



# Caring for someone with cancer

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This booklet has been written to help you to understand what is involved in caring for someone with cancer. It has been prepared and checked by cancer nurses and other relevant health and social care professionals. It also includes some words from people who have cared for a loved one with cancer.

You might find it useful to list below any contact names and information you may need.

	NAME	TELEPHONE
Specialist nurse		
Family doctor (GP)		
Consultant		
Medical social worker		
Community / Public Health Nurse		
Homecare team		
Emergency number		

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

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## 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 people 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! 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 like 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 37 for more about support.

## 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 Cancer Nurseline on Freephone 1800 200 700
- Drop into a Daffodil Centre
- Email us: [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

See page 59 for more about our services and how to find your nearest Daffodil Centre. You can also visit our website at [www.cancer.ie](http://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 had it any other way. She cared for me for long enough. I wanted to give back.'

## What does a carer do?

A carer is a person who helps a patient with cancer. This can mean giving 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.

- 'The most rewarding days I ever had with him.'

### 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 [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie). You can also look at our webpage [www.cancer.ie/youngcarers](http://www.cancer.ie/youngcarers)

## 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 give different types of care at different times:

- **Medical care:** For example, giving medications and nursing or personal care (see page 11)
- **Practical care:** For example, giving lifts, shopping, cooking and cleaning (see page 19)
- **Emotional care:** Giving a listening ear, sympathy and support (see page 25)

It can be hard to manage all these 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 giving medical care.

### 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 22.



## Giving medical care

Medical care can include:

- Giving nursing care (personal care)
- Managing and giving medications
- Managing side-effects
- Going with your loved one to their hospital appointments
- Reporting problems to the medical team

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 this type of care, but there are things that can help.

### Tips on giving medical care

#### 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.
- Write down any questions you have and bring them to hospital appointments so you can ask the medical team.
- Call or email our Cancer Nurseline 1800 200 700 if you have any questions, or drop into a Daffodil Centre.

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. For free booklets, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre, or download or order them from [www.cancer.ie](http://www.cancer.ie)

## Ask for advice

Ask the hospital doctors, nurses and other relevant health care 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 14). 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 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 your family member or loved one what help they would like. They know best and may not be comfortable with intimate contact. You can also hire a private nurse or carer to give care in your loved one's home.

## 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 clothing that is easy to put on and take off, such as clothes 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 your 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 advisor.
- 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 and giving 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 drink? 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 on what 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, where tablets are divided into separate compartments for each time of each day.

- **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](http://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 using the Med 1 Claim form to claim back some of the expenses from the Revenue Commissioners.

●●● 'You need to keep on top of medicines. I used blister packs and made up the meds for the week in a separate container as it changed daily.'

## Managing side-effects

If your loved one is having a symptom or side-effect 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.

You can also speak to a cancer nurse by calling our Cancer Nurseline on Freephone 1800 200 700 or by visiting a Daffodil Centre. We have several useful booklets on subjects such as cancer symptoms, treatments and side-effects.

For a free copy of any of these booklets, ring our Cancer Nurseline, pick up a copy from a Daffodil Centre or download them from the publications section on our website [www.cancer.ie](http://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.
- Chat to your loved one before the appointment and see if they have any questions or worries. Write their questions down in a notebook so you can ask them, as well as any of your own.
- Make a note of what they 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.
- Time with the doctor is very important for your loved one and your family. The doctor may be busy, but try not to let yourself be rushed and 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 consultant, registrar, specialist nurse, occupational therapist, medical social worker, physiotherapist.

### Get telephone numbers and email addresses

Keep a record of important names, phone numbers and email addresses. Ask the nurses in the hospital for a phone number or email address 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 your loved one 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 that 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.

## Sharing information and confidentiality

### 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.

## Giving practical care

Carers often give practical care to patients. This can include:

- Doing household chores like cleaning
- Shopping
- Preparing meals
- Providing transport – day-to-day transport and travelling to the GP and to hospital appointments
- Dealing with money matters

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

Try to write a list of all the jobs that need to be done. Then 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 39 for tips on working together.

### Household chores

Ask your family member or loved one what they would like help with. Remember it's their home. Your loved one may be entitled to home care supports (see page 21), 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 they may need a special diet, like 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 for carers about meals for someone with cancer.

If you're very busy as a carer, ask people 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.

## 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 to help with travelling to and from appointments.

- The **Volunteer Driver Service**, where trained volunteer drivers give patients and their carer a lift to and from chemotherapy appointments
- The **Travel2Care programme**, which helps with the costs of transport to hospital for diagnosis or treatment appointments

Some local cancer support centres and other charities also provide volunteer driver schemes. For more information on these services, ask the medical social worker at the hospital or talk to one of our cancer nurses – call the Cancer Nurseline on 1800 200 700, drop in to a Daffodil Centre, or email the nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

## Medical equipment

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

## The Home Care Package Scheme (HCP)



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 care 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.

The package may include the services of nurses, home helps and various therapies including physiotherapy and occupational therapy services. Your loved one might also receive some respite care or aids or appliances as part of the HCP 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, and the levels of other supports 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/>

## 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 pages 56-58.

### Hints and tips

- 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 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.
- If you have health insurance it's a good idea to call your insurer as soon as possible. Tell them about your loved one's treatment and find out what they are covered for.
- 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 your health insurer or as tax relief using the Med 1 Claim form.
- 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.

## 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 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 €1700 per year (in 2017). If you are in receipt of a half Carer's Allowance, you will get 50% of the Carer's Support Grant (€850).

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, but it's best to check with the medical social worker at the hospital or the Department of Social Protection for up-to-date benefits information.

There's more information on money matters, who to contact and support available from the Irish Cancer Society on pages 56–60. You can also call our Financial Support Advisor on 01 231 6643.

## Giving emotional care

Knowing how your loved one is feeling and what you can say or do to help is often difficult. Here are some tips on how to give emotional care to your loved one.

### Listening to your loved one

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.

Listening is a simple but powerful way to communicate. It's about focusing on what your loved one is saying, not thinking about what you are going to say next or waiting to offer advice or give an answer.

- '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.'

The Irish Cancer Society has a booklet with more advice and tips: *How to talk to someone about cancer*. Read or download it or order a copy on our website [www.cancer.ie](http://www.cancer.ie). You can also get a booklet by calling our Cancer Nurseline on 1800 200 700 or by calling in to a Daffodil Centre.

### You know your loved one best

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.

## Hints and tips: How to listen



- Sit down together in a private place.
- Make sure you have plenty of time. Let your loved one know you are there for as long as needed.
- Put your phone on silent.
- Maintain as much eye contact as possible.
- Encourage your loved one to talk by asking 'open' questions. For example, 'How are you feeling today?'
- Try to avoid 'closed' questions. Closed questions normally only require a yes or no answer and don't encourage the other person to talk.
- Focus on what your loved one is saying. Try not to think about something else or what you plan to say next.
- Don't interrupt or change the subject. If your loved one stops talking, remember they might be thinking about what they want to say next. Give them time to do that.
- Allow the patient to be sad or upset and tell them that it's okay to feel that way. It might make you feel uncomfortable to see them upset, but you are helping by being there and listening.
- Try not to say things like, 'It will be ok' or 'Stay positive'. This might stop them from telling you how they really feel.
- Make sure you have understood what your loved one has said. A good way to do this is repeat some of the words they have used.
- Follow their lead. If they laugh it's ok to laugh with them. If they cry, give them time to do this too. If they look uncomfortable, nod and smile and show them you are there to listen.

## 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 because you don't know what to expect. The following stages may be very 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.

Everyone deals with cancer in a different way. As a carer you will also have your own reactions. See page 36 for ways to manage your own feelings.

- '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 59 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 a cancer nurse. See page 59 for more about Daffodil Centres.

If you are worried that your loved one isn't coping well 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 Cancer Nurseline on Freephone 1800 200 700, or email [cancernurseline@irishcancer.ie](mailto:cancernurseline@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 your chosen method is safe. For more information see our booklet *Understanding Complementary and Alternative Therapies*. You can get a copy by calling our Cancer Nurseline on 1800 200 700 or from a Daffodil Centre. You can also read or order the booklet online at [www.cancer.ie](http://www.cancer.ie)

## 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 it can be a welcome break from thinking about their illness.

### Useful resources

We have booklets to help with emotional care:

- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Talking About Your Cancer*

You can get copies from a Daffodil Centre, or from our Cancer Nurseline on 1800 200 700. You can also read, order or download the booklets at [www.cancer.ie](http://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.'

### Caring for a child with cancer

Sometimes being a carer means looking after children affected by cancer. For more information, see our web section on children and cancer at [www.cancer.ie](http://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 Cancer Nurseline 1800 200 700. You can also get the booklets on our website.







## 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.

Regular family meetings can help. They can ensure that everyone knows what's happening and is working together. See page 42 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 yourself

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** – Eat a variety of foods including 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.
- **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 as a way to relax** – At the end of a day caring for your loved one you need to unwind, but alcohol and drugs can mean you get poorer quality sleep, feel unwell the morning after or feel more anxious or down, which can make it harder to cope. Or you may start to depend on it, and find it hard to manage without it. Also be careful if you are taking any medication like sleeping tablets or anti-anxiety medication. Stick to the dose your doctor has prescribed and don't take these types of medicines unless they are prescribed for you. For example, don't take tablets prescribed for other people, if someone offers them to you.
- **Handle stress** – Try healthy ways like exercising, sharing your feelings or complementary therapies like mindfulness or meditation.
- **Get health problems checked out early** – If you are very busy with your caring, or if you find it hard to leave the house, you may be tempted to ignore your own health problems. But it's important to go to the GP if you are unwell or feel you aren't coping. Sorting out problems early is usually much easier and quicker.
- **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

You may not realise that caring is beginning to affect your physical or 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 go to your GP.

## Take time out

It's important to take some time away from caring, even if it's only for a few minutes. Try to do this from the start, even if you feel you are coping OK. For example, if you can't leave your loved one, you could ask a neighbour to come in for half an hour every day 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 37 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.

## Care plans

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
- 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.

# 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.
- **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 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.
- **Sadness:** 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.
- **Anxiety:** 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.

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 for yourself

**Talk to your GP:** Talk to your GP if you need support or are finding it hard to cope. As well as caring for you, they can also organise services that will help 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 dependent relative like stress, financial worries, anger and depression, loss and bereavement, addiction, isolation, loneliness and concerns around elder and child abuse or 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 61 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](http://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 one of our cancer nurses.

**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 61 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 Cancer Nurseline 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 pages 11-15)
  - Going to hospital appointments (see page 16)
  - 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 and admin – paying bills, budgeting, health insurance, legal
  - Other jobs that help you, 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. <b>HELEN</b>	Drop prescription to pharmacy. <b>MARK</b>	Sam visiting 6-7pm
Tuesday	Collect prescription <b>MARK</b>	Call Citizens Information re Carer's Leave <b>PADDY</b>	Making dinner and caring 5-8pm <b>SUE</b>
Wednesday	Cleaning 10-11am <b>PAT</b>	Chemo appointment 2pm <b>KEVIN</b>	Relief for Mary 6-9pm <b>JACK</b>
Thursday	Take car for NCT <b>TARA</b>		
Friday	Oncology consultant appointment. Accompany and message everyone with an update. <b>PETER</b>	Ted visiting 2pm	Making dinner and caring 5-8pm <b>SUE</b>
Saturday	Ironing <b>JO</b>	Fill in Drugs Payment Scheme claim form and send off. <b>GERRY</b>	
Sunday	Cleaning 10-11am <b>PAT</b> Lift to Mass <b>SINEAD</b>		Sort out pill box for next week <b>MARK</b>

## 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 person 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.

### 3 steps to getting help

- 1 Make the first move – Don't wait for them to offer.
- 2 Be specific about what help you need.
- 3 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 to 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 page 35) 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 37 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.

## Sex and physical closeness

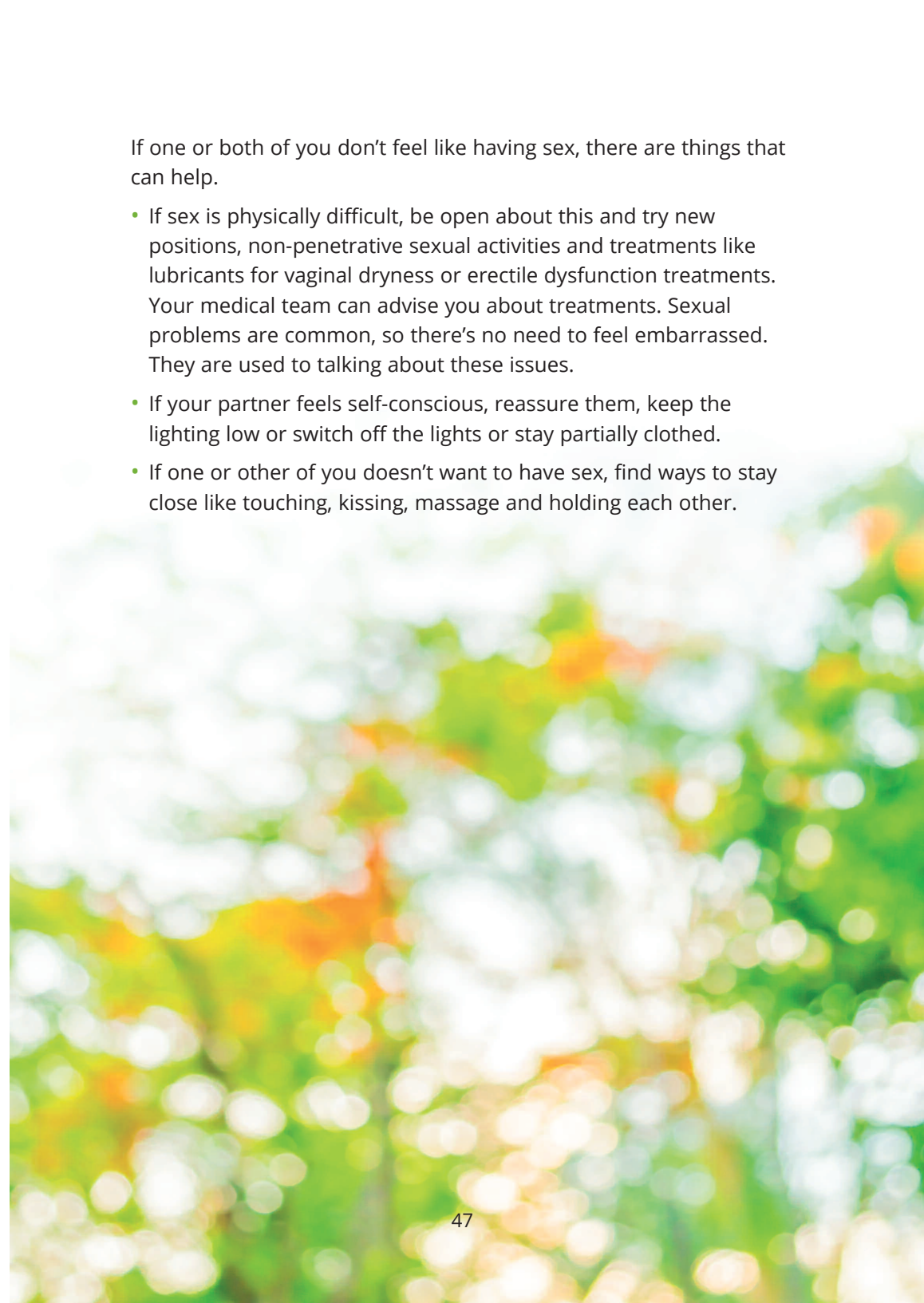
Cancer and cancer treatments may affect your sex life.

- Some treatments can cause physical side effects that make it more difficult to have sex, like a man having problems getting an erection or a woman having vaginal dryness.
- Sometimes a person with cancer may not feel like having sex for many reasons, such as physical changes to their body, which make them feel uncomfortable, or cancer related fatigue (extreme tiredness) or loss of libido (desire to have sex).
- There are also problems that can affect both the patient and the carer, such as tiredness, stress, depression, difficult emotions about the cancer or your changed roles.

Some of these changes are temporary, some may be permanent.

If one or both of you don't feel like having sex, there are things that can help.

- If sex is physically difficult, be open about this and try new positions, non-penetrative sexual activities and treatments like lubricants for vaginal dryness or erectile dysfunction treatments. Your medical team can advise you about treatments. Sexual problems are common, so there's no need to feel embarrassed. They are used to talking about these issues.
- If your partner feels self-conscious, reassure them, keep the lighting low or switch off the lights or stay partially clothed.
- If one or other of you doesn't want to have sex, find ways to stay close like touching, kissing, massage and holding each other.



## 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 51).

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 will 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 26 for more about listening.

You might find our booklets *Lost for Words – How to Talk to Someone with Cancer* and *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 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](http://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 Cancer Nurseline 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 homecare team. This is a team of nurses and doctors who can call to a patient at home and check their symptoms. For example, the homecare team can control your loved one's pain and make changes to their pain medicine if needed. The homecare 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 homecare team.

For more information and some frequently asked questions about palliative care, see our website [www.cancer.ie](http://www.cancer.ie). You can also speak to a cancer nurse by calling our Cancer Nurseline 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 give 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.

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](http://www.cancer.ie) or get a free copy at a Daffodil Centre or by calling our Cancer Nurseline on 1800 200 700.

## 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 about life after caring?

- **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 problems of your own 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 up front 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 Cancer Nurseline 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.'

# Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. It may be harder for you to deal with cancer if you are worried about money.

## Medical expenses

Medical expenses include:

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

The amount of medical expenses depends on whether or not the patient qualifies for a medical card and what type of health insurance they have, if any.

**If they have a medical card**, there will probably be very little to pay for hospital and GP (family doctor) care or medications.

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

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

**If they do not have a medical card** they will have to pay some of the cost of their care and medication.

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

## Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave (see page 23).

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

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

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

## If you have financial difficulties

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 60 for more details of our Volunteer Driving Service and the Travel2Care fund.

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

### More information

For more information go to [www.cancer.ie/publications](http://www.cancer.ie/publications) and check out our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer



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

## Irish Cancer Society services

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

- Cancer Nurseline
  - Daffodil Centres
  - Survivor Support
  - Support in your area
  - Patient travel and financial support services
  - Night nursing
  - Publications and website information
- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie) or visit our Online Community at [www.cancer.ie](http://www.cancer.ie)
- For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: [remote@slis.ie](mailto:remote@slis.ie)
- Our **Daffodil Centres**. There are centres in thirteen hospitals nationwide. They are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer. To find your nearest centre email [daffodilcentreinfo@irishcancer.ie](mailto:daffodilcentreinfo@irishcancer.ie)
  - Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including one-to-one counselling. See page 61 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

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

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

## Local cancer support services

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

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

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

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



## Other useful organisations

### Carers support and information

**Family Carers Ireland**  
Careline 1800 240 724  
Email: [info@familycarers.ie](mailto:info@familycarers.ie)  
Website: [familycarers.ie](http://familycarers.ie)

**Young Carers' Programme**  
Website: [www.youngcarers.ie](http://www.youngcarers.ie)

**Care Alliance Ireland**  
Tel: 01 874 7776  
Email: [info@carealliance.ie](mailto:info@carealliance.ie)  
Website: [www.carealliance.ie](http://www.carealliance.ie)

### Healthcare, services and treatment

**HSE Live**  
Tel: Callsave 1850 24 1850  
Email: [hselive@hse.ie](mailto:hselive@hse.ie)  
Website: [www.hse.ie/HSELive](http://www.hse.ie/HSELive)  
Twitter: @HSELive

### Benefits and entitlements

**Citizens Information**  
Tel: 0761 074 000  
Website:  
[www.citizensinformation.ie](http://www.citizensinformation.ie)

**Department of Social Protection**  
Tel: 1890 662 244  
Website: [www.welfare.ie](http://www.welfare.ie)

### Financial support

**Money Advice and Budgeting Service (MABS)**  
Free Helpline: 0761 07 2000  
Website: [www.mabs.ie](http://www.mabs.ie)

### Medical equipment

**Assist Ireland**  
Website: [www.assistireland.ie](http://www.assistireland.ie)

**Irish Wheelchair Association**  
Tel: 01 818 6400  
Website: [www.iwa.ie](http://www.iwa.ie)

### Palliative and end-of life care

**Irish Association for Palliative Care (IAPC)**  
Tel: 01 873 4735  
Email: [info@palliativecare.ie](mailto:info@palliativecare.ie)  
Website: [www.iapc.ie](http://www.iapc.ie)  
Website: [www.palliativecare.ie](http://www.palliativecare.ie)

**Irish Hospice Foundation**  
Tel: 01 6793 188  
Email: [info@hospicefoundation.ie](mailto:info@hospicefoundation.ie)  
Website: [www.hospicefoundation.ie](http://www.hospicefoundation.ie)

## Helpful books

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

You may find the following helpful:

### Treatment and side-effects

*Understanding Chemotherapy*

*Understanding Radiotherapy*

*Understanding Cancer and Complementary Therapies*

*Diet and Cancer*

*Coping with Fatigue*

### Coping and emotions

*Understanding the Emotional Effects of Cancer*

*Lost for Words: How to Talk to Someone with Cancer*

*Who Can Ever Understand? Talking About Your Cancer*

*Talking to Children about Cancer: A Guide for Parents*

*A Time to Care: Caring for Someone Seriously Ill at Home*



## Join the Irish Cancer Society team

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

### Support people affected by cancer

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

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

### Share your experiences

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

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

### Raise money

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

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

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

## Did you like this booklet?

We would love to hear your comments or suggestions.  
Please email [reviewers@irishcancer.ie](mailto:reviewers@irishcancer.ie)

## More information and support

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

**Irish Cancer Society**

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: [info@irishcancer.ie](mailto:info@irishcancer.ie)

W: [www.cancer.ie](http://www.cancer.ie)

Cancer Nurseline Freephone 1800 200 700

Email: [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

