

# Lost for Words

How to talk to someone with cancer

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## WE ARE MACMILLAN. CANCER SUPPORT

The Irish Cancer Society thanks Macmillan Cancer Support for permission to adapt the text of their booklet *Lost for Words: How to Talk to Someone with Cancer* and acknowledges the contribution of the original authors of the booklet. 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.

ORIGINAL TEXT Dr Robert Buckman, Medical Oncologist and Lecturer in Communication

#### CONTENT ADVISER

Tony Carlin, Principal Medical Social Worker

#### EDITOR

Tara Droog

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## Introduction

This booklet has been written to help you support someone close to you who has cancer. Many people find it difficult to talk to someone who has cancer, or to know how to give support. This booklet gives advice and tips that might help you to feel more confident about supporting your friend or relative. If reading this book helps you, why not pass it on to family and friends who might find it helpful too.

#### 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 27 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.



# How to talk to someone with cancer

## You're not alone

I bumped into John in the lobby of the hospital. I was a student and my family and John's family had been friends for as long as I could remember. Now John's mother had been admitted to hospital and was found to have cancer of the kidney. John was sitting downstairs in the lobby looking very upset. I asked him whether he was on his way up to see his mother. 'I've been sitting here for half an hour,' he said. 'I want to go and see her, but I'm stuck. I don't know what to say.'

That story explains how most of us feel when someone we love has been told that they have cancer. It is important to know that what you are feeling is normal and that you are not alone.

We may feel stuck and helpless, maybe lost for words, when a friend of ours receives some bad news. We may feel that we don't know what to say or that there are things we should be saying which will make it easier for the person with cancer – if only we knew what they were. We also might be afraid of saying something that will add to our friend or relative's upset.

There are ways to overcome these feelings so that you can give practical and useful support. To put it simply, if you want to help but don't know how, then this booklet is for you.

There are no magic formulas, phrases or approaches which are 'the right thing' to say or do during this difficult time. There isn't a 'right' set of words or attitudes that will always help, that everybody else knows and you don't. If you really want to help your friend or relative then your desire to help is the most important thing.

>>> There is no 'right' thing to say. What is most important is your desire to help.

The second point is that most of us – like John in the story – feel that we don't know what to say. But the important bit is not what we say – it's that you are there, and how you listen. In some respects, the single most important thing that you can do for your friend or relative with cancer is to listen. Once you've learned the few simple rules of good listening, then you'll already be of great help and support – and everything will improve from there. The secret is to start – and starting means learning how to be a good listener, and that begins with understanding why listening and talking are so valuable.

#### The word 'cancer'

Before we move on to the specific details of listening and supporting, we should recognise the particular problems created by the word 'cancer'. For most people, when they are told they have cancer, the diagnosis seems to bring a unique sense of fear. The patient's relatives and friends, and sometimes the doctors and nurses looking after the patient as well, often have similar feelings.

The good news is that new treatments are more effective at curing and controlling cancer than ever. Many people with cancer can be cured and many people live with cancer for a long time. Even so, the word 'cancer' appears to have a more devastating effect than most other diagnoses, and this can make it harder to talk about. Check that your relative or friend is comfortable using the word cancer. Sometimes people find it difficult to say or hear the word out loud.



# Why talk? Why listen?

So you want to help, but you're not sure what to do for the best. Perhaps the most logical place to start is to look at what you're trying to achieve. There are basically three very good reasons for talking and listening and they are:

#### 1 Talking to each other is the best way to communicate

There are, of course, many different ways of communicating – kissing, touching, laughing, frowning, even 'not talking'. However, talking is the most efficient and the most specific way that you have of communicating. It is by far the best way of making any communication clear between you and another person. Other methods of communication are very important, but for them to be of use you usually have to talk first.

#### 2 Simply talking about distress can help relieve it

There are many things that a conversation can achieve and there are many reasons for us to talk. There are obvious ones – such as telling the children not to touch the hot stove, telling a joke, asking about the football results and so on. But there are also less obvious reasons for talking, and one of these is the simple human desire to be listened to.

Often, people talk in order to get what is bothering them off their chest, and to be heard, particularly when things go wrong. This serves a useful function. It can release a bit of stress, and human beings can only stand so much stress. You can provide relief for a sick person by listening and by simply allowing them to talk. That in turn means that you can help your friend or relative even if you don't have all the answers.

# >>> You can help your friend even if you don't have all the answers.

In fact, 'good listening' is known to be helpful in itself. A research study took place in the United States in which a number of people were taught the simple techniques of good listening. Volunteer patients then came to see them to talk about their problems. The listeners in this study were not allowed to say or do anything at all. They just nodded and said 'I see' or 'tell me more'. They were not allowed to ask questions, or say anything at all about the problems that the patients described. At the end of the hour, almost all of the patients thought they had got very good help and support - and some of them rang the 'therapists' to ask if they could see them again, and to thank them for the therapy.

It is always worth remembering that you don't have to have the answers. Just listening to the questions can be just as helpful.

#### **3** Try not to shut out your thoughts

It can be hard to know what to say when someone close to you is diagnosed with cancer. It may seem best to pretend that everything is fine and carry on as normal. You may not want to add to the person's worry by seeming afraid or by saying the wrong thing.

Research from studies done by psychologists talking to people with terminal illness has shown that conversations between the people who were ill and their relatives and friends did not create new fears and anxieties. In fact the opposite was true; not talking about a fear makes it bigger.

People who have nobody to talk to are more likely to be anxious and depressed. Research has also shown that when people are seriously ill one of their biggest problems is that other people won't talk to them. Feelings of isolation can add a great deal to their burden. Often, if a major anxiety is occupying someone's mind, the person may find it difficult to talk about anything else at all.

#### >>> People who have nobody to talk to can become anxious and depressed.

One of the reasons that people bottle up their feelings is shame. Many people are ashamed of some of their feelings – particularly of their fears and anxieties. They are afraid of something but feel that they are not 'supposed' to be, and so they become ashamed of themselves.

One of the greatest services you can do for your friend or relative is to listen to their fears and stay close when you've heard them. By not backing away, you show that you accept and understand them. This will, in itself, help to reduce the fear and the shame, and help the person get their sense of perspective back.

So for all these reasons, you have everything to gain and nothing to lose by trying to talk to, and listen to, someone who has just been told that they have cancer. Starting a conversation in these circumstances often feels very awkward and embarrassing, but there are ways to overcome obstacles to conversation.

# **Obstacles to talking**

There are six major kinds of obstacles to free communication between you and the person who is ill. They are:



- 1 The person who is ill wants to talk but you don't.
- 2 The person who is ill doesn't want to talk but you do.
- 3 The person who is ill wants to talk, but feels they ought not to.
- 4 You don't know how to encourage the person with cancer to talk.
- 5 The person who is ill appears not to want to talk, but really needs to.
- 6 You do not know what is best and don't want to say anything that may make things worse.

These seem like major barriers, but don't let that alarm you. There are ways of making yourself available for listening and talking without overwhelming your friend or relative. You can work out whether they want to talk by asking one or two simple questions. For example: How are you? Did you get a shock when you heard the news? Is there anything I can do?



Cancer Nurseline Freephone 1800 200 700

#### > Talking about bad news



You might find yourself saying nothing at all because you don't know what to say. As a result, you might withhold information from a family member or your relative or friend with cancer. Try to be as open and honest as you can, even when dealing with a difficult subject like cancer.

Some families think it is better not to discuss a diagnosis or a poor prognosis. (A prognosis is information about how a disease is likely to progress.) But not talking about an illness can lead to confusion and distress. Remember it is normal if your relative or friend gets upset if told bad news. Discussing bad news does not cause more distress. **The news itself will make them upset, not you talking about it.** In fact, not talking about a problem can make it seem bigger.

# How to be a good listener

Basically, good listening can be divided into two parts – the physical part and the mental part. A lot of the most awkward gaps in communication are caused by not knowing a few simple rules that encourage free conversation.

#### 1 Get the setting right

This is important, and it's worth getting the details correct at the start. Get comfortable, sit down, try and look relaxed even if you don't feel it. Try to signal the fact that you are there to spend some time (for instance, take your coat off!).

Keep your eyes on the same level as the person you're talking to, which almost always means sitting down. As a general rule, if your friend is in hospital and chairs are unavailable or too low, sitting on the bed is better than standing.

Try and keep the atmosphere as private as possible. Don't try to talk in a corridor, or on a staircase. That may seem obvious, but often conversations go wrong because of these simple things.

>>> Try and keep the atmosphere as private as possible.

Generally there should be a comfortable amount of space between you and the person you are talking to. A longer distance makes conversation feel awkward and formal, and a shorter distance can make the other person feel hemmed in, particularly if they are in bed and so cannot back away. Try to make sure there are no desks or bedside tables between you. Again, that may not be easy, but if you say something, it can help you both. For example, 'It's not very easy to talk across this table, can I move it aside for a moment?'

Keep looking at the person while they are talking and while you talk. Eye contact is what tells the other person that the conversation is solely between the two of you. If, during a painful moment, you can't look directly at each other, at least stay close and hold the person's hand or touch them if you can.

>>> Keep looking at the person while they are talking and while you talk.

#### 2 Find out if the person who is ill wants to talk

It may be that they are simply not in the mood to talk to you that day. It's also quite possible that they may want to talk about quite ordinary 'little' things, such as television programmes or sports events or other everyday subjects. If that is the case, go with the flow.

Even if you are mentally prepared for a major conversation with your friend, try not to be offended if they do not want that at this particular moment. You may still do them a valuable service by simply listening and being there while they talk about everyday matters – or perhaps don't talk at all. If you're not sure what they want, you can always ask 'Do you feel like talking?' This is always better than launching into a deep conversation (such as 'Tell me about your feelings') if they are tired or have just been talking to someone else.

#### 3 Listen and show you're listening

When your friend or relative is talking, try to do two things. Firstly, listen to them instead of thinking of what you're going to say next, and secondly, show that you're listening. To listen properly, you must be

thinking about what your friend is saying. You should not be rehearsing your reply. Doing that means you are anticipating what you think they are about to say, and not listening to what they are actually saying.

#### >>> To listen properly, you must focus on what your friend is saying.

Try not to interrupt. Don't talk while they are talking but wait for them to stop speaking before you start. If they interrupt you while you're saying something with a 'but' or 'I thought' or something similar, you should stop and let them continue.

#### 4 Encourage the person with cancer to talk

Good listening doesn't mean just sitting there while another person talks. You can actually help the person who is ill talk about what's on their mind by encouraging them. Simple things work very well. Try nodding, or saying things like 'Yes', 'I see' or 'What happened next?' These all sound simple, but at times of great stress it's the simple things that help things along.

>>> You can help the person who is ill talk about what's on their mind by encouraging them.

You can also show that you're hearing, and listening, by repeating two or three words from the person's last sentence. This really does help the talker to feel that their words are being taken on board. You can also repeat back to the talker what you've heard. This is partly to check that you've got it right, and partly to show that you're listening and trying to understand. You can say things like 'So you mean that...' or 'If I've got that right, you feel...'

#### 5 Don't forget silence and non-verbal communication

If someone stops talking, it usually means that they are thinking about something painful or sensitive. Wait with them for a moment and then ask them what they were thinking about. You can hold their hand or touch them if you feel it is appropriate. Don't rush it, even if the silence does seem to last for a long time. Try to be comfortable with silence. Another point about silences is that sometimes you may think 'I don't know what to say'. This may be because there isn't anything to say. If that's the case, do not be afraid to say nothing and just stay close. At times like this, just being there, a touch, or an arm round a shoulder can be of greater value than anything you say.

#### >>> Don't be afraid to say nothing and just stay close.

Sometimes, non-verbal communication, such as the way a person holds their body or how they move, tells you much more about them than you expect. Here's one example from a doctor's experience:

Recently, I was looking after a middle-aged woman called Mary who seemed at first to be very angry and didn't want to talk.

I tried encouraging her to talk but without much success. During one interview, while I was talking, I put my hand out to hers – rather tentatively because I wasn't sure it was the right thing. To my surprise, she seized it, held it tightly and wouldn't let go. The atmosphere changed suddenly and she instantly started talking about her fears of further surgery and of being abandoned by her family.

The message with non-verbal contact is 'Try it and see'. If, for example, Mary had not responded so positively, I would have been able to take my hand away and neither of us would have suffered any setback as a result of it.

#### 6 Don't be afraid of describing your own feelings

You're allowed to say things like 'I find this difficult to talk about' or 'I'm not very good at talking about...' or even 'I don't know what to say'.

An acknowledgement of the feelings that are usually quite obvious to both of you (even if those feelings are yours rather than your friend's) can dramatically improve the atmosphere. It usually reduces the feelings of awkwardness or embarrassment that we all feel from time to time. It's remarkable how much this can improve communication.

#### 7 Make sure you haven't misunderstood

If you are sure you understand what your friend means, you can say so. Responses such as 'You sound very low' or 'I imagine that must have made you very angry' are replies that tell them that you have picked up the emotions they have been talking about or showing. But if you're not sure what they mean, then ask: 'What did that feel like?', 'What do you think of it?', 'How do you feel now?' Misunderstandings can arise if you make assumptions and are wrong. Something like 'Help me understand what you mean a bit more' is quite useful.

#### 8 Don't change the subject

If your friend wants to talk about how rotten they feel, let them. It may be distressing for you to hear some of the things they are saying, but if you can manage it then stay with them while they talk. If you find it too uncomfortable, and think you just can't handle the conversation at that moment, then you should say so. Offer to try to discuss it again later. You can even say very simple and obvious things like 'This is making me feel very uncomfortable at the moment – can we come back to it later?' Do not change the subject without acknowledging the fact that your friend has raised it.

>>> If your friend wants to talk about how rotten they feel, let them.

#### 9 Don't give advice early

Ideally, you should not give advice unless it's asked for. However, this isn't an ideal world and quite often you might find yourself giving advice when you haven't quite been asked. Try not to give advice early in the conversation, because it stops dialogue. If you're bursting to give advice it's often easier to use phrases like: 'Have you thought about trying...' or 'A friend of mine once tried...' Those are both less bold than 'If I were you I'd...', which makes your friend think (or even say) 'but you're not me', which really is a conversation-stopper.

>>> You should not give advice unless it's asked for.

#### 10 Respond to humour

Many people imagine that there cannot possibly be anything to laugh about if you are seriously ill or dying. However, they are missing an extremely important point about humour. Humour serves an important function in our way of coping with major threats and fears. It allows us to get rid of intense feelings and to get things in perspective. Humour is one of the ways human beings deal with things that seem too difficult to deal with.

Think for a moment about the commonest subjects of jokes: mothersin-law, fear of flying, hospitals and doctors, sex and so on. None of those subjects are funny in themselves. An argument with a motherin-law, for instance, can be very distressing but arguing with the mother-in-law has been an easy laugh for the stand-up comedian for centuries. We often laugh most easily at the things we cope with least easily. We laugh at things to get them in perspective or to reduce them in size and threat.

# >>> We often laugh most easily at the things we cope with least easily.

One woman in her early forties needed to have a tube (catheter) in her bladder as part of her treatment. While she was in hospital she carried the drainage bag like a handbag and used to say loudly that it was a shame nobody made a drainage bag that matched her gloves. Out of context that may sound grim, but for this particular woman it was a method of dealing with a very distressing problem. It showed her bravery and desire to rise above her physical problems. For her it was very much in character.

Laughter can help people to get a different handle on their situation. If your friend or relative wants to use humour – even humour that to an outsider might seem grim – you should certainly go along with it. It may be helping them to cope. This does not mean that you should try and cheer them up with a supply of jokes. You can best help your friend or relative by responding sensitively to their humour, rather than trying to set the mood with your own.



### To sum up

- The aim of sensitive listening is to understand as completely as you can what the other person is feeling.
- You can never achieve complete understanding but the closer you get, the better the communication between you and your friend will be.
- Your friend may find it difficult if you say 'I understand how you feel', because the truth is that you cannot completely understand. However, the more you try to understand your friend's feelings, the more support you are giving.



# Understanding what your friend is facing

It may help you to try and understand something of what your friend is facing, and to see the fears that he or she may have. There are different aspects to any illness that can cause fear, and when the diagnosis is cancer, those fears may be greater. To help you encourage your friend or relative to talk about their feelings, here are some common worries:

#### The threat to health

When we are in good health, the threat of serious illness seems far away, and very few of us think about it before it happens. When it happens to us we are shocked and confused, and often angry or even bitter.

#### Uncertainty

A state of uncertainty may be even harder to deal with than either good news or bad news. Similarly, 'not knowing where you are and not knowing what to prepare for' is a very painful state in itself. You can help your friend a lot by simply acknowledging the unpleasantness of uncertainty.

#### Not knowing about tests and treatments

Tests and treatment for cancer can often involve many different professionals, each with their own expertise. Very often the person with the cancer may feel unskilled and foolish. You can help by reinforcing the fact that nobody is 'supposed' to know all the details in advance.

#### **Physical symptoms**

This booklet focuses particularly on psychological problems, but of course physical symptoms are very important too. Your friend or relative may, at various stages in the treatment, have a variety of symptoms (including pain or nausea for example). Allow them opportunities to talk about these symptoms.

#### Visible signs of treatment or disease

The same is true of outward signs of cancer or its treatment, for example, hair loss due to chemotherapy or radiotherapy (to the head). You can help your friend feel less self-conscious, perhaps by helping them to choose a wig or scarf.

#### **Social isolation**

Most serious diseases, and particularly cancer, seem to put up an invisible barrier between the person who is ill and the rest of society. Visiting them and encouraging mutual friends to do the same is a good way of helping reduce that barrier.

#### The threat of death

Many people are cured of cancer, but the threat of cancer coming back and possibly dying from cancer is always there. It may continue to haunt people who are cured. You can't get rid of that fear, but you can allow your friend to talk about it. By listening, you can reduce the impact and the pain of that threat. As always, you don't have to have all the answers. Simply listening to the questions can help a lot.

# >>> You don't have to have all the answers. Listening to the questions can help a lot.

Naturally this is only a partial list, but it will at least give you a glimpse of what may be going through your friend or relative's mind. All of these fears and concerns are normal and natural – what is 'wrong' or 'unnatural' is not having anybody to talk to about them. That's why you can be so important to your friend or relative.

# How to help – a practical checklist

One of the most common problems in trying to help a person with cancer is that friends and relatives simply don't know where to start. They want to help, but don't know what to do first. In this section we outline a logical plan that you can follow. It will help you to decide where your help is most useful and where you can start.

#### Make your offer

You must first find out whether or not your help is wanted. If it is, make your offer. Be clear about what you are offering to do (not just 'let me know what I can do'). You should say clearly that you will check back to see if there are things you can help with. Obviously, if you are the parent of a sick child or the spouse or partner of someone with cancer you don't need to ask. However, in most circumstances, it is important to know whether you're in the right position to help.

Sometimes a distant acquaintance or colleague is more welcome than a close relative, so don't be upset if your friend or relative does not seem to want your support. Don't take it personally. If you are still keen to help, see if there are other family members who you can help. You might be able to help indirectly by doing extra school runs or shopping for elderly relatives.

After you have offered to help, don't wait to be called, but check back with some suggestions: Do you need a lift anywhere the next few days? Shall I bring over some groceries? Can I come round do some housework?

#### **Become informed**

If you are to be useful to your friend, you will need some information about what the medical situation is, but only enough to make sensible plans. You do not need to know all the details. Just find out enough about the illness so you can better understand your friend's situation. Some people make suggestions to the person with cancer about things they should do or treatments that they should try. This well-meaning advice can often put pressure on the person with the cancer and cause them stress. It is best to offer advice only if the person asks for it and advise them to talk to their doctor about medical matters.

#### Assess the needs

This means finding out the needs of the person who is ill and of the rest of the family. It's hard to be sure what their needs might be, as things may change, but you should try and think about the needs of the person who is ill. These will, of course, be different at different times, depending on the stage of their cancer, and any treatment they may be having or if they have any side-effects or symptoms. If the person has serious physical problems, here are some questions you might ask yourself:

- Who is going to look after them during the day?
- Can they get from the bed to the toilet?
- Can they prepare their own meals?
- Do they need medicines that they cannot take without help?

It's also important to think of other family members.

- Are there children who need to be taken to and from school?
- Is the partner medically fit or are there things they need?
- Is the home suitable for nursing someone with the person's medical condition or are there things that need to be done there?

Any list will be long and almost certainly incomplete, but it is a start. Check your list by going through a day in the life of your friend or relative and thinking what they may need at each stage.

#### Decide what you can do and want to do



- What are you good at?
- Can you cook for your friend? Taking round pre-cooked frozen meals may be welcomed. Can you prepare meals for other family members?
- Are you handy around the house? Could you put up handrails or wheelchair ramps if needed?

- Could you house-sit, so that their partner can visit them in hospital? Could you take the children out for the day to give the couple some time together?
- If you aren't good at any of these things, would you be prepared to pay for, say, a cleaner for a half-day a week to help out?
- Could you get relevant booklets for your friend?
- Can you arrange for them to have a laptop or tablet for reading or watching movies?
- Do they need the furniture rearranged? (For instance, so that the person can sleep on the ground floor because they cannot manage stairs.) If so, could you help them to do it?
- Does their home need to be cleaned and made comfortable for when the person gets out of hospital?

#### Start with small practical things

Look at the list of the things you are prepared to do, and perhaps start off by offering to do a few of them. Offering all of them may overwhelm your friend or relative. Pick some small tasks that are practical that your friend or relative might not be able to do easily. Offering to do a few small tasks and succeeding is far better than promising too much and failing. It may need a little thought and some inside knowledge.

For instance, one person, David, used to get his hair cut every week. It wasn't a big thing, but it was part of his regular routine. When he was in hospital, his friend Peter arranged for the hospital barber to call weekly. It was a nice and thoughtful touch.

#### **Avoid excesses**

Don't give huge gifts that overwhelm and embarrass. Most large gifts spring from a sense of guilt on the part of the donor, and may make the recipient feel guilty. Similarly, your offers of help need to be modest and suited to your relative or friend and their family.

#### Listen

Time is a present you can always give. You can refer to page 10 for some guidelines on sensitive listening. Try to spend regular time with your friend. It's better to try to spend 10 or 15 minutes once a day or every 2 days, if you can, rather than 2 hours once a month. Be reliable and be there for your friend.

#### Being with your friend at the clinic

People with cancer are often encouraged to take someone with them when they see the doctor for the first time or for follow-up visits. If your friend wants you to be there, you could offer to help them prepare for the appointment. The following suggestions may be useful:

- Ask them to think about the questions that they want answered.
- Help them to organise and write out their questions.
- Suggest that they put their two or three most important questions at the top of the list.



During the appointment don't try and speak on behalf of your friend or relative, unless they ask you to. Remember it's their questions that are important. Listen very carefully to the information and answers the doctor gives. It can also be helpful to take notes. With the doctor's permission, you could also record what they say.

Your friend or relative may find it difficult to take in all the information they are given, especially if they receive bad news. Afterwards you can help by reminding them of the information and the answers the doctor gave, as you are likely to remember things they have forgotten. Again, listening and being there to support your friend may be the most important help you can give. You may find that you feel upset by the news given. Don't try and hide your feelings but remember you are the person who is giving support. Later you may find it helpful to talk to someone close to you. You may also find it helpful to go to a support group. Many have services for friends and family members. There is more information on support groups on page 29. You can also visit a Daffodil Centre or call our Cancer Nurseline on 1800 200 700 to talk to a cancer nurse in confidence. >>> Listening and being there to support your friend may be the most important help you can give.

#### Involve other people

Be fair to yourself and recognise your own limitations. Every helper and supporter wants to do his or her best. You may be very tempted to undertake heroic tasks, out of a sense of anger and rage against your friend's situation and the injustice of it. But if you attempt to make heroic gestures and then fail, you will become part of the problem instead of helping with the solution. You owe it to yourself and to your friend to undertake reasonable tasks so that you succeed. This means you should always be realistic about what you can do. You can always get other people to help with the things you cannot do.

Going through this list in your mind is valuable because it offers a genuinely practical approach to something that is probably unfamiliar to you, and because it eases your own sense of pain at not knowing where to start. Whatever plans you make will certainly change with time as conditions change. Be prepared to be flexible and learn as you go along.

# Conclusion

Of course it's very frightening when someone close to you is told that they have cancer. By listening to your friend's worries, being aware of their feelings and by helping them to find the right information and understand it, you can be a vital part of your friend's support system. And that is one of the most important things that one human being can do for another.

Email cancernurseline@irishcancer.ie



# 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)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

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 Benefitand 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 28 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 see our booklet, Managing the Financial Impact of Cancer – A Guide for Patients and their Families at

www.cancer.ie/publications. This explains:

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



# 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 Daffodil Centres
- Patient travel and financial support services
- Survivor Support
- Night nursing
- Support in your area
- Publications and website information
- 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 29 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 sideeffects, 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:

- Understanding the Emotional Effects of Cancer
- Who Can Ever Understand? Talking About Your Cancer
- Coping with Fatigue
- Understanding Cancer and Complementary Therapies
- Talking to Children about Cancer: A Guide for Parents
- A Time to Care: Caring for Someone Seriously Ill at Home





### 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

Irish Cancer Society 43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700 Email: cancernurseline@irishcancer.ie

Find us on Facebook Follow us on Twitter: @lrishCancerSoc



