

A guide for carers, by carers



**HELLO,
AND HOW ARE
YOU?**

**WE ARE
MACMILLAN.
CANCER SUPPORT**



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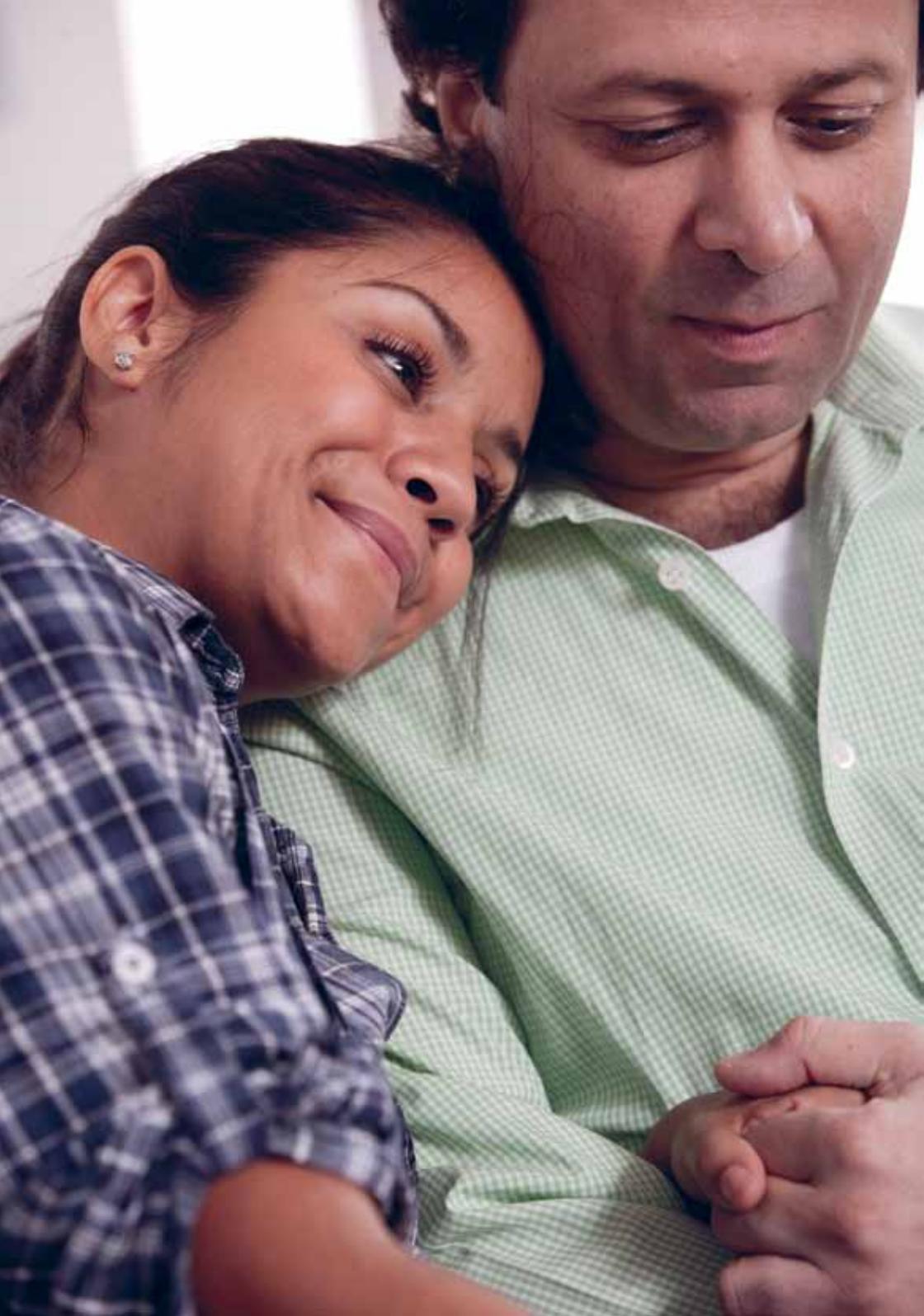
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INTRO

Introduction

A message from the Experienced Carers Group

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More and more people are living with cancer because of earlier diagnosis and better treatments. This has resulted in a growing need for people like you, who care for someone with cancer.

A carer is someone who provides unpaid support to a family member or friend who could not manage without this help. Caring can mean many things, including being a good listener, helping with personal care, providing transport or assisting with everyday chores.

During our time caring for a loved one with cancer, we became aware that a carer can often become a forgotten figure who isn't provided with the information and support they need. Like us, you may find yourself in a variety of situations, some of which may be difficult and challenging. However, many of us found that being a carer can be a rewarding experience.

Working with Macmillan Cancer Support, we have used our experiences to develop, shape and write a handbook to support other people caring for adults with cancer. This handbook is the result of that work. It contains practical tips, which we hope you'll find useful when it comes to dealing with the ups and downs of caring for someone with cancer.

We've also included information about organisations and other sources of support that helped us during this time. We hope they provide you with the support you need too.

As you read this handbook ...

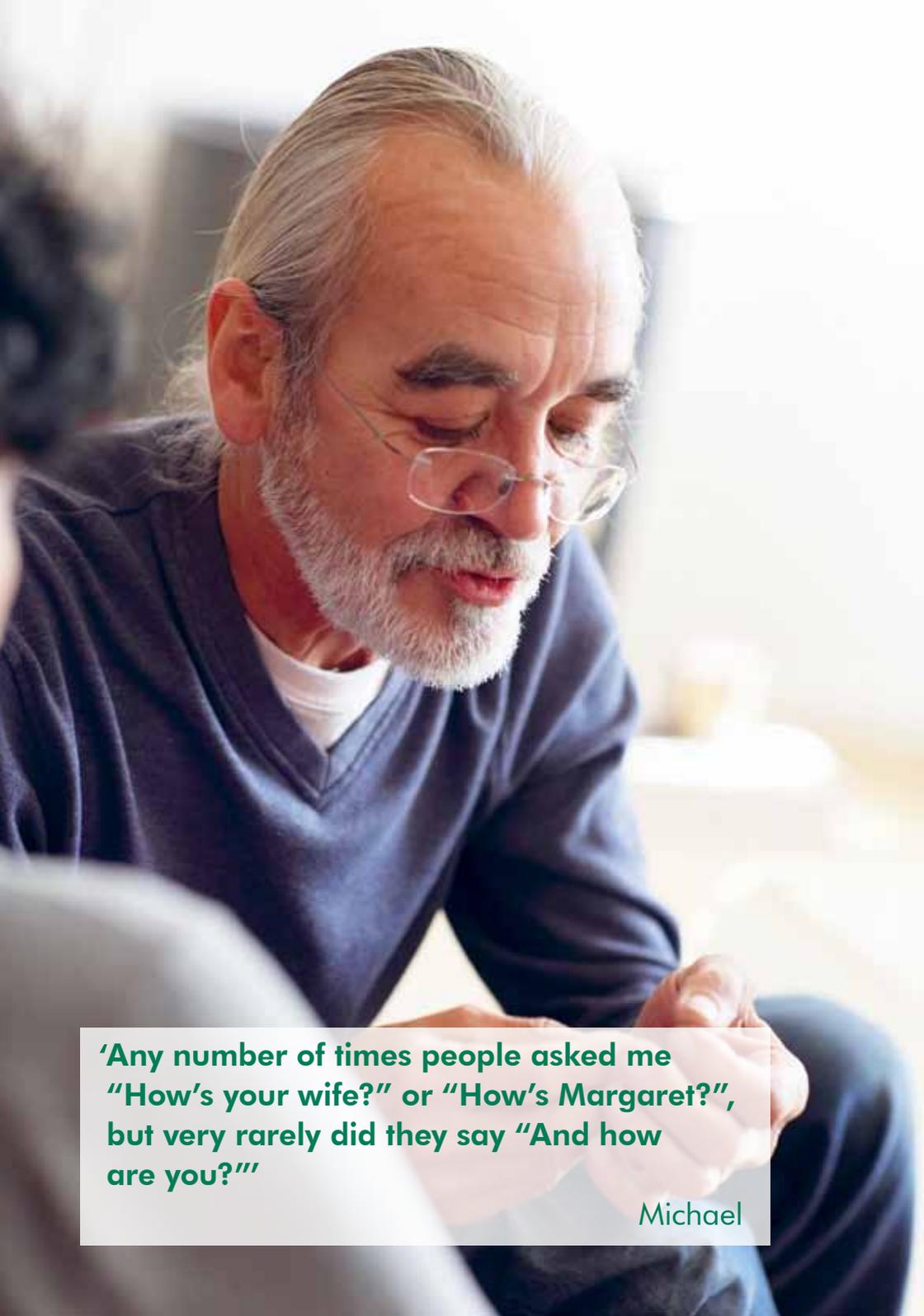
- Remember that no two situations are identical and no two experiences of caring are the same. This is why the handbook is not intended to be a book of instructions on how to be a carer. Instead, it includes lots of things that will hopefully strike a chord with you.
- When it comes to medical questions, it's essential you speak to a healthcare professional for advice.
- You will often see reference to 'the patient'. Although this may not be the ideal choice of words, it's a practical way to refer to the person you are caring for – a shorthand way that's easily understood.

If you'd like to discuss the information in this handbook, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. Macmillan has a team of experts who can answer any questions you have, offer support or simply listen if you need a chat.

If you're hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

If you find this handbook helpful, you could pass it on to family and friends or the patient's healthcare team. They may also want information to help them support you.

The Experienced Carers Group



'Any number of times people asked me "How's your wife?" or "How's Margaret?", but very rarely did they say "And how are you?"'

Michael



Information and support

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Sometimes, as a carer, it can feel as if you're on your own. But getting reliable information, in a format to suit you, can help you feel more in control of your situation.

We found having information helped us feel less isolated, and reassured us that help was available. It also relieved some of our worry and stress.

Information can make it easier to anticipate some of the difficulties you and the person you are caring for may face, helping you to be prepared and plan ahead. It can help you get the right support at the right time.

We found it a real help to have information about the cancer itself, about organisations and professionals who can help, and information about the support available for carers.

Information about services

There's lots of information available about cancer and caring for someone with cancer, and there are many organisations that can help. Below are some of the ways you can get hold of this information. Just bear in mind that services may differ across the UK:

- Call the Macmillan Support Line on **0808 808 00 00**.
- Ask your key worker (see page 20), a hospital social worker, practice nurse, district nurse or your GP.
- Ask the staff in your hospital if there's a local cancer information and support service. You can also search for one at **[macmillan.org.uk/informationcentres](https://www.macmillan.org.uk/informationcentres)**

- Every hospital and NHS Trust in England has a Patient Advice and Liaison Service (PALS). It should be able to direct you to local sources of cancer information.
- In Scotland, visit **scot.nhs.uk/organisations** to find local sources of cancer information, or call NHS Scotland on **08454 24 24 24**. In Wales, you could ask your local Community Health Council – call **0845 644 7814** for information about your local branch. In Northern Ireland, you can find this information on the Northern Ireland Cancer Network’s website **cancerni.net** or call the Northern Ireland Cancer Helpline on **0800 783 3339**.
- Your local hospice may also be a good source of information. It’s there to provide support to people with life-threatening illnesses and not just to those who are terminally ill. They may have information about training courses available to help you with your caring role.
- The internet may be helpful, but it’s always important to go to websites where the information is reliable and quality-checked. See pages 121–122 for some websites that are considered to be accurate and up-to-date.

Speaking to people who are going through the same thing as you can be helpful. Online forums, where you can chat about cancer and the caring role, can be a good place to share your experiences and feelings, get support and ask for information about services. Macmillan’s online community is a good place to talk to other carers. Visit **macmillan.org.uk/community**

Attending a self-help and support group – a group that meets so people can share similar experiences and support each other – may be something you’d benefit from. Visit **macmillan.org.uk/selfhelpandsupport** or call **0808 808 00 00** for information about groups in your area.

Your local council may also run a carers' group or forum where you can find out about services and support in your area. Contact your local social services or social work department for further details.

Practical tip



Always try to follow up the leads you are given – you'll find there's a lot of information, help and support out there.

Don't be put off if you find someone unhelpful when you're looking for information – keep on asking until you get the answers you need.

Organisations that can help

Carers' centres provide a variety of support for carers, including information, advice and training. You can find your local carers' centre by calling The Princess Royal Trust for Carers (see page 107) or by searching at [carers.org/carers-centres](https://www.carers.org/carers-centres)

Carers Direct is a free, confidential service provided by the NHS. Its helpline and website provide information and advice for carers. It can also tell you about national and local services for carers that can provide more in-depth support, such as advocacy and counselling. Call Carers Direct on **0808 802 0202** or visit [nhs.uk/carersdirect](https://www.nhs.uk/carersdirect)

Caring with Confidence is a free, online training programme for unpaid carers. It provides carers with information and support to empower and help them develop their caring

skills. It includes online sessions and downloadable self-study workbooks. Some group sessions may be available through your local council. To find out more, contact Carers Direct or visit caringwithconfidenceonline.co.uk

Carers UK offers information and support to carers and can put you in touch with local support groups – see page 106 for contact details.

Crossroads Care services provide practical care and support in the home to give carers a break – see pages 106–107.

Macmillan Cancer Support helps carers every day. It offers a wide variety of information and support, including free training and development opportunities for people affected by cancer. See chapter 10 for more information about the services it provides.

Getting information about the disease and how it will progress

Remember, there are no definitive answers – this is your personal journey, specific to you and the person you are caring for.

Practical tip



We found that many healthcare professionals will only give you the information you ask for, so you may find it helpful to make a list of questions before talking to them. And don't be afraid to ask something more than once if there's anything you don't understand.

Having detailed information helped us understand more about the particular cancer we were dealing with, for example, where secondary cancers may occur. But bear in mind that as a carer you may want information that the patient isn't, and may never be, ready for.

Information booklets can be useful. You can visit your local cancer information and support centre or call **0808 808 00 00** to find out what's available. You can also order Macmillan resources at **be.macmillan.org.uk** or see the information online at **macmillan.org.uk/cancerinformation**

Many organisations concentrate on a particular type of cancer, such as lung cancer or breast cancer. You can find out about these organisations by calling Macmillan. The Rarer Cancers Foundation offers advice and information to individuals with rare and less common cancers, and their carers. Call **0800 334 5551** or visit **rarecancers.org.uk**

Some healthcare professionals may provide you with an information prescription. This is written information (printed or emailed) that's tailored to your individual needs.

Your rights as a carer

Carer's assessment

If you provide 'regular and substantial' care for someone over 18, you have the right to a carer's assessment from the social services department at your local council. This is a chance to discuss what help you need as a carer.

This is your right by law, under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children

Act 2000. You don't have to be living with, or related to, the person you care for to be assessed.

The person you care for can also have their needs assessed (called a community care assessment), but if they don't wish to, you are still entitled to an assessment of your needs.

To get a carer's assessment, contact your local council's social services department (social work department in Scotland) – you'll find the number in the phone book.

Social services must provide you with relevant information and reach an agreement with you on the services they're going to provide. They should respect your wishes and the wishes of the person you're caring for.

As a result of the carer's assessment, social services may provide you with things such as breaks from caring or help with cleaning your house. Your right to an assessment, and to the services and support you may receive, is not linked to your income or capital. However, after the assessment, your local council will look at your savings and property to decide which care services you may be charged for.

It's important to be aware that even though your needs may be recognised, it doesn't necessarily mean you will get the help you need. If you aren't happy with how the assessment was carried out or don't think you're getting the support you need, you can contact your local council to complain. Also, if the situation changes, contact social services again to have your needs reassessed.

For more information about carer's assessments, contact your local council or Carers Direct (see page 106).



A guide to benefits and financial help
for people affected by cancer

HELP WITH THE COST OF CANCER

Practical tip

We found that some services didn't offer the level of care we expected and some people we dealt with didn't understand what we were going through. Be prepared to have a thick skin.

Flexible working and time off in an emergency

If you are caring for an adult who is a relative or lives at the same address as you, you have the right to ask your employer for flexible working hours. You also have the right to take unpaid time off work for dependants in an emergency. See chapter 6 for more information.

Protection from discrimination and harassment

People with cancer and their carers are protected from direct discrimination and harassment under the Equality Act 2010. This applies to people living in England, Scotland and Wales.

The law in Northern Ireland is different – people with cancer are protected by the Disability Discrimination Act 1995 (DDA). Following the decision by the European Court of Justice in *Coleman v Attridge Law* (2008), carers who are also employees are protected under the DDA (as amended) from direct discrimination and harassment in the workplace in Northern Ireland. See chapter 6 for more information about your rights as a carer.

Entitlement to financial support

You may be entitled to certain benefits and financial support as a carer. You can speak to a benefits adviser by calling Macmillan on **0808 808 00 00**.



‘Working with professionals is about sharing the care. We both have a role to play.’

Jean

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Working with professionals

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When someone close to you is living with cancer, you are likely to come into contact with a number of health and social care professionals. These could include social workers, physiotherapists and occupational therapists, as well as the GP, oncologist and district nurse.

Increasingly, there will be one person who is the main point of contact for you and the patient – professionals may call this person your **key worker**.

We found it was helpful to treat our relationships with these professionals as a partnership. Sometimes we found we had to take the initiative to make this happen. Working together as a team will help you and the patient get the best from the knowledge and skills they can offer.

Practical tip



Healthcare professionals don't always have all the answers. Try to find out as much as you can about each individual's role. Then you can turn to the right person straight away when you have a question or problem. It will also give you realistic expectations about what they can do for you and the person you're caring for.

If you can give them as much up-to-date information as you can about both the patient's situation and how it's affecting you, they will be better equipped to help you both.

Remember that the key worker and the healthcare team are there for you as well as the patient – you can ask them questions about the cancer and your caring role. But there may be times when they can't share information with you about the patient, or with the patient about you, particularly if you or the patient have asked them not to.

Organising

We found it helpful to add all useful telephone numbers (for the key worker, district nurse, GP, cancer ward and local hospice) into our home and mobile phones, and we noted down the name of receptionists.

You could also keep a notebook with details of every visit to hospital or from any professional at home. Try using a file to keep all leaflets, information sheets, appointment details and other useful information together in one place.

It may also be useful to keep a record of blood tests or x-ray appointments and their results. This will make it easier to query any oversights and may help if you need medical assistance out of hours (see pages 22–23 for more information about this).

Make sure your GP knows you are caring for someone. Tell them this even if you and the patient are registered at the same practice. They may not be aware you are a carer.

Before going to an appointment with a healthcare professional, talk to the person you are caring for about which questions they want to ask and what you want to ask. Write them down so you don't forget.

2 If the person you are caring for is coming home from hospital, ensure you have all the information you need to cope at home before they leave.

Getting hold of professionals in an emergency or out of hours

The out-of-hours period generally runs from 5pm–8am on weekdays, and all day at the weekends and on bank holidays. This is a large amount of time when many services are unavailable, and out-of-hours services can vary depending on where you live. We found that distressing things can happen during these times and some of us had to take on responsibility for healthcare tasks ourselves.

Make sure you know the out-of-hours arrangements for your area. Ask your GP or key worker: what signs, symptoms or situations would indicate concern; who you should contact in case of an emergency; and how to do this. Make sure the telephone numbers you need are always to hand – either programmed into your phone or taped to the fridge.

You can get medical advice out of hours by calling NHS Direct in England and Wales on **0845 46 47**, or NHS 24 in Scotland on **08454 24 24 24**. Contact numbers in Northern Ireland vary, but are listed at **nidirect.gov.uk/out-of-hours-service**

If you're concerned that the patient's condition, symptoms or needs have changed, contact the hospital or your key worker immediately. If it's left until near the weekend, it will be more difficult to sort out and the patient's condition may deteriorate.

If the situation is urgent, either call your key worker or the hospital ward or department where they were last looked after

for immediate advice. If you do need to go to Accident and Emergency (A&E), any information you can bring along will help, such as a patient diary or treatment summary record.

Practical tip



Try to anticipate problems that may come up out of hours so you can discuss them with professionals during the working day and decide in advance what you should do for each situation. It's also helpful to have a plan in case you can't care for the patient at short notice, for example, if you're ill. We discussed this with social services and the local carers' centre, which provided emergency numbers for the patient. If you need help and support, say so.

Communication between different professionals

Note down the names of all the professionals, and their secretaries if possible, involved in the patient's care. Try to find out how they work together to keep each other informed and up-to-date. For example, how often do they meet and when?

Although the healthcare professionals will keep the patient's medical records, it's helpful to have your own notes of appointments, conversations and other important information, as it provides a personal record and helps you keep track of what's been agreed.

Keep records of the drugs the patient is taking so you can double-check prescriptions are correct. You can also monitor and note down how the patient is feeling, for example, between each chemotherapy session.

Care plans

2

Everyone with a long-term condition should have a care plan if they want one. A care plan is an agreement between the patient and their healthcare professional (and/or social services) to help them manage their day-to-day health.

Ask the key worker or oncologist what care plan has been organised for the patient, including what support they will get following treatment or after leaving hospital. Make sure you are clear about what support is available, and ask to have the details explained to you. If you are offered help with personal care, make sure you ask if there is a cost involved, as these services are not always free.

Support for professionals

Remember, they're human too! A smile and saying thank you can go a long way.

You may find that professionals get emotionally involved, especially if they are working with you and the patient for a long period of time.

During treatment and procedures you may be able to offer practical support, for example by holding the patient in a certain position, or comforting the patient by simply holding their hand.

Predicting the outcome (prognosis)

Cancer is a very personal journey. It can be difficult to accept, but a prognosis is only an informed estimate – everyone is different. Be aware that professionals often don't and can't know everything – things can turn out differently from what's expected.

Being assertive

As a carer, being assertive is really important. You will need to be prepared to challenge people – you may find this easier than you think! Don't let others rush you.

Learn as much as you can about cancer care. If you don't understand something, ask for it to be described in more basic terms. You can't be expected to understand complicated medical terms and jargon.

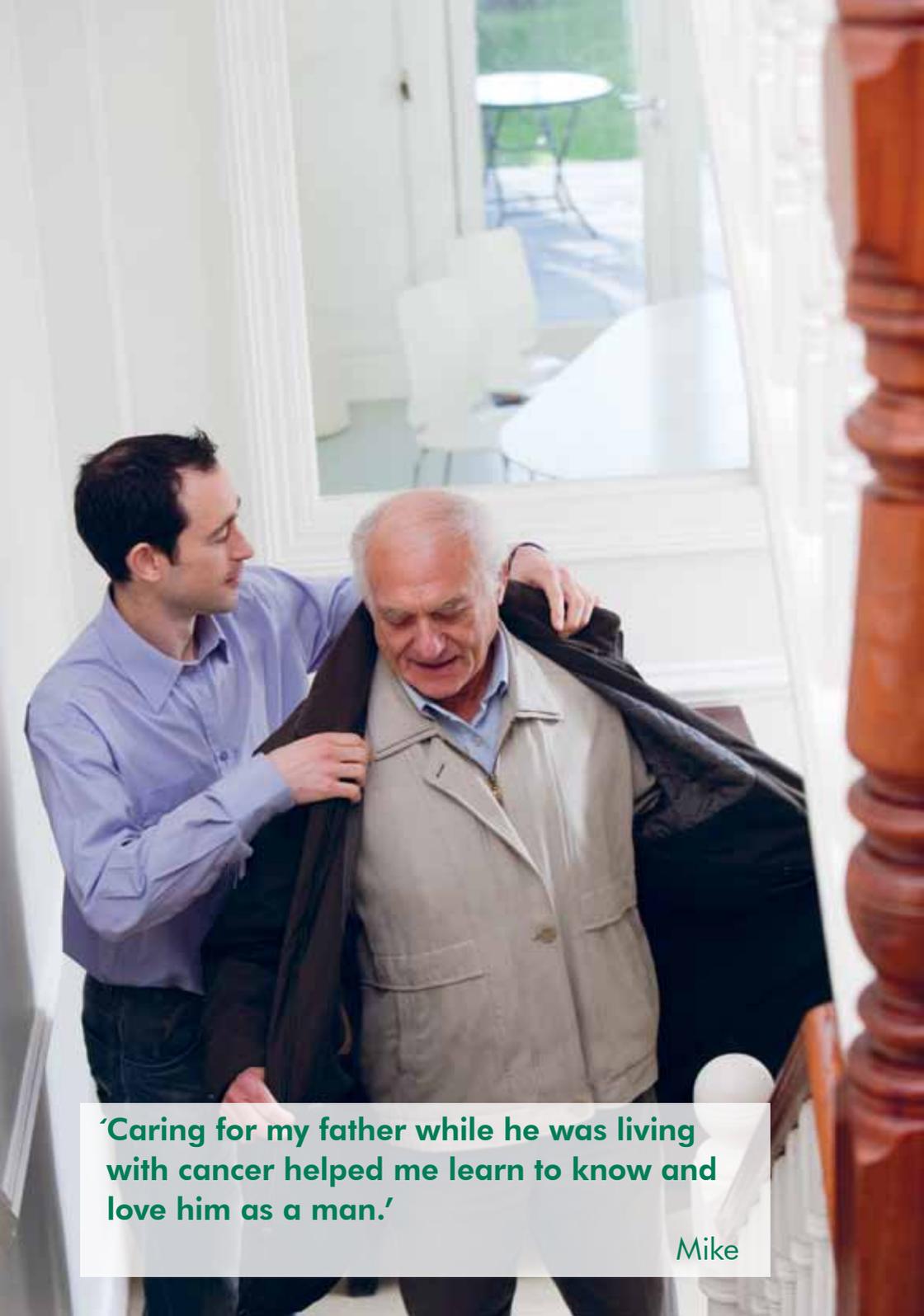
If you're unhappy with the treatment the patient is receiving, say loud and clear that this is how you feel. Macmillan's leaflet *Getting the best from your cancer services* contains questions patients can ask professionals at any time during their cancer experience. Each question is followed by a description of what should happen according to national guidelines.

Practical tip



Take your notebook of information about the patient's care with you to hospital visits. It will help you remember key points about their health so you can answer questions easily. Also ask for a copy of any patient notes and letters during your visit. You will need to ask for the patient's permission before doing this.

Try to be brave enough to tell people when it's not a good time to visit – seeing the wrong person at the wrong time can make the patient feel much worse.



‘Caring for my father while he was living with cancer helped me learn to know and love him as a man.’

Mike

3

Relationships

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Relationships play a very important part in our lives. We found that when we were caring for someone close to us, our relationships with that person, and with family members and friends, could come under a lot of extra strain.

Our relationships also changed and developed, sometimes in very positive ways.

When someone close to you has cancer, you and the people around you will face many situations you are unlikely to have met before.

People have their own ways of coping when faced with a stressful situation – you may see changes in someone’s personality.

Try to tackle any issues with your relationships rather than ignoring them. If your relationships are difficult, it can make the caring role even harder.

We also found that coping with cancer can be an experience that brings people closer together. Relationships that are working well can be a great source of strength – both to the person you are caring for and to you as a carer.

Your relationship with the patient

Patients and carers form a partnership. What has an effect on one usually has an impact on the other. You’re not in this on your own.

Try to be prepared for the ups and downs. This isn't going to be easy for either of you. You may both be trying to protect one another and find it hard to show emotion. You may be coping with your own illness or health condition too.

It's important to still nurture the relationship you had with the patient before their illness. You are still a mother/brother/partner/friend. Be positive, supportive and reassuring, but most of all be there for them.

Practical tip



Try to be yourself and live as normally as possible. Behaving differently can make the patient feel more aware of their condition.

It's important to let the patient know, when possible, that although you are there to help, they are still in control. Make a point of asking if the patient needs you to do something. Be careful not to make all the decisions – make sure the patient always has a choice.

We found maintaining continuity and a sense of normality in day-to-day life is important, especially when children are involved. Patience and humour are invaluable, so don't be afraid to laugh.

Family relationships

It's important to be aware that your family will have certain ways of doing things. When a family member is seriously ill, these may be affected. If there are already strains and tensions,

these can be magnified in a stressful situation. Spending time together and talking openly is important.

Don't be surprised if difficult and emotional situations arise. Be honest with each other about how you are feeling and make sure you give each other space when needed.

Inevitably, as the main carer, you may feel pressured to act as a counsellor for the rest of the family, and possibly others as well. While it is good to talk, be wary of taking on other peoples' problems. You won't be able to please everyone, so don't try – and don't worry about it.

Try not to become defined by your caring role alone. Recognise that you may benefit from counselling, support from a professional, or at least by talking to someone outside the family. You will have a lot to cope with and it may help to draw up a list of priorities.

Have the courage to say 'no' to people when necessary, especially if their request isn't a priority for you. Also be prepared to agree on boundaries, for example, when and for how long people should visit.

Younger family members

Young people can be more accepting and realistic than adults. They are also likely to ask more questions. *Let's talk about you*, Macmillan's booklet for young carers aged 12–18, has lots of useful tips and advice for young people who may have some caring responsibilities. You may also like to read Macmillan's booklet *Talking to children when an adult has cancer*. Macmillan runs courses that may improve the way you communicate with the patient and your family and friends.

See pages 100–102 for details.

Juggling responsibilities

Sharing responsibilities can help you cope – discuss how you can do this with family members, friends and other carers.

You may need to share out some of the everyday responsibilities that you no longer have time to take care of. Consider using a rota to show individual family members' specific responsibilities and needs.

You may feel reluctant to receive help. Having a list of simple things people can help you with can make it easier to accept support. For example, someone could do some shopping for you, take the kids out for an afternoon or collect prescriptions. Stick the list on the fridge or carry it around with you.

Make sure the patient feels involved. Allow them to take as much responsibility as they are able to for their own care, family issues, finances and other decisions. Try to be sensitive to feelings and upsets. Take each day and its problems one step at a time, and try to keep family life as normal as possible.

Friends

Your friends, colleagues and neighbours may be able to provide emotional support too, but if there are people that the patient doesn't want to see, don't be afraid to tell them it's not a good time to visit.

Sometimes, family and friends may avoid you and the patient altogether. We found this difficult, but it's likely that they just don't know how to open up. You could try breaking the ice by inviting them to ask questions.



Living on your own

Not everyone will have the support of family or friends when they are caring for someone with cancer. However, there are services and organisations (see chapter 11) out there to help you feel less isolated and provide you with someone to talk to about any difficulties you are facing.

Further information

You could join a self-help and support group and speak to other people affected by cancer. Visit [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport) or call Macmillan to find a group in your area.

You can talk to other people affected by cancer, including carers, online. Macmillan's online community can be found at [macmillan.org.uk/community](https://www.macmillan.org.uk/community) You can also call Macmillan's cancer support specialists on **0808 808 00 00**. They will listen to your particular issues with empathy and respect.

You can get confidential information and advice from Carers UK by calling **0808 808 7777**. The Princess Royal Trust for Carers also provides support and advice – see page 107. Crossroads Care runs schemes in England and Wales that provide practical support to carers. Crossroads Caring Scotland and Crossroads Caring for Carers (Northern Ireland) offer similar services. See page 106–107 for contact details.

Time for yourself

You will need time for yourself, so don't be afraid to ask for help from friends and family or accept help when it's offered.

Even short periods of time to yourself can make a huge difference. We found having a hobby, such as gardening, was a good way to get some time away from caring for a few hours.

You may feel that you want to be there all the time, particularly if the patient is nearing the end of their life. It's up to you to decide what's best for you and the person you're caring for.

Make sure people who offer to help know what's involved and be specific about how you would like them to help.

Some offers of help may come from people who can't offer the support you need, or who you or the patient don't necessarily want to help you at the time. It's okay to turn down offers of help.

Sex and intimacy

If you are caring for your partner, it's normal for your sex life and the way both of you feel about your sexuality to be affected by cancer and its treatment. However, sex may be one of the things that brings normality to your lives.

Talking openly with your partner about sex can help you overcome any problems and lessen your worry.

Speak to your partner about whether or not they need time and space to recover from treatment. You may feel that you want

to be more attentive to each other and that you have a more active sex life following the patient's diagnosis.

We found that touching, kissing and massaging can be a comforting and relaxing way to be intimate with each other. It can also be soothing to touch and stroke the patient's scars from surgery.

You may need to use condoms for a few days after the patient's had chemotherapy. Talk to a doctor or nurse about this.

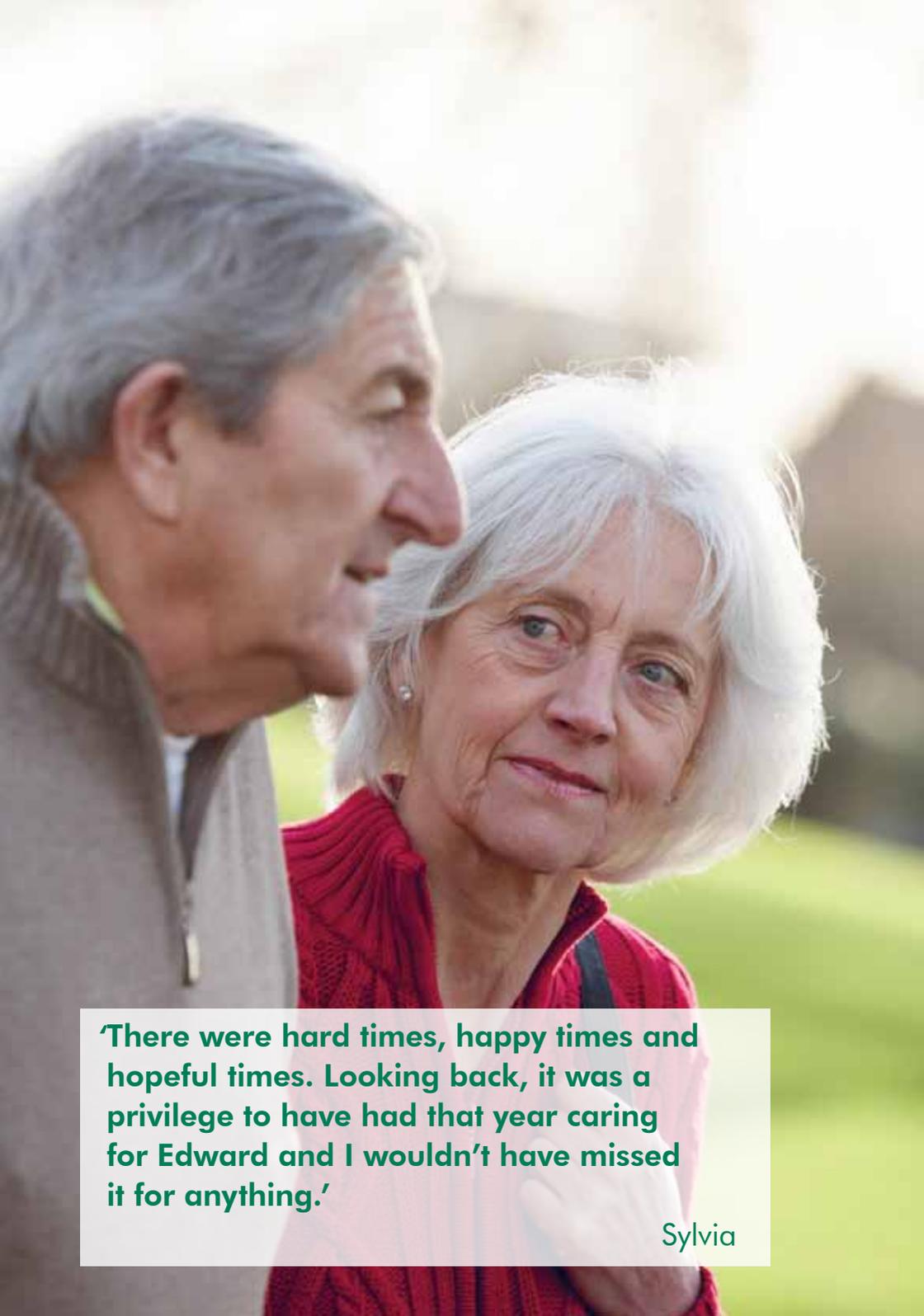
Remember that doctors and nurses will have previously talked to other carers and patients about delicate issues like sex. If you feel comfortable, talk to them about any concerns. They can talk to you about how cancer and treatment may affect your sex life.

Macmillan has information about relationships, sexuality and communication. You can order it by calling 0808 808 00 00 or visiting be.macmillan.org.uk

Symptom transfer

You may have feelings of guilt about a loved one's pain and wish you could take it away.

Occasionally, carers can find themselves getting minor ailments and/or symptoms similar to the person they are caring for – as if the symptoms are transferring themselves from patient to the carer. While this is unusual, it can happen. See your GP to make sure there is no actual physical cause for your problem.



'There were hard times, happy times and hopeful times. Looking back, it was a privilege to have had that year caring for Edward and I wouldn't have missed it for anything.'

Sylvia

4

Moods and emotions

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Denial	43

Moods and emotions – you have them too, and they matter! As a carer you are likely to be very aware of the feelings and emotions the patient is experiencing.

4 Family and friends will be thinking about this too. But it isn't only the patient who has feelings. People may forget to ask how you are feeling, but your feelings are important and you shouldn't assume that you must always put them to one side. However you feel is okay.

There's no need to apologise or feel guilty for having strong emotions or moods yourself – it's only natural. It's important that you find ways to express them, and to find the support and space that you need for yourself.

In this chapter, we've put together some ideas about coping with some of the feelings you and the patient may come up against.

Patient's depression/anxiety

If you're concerned that the patient is depressed, tell a healthcare professional and consider suggesting counselling.

If the patient is very unwell, they may become preoccupied and inward-looking. You may also notice that they have less empathy if they are taking strong painkillers.

There are things that can help to lift their spirits, such as relaxation techniques, mood music, books or audiobooks, or having a television in the bedroom.

Visitors can also help to lift the patient's spirits, or you could encourage the patient to talk to other people in a similar situation.

Many people find that complementary therapies such as reflexology, massage or aromatherapy can be helpful.

If the patient is experiencing panic attacks it can be helpful to keep a supply of paper bags nearby. Breathing into a paper bag can slow down their breathing and help them feel better.

Take time to sit together with family or friends and talk about your favourite memories. Remember that you're not the cause of the depression or anxiety.

Carer's depression/anxiety

Don't be afraid of your own emotions – this is a very difficult time and strong and confusing emotions are not unusual. Ask for support whenever you need it.

Take some time out from caring. There is usually help available so the patient isn't left alone while you recharge. Some carer organisations offer free respite care – see pages 106–107 for details.

Ask a good friend to listen to your worries and concerns. Also talk to the person you're caring for about how you are feeling. They may be able to offer you support and may be glad to be asked.

Gentle exercise, like a 10-minute walk, can also help to improve symptoms of depression and anxiety. Be careful about drinking too much alcohol.

Spend some time alone relaxing – have a candle-lit bath, listen to some of your favourite music or treat yourself to some of your favourite foods.

Consider speaking to your GP or a counsellor too. They can help you manage any depression and it may help to speak to someone outside of your caring situation.

If you are feeling distressed, you could also call Samaritans – a confidential emotional support service available 24 hours a day – on **08457 90 90 90**.

Remaining positive

Don't forget that you are only human and that your best is good enough. Trying to get the most out of your day personally can help you remain positive. If you have any spare time to yourself, think about what will give you a boost. It may just be reading a newspaper and having a cup of tea.

Try some activities that divert you from the situation. For example, we found it useful to try to carry on with our hobbies and interests where possible.

Continuing to work, if you can, may be a good distraction or release and it can provide a sense of continuity in your life. There's more information about work matters in chapter 6.

Talking about good times with the patient and not worrying about your current situation can help to lift spirits.

Feel good that you have made a difference to the person you are caring for. Remember that you're doing something very positive by helping to reduce their stress and pain.

At the end of each day try to remember something good you and the patient did together or something that made you both laugh.

Be Good to Yourself is a workshop run by Macmillan that could help you manage negative thinking and plan ways to live a healthier life. To find out more, call **0808 808 00 00**, email **learning@macmillan.org.uk** or visit **macmillan.org.uk/learnzone**

Guilt

Feelings of guilt and rejection are common. Don't worry if you or the person you are caring for experience these feelings. If you can, try to share your feelings with your family and friends.

Remember, whatever you feel able to do is enough. Try not to feel guilty about having time to yourself – it's very important and can help you be a better carer.

Feeling isolated

Try to share your worries with the person you are caring for. Touch and cuddle the patient – a loving touch can work wonders.

Some of us had trouble communicating with the patient, but talking to a professional helped.

You could speak to other people affected by cancer by joining a support group. You can find your nearest support group by calling Macmillan on **0808 808 00 00**.

Fear

Try to understand what you are afraid of. We often fear the unknown most of all, so the more you can learn about what frightens you, the easier it will be to deal with your situation.

Don't be afraid to ask questions. Knowing the facts will often help alleviate fear. Religious and spiritual leaders may be a good source of support and comfort to you.

Anger and frustration

You may not experience anger, but don't worry if you do find yourself feeling this way as it's a common reaction. It's really important to express your feelings as they arise, because they may intensify if you try to suppress them.

If you do feel angry, a hobby or sport where you can release your anger and frustrations may help. You may find it helpful to talk about the anger you are feeling to a friend, counsellor or someone at a support group.

When you are feeling angry or resentful of your situation, it may be helpful to write things down. Even with members of your family and close friends, it's difficult to fully express how you feel.

Patients can sometimes take their anger out on the people closest to them. Try not to feel responsible for their emotional turmoil. Some cancers can affect a patient's personality – for example, lead them to have sudden fits of anger. Speak to a healthcare professional about whether the person you are caring for may be affected in this way.

Carer's tiredness/exhaustion

Rest whenever you can. Short naps can help to revive you. Try a relaxation CD – an hour or so in a state of deep relaxation can make you feel as if you've had a long sleep.

It's important to look after yourself by eating healthily and keeping up your fitness.

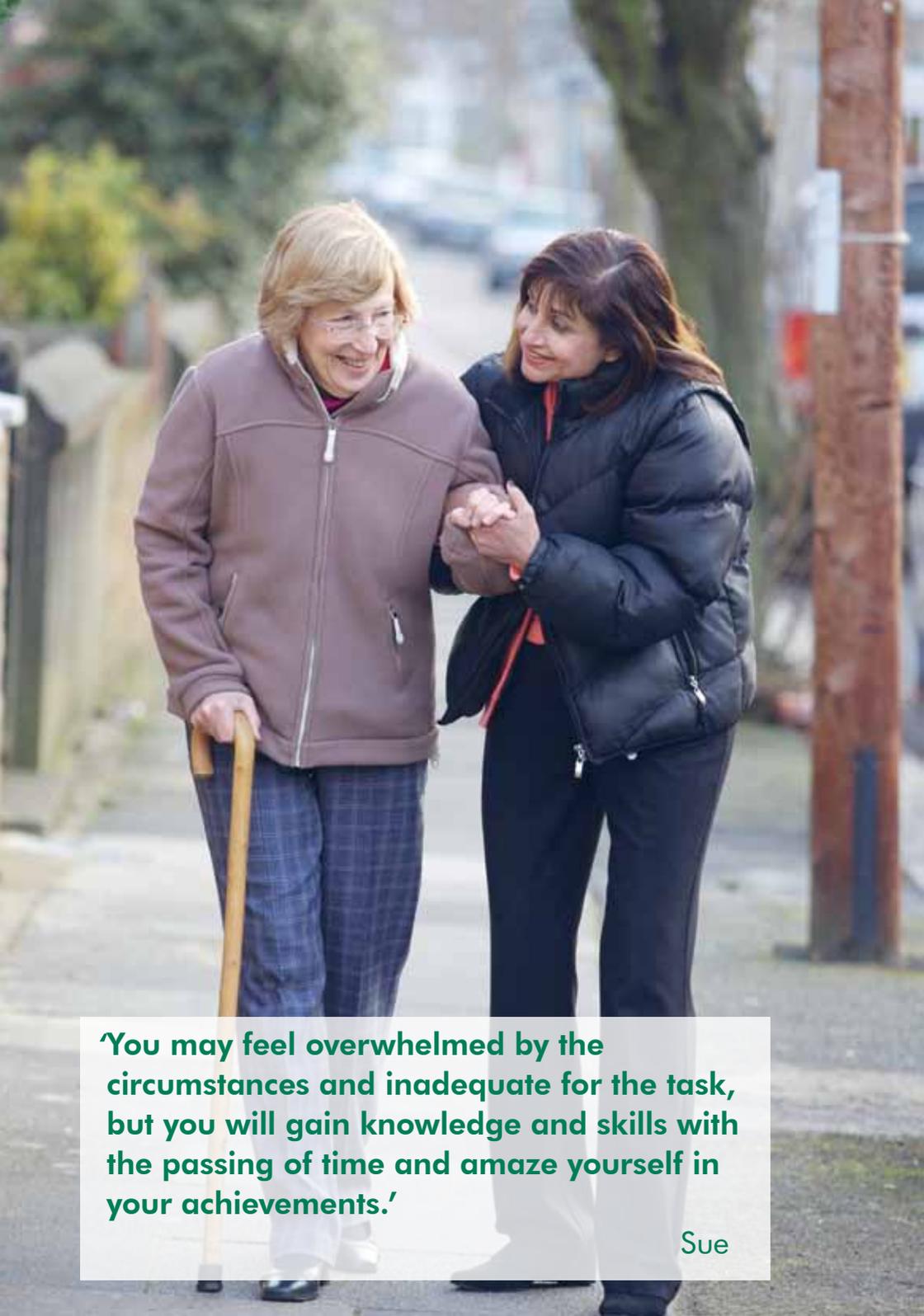
Consider having a flu jab. Carers are automatically entitled to one for free so ask your GP about getting one. Don't neglect your own health – if you get ill, see your doctor as soon as you can.

Denial

In our experience, denying a cancer diagnosis is a normal reaction. However, avoiding the reality of a situation can stop people from doing things that they need to do, like going for treatment or sorting out any money problems.

Denial is not just something the patient may experience – it can affect you and your family and friends too. If you are in denial, don't blame yourself or feel that you must hurry to overcome it. Denial is a coping mechanism that both a patient and carer will often use when the patient is diagnosed with terminal cancer. We talk more about this in chapter 8 – 'Death, dying and bereavement'.

Consider speaking to your local hospice about the support they can provide to give you some time off from caring. Denial can be a useful way of handling news of a cancer diagnosis, but if it goes on for weeks or months – or causes problems in communication – it can become harmful or a problem.



'You may feel overwhelmed by the circumstances and inadequate for the task, but you will gain knowledge and skills with the passing of time and amaze yourself in your achievements.'

Sue

S

Practicalities

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There is a variety of practical issues you will find yourself having to deal with as a carer.

Day-to-day activities, such as housework, handling finances and personal care, are all important parts of caring for someone with cancer – and may be things you've not had to tackle before.

The practical help you give the patient can help you feel more confident as a carer. For example, if you can do small practical things to help the patient feel more comfortable, this can make you feel better too.

Practical tip

A local Crossroads scheme may be able to provide you with practical help around the house. See pages 106–107 for contact details.

In this chapter we have put together some tips for taking on practical tasks that may be new to you.

Food and eating

If possible, speak to a doctor or nurse about getting advice on food and drinks from a dietitian. The patient is likely to have changes in their appetite, so try preparing smaller meals more frequently for them. You can make small meals as energy-giving as possible. Try using high-calorie drinks, or adding milk powder to mashed potato. You could also add food supplements to the patient's portion of family meals.

Cancer treatment can alter the sense of taste, so it may help to offer the patient foods with a variety of textures as they may all taste the same.

Try not to make a big issue out of food and mealtimes. We used distractions like television to take the patient's mind off eating. Always ask them what they'd like to eat and try to include them in family mealtimes. If the patient really doesn't want to eat, accept it.

Moving and handling

The patient may need your help when moving around, for example, if their balance isn't good. We found that learning to move and handle the patient safely was beneficial to the patient and ourselves. Make sure you do this with care, and discuss with the patient what help they want from you. You may need a second person to help you with some manoeuvres to avoid injuring yourself.

Your local carers' centre may offer training in areas such as first aid and moving and handling. You could also contact the Age UK helpline on **0800 169 6565** or speak to your GP or district nurse.

Find out in advance what is offered locally by emergency services in the event of the patient falling or a similar accident.

Organising equipment and transport

There are aids that can help the patient cope at home. Ask the hospital or local social services department about household aids and wheelchairs. The British Red Cross also offers free courses for patient handling and can supply equipment.

Homemade aids can be very useful. For example, a plastic carrier bag on the car seat will help the patient to swivel in and out of the car if you don't have a special cushion.

Plan ahead. Take advice from healthcare professionals about what you may need in advance so the equipment is there when you need it. You can also ask them about getting free transport to and from hospital appointments. We often found that if you don't ask, you may not be offered the help you need.

Grants may be available from Macmillan and other charities for expenses like equipment and transport. Call **0808 808 00 00** for more information.

If you think that you are being supplied with equipment you won't use, make it clear to the appropriate person that you do not need it. Unnecessary equipment can clutter a house and be an inconvenience.

There is more information about reducing travel and parking costs in Macmillan's booklet *Help with the cost of cancer*.

Personal care

There are a number of things you can do to make the patient more comfortable. In the bath you could use a towel under the patient's arms and make a bath cushion out of foam and tied plastic bags. You could also put a towel on the edge of the toilet seat so that the patient can sit down more comfortably.

If required, try using a plastic urinal, commode or bowl so that the patient doesn't have to leave the bedroom to go to the toilet.

Some equipment may be obtained through a community equipment loan service, which is run locally by the NHS. Your district nurse, community nurse or physiotherapist will be able to arrange this for you. This equipment must be returned if you no longer require it.

Carry a thin foam cushion in a bag that you can discreetly put down to make the patient more comfortable when they are out. If the patient has problems leaving their bed, you could help them shave or wash their face with a bowl and mirror.

Consider buying a sofa-bed for the living room so the patient can lie down in the day and watch TV, see friends and be part of family life. This also means you don't have to run up and down the stairs, for example to take them food.

Investing in a high-quality adjustable bed can bring a lot of comfort to the patient and you. A Macmillan grant may be able to help with the cost of a bed or other items that will improve your quality of life or the patient's. Call Macmillan to find out more.

Prescriptions

Prescriptions are free for everyone in Scotland, Wales and Northern Ireland. People with cancer in England are eligible for free prescriptions. Ask your GP surgery or oncology clinic for an exemption certificate.

You may also be eligible for free prescriptions. Read Macmillan's booklet *Help with the cost of cancer* for more information or call **0808 808 00 00**.

Availability of drugs

It's good to be aware that not all pharmacies will stock the drugs the patient needs. Speak to a pharmacist about ordering drugs.

The majority of pharmacists now deliver drugs to patients and may deliver on Saturday. Your local pharmacist should be able to give you more information about this.

Pain control

Pain can be a real issue for people with cancer. People are often advised to take regular doses of medication so the pain relief is always in their system. Make sure any pain relief is taken as advised by the doctor.

If you have been asked to administer pain relief to the patient yourself, ask for clear guidance. It can be a frightening situation and it will help to know exactly what is expected of you.

Try using a tablet box so you can separate all the pills the patient needs to take that day. Keep a chart that shows all the pain relief being taken. It will help you develop a system that works. Some pharmacists can help with this, for example, by filling the tablet box with medication for you.

Tumours will sometimes put pressure on nerves, which can be very painful. Let the patient's doctor or nurse know if the pain isn't well-controlled.

You may worry if the person you're caring for is taking high doses of strong painkillers. It's important to remember that the right dose is the one that controls the pain, and this can vary.

If the person you are caring for has difficulty swallowing tablets, which is not uncommon, ask their key worker about other methods of pain control. It may be possible to use a syringe driver instead, which can be fitted to the patient and give automatic controlled doses of painkillers, avoiding the need for tablets.

Clinical trials

Clinical trials are medical research trials involving patients. They are carried out to try to find new and better treatments, including those for cancer.

Macmillan has more information about clinical trials.
Call **0808 808 00 00**.

Dealing with practical chores

Try to prioritise – do what has to be done to keep the house hygienic and don't worry too much about the rest. If you don't usually do the housework and cooking, ask a person who does to teach you.

Household finances

Due to the patient's illness, you may now need to manage the household finances. If you weren't already doing this it may seem daunting, but there's a lot of advice out there to help you deal with utility companies and banks.

Your local Citizens Advice can help. You could also call Macmillan, or the Carers UK helpline. Or go to a local carers' centre – find yours by searching at **carers.org/carers-centres** or by calling The Princess Royal Trust for Carers (see page 107).

Macmillan's guide *It all adds up* has more information about managing finances. Call **0808 808 00 00** to order a copy.

Financial help

Having cancer can be expensive for both you and the person you are caring for. There can be extra costs, such as travel to hospital, and as a carer, your income may reduce because you have to give up work or reduce your hours. However, there's help available, including benefits, tax credits and grants. This includes help to meet NHS costs, such as prescriptions, wigs, dental treatment, sight tests and glasses. Always ask for help when you need it.

As benefits change from time to time, it's a good idea to speak to an experienced benefits adviser. Macmillan can give you advice and help you access benefits and other kinds of financial support, or tell you if there's a local benefits advice service in your area. Call free on **0808 808 00 00**. You can also call the Benefit Enquiry Line on **0800 882 200** or Citizens Advice (see page 108).

The health and social care professionals involved with the patient may also be able give you advice and information on benefits and filling in forms, or put you in contact with someone else who can help.

Your local social services or social work department can put you in touch with a social worker or benefits adviser.

Grants are available from Macmillan to help people living with cancer meet some of the extra costs it can bring. Call **0808 808 00 00** to find out more.

Carer's Allowance is the main benefit for carers. It's a weekly benefit for someone caring for a person who is getting the care component of Disability Living Allowance (highest or middle rate) or Attendance Allowance. You need to care for someone for more than 35 hours a week to receive it, so it's handy to keep a diary of all the time you spend caring. This can help with your application. If you qualify, you may become eligible for other benefits.

There is also a national insurance credit called **Carer's Credit**. It enables carers to build up qualifying years for the basic State Pension, the additional State Pension, and Bereavement benefits.

If your caring role ends, it's important to let the Carer's Allowance Unit (Disability and Carers service in Northern Ireland) and other relevant benefits offices know about the change in your situation. This will help you to avoid problems further down the line. If you have a low income once your carers' benefits stop, you may be able to claim other benefits.

You can also find information about financial support for carers at **direct.gov.uk** If you live in Northern Ireland, visit **nidirect.gov.uk**

The patient may be entitled to a disabled parking badge for your car, which you can use when you're taking the patient out. Contact your local social services or social work department for more information.

You may also be entitled to a free tax disc (vehicle tax exemption). To find out, contact the Driver and Vehicle Licensing Agency (DVLA) on **0300 790 6801** or visit **dvla.gov.uk** In Northern Ireland, visit **dvani.gov.uk**

If you or the patient have to give up work and your income falls, you may be eligible for a tax refund. To find out, contact your local HM Revenue & Customs Enquiry Centre – look in the phone book or visit hmrc.gov.uk If your circumstances change, it's also worth asking if you are paying the right amount of tax.

Macmillan's booklet *Help with the cost of cancer* has more information about benefits and financial help. Call **0808 808 00 00** to order a free copy.

Getting documents in order

If the person you are caring for is dying, try to get all their financial papers in order. The hospital, your local Jobcentre or social security office may have helpful leaflets. If you feel it's a subject you can raise, find out whether the patient has made a will or not. If you have been asked to take on power of attorney, make sure you know what your responsibilities are and that the documents have been drawn up properly. See chapter 7 for more information about legal matters.

Other ideas

Check any life insurance policies – some pay out on diagnosis. If you and the patient look through your policies, you may find that you are covered for loss of income, medical treatment, credit cards, mortgage payments or other expenses.

Side effects of treatment

Treatments for cancer can have some unexpected and uncomfortable side effects. Ask the patient's doctor or key worker about what kind of side effects the patient may experience and how they can be managed.

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If you have an idea of what to expect, it will help you tell the difference between a normal side effect and something more serious. This can reduce unnecessary trips to hospital and save you a lot of worry. But remember, side effects vary from person to person, and they're not always possible to predict.

Being prepared for the effects of treatment, such as a dry mouth, nausea or constipation, means you can learn ways to handle these problems. Being able to alleviate some of these side effects can help you feel like you're doing something positive to help the person you're caring for.

Not all of us knew what side effects to expect or ways we could handle them. We urge you to find out as much as you can.

Here are some of the common side effects the people we were caring for experienced – it's not an exhaustive list. The tips for treating these side effects are things that worked for us.

Dry and sore mouth

- Ideally, the patient needs to see their dentist before they start any treatment. They should tell the dentist that they have cancer.
- It's possible that dental work may be done on the NHS, either at the hospital or a local dental practice.
- Hygiene is very important – the patient should use mouthwashes and regularly replace their toothbrush.
- Eating pineapple before a meal can enhance taste buds and increase saliva production. Drinking pineapple juice may also help.

- Sucking on pineapple or frozen grapes, or gargling with water and a few drops of tea tree oil, can soothe the mouth.
- Always have a drink to hand.

A sore and dry mouth is a symptom that can continue after the patient is better.

Indigestion, nausea and vomiting

- Frequent, small amounts of food can often help, even if the patient doesn't feel hungry.
- Try peppermint or ginger tea, or crystallised ginger.
- If the patient has indigestion, discuss it with the doctor.

Constipation

- Try to learn what you can about the causes of constipation and its treatment.
- Talk to the patient about what you can do to help them deal with this side effect.
- The patient may need to use suppositories or enemas – the district nurse can administer these.
- Prunes and liquorice can help.

Thrush

- This can be easily treated by the doctor.

Hair loss

- Tea tree oil shampoos can help relieve an itchy scalp.
- If a patient prefers to wear a hat when they are outside, make sure you have one to hand.

Other side effects of treatment

- Cancer treatment can seriously reduce a patient's natural immunity. So visitors shouldn't see the patient if they have an infection. If someone has been recently immunised, check with your GP if it's safe for them to visit the patient.
- Breathlessness can be a problem with certain types of cancer.
- Seek medical advice about sex during treatment.

Macmillan has information about coping with symptoms and side effects, including all of those mentioned above. Order it by calling 0808 808 00 00 or visiting be.macmillan.org.uk.



'While my wife survived cancer, the disease killed my business.'

Michael



Employment and work

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When you are a carer, finding a balance between work and caring can be difficult, but it's definitely not impossible.

You may be feeling unsure about whether to stay at work, leave or return to work. You may be self-employed and wondering if you can run a business and be a carer. Remember, you can take your time when making these decisions.

Speak to organisations that can give you independent advice. Having as much information as possible about your rights, who can support you and the options that are available to you is invaluable. You'll also find that speaking openly with the person you are caring for can help. They may surprise you with their thoughts on the situation.

Many patients see that work is something that provides carers with a release from their caring role. Whatever you decide to do, make sure it's the right thing for you as well as the patient.

Considering your options

Talk openly to the person you are caring for about how leaving or remaining at work may affect your situation.

Remember that if you don't consider what's best for you as well as them, problems may arise in the future and you may become resentful of the earlier decision. Take your time when considering your options. Naturally, you may feel emotional following the patient's cancer diagnosis. This may lead you to make rash decisions. Try to take some time off work so you have time and space to think.

If you are employed, it's a good idea to find out as much information as possible about your rights before speaking to an employer about your caring role. This also applies if your situation changes.

Cancer is considered a disability under the Equality Act 2010 (England, Wales and Scotland) and the Disability Discrimination Act 1995 (Northern Ireland). As a carer, you are also protected from harassment and discrimination under these acts. You can get independent advice from organisations such as Macmillan, Citizens Advice, Carers UK and the Equality and Human Rights Commission or Equality Commission for Northern Ireland.

Once you know more about your rights, speak to your employer about what options are available to you and be clear about what you need. For example, could you work flexible hours, do a job share or work from home?

The Work and Families Act 2006 and the Employment Rights Act 1996 give employed carers the right to ask their employer for flexible working if they're caring for: an adult who is a near relative, spouse or partner; a child; or someone who lives at the same address. An employer can refuse this request, but only where there is a recognised business case for doing so. If this happens, an employee can appeal the decision within 14 days.

You can find information about flexible working, work/life balance and caring for someone while working at **direct.gov.uk** You can also call Macmillan on **0808 808 00 00** or visit **macmillan.org.uk/carers**

If you are a member of a trade union, speak to your trade union official – they will be able to help you with any problems or legal issues you have at work.

If you find it difficult to resolve any work issues, you can contact ACAS (Advisory, Conciliation and Arbitration Service), an independent organisation that works with employees and employers to solve problems. Call their helpline on **08457 47 47 47** or visit **acas.org.uk**

Macmillan's booklet *Working while caring for someone with cancer* has lots more information.

Self-employment

If you're self-employed, you will have much more control over your working life than someone who is employed. However, you won't have the same rights and protection.

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We found it helped to be prepared. Talk to your bank manager and your accountant as soon as possible, and be prepared to answer questions about your situation. Also try to pay your tax promptly.

If you're considering applying for any benefits, it's a good idea to speak to an experienced benefits adviser, as it can be more complicated for people who are self-employed.

You'll need to decide whether or not to tell your clients about your situation. It can be helpful to think this through first and try to imagine what their reactions might be. Then you can be ready with information and suggestions to address any concerns they may have. If you belong to a professional association, they may be able to give you some guidance.

You may wish to take some time off work. Is there anyone who could cover for you? Family and friends may be able to help, or you could hire temporary staff or services. If you have

colleagues or associates, they may be able take on some of your work, but bear in mind the risk of losing clients.

We found it helpful to discuss our business commitments openly with the person we cared for. Together we were able to decide when they needed our support most and to keep these times free, for example, to attend key hospital appointments.

There are services to support small businesses and self-employed people. You can find details of these in Macmillan's booklet *Self-employment and cancer*.

Other ideas

Ask you local social services or social work department for a carer's assessment. See pages 14–15 for more about this.

Carers UK has a section on its website about work and caring. Visit [carersuk.org](https://www.carersuk.org) or call on **0808 808 7777** for advice on employment issues. Working Families also covers these topics on its website. Visit [workingfamilies.org.uk](https://www.workingfamilies.org.uk) or call **0800 013 0313**.

Jobcentre has a useful leaflet called *Help if you are ill or disabled*. It has information on financial and practical help, and is available from your local Jobcentre office. You can find the information online at [direct.gov.uk](https://www.direct.gov.uk) In Northern Ireland, visit [nidirect.gov.uk](https://www.nidirect.gov.uk) or contact the Social Security Agency (see page 109).

Remaining at work

If you work for an employer, you don't have to tell them that you are caring for someone, although it may help avoid problems in the future if you do.

Ask them for a private meeting. Speak to your manager or someone in the human resources (HR) department about your situation and ask them what options are available to you. Remember though, that their interests may not be the same as yours.

If you feel comfortable, tell colleagues about your situation. They may provide some invaluable support to you.

6

Many of us found work a welcome distraction. It took our minds off some of the problems we were facing at home and provided social contact.

At work you may feel worried or guilty about leaving the patient at home or about needing time off. Upsetting feelings can creep up on you. If you get distressed, ask your employer if you can go home for the day.

As a carer, you have the right to take unpaid time off work to look after dependants in cases of emergency. This right is covered by the Employment Rights Act 1996, as amended by the Employment Relations Act 1999. In Northern Ireland these laws are called the Employment Rights (Northern Ireland) Order 1996 and the Employment Relations (Northern Ireland) Order 1999.

Possible emergencies may include a breakdown in care arrangements, the patient becoming ill or having an accident, or you needing to make longer-term care arrangements.

Your employer may also have a policy for taking time off work, such as carers' leave or compassionate leave.

You also have the right to ask your employer for flexible working hours – see page 17.

If your situation does change, consider speaking to Macmillan or Citizens Advice about your rights before you talk to your manager or HR department.

Leaving work

Think carefully before you resign. Resigning is a permanent step, and the way you leave can have an impact on your finances. Consider whether giving up work is something you can practically afford to do.

Get expert advice before you announce your decision, as your pensions, insurance and benefits could be affected. Citizens Advice, the Pensions Advisory Service (see page 109) or an independent financial adviser (see page 109) could help you. Macmillan's cancer support specialists can also help.

Make sure you don't feel pressured to give up your job. If you do, speak to someone in your HR department, or call Macmillan or the Carers UK helpline for advice.

If you are sure that you want to leave work, think about asking for a career break and see if you can come back once your caring role ends.

If early retirement is an option, discuss it with your employer. Remember that for some people it's an advantage, but for

others it can leave them financially worse off. Get expert advice to see if you would benefit from early retirement.

Returning to work

Before returning to work, it may be worth seeking advice from an independent organisation about your rights and how your pensions, insurance and benefits could be affected.

Try Citizens Advice, the Pensions Advisory Service or an independent financial adviser (see page 109).

After having time off from work, which may have covered a period of weeks, months or years, it may be helpful to have a gradual, flexible return to work. If you are returning to your old place of work, have a catch-up meeting with your employer before you return.

If you are still caring for someone after returning to work, consider asking your employer for regular reviews so you can discuss any changes in your situation.

Once you have returned to work, your situation may change again. It's helpful to know in advance what options you have if changes do occur. Speak to your manager or HR department about this.

Employers appreciate having all the facts in front of them when considering potential employees. If you have gaps in your employment history because of your caring role, explain this on your CV or in person at an interview.

Your local Jobcentre or Jobs and Benefits Office should offer you job search support. Consider your skills and interests before applying for a job. Make sure it's the right one for you.

You can get lots of practical advice on writing your CV, filling in application forms and performing well in interviews from books in your local library. Some useful websites include **nextstep.direct.gov.uk**, **jobcentreonline.com**, **skillsdevelopmentscotland.co.uk** and **careerswales.com**

Don't forget that you have developed many skills as a carer. These are something you could mention on your CV if appropriate.

Benefits

Whether you are a full-time carer or still working while you are caring for someone, you may be entitled to benefits. To find out what they are, call Macmillan on **0808 808 00 00**.



'My dad didn't want to talk about what would happen at the end. So we talked things through together as a family and made decisions based on what we felt was best.'

Lindsey



Ethical and legal matters

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Understanding the ethical and legal side of caring for someone with cancer can be daunting. You may have questions about making decisions that affect the person you care for or how the law affects you as a carer.

This chapter can help you with some of the issues that may come up, particularly if the patient has advanced cancer. We found that having open and honest conversations with the person we cared for, and their healthcare team, helped during difficult times.

Making decisions

There may come a time when the person you care for can no longer make decisions for themselves. As a carer, you may need to make decisions on their behalf or you may be consulted about decisions that affect them. For example, the doctor or nurse may consult you about stopping treatment or whether the patient should be resuscitated or not. You may be wondering when these kinds of decisions need to be made, and who should make them.

We found it helpful to discuss this with the person we cared for early on in their illness, and to talk about it on a regular basis. The earlier you discuss these issues, the more prepared you will be for them if they arise and you will know what to do in different situations. It can also help to put the patient's mind at ease.





Practical tip

If the person you're caring for wants you to make decisions about their care if they're unable to, you will need to be given power of attorney to do so (see page 73). Otherwise decisions, such as whether or not to resuscitate, are made by the doctor. If you're unsure, ask the person you're caring for exactly which decisions they would like you to be involved with.

Sometimes it can be difficult to make decisions because other people, such as family members, wish to be involved. Or you may not want to be involved in making decisions at all. Every person and relationship is different. Use your own judgement and rely on the trust that exists between you and the person you are caring for. We found that if you keep an open dialogue going, it can help if the time comes to make such decisions.

It can also help to have an open and frank discussion with the professionals involved in the patient's care. If you are consulted about the patient's care and treatment, it's important that you know what the procedures involve and how they will affect the patient. It can be helpful to speak to the patient's doctor to get expert medical information and advice.

When decisions have to be made, engage with those around you and make sure everyone is in agreement. The professionals around you can be a source of support as well.

Macmillan has two booklets that you may find useful – *Caring for someone with advanced cancer* and *Talking about your cancer*. You can order these by calling 0808 808 00 00.

Advance care planning

Advance care planning helps identify a person's wishes and choices for their care towards the end of their life. Making an advance care plan can help the patient think about the future. They can communicate their wishes to professionals and other people involved in their care. For you as the carer, it may help to remove some of the uncertainty around making decisions. It can also make things easier for the patient's family.

The patient may refuse specific treatments in advance by making what is called an **advance decision to refuse treatment**. It's a good idea to talk about these decisions with the patient's healthcare team.

There may be times when the patient's wishes, such as dying at home, cannot be met and there may be a good reason for this. If the patient needs to be taken to hospital, the professionals caring for them should explain why. There may also be times when you can't cope and it has become too difficult to care for the patient at home.

The National Council for Palliative Care has more information on advance care planning. Visit [ncpc.org.uk](https://www.ncpc.org.uk) or call **020 7697 1520**.

Relevant areas of law

The Mental Capacity Act 2005 aims to protect people who are unable to make decisions for themselves. It applies to England and Wales. This means that a person can plan ahead for a time when they may not be able to make decisions on their own behalf. This includes decisions about financial matters and their health and social care.

For carers, this means that there is guidance in place for you to make decisions on behalf of the patient if needed. For more information, visit [direct.gov.uk/en/governmentcitizensandrights/mentalcapacityandthelaw](https://www.direct.gov.uk/en/governmentcitizensandrights/mentalcapacityandthelaw)

People in Scotland are covered by the Adults with Incapacity (Scotland) Act 2000. Northern Ireland does not have a similar statute at the moment.

The person you care for can legally appoint you or someone else to make decisions about their personal welfare, including their health and social care. This is called a power of attorney. Power of attorney will only be used if the person who made it cannot make decisions for themselves.

It can take around a couple of months to organise. Some of us found the process complicated, so it was helpful to have legal advice from a solicitor. There is a fee for registering the power of attorney, but you may not have to pay the full amount.

The Office of the Public Guardian has information about making decisions for people who lack capacity or would like to plan their future. If you live in England or Wales, visit [direct.gov.uk](https://www.direct.gov.uk) or call **0300 456 0300**.

If you live in Scotland, visit [publicguardian-scotland.gov.uk](https://www.publicguardian-scotland.gov.uk) or call **01324 678 300**. If you live in Northern Ireland, visit [courtsni.gov.uk](https://www.courtsni.gov.uk) or call the Office of Care and Protection on **028 9072 4733**.

There is more detailed information about power of attorney in Macmillan's booklet *Sorting out your affairs*.

Relevant government strategies

The *End of Life Care Strategy* (2008) may also affect your role as a carer. It aims to promote high-quality care and greater choice for all people reaching the end of their lives. This means that you have the right to discuss the patient's personal needs and preferences with the people supporting you. It also means that the patient's care should be well-planned and coordinated by professionals, and that the patient's choices will be respected. For a summary of the strategy, visit **[dh.gov.uk](https://www.dh.gov.uk)**

Scotland has a similar strategy called *Living and Dying Well* (2008), available at **[scotland.gov.uk/publications](https://www.scotland.gov.uk/publications)**

Northern Ireland's strategy is called *Living Matters: Dying Matters* (2010), and you can read this at **[dhsspsni.gov.uk/8555_palliative_final.pdf](https://www.dhsspsni.gov.uk/8555_palliative_final.pdf)**

Confidentiality and sharing information

7 At times, you may be concerned about the condition of the person you are caring for and how to look after them. You may feel unable to ask the professionals questions or that you aren't being kept up-to-date and consulted. You may also want the opportunity to express your own feelings.

Professionals may prefer to only share information with relatives or a person nominated by the patient. The Data Protection Act 1998 requires any organisation, corporation or governmental body that collects personal information to handle it safely. If the patient would like the people involved in their care to share information with you, they should let the professionals know as early as possible. You should also let the patient's healthcare team know that you are the carer.

Talking to the person you care for

If you are caring for someone with advanced cancer, you may notice that they seem depressed or are having difficulty coping. Depression can often go undiagnosed in people with cancer. They may seem worried about the future and express concerns about dying. They may have also talked to you about ending their life.

You may also be feeling anxious, so it could be a good opportunity to discuss your concerns together, and explore what support you need. It could also lead the way to a discussion about advance care planning.

You and the person you are caring for may also find it helpful to talk to the doctor or clinical nurse specialist about getting some emotional support. You may also find spiritual support helpful at this time.

The Dying Matters website has leaflets and a DVD to help support people having these conversations. Visit **dyingmatters.org/overview/resources**

Families Facing Cancer can offer you emotional and practical support. Visit **familiesfacingcancer.org/information** or call **0844 35 77 959**.

Alternatively, call Macmillan on 0808 808 00 00 or visit macmillan.org.uk



'It isn't easy dealing with the death of a loved one, but do ask for help as soon as you can. Remember that your grief is not the same as that of other family members.'

Alex

8

Death, dying and bereavement

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While many people with cancer get better from periods of treatment or temporary relapses, others sadly will not.

If you are caring for someone who is dying, it may be extremely difficult to come to terms with this, especially if the patient hasn't accepted that they are going to die.

Those of us who cared for someone with terminal cancer found that talking openly with them made the situation less frightening for everyone involved.

You may want to know what to expect if you are going to be with someone when they die. Remember that you can talk to one of the healthcare professionals involved in caring for the patient – they may be able to help with any questions you have.

The person you are caring for may want to make decisions about where they would prefer to die and what sort of funeral they'll have. If you are clear about what you and they want, you can help to make arrangements.

Their wishes may not always be possible, but talking about them will increase the chance of making them happen. It can be comforting to know you've tried to help them achieve their wishes in their last days.

Information and support

Professionals may use the term 'palliative care' to describe care for the patient when their condition can't be cured. Palliative care is based on relieving pain and other symptoms, and providing emotional and spiritual support for the patient and

their family. If you are caring for someone who is dying at home, there are services and support available. Speak to the district nurse, GP or social worker about the help you need and what is available in your area.

Macmillan has a booklet called *Caring for someone with advanced cancer*, which you may find useful.

If you need to take a break from caring for the patient, your local hospice may be able to care for them for a period of time. If you prefer, you could ask if the patient could attend the hospice's day care centre. Marie Curie nurses can also give you a break by providing free nursing care to people with cancer in their own homes. For more information on how to get a Marie Curie nurse, see page 111.

Marie Curie Cancer Care and Macmillan have an informative booklet called *End of life: the facts*, for people in the final stages of life and their carers. You can order it from Marie Curie on **0800 716 146** or you can download it from **mariecurie.org.uk/endoflife**

You may hear healthcare professionals talking about the Liverpool Care Pathway. This is a plan for how people should be looked after when they are dying. The idea is to make sure that people get the same high standard of care, whether they are dying in a hospice, at home, in hospital or in a care home. For more information, visit **mcpcil.org.uk**

There is more information about government strategies for end-of-life care on page 74.

Physical changes

The moment of death is not always recognisable, but there are some changes or actions that indicate someone is dying. Knowing what to expect can help prepare you, but you need to decide for yourself how much you want to know about the process of dying.

Because each situation is different, your local hospice is often a good place to contact for information about what to expect, or to ask questions about any particular worries you have.

Practical tip



We found it important to know that when someone is dying they're often still able to hear, even if they don't respond – so keep talking to them.

You may be frightened to be alone with someone in their final hours. There will usually be people around you at this time, but if there isn't, you could ask someone close to you – a family member, friend or healthcare professional – to be available to support you.

Denial

As a carer, you may have feelings of fear, guilt, anger, sadness or frustration, all of which can be magnified if the patient is in denial about the fact that they have a terminal illness. This is an especially difficult issue in some cultures and age groups.

It's our experience that any solutions are individual and personal. However, we hope to shed some light on the issue. It's important to remember that denial is not an unusual reaction – you're not alone.

It can be very difficult if the patient and carer are in different 'places' – for example, one accepts the situation while the other prefers to deny it's happening. This can cause conflicting emotions.

Sometimes the patient may not actually be in denial, rather they are trying to protect friends and family by not admitting to how serious the situation is. As a carer, you may or may not recognise that this is the case.

It's not just the patient who may experience denial. This could also affect you and may be an issue for family and friends too. Denial may mean that you aren't able to share all your feelings with one another.

If you or the patient remains in denial about what is going to happen, it may not be possible to look at all the practicalities that need to be taken care of, such as the patient's will or other financial arrangements.

However, some things can be organised or talked about without it being explicit that you're doing this because the patient is dying. For example, you may talk generally about finances, or suggest that you both update your wills. It may also help you to simply relive old times together.

If you are worried that the patient is not accepting the reality of the situation, you can ask a healthcare professional to talk to them. For example, specialist palliative care nurses are trained

in listening and counselling skills. Spiritual support may be available in the hospital too.

If the patient is in denial, it's okay to try to get them to talk about it. But if things don't change, you may have to accept that this is the way they want to deal with it. Denial can be a very strong coping mechanism and should be respected.

If at any time you need help and support to cope with the fact that someone you are caring for is in denial, just ask. Remember there are professionals ready to help you.

Feelings can change. If the patient begins to feel more ill, they may start to accept that they are going to die, but you as a carer may start to feel denial, particularly if they have lived longer than originally expected.

Healthcare professionals can make incorrect assumptions about your, or the patient's, acceptance of the illness. It can be helpful to let them know how you really feel.

Practicalities

There are two useful booklets called *What to do after a death in England and Wales* and *What to do after a death in Scotland*. You can get these from libraries, hospitals or healthcare professionals. You can also download them at [dwp.gov.uk/docs/dwp1027.pdf](https://www.dwp.gov.uk/docs/dwp1027.pdf) and [scotland.gov.uk/Resource/Doc/277028/0083194.pdf](https://www.scotland.gov.uk/Resource/Doc/277028/0083194.pdf) For information about what to do after a death in Northern Ireland, visit nidirect.gov.uk/death-and-bereavement

If you have the opportunity to plan ahead, it may be helpful to choose a funeral director and talk to them about arrangements.

This can save you talking about practicalities when you are feeling emotional after the patient's death.

Phone your GP or out-of-hours service if the person you are caring for dies at home. You should leave the patient and any medical equipment (eg syringe drivers) untouched until the GP arrives.

Be aware that funeral directors may charge you more if you use their night service. If you feel comfortable doing so, and after the GP has done the necessary paper work, you can wait until the morning before speaking to the funeral director.

Occasionally a post-mortem may be necessary, for example, if the death was sudden. This is a medical examination of the body to find out more about the cause of death. The doctor or coroner may consult you about this, so if you need more information, the booklets and websites listed on the previous page can help.

Practical tip



When registering the death, get five or six copies of the death certificate from the registrar, as you may need them to sort out financial affairs, such as insurance policies.

Advice on registering a death can be found at [direct.gov.uk/en/governmentcitizensandrights/death](https://www.direct.gov.uk/en/governmentcitizensandrights/death)

Your chosen funeral director will guide you through all the formalities and practical issues relating to the funeral.

If the funeral is going to be a long distance from where the patient dies, it may be helpful to get a funeral director from the area where you want the funeral to be held. You don't need to have the person's body removed immediately if you don't want to.

Think about whether or not you want to be involved in the washing and dressing of the person's body before they go to the undertaker. You can talk to your funeral director about this.

Funeral arrangements are personal and individual. For example, you don't have to conform to timescales, you may want to take photos and you don't have to wear black. The patient may have mentioned the arrangements in their will.

Remember to consider the religious or spiritual beliefs of the person you were caring for when it comes to arranging their funeral. Be aware that your plans can be affected by practicalities such as the availability of funeral services.

If you want people to make a donation to charity in lieu of flowers, you may need to speak to that chosen charity first. They may be able to help you, for example, by providing collection envelopes.

Further information

Carers UK and Help the Hospices have produced a helpful guide called *When caring comes to an end*. Contact either organisation for a copy – see pages 106–112 for details.

Moods and emotions

Bereavement doesn't necessarily start when someone dies. You may feel a sense of loss before the patient dies. For example, you may already miss the way your relationship used to be and all the things you used to do together.

The patient may suffer grief at the loss of their future, for example, not being present at their children's milestones.

Try to share your feelings of loss with the patient and grieve together with them and the family before they die. Comfort each other and talk about the things in your lives together that have been good. Give yourself time and allow yourself to grieve in your own way. You may want to share your loss with family and friends. Try to talk to them about how you are feeling.

Be prepared for other people's reactions to death and respect each other's ways of grieving. However you react, feel and behave is okay – some of us felt numb, others felt relief; some of us went on holiday, others went to the funeral home every day.

Be aware that grief can manifest itself in physical ways too, for example, loss of appetite, insomnia or weight loss. Let yourself cry whenever you need to. Some of us felt guilty – guilty that we were alive and the person we were caring for wasn't, guilty for feeling relief, or guilty about looking to the future.

Take opportunities to talk about your loved one. Some of us found that having photos of them around the house, and even talking to them, could be comforting.

Your future

Think carefully before making any major life decisions just after the person you were caring for has died – consider putting decisions on hold at this time.

Think about how you want to deal with the patient's clothes and personal items. Don't feel pressured to do this before you are ready – you can do this how and when you want to. You may want to ask for help from family and friends. Some of us found that sorting out personal items can bring conflict in the wider family network.

You or your family and friends may find comfort in the traditions of other cultures. For example, in Japan they have a tradition of writing to and sending notes or photos to the person who has died.

Consider having a celebration of the person's life. We also found it helped to make plans for days in the future that may be particularly difficult, like birthdays and anniversaries, Father's Day and Mother's Day.

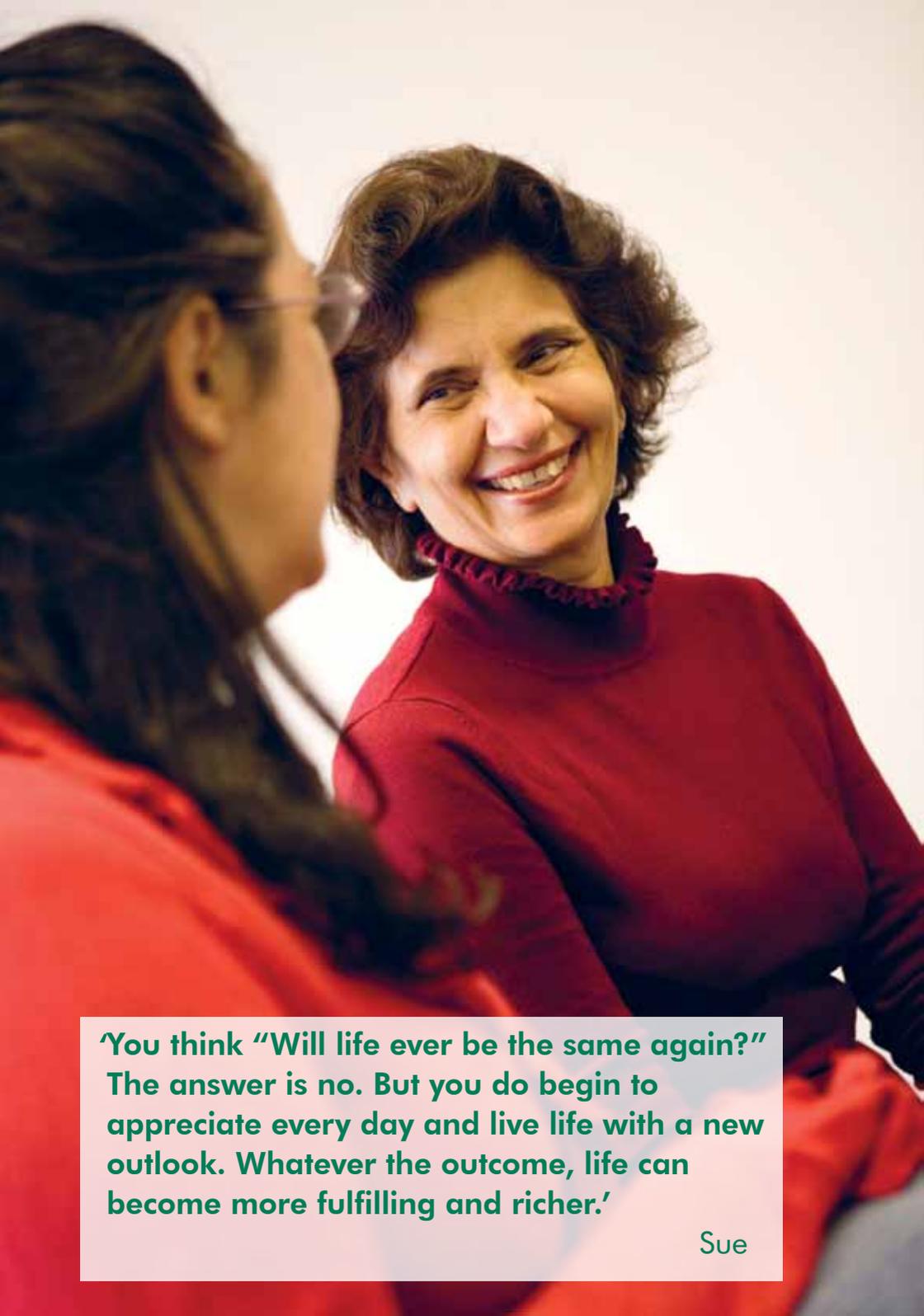
Your local hospice may have a bereavement group you can join or you could consider having some bereavement counselling. There may be a branch of Cruse Bereavement Care in your area, which can provide help and advice. See page 113 for contact details.

When a child dies or when a child is bereaved of someone important in their lives, the right information, support and resources are vital. We have listed some child bereavement services in chapter 11.

Sometimes changing things around in the home to make it look a little different can help the process of moving on.

When you are bereaved of someone, especially a partner, things such as taxes and benefits can be affected dramatically. Citizens Advice can offer you independent advice about this.

We talk about other things you may need to consider or want to do after you stop being a carer in the next chapter – ‘Life after caring’.



**'You think "Will life ever be the same again?"
The answer is no. But you do begin to
appreciate every day and live life with a new
outlook. Whatever the outcome, life can
become more fulfilling and richer.'**

Sue



Life after caring

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For many of us, it took some time to adjust to the end of our caring role, whether that was because the patient had recovered and no longer needed care, they had moved into residential or nursing care, or because they had died.

You can have a lot of time to fill, which can make you feel adrift, without purpose or direction. It's not uncommon to walk around the house talking to yourself.

It's a natural reaction to want to do something positive straight away, but give yourself some time. You'll need to come to terms with the fact you are no longer a carer, and with any feelings that may come with that. If you don't return to work, this may be a good time to learn something new, volunteer or campaign to improve information and support for carers. See 'New challenges' on page 93 for more information about this.

Some of us also found that when we stopped being a carer, exhaustion – both physical and emotional – caught up with us and that we were susceptible to getting ill. Having spent a lot of time caring for someone else and putting their needs first, it's important that you take care of yourself and, where possible, let other people look after you.

Initially, you will have to deal with some practical matters fairly quickly, such as benefits, but you don't have to rush into decisions about what you will do next. Take your time and remember there are lots of people and organisations out there to support you.

Practicalities

Writing down what we needed to do in the short- and long-term was handy for a lot of us.

If you are claiming Carer's Allowance, it's important that you let the Carer's Allowance Unit know you have stopped being a carer. There may also be a change in any other benefits you are entitled to. It's best to find out as quickly as possible what you need to do about benefits as this will help to avoid problems later on.

You can call Macmillan on **0808 808 00 00** for advice. The Carers UK website also has useful information. Visit **carersuk.org/help-and-advice**

Try to accept help that's offered to you. After putting the needs of someone else first for so long, you shouldn't feel guilty about accepting support.

After your caring role ends and life is not as hectic, it's not unusual to be affected physically and mentally by your experience. This may occur weeks, months, or even years or more after you stop being a carer. Make sure you keep a close eye on any changes to your health.

Many of us found it difficult to pick up the pieces and start again with regards to work, friendships and outside interests once we stopped being a carer.

Don't force yourself to go back to the life you had before you were a carer. You may have changed a lot because of your experience.

Emotions

It's not unusual to feel guilty about returning to a 'normal' life free of caring responsibilities. It can feel strange when your caring role ends. You may want to take time out or you may go into autopilot and carry on with life as if nothing has changed. Do whatever feels right for you.

People are likely to rally around you for the first few days or weeks if the person you were caring for has died. Sometimes it may take months or years before you are fully hit by your loss. Some of us felt very lonely, especially when going to social engagements that we would have normally attended with the patient.

Remember that there are still many support services out there to help you. See 'Your future' in chapter 8.

Many of us are still benefitting emotionally from attending support groups even though our caring role has ended. Call Macmillan or visit [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport) to find your nearest group.

If you are finding it difficult to express your emotions, consider keeping a journal.

Despite the fact that you have stopped caring for the patient, you may find it hard to disassociate yourself from that role.

You may constantly feel an overwhelming need to help others or you may want to keep in contact with the hospital or hospice that provided support to the patient. This is normal and something you can use positively. See the 'New challenges' section on the next page.

If the person you were caring for has recovered, you may find that you constantly worry about the cancer coming back. This may lead to you being more protective than usual. Try to live life without this worry hanging over you.

Further information

When caring comes to an end is a helpful guide produced by Carers UK (see page 106) and Help the Hospices (see page 111). Contact either organisation to order a copy.

New challenges

Returning to work may be a necessity and something you wish to do to bring some direction into your life. For more information about how best to do this, see the 'Returning to work' section on pages 66–67.

You may want to refresh skills that you have not used for a while or learn something new. Your local library or adult education centres can find suitable courses in your area.

These websites can also provide you with useful information: learndirect.co.uk and direct.gov.uk/en/educationandlearning/adultlearning

Many of us have gone on to use our experiences to help provide better support and information for carers. This handbook is an example of that work. You can do similar work by joining a local user group, working with a charity or speaking directly to your local council about carer services in your area.

Volunteering is another great way to make a difference, meet new people and develop new skills. You could help

out at the hospital where the patient received treatment or your local carers' centre, or volunteer for a charity.

It's good to be aware that organisations and charities may have restrictions on who they will accept as volunteers, especially if a potential volunteer has recently been bereaved. Speak to the organisation or charity about any restrictions they may have.

Further information

Macmillan Cancer Voices is a UK-wide network that uses people's experiences of cancer to improve cancer care. You can find out more about its work by visiting **macmillan.org.uk/cancervoices**, calling **0808 808 00 00** or emailing **cancervoices@macmillan.org.uk**

If you are interested in volunteering for Macmillan, contact your local volunteering adviser – details can be found at **macmillan.org.uk/volunteer** or for general enquiries, call **0808 808 00 00**.





AFFECTED
BY CANCER?

WE
CAN





How Macmillan can help

Macmillan Cancer Support

89 Albert Embankment,
London SE1 7UQ

General enquiries

020 7840 7840

**Questions about living
with cancer?** Call free on

0808 808 00 00

(Mon–Fri, 9am–8pm)

Alternatively, visit

macmillan.org.uk

Hard of hearing?

Use textphone 0808 808

0121, or Text Relay.

Non-English speaker?

Interpreters available.

Macmillan Cancer Support improves the lives of people affected by cancer. It is a source of support: providing practical, medical, emotional and financial help. It's a force for change: listening to people affected by cancer and working together to improve cancer care locally and nationally.

Macmillan has a wide variety of services and activities that might be of help and interest.

Clear, reliable information

Macmillan provides expert, up-to-date information about cancer – the different types, tests and treatments, and living with the condition.

It can help you by phone, email, via the website and publications, or in person. And its information is free to everyone – people with cancer, families and friends, as well as professionals.

Just call and speak to a cancer support specialist. Or visit one of Macmillan's information and support centres – based in hospitals, libraries and mobile centres – and speak with someone face-to-face.

Need out-of-hours support? Someone to talk to

The Macmillan Support Line is open Monday–Friday, 9am–8pm. At any time of day, you can find a lot of information on the website, macmillan.org.uk or join the online community at macmillan.org.uk/community

For medical attention out of hours, please contact your GP for their out-of-hours service.

The following organisations can offer immediate information and support:

NHS Direct
0845 46 47
www.nhsdirect.nhs.uk

NHS Scotland
08454 24 24 24
www.nhs24.com

Samaritans
0845 790 9090
www.samaritans.org

When someone close to you has cancer, it can be difficult sometimes to talk about how you're feeling. You can call Macmillan's cancer support specialists to talk about how you feel and what's worrying you.

Alternatively, they can help you find support in your local area, so you can speak face-to-face with people who understand what you're going through.

Professional help

Macmillan nurses, doctors and other health and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until people decide they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call Macmillan.

Support for each other

No one knows more about the impact cancer has on a person's life than those who have been affected by the disease themselves. That's why Macmillan helps bring people with cancer and carers together in their communities and online.

You can find out about people affected by cancer who meet in your area to support each other by calling Macmillan or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

You can also share your experiences, ask questions and get support from others by heading to the online community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you've been affected in this way, Macmillan can help. All you need to do is call their helpline and a specialist will tell you about the benefits and other financial help you may be entitled to. They can also give you information about your rights as an employee, and help you find further support.

Helping you to help yourself

Many people affected by cancer want to take control of their lives again and regain their independence. Macmillan can help you do this by providing opportunities to learn how to manage the impact cancer can have on your life.

Macmillan offers a range of free training and development opportunities for people affected by cancer. Call **0808 808 00 00**, email learning@macmillan.org.uk or visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

The courses are divided into three categories:

Helping yourself (self-management)

Learning how to manage the day-to-day impact of living with cancer could make a big difference to the patient's quality of life. Macmillan offers a range of free self-management courses, workshops and e-learning to help people take control and make the most out of life.

These include:

- Be Good to Yourself
- Body Image, Sexuality and Cancer
- Exploring your Cancer Journey through Art
- Healthy Eating and Cancer
- HOPE – Helping to Overcome Problems Effectively
- New Perspectives
- Relaxation and Visualisation

Supporting others

Supporting people affected by cancer through volunteering and self-help and support groups can bring great rewards, both to you and the people you support.

Courses include:

- Buddying and Befriending
- Cancer and its Treatments
- Cancer and Relationships
- Cancer Support Course
- Developing your Group
- Good Practice in Starting a Group
- Listening and Responding
- Putting Life Back into your Group
- Running Effective Meetings
- Supporting others through Loss
- Talking to Children about Cancer
- Telephone Skills
- Using Macmillan's Learning and Development Toolkits with your Group

Getting involved (user involvement)

Your experience with cancer may have inspired you to take action and to help improve cancer services for the benefit of other people.

Our free courses, workshops and e-learning programmes can help you turn your cancer experience into something that makes things better for everybody. These include:

- Consumer Research Skills
- Getting Involved in Site-specific Groups
- Improving Cancer Services – an Introduction to User Involvement
- Making a Difference (for user groups)
- User Group Development – Away Day

Macmillan also produces booklets on specific cancers and treatments to help you manage the disease and side effects.

Get involved

There are many ways that you, your friends or family can get involved with Macmillan and help other people affected by cancer.

Review our information

Help to make Macmillan resources even better for people affected by cancer. Being a reviewer gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets and website text.

Use your experience to speak out

Share your experiences – online, in the media, with each other. Or use your experience to improve cancer care – join Macmillan Cancer Voices and get involved in opportunities that can make a real difference to people's lives.

Campaign

Join one of the charity's campaigns – help to fight discrimination, tackle inequalities and get a better deal for people affected by cancer.

Give your time

Become a volunteer – give a bit of your time and energy to make a difference to others, and meet new friends at the same time.

Fundraise

Raise some money – host a coffee morning, hold a street collection or organise your own sponsored event.

Donate

Give some money – whether you give a one-off donation, set up a direct debit, donate through payroll giving or leave a legacy, Macmillan will use every penny to help support people affected by cancer.

Find out more about all these opportunities on **[macmillan.org.uk](https://www.macmillan.org.uk)**



'If this handbook helps in some small way to ease your journey, then our efforts will be well rewarded.'

Roberta



Useful organisations

Support for carers

Carers Direct

PO Box 4338,

Manchester M61 0BY

Helpline 0808 802 0202

(Mon–Fri, 8am–9pm,
weekends, 11am–4pm)

Email from the website

**[www.nhs.uk/carersdirect/
Pages/CarersDirectHome.
aspx](http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx)**

Aims to offer all the information you need as a carer to access the financial help you're entitled to. Also offers advice on getting a break from caring, going to work and much more.

Carers UK

20 Great Dover Street,
London SE1 4LX

Carers line 0808 808 7777

(Wed and Thurs,
10am–12pm and 2–4pm)

Email info@carersuk.org

www.carersuk.org

Offers information and support to carers. Can put people in touch with local support groups. Has national offices for Scotland, Wales and Northern Ireland:

Carers Scotland

The Cottage, 21 Pearce Street,
Glasgow G51 3UT

Tel 0141 445 3070

Email info@carerscotland.org

www.carersuk.org/scotland

Carers Wales

River House, Ynsbridge Court,
Gwaelod-y-Garth,
Cardiff CF15 9SS

Tel 029 2081 1370

Email info@carerswales.org

www.carersuk.org/wales

Carers Northern Ireland

58 Howard Street,
Belfast BT1 6PJ

Tel 028 9043 9843

Email info@carersni.org

**[www.carersuk.org/
northernireland](http://www.carersuk.org/northernireland)**

Crossroads Care

10 Regent Place, Rugby,
Warwickshire CV21 2PN

Tel 0845 450 0350

Email from the website

www.crossroads.org.uk

Provides services through a network of local independent charities across England and Wales, each offering Crossroads' core service where

a trained carer support worker comes into the home to take over the caring responsibilities. Each charity has its own funding and can provide other services according to funding and demand at a local level.

Crossroads Caring Scotland

24 George Square,
Glasgow G2 1EG

Carers Information and

Support Line 0141 353 6504

Email info@crossroads-scotland.co.uk

www.crossroads-scotland.co.uk

A charity providing short breaks for carers within their own homes. Has services throughout Scotland that provide practical support for carers of all ages.

Crossroads Caring for Carers (Northern Ireland)

7 Regent Street,
Newtownards, Co Down,
Northern Ireland BT23 4AB

Tel 028 9181 4455

Email

mail@crossroadscare.co.uk

www.crossroadscare.co.uk

A Northern Ireland-based charity providing respite for carers by providing them with a much-needed break, providing peace of mind that their loved one is well taken care of by a Crossroads care attendant.

The Princess Royal Trust for Carers

Unit 14, Bourne Court,
Southend Road, Woodford
Green IG8 8HD

Tel 0844 800 4361

Email info@carers.org

www.carers.org and

www.youngcarers.org

Largest provider of carers' support services in the UK. Through its network of 144 independently managed carers' centres, 85 young carers' services and interactive websites, the trust currently provides information, advice and support services to more than 400,000 carers, including approximately 25,000 young carers.

Financial or legal advice and information

Benefit Enquiry Line

Warbreck House, Warbreck Hill Road, Blackpool FY2 0YE

Freephone 0800 882 200

Free textphone

0800 243 355

Email BEL-Customer-Services@dwp.gsi.gov.uk

www.direct.gov.uk/disabilitymoney

Provides advice about benefits and can also provide help with the completion of some disability-related claim packs.

Citizens Advice

Provides free, confidential, independent advice on a variety of issues including financial, legal, housing and employment. Find contact details for your local office in the phone book or at

citizensadvice.org.uk

Find advice for the UK online, in a variety of languages, at **adviceguide.org.uk**

Citizens Advice Scotland

www.cas.org.uk

Department for Work and Pensions

Bereavement Service

Tel 0845 606 0265

Textphone 0845 606 0285

Tel (Welsh) 0845 606 0275

Textphone (Welsh)

0845 606 0295

Can take your claim for bereavement benefits over the phone and check to see if you qualify for any other benefits.

Equality and Human Rights Commission

Tel (England) 0845 604 6610

Tel (Scotland) 0845 604 5510

Tel (Wales) 0845 604 8810

Email from the website

www.equalityhumanrights.com

Promotes equality and provides information to people about their rights.

Equality Commission Northern Ireland

Equality House,
7-9 Shaftesbury Square,
Belfast BT2 7DP

Tel 028 9089 0890

www.equalityni.org

Aims to advance equality, promote equality of

opportunity, encourage good relations and challenge discrimination through promotion, advice and enforcement.

Pensions Advisory Service

11 Belgrave Road,
London SW1V 1RB

Tel 0845 601 2923

www.pensionsadvisoryservice.org.uk

An independent, non-profit organisation that provides free information, advice and guidance on pensions.

Social Security

Agency (SSA)

Benefit Enquiry Line (BEL)

0800 220 674

Minicom 0800 243 787

Responsible for social security benefits in Northern Ireland.

Visit **nidirect.gov.uk** for a variety of online information from the government for disabled people and carers. They can also help you fill in certain claim forms.

Unbiased Ltd

(to find an independent financial adviser)

117 Farringdon Road,
London EC1R 3BX

Email

ifacontact@unbiased.co.uk

www.unbiased.co.uk

Helps people search for details of local member independent financial advisers via online searches at **unbiased.co.uk** and **moneyadvice.service.org.uk**

Equipment and advice on living with disability

Assist UK

Redbank House,
1 Portland Street,
Manchester M1 3BE

Tel 0161 238 8776

Email

general.info@assist-uk.org

www.assist-uk.org

An independent voluntary organisation with a network of disabled living centres throughout the UK. Centres offer advice and a range of products and equipment for people who have difficulty with daily activities.

The Blue Badge Scheme (Department for Transport)

Advice Line 020 7944 2914
or 0161 367 0009

**www.dft.gov.uk/
transportforyou/access/
bluebadge**

Provides a national arrangement of parking concessions for people with severe walking difficulties who travel either as drivers or passengers. It allows badge holders parking concessions so they can park close to their destination. The scheme operates throughout the UK and is administered by local authorities who deal with applications and issue badges.

British Red Cross

44 Moorfields,
London EC2Y 9AL
Tel 0844 871 11 11

Email

information@redcross.org.uk

www.redcross.org.uk

Offers a number of services for people with a disability, including a medical equipment loan service and a transport service.

British Red Cross Scotland, Northern Ireland and the Isle of Man

4 Nasmyth Place, Hillington,
Glasgow G52 4PR

Tel 0141 891 4000

Email

scotland@redcross.org.uk

www.redcross.org.uk

Disability Alliance

Universal House,
88–94 Wentworth Street,
London E1 7SA

Tel (voice and minicom)

020 7247 8776

Email

office@disabilityalliance.org

www.disabilityalliance.org

A national charity that works to improve the living standards of disabled people. Provides information on social security benefits and disability rights.

Disabled Living Foundation (DLF)

380–384 Harrow Road,
London W9 2HU

Helpline 0845 130 9177
(Mon–Fri, 10am–4pm)

Email helpline@dlf.org.uk
www.dlf.org.uk

A national charity that provides free, impartial advice about disability equipment and mobility products through its helpline, website and demonstration centre.

DIAL UK

St Catherine's, Tickhill Road,
Balby, Doncaster DN4 8QN

Tel 01302 310 123

Email informationenquiries@dialuk.org.uk

www.dialuk.info

A national network of approximately 120 local Disability Information and Advice Line services (DIALs) run by and for disabled people. Based throughout the UK, the services provide information and advice to disabled people and others on all aspects of living with a disability. You can search for your local DIAL on its website.

Advanced cancer/end-of-life care

Marie Curie Cancer Care

89 Albert Embankment,
London SE1 7TP

Freephone 0800 716 146

Tel 020 7599 7777 (England)
0131 561 3900 (Scotland)
01495 740 888 (Wales)
028 9088 2060 (NI)

Email info@mariecurie.org.uk
www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care to people with cancer in their own homes, 24 hours a day, 365 days a year. There are also Marie Curie hospices across the UK.

Help the Hospices

Hospice House,
34–44 Britannia Street,
London WC1X 9JG

Tel 020 7520 8200

Email

info@helpthehospices.org.uk
www.helpthehospices.org.uk

Provides information about living with advanced illness. Compiles a directory of hospice services, as well as

practical booklets. These are all available free on the website.

Counselling, bereavement and emotional support

British Association for Counselling and Psychotherapy (BACP)

BACP House, 15 St John's Business Park, Lutterworth LE17 4HB

Tel 01455 883 300

Email enquiries@bacp.co.uk

www.bacp.co.uk

Promotes awareness and availability of counselling and signposts people to appropriate services. Has a database on the website where you can search for a qualified counsellor.

Child Bereavement Charity

The Saunderton Estate, Wycombe Road, Saunderton HP14 4BF

General enquires

01494 568 900

Bereavement Services

01494 568 900

Email [support@](mailto:support@childbereavement.org.uk)

childbereavement.org.uk **or** enquiries@childbereavement.org.uk

www.childbereavement.org.uk

A charity offering information, support and resources to families when a child dies, and when a child is bereaved of someone important in their life.

Childhood Bereavement Network

8 Wakley Street, London EC1V 7QE

Tel 020 7843 6309

Email cbn@ncb.org.uk

www.childhoodbereavementnetwork.org.uk

A national, multi-professional group of organisations and individuals working with bereaved children and young people. Has an online directory, which you can search for local services.

Compassionate Friends

53 North Street, Bristol BS3 1EN

Tel 0845 120 3785

Helpline 0845 123 2304 (daily, 10am–4pm)

and 7–10pm)

Helpline email

helpline@tcf.org.uk

www.tcf.org.uk

A befriending service for the family of children who have died. The helpline is always answered by a bereaved parent who is there to listen when you need someone to talk to.

Cruse Bereavement Care

PO Box 800,
Richmond TW9 1RG

Helpline 0844 477 9400

(Mon–Fri, 9.30am–5pm)

Helpline email

helpline@cruse.org.uk

Young person’s freephone

helpline 0808 808 1677

Young person’s helpline

email info@rd4u.org.uk

**www.crusebereavement
care.org.uk**

Provides bereavement counselling, information and support to anyone who has been bereaved. Has a network of branches across the UK.

RD4U

PO Box 800,
Richmond TW9 1RG

Freephone helpline

0808 808 1677

(Mon–Fri, 9.30am–5pm)

Email info@rd4u.org.uk

www.rd4u.org.uk

A website designed by young people to support other young people after the death of someone close. Part of Cruse Bereavement Care’s Youth Involvement Project.

Relate

Premier House,
Carolina Court, Lakeside,
Doncaster DN4 5RA

Tel 0300 100 1234

www.relate.org.uk

Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and face-to-face support, by phone and through its website.

Samaritans

Chris, PO Box 9090,
Stirling FK8 2SA

Tel 08457 90 90 90

Email jo@samaritans.org

www.samaritans.org

Provides 24-hour confidential, non-judgemental and emotional support for people experiencing feelings of distress or despair, including those that could lead to suicide. Service provided by phone, email or letter.

Winston's Wish

4th Floor, St James's House,
St James Square,
Cheltenham GL50 3PR

General enquiries

01242 515 157

Helpline 08452 03 04 05

Email

info@winstonswish.org.uk

www.winstonswish.org.uk

Helps bereaved children and young people rebuild their lives after a family death. Offers practical support and guidance to families, professionals and anyone concerned about a grieving child.

General cancer support organisations

Cancer Black Care

79 Acton Lane,
London NW10 8UT

Tel 020 8961 4151

(Mon–Fri, 9.30am–4.30pm)

Email

info@cancerblackcare.org.uk

www.cancerblackcare.

org.uk

Offers a variety of information and support for people with cancer from ethnic communities, their families, carers and friends. Welcomes people from different ethnic groups including African, Asian, Turkish and African-Caribbean communities.

Irish Cancer Society

43–45 Northumberland Road,
Dublin 4, Ireland

Cancer Helpline

1800 200 700 (Mon–Thurs,
9am–7pm, Fri, 9am–5pm)

Email helpline@irishcancer.ie

www.cancer.ie

Operates Ireland's only freephone cancer helpline, which is staffed by qualified nurses trained in cancer care.

Leukaemia & Lymphoma Research

39–40 Eagle Street
London WC1R 4TH

Tel 020 7405 0101

(Mon–Fri, 9am–5pm)

Email info@

beatingbloodcancers.org.uk

www.beatingbloodcancers.org.uk

Dedicated to researching blood cancers including leukaemia, lymphoma and myeloma. Research focuses on finding causes, improving diagnosis and treatments and running trials for blood cancer patients.

Maggie’s Cancer Caring Centres

8 Newton Place,
Glasgow G3 7PR

Tel 0300 123 1801

Email

enquiries@maggiescentres.org

www.maggiescentres.org

Located throughout the country, Maggie’s Centres offer free, comprehensive support for anyone affected by cancer. You can access information, benefits advice, and emotional or psychological support.

Tak Tent Cancer Support – Scotland

Flat 5, 30 Shelley Court,
Gartnavel Complex,
Glasgow G12 0YN

Tel 0141 211 0122

Email taktent4u@gmail.com

www.taktent.org

Offers information and support for cancer patients, families, friends, and healthcare professionals. Runs a network of monthly support groups across Scotland. Also provides counselling and complementary therapies.

Tenovus

9th Floor, Gleider House,
Ty Glas Road, Llanishen,
Cardiff CF14 5BD

Freephone helpline

0808 808 1010

Tel 029 2076 8850

Email post@tenovus.com

www.tenovus.org.uk

Provides a variety of services to people with cancer and their families, including counselling and a freephone cancer helpline.

**The Ulster Cancer
Foundation**

40–44 Eglantine Avenue,
Belfast BT9 6DX

Freephone helpline

0800 783 3339

Helpline email

infocis@ulstercancer.org

Tel 028 9066 3281

Email info@ulstercancer.org

www.ulstercancer.org

Provides a variety of services for people with cancer and their families, including a free telephone helpline, which is staffed by specially trained nurses with experience in cancer care.







Further resources

Related Macmillan information

You may want to order some of the booklets mentioned in this handbook. These include:

- *Caring for someone with advanced cancer*
- *Getting the best from your cancer services*
- *Help with the cost of cancer*
- *It all adds up*
- *Let's talk about you – a guide for young people caring for someone with cancer*
- *Self-employment and cancer*
- *Sorting out your affairs*
- *Talking about your cancer*
- *Talking to children when an adult has cancer*
- *Working while caring for someone with cancer*

To order, visit **be.macmillan.org.uk** or call **0808 808 00 00**. All of this information

is also available online at **macmillan.org.uk/cancerinformation**

Macmillan audio resources

Macmillan's high-quality audio materials, based on their variety of booklets, include information about cancer types, different treatments and living with cancer.

To order your free CD, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

Macmillan videos

There are many videos on the Macmillan website featuring real-life stories and information from health and social care professionals.

There's a video about caring for someone with advanced cancer at **macmillan.org.uk/caringduringadvancedcancer**

Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

Macmillan Cancer Support www.macmillan.org.uk

Find out more about living with the practical, emotional and financial effects of cancer. The Macmillan website contains expert, accurate up-to-date information on cancer and its treatments, including:

- their 100+ booklets, 350+ fact sheets, and videos featuring real-life stories from people affected by cancer and information from medical professionals
- how Macmillan can help, the services they offer and where to get support
- how to contact Macmillan's cancer support specialists,

including an email form to send your questions

- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

www.cancer.gov (National Cancer Institute – National Institute of Health – USA)

Gives comprehensive information on cancer and treatments.

www.cancer.org (American Cancer Society)

Nationwide community-based voluntary health organisation dedicated to eliminating cancer as a major health problem. It aims to do this through research, education, advocacy and service.

**www.cancerhelp.org.uk
(Cancer Research UK)**

Contains patient information on all types of cancer and has a clinical trials database.

**www.healthtalkonline.org
www.youthhealthtalk.org
(site for young people)**

Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

www.nhs.uk (NHS Choices)

NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and gives all the information you need to make choices about your health.

**www.nhsdirect.nhs.uk
(NHS Direct Online)**

NHS health information site for England – covers all aspects of health, illness and treatments.

**www.nhs24.com
(NHS 24 in Scotland)**

**www.nhsdirect.wales.nhs.uk
(NHS Direct Wales)**

**www.n-i.nhs.uk
(Health and Social Care
in Northern Ireland)**

**www.patient.co.uk
(Patient UK)**

Provides good-quality information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

www.riprap.org.uk (Riprap)

Developed especially for teenagers who have a parent with cancer.

Disclaimer

We make every effort to ensure that the information we provide is accurate and up-to-date but it should not be relied upon to reflect the current state of medical research, which is constantly changing.

If you are concerned about your health, you should consult a doctor. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third-party information such as information on websites to which we link.

We feature real-life stories in all our articles. Some photographs are of models. All quotes sourced from the Experienced Carers Group and people affected by cancer.

Thanks

This booklet has been written and revised by carers, all of whom have experience of caring for someone close to them with cancer. It has been edited by Macmillan's Cancer Information Development team and approved by Charlotte Argyle, Carers Support Manager and our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

With thanks to: Simon Chapman, Director of Policy and Public Affairs, National Council for Palliative Care; Julie Cunneen, Macmillan Clinical Lead Nurse for Birmingham Lymphoedema Services; Steve Marshall, Social Worker – Cancer Services; Sara Padhiar-Tutton and Liz Gough, Support and Outreach workers at Brighton Carers' Centre; and the people affected by cancer who reviewed this edition.

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Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community supporting you online, any time. The fundraisers who make it all possible.

You don't have to face cancer alone. We can give you the strength to get through it. We are Macmillan Cancer Support.

Questions about living with cancer?
Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm)
Alternatively, visit macmillan.org.uk

Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.



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