

**HELLO,
AND
HOW
ARE
YOU?**

**WE ARE
MACMILLAN.
CANCER SUPPORT**

**A guide for carers,
by carers**



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

This resource has been produced for you by carers of people with cancer. During our time caring for a loved one with cancer, we became aware that a carer can often become a forgotten figure who is not provided with the information and support they need.

Working with Macmillan Cancer Support, we have used our experiences to develop, shape and write a resource to support other people caring for adults with cancer. This handbook is the result of that work. It can also be helpful for professionals who support carers of people with cancer.

The handbook contains handy tips we hope you will find useful when it comes to dealing with the ups and downs of caring for someone with cancer. We have also included information on organisations and other sources of support that helped us during this demanding time. We hope they provide you with the support you need too.

Hello, and how are you?

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 – a ‘how to be a carer’ book. Instead, it includes lots of things that will hopefully strike a chord with you.
- Always remember that when it comes to medical questions, it is essential you speak to a healthcare professional for advice.
- You will often see reference to ‘the patient’. We felt that although this may not be the ideal choice of words, it was a practical way to refer to the person you are caring for – a shorthand way that is easily understood.
- You will see references to many organisations and services within this handbook. If the contact details for these organisations and services are not provided on the page, you will find them in the **Further information** chapter at the back of the handbook.

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1 Information and support

- Information about services
- Organisations that can help
- Information about the disease and how it will progress
- Information on your rights as a carer

'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



1 Information and support

Getting reliable information in a format to suit you is a really important way to help you feel more in control of your situation. Sometimes, as a carer, you can feel as if you are on your own.

Having information can help you feel less isolated and reassured that help is available if you need it. It can also relieve some of your worry and stress.

Information can make it easier to anticipate some of the difficulties you and the person you are caring for might 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, organisations and healthcare professionals who can help, as well as information on support that may be available to you as a carer.

Information about services

There's lots of information available about cancer, caring for someone with cancer and organisations that can help. Here are some ways you can get hold of this information:

- Ask a hospital social worker, practice nurse, district nurse or your GP.
- Ask in your hospital if there is a local cancer information and support service.
- Every hospital in England now has a Patient Advice and Liaison Service (PALS) which should be able to direct you to local sources of cancer information.
- In Wales, you could ask your local Community Health Council about local sources of cancer information. In Northern Ireland, you can find this information on the website of the Northern Ireland Cancer Network – cancerni.net In Scotland, see scot.nhs.uk/organisations

1 Information and support

- Your local hospice may also be a good source of information. It is there to provide support to people with life-threatening illnesses, not just to those who are terminally ill. They may also have information about training courses available to you, to help with your caring role.
- The internet may be helpful. It's important always to go to sites where the information is reliable and quality-checked.

Speaking to people who are going through the same thing as you can be very supportive. Forums on the internet where you can talk 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.

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 or call Macmillan 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.

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

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

If you want to get involved in influencing cancer services, contact your local user group. You can find out if there is one in your area by contacting Macmillan.

Information and support 1

Organisations that can help

- You can find out about information and support services in your area by calling Macmillan on **0808 808 00 00**.
- At **macmillan.org.uk** you can use your postcode to find your nearest cancer information centre or Macmillan mobile cancer information centre.
- The online community on Macmillan's website – **macmillan.org.uk/community** – is a good place to talk to other people affected by cancer.
- Carers' centres provide a range of support for carers, including information, advice and training. You can find your local carer centre by searching at **carers.org** or by calling The Princess Royal Trust for Carers regional offices. See **Further information** for contact details.
- Carers Direct is a free, confidential service provided by the NHS. Their helpline and website provide information and advice for carers. They can also tell you about national and local services for carers that can provide more indepth support, such as advocacy and counselling. Call Carers Direct on **0808 802 0202** or see **nhs.uk/carersdirect**
- Crossroads Care services provide practical care and support in the home to give carers a break. Several Crossroads branches are working in partnership with Macmillan to provide a specialist service for patients with a cancer diagnosis, their carers and families. See **Further information** for contact details.
- Jobcentre Plus has produced 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 Plus office. You can also download it from **jobcentreplus.gov.uk/jcp/customers/leaflets_and_guides** In Northern Ireland, see **dsdni.gov.uk/index/ssa** for information about financial help available from the Social Security Agency.

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- Macmillan Cancer Voices is a UK-wide network of people affected by cancer who use their experiences to improve cancer care. To find out more about its work, visit macmillan.org.uk/cancervoices, call **020 7091 2006** or email cancervoices@macmillan.org.uk
- Caring with Confidence is a free training programme for carers aged 18 and over in England. It provides carers with training and information to empower them and help them develop their caring skills. To find out more contact **0800 849 2349** or email cwc.info@caringswithconfidence.net
- An accredited course called 'The Cancer Support Course' is run by Macmillan. This offers helpful training to anyone who supports people affected by cancer. You can find out more about it by calling Macmillan's Training Administrator on **020 7091 2008**, emailing csc@macmillan.org.uk or by visiting macmillan.org.uk/learnzone
- Macmillan also offers a six-week course called New Perspectives. This is run by people who have cared for someone with cancer, and helps carers to develop self-management skills. You can find out more by calling **020 7091 2010**, emailing workshops@macmillan.org.uk or by visiting macmillan.org.uk/learnzone

Other ideas

- The cancer information section at macmillan.org.uk/cancerinformation and the website cancerhelp.org.uk have information about what cancer is and types of cancer.
- Macmillan runs a workshop called Cancer and its treatments, which can help you understand more about the disease. You can find out more about it by calling **020 7091 2010** or by emailing workshops@macmillan.org.uk

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.

In our experience, you need to ask questions, followed by more questions, and not be afraid to ask something more than once. We found that many health professionals will only give you information that you ask for.

Having detailed information can help you understand more about the particular cancer you are dealing with, for example, where secondary cancers might occur.

Information booklets can be useful. You can visit your local cancer information and support centre or ring Macmillan to find out what's available, or you can order Macmillan resources online from be.macmillan.org.uk

Many organisations concentrate on a particular type of cancer, such as lung cancer or breast

cancer. You can find out about some of these organisations by ringing Macmillan. The Rarer Cancers Forum offers advice and information to individuals with rare and less common cancers, and their carers. Please call **01227 738279** or see rarercancers.org.uk

Again, searching the internet may be helpful, but it's important to go to sites where the information is reliable and quality-checked. Bear in mind that as a carer you might want information that the patient isn't, and may never be, ready for.

Information on your rights as a carer

As somebody who provides 'regular and substantial' care for someone, you have the right to a **carer's assessment** from Social Services. 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.

The emphasis of the carer's assessment is on assessing and

1 Information and support

providing the support you need so you can continue being a carer as long as you wish to do so. The person you care for can also have their needs assessed, but if they don't wish to, you are still entitled to an assessment of your needs.

As a result of the carer's assessment, Social Services can provide you with things such as breaks from caring or help with cleaning your house.

To get a carer's assessment, you should contact your local Social Services (Social Work department in Scotland) – you will find the number in the phonebook.

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**. An employer can refuse this request only where there is a recognised business case for doing so. Also, see **Employment and work**.

As a carer, you have the right to take (unpaid) time off work for dependants in an emergency.

You may be entitled to certain **benefits and financial support** as a carer. You can speak to an experienced benefits adviser by calling the Macmillan on **0808 808 00 00**. Also see the 'Household finances' section in the chapter **Practicalities**.

Other ideas

- You can find lots of useful information on carers' rights at the Carers UK website – carersuk.org

2 Working with professionals

- Organising
- Getting hold of professionals in an emergency or 'out of hours'
- Communication between different health professionals
- Follow-up care
- Support for professionals
- Predicting the outcome (prognosis)
- Being assertive

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

Jean



2 Working with professionals

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. For us, it was helpful to develop 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.

Remember that health professionals don't always have all the answers. Try to find out as much as you can about each individual's role.

This will help you to 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 are 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 is affecting you, they will be better equipped to help you both.

Remember that the professionals are there for you as well as the patient. 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

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'.

Programme all useful telephone numbers (such as your district nurse, GP, cancer ward and local hospice) into your home and mobile phones, and note down the name of receptionists.

Keep a notebook with details of every visit to hospital or from any health or social care professional at home.

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Use a file to keep all leaflets and information sheets, appointment details and other useful information together in one place.

It might also be useful to keep a record of blood test or x-ray appointments and their results. This will make it easier to query any oversights.

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.

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

Getting hold of professionals in an emergency or 'out of hours'

Make sure you know the 'out of hours' arrangements for your key health professionals. Check with them who you should contact in case of an emergency, and how to do this. It may be best to avoid going to Accident and Emergency unless you are advised to do so.

Make sure the telephone numbers you need are always to hand – either programmed into your phone or taped to the fridge.

Call the cancer ward at the hospital if you are worried. If they aren't able to help, try your local hospice.

If you are concerned about a developing condition, symptoms or changes, don't let it go beyond the middle of the week without alerting the relevant health professional. If it is left until near the weekend, it will be more difficult to sort out. Only a small proportion of the country has 'out of hours' support services at the moment.

Try to anticipate problems that may come up 'out of hours' so you can discuss them with health professionals during the working day. We also found it helpful to have a plan in case you can't care for the patient at short notice, eg if you are ill. We discussed this with Social Services and the local carers' centre who provided emergency contact numbers for the patient.

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Communication between different health professionals

Note down the names of all the professionals, and their secretaries where 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 health 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.

Follow-up care

Ask the health professionals what aftercare has been organised for the patient, for example, what

support they will get following treatment or after leaving hospital.

Make sure you are clear about what support packages are available, and take up offers of help provided by professionals.

Support for professionals

Remember, they are 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.

You may be able to offer practical support during treatment and procedures, for example, by holding the patient in a certain position or comforting them 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

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don't and can't know everything – things can turn out differently from 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 are unhappy with the treatment the patient is receiving, say loud and clear that this is how you feel.

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.

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

Other ideas

- The Department of Health has published a leaflet called *Questions to ask: getting the most out of your appointment*. Although aimed at patients, you may also find it useful. Visit the 'Publications' section of the Department of Health's website – dh.gov.uk – to download a leaflet of the questions.
- Macmillan runs a workshop on assertiveness that could help you feel more confident when you are trying to get answers and things done. Call **020 7091 2010** or email workshops@macmillan.org.uk to find out more.

3 Relationships

- Relationship with the patient
- Family relationships
- Juggling responsibilities
- Needs of other family members and friends
- Living on your own
- Time for yourself
- Sex and intimacy
- Symptom transfer

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

Mike V



3 Relationships

Relationships always 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, 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 might see changes in someone's personality.

Try not to be afraid 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 could 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.

Relationship with the patient

Patients and carers are 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 is not going to be easy for either of you.

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

Try to be yourself and live as normally as possible. Behaving differently can make the person you are caring for feel more aware of their condition.

It's important to let the person you are caring for know, when possible, that although you are there to help, they are still in control.

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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.

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.

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. But while it is good to talk, be wary of taking on other peoples' problems.

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

Other ideas

- Macmillan runs workshops that may improve the way you communicate with the patient and your family and friends, eg Listening and responding. To find out more about them, call **020 7091 2010** or email workshops@macmillan.org.uk
- Macmillan also has a booklet called *Lost for words – talking to someone with cancer*. You may find this helpful. It can be ordered by calling **0808 808 00 00** or online at be.macmillan.org.uk

Have the courage to say 'no' to people when necessary, especially if their request isn't a priority for you.

If necessary, be prepared to agree boundaries, for example, when and for how long people should visit.

Juggling responsibilities

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

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

You may feel reluctant to receive help. Having a list at hand 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, collect prescriptions, etc. 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 at a time, and try to keep family life as normal as possible.

Needs of other family members and friends

There may be lots of conflicts of interest among family members and other carers. You won't be able to please everyone, so don't try – and don't worry about it.

However, try as far as possible to include all the carers and family members in important events and decisions. Spending time together and talking openly is important.

Where possible, try to spend time doing everyday things as a family. 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.

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Living on your own

Not everyone will have the support of a family or friends when they are caring for someone with cancer. However, there are services and organisations out there that can stop you feeling isolated, and can provide you with someone to talk to about any difficulties you are facing:

- You can talk to other people affected by cancer, including carers, on discussion forums on the internet. Many will be run by carers or cancer organisations. Macmillan's online community can be found at macmillan.org.uk/community
- You can get confidential information and advice from Carer UK's CarersLine on **0808 808 7777**.
- You can also call Macmillan on **0808 808 00 00** and speak to cancer support specialists who will listen to your particular issues with empathy and respect.

- You could join a self-help and support group and speak to other people affected by cancer. Visit macmillan.org.uk/supportgroups to search for a group in your area. Or call Macmillan to find a group.
- Crossroads Care runs schemes in England and Wales that provide practical support to carers. Crossroads Caring for Carers Scotland and Crossroads Caring for Carers Northern Ireland offer similar services. See **Further information** 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. A local Crossroads scheme (see **Further information** for contact details) may also be able to support you. Even short periods of time to yourself can make a huge difference.

We found it was usually beneficial to accept help and support when it was offered.

However, you may feel that you want to be there all the time, particularly if the person you are caring for 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 is 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 is okay to turn down offers of help.

Sex and intimacy

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

Talking openly with your partner about your sex life can help to lessen any worries and overcome any problems.

Speak to your partner about whether they need time and space to recover from treatment. You may feel that you want to be more attentive with each other and that you have a more active sex life following the patient's diagnosis.

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 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 advise on how cancer and treatment may affect your sex life.

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The Macmillan website has information on living with and after cancer. This includes a section on relationships and communication, covering topics such as sexuality. See macmillan.org.uk/cancerinformation

You can also call Macmillan's cancer support specialists for advice and emotional support on **0808 808 00 00**.

Symptom transfer

You may have feelings of guilt about a loved one's pain, and wish you could take their pain 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. Be aware that while this is unusual, it can happen.

See your GP to make sure there is no actual physical cause for your problem.

Other ideas

- The 'Coping with cancer' section of CancerHelp UK's website – cancerhelp.org.uk – has lots of useful information about sex, sexuality and cancer. Or visit the 'cancer information' section of Macmillan's website macmillan.org.uk/cancerinformation

4 Moods and emotions

- Patient's depression
- Carer's depression/anxiety
- Remaining positive
- Guilt
- Feeling isolated
- Fear
- Anger and frustration
- Carer's tiredness/exhaustion
- Denial

'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

You have them too – and they matter! As a carer you are likely to be very aware of the feelings and emotions the person you are caring for is experiencing. The rest of the family and your 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.

There's no need to apologise or feel guilty that you have strong emotions or moods yourself. It's only natural, and it's important that you find ways to express them sometimes, 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 person you are caring for may come up against.

Patient's depression

If you are concerned that the patient is depressed, tell a health professional and consider suggesting counselling.

There are things that can help to lift the patient's spirits, such as relaxation techniques, mood music, books or audio books, having a television in the bedroom, etc.

Visitors can also help to lift the patient's spirits, or you could encourage the person you are caring for 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.

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Take time to sit together as a family 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.

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

Take time out with your friends to relax. Gentle exercise, something like a 10-minute walk, can also help to improve symptoms of depression and anxiety.

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

Remaining positive

Try to keep in mind 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 to remain positive. If you have any spare time to yourself, think about what will give you a boost. It might just be reading a newspaper and having a cup of tea.

Try some activities that divert 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.

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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 are 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.

Using your experience of cancer to improve services for carers and patients can help you feel more positive. You can find out the contact details of your local user group by calling Macmillan.

Guilt

Feelings of guilt are a common reaction. 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 to 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.

Sometimes you may have trouble communicating with the patient but talking to a professional may help.

You could speak to other people affected by cancer on a discussion forum on the internet. Macmillan's online community is available at macmillan.org.uk/community

4 Moods and emotions

Fear

Try to understand what it is you are afraid of. We 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 as they may intensify if you try to suppress them.

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

Other ideas

- Get involved with a support group and speak to others who can relate to your experiences. Find your nearest support group by calling Macmillan on **0808 808 00 00** or by visiting macmillan.org.uk/supportgroups
- Macmillan Cancer Voices is also somewhere you can use your experience to positive effect. To find out more information, visit macmillan.org.uk/cancervoices, call **0207 091 2006** or email cancervoices@macmillan.org.uk
- A 'Be good to yourself' workshop is run by Macmillan that could help you manage negative thinking and improve the way you look after yourself physically and emotionally. Call **020 7091 2010** or email workshops@macmillan.org.uk

Moods and emotions 4

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 is difficult to fully express how you are feeling.

Patients can sometimes take their anger out on people closest to them. Try not to feel responsible for their emotional turmoil.

Some cancers can affect a patient's personality, eg lead to them having sudden fits of anger. Speak to a health professional about whether the person you are caring for may be affected in this way.

Carer's tiredness/exhaustion

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

It is important to look after yourself by eating extra fruit and vegetables and keeping up your fitness.

Consider having a flu jab. Carers are automatically entitled to one for free. Ask your GP about getting one. Also, 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 also 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.

Other ideas

- Consider speaking to your local hospice about the support they can provide to give you some time off from your caring role.

4 Moods and emotions

Denial can be a useful way of handling the 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. 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 the **Death, dying and bereavement** chapter.

5 Practicalities

- Food and eating
- Moving and handling
- Organising equipment and transport
- Availability of drugs
- Pain control
- Clinical trials
- Personal care
- Dealing with practical chores
- Household finances
- Side effects of treatment

'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



5 Practicalities

There is a whole range 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 have 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 person you are caring for feel more comfortable, this can make you feel better too.

In this chapter we have put together some tips about 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 liquid from a nutritionist.

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 things like milk powder in mashed potato or high calorie drinks. You could also add food supplements to the patient's portion of family meals.

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

5 Practicalities

Moving and handling

We found that learning to move and handle the patient safely was beneficial to the patient and ourselves. Ask your GP or district nurse where you can get advice about this.

If a patient's balance isn't good, they may need your help when moving around. Make sure you do this with care, and discuss with the patient what help they want from you.

There are aids that can help you cope at home; ask at your hospital if you can speak to an occupational therapist about them.

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.

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

Ask the hospital or local Social Services department about household aids and wheelchairs. Organisations such as the Red Cross and Age Concern can also supply these items.

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

Plan ahead. Take advice from health professionals about what you might need in advance so the equipment is there when you need it.

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

Availability of drugs

It's good to be aware that not all pharmacies will stock the drugs the person you are caring for needs. Speak to a pharmacist about ordering in drugs.

Pain control

Try using a tablet box so you can separate out all the pills the patient needs to take that day.

Keep a chart which shows all the pain relief being taken. It will help you develop a pattern that works.

People are often advised to take regular doses so the pain relief is always in their system. Make sure the pain relief is taken as advised by the doctor.

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 are caring for is taking high doses of strong painkillers. It is important to remember that the right dose is the one that controls the pain, and this can vary.

Clinical trials

Clinical trials are medical research trials involving patients. They are carried out to try and find new and better treatments, including for cancer. If you and the person you are caring for would like to find out more, see the cancer information section of the Macmillan website.

Other ideas

- A local Crossroads scheme may be able to provide you with practical help around the house. For contact details see **Further information**.
- Your local carers centre may offer training to help you with caring – such as first aid, and moving and handling.

5 Practicalities

Personal care

There are a number of things you can do to make the person you are caring for 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.

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 to take them food, etc.

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 the quality of your life or the patient's. Call Macmillan to find out more information.

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 the person who does to teach you about these tasks. Ensure you're getting all the benefits and other financial help you are entitled to (see **Household finances** section) – this may help to pay for a cleaner or a gardener.

Household finances

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

Your local Citizens Advice can provide you with advice. You could also call Macmillan, the Carers UK helpline or go to a local carers' centre – find yours by searching at carers.org or by calling The Princess Royal Trust for Carers regional offices. See **Further information** for contact details.

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 is help available, including benefits, tax credits and grants. This includes help to meet NHS costs, such as travel for hospital treatment, prescriptions, wigs, dental treatment and glasses and sight tests.

Always ask for help when you need it. The health and social care professionals involved with the patient will be able either to give you advice and information on benefits and filling in forms or to put you in contact with someone else who can help.

You can get details of local benefits advice services in your area by calling Macmillan. Also, your local Social Services or Social Work department can put you in touch with a social worker or benefits adviser.

Macmillan can offer you advice and help you to access benefits and other kinds of financial support. We can also help you fill in benefit claim forms. Call free on **0808 808 00 00**.

Grants are available from Macmillan to help people living with cancer meet some of the extra costs it can bring. Call Macmillan for more information.

Citizens Advice can help with benefits advice and form filling. Your phonebook will have details

5 Practicalities

of your nearest bureau, or visit citizensadvice.org.uk for more information.

Carer's Allowance is the main benefit you may be entitled to. 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 for Carer's Allowance. A new carer's credit is also being introduced for carers who reach State Pension age on or after 6 April 2010.

For more information, contact your local benefits advice service or call one of the helplines mentioned above. You can also find information on financial support for carers at the Directgov website direct.gov.uk in the 'Caring for Someone' section. In Northern Ireland, see nidirect.gov.uk

People with cancer in England are now entitled to free prescriptions. Your GP surgery or oncology clinic can advise on how to apply for an exemption certificate. Prescription charges for people with cancer have been abolished in Wales, and are going to be abolished in Northern Ireland in 2010 and in Scotland in 2011.

The patient may be entitled to a disabled parking badge for your car to use when you are taking the patient out. Contact your local Social Services or Social Work department for more information. You'll find the number in the phonebook.

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

Other ideas

- An information booklet called *Help with the cost of cancer* is available from Macmillan. It has details of the types of practical and financial help you might be entitled to. You can get a free copy by calling **0808 808 00 00** or by ordering one from be.macmillan.org.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 – see the phonebook or visit hmrc.gov.uk If your circumstances change, it is also worth asking if you are paying the right amount of tax.

If the person you are caring for is dying, try to get all financial papers in order. The hospital, your Jobcentre Plus or Social Security office may have helpful leaflets.

If you feel it is a subject you can raise, find out whether the patient has made a Will. Check life insurance policies – some pay out on diagnosis. If you and the patient look through your policies,

Other ideas continued

- You can download *Help with the cost of cancer* from the 'Financial support' section of the Macmillan website – macmillan.org.uk/financialsupport This section also contains lots of other useful information, including where to find benefits advice services in your area.
- The Carers UK website has a lot of information about benefits you may be entitled to – carersuk.org/Information/Financialhelp
- The Jobcentre Plus website has useful information about financial help, including Carer's Allowance. See jobcentreplus.gov.uk In Northern Ireland, see dsdni.gov.uk/ssa
- The Directgov website has useful information about money matters, including direct payments and pensions. Go to direct.gov.uk/en/CaringForSomeone/MoneyMatters In Northern Ireland, see nidirect.gov.uk/index/caring-for-someone

5 Practicalities

you may find that you are covered for loss of income, medical treatment, credit cards, mortgage payments or other expenses.

If your caring role ends, it is important to let your 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 major problems further down the line and find out what benefits you can claim now. You can also call Macmillan for advice about this.

If you have a low income once your carer's benefits stop, you may be able to claim other benefits.

Side effects of treatment

Treatments for cancer can have some unexpected and uncomfortable side effects. Ask your doctor and other health professionals about what kind of side effects the person you are caring for may experience and how they can be managed.

If you have an idea of what to expect, it will help you to 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 are not always possible to predict.

Being prepared for the effects of treatment, such as a dry mouth, nausea or constipation means you can learn about ways to handle these problems. Being able to alleviate some of these side effects can help you feel you are doing something positive to help the person you are 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 on treating these side effects are things we found worked for us.

Dry and sore mouth

- Ideally, the patient needs to see their dentist before they start any treatment and advise 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 mouth washes and regularly replace their toothbrush.
- Eating pineapple before a meal can enhance taste buds.
- 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.

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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

- Seek medical advice about sex during 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 is safe for them to visit the patient.

- Breathlessness can be a problem with certain types of cancer.

The Macmillan website has information on coping with symptoms and side effects, including breathlessness and fatigue. See macmillan.org.uk/cancerinformation/livingwithandaftercancer

You can also call Macmillan's cancer support specialists for advice on **0808 808 00 00**.

Other ideas

- Macmillan has a range of information booklets on topics such as controlling cancer pain, coping with fatigue or hair loss and diet. These can be ordered by calling **0808 808 00 00** or at be.macmillan.org.uk

6 Employment and work

- Considering your options
- Remaining at work
- Leaving work
- Returning to work
- Benefits

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

Michael



6 Employment and work

When you are a carer, finding a balance between work and caring can be difficult, but it's definitely not impossible. You may feel unsure about whether to stay at work, leave or return to work.

The thing to remember is to take your time before you make any decisions.

Also speak to organisations that can give you independent advice. Knowing 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 is helpful. They may surprise you with their thoughts on the situation.

Many patients see that work is something that provides a release for carers from their caring role. Whatever you decide to do, make sure it is 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 is 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 to you making rash decisions. Ask for time off work so you have space to think.

It may be wise to find out as much information as possible about your rights before initially speaking to an employer about your caring role. This also applies if your situation changes. Get independent advice from organisations such as Citizens Advice.

Once you know more about your rights, speak to your employer about what options are available

6 Employment and work

to you and be clear about what you need. For example, could you work flexible hours, do a job share or work from home?

By law you have the statutory right to ask your employer for flexible working if you are caring for an adult who is a relative, spouse or partner, or who lives at the same address as you. An employer can refuse this request only where there is a recognised business case for doing so.

Ask your local Social Services or Social Work department for a carer's assessment. You are entitled to one if you care for someone for 'a substantial amount of time and on a regular basis'.

The purpose of the assessment is to see what help you need with caring, plus what will help you to remain healthy and keep up your life, work and family commitments. You'll find the contact number for your local Social Services or Social Work department in the phonebook.

Consider short-term and long-term employment plans. If you are

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

Remaining at work

Although you do not have to tell your employer that you are caring for someone, it may help to avoid problems in the future if you do. Ask them for a private meeting.

Speak to someone in your human resources department about your situation and what options are available to you in the future. Remember though, 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.

For many of us, we 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

Employment and work 6

home or that you need 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 for dependants in cases of emergency. And don't forget you have the right to ask for flexible working.

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

If your situation does change, consider speaking to Citizens Advice about your rights before you talk to your manager or someone in your human resources department.

Other ideas

- Macmillan's *Working while caring for someone with cancer* booklet features useful information about cancer and employment. You can order it by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**
- Carers UK has a section on its website about work and caring. Visit **carersuk.org** or call the CarersLine on **0808 808 7777** for advice on employment issues.
- 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 their website **atacas.org.uk**
- You can find information about flexible working, work life balance and caring for someone while working in the 'Employment' section at **direct.gov.uk**
- Working Families also covers these topics on their website. See **workingfamilies.org**

6 Employment and work

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 or an independent financial adviser could help you. Macmillan's cancer support specialists can also help.

Make sure you don't feel pressurised to give up your job. If you do, speak to someone in your human resources 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 say that you will be back once your caring role ends.

If early retirement is an option, discuss it with your employer. Remember, though, that although for some people it is an advantage, for others it can leave them worse off financially. Get expert advice to see if you would benefit from early retirement.

Returning to work

Before returning to work, it may be advisable to seek advice from independent organisations 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.

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.

Employment and work 6

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 will have if changes do occur. Speak to your employer or human resources 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 Plus or Jobs and Benefits Office should offer you a range of job search support.

Consider your skills and interests before applying for a job. Make sure it is 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. Jobcentre Plus also recommends the following websites: careersscotland.org.uk, careerswales.com, jobseekersdirect.gov.uk and jobcentreonline.com

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

Other ideas

- The Jobcentre Plus website has useful information on returning to work. Go to jobcentreplus.gov.uk/jcp/customers/disabled_people_and_carers In Northern Ireland, see dsdni.gov.uk/ssa

6 Employment and work

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**. Or for more information on benefits, see the 'Household finances' section in **Practicalities**.

7 Ethical and legal matters

- Making decisions
- Advance care planning
- Relevant areas of law
- Confidentiality and sharing information
- Talking to the person you care for

'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



7 Ethical and legal matters

Understanding the ethical and legal side of caring for someone with cancer can be daunting. You might 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 person you are caring for 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. 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 might consult you about stopping treatment, or whether the patient should be resuscitated. You might 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 keep talking about it day-to-day. The earlier you discuss these issues, the more prepared you will be for them if they arise. It can also help to put the patient's mind at ease.

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

Other ideas

- Macmillan has two booklets called *Caring for someone with advanced cancer* and *Talking about your cancer*. You may find these useful and copies can be ordered by calling **0808 808 00 00** or going to **be.macmillan.org.uk**
- The Cancer Counselling Trust offers free, confidential counselling to people affected by cancer. For more details, go to **cancercounselling.org.uk** or call **020 7843 2292**.

7 Ethical and legal matters

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.

Advance care planning

Advance care planning (also known as statements of wishes and preferences) 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 health professionals, and other people involved in their care. For you as the carer, it may help to remove some of the uncertainty about making decisions. It can also make things easier for the patient's family.

The patient may want to make a specific decision about their future treatment. This is sometimes called an advanced decision. It is a good idea to talk about these decisions with the patient's healthcare team. For more information on advance care planning, you can visit the National Council for Palliative Care website at ncpc.org.uk/publications or call 020 7697 1520, or go to the 'Wills and probate' section of direct.gov.uk

Relevant areas of law

The **Mental Capacity Act (2005)** aims to protect people who are unable to make decisions for themselves. 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, go to publicguardian.gov.uk/mca/mca.htm

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 **Lasting Power of Attorney (LPA)**. LPAs will only be used if the person who made it cannot make decisions for themselves.

LPAs can take around a couple of months to organise. Some of us found the process complicated, and it was helpful to have legal advice from a solicitor. There is a

fee for registering the LPA, but you may not have to pay the full amount. For more information, go to publicguardian.gov.uk/forms/Making-an-LPA.htm

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. For you and the person you care for, it means that you have the right to discuss the patient's personal needs and preferences with the people who will support 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 more information on the strategy go to dh.gov.uk

Other ideas

- The National Council of Palliative Care has more information about decision-making and advance care planning. Their booklets can be ordered through ncpc.org.uk or by calling 020 7697 1520.
- The Office of the Public Guardian website has information about making decisions for people who can't make decisions for themselves. Go to publicguardian.gov.uk or call 0300 456 0300

7 Ethical and legal matters

Confidentiality and sharing information

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 that you're not able 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 the person who is named as the patient's next of kin. 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, the patient should let them know as early as possible. Make sure that the healthcare team involved in the patient's care know that you

are the carer. The patient may also wish to name you as their next of kin.

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 the end of their life. You may also be feeling anxious, so it could be a good opportunity to explore your concerns together. 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.

Other ideas

- Families Facing Cancer can offer you emotional and practical support. Go to familiesfacingcancer.org or call **0844 35 77 959**
- Alternatively, you can call Macmillan on **0808 808 00 00** or visit our website at macmillan.org.uk

8 Death, dying and bereavement

- Information and support
- Physical changes
- Denial
- Practicalities
- Moods and emotions
- Your future

'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

If you are caring for someone who is dying, it may be extremely difficult to confront this fact, especially if the patient has not 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 feel you 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 health 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 have. If you are clear about what you and they want, you can help to make arrangements.

It may not always be possible, but talking will increase the chance of making it 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 if 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.

Other ideas

- Macmillan has a booklet called *Caring for someone with advanced cancer*. You may find this useful and it can be ordered by calling 0808 808 00 00 or going to be.macmillan.org.uk

8 Death, dying and bereavement

- If you need to take a break from caring for a patient who is dying, 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 and provide free nursing care to cancer patients in their own homes. For more information on how to get a Marie Curie nurse, see **Further information**.
- Marie Curie Cancer Care and Macmillan produce 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 health 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, see mcpil.org.uk

- The End of Life Care Strategy (2008) promotes high-quality care and greater choice for all people reaching the end of their lives. The strategy covers adults in England. For more information, see dh.gov.uk

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 you might expect, or to ask questions about any particular worries you may have.

Death, dying and bereavement 8

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. 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. In some cultures and age groups this is an especially difficult issue.

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 at different 'places', for example one accepts the situation while the other prefers to deny it is 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 might 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 might 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.

8 Death, dying and bereavement

If there is denial, some things can be organised or talked about without being explicit that you are 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 health professional to talk to them. Specialist palliative care nurses, for example, 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 and 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 always be respected.

If at any time you need help and support to cope with the fact someone you are caring for is in denial, 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 health professionals. You can also download the English version from the 'Leaflets and guides' section of the Jobcentre Plus website at jobcentreplus.gov.uk/JCP/Customers

Death, dying and bereavement 8

For information regarding Scotland, see scotland.gov.uk
For information about what to do after a death in Northern Ireland, see nidirect.gov.uk

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.

Be aware that funeral directors may charge you more if you use their night service. After getting

the GP out to do the necessary paper work, and if you feel comfortable doing so, 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 above can help.

Advice on registering a death can be found on the Directgov website direct.gov.uk

Other ideas

- Carers UK and Help the Hospices have produced a helpful guide called *When caring comes to an end*. It has a useful section called 'When the person you care for has died'. You can get hold of the guide for free by calling **0845 241 0963** or emailing publications@carersuk.org. You can also download it from carersuk.org or see the carers section of the Help the Hospices website helpthehospices.org.uk
- Macmillan runs a workshop on loss and bereavement. To find out more about how it could help you, call **0207 091 2010** or email workshops@macmillan.org.uk

8 Death, dying and bereavement

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

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 do not need to have the person's body removed immediately if you don't want to.

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

Moods and emotions

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

Try to share your feelings of loss with the patient and grieve together with them and the family before they die.

Death, dying and bereavement 8

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 found we 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. You can do this how and when you want to. You might want to ask for help from friends and family. 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.

8 Death, dying and bereavement

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

Your local hospice may have bereavement groups you can join. Also, consider bereavement counselling. For example, there may be a branch of Cruse Bereavement Care in your area for help and advice. Call their helpline on **0870 167 1677** or call Macmillan.

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 a number of child bereavement services in **Further information**.

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 can turn your back on tomorrow and live yesterday
Or you can be happy for tomorrow because of yesterday.'**

Extract from 'Courage' (anon) suggested by Hilary.

9 Life after caring

- Practicalities
- Emotions
- New challenges

'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



9 Life after caring

For many of us, it took some time to adjust to the end of our caring role, whether that was because the patient moved into residential or nursing care, was now able to care for themselves or that they had died.

You can have a lot of time to fill and you can feel quite adrift, without purpose or direction. If you don't return to work, this is a good time to learn something new, volunteer or campaign to improve information and support for carers.

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 falling 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

do not have to rush into decisions about what you will do next straight away.

Take your time, and remember that there are a lot of people and organisations out there that can 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 what other benefits you are entitled to. It's best to find out as quickly as possible what you need to do regarding benefits as this will help to avoid problems later on. Call Macmillan on **0808 808 00 00** for advice. Carers UK's website also has useful information. Go to [carersuk.org/Information/Whencaringends/Lifeaftercaring](https://www.carersuk.org/Information/Whencaringends/Lifeaftercaring)

9 Life after caring

Try to accept help that is 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 from 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 from 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 might go into automatic pilot and carry on with life as if nothing has changed. Do whatever feels right for you.

Other ideas

- *When caring comes to an end*, a guide produced by Carers UK and Help the Hospices, features helpful information on 'When the person you care for moves into residential or nursing care', 'When the person you care for has died' and 'Life after caring'. You can get hold of *When caring comes to an end* for free by calling **0845 241 0963** or emailing publications@carersuk.org. Or you can download it from carersuk.org or see the carers section of the Help the Hospices website helpthehospices.org.uk

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.

Remember that there are still many support services out there to help you. See 'Your future' section in **Death, dying and bereavement**.

Many of us are still benefitting emotionally from attending support groups even though our caring role has ended. Call Macmillan to find your nearest one or visit macmillan.org.uk/supportgroups

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 quite normal and something you can use to positive effect. See the 'New challenges' section below.

You may find that you constantly worry about the patient getting cancer again. This may lead to you becoming over-protective. Try to live life without this worry hanging over you.

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 in **Employment and work**.

You may feel that you 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.

9 Life after caring

The following websites can also provide you with useful information: learnndirect.co.uk and the 'Adult learning' section on direct.gov.uk

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.

Other ideas

- Macmillan Cancer Voices is a UK-wide network that uses peoples' experiences of cancer to improve cancer care for patients and carers. You can find out more about its work by visiting macmillan.org.uk/cancervoices, calling **0207 091 2006** or emailing cancervoices@macmillan.org.uk
- If you are interested in volunteering for Macmillan, contact your area's volunteering adviser – details at macmillan.org.uk/getinvolved/volunteer or for general enquiries, call **020 7840 4961**.

10 Further information

- Organisations for carers
- Young carers
- General cancer information
- Hospices
- Public services and information
- Bereavement
- Macmillan training courses
- Macmillan workshops
- Your notes

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

Roberta



10 Further information

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 are available.

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

We have a wide range of services and activities that might be of help and interest. We provide expert, up-to-date information about cancer – the different types, tests and treatments, and living with the condition.

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

Just call and speak to one of our cancer support specialists. Or visit one of our information and support centres – based in hospitals, libraries and mobile centres – and speak with someone face-to-face.

10 Further information

Organisations for carers

Carers UK

20 Great Dover Street
London SE1 4LX
Tel 020 7378 4999
www.carersuk.org.uk
info@carersuk.org

A UK-wide organisation offering support, information and advice on all aspects of caring to both carers and professionals. Carers UK also campaigns on behalf of carers for recognition and equality and informs carers of their rights and how to get support.

CarersLine

Tel 0808 808 7777
(free advice service)
Wednesday and Thursday
10am–12pm and 2–4pm

Crossroads Care England and Wales

10 Regent Place
Rugby
Warwickshire CV21 2PN
Tel 0845 450 0350
www.crossroads.org.uk

Crossroads services provide practical care and support in the

home to give carers a break from their caring responsibilities.

The service includes day, night and weekend care and is usually free of charge.

There are schemes in most parts of England and Wales, which provide a range of services to meet local needs.

Several Crossroads branches are working in partnership with Macmillan to provide a specialist service for patients with a cancer diagnosis, their carers and families.

Details of local carers schemes provided by Crossroads can be found on their website or by phoning their helpline.

Crossroads Caring for Carers Scotland

24 George Square
Glasgow
G2 1EG
Tel 0141 226 3793
www.crossroads-scotland.co.uk
info@crossroads-scotland.co.uk

There are over 40 local Crossroads services in Scotland.

Crossroads Caring for Carers Northern Ireland

7 Regent Street
Newtownards
County Down
BT23 4AB
Tel 028 9181 4455
www.crossroadscare.co.uk
mail@crossroadscare.co.uk

The Princess Royal Trust for Carers

Unit B, Bourne Court
Southend Road
Woodford Green
Essex IG8 8HD
London office: 0844 800 4361
info@carers.org
Glasgow office: 0141 221 5066
infoscotland@carers.org
Northern office: 01257 234 070
infochorley@carers.org
www.carers.org

Provides information, advice and support services to carers through a network of over 144 independently managed carers centres across the UK. Local centres can be found on the website or by phoning your nearest office.

Young carers

www.youngcarers.net

An online service for young carers from The Princess Royal Trust for Carers. The site allows you to search for young carers' projects and support groups by postcode.

www.youngcarer.com

A site for young carers, their families and those who work to support them across the UK. The site was created as part of The Children's Society National Young Carers Initiative.

General cancer information

Cancer Research UK

PO Box 123
Lincoln's Inn Fields
London WC2A 3PX
Tel 020 7121 6699
www.cancerresearchuk.org

The UK's leading charity dedicated to cancer research. Its website features extensive information about cancer and the work of the charity.

10 Further information

www.cancerhelp.org.uk

CancerHelp UK is one of Cancer Research UK's five main websites. It provides free information about cancer and cancer care for people with cancer and their families. If you have a question about cancer, you can call their team of specialist nurses on 020 7061 8355, or freephone 0808 800 4040. Lines are open Monday to Friday between 9am and 5pm.

Marie Curie Cancer Care

89 Albert Embankment
London SE1 7TP
England office: 020 7599 7777
Northern Ireland office:
028 9088 2060
Scotland office: 0131 561 3900
Wales office: 01495 740827
www.mariecurie.org.uk
Email contact details are available on the website.

A UK charity that employs more than 2,700 nurses, doctors and other healthcare professionals, it provides care to around 25,000 people with cancer every year, along with support for their families. The charity also cares

for people with other life-limiting illnesses.

For information about getting a Marie Curie nurse, call your district nurse or key worker.

Hospices

Hospice Information

Help the Hospices
Hospice House
34–44 Britannia Street
London WC1X 9JG
www.hospiceinformation.info

An information service for the public and health professionals about hospice and palliative care. Includes details of services in the UK and worldwide. You can contact a member of the team by calling 0870 903 3 903 (calls charged at national call rates), alternatively you can call 020 7520 8232 between 9am and 5pm, Mondays to Fridays.

Public services and information

Citizens Advice

www.citizensadvice.org.uk

The Citizens Advice service helps people resolve their legal, money and other problems by providing free information and advice from over 3,000 locations, and by influencing policymakers. You can find your local bureau by looking in your phonebook or by visiting adviceguide.org.uk You can also get online advice and guidance from this website.

www.direct.gov.uk

The website provides a wide range of public service information and services online. The caring section on the site includes information about employment, health, money matters and carers' rights.

Bereavement

Cruse Bereavement Care

PO Box 800

Richmond

Surrey TW9 1RG

Tel 020 8939 9530

info@cruse.org.uk

Helpline 0844 477 9400

helpline@cruse.org.uk

www.crusebereavementcare.org.uk

A UK-wide organisation providing help to people who have been bereaved. Services include counselling and support, information, advice, education and training services. Its website allows you to search for your local branch.

Northern Ireland office:

028 9079 2419

northern.ireland@cruse.org.uk

Wales office:

029 2088 6913

wales.cymru@cruse.org.uk

Scotland office:

01738 444178

www.crusescotland.org.uk

info@crusescotland.org.uk

10 Further information

Cruse Youth Bereavement Service

Helpline 0808 808 1677

Monday to Friday 9.30am–5.00pm

www.rd4u.org.uk

info@rd4u.org.uk

RD4U is a website designed to support young people after the death of someone close.

Winston's Wish

Westmoreland House

80–86 Bath Road

Cheltenham

Gloucestershire GL53 7JT

Helpline 08452 03 04 05

www.winstonswish.org.uk

info@winstonswish.org.uk

A child bereavement charity that helps young people readjust to life after the death of a parent or sibling.

Child Bereavement Charity

Aston House

West Wycombe

High Wycombe

Buckinghamshire HP14 3AG

Tel 01494 446648

www.childbereavement.org.uk

support@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.

Macmillan training courses

Macmillan offers a range of free training and development opportunities for people affected by cancer. You can find out more at macmillan.org.uk/learnzone

New Perspectives course

– for carers

A six-week course run by people who have cared for someone with cancer that helps carers to develop self-management skills.

Cancer Support Course

An accredited course that focuses on the skills needed to support people affected by cancer. The course, which lasts one year, is split into five units:

- Effective communication skills to support people affected by cancer
- Introduction to counselling skills
- Working with loss and bereavement

- Cancer awareness
- Health and well-being

In addition, there are three more units which can be taken as options:

- Support for people affected by cancer
- Good practice for cancer support groups
- Skills for user involvement

For further information about the above two courses, call **020 7091 2008** or email csc@macmillan.org.uk

Macmillan workshops

Macmillan runs a number of one and two day workshops that help people affected by cancer develop themselves and their coping skills.

Be good to yourself

A one-day workshop that gives you a taste of the different ways in which you can look after yourself physically and emotionally when you are affected by cancer.

Listening and responding

Develop your listening skills so you can support people affected by cancer.

Cancer and its treatments

Increase your knowledge of cancer and its treatments in order to support others who are affected by cancer.

Making a difference workshops

These one or two day workshops are for people who have experienced cancer and want to use this experience to influence and improve cancer care.

Macmillan can also provide training around interpersonal skills, which covers topics such as **Assertiveness** and **Dealing with anger**.

For further information about the above courses, call **020 7091 2010** or email workshops@macmillan.org.uk

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.

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 and approved by Macmillan's Information Development team and Carers Support Manager.

With thanks to our medical editor, the people affected by cancer and the professionals who reviewed this edition, and the National Council for Palliative Care for their help.



Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care.

One in three of us will get cancer.
Two million of us are living with it.
We are all affected by cancer.
We can all help. We are Macmillan.

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.

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