps to write down how they feel. Keeping a diary or journal is a practical way to help you express your feelings, especially if you cannot talk about them with other people. The Journey Journal from the Irish Cancer Society is useful to write notes about your feelings and discuss them with your medical team at the hospital. To get a copy, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie
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How to ask for what you need and want

So now you’ve identified the person with whom you stand the best chance of having supportive conversation – what next? Well, first of all, simply because you have cancer doesn’t mean you’re not allowed to talk about anything else! Most people find it quite normal to talk about the minor aspects of everyday life as well as the major issues confronting them. Talk about the day-to-day things if and when you want to. But when it comes to talking about your current situation, here are a few hints that may make the conversation easier:

- **Have two or three topics:** Try to decide which are the things that you really want to talk about. Quite often you’ll find that it’s only two or three things that you really want to discuss.

- **Introduce the topic:** In order to introduce the topics that matter to you, it’s quite helpful if you can give a headline first. It may be something such as ‘Look, I want to say a couple of things that are on my mind. Is that OK with you?’ By doing this you will alert your listener to the fact that what follows is something that really matters to you.

- **Be specific:** Try to be specific about the things that concern you.

- **Check the person is following you:** When you’re doing the talking it’s a good idea to break up your own speech to see if the other person is following you. You can use any little phrase you like to do that: ‘Do you see what I mean?’ or ‘Does that make sense to you?’ or the more universal ‘Are you with me?’

- **Check what’s been said:** Towards the end of the conversation try to make sure that what you’ve said has been heard. If you have asked for some things to be done, for example, it’s worth summarising: ‘So you’ll ring your mother about next weekend, and also ask Mary to collect the children on Friday.’ After you’ve covered the main topics, don’t feel embarrassed to go back to small talk: ‘Let’s talk about some little things. I like talking about small things, ordinary things.’ The heavy bricks of important issues would just collapse without normal human nattering in between!

- **Humour:** A lot of people ask whether humour is a good thing to use when talking about tense issues and subjects. If humour was useful to you before you were ill, it will be useful to you now. Humour can be used to help you cope with a stressful situation. It may help you to draw a frame around something that is threatening. Laughing at it helps to reduce its importance and the size of the threat. If humour has been part of the way you have coped with threatening crises in the past, it will help you now. If, on the other hand, you have not used humour as part of your armour in the past, this may not be a good time to start doing so.

How to talk about your feelings

You might not be used to talking about your own feelings. If you try it, you may feel a bit awkward. When something serious happens, particularly a diagnosis like cancer, you may find that although you want talk about how you feel, you are not used to it. You may feel a bit clumsy. This is a normal way to feel.

If you (or your listeners) have strong emotions that are not talked about, you won’t be able to talk about any subject easily. An emotion that nobody admits to has a paralysing effect on all conversation. So if you or your listener is feeling angry or embarrassed or very sad, your conversation will feel very sticky. Both of you will be preoccupied and will not be listening. The moment one of you acknowledges the emotion, ‘I’m sorry I seem in such a bad mood today, but I’ve just been told that...’ you will suddenly find communication much easier.
Guidelines for communicating

- Always try to acknowledge any strong emotion – your own or your listener’s.
- Always try to describe your feelings rather than simply display them. There’s a great deal of difference between saying ‘I’m feeling really angry today because...’ (which starts a conversation) and simply showing your anger by being curt or rude (which stops conversation).
- You are perfectly entitled to feel any way you like! The way you feel is the way you feel. Emotions are not right or wrong. It is only if you try to cover up any strong feeling that problems really become unsolvable.
- Don’t be afraid to tell the other person how much she or he means to you. Again, in our daily lives we don’t often do that. But when there is a crisis, it’s really worthwhile to explain to the other person how you feel about them.
- Don’t be afraid to acknowledge uncertainties. If you don’t know how you feel, or if you don’t know what is going to happen or how you are going to cope, you should say so. More harm is done by pretending that you do know, than by confirming that you don’t.
- There are many occasions when words aren’t needed. Holding someone’s hand or hugging or simply sitting together in silence can often achieve as much or more than words, once you are both clear about the situation.
- Everybody has some regrets in their life. Don’t feel that you are not allowed to express any regrets you feel. More than any other emotion, regret is reduced when it is shared, and may even prove a double bond between you and your listener.
- Listening is an important part of communication; it is important that you feel heard and listened to, especially when talking about such a serious issue. Always give yourself enough time and make sure you are comfortable.
How to respond to other people’s reactions

Even though you are the person facing the diagnosis of cancer, you may have more difficulty in dealing with your friends’ emotions than with your own. This is because when people are unable to cope with their own emotions, they tend to avoid the situation altogether. So your friends might be very tempted to stay away from you. They may not want to face the fact that they have strong emotions and don’t know how to deal with them.

- **Always try to acknowledge your friend’s feelings.** If you are a good guesser, then the ideal is to identify your friend’s emotion and what caused it. This can be quite simple, such as ‘You look as if you’re feeling really uneasy when I talk about the cancer’ or ‘I guess coming here makes you very upset.’ In an ideal world, of course, this wouldn’t be necessary. Your friend would be able to explain what he or she was feeling and then bring the focus on to you and what you want to talk about. But this isn’t an ideal world, so you may have to do some of the groundwork to get the support you need.

- **Don’t be afraid to acknowledge how you feel.** ‘This is making both of us feel awful’ or ‘I know you’re worried about what’s going to happen next and so am I.’ The more you are each aware of your own feelings and the other person’s, the easier it will be to talk.

- **If you get into some form of conflict** (and that happens quite often) see the section called ‘Hints for resolving conflict’ on page 26.

The effect of cancer on sexuality

Cancer or its treatment can affect your sex life. If you have had an active sex life before your illness, it will most likely be affected by your cancer diagnosis. There may be times when you feel tired or perhaps not strong enough for the level of physical activity you are used to during sex. Some emotions such as sadness may cause you to lose the desire for sex. You or your partner may have a fear of the illness and treatment and resent the effect the illness has on your lives. You may also have thoughts and feelings about your body and body image. You may worry about how your partner may react to any change in your appearance.

All of these are linked, so if there is a problem in one area it may have an impact on another. Both you and your partner might withdraw from each other physically and feel shy and awkward. Quite often, sex may stop completely. This may occur at a time when you most need to be reassured and cuddled.

If that happens, then you must say so, as coolly and calmly as possible. Do explain your needs and wants and discuss what one or both of you can do. Of course, it can be embarrassing to talk about these things. But a very small amount of dialogue makes a great deal of difference. Try not to ignore the subject of sex with your partner, as it may cause serious resentment and mistrust on both sides. For more information or advice in confidence, call the National Cancer Helpline on 1800 200 700 or visit your local Daffodil Centre.
How to tell other people

One of the most awkward and difficult aspects of being ill is the need to tell friends and family about your illness. You may feel that you do not know where to begin. If the person is your spouse or partner or a close friend, then it is usually possible to have him or her present when your doctor talks to you. That way you both hear the same thing.

If your friend cannot be present, you may find the following guidelines useful in telling him or her what the situation is.

- **Physical setting:** Try to get the physical setting right. You and your friend should go somewhere quiet and private to talk. Make sure that you are both comfortable and that you can look at each other’s face easily.

- **Introduce the subject:** It’s always worth introducing the subject, rather than just starting straight off. Something like ‘I think it would be best if I tell you what’s going on. Is that OK?’

- **Find out what your friend knows:** Your friend may know some of what has been happening. It can be quite useful to ask about that, before you go over ground that has already been covered: ‘You probably know some of this already, so why don’t you tell me what you make of the situation so far, then I’ll take it on from there.’

- **Opening statement:** It often helps to start with an opening statement. For example, if the situation is serious, you can actually say ‘Well, it sounds as if it might be serious’. If it’s worrying but sounds as if it will be all right in the long term, you can say that.

- **Small chunks of information:** Give the information in small chunks – a few sentences at a time. Ask your friend if he or she understands what you’re saying before you continue. You can use one of several little phrases for that purpose – things such as ‘Do you see what I mean?’, ‘Do you follow me?’, ‘Is this making sense?’ and so on.

- **Silences:** There will often be silences. Do not be put off by them. You or your friend may well find that just holding hands or sitting together in the same room seems to say more than any words.

If you find that a silence makes you feel uncomfortable, the easiest way to break it is with simple questions such as ‘What are you thinking about?’

- **Keep to reality:** When you tell someone close to you that something serious is wrong with you, he or she may feel very low and depressed, in sympathy with your situation. As a result, you may feel that you should put a positive side to the situation in order to relieve your friend’s feelings. If the facts of your situation support that, of course it’s good to do that. But if there is a great deal of uncertainty or worry about the future, you shouldn’t feel that you need to disguise that from your friend in order not to hurt his or her feelings. In other words, **try to stay as close to the real situation as you can**. It may be painful for your friend at this particular moment, but if you paint an over-rosy picture that then turns out to be wrong, your friend will be much more disappointed (and even feel hurt) later on.

You’ll find that these principles will make what is always a difficult conversation a bit less awkward. It’s not really fair that you should have to do so much, particularly at a time when your needs are so great and many. However, it often happens like that, and in this way your friend will be much better equipped to give you support in the future.

Talking to your doctors and carers

It is important that everyone involved in your care understands how you are feeling. Good communication and relationships with your doctors, nurses and carers can really help you.

Talking about your symptoms

There will be occasions in which you are asked to describe your symptoms. These may include pain, nausea, shortness of breath or some other medical problem. It’s just as important to describe and talk about feelings and symptoms of depression and anxiety. You may find it difficult to explain your problems clearly.
Here are a few pointers, which may help:

- **Try to stick to the facts and be as open as you can when you describe the problem.** You may feel that you have to exaggerate pain or nausea to convince the doctor and produce better or more urgent therapy. At other times you may play down the symptoms to appear strong or brave. If possible, ignore both of these temptations. Try to describe the problems in as honest and factual terms as you can. It’s not easy, but if you do that, you will end up with the full understanding of your doctor or nurse. If you try to overplay or underplay your problems, there is a risk that they will feel out of touch and will be less able to help you. You don’t need to convince your doctor of either the severity of your symptoms or of your own personal courage.

- **Use your own language.** Just because your doctors or nurses use medical jargon, you don’t need to. There’s nothing wrong with using your own words to describe the problem. In fact, using jargon that you only partly understand might cause difficulties by giving the wrong slant to your problem.

- **When you’re embarrassed, don’t hesitate to say so!** You may find certain kinds of medical symptoms and problems embarrassing. They are very often the kind of personal matters you don’t talk about to someone else. So when you start talking about something that is embarrassing, just say so (‘I’m sorry ... this is embarrassing to talk about’).

### Asking for information

When it comes to getting information from your medical team, your own feelings and fears may make it a bit difficult for you to ask the right questions and to remember the answers.

### Finding out more about your illness

Try to think of the most important questions before the discussion with your doctor.

- **As well as a written list, it’s a good idea to take a friend or relative with you.**

You may find it helpful to write down a list of questions and bring it with you. As well as a written list, it’s a good idea to take a friend or relative with you. Often the other person can remember things the doctor said which you later forget. He or she may also remember the questions you wanted to ask but haven’t got round to yet. You may find it difficult to understand and retain medical information. It is even more difficult when it is serious and when it is about you. Nobody will mind you writing things down or making a list of your questions. Ask your doctor or nurse to write information down so that you can go over it again later. There are booklets available that discuss all aspects of cancer and its treatment. For more information, go to our website, [www.cancer.ie](http://www.cancer.ie), call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

### If you don’t understand, ask again

Sometimes there won’t be advance notice of an important subject. You might hear bad news quite unexpectedly. If you’re not clear about what someone has told you, do ask him or her to explain. Once your doctor or nurse has answered your questions, it’s a good idea for you to sum up the answer you received. Perhaps say something like: ‘So you’re saying that...’ or ‘If I’ve got that right, you mean that...’ These make it clear what you have understood. It may also encourage your doctor or nurse to explain things more clearly. You may need time to
think about what has been said to you. You can always ask more questions at your next visit. Keep on asking questions until you have all the information that you need.

Keep on asking questions until you have all the information that you need.

Uncertainty

Being concerned about your future is a normal way to feel. Sometimes it can be hard for your doctor to predict the outcome of your treatment. Not knowing can make you feel anxious. The more you find out about your illness and treatment the less anxious you will be. It’s good if you can accept that uncertainties about the future are common. When the conversation is about very serious matters that threaten your health or your view of the future, it’s easy to imagine that your doctor or nurse knows what is going to happen but will not tell you. Usually, that’s not the case. It may help if you can understand how progress will be measured. You can say ‘So you’ll decide from the X-rays if the treatment is working’. This kind of information will help you.

The more you find out about your illness and treatment the less anxious you will be.

If you are not happy with some aspect of your treatment, try and express those doubts, as politely as you can. Most doctors and nurses, like all human beings, react to constructive criticism well, and react to destructive criticism either defensively or angrily. If you can be balanced in your criticism, your doctors and nurses are more likely to accept your concerns and do something about them.

To sum up

- Find somewhere quiet, comfortable and private to talk.
- Introduce the subject and find out what your friend knows.
- Give information in small chunks.
- Being silent or just holding hands or hugging can help too.
- Stay as close to reality as you can. Don’t feel you have to protect your friends from your illness or put on a brave face all the time.
- When talking to your doctor, be as factual and open as you can. Use your own language and admit if you feel embarrassed talking about a particular subject.
- Make a list of things you want to ask your doctor and write down the answers.
- If you don’t understand something, ask again.

National Cancer Helpline Freephone 1800 200 700.
Hints for resolving conflict

When the diagnosis is cancer, people are often worried and nervous, and conflict is common. It might be conflict with your friends or family or with some member of your healthcare team. Of course a lot of complaints will turn out to be justifiable, and many can be resolved with time.

However, some patients find themselves getting almost uncontrollably angry with friends or the healthcare team. Some of this feeling comes from the basic human reaction of blaming the messenger for the message. If somebody tells you that you have cancer, you may find it difficult to focus your anger on the cancer itself so you feel angry with the person who tells you. The feeling that you have the misfortune to have this disease and the other person has not often increases your anger. In all events, it is quite possible that there will be conflict at some stage between you and somebody else.

Guidelines to help with conflict

- Whenever possible, describe your feelings rather than displaying them.
- Acknowledge all emotions – whether they are yours or the other person's.
- Separate yourself from the result of the argument. In other words, try to stop feeling that your worth as a human being is tied to the outcome of the dispute. It's easy to imagine that if you win, you're a wonderful person, and if you lose you're not. That is untrue of almost every conflict known to humankind. So tell yourself that you are still a perfectly satisfactory person even if you lose this argument.
- If there is an issue or an area over which you simply cannot agree, try to define that area even though you can't resolve it. In other words, aim to 'agree to disagree' on this issue.
- Talk the dispute over with someone else. As you describe it, try not to turn the other party in the dispute into a monster. That way, you may see a way out of the argument simply by describing it at a distance.

Talking to children

Talking to children about your illness or about their illness, if a child happens to be the patient, is especially difficult. We all think of childhood as a time of innocence and freedom from pain or guilt. We all hope that unpleasant or painful facts will never intrude on our children until they are older and have what we think are adequate coping skills.

Unfortunately, serious illness in the family does not respect the age of the people affected by it. Usually patients do need to tell their children what is happening. This is often the most awkward and painful part of the illness, but the following guidelines will help.

How to tell a child that you have cancer

Ask yourself if you would like some help with telling a child about your cancer. Very often, a member of your healthcare team being present at such a difficult time can be very helpful. The child can often focus any anger or resentment on the professional instead of on the parent. Also there may be questions which are very difficult to answer – and again the professional can relieve you of some of that. So it’s worth thinking about and discussing with your healthcare team. Ask if there is a doctor, nurse, therapist or social worker or anyone else who can and will help you.

An open, honest approach is usually the best way for all children.

Explaining your illness

Use simple language and terms that your child will understand. Pitch the information at the level of your child’s understanding, not your child’s age. Children differ enormously in what they can understand and what they cannot. Some 5-year-olds can understand concepts that escape other children of 10. Check as you go along to see what the child is understanding, and tailor what you say to that. An open, honest approach is usually the best way for all children.
Repeat the information
Give your children time to ask questions and express their feelings. Be prepared to repeat the information. Children usually ask for important information to be repeated, perhaps several or many times.

Children need to be reassured that your illness is not their fault.

If the subject is painful to you, then you may be tempted to stop the conversation (‘I’ve answered that three times already – that’s enough now!’). But when children ask for repetition, it’s not because they are stupid or malicious, they simply need to check that you really meant what you said. So try and be more patient than usual and go over the ground again, being consistent with what you said last time.

Blame
Be aware of what is known as ‘magical thinking’. Children can feel very guilty when things go wrong around them. Whether they show it or not, children may somehow feel they are to blame for your illness: ‘If I’d tidied my room up like mum told me, she wouldn’t be ill now.’ They need to be reassured that your illness is not their fault. It’s often worth building that into an overall statement such as: ‘This is just one of those bad things that happen occasionally and it’s nobody’s fault. It’s not my fault, it’s not the doctor’s fault and it’s certainly not your fault, it’s just a piece of really bad luck.’

Explaining difficult or threatening facts to a child is always painful. These guidelines may help a bit, but don’t hesitate to ask for whatever help is available to you. Let other adults in your children’s lives know as well. These could be relatives, teachers or neighbours. These adults may be able to support you and your child too. The Irish Cancer Society has a booklet, Talking to Children about Cancer: A Guide for Parents, which you may find helpful. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a copy. You can also download it from www.cancer.ie

To sum up
- Conflict may happen between you and somebody else during your illness.
- If you have strong emotions, describe them rather than displaying them.
- If you are angry, try to separate yourself from the argument. Don’t think everything depends on winning or losing an argument.
- Agree to disagree if you cannot agree with someone.
- Talk the dispute over with someone else.
- When telling children about cancer, seek help from your doctor, nurse or social worker.
- Use simple language and terms your child will understand.
- Give your child time to ask questions and express their feelings.
- Repeat the same information so that your children are sure what you mean.
- Reassure your child that your illness is not their fault.
Conclusion

Serious illness is always perceived as a threat to health and life. You may want to shut the whole thing from your mind and hope that it will just go away. Sadly, that’s not usually a helpful thing to do – for you or your friends. The hints and guidelines in this booklet will help you make real contact with your friends, at a time when your illness itself threatens to pull you away from each other. You may be quite surprised and pleased with the changes that can be brought about by these relatively simple techniques of talking and communicating.

The emotional contact that is made between you and your friend or friends underlines many of the most important aspects of your life. The closer you are to someone, the more meaning you will both see in your life and the way you lead it. Many patients have said that being diagnosed with cancer had some unexpected benefits. For some people, a crisis or a challenge can help them sort out what really matters in their lives. It may help you to decide who is a real friend and who is not, who really matters and who is just an acquaintance.

Of course everyone who has cancer would much prefer not to have it, or to be cured of it. Often that can be achieved, but even if it cannot, the contact between you and your friends can be an extraordinary and wonderful proof of the value of human companionship. Serious illness may threaten a life, but it does not rob that life of meaning.

Support on the web

If you are an internet user, you may want to join an internet support group or chatroom. There are a number of online groups for various cancers. These are easy to join and you can ‘talk’ to other people in real time. If you prefer, you can stay anonymous and just read other people’s emails or posts. This can be very supportive, as you can find that other people have similar thoughts, emotions and experiences.

- Visit the online Message Board of the Irish Cancer Society at www.cancer.ie
- Visit the healthtalkonline forum at www.healthtalkonline.org
- Visit Cancer Chat of Cancer Research UK at www.cancerresearchuk.org

Support resources

Irish Cancer Society services

The Irish Cancer Society funds a range of cancer support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support services
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The National Cancer Helpline 1800 200 700 is a freephone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website www.cancer.ie provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie
- Message Board is a discussion space on our website (www.cancer.ie) to share your stories, ideas and advice with others.
- The CancerChat service is a live chatroom with a link to a Cancer Information Service nurse.
- The walk-in caller service allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on Facebook and follow us on Twitter (@IrishCancerSoc).
Who can ever understand? Talking about your cancer

Daffodil Centres
Daffodil Centres are located in a number of Irish hospitals. These have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support services
The Irish Cancer Society funds a range of services set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 36 for more details.

Survivors Supporting Survivors
Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides peer support to people who have been diagnosed with cancer. All of the volunteers have had a cancer diagnosis and have been carefully selected and trained to give you support, practical information and reassurance when you need it most. You can speak to someone who really knows what you are going through. If you would like to make contact with a volunteer, please call the National Cancer Helpline on 1800 200 700.

Counselling
Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the helpline 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing
The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Oncology liaison nurses
The Society funds some oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer information booklets and factsheets
Our booklets provide information on all aspects of cancer and its treatment, while our factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. The booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from www.cancer.ie or picked up at a Daffodil Centre.

Financial support
A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society may be able to provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid.
Travel2Care: Travel2Care can help with your travel costs if you have genuine financial hardship due to travelling over 50 kilometres to a rapid access diagnostic clinic for tests or to a designated cancer centre or approved satellite centre for cancer treatment. The scheme is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. Travel2Care can help with some of the costs of public transport, such as trains or buses, private transport costs, or petrol expenses.

If this applies to you, contact the medical social work department in your hospital or speak to your cancer care nurse. You can also contact the Irish Cancer Society on (01) 231 6643 / 231 6619 or email: travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your cancer care nurse or contact the Irish Cancer Society at (01) 231 6619.

Care to Drive transport project
Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 to find out if Care to Drive is available in your hospital.

If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700.
Who can ever understand? Talking about your cancer

CARE Cancer Support Centre
14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: caresupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House
Clifdane
5 O’Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: info@corkcancersupport.ie
Website: www.corkcancersupport.ie

Kerry Cancer Support Group
124 Tralee Town House Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupportgroup@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven
5 Haig’s Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.com

Sláinte an Cháir: Clare Cancer Support
Tir Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630 / 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

South Eastern Cancer Foundation
Solas Centre
Williamstown
Waterford
Tel: 051 304 604
Email: info@solascentre.ie
Website: www.solascentre.ie

Ulster support services

Cancer Support and Social Club
Tírnaláighe
Carndonagh
Co Donegal
Tel: 086 602 8993 / 087 763 4596

Coiste Scaoil Saor ó Ailse
C/O Ionad Níomh Padraig
Upper Dore
Bunbeg
Letterkenny
Co Donegal
Tel: 074 953 2949
Email: ionadnpi@eircom.net
Website: www.scailsaor.ie

Crocus: Monaghan Cancer Support Centre
The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965 / 047 62565
Email: crocus.2011@yahoo.com
Who can ever understand? Talking about your cancer

Macmillan Cancer Support (UK)
Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre
Belfast City Hospital Trust
77–81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net
Website: www.cancerni.net

National Cancer Institute (US)
Website: www.nci.nih.gov

Cuan Cancer Social Support and Wellness Group
2nd Floor, Cootehill Credit Union
22–24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

The Forge Cancer Support Service
The Forge Family Resource Centre
Petitgo
Co Donegal
Tel: 071 986 1924
Email: theforgefrc@eircom.net

Living Beyond Cancer
Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477
Email: noreen.rogers@hse.ie

Other support services
Cancer Care West
72 Seamus Quirke Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Cúnamh: Bons Secours Cancer Support Group
Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group
Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

Killybegs Cancer Support Group
Killeen
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Newbridge Cancer Support Group
Tel: 083 360 9898
Email: newbridgecancerhealinghelp@gmail.com

Solace: Donegal Cancer Support Centre
St Joseph’s Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

Useful contacts outside Republic of Ireland

Action Cancer
Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society
Website: www.cancer.org

Cancer Focus Northern Ireland
40–44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancercfokusni.org
Website: www.cancercfokusni.org

Cancer Network Buddies
Website: www.cancerbuddiesnetwork.org

Cancer Research UK
Tel: 0044 20 7242 0200
Website: www.cancerresearchuk.org

Healthtalkonline
Website: www.healthtalkonline.org

For other support services in your area, call 1800 200 700.
Helpful books

Free booklets from the Irish Cancer Society:
- Coping with Fatigue
- Understanding the Emotional Effects of Cancer
- Understanding Cancer and Complementary Therapies
- Lost for Words: How to Talk to Someone with Cancer
- Talking to Children about Cancer: A Guide for Parents
- A Time to Care: Caring for Someone Seriously Ill at Home
- Managing the Financial Impact of Cancer
- Journey Journal: Keeping Track of Your Cancer Treatment

The Cancer Survivor’s Companion
Dr Frances Goodhart & Lucy Atkins
Piatkus, 2013
ISBN 0749954906

Cancer at Your Fingertips
Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 1859590365

Cancer Positive: The Role of the Mind in Tackling Cancers
Dr James Colthurst (with Patrick Scrivenor)
ISBN 185479860X

Challenging Cancer: Fighting Back, Taking Control, Finding Options
(2nd edn) Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1859590683

Taking Control of Cancer
Beverley van der Molen
Class Publishing, 2003
ISBN 1859590918

The Secret C: Straight Talking About Cancer
[explaining cancer to children]
(2nd edn) Julie A Stokes
Winston’s Wish, 2009
ISBN 095553928

Understanding Cancer
Gareth Rees
Family Doctor Publications, 2005
ISBN 1898205515

What You Really Need to Know about Cancer
Dr Robert Buckman
Pan, 1997
ISBN 0330336282

For more details on helpful and up-to-date books and their availability, call the National Cancer Helpline 1800 200 700.
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Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please call the National Cancer Helpline 1800 200 700.

Would you like to be a patient reviewer?

If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome.

Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers. If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at reviewers@irishcancer.ie

If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. This includes our patient booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email fundraising@irishcancer.ie.

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.
Tel: 01 231 0500 Email: info@irishcancer.ie Website: www.cancer.ie