

**HELLO,
AND
HOW
ARE
YOU?**

**WE ARE
MACMILLAN.
CANCER SUPPORT**

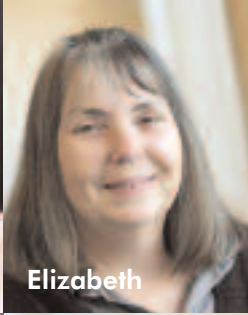
A guide for carers, by carers



Sue



Mike V



Elizabeth



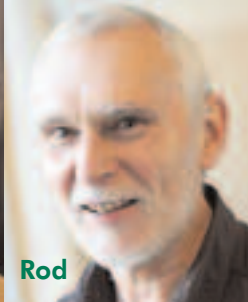
Daroo



Michael



Roberta



Rod



Pauline



Hilary



Alex



Jean

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Cancer is no longer a death sentence. More and more people are living with the disease because of earlier diagnoses and better treatments. This has resulted in a growing need for people like you and people like us: individuals who care for someone 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.

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.

All the best,

Danoo Banerjee, Lis Blyth, Alex Burton, Ethel Culling,
Pauline Donoghue, Dawn Ford, Jean Fraser,
Jane Gambrell, Roberta Lovick, Elizabeth Newbould,
Hilary Plumtree, Mike Porteous, Stacey Prince,
Michael Scanes, Susan Tulip, Jean Turner,
Mike Vincent, Rodney Waite

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 more 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 now has a Patient Advice and Liaison Service (PALS) which should be able to direct you to local sources of cancer information.
- 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.

1 Information and support

- 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 www.macmillan.org.uk/supportgroups or phone the Macmillan CancerLine for information about groups in your area.

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 the Macmillan CancerLine.

Organisations that can help

- You can find out about information and support services in your area by calling the Macmillan CancerLine on 0808 808 2020.
- Macmillan also has three South Asian helplines operated by trained advisers: Hindi 0808 808 0100, Punjabi 0808 808 0101, Urdu 0808 808 0102.
- The Macmillan YouthLine (0808 808 0800) provides support for 12 to 21-year-olds affected by cancer.

- At www.macmillan.org.uk/map you can use your postcode to find your nearest cancer information centre or Macmillan Mobile Cancer Information Centre.
- The Share discussion forum on Macmillan's website – www.macmillan.org.uk/share – is a good place to talk to other people affected by cancer.
- You can find your local carer centre by searching at www.carers.org or by calling The Princess Royal Trust for Carer's regional offices. See **Further information** for contact details.
- Crossroads Caring for Carers services provide practical care and support 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 *A guide for disabled people, those with health conditions, and carers*. It has information on financial and practical help, and is available from your local Jobcentre Plus office. You can also download it from www.jobcentreplus.gov.uk/jcp/customers/leaflets_and_guides
- Macmillan Cancer Voices is a UK-wide network that uses people's experience of cancer to improve cancer care. To find out more about its work, visit www.macmillan.org.uk/cancervoices, call 0207 091 2007 or email cancervoices@macmillan.org.uk
- An NHS-based training programme called the Expert Carers Programme is launching in August 2008. It will provide carers with vital training and information that will empower them and help them support the person they assist more effectively. To find out more about it, call the Department of Health's helpline on 020 7210 4850.

1 Information and support

- A year-long 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 www.learnzone.macmillan.org.uk
- Macmillan also offers a six-week course called 'Living with cancer – for carers'. 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 using the contact details above.

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.

Other ideas

- The Get Support section at www.macmillan.org.uk and the website www.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 booklets, such as those from Cancerbackup, can be useful. You can also visit your local cancer information and support centre or ring the Macmillan CancerLine to find out what's available.

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 the Macmillan CancerLine.

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, by law (the Carers [Recognition and Services] Act), to a carer's assessment from Social Services.

The emphasis of the carer's assessment is on assessing and providing the support you need so you can continue being a carer as long as you wish to do so.

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 – you'll 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 issues**.

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

1 Information and support

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 Benefits Helpline on 0808 801 0304. Also see the 'Financial help' section in the chapter **Practicalities**.

Other ideas

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

2 Working with professionals

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 A&E 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.

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! If you smile and say thank you, this will often make their day.

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.

2 Working with professionals

Be aware that professionals often 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 – www.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, 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 and be yourself to 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.

3 Relationships

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 two workshops that may improve the way you communicate with the patient and your family and friends – 'Listening and responding' and 'Intimate relationships and cancer'. To find out more about them, call 020 7091 2010 or email workshops@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.

3 Relationships

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 Share discussion forum is available at www.macmillan.org.uk/share
- You can get confidential information and advice from Carer UK's CarersLine on 0808 808 7777.
- You can also call the Macmillan CancerLine on 0808 808 2020 and speak to specialist advisers 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 www.macmillan.org.uk/supportgroups to search for a group in your area. Or call the Macmillan CancerLine to find a group.
- Crossroads Caring for Carers run schemes across the UK that provide practical support to carers. 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 healing to touch and stroke the patient's scars from surgery.

Some cancer treatments can be transferred via semen. 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.

3 Relationships

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 'Living with cancer' section of CancerHelp UK's website – www.cancerhelp.org.uk – has lots of useful information about sex, sexuality and cancer.

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 ready for them to breathe into.

4 Moods and emotions

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.

Other ideas

- Macmillan runs a workshop that can help you develop relaxation and visualisation techniques to ease depression and anxiety. You can find out more about the workshop by calling 020 7091 2010 or emailing workshops@macmillan.org.uk

Try some activities that divert from the situation. For example, we found it useful to try and 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.

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 the Macmillan CancerLine.

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 Share forum is available at www.macmillan.org.uk/share

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.

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 the Macmillan CancerLine on 0808 808 2020 or by visiting www.macmillan.org.uk/supportgroups.
- Macmillan Cancer Voices is also somewhere you can use your experience to positive effect. To find out more information, visit www.macmillan.org.uk/cancervoices, call 0207 091 2007 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

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

Some cancers can have a strong affect on a patient's personality and 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.

You may find it helpful to speak to a friend, counsellor or someone at a support group about the anger you are feeling.

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.

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.

When you are tired you are more at risk of infection, so try to make sure you are getting enough vitamins, either by eating extra fruit and vegetables or taking supplements.

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.

Other ideas

- Macmillan runs a 'Dealing with anger' workshop. To find out more information about how it could help you, call 020 7091 2010 or email workshops@macmillan.org.uk

4 Moods and emotions

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.

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.

Other ideas

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

5 Practicalities

Food and eating

Moving and handling

Organising equipment and transport

Availability of drugs

Pain control

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 are 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, high calorie juices or making fresh lemon curd to replace traditional energy puddings. 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 you swivel the patient 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 can also supply these items.

Grants may be available from Macmillan Cancer Support for expenses like equipment and transport. Call the Macmillan CancerLine on 0808 808 2020 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.

If necessary, the patient should 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, so a change in position may help to relieve some pain.

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.

Other ideas

- A local Crossroads Caring for Carers scheme may be able to provide you with practical help around the house. For contact details see **Further information.**

5 Practicalities

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 the Macmillan CancerLine 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 **Financial help** section) – this may help to pay for a cleaner or a gardener.

Household finances

Due to the patient's illness, it may be necessary for you 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 Citizen's Advice can provide you with advice. You could also call the Macmillan CancerLine, the Carers UK helpline or go to a local carers centre – find yours by searching at www.carers.org or by calling The Princess Royal Trust for Carer's 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 prescriptions and 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.

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 the Macmillan CancerLine. Also, your local Social Services department can put you in touch with a social worker or benefits adviser.

The Macmillan Benefits Helpline can offer you advice and help you to access benefits and other kinds of financial support. They can also help you fill in benefit claim forms. Call freephone on 0808 801 0304.

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

Citizens Advice can help with benefits advice and form filling.

Your phone book will have details of your nearest bureau, or visit www.citizensadvice.org.uk for more information.

Carer's Allowance is the main benefit you may be entitled to. As you need to care for someone for more than 35 hours a week to receive it, it is handy to keep a diary of all the time you spend caring for someone. This can help with your Carer's Allowance application. You'll find more information about Carer's Allowance at the Directgov website in the 'Other ideas' section.

You 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 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 0870 240 0010 or visit www.dvla.gov.uk

5 Practicalities

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 and Customs Enquiry Centre – see the phonebook or visit www.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, 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 Caring Allowance Unit 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 the Macmillan Benefits Helpline for advice about this.

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

Other ideas

- An information booklet called *Help with the cost of cancer* is available from Macmillan Cancer Support. It has details of the types of practical and financial help you might be entitled to. You can get a free copy by calling 0800 500 800 or by ordering one from www.be.macmillan.org.uk

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

Other ideas continued

- You can download *Help with the cost of cancer* from the 'Financial help' section of the Macmillan website – www.macmillan.org.uk/financialhelp. 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 – www.carersuk.org/Information/Financialhelp
- The Jobcentre Plus leaflet *A guide for disabled people, those with health conditions, and carers* contains useful information about financial help. It is available from your local Jobcentre Plus office, or you can download it from www.jobcentreplus.gov.uk/jcp/customers/leaflets_and_guides
- The Directgov website has useful information about money matters, including direct payments and pensions. Go to www.direct.gov.uk/en/CaringForSomeone/MoneyMatters

5 Practicalities

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 treated with live natural yoghurt which contains bacteria, or treatments can be bought over the counter at the chemist.

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

- Some cancer treatments can be transferred via semen. 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.

6 Employment and work issues

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 issues

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 taking 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 issues

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 or 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 Social Services 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'.

Other ideas

- Macmillan's *Working through cancer* booklet features useful information about cancer and employment. You can order it by calling 0800 500 800, visiting www.be.macmillan.org.uk, or you can download it from www.macmillan.org.uk/work
- Carers UK has a section on their website aimed at employers who want to support employees with caring responsibilities. It may provide you with useful information. Visit www.carersuk.org/employersforcarers, 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 at www.acas.org.uk
- You can find information about flexible working, work life balance and caring for someone while working in the 'Employment' section at www.direct.gov.uk

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 department in the phone book.

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 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.

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.

6 Employment and work issues

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. The Macmillan Benefits Helpline (0808 801 0304) might also be useful.

Make sure you don't feel pressurised to give up your job. If you do, speak to someone in your human resources department, call the Macmillan CancerLine 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.

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 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 and in your local library. Jobcentre Plus also recommends the following websites – www.worktrain.gov.uk, www.careersscotland.org.uk and www.careerswales.com

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

Benefits

Whether you are a full-time carer or still working while you are caring for someone, you may be entitled to benefits. To find out what they are, call the Macmillan Benefits Helpline on 0808 801 0304. Or for more information on benefits, see the 'Financial help' section in **Practicalities**.

Other ideas

- Jobcentre Plus also has a useful information leaflet called *A guide for disabled people, those with health conditions, and carers*, which provides information on returning to work. It should be available in your local Jobcentre Plus office and you can download it from www.jobcentreplus.gov.uk/jcp/customers/leaflets_and_guides/

7 Death, dying and bereavement

Information and support

Physical changes

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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

7 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

- 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 and Cancerbackup have produced 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 or Cancerbackup, or you can download it from www.mariecurie.org.uk/endoflife

7 Death, dying and bereavement

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.

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.

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.

7 Death, dying and bereavement

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 booklets from the Department for Work and Pension's resource centre www.dwp.gov.uk/resourcecentre/socialfund.asp

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.

Advice on registering a death can be found on the General Register Office's (GRO's) website at www.gro.gov.uk/gro/content/deaths You can also contact the GRO's Births and Deaths section on 0151 471 4805.

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 patient'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 patient'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.

Comfort each other and talk about the things in your lives together that have been good.

Other ideas

- Carers UK and Help the Hospices have produced a helpful guide *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 www.carersuk.org and www.timetocare.org.uk

7 Death, dying and bereavement

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.

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 the Macmillan CancerLine.

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.

8 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

8 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.

Because you have stopped being a carer, it is important that you inform your Caring Allowance Unit about this.

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 the Macmillan Benefits Helpline on 0808 801 0304 for advice. Carers UK's website also has useful information – www.carersuk.org/Information/Whencaringends/Lifeaftercaring

8 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 www.carersuk.org and www.timetocare.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 the Macmillan CancerLine to find your nearest one or visit www.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 and 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 issues**.

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.

The following websites can also provide you with useful information – www.learnndirect-

8 Life after caring

advice.co.uk, the 'Adult learning' section on www.direct.gov.uk and www.nextstep.org.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 www.macmillan.org.uk/cancervoices, calling 0207 091 2007 or emailing cancervoices@macmillan.org.uk
- If you are interested in volunteering for Macmillan, contact your area's volunteering adviser – details at www.macmillan.org.uk/volunteer Or for general enquiries, call 020 7840 4961.

9 Further information

Organisations for carers

Young carers

General cancer information

Hospices

Public services and information

Bereavement

Macmillan training courses

Macmillan workshops

Your feedback

Useful numbers

Your notes

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

Roberta

9 Further information

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ
www.macmillan.org.uk

Macmillan improve the lives of people affected by cancer by providing practical, medical, emotional and financial support and campaigning for better cancer care.

Macmillan CancerLine

Monday to Friday 9am-9pm
Freephone 0808 808 2020
Textphone 0808 808 0121
cancerline@macmillan.org.uk

The Macmillan CancerLine helps people living with cancer, and their family, friends and carers. Trained advisers offer information and emotional support by phone, letter and email, including advice for carers and details about local support groups.

There is a translation service for people whose first language is not English and a textphone service for people who are deaf or hard of hearing.

Macmillan YouthLine

Monday to Friday 9am-9pm
Freephone 0808 808 0800

Trained advisers can provide confidential support to young people affected by cancer aged between 12 and 21. There is also information about cancer for young people and children at www.macmillan.org.uk/whybother

Macmillan South Asian CancerLine

Monday to Friday 9am-6pm
Hindi 0808 808 0100
Punjabi 0808 808 0101
Urdu 0808 808 0102

Trained advisers can answer questions or concerns about cancer in Hindi, Punjabi and Urdu. Calls are free and confidential.

Macmillan Benefits Helpline

Freephone 0808 801 0304
Monday, Tuesday, Thursday, Friday
10am-5pm
Wednesday 12-5pm

9 Further information

The Macmillan Benefits Helpline is a telephone advice service for people with cancer, their family and carers who need help to access benefits and other kinds of financial support. Calls are answered by experienced benefits advisers who can check what benefits you are able to claim and help you fill in the necessary forms.

Macmillan Share discussion forum

www.macmillan.org.uk/share

Share your experiences and feelings, ask questions and get support from other people affected by cancer.

Macmillan publications

You can view the range of booklets and leaflets Macmillan publishes at www.be.macmillan.org.uk. You can order the materials from be.macmillan or by calling 0800 500 800. You can also order Macmillan publications, and search for other cancer publications, at www.macmillan.org.uk/publications

Organisations for carers

Carers UK

20/25 Glasshouse Yard
London EC1A 4JT
Tel 020 7490 8818
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 Caring for Carers England and Wales

10 Regent Place
Rugby
Warwickshire CV21 2PN
Tel 0845 450 0350
www.crossroads.org.uk
communications@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
Lanarkshire 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
BT23 4AB
Tel 028 9181 4455
www.crossroadscare.co.uk

The Princess Royal Trust for Carers

142 Minorities
London EC3N 1LB
London office: 020 7480 7788
help@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 100 independently managed carers centres across the UK. Local centres can be found on the website or by phoning your nearest office.

9 Further information

Time to care

www.timetocare.org.uk

A website produced by Help the Hospices for carers and professionals working with carers. Includes information on publications and organisations which provide support for carers.

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 The Children's Society National Young Carers Initiative.

General cancer information

Cancerbackup

3 Bath Place, Rivington Street
London EC2A 3JR
Freephone 0808 800 1234
www.cancerbackup.org.uk
info@cancerbackup.org

Provides practical advice and support for cancer patients, their families and carers. This includes comprehensive information on specific cancers and treatments, and advice on caring for someone with cancer.

Cancer Research UK

PO Box 123
Lincoln's Inn Fields
London WC2A 3PX
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.

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:
02890 882 060

Scotland office: 0131 456 3700

Wales office: 01873 30 3000

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 0800 716 146.

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

9 Further information

over 3,000 locations, and by influencing policymakers. You can find your local bureau by looking in your phone book or by visiting www.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:

02890 792419

northern.ireland@cruse.org.uk

Wales office:

02920 444178

wales.cymru@cruse.org.uk

Scotland office:

01738 444178

www.crusescotland.org.uk/

info@crusescotland.org.uk

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

The Clara Burgess Centre

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 <http://learnzone.macmillan.org.uk>

Living with cancer 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 wellbeing

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

9 Further information

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.

Relaxation and visualisation

Learn about relaxation and visualisation techniques, and discover other ways to relax and relieve stress.

Close relationships and cancer

Find out how cancer affects relationships and develop strategies for changing and improving relationships that have been 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

Your feedback

To help us make sure we are providing the right information and support, we would really appreciate your thoughts and views on the content of this handbook. Please fill in your comments below and send them to:

Information Resources Manager
Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ

Or you can email your comments to:
cancerinformationteam@macmillan.org.uk

**Was the handbook helpful? Was it of any practical use?
Please say in what ways.**

Is there anything you think we should add to make it more useful/helpful?

Useful numbers

We found it was helpful to keep important telephone numbers easily to hand. We hope these push-out-and-keep cards will be useful.

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Useful telephone numbers

Name _____
Tel _____
Name _____
Tel _____

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Useful telephone numbers

Name _____
Tel _____
Name _____
Tel _____

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Useful telephone numbers

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**WE ARE
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Useful telephone numbers

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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. 1.2 million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

For further copies, call us on 0800 500 800 or visit www.be.macmillan.org.uk

Macmillan Cancer Support
89 Albert Embankment, London SE1 7UQ
Tel 0800 500 800
CancerLine 0808 808 2020
www.macmillan.org.uk

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