

Who Can Ever Understand?

Talking about your cancer

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Who can ever
understand?

Talking about your cancer

This booklet has been produced by 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. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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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.



Reading this booklet

You may want to read all of this booklet, or you may find that certain sections are useful at certain times.

If you do not understand something that has been written, discuss it with your doctor or nurse or another healthcare professional. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 33 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.



Cancer Nurseline Freephone 1800 200 700

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 or more difficult 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.

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.

Cancer is something most of us are unprepared for. Even if you feared that your problem was cancer, the moment when 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 or not being able to work.

Denial

Often the feeling of disbelief is accompanied by a desire to shut out and deny the news. Many people use denial as a 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 feeling overwhelmed. If denial goes on for a long time, perhaps for many weeks or months, it can become 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 may 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 our Cancer Nurseline on 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. Try not to worry about this, as crying can often have a very positive effect on you, because it lets you express and release your emotions in a very safe and open way.

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 make it worse in some way. For example, if you share your worries that the treatment might not work, then it won't.

While of course, there's absolutely no truth to this, it unfortunately 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 makes things easier for you if you can say what you need or want. You'll be surprised how many people will be really glad to hear clearly from you what you need.

>>> It makes things easier for you if you can say what you need or want.

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's usually possible to have him or her with you when your doctor talks to you. That way you both hear the same thing.

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

- **Think about where to talk:** 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's 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 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 a phrase 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. Try not to worry if this happens. 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 to make your friend feel better. 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.

These tips can help to make 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.

Email cancernurseline@irishcancer.ie



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.

Other people's attitudes

You may worry that the people you want to talk to will feel uncomfortable talking about these things. This may well be true. While they may be very keen to help you, they may feel uncomfortable because:

- They have no idea what to say, especially if they haven't had to talk about serious illness before.
- They may feel that they ought to know what to say but don't.
- They may not know where to start or be afraid of upsetting you by saying the wrong thing.
- They may be unsure of what you want, and not know how to ask you.
- They may be worried about how you'll react. For example, they may think they won't know what to do if you cry or get angry.

If your friends or relatives have any or all of these feelings, they may avoid talking about the situation altogether. This booklet has advice about how you can help them to overcome these anxieties. Our booklet, *Lost for Words: How to Talk to Someone with Cancer*, is a booklet on talking about cancer for friends, families and carers. If you would like a copy call our Cancer Nurseline 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 problem shared is a problem halved'.

Talking about something can also teach you how you feel about it. 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.

>>> 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.

Talking about something very emotional or personal can bring the people talking closer together and make the bond between you stronger.

You may not feel like talking about your cancer, and getting on with your normal activities may help you to cope, but try to notice how you are feeling and try not to bottle up your emotions.

How to feel more in control of your situation

If you are diagnosed with cancer, it's quite common to feel that you have little or no control over the disease or its treatment. You may often be presented with one specific treatment plan and feel that you have no real choice. You can always decide not to have any treatment. Sometimes this may be the right decision, but often it isn't. That feeling of 'I haven't got a choice really' is very common and also very unpleasant. It may lead to feelings of powerlessness and resentment.

It may help you to 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, it may help you to cope better.



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.
- Don't be afraid to cry, as it's a really good way of releasing your emotions and opening up communication.
- Saying what you need or want can help you.
- Talking openly can help you through any difficulties that lie ahead.
- Finding out more about cancer and its treatment can help some people 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 soul mate. 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, cousin, counsellor, 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 can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk to a cancer nurse in confidence.

You may find it useful to fill in the table on pages 14/15. It can help you to identify people you know who are most likely to be helpful to you and who are best able to give the sort of support you need at a particular time.

How to use the table: Fill in as many boxes as you can with the names or initials of the appropriate people. Try to include different people in different boxes so that you are not relying on just a few people for everything. The many different sorts of support will increase the chance of you being able to do this. However, you might find that some boxes remain empty and that the same name appears in several boxes.

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. Our cancer nurses can advise you about the different support groups that are available. There's also a list of groups on our website www.cancer.ie/support/support-in-your-area/directory

>>> There are many groups that have been set up to support people with specific cancers.

Some people find support groups very helpful. They may form bonds with other group members that are deeper and more significant than almost anything in their past. But some people get embarrassed or uncomfortable talking about personal issues with strangers. If groups are not your style, don't worry, and remember you can always chat to one of our cancer nurses in confidence at a Daffodil Centre or by calling our Cancer Nurseline on 1800 200 700.

Online support

There are special websites called online communities where people with cancer can write questions, share stories and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community. You can also email one of our cancer nurses if you have any questions or need support at cancernurseline@irishcancer.ie

Type of support	Names (fill in)
People who make me feel good about myself	
People who help me to cheer up	
People who help me to feel positive about my future	
People I can talk to about my physical symptoms	
People I can talk to about my emotions	
People I can talk to when I'm frightened	
People I can cry with	
People I can rely on in a crisis	
People I can be quiet with	
People who are good listeners	
People I can be totally myself with	
People who give me honest criticism when I need it	

Type of support	Names (fill in)
People who help me to see all sides of a situation when I'm making a decision	
People who have the same interests and hobbies as me	
People I can reminisce with	
People I can talk to about spiritual matters	
People who give me sound advice about legal matters	
People who give me sound advice about financial matters	
People who give me sound advice about insurance matters	
People who give me sound advice about employment matters	
People who are frank with me about my illness	
People who give me explanations about my illness and treatment	
People who are coping well with cancer	
People who benefit from talking to me	

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 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 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. You can start off talking about awkward subjects with phrases we all use: 'Can we talk about the way things are at the moment' or something like that. You will then find it's easier to move to more specific areas: 'Look, I'm just not sure how long I'm going to be in hospital this time.' If there is something you've been worrying about a lot, it's perfectly OK to say so: 'For the last few days, I've really been wondering about...' That way you'll ease your way into important topics and your listener will be drawn into focusing on what it is you want or need.
- **Check the person understands what you're saying:** 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: 'Do you see what I mean?', 'Does that make sense to you?' or '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.'

- **Humour:** A lot of people ask whether humour is a good thing to use when talking about tense issues and subjects. Humour can be used to help you cope with a stressful situation. Laughing at something that scares you can help to make it feel less important and threatening.

If humour has been part of the way you have coped with fears and difficulties 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 may feel awkward or you may be caught up in your own feelings and not really hear each other. 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 difficult to sort out.
- 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 admitting that you don’t.
- There are times 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’s 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.

Your friends might be 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.
- **Resolve any conflicts** Conflicts happen quite often. See page 26 for some tips on for resolving conflict.



To sum up

- Talk to the person who makes you feel most comfortable when talking about difficult problems.
- Pick two or three things that you really want to talk about.
- When talking, introduce the subject and be specific.
- Check to see if the person is following what you say. Make sure they understand what you’ve said.
- Acknowledge any strong emotions you may have.
- Describe your feelings rather than display them.
- Tell the person how much they mean to you.
- Acknowledge any uncertainties or regrets.
- Acknowledge other people’s reactions.



You and your partner



You or your partner might find that your emotions are overwhelming and it's 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 to 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. 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's important to talk openly with your partner. This can help you 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 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 happen at a time when you most need to be reassured and cuddled. If that happens, calmly 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 can make a great deal of difference. Try not to ignore the subject of sex with your partner, as it may cause resentment and mistrust on both sides. For more information or advice in confidence, call our Cancer Nurseline on 1800 200 700 or visit your local Daffodil Centre. You can also email the nurses at cancernurseline@irishcancer.ie



Talking to your doctors and carers

It's 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 times when you need 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 that you need medication or other help. At other times you may play down the symptoms to appear strong or brave. If possible, try to describe the problems in as honest and factual terms as you can. It's not easy, but if you do that, your doctor or nurse will understand how you really feel. 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 language and expressions, you don't need to. There's nothing wrong with using your own words to describe the problem. In fact, using medical terms that you may not fully understand could cause difficulties by giving the wrong message to your doctors. If the doctor, nurse or other healthcare professional uses terms that you don't understand, tell them so immediately and ask them to explain what they mean. If you don't ask they will probably assume that you understand.
- **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'). Remember, though, that your doctors and nurses have likely seen these problems before and will be quite comfortable for you to talk about anything that is troubling you.

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.

»»» As well as a written list, it's a good idea to take a friend or relative with you.

Finding out more about your illness

Try to think of the most important questions before the discussion with your doctor. 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. They may remember things the doctor said that you forgot. He or she can also help you to remember the questions you wanted to ask.

You may find it difficult to understand and remember medical information. It can be even more difficult when it's serious and when it's about you.

Nobody will mind you writing things down or making a list of your questions. You could also ask the doctor's permission to record his/her conversation with you, though some may be reluctant to allow this. Ask your doctor or nurse to write information down so that you can go over it again later. The Irish Cancer Society has a range of booklets that discuss all aspects of cancer, its treatment and how to cope. Some are listed on page 36. Having a booklet means you can get information in your own time, as you need it. Call our Cancer Nurseline or visit a Daffodil Centre for free copies of our booklets. You can also read them or order copies on our website, www.cancer.ie

If you don't understand, ask again

Sometimes you might hear bad news quite unexpectedly or get a lot of medical information when you are not expecting it. If you're not clear about what someone has told you, ask him or her to explain again. 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. If you have any worries or unanswered questions between appointments, you can talk to a cancer nurse in confidence by calling our Cancer Nurseline on 1800 200 700 or by visiting a Daffodil Centre. You can also email the nurses on cancernurseline@irishcancer.ie

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

Uncertainty

Being worried about your future is a normal way to feel. Finding out more about your illness and treatment may make you feel less anxious.

Sometimes it can be hard for doctors to predict what will happen or how successful your treatment will be. This can make you feel anxious. You may also worry that the doctor knows what's going to happen but won't tell you.

Doctors may not always give you full information unless you ask, because not everyone wants a lot of information. If you ask, though, your doctor should tell you as much as he or she can.

It can be hard to accept uncertainty, especially when it's about something as serious as your health. 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 may help you to focus on the next step and help you to feel less anxious.

Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). It's often difficult to be certain about how a disease will progress. Doctors base their information on what 'usually' happens. What happens to you might be quite different from what the doctor expects.

If you decide you want information on your prognosis:

- **Think about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** He or she knows your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other helpful services.

If you're 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, but may react to purely negative 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

- 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 or don't have all the information you want, ask again.

Hints for resolving conflict

If you have been diagnosed with cancer, you and the people around you may be stressed, angry, worried or nervous. When emotions are high, it can lead to conflict. It might be conflict with your friends or family or with some member of your healthcare team.

You may have genuine problems and complaints, which can usually be sorted out in time. But some patients find themselves getting almost uncontrollably angry with friends or the healthcare team. It's natural to lash out at the people closest to you when you are trying to manage difficult emotions. And you may associate your anger or sadness about having cancer with the hospital team. For example, you may find it difficult to focus your anger on the cancer itself so you feel angry with the person who tells you. Or you may feel resentful that you have cancer while the people around you don't.

While it's normal to feel this way, it can leave you and the people around you hurt and isolated. Try to recognise the feelings behind the conflict and find a way to resolve things in a positive way.

Cancer Nurseline Freephone 1800 200 700



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 can't 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 cancer can be very difficult. We all think of childhood as a time of innocence and freedom from pain or guilt. We 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 feel the 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.

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

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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a copy. You can also download it from www.cancer.ie



To sum up

- When telling children about cancer, get some advice 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 resources

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Medicines
- Visits to hospital
- Appliances, like wigs
- Overnight stays in hospital

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Partial Capacity Benefit, Carer's Allowance, Carer's Benefit and Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 34 for more details of our Volunteer Driving Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for



- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

For a free copy of the booklet, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The booklet is also available on our website: www.cancer.ie

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- | | |
|------------------------|---|
| ■ Cancer Nurseline | ■ Patient travel and financial support services |
| ■ Daffodil Centres | ■ Night nursing |
| ■ Survivor Support | ■ Publications and website information |
| ■ Support in your area | |

- **Our Cancer Nurseline Freephone 1800 200 700.** Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

- **Our Daffodil Centres.** Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- **Our Survivor Support.** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide

emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 35 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
 - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
 - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- **Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.



If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

Email cancernurseline@irishcancer.ie

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: **www.cancer.ie**.

You may find the following helpful:

- *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. A Guide for Patients and their Families.*



Notes





Notes



Notes



Join the Irish Cancer Society team



If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments and suggestions.
Please email reviewers@irishcancer.ie

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

Cancer Nurseline Freephone 1800 200 700

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