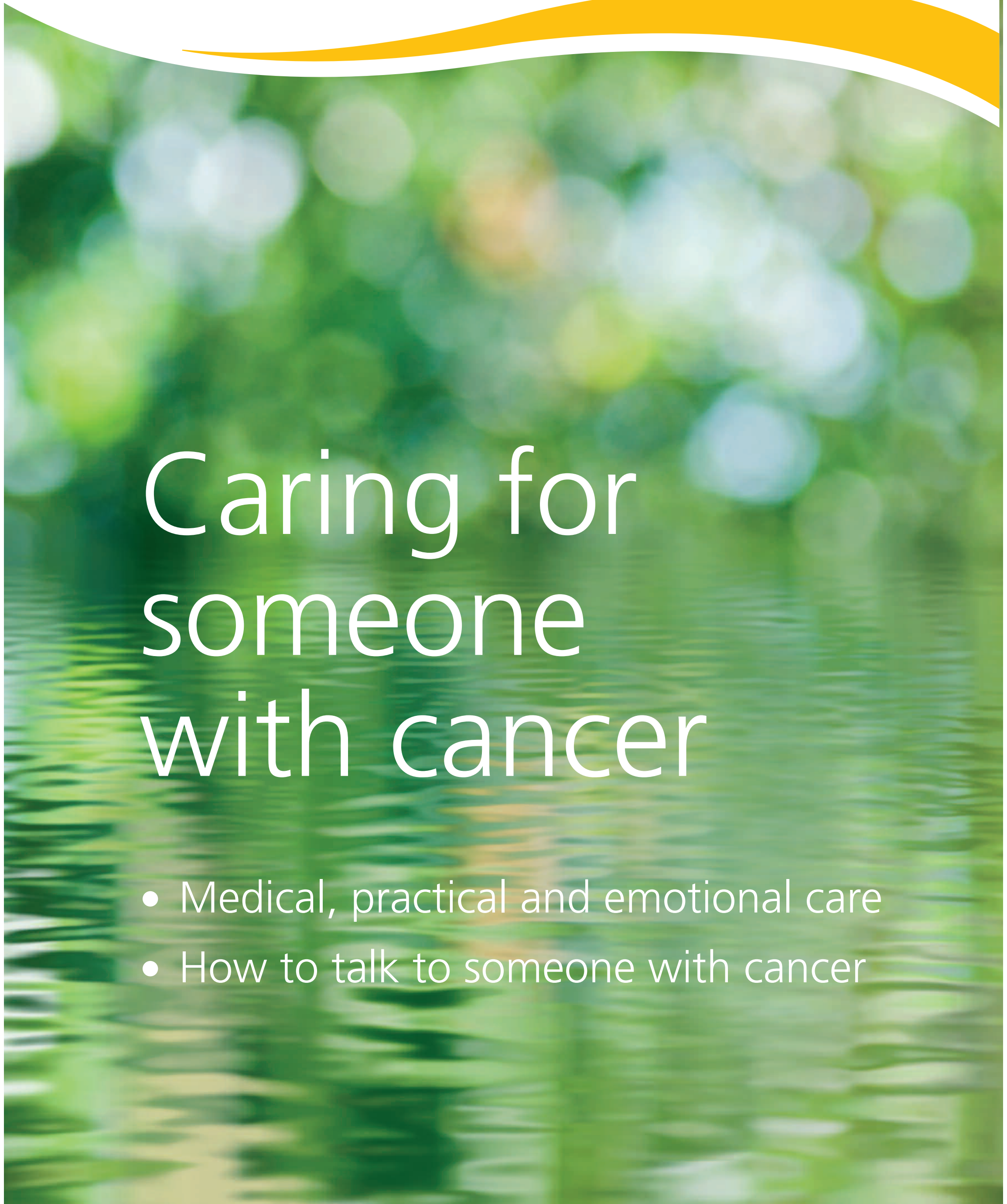
Irish
Cancer
Society



Caring for someone with cancer

- Medical, practical and emotional care
- How to talk to someone with cancer

Caring for someone with cancer

This booklet has information on:

- Medical, practical and emotional care
- How to talk to someone with cancer
- Looking after yourself
- Carers' entitlements
- Supports for you and your loved one

> 'It made me happy caring for him after all he did for me. I got to spend precious time with Dad which I will remember forever.'

Useful numbers

Specialist nurse

Family doctor (GP)

Consultant

Medical social worker

Community/Public Health Nurse

Homecare team

Emergency number

Contents

We're here for you

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses in confidence.

Ways to get in touch

Call our Support Line on **Freephone 1800 200 700**

- Drop into a Daffodil Centre
- email us: **supportline@irishcancer.ie**

See page 106 for more about our services and how to find your nearest Daffodil Centre. You can also visit our website at **www.cancer.ie** for more information and to join our online community.

> 'I'm so glad I could be my mam's carer. I wouldn't have it any other way. She cared for me for long enough. I wanted to give back.'

Being a carer

What does a carer do?

A carer is a person who helps a patient with cancer. This can mean providing nursing and personal care at home, supporting them emotionally or dealing with practical matters like housework or managing money. A carer could be a family member, partner, friend or neighbour.

A carer is often the person who knows the most about the patient and cares very deeply about them. A carer is also often the link between the patient and all the other people caring for them.

How does it feel to be a carer?

Caring can be a special time that brings you and your loved ones closer together. Some people get a lot of satisfaction from helping their loved one when they are sick.

The caring role can also be challenging, both physically and emotionally. At times you may feel overwhelmed by caring. If other people offer help, accept it rather than trying to do it all yourself.

Young carers

Life may be very different if your parent has been diagnosed with cancer. Being a carer can feel overwhelming, with all the new information you have to learn. You may feel you have less in common with your friends. This may make you feel isolated and frustrated. You may have a lot of strong feelings and emotions. This is not uncommon and you are not alone.

Talking about how you're feeling and getting advice, information and support, and making contact with other young people going through a similar experience can help you to feel better and cope better.

You can talk to one of our cancer nurses in confidence if you have any worries or questions, or if you need help getting support. You can call us on Freephone 1800 200 700, or email us on supportline@irishcancer.ie. You can also look at our webpage **www.cancer.ie/youngcarers**

Advice for carers

- **Get organised.** Try to divide up the caring and other practical and financial jobs so that everyone can help and you are supported from the start.
- **Accept help.** If people don't offer help, don't be afraid to ask. Suggest specific jobs that others can do and let them know how much you appreciate their help.
- **Look after yourself.** Don't forget to take care of your own physical and emotional health.
- **Be kind to yourself.** Don't expect too much from yourself. Caring can be hard. You are doing a wonderful thing by taking on this role. You can only do your best.
- **Take time out – and don't feel guilty about it!** It's good for you and the person you are caring for if you get regular breaks from the demands of being a carer.
- **Connect with other carers.** Join a support group or online community. It can be really helpful to talk to other people in a similar situation.

Support for carers

Your GP, local cancer support centres, carers' organisations such as Family Carers Ireland and The Care Alliance, counsellors, online communities and cancer support groups, as well as the Irish Cancer Society cancer nurses are all there to help you and your family and friends. See page 75 for more about support.

My caring story

‘I cared for my dad who had non-small-cell lung cancer. Dad didn’t really want others apart from immediate family helping out with care, so we managed it ourselves mostly. My mother wanted to do a lot of it herself. She refused home help and we respected her decision, although we may not have all agreed with it.

Two aunts cooked dinners every week for us, which was great. Also neighbours used to just drop off food and not stay. You remember those people and what they did to help in their own way.

For my dad, he just wanted to watch TV, chat a bit and us to be there to help him when needed. No fussing needed. I took time off work to be there as much as I could.

I found it hard talking to him about his illness as he didn’t really want to discuss it. I also found it hard dealing with all the visitors and tried to put some rules on visits, but my mother wanted everyone to call in. There were lots of small arguments and sometimes it got to me.

Being a carer was very tiring on the body. I slept in the room with him a lot of the time so my sleep was broken. Your life is changed totally while caring and I think others don’t really get it unless they have been through it. I met friends for coffee once or twice a week just to talk about it with someone other than family. That really helped me.

It made me happy caring for him after all he did for me. I got to spend precious time with Dad which I will remember forever.’

Types of care

As a carer you will probably provide different types of care at different times:

- **Medical care:** For example, giving medications and nursing or personal care (see page 13)
- **Practical care:** For example, giving lifts, shopping, cooking and cleaning (see page 23)
- **Emotional care:** Providing a listening ear, sympathy and support (see page 31)

It can be hard to manage all the different types of care, especially if you don’t feel confident about taking on these responsibilities. For example, a lot of carers feel nervous about providing medical care. However, you may surprise yourself with how much you are able to do.

Money matters

As a carer you may need to take care of financial matters like dealing with health insurance or finding out about benefits. See page 103.

Medical care

Medical care

A carer is an important part of a person's healthcare team. Carers often have to keep track of tests, treatments and medication, make sure their loved one attends appointments and communicate with doctors and the patient.

Lots of carers feel nervous or overwhelmed about giving medical care, but there are some things you can do that will help you feel more confident.

Learn about cancer

- Try to learn about your loved one's cancer, treatments and possible side-effects and symptoms, and get to know some of the medical terms that the doctors and nurses use. Be careful with online information – it might not be correct. Or it may not really apply to your situation or the particular cancer. Ask the doctor or nurse for recommended websites.
- Write down any questions you have and bring them to hospital appointments so you can ask the medical team.
- Call or email our Support Line 1800 200 700 if you have any questions, or drop into a Daffodil Centre to speak to a cancer nurse. We have booklets and web information on different types of cancers, treatments and side-effects that can help you to understand your loved one's illness better. These are available through our Support Line on 1800 200 700, at your local Daffodil Centre, or you can download them from **www.cancer.ie**

Ask for advice

Ask the hospital doctors, nurses and other relevant healthcare professionals such as the physiotherapist and dietician for advice on how to care for your loved one. Make sure you understand about any medication they need to take (see page 18). If they need dressings for wounds, injections or other medical care, the nurses can advise you on what to do or where to go.

If you feel comfortable, the nurses will teach you how to give medical care. If not, they will explain what services are available in the community. For example, the family doctor (GP) or the community or public health nurse.

Giving nursing care (personal care)

As a carer, you will probably need to look after some of the day-to-day nursing needs of your loved one. For example, you may help them to wash or get dressed. It's important to ask them what help they would like. They know best and may not be comfortable with intimate contact. They may prefer to have a private nurse or carer coming in to give personal care at home.

Email: supportline@irishcancer.ie

Hints and tips: personal care

- Regular washing can help someone feel more comfortable and lift their mood. It may also help prevent infections. If you need help with bathing, talk to the public health or community nurse.
- Suggest that your loved one wears clothes that are easy to put on and take off, such as trousers or skirts with elasticated waistbands, front fastenings and slip-on shoes.
- Ask the public health or community nurse or your pharmacist about special devices to help with personal care, such as hair-washing trays.
- Look for mobile services like beauticians, chiropodists and hairdressers. Having a haircut or a beauty treatment may also give your loved one a boost if they can't get out of the house easily.
- Check with the hospital about suitable creams, shampoos and other products. Treatments like chemotherapy and radiotherapy can sometimes make skin extra sensitive.
- Tell the public health or community nurse or GP if your loved one finds it difficult to get to the toilet or to use the toilet. They may be able to arrange equipment to help.
- If your loved one has problems with incontinence, talk to the public health or community nurse about supplies like pads and protective bedding. They may also be able to advise you about seeing a continence adviser. Your local pharmacist may be able to tell you about products that might help.
- If your loved one is spending a lot of time in bed or their balance or mobility is affected by their cancer or the treatment they've had, they may be at risk of falling. Ask the GP or public health or community nurse for advice on preventing falls and what to do if your loved one falls. You might hurt yourself or them if you try to lift them.

Managing medications

Often carers help patients with their medication. Your loved one may have a lot of medications to take. Some may need to be taken regularly and others may be taken as they are needed. Here are some tips to help you.

- **Try to talk to the healthcare team in the hospital so you understand the medication.**
  - What medicines have been prescribed?
  - What are they for?
  - When should they be taken?
  - What is the dose?
  - How to take the medicine – with food or on an empty stomach?
  - Will there be any side-effects?
  - How long should it take to work?
  - Is there a risk of interactions – with other medicines, supplements, vitamins, alcohol or foods?
  - What if a dose is missed? Is it best to take another one or wait until the next dose is due? Ask at the hospital for a printout with information about the medicine, which you can take home. You can also ask your local pharmacist about medicines. They can be a great help, especially if your loved one is on a complex medicine regime.
- **Find a way to keep track of their medicines.** For example, a chart so you can write which pills / medicine they need every day and cross off when each dose has been taken. Or use a weekly pill box, so you can fill it with the pills needed at different times every day. You could also ask your pharmacist if they can pre-pack medications for you, dividing tablets into separate compartments for each time of each day. There may be a fee for this.

- **Make sure you don't run out of medication.** Keep an eye on supplies and take the prescription to the pharmacist in good time.
- **See if your local pharmacist has a home-delivery service.** Or you could leave your prescription in the pharmacy and call ahead so that the medicines will be ready for you to collect.
- **Ask your pharmacist about registering for the Drugs Payment Scheme.** This limits the amount you pay for prescribed medicines and appliances every month. They may also be able to advise you about other benefits like the medical card. You can also get information from the HSE (online at **www.hse.ie/hselive** or by calling the HSE Live helpline 1850 24 1850) or your local health office.
- **Keep the receipts for medical costs** if you will be claiming back expenses from your health insurer or through your annual tax return.

Managing side-effects

If your loved one is having a symptom or side-effect as a result of their treatment, speak to the nurses and doctors in the hospital. There are medications and other treatments to help with many of the side-effects of treatment. If one treatment doesn't help, don't give up. Ask if there is something else your loved one can try. It may also be helpful to keep a record of any side-effects, so you have it for future reference. You can also speak to a cancer nurse by calling our Support Line on Freephone 1800 200 700 or by visiting a Daffodil Centre. We have several useful booklets on different cancer types, their treatment and possible side-effects.

For a free copy of any of these booklets, ring our Support Line, pick up a copy from a Daffodil Centre or download them from the publications section on our website **www.cancer.ie**

Hints and tips: going to hospital appointments

- **Appointments can make the patient very anxious,** especially if test results or treatment decisions are going to be discussed. For this reason, try to go to appointments with your family member or loved one. If the appointment is over the phone, or by video call, stay in the room with them if you can.
- **Chat to your loved one before the appointment** and see if they have any questions or worries. Jot these down, along with your own, so that you don't forget anything.
- **Make a note of what the doctor says.** Keeping a record of what the doctor says will help you to share information with the rest of the family or friends afterwards. Some doctors may be happy for you to record the meeting, but make sure you ask for their permission before doing so.
- **Time with the doctor is very important for your loved one and your family.** The doctor may be busy, but try not to feel rushed. Make sure you are happy that you have asked all your questions and have all the information you need before you leave.

> 'Get involved early. I missed appointments at the start when they were deciding treatment, which I regret ... Make sure to support them during treatment as they really need it.'

Reporting problems to the medical team

Find out who's who

Find out who is on the medical team and what help they can give you. For example, the consultant, registrar, specialist nurse, occupational therapist, medical social worker, physiotherapist.

Get telephone numbers

Keep a record of important names and phone numbers. Ask the nurses in the hospital for a phone number in case you need to ask a question between appointments. Also write down who to call if your loved one becomes unwell at home and if they need out-of-hours care. Make sure the list of numbers is available so that anyone caring for your loved one knows where to find them.

Don't be afraid to call

If you're worried about your loved one's health or if they're troubled by a side-effect or symptom, let a member of their care team know.

If your loved one needs to go into hospital urgently...

Make sure they have everything they need for a stay in hospital, including any medicines they are taking (including non-cancer related ones). It may be helpful to have an overnight bag ready, packed with a few essentials. Let other carers and healthcare professionals know that your loved one is in hospital.

Confidentiality and sharing information

Getting information about the patient

There may be limits on how much information health and social care professionals can share with you about your loved one, especially if you are not a family member. If the person you care for would like professionals to share information with you, they should let them know. If written permission is needed, ask at the hospital how to go about this, and keep a copy of the document for your own files.

You can ask professionals for general advice. For example, ‘What’s the best way to manage nausea from chemotherapy?’ ‘If a patient has a very high temperature, who is the best person to call?’

Sharing information about your loved one

Let your loved one’s healthcare team know that you are their carer. You can share information about the patient that might be helpful to them, as long as your loved one is happy for you to do this.

Practical care

Practical care

There can often be a lot of practical work involved in caring. This may include household chores, bringing the patient to and from appointments and dealing with financial matters.

Sometimes these roles can be overwhelming, especially if you have other responsibilities such as running your own home, looking after children or going to work.

Write a list of all the jobs that need to be done. That way, you can prioritise the most important jobs. A list will also help you to share out the jobs with other carers who are looking after your loved one. See page 78 for tips on working together.

Household chores

Household chores may involve regular cleaning, shopping and preparing meals. Ask your loved one what practical help they would like around the house. They may be entitled to homecare supports (see page 27), so speak to the medical social worker in the hospital or your local Health Service Executive (HSE) office. You can also ring the HSE Live helpline on 1850 24 1850.

Preparing meals

If your loved one isn't feeling well, or is having side-effects after their treatment, they may not have much appetite or interest in preparing food. Or they may need a special diet, such as a soft diet or a high-calorie diet. Ask to speak to the hospital dietitian if you have any questions about preparing food. You could also read our booklet ***Diet and Cancer***. It has helpful tips about meals for someone with cancer.

If you're very busy as a carer, ask others to bring meals in plastic containers that you can use or freeze for later. Stocking up on some good quality, nutritious ready meals or using a healthy meal-delivery service can also help.

Home Support Service

This HSE scheme is for people who need to be cared for in their own homes. It can reduce the amount of physical and practical care that you have to give to your loved one.

If your loved one is being discharged from hospital, make sure you ask the medical social worker in the hospital about a home support package. If there is no medical social worker in the hospital, then ask to see the discharge coordinator and ask them about referral to these services. If your loved one is already at home, ask your community or public health nurse about this scheme.

In addition to the services of professional care attendants, the package may include assistance from from nurses, physiotherapists, occupational therapists and home helps, where available.

Your loved one might also receive some respite care or aids or appliances as part of the package if these are needed to support them to stay in their own home. The services that are supplied will depend on your loved one's individual needs, as assessed by the HSE, the level of support available from you and/or other family members or friends and on where in the country you live.

Check with your local health office for more details on the scheme in your area. You may be able to access free caring supports, including respite and palliative care, if you discuss your needs with a public health nurse in your local health centre. To find your local health centre see here: **http://www.hse.ie/eng/services/list/1/LHO/**

Transport

Carers often support their loved ones with travel to hospital for appointments and treatment. But if they can't help with these important journeys, help is available. The Irish Cancer Society runs two programmes – the Volunteer Driver Service and the Travel2Care programme – to help with travelling to and from appointments. See page 109 for more details.

You can also ask the medical social worker at the hospital for more information on these services, or talk to one of our cancer nurses on our Support Line 1800 200 700, drop in to a Daffodil Centre, or email the nurses at supportline@irishcancer.ie

Medical equipment

If your loved one needs medical equipment, such as a wheelchair, speak to your public health nurse, the occupational therapist, the nurses or the medical social worker at the hospital. They will advise you.

Dealing with money matters

Money may well be the last thing on your mind if your loved one has been diagnosed with cancer, but it can make things easier in the long run if you get organised from the start. There's more about managing the financial impact of cancer on page 103.

Tips for dealing with money matters €

- If you find it difficult to deal with financial matters or fill in forms, ask a friend or family member to take on that job.
- Find out if there is a medical social worker at the hospital and ask to speak to them. They can give you advice about benefits and allowances to apply for and supports and services available.
- Ask about any costs and charges when your loved one is first admitted to hospital, to see if you will have to pay anything. In some circumstances your loved one may be able to have their hospital charges waived. Again, talk to the medical social worker about this.
- If the patient has health insurance it's a good idea to call the insurer as soon as possible to find out what tests and treatment are covered under their plan.
- Ask your pharmacist or the medical social worker about the drugs payment scheme, medical card or the long-term illness card.
- Keep a folder for receipts, if you will be claiming back any medical costs from the health insurer or as part of a tax return.
- Your local Intreo (social welfare) office can give you advice about applying for benefits that you or your loved one may be entitled to if you have to give up work, as well as other illness-related payments. Your local Citizens Information Centre is also a useful resource for health-related entitlements. See also Carers' entitlements, page 68.

Emotional care

Emotional care

Knowing how your loved one is feeling and what you can say or do to help is often difficult. You know your loved one best so don't be afraid to talk to them. Sharing your feelings can bring you both a lot of comfort.

When talking with your loved one about their illness, it can be tempting to try to 'solve' their problems. You can't change the fact that they are sick, but you can help them a lot just by listening to them – finding out how they’re feeling and if they’re worried about anything. See the section 'How to talk to someone with cancer' on page 39 for more about talking to your loved one and listening to what they say.

> ‘Don’t be afraid to talk to your loved one about their illness. They will be reassured that you are trying to understand what they are going through.’

Reactions to a cancer diagnosis

You may be surprised at how your loved one reacts to their cancer diagnosis. It's normal for people to cope in many different ways. Sadness, anger, anxiety and denial are all common reactions.

Different feelings at different times

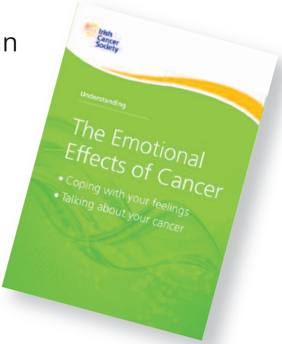
It's also normal for your loved one to experience different feelings during the course of their illness. It can be hard for you as a carer if you don't know what to expect. The following stages may be challenging for your loved one:

- After diagnosis
- Waiting for test results
- Before a follow-up appointment
- When treatment is finished
- If the cancer returns after treatment
- If the treatment has not worked

As a carer, your main role is to support your family member or loved one, not to change how they feel. Listening and trying to accept how they feel will show that you really support them.

As a carer you will also have your own reactions. See page 71 for ways to manage your own feelings.

See also our booklet, ***Understanding the Emotional Effects of Cancer*** – which you can order through our Support Line 1800 700 200 or download from our website **www.cancer.ie**



Irish Cancer Society

Understanding

The Emotional Effects of Cancer

- Coping with your feelings
- Talking about your cancer

> 'It's a tough time, but being with him was so special.'

Getting support for your loved one

There's a lot of support available for cancer patients. This includes cancer support centres, support groups for different types of cancers, counsellors, booklets and online forums. See page 106 for more about free services from the Irish Cancer Society. You can help your loved one by finding out what's available in your area. Some hospitals have a Daffodil Centre where you can speak to one of our cancer nurses. See page 107 for more about Daffodil Centres.

If you are concerned that your loved one is having difficulty coping with their illness, speak to their doctors, nurses or medical social worker. Some hospitals have a psycho-oncology service. This is a team of nurses and doctors, psychologists and social workers who specialise in helping cancer patients who feel unable to cope, despite their best efforts. For more information, contact our Support Line on Freephone 1800 200 700, or email supportline@irishcancer.ie, or you can visit a Daffodil Centre to speak to a cancer nurse in confidence.

Complementary therapies

Some patients find that complementary therapies such as massage, exercise-based activities, mindfulness and yoga help them to feel better in themselves during and after treatment. Check with the hospital before using complementary therapies to make sure it is safe to use them. For more information see our booklet ***Understanding Cancer and Complementary Therapies***. You can get a copy by calling our Support Line on 1800 200 700 or from a Daffodil Centre. You can also read it or download it at **www.cancer.ie**

> 'Just be yourself around the patient. They are still the same person. Respect their wishes and don't treat them any different to before their illness.'

Keeping life as normal as possible

Cancer will have a big impact on your loved one's life, but try not to let it take over. They are still the same person. Try to keep living as normally as possible. Remember to include your loved one in special activities like birthday celebrations or other events and outings. Everyone needs something to look forward to and doing normal things can be a welcome break from thinking about their illness. Some people may use humour to help them cope, which can bring some light relief to difficult situations. Try to follow the patient's lead on this.

Caring for a child with cancer

Sometimes being a carer means looking after children affected by cancer. For more information, see our children's cancer web section at **www.cancer.ie**. We also have booklets for parents such as ***Children and Young People with Cancer: A Guide for Parents*** and ***Talking to Children about Cancer.*** They are available at Daffodil Centres or by calling our Support Line 1800 200 700. You can also get the booklets on our website.

How to talk to someone with cancer

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 they have cancer. It is important to know that what you are feeling is normal and that you are not alone.

You may feel stuck and helpless, maybe lost for words, when a friend or family member receives bad news. You may feel that you don't know what to say or if there are things you should be saying which would make it easier for the person with cancer. You also might be afraid of saying something that would add to your friend or relative's upset.

There are ways to overcome these feelings so that you can give practical and useful support.

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 loved one, then your desire to help is the most important thing.

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. The single most important thing that you can do for your friend or relative with cancer is to **listen**. Once you've learned the simple rules of good listening, this will help you greatly in supporting your loved one and hopefully things will improve from there on. The secret is to start 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 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 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 loved one is comfortable using the word cancer. Sometimes people find it difficult to say or hear the word out loud. The good news is that new treatments are more effective than ever at treating and controlling cancer. Many people are treated successfully and many others live with cancer for a long time.

Why talk, why listen?

There are three very good reasons for talking and listening:

1 Talking to each other is the best way to communicate

There are, of course, many ways of communicating – kissing, touching, laughing, frowning, even 'not talking'. However, talking is the most efficient and most specific way 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 as a useful function. It can release a bit of stress, and human beings can only withstand 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 loved one 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 Sharing thoughts and feelings helps

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 don'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 about having cancer 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.

You have everything to gain and nothing to lose by trying to talk to, and listen to, someone who has 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 a number of obstacles to free-flowing communication between you and the person who is ill. These are:

- The person who is ill wants to talk but you don't.
- The person who is ill doesn't want to talk but you do.
- The person who is ill wants to talk but feels they ought not to.
- You don't know how to encourage the person with cancer to talk.
- The person who is ill appears not to want to talk, but really needs to.
- 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 loved one. 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?

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 the person 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 psychological part. A lot of the most awkward gaps in communication can be caused by not knowing the simple rules that encourage free conversation.

Get the setting right

Get comfortable, try to 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 to 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 between you can make 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 you could say something like: '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.

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 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 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 say '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.

Listen and show you're listening

When your loved one is talking, try to do two things. Firstly, actively listen to them instead of thinking of what you're going to say next, and secondly, show that you're listening. To listen properly and actively, 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.

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?' 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...'

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 seems to last for a long time. Try to be comfortable with silence as it is a natural part of the communication process.

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 of silence 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.

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.

Make sure you haven't misunderstood

If you are sure you understand what your loved one 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.

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.

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.

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 can serve an important function in our way of coping with major threats and fears. It can allow us to get rid of intense feelings and to get things in perspective. Humour can be a way to deal with things that seem too difficult to deal with.

Think for a moment about the commonest subjects of jokes: mothers-in-law, fear of flying, hospitals and doctors, sex and so on. The subjects are not funny in themselves. An argument with a mother-in-law, for instance, can be very distressing, but arguing with the mother-in-law has been an easy laugh for comedians 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.

One woman in her early 40s 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 woman it was a method of dealing with a very distressing problem. It showed her bravery and desire to rise above her physical problems.

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

Laughter can help people to get a different handle on their situation. If your loved one 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.

Understand what they are facing

It may help you to try and understand something of what your loved one is facing, and to get a sense of the fears they 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 loved one to talk about their feelings, here are some common worries/fears that they may be experiencing:

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, foolish and without any control of their situation. You can help by telling them that this is a time of great uncertainty, that the various professionals are trying to make an accurate assessment of the cancer, which will influence the treatment plan, and that it is impossible for them to have a detailed assessment of the cancer in advance.

Physical symptoms

We have been focusing on psychological problems associated with having a cancer diagnosis. However, your loved one may frequently experience physical problems. It is extremely important to acknowledge these and to help address them. At various stages in their treatment, they may experience pain, nausea and extreme fatigue, 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 who have had a successful outcome from treatment, worry that it will come back and that they might die if it does.

You can’t get rid of that fear for your loved one, but you can allow them 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.

Naturally this is only a partial list, but it will at least give you an insight into what may be going through your loved one’s mind.
All 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 such an important support to your friend or relative.

You don’t have to have all the answers.
Listening to the questions can help a lot.

Taking care of yourself

Taking care of yourself

Even if you are happy to be a carer, it can be a very hard job. You may be looking after your loved one 24 hours a day and you may be doing a lot of the caring on your own. It’s not unusual for carers to become tired and stressed, especially if they are putting their own needs second. Here are some tips to help you stay well when you are caring.

Get organised

Life can suddenly become very busy when a loved one becomes sick. Use a notebook and make lists of what needs to be done. This will help you prioritise the important things. There may be online or local courses on caring for someone that may be of help. For example, Family Carers Ireland has an online education course on continence care.

Regular family meetings can help. They can ensure that everyone knows what’s happening and is working together. See page 81 for more about family meetings. You could also ask the medical social worker at the hospital for advice about family meetings.

Know your limits

You shouldn’t have to do everything on your own – it's okay to ask for help. If you are finding it hard being a carer, tell your other family members, friends and your loved one. Make sure the work of caring is shared out fairly. Even if you feel you are coping well, it’s still a good idea to share out the work from the start, so that you don’t get worn out and keep a little time to yourself. If you don’t have other people to help, talk to your GP or the medical social worker at the hospital to see what help is available.

> ‘Always make time for yourself at least once a week. Let someone help when they ask.’

Look after your health

When someone you care about is unwell, all your attention may be on them. But it’s important to remember to look after your own health and wellbeing, so that you can cope with the demands of being a carer.

Self-care means looking after yourself – physically and emotionally. It’s about being kind to yourself, knowing that you are important and doing things that make you feel good and positive – without feeling guilty!

Staying healthy

- **Eat well** – make sure to include plenty of fruit and vegetables.
- **Get enough sleep** – take naps if you’re tired or ask someone to give you a break at night if you need it. Even if you cannot sleep, try to lie down and rest.
- **Take some exercise** – a 30-minute walk can boost your energy, lift your mood, keep you fit and give you a break from caring.
- **Avoid using alcohol or drugs not prescribed for you as a way to relax** – at the end of a day of caring you will need to unwind. It is best to avoid alcohol and drugs not prescribed for you as they can lead to poor quality sleep, anxiety, and general unwellness the next day. If you are on medication for anxiety or sleeping difficulties, stick to the prescribed dose. Talk to your GP if you feel these aren’t working for you. Contact your local cancer support centre for courses on relaxation.
- **Manage stress** – try healthy ways like exercising, sharing your feelings or contact your local cancer support centre for courses on relaxation and complementary therapies such as mindfulness or meditation. Try things you have used before to help you relax.
- **Get health problems checked out early** – if you are very busy in your caring role, or if you find it hard to leave the house, you may be tempted to ignore your own health problems. However, you need to stay as well as possible to be able to look after someone else. It’s important to go to the GP if you are unwell or feel you aren’t coping. It is usually easier, and quicker, to sort out problems if tackled early.
- **Protect yourself from injuries,** for example when lifting or moving the patient.

> ‘Complementary therapies are not only for the patients but their carers too. They helped me learn how to relax and be in the moment.’

Watch out for warning signs

Watch out for your physical and mental health. If you are feeling tired or unwell, not sleeping well, losing your appetite or if you are tearful or angry or finding it hard to cope, tell someone and get some support sooner rather than later. Talk to a friend or family member, or speak to your GP.

Take time out

It’s important to take some time away from caring, even if it’s only for a short while each day. Try to do this from the start, even if you feel you are coping. For example, if you can’t leave your loved one, you could ask a neighbour to come in for half an hour while you go for a walk or a cup of coffee. Or just take some time out to read or watch your favourite TV programme.

It’s easy to get isolated from other people if you’re always busy with your caring role, so try to meet up with friends or family regularly and carry on with your hobbies or interests if you can. You may not feel like it, but in the longer term it’s good to keep a life outside caring.

Some people find it useful to keep a diary and write down how they are feeling. If you're not comfortable with this, try to talk to someone. It's important to have support from friends, family members and others that you can turn to when you are tired and stressed. See page 75 for more about getting support. Try to plan outings and meetings that don't involve discussing your loved one. It's okay to need a break.

Have a care plan

If someone else will be caring for your loved one, it can help to have a written care plan. A care plan is a description of the type of care your loved one needs. This could include:

- What your loved one needs at different times of the day – for example, medications they need to take, change of dressing and so on
- What kind of food and drink they like, and anything they should avoid
- What to do / who to call in an emergency

Having a written care plan makes it easier for the person doing the caring and can put your mind at rest if you feel nervous about handing care over to someone else.

Be kind to yourself

Being a carer is a wonderful achievement, giving so much of yourself to help your loved one at a very difficult time in their life. If you have a tough day, remind yourself of this. Being a carer isn’t always easy – you're doing the best you can.

Carers' entitlements

Taking time off work to care

The Carer's Leave Act 2001 allows employees in Ireland to leave their job temporarily to care for someone who needs full-time care and attention. The shortest period of leave allowed is 13 weeks and the longest is 104 weeks. Carer's Leave is unpaid but your employer must keep your job open for you while you are on leave.

Carer's Benefit and Carer's Allowance

You may be eligible for Carer's Benefit if you have enough PRSI contributions. If you do not qualify for Carer's Benefit, you may qualify for Carer's Allowance, which is means tested. In other words, the payment will be based on the income that your family receives through work or other social welfare payments.

If you're already on a social welfare payment, you may also be eligible to apply for a half-rate Carer's Allowance. If you are in receipt of Carer's Allowance you will also automatically qualify for a Free Travel Pass and possibly the Household Benefits Package. You can still take Carer's Leave even if you do not qualify for any of the above payments.

Carer's Support Grant

The Carer's Support Grant (formerly called the Respite Care Grant) is automatically paid to people getting Carer's Allowance or Carer's Benefit. It is paid on the first Thursday of June of each year. It is a tax free payment. It is currently €1,850 per year. If you are in receipt of a half-rate Carer's allowance, you will get half of the Carer's Support Grant (€925).

You can also call into your Intreo office and speak to a Department of Social Protection (DSP) official about exceptional needs payments. These payments used to be available from the HSE's Community Welfare Officers, but are now assessed by DSP officers. Or, you can talk to an information officer in your local Citizens Information Centre.

Find out more

The information on this page is correct at the time of going to print (June 2021), but it's best to check with the medical social worker at the hospital or the Department of Social Protection for up-to-date information on benefits and allowances.

There's more information on money matters, who to contact and support available from the Irish Cancer Society on page 101. You can also call our Financial Support adviser on 01 231 6643.

Coping with your emotions

Coping with your emotions

As a carer, you may experience many different feelings. These include:

Feeling overwhelmed

Becoming a carer can be a sudden and dramatic change to your life. So it's normal to feel overwhelmed at times. Let other carers, family and friends know your feelings and try to share out the role of caring fairly, if you can.

Guilt

Witnessing a loved one become sick is not easy. You may feel that you're not doing enough, or you may feel guilty because you wish you didn't have to be a carer. You may even feel guilty that they got sick and not you. Many carers feel like this. Try to talk to someone about how you're feeling. Know that you're doing your best. Rather than focusing on these feelings, try to think about positive ways you can help.

Anger

Anger is a very common feeling for both patients and carers. You can be angry for many different reasons, including anger at the cancer itself and the changes it has brought into your life. Anger can affect your ability to think clearly. You may also be short-tempered with your loved one if things get on top of you. It can help to talk to someone and work out why you are feeling angry. If you're finding it hard to talk to your family and friends, discuss your feelings of anger with your GP.

Sad

As well as dealing with new responsibilities, you have to deal with the sad news that someone you love and care for is sick. You might also feel sad about the change in your relationship. This can be very difficult. Try to share your feelings with a friend or family member. Be as honest as you can with your loved one. They will probably be feeling this way too.

Anxious

Carers can feel anxious for different reasons. You may feel overwhelmed at your new responsibilities or take on your loved one’s worries. Talk to them and to other carers about your concerns.

Recognise your feelings

Feeling angry, frustrated or sad is normal. It doesn’t mean you love the person any less. But it’s important to recognise and manage your feelings. Otherwise, feelings can overwhelm you and make you irritable, resentful, depressed or unwell.

Getting support

Talk to your GP

Talk to your GP if you need support or are finding it hard to cope. As well as providing you with medical care, they can help with organising other services to support you, such as occupational therapy, public/community health nursing, home care packages and palliative care.

Talk to the medical social worker at the hospital

Medical social workers help patients and their families with any psychological, emotional, social or practical difficulties during their hospital stay. They can help with issues related to caring for a relative like stress, financial worries, anger and depression, loss and bereavement, addiction, isolation and loneliness. They can also advise and assist in relation to concerns about adult safeguarding, child protection and welfare and domestic violence.

They help patients and their families deal not only with how they are feeling about a situation but also with what they can do to bring about change for the better. They also give information and support to help you access other helpful services. For example, arranging home supports and nursing home care as well as supporting applications to other agencies and advocating on behalf of the patient and his/her family.

Find out about cancer support services in your area

There are lots of local cancer support services that provide a range of helpful services to carers, as well as to people with cancer. See page 112 for more about cancer support services.

Join a support group

Support groups give you the chance to get a break from caring, and meet people in a similar situation. You can give each other support, share feelings, information and advice and learn from each other’s experiences. There are general support groups for carers as well as support groups for specific types of cancer. You might also feel supported by being part of a general social or community group, such as your local Men's Shed, an active retirement group or a volunteer or charitable group.

Get online support

There are special websites called online communities where people with cancer and their friends and families 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.

Talk things through

It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to a cancer nurse on our Support Line 1800 200 700 or at your local Daffodil Centre.

Speak to a counsellor

Sometimes it can be hard to talk to the people closest to you if you're feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your loved one, friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears, get a different perspective on the situation and make sense of your feelings. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better, as well as offering you some space and time to focus on yourself. Some local support centres offer free one-to-one counselling for carers. See page 112 for more. There are also online counselling services.

It's important to find a counsellor who is professionally qualified and recommended. Call our cancer nurses or ask your local cancer support centre or your medical social worker for advice and information.

Seek spiritual support

For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life. Your local church or religious centre may also have a social or support group.

If you need more information or help with finding support, call our Support Line on 1800 200 700 or drop into a Daffodil Centre.

Relationships with other people

Often there are a number of people who can help to care for a person with cancer – different family members, neighbours and friends. Other people can be a great help, but when someone is ill, sometimes relationships can be difficult.

Sharing the caring: working together as a team

If you do most of the caring, it's important to have support from other people. It's easy to get worn out or overwhelmed if you are trying to do everything on your own.

Trying to organise help from other carers may feel like another job to do. You may feel it's easier just to do everything yourself. But the more you take on, the more people may believe that you can handle things alone, and that they're not needed.

Including other people from the start and having a plan in place can make things much easier in the long run.

Hints and tips: making a plan

List jobs: Write a list of jobs that need doing, such as:

- Direct care of the person who has cancer, like personal care and giving medications (see page 13)
- Going to hospital appointments (see page 28)
- Keeping the patient company
- Household jobs like cooking, cleaning and washing clothes
- Running errands, like collecting medications from the pharmacy
- Giving lifts – to medical appointments or to visit friends, attend activities or to non-medical appointments
- Organising carers and keeping in contact with other family members
- Money matters – paying bills, budgeting, health insurance, legal issues
- Other jobs that help you, as the main carer. For example, looking after your children, running errands for you.

Ask for volunteers: Ask people to volunteer for jobs at times that suit them. If a person can't do their job one day, ask them to organise a replacement themselves.

Make a monthly plan: Ask people to do the same jobs each week – this is easier than trying to organise everyone week by week.

Have a list of phone numbers: Make a list of the phone numbers of everyone on the caring 'team' and who to call in an emergency. Make sure everyone has a copy.

Sample plan

A plan can include:

- A 'calendar' of things that need doing regularly, like regular cleaning, organising medicines for the week, or giving the main carer a break.
- Occasional events like hospital appointments.
- Blank spaces, where people can volunteer to call in and help out.

	Morning	Afternoon	Evening
Monday	Call Irish Cancer Society to arrange a driver for next week's chemo appointment. **HELEN**	Drop prescription to pharmacy. **MARK**	**SAM** visiting 6-7pm
Tuesday	Collect prescription **MARK**		Making dinner and caring 5-8pm **SUE**
Wednesday	Cleaning 10-11am **PAT**	Chemo appointment 2pm **KEVIN**	Relief for Mary 6-9pm **JACK**
Thursday	Take car for NCT **TARA**		
Friday	Oncology consultant appointment. Accompany and message everyone with an update. **PETER**	Ted visiting 2pm	Making dinner and caring 5-8pm **SUE**
Saturday	Ironing **JO**		
Sunday	Cleaning 10-11am **PAT**		Sort out pill box for next week **MARK**

Organising meetings

Having meetings to keep everyone up to date and talk about the best way to help your loved one can be very helpful and can help you feel less alone.

Include your loved one in the meeting or talk to them beforehand so that they are involved in the decisions about their care. What you might like to talk about:

- The latest report from the doctor: how things are going; what to expect next
- What the person with cancer wants and needs
- Sharing feelings and concerns
- How much time each family member has to help out or visit
- What the main jobs are and ways each person can help. For example, sharing news with other carers, giving lifts to hospital, cooking, communicating with healthcare team
- What the main carer wants and needs
- Ways to support the main caregiver practically and emotionally, including making sure they have time off from caring

It's a good idea to write a list of what you all want to talk about, so that you don't forget or miss anything. If you think it will help, you could set some rules beforehand. For example, how often you will have meetings, how long the meeting will last, how to make sure everyone who wants to talk gets time to speak.

If you find it hard to ask for help...

If you need more help, especially if you find it hard to ask for help, try starting with small favours. You could ask someone to pick up a few items of shopping for you or to sit with the patient while you pop out for a few minutes. Getting people involved in a small way and letting them know how much you appreciate them can open the door to them helping again.

How to get help

- Make the first move – don't wait for them to offer.
- Be specific about what help you need.
- Say thanks.

Setting limits

Remember that it's OK to say no. It can be very hard to say you are not willing to do something or take on all the responsibility. But if you're clear, people will respect you. You may feel like you're being weak or letting your loved one down. But you need to look after yourself too. If there are other people who can help, it's OK to say that you need other people to share the load.

When relationships are difficult

When a person in the family has cancer, it can sometimes put a strain on relationships. For example:

- Other people may comment on or criticise the way you are caring
- You may feel that other people don't realise or appreciate how much you are doing
- You may start to resent other people for not helping enough
- People may feel frustrated or left out if you find it hard to trust them to look after your loved one

What you can do

Talk about it: If there is conflict or bad feeling between you and other people in your loved one's life, it can be helpful to try and talk about it honestly. Give everyone the chance to say their piece without interruption.

Be understanding: Try to find out how everyone is feeling. Explain how you feel and how you are affected. Some carers may be struggling with difficult emotions and find it hard to be around the person who is ill. Some carers may have less time to offer if they have a full-time job or young children. Try be understanding and support each other.

Look for solutions: Rather than letting resentment and bad feelings build up, see if you can find solutions together. If someone is finding it hard to come to terms with your loved one's illness, they may need help to deal with this before they can join in with caring. If someone is very busy with their own life, they may need support themselves to help them find time for extra jobs. If you find it hard to trust other people with caring responsibilities, writing a detailed care plan (see sample plan on page 80) means you know they have the information they need. This may help you to feel happier about letting go.

Get support for yourself: If you're finding it hard to deal with other carers, try sharing your feelings with someone else, like another carer – online or in a support group – or a friend. See page 75 for ways to get support.

> Remember, it's normal for everyone to give care in their own way.

You and your partner

Going through cancer with your partner can bring you closer together and deepen and strengthen your relationship. Unfortunately, a diagnosis of cancer and the demands of caring can also put a strain on your relationship. Recognising some of the challenges can help you to deal with them.

Changing roles

When one person is unwell, it can change the roles in a relationship. For example, if your partner was the one who managed practical matters like bills or did most of the household chores you may feel overwhelmed at having to manage them. Whatever the change, it's very normal for you both to feel sad or frustrated about the change in your relationship.

Talk to your partner about any changes you notice in your relationship and see if there are ways your partner can get involved in their previous role – even by giving you advice and support. Try to get some support for yourself if you're feeling overwhelmed by taking on a new, unfamiliar role.

> 'It was difficult to accept that our roles had reversed…but we got through that.'

Feeling lonely

You might be afraid to share your worries or difficulties with the person who is sick because you don't want to upset them. It can make you feel lonely if you feel you can't talk to the person you used to confide in and who used to support you.

It's important to try and share your feelings as much as you can, to stay close to your partner. Bottling things up can cause frustration, resentment and anger. You may find your partner is having the same feelings as you and will be relieved to be able to talk about them.

You and your sex life

Cancer or its treatment can affect your sex life:

- You or your partner may feel too tired to have sex.
- Your partner may not feel like having sex – dealing with difficult emotions, treatments such as hormone therapies or side-effects such as fatigue can all affect a person's sex drive.
- You or they may find it hard to relax, if you're feeling anxious or stressed.
- There may be tension between you and your partner if there are unresolved issues between you, linked to their cancer.
- Your partner may feel self-conscious if their body has changed as a result of the cancer or treatment.
- You may be afraid to be intimate with your partner – you may feel they won't want to have sex when they aren't well or be afraid of hurting them.

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. There's more on sexual relationships and coping with sexual side-effects on our website, **www.cancer.ie**. You can also get information or advice in confidence from our cancer nurses. Call our Support Line on 1800 200 700 or visit your local Daffodil Centre. You can also email the nurses at supportline@irishcancer.ie

Tips on staying close to your partner

- Even if your partner doesn't feel like having sex or can't have sex, it's important to talk about it and acknowledge how you're both feeling – as feelings of resentment or rejection can build up.
- Try to stay physically close. You can still hug, kiss and touch each other.
- Try to work through any problems once you've talked about them. For example, if they're self-conscious about their body, you might prefer to keep the lights off. If penetrative sex is difficult, try other things.
- Tell the doctor or nurse about difficulties due to the cancer or side-effects of treatments. They are used to talking about sexual side-effects and can recommend treatments to help.

Caring for someone with advanced cancer

Caring for someone with advanced cancer

If your loved one is diagnosed with advanced cancer, it means that a cure is no longer possible. Instead treatment is to keep the cancer under control and relieve any symptoms. Care to relieve symptoms is called palliative care (see page 92).

Being diagnosed with advanced cancer doesn't necessarily mean that your loved one will die soon. Some people live for a long time with advanced cancer, but it may take some time for them to adjust to living with advanced cancer.

What kind of care will be needed?

The type of care your loved one needs will depend on how their cancer is affecting them.

Emotional support

Some people with advanced cancer may need very little practical or medical support, especially early on in their illness or if their cancer is not affecting their daily lives too much. But they may need emotional support and a listening ear to try to come to terms with their diagnosis. See page 48 for more about listening.

You might find our booklet ***Understanding the Emotional Effects of Cancer*** useful if you are giving emotional support to someone with advanced cancer.

> 'Every moment with him was precious. I was very close to him and we were able to talk to each other about his illness.'

Medical support

Advanced cancer can cause side-effects that can be distressing and affect day-to-day life. For example, breathlessness, fatigue or pain. Ways that you can help to support with medical care:

- Learn about the causes of side-effects and the treatments that are available. This can help you to reassure your loved one and support them in getting the medical care that they need.
- Encourage your loved one to tell their medical team about any side-effects they have so that they can get help.
- Attend appointments with them so that the doctor can spot and treat any problems early.
- Make sure they take any medications they are prescribed.
- Ask your doctor or hospital team about how to get palliative care support. The palliative care team are experts at managing the symptoms of advanced cancer.

> 'Use the palliative homecare team and night nurses, they are just unbelievable people and help to the family.'

Planning ahead

It's very understandable that you might feel anxious or reluctant to talk to your loved one about how they might like to be looked after if their cancer progresses, for fear of upsetting yourself or them. But some people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time.

Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead may include:

- Deciding how they feel about different types of medical treatment, including if they might want to stop treatment at any stage or carry on for as long as possible.
- Writing an advance care directive. This is where a person can write down their wishes about medical care. Doctors can use this if the person is not well enough to say what they want.
- Picking someone to make medical decisions if they are not well enough (this person is called a 'patient-designated healthcare representative').
- Making a will.
- Thinking about any preferences about end-of-life care, such as whether they prefer to stay at home, if possible, or in a hospital or hospice.

Your loved one may not wish to talk to you about these issues. They may prefer to talk to someone else who is not as emotionally involved with their care as you, such as a solicitor, GP, or a medical social worker.

More information on planning ahead

Think Ahead is a booklet to help you plan, where you can fill in your personal, medical, financial and legal information and preferences. Go to **www.thinkahead.ie** to find out more. If you want more information about planning ahead you could speak to the medical social worker at the hospital. To talk to a cancer nurse in confidence about any aspect of planning ahead or about advanced cancer, call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre.

Palliative care

Palliative care is care given to patients to improve their symptoms and quality of life. Many people are frightened when they hear the word 'palliative' because they think this means the patient will die soon. Palliative care does include end-of-life care, but it is not just for people at the end of their lives. The palliative care team are experts in helping patients and their loved ones cope with the emotional and physical effects of advanced cancer. Palliative care can be given in hospital or at home.

It's a good idea to ask about palliative care early on. Having the palliative care team involved early can mean symptoms are better controlled and potential problems kept in check. It also means you will have extra support at this difficult time.

At home, palliative care is given by the community palliative care team. This is a team of nurses and doctors who can call to a patient at home and check their symptoms. For example, the team can control your loved one's pain and make changes to their pain medicine if needed. The palliative care team works closely with the GP and can be a useful support for your loved one and his or her carers.

The palliative care team in the hospital can also refer your loved one to the community palliative care team.

For more information and some frequently asked questions about palliative care, see our website **www.cancer.ie**. You can also speak to a cancer nurse by calling our Support Line 1800 200 700 or by dropping into a Daffodil Centre.

> 'I questioned the palliative care nurses a lot when Dad was at home and in the hospice. I think Dad didn't really ask the hard questions so I made it my business to get answers where I could.'

End-of-life care

As a carer, you may need to provide end-of-life care to your loved one. This may be very difficult for you, both emotionally and practically. It is hard to give end-of-life care on your own. It's important to connect with services that can give you support. Your GP is your first point of contact if your loved one needs care at home. Your GP can help you to organise the other services that you will need. For example, homecare nurses, the public health nurse and hospice care.

The Irish Cancer Society Night Nursing Service provides a night nurse for end-of-life care at home. The service is free and available for up to 10 nights (see page 110). Our booklet, ***A Time to Care – Caring for a Loved One at Home***, also has information and advice to support you. You can read or download it at **www.cancer.ie** or get a free copy at a Daffodil Centre or by calling our Support Line on 1800 200 700.

Life after caring

Life after caring

While some people may be relieved to move on from caring responsibilities, many people find it difficult to adjust to life after caring, especially if they have been a full-time carer.

How might I feel?

- **Empty or without purpose:** Caring for someone who is seriously ill can take up most of your time. If you are no longer needed as a carer it can leave a void or sense of emptiness. You may feel your life has no purpose. It can take some time to get used to this, even if your loved one has recovered.
- **Alone:** You may miss the support of the hospital medical team and other services.
- **Lonely:** Your caring responsibilities might have left you isolated, if you were too busy to have a social life or spend time with friends and family.
- **Anxious about getting back to normal:** For example, you may be worried about returning to work, if you took a break to care for your loved one.
- **Worried about problems:** You may have problems that you didn't deal with while you were busy caring. For example, you may have financial problems or health issues that you now need to deal with.
- **Sad:** If your loved one passed away you may find it hard to deal with your loss and feelings of grief.

How can I adjust to life after caring?

Most people who have been carers need to go through a period of adjustment before their lives can return to some kind of normality again. Give yourself time to adjust and deal with your feelings. For example, any worries you might have or feelings of guilt, loss or grief. And be kind to yourself. Reflect on your time as a carer and the fact that you were there for your loved one when they needed you.

Hints and tips: Going back to work

If you have been caring for some time, you may feel nervous about going back to work or worried that you no longer have the skills you once had.

- **Get professional help with your CV. Include the skills you learned from your experience as a carer and be upfront about your career break.**
- **Take a course to build up your skills.**
- **Get some experience through a work placement or voluntary work, to build your skills and confidence.**
- **Start off with part-time work, to get used to working again.**
- **Use support services like Family Carers Ireland for advice if you have been caring for a long time and want to get back into the job market. If you are on Carer's Leave, you must give notice in writing to your employer that you intend to return to work 4 weeks before the date you will return to work.**

Support after caring

If you are feeling very sad, stressed or finding it hard to deal with your emotions or your relationships, there are lots of people who can help you. For example, counsellors, services offering financial and legal advice, bereavement and carers' support groups. You can call our Support Line on 1800 200 700 or visit a Daffodil Centre to talk in confidence or for information on where to get help.

Moving on

Most people find a way to move on with their lives, after a period of adjustment. You may find new purpose in your life through:

- Returning to work
- Spending more time with family and friends
- Taking up a new interest or occupation
- Being involved with support groups
- Volunteering

Try not to feel guilty about doing things for yourself. Instead, treat yourself and try to find things you enjoy to fill any extra time you have.

> 'We had lots of soul-baring times, lots of sad times and lots of laughs … it takes away a piece of the carer that never returns but I would not have had it any other way.'

Support resources

Money matters

A diagnosis of cancer can often bring extra expenses, such as medication, travel, heating and childcare costs. This may cause even more stress for the person who is ill. It may be harder for them to deal with their illness if they are worried about money.

Medical expenses

Medical expenses might include:

- Visits to the family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Medical aids and equipment (appliances), like wigs

How much they pay towards medical expenses depends on whether they qualify for a medical card and the type of health insurance they have, if any.

If they have a medical card, they will probably have very little to pay for hospital and GP (family doctor) care or medications. If they are not eligible for a medical card, they may be eligible for a GP visit card. This allows them to visit a participating GP for free. It is available to everyone aged over 70. If they are under 70, eligibility for the GP visit card is means tested. That is, their income is assessed by the HSE as part of the application process.

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

An emergency medical card may be issued if the patient is terminally ill and in palliative care, irrespective of their income.

If they don't have a medical card they will have to pay some of the cost of care and medication.

If they have health insurance the insurance company will pay some of the costs, but the amount will depend on the insurance plan. It's important to contact the insurance company before starting treatment to check what is covered.

Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, 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 Employment Affairs and Social Protection** – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Make sure the patient has their PPS number to hand when asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

Money problems

If they, or you as a family, 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 109 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

Go to **www.cancer.ie/publications** and check out our booklet, ***Managing the Financial Impact of Cancer***. 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**

Managing

The Financial Impact of Cancer

The booklet also has lots of other information to help 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:

- **Support Line**
- **Daffodil Centres**
- **Survivor Support**
- **Support in your area**
- **Patient travel and financial support services**
- **Night nursing**
- **Publications and website information**

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information.
The Support Line is open Monday–Friday, 9am to 5pm.
You can email us at any time on **supportline@irishcancer.ie** or visit our Online Community at **www.cancer.ie**

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

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free confidential advice, support and information to anyone concerned about or affected by cancer.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

You can email daffodilcentreinfo@irishcancer.ie or visit **www.cancer.ie** to find your local Daffodil Centre.

Survivor Support

Your loved one might like to speak to someone who has been through a diagnosis similar to theirs. 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 and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to **www.cancer.ie** and search 'Find Support'.

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 travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is mainly for patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.

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 a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

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 Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line 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 one-to-one counselling through 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 and reflexology
- **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 Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at **www.cancer.ie/cancer-information-and-support/cancer-support/find-support**

Useful organisations

Carers support and information

Family Carers Ireland
Careline 1800 240 724
email: info@familycarers.ie
Website: familycarers.ie

Young Carers' Programme
Website: www.youngcarers.ie

Care Alliance Ireland
Tel: 01 874 7776
email: info@carealliance.ie
Website: www.carealliance.ie

Healthcare, services and treatment

HSE Live
Tel: Callsave 1850 24 1850
email: hselive@hse.ie
Website: www.hse.ie/hSelive
Twitter: @hSelive

Benefits and entitlements

Citizens Information
Tel: 0761 074 000
Website:
www.citizensinformation.ie

Department of Social Protection
Tel: 1890 662 244
Website: www.welfare.ie

Financial support

Money Advice and Budgeting Service (MABS)
Free helpline: 0761 07 2000
Website: www.mabs.ie

Palliative and end-of-life care

Irish Association for Palliative Care (IAPC)
Tel: 01 873 4735
email: info@palliativecare.ie
Website: www.iapc.ie
Website: www.palliativecare.ie

Irish Hospice Foundation
Tel: 01 6793 188
email: info@hospicefoundation.ie
Website: www.hospicefoundation.ie

Acknowledgments

We would like to thank the healthcare professionals who so kindly gave up their time and expertise to contribute to this booklet. We especially thank the patients and families who generously shared their personal experiences throughout this booklet, and in previous editions.

CONTENT ADVISER
Tony Carlin, Principal Medical Social Worker

CONTRIBUTOR
Teraze Toby, Daffodil Centre Nurse

EDITOR
Claire McGinn

Published in Ireland by the Irish Cancer Society.

The Irish Cancer Society is a registered charity, number CHY5863.

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 Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

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

Irish Cancer Society
43/45 Northumberland Road, Dublin D04 VX65

T: 01 231 0500
E: info@irishcancer.ie
W: www.cancer.ie

Support Line Freephone 1800 200 700
Email: supportline@irishcancer.ie

Find us on Facebook
Follow us on Twitter: @IrishCancerSoc

The National Cancer Charity

Irish Cancer Society