

A practical guide to living  
with and after cancer

# CARING FOR SOMEONE WITH ADVANCED CANCER

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MACMILLAN.  
CANCER SUPPORT**

# About this booklet

## **This booklet is for anyone caring for a person with advanced cancer.**

A carer is someone who gives unpaid support to a relative or friend who has cancer. You may not think of yourself as a carer. You may say 'I'm just being their husband, partner, daughter or friend...'. But the support you provide is very important – from helping with shopping, dressing or taking them to the hospital, to being there when they need to talk.

Many people with advanced cancer have treatments that can successfully control their cancer. For some people, this may be for a long time and for others it may be a shorter time.

When a person's cancer can no longer be controlled, they may start to feel weaker and need more help with tasks such as bathing, dressing and cooking meals. If you care for someone with advanced cancer who needs help with their everyday needs, then this booklet is for you.

You may want to show the person you are looking after how much you care. You may also want to plan how best to look after them and make them comfortable. You may be worried that you won't have the physical or emotional strength to cope, or that it will be difficult to get the practical support you need to make life at home easier. This booklet will give you some tips and ideas on how to deal with these issues. It will guide you to get the help you may need. There is support available for you.

The booklet is divided into the following sections:

- **Getting ready for coming home** This section lists some of the practical things you may want to think about and plan before the person with cancer comes home (see pages 7–15).
- **Who can help you?** This section looks at how family and friends, health and social care professionals and voluntary organisations can help you (see pages 17–29).
- **Caring at home** This section has useful tips for you on caring for the person when they are at home (see pages 31–43).
- **Other care options** This section gives you information about other care options such as respite care, care in homes and hospice care (see pages 45–49).
- **Planning ahead** This section gives you information about advance care planning, making or updating a will and funeral planning (see pages 51–57).
- **Financial help** This section has information about the different sources of financial support to help you and the person you are caring for (see pages 59–63).
- **Your feelings and emotions** This section looks at the feelings you may have as a carer and has some tips for looking after yourself (see pages 65–79).

If you think it will be too difficult for you to read through the booklet in one go, you can choose which section may be useful or relevant for you. It may be that some sections are useful now and some may be more helpful to you in the future.

To help you understand what the person you are caring for is coping with, you may find it helpful to read our booklet *Coping with advanced cancer*, which is written for people with advanced cancer.

We also have another booklet called *End of life: a guide*. It explains what happens at the end of someone's life, how to plan for it and what to do after they have died. It has information which isn't included in this publication.

If you would like a free copy of any of these booklets, please call us on **0808 808 0000** or visit **be.macmillan.org.uk**

At the end of this publication, we give details of organisations you may want to contact for help, information, or to talk about how you feel. You'll find organisations and lists of helpful publications and websites on pages 86–96. We've included some comments in this booklet from other carers (from **healthtalkonline.com**). Some names have been changed. We hope you find them useful.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

If you find this booklet helpful, please pass it on to family members or friends. They may also want information to help them support you and the person you are caring for.



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# 1

## GETTING READY FOR COMING HOME

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**This section is about some of the things you may want to consider if the person you are caring for is about to be discharged home from a hospital or hospice. If you've been looking after them at home before, you may want to skip this section. If they are now less well and their needs have changed, you may find some of the information here useful.**

Before your relative or friend comes home, it's a good idea to talk to them about how they want to be looked after and how you can help care for them. Even if they're not feeling well, they may still want to be involved in making plans about their care. Including them in these plans will help them to feel valued and loved.

## **Help from family and friends**

If other family members and friends will be sharing the care, it's also useful to involve them in discussions at an early stage. You will then be able to see how each person can help, and where you may need further help.

You may find that you're asked to keep everyone informed as things change. This can be very stressful, especially if you find you have to break bad news to a number of different people. You might like to think about asking another family member or a friend to help you do this.

## Organising help and services

Before your relative or friend goes home, all the practical help and services that are needed should already have been set up. This is usually done by the hospital or hospice staff together with a social worker (see pages 24–26). All hospitals and organisations have discharge policies to help make sure a person is safely discharged and the care they need has been organised.

The person you're caring for may have a holistic needs assessment carried out before they come home. They will be asked lots of questions about how they are feeling and what sort of help they may need. This is to make sure they get the right sort of help and support. The people involved in their care should have a copy of this, including the GP. You can ask the ward staff about this.

If there are a lot of things to consider, a meeting may be organised before discharge so that everything can be carefully discussed and planned. This is usually organised by the ward staff and may involve the doctor, specialist nurses, an occupational therapist (OT) or a social worker. The person with cancer and their carer can also be involved in this meeting.

As a carer, you should be involved in any discharge planning. You should never be left to take your relative or friend home without the support and practical help you need. If you aren't sure of the arrangements that are being planned, talk to the nurses or ward manager. They can discuss the plans with you and arrange for you to see the social worker. This is so you can discuss with them any help you may need. If you aren't happy with anything that has been arranged, say so. Don't agree to something you know won't be helpful or miss out something you think you will need.

If you find it difficult to discuss your needs with the staff, try writing them down. You may also find it helpful to have someone else with you when you meet with them. As well as giving you support, they can remind you of anything you may have forgotten.

Remember that the arrangements can be altered later on if the situation changes. For example, when the person first goes home you may not need any help to look after them, but if they begin to get weaker you may need help with their personal care.

Ideally, the person you're caring for should be given information from the hospital or hospice to take home. This may give details about medicines, dietary needs and where to get help if needed. If the information isn't clear, ask for more details. You have the right to ask any questions you want.

Make sure the person you are caring for has the medicine they need when they are discharged. You will need enough to last until a new prescription can be arranged from the GP.

There is more information about the help and services you can set up before your relative or friend comes home in the next section (pages 17–29).

## **GP and community services**

The GP and the community nursing team should have been informed that the person you are caring for is soon to be discharged home. You may be given a letter to take to the GP. During the first few days at home, the GP may visit or contact you by phone. If this doesn't happen, contact the surgery and tell them that the person you're looking after has just come out of hospital. The sooner the GP makes contact with you both, the better. Even if you think you don't need much help at the time. There is more information about the help you can get from a GP on pages 19–20.

## Practical aids and equipment

Before the person you care for is discharged, it's important that the hospital or hospice staff talk to you both about any equipment you will need at home. They can arrange for an occupational therapist (OT) to visit and make an assessment of your home (see page 23). Some hospitals and hospices are able to supply some equipment a day or so before discharge, so that it's ready when they arrive home. Some equipment can also be loaned from voluntary organisations and charities, such as the British Red Cross (see page 89).

### Beds

Being comfortable in bed can be very important for anyone who is feeling unwell. They may need to spend a lot of time there. The district nurse (see pages 20–21) can arrange equipment for the bedroom. This may include lending you a pressure-relieving mattress or a hospital bed. Once your relative or friend is home, you can ask the district nurse for advice on the best way of making them comfortable.

Try to provide lots of pillows of different shapes and sizes. A V-shaped pillow is especially comfortable and can help to relieve pressure on the back. If the person has swollen arms or legs, extra pillows can be used to keep the affected limbs higher than the rest of the body.

### Chairs

If the person you're looking after is able to spend time in a chair, it's important that they are well supported and comfortable. An OT or physiotherapist can give you advice on the best sort of chair for comfort and support. The district nurse can usually arrange for the loan of a pressure-relieving cushion.

### **Commodes, bedpans and urinals**

If the person you are caring for finds it difficult to get to and from the toilet, they may need a commode, bedpan or urinal. The community nurses should be able to arrange this. You can also buy these from chemists or pharmacies. Some commodes are made to look like ordinary bedroom chairs. Some have wheels so that you can wheel them into the bathroom. The British Red Cross (see page 89) can also loan you toilet equipment.

### **Bathing equipment**

It may be difficult for the person you are caring for to have a bath or shower. Using a bath chair, bath board or shower stool may help. An OT or physiotherapist will be able to advise which equipment is best for them, once they've assessed their needs.

### **Breathing equipment**

If the person you're caring for has breathing problems, their healthcare team can assess and arrange for equipment such as a nebuliser, oxygen concentrator or cylinder to be provided at home.

### **Wheelchairs and walking aids**

If your relative or friend has difficulty walking, an OT or a member of the healthcare team should be able to arrange for a wheelchair, walking sticks or a walking frame. The British Red Cross can also loan wheelchairs.

### **Diet**

If the person you care for has a poor appetite or is having trouble eating, you may want to stock up with foods that they enjoy. The hospital dietitian or ward nurses can give you advice and may be able to supply supplement drinks and foods (see pages 37–39).

## Other equipment

There are many other smaller pieces of equipment that you might be able to get from the OT. These include two-handled mugs, an adjustable bed rest, bed raisers and grab rails.

If you can afford it, there are shops and organisations that sell or hire out aids and equipment (look under 'Disabled' in the Yellow Pages or online). Your local chemist can also tell you what they have available.

Some people may be eligible for a Macmillan grant to help pay for equipment (see page 62).

The healthcare team should be able to give you advice about how to get hold of any equipment you may need. Organisations that give advice on equipment and living with disability are listed on page 89.

## Blue Badge scheme

If the person you're caring for has mobility problems but they are still able to go out in a car, you may want to think about the Blue Badge scheme. This scheme provides car parking concessions for people with mobility problems. It means that they can park (or someone else can park them) close to where they want to go.

To apply for a badge, contact the local council. A healthcare professional, welfare rights advisor or social worker will be able to help with the application.

## Preparing your home

There are some practical things you can do to get ready before the person you care for comes home. It can help to get these sorted out before they arrive, so that you can focus on caring for them.

## Home adaptations

You may need to make some changes to your home, in order to make life easier for you both. For example, if the person you're caring for needs to use a wheelchair, you may be able to have some doors widened and ramps built over steps.

An OT can advise you on the safety of the house's layout and on making minor changes. These may include putting handrails on the stairs or in the bathroom, or moving a bed downstairs.

Major adaptations might be possible, such as putting in a toilet or shower downstairs, or installing a stair lift. These kinds of alterations can, however, take several months of planning and may not be possible before the person comes home. They also involve the disturbance of building work. You will need to discuss whether you want to make these changes.

If you live in a council or housing association house or flat, adaptations are usually paid for by the local authority. However, this varies from area to area and depends on local policy and the funds available. If you own your home or rent it privately, you may still be able to get some financial help. Ask the OT, social worker, or your local social services (Social Services Department in England and Wales, Social Work Department in Scotland, or Health and Social Care Trust in Northern Ireland). Make sure you claim financial help before you get any work done.

## Organising their room

One of the most important things to do is to get your relative or friend's room ready. They may need to spend a lot of time there so it's important that they are happy in it and it feels welcoming. Discuss which room they'd prefer and, if you live in a house, whether they would like to be upstairs or downstairs.

Some people prefer to be downstairs so they are near you or other family members. Others may prefer the peace and quiet of an upstairs room. If they can't get around easily, they may want to be in the room nearest the bathroom. Or they may want the lightest and sunniest room.

Put their bed or chair in a good position, preferably with a view out of a window. You could move a small table into the room next to the bed, and if there's space, add a chair for visitors. Ask your relative or friend if there's anything they'd like in the room. You may want to hang up their favourite pictures or photos. They might like to have a radio, CD player, television, computer, tablet or DVD player.

You may be able to have a phone extension put into the room or use a cordless phone or mobile. They will then be able to talk with family and friends more easily. If they won't be able to get out of bed, you may be able to get an intercom, such as a two-way baby alarm, so they can talk to you when you're elsewhere in the house.

If the person you care for is sleeping in a room with or near a gas appliance, such as a gas heater, it's a good idea to fit a carbon monoxide detector.

### **Sleep arrangements**

It's important that you get plenty of sleep and rest. If you're caring for a partner and are used to sharing a bed, you may want to discuss if you should continue to do this. Sleeping apart may allow you both to get the rest you need. But sleeping together and feeling close to someone is also important. It may help you to talk to your partner so you can both decide what is best.





# 2

## WHO CAN HELP YOU?

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**Caring for someone is very hard work, both physically and emotionally. Many carers don't find it easy to ask for help and are tempted to try to do everything themselves, especially at first. If you've been caring for your relative or friend for some time, you may feel more tired as time moves on. Having help and support may stop you feeling so tired.**

There are a number of people who can help you:

- family and friends (see pages 18–19)
- health and social care professionals (see pages 19–28)
- voluntary organisations (see pages 28–29).

The type and amount of support you get will depend on where you live and how the services are organised in your area.

The organisations listed on pages 86–92 can tell you about how to get the help you need.

## **Family and friends**

It's helpful to think about the kind of help you might need from your family, friends and neighbours. Building up a support network can be useful.

Some relatives and friends might be best helping with washing or shopping. Others will be happier to sit and talk to the person you're caring for so that you can have time off. Some are good at listening to you and letting you talk about the things you're worrying about.

It's very important that you know who you can turn to and how they'll be able to help. If you always seem to be good at coping with everything, your relatives and friends may not realise how badly you need help. Or, they may be waiting for you to ask them for help.

Try to identify a few key people. They could be parents, grown-up children, close friends or colleagues, neighbours, or someone from a local carers' or cancer support group (see pages 78–79).

If you're feeling a bit overwhelmed, try making a list of things that you need help with. You could then ask family and friends what they would be able and happy to do. Remember that even having them cook a meal for you or simply spend time with the person you care for can help.

Some people may be able to help on a regular basis, for example for a couple of hours a week. Others may be happy to help every now and again. Find out what suits them and write a list of people you can ask if you need extra help.

## Health and social care professionals

There are a number of community health and social care professionals who can support you.

### GP (family doctor)

A GP has overall responsibility for the healthcare of ill people who are being looked after at home. They can:

- prescribe drugs
- organise nursing help if needed – for example, visits from a district or specialist palliative care nurse, physiotherapist or occupational therapist (OT)

- arrange for the person you're caring for to go into a hospital hospice or nursing home (see pages 48–49). This may be so that you can have a break from your caring responsibilities. This is known as respite care.

If the person you're caring for has moved to your home from another area since they became ill, you will need to register them with a local surgery. Let their previous GP know what has happened and register them at the new surgery. You will need the name and address of their previous GP and, if possible, their NHS medical card.

Contact the GP if you are worried about something. It may be that the person you are caring for has new or worsening symptoms or there is a sudden change in their condition. The GP may arrange to make a home visit, give you advice on the phone or suggest a visit to the surgery. You should also let the GP know that you're a carer. They may be able to signpost you to local support services.

GP surgeries must provide a 24-hour service. If you call for a doctor after the surgery has closed or at weekends, you're likely to be put through to an out-of-hours doctor.

In Northern Ireland, Wales and Scotland, people with cancer can get free prescriptions. If you live in England, prescriptions are also free but your friend or relative needs to apply for a prescription exemption certificate. You can ask for an application form (FP92A) at their GP surgery or at the hospital.

### **District and community nurses**

The district nurse is a key person in the care of someone who is ill at home. The district nurse will assess the person's needs and arrange for other nurses in their team to give nursing care. This may include giving injections, changing dressings and giving advice on nutrition, pressure area care, bowel problems and incontinence.

They can show you how to carry out everyday nursing tasks, such as washing, moving the person, and personal care.

The district nurse can also arrange for special equipment to be delivered, such as a:

- commode
- special mattress or cushion
- bedpan
- hoist or sling
- hospital bed.

The hospital or hospice should let the district nurse know that the person you're caring for is coming home, or the GP may arrange for them to visit.

The first home visit you have will often be from a district nurse. They will have overall responsibility for the nursing help you are given. They will talk to you about the care that will be provided. After that, the district nurse will usually organise for other nurses (also known as community nurses) who work in their team to make regular visits. You will usually see the same one or two nurses.

Community nurses may be able to visit up to three times a day; in the morning, afternoon and evening. Although this may vary depending on the services available in your area. District and community nurses will deal with the more complex needs of the person you are caring for. Your social worker can organise a care attendant or carer to help with personal needs such as bathing or home help.

### **Continence adviser**

The person you're looking after may be having trouble controlling their bladder or bowels. This is known as incontinence. It can be emotionally and practically difficult for both of you. Your district nurse will be able to help you and may suggest that a continence adviser visits you. This is a specialist nurse who can give advice and information about aids to help you manage continence problems.

### **Community specialist palliative care team**

These teams specialise in pain and symptom control, as well as offering emotional support. They are usually based in a hospice and have specialist nurses who can visit people who are being looked after at home.

These specialist nurses are sometimes referred to as Macmillan nurses or specialist palliative care nurses. They will work closely with your relative or friend's GP, district nurse and other hospital services.

Specialist palliative care teams often provide support and advice seven days a week. At night-time, they usually only offer telephone support. They will tell you more about their services and the services provided by the hospice.

### **Marie Curie nurse**

If you need extra nursing help, especially during the night, a member of the healthcare team may suggest that a Marie Curie nurse visits. This can be either a registered nurse or a senior healthcare assistant.

Marie Curie nurses are trained to look after people with palliative care needs. They normally provide care during acute illness or the last few months of someone's life. They specialise in giving practical nursing care and can spend the night or part of the day in your home, giving you a break.

Marie Curie is a charity and their nurses are free. They are usually arranged through the district nurse or community team.

### **Occupational therapist (OT)**

Occupational therapists look at practical ways of making a home safe, comfortable and easy to live in. They help people who have difficulty moving around or doing everyday tasks such as dressing, washing or cooking.

OTs can suggest and arrange for minor changes to be made to your home to help the person you are caring for with everyday living (see pages 26–27). They can also help you by ordering a wheelchair, equipment to make bathing or showering easier, or specially adapted cutlery.

Your social worker or district nurse should be able to arrange for an OT to visit your home.

### **Physiotherapist**

If the person you're caring for has mobility problems, their GP, district nurse or specialist palliative care team may refer them to a physiotherapist. Physiotherapists give advice on exercises and ways to keep as mobile as possible. They can also help with breathing exercises.

Your relative or friend may need to see the physiotherapist. This may be as an outpatient at either the hospice or local hospital. Some physiotherapy teams may visit a person at home.

### **Private nurses (agency nurses)**

Private nursing is available. It can be very expensive and may only be practical as a short-term solution. It can be useful if you're working and you need a carer at home while you're out.



There are many private nursing agencies that can supply qualified nurses to come into your home. You may want to ask the local social services or a carers' or cancer support group for advice. We can give you details of cancer support groups in your area. Call free on **0808 808 00 00** to speak to one of our cancer support specialists.

Your local phone book will list agencies under the heading 'Nursing Agencies' or you can search online. See page 95 for how to check the standards of care a nursing agency provides.

### **Social services**

A social worker (sometimes called a care manager) has responsibility for assessing what practical and social help you and the person with advanced cancer need. If you don't already have a social worker, the GP or a nurse involved in the care of your relative or friend can arrange a referral. Or, you could contact the local social services department. You'll find their number in the phone book under the name of your local authority, council or your health and social care trust.

The social worker will visit and carry out a community care assessment. The local authority will then decide if they will provide or arrange the services. Each local authority has its own eligibility criteria, so the services that are provided will vary from area to area.

If the needs of the person you are caring for are assessed as high (or sometimes moderate), your local authority has a duty to provide services to meet those needs. Services can be provided by social services or arranged to be given by other organisations, such as charities.

These services include:

- home care (home helps and care attendants/carers)
- sitting service (someone to sit with the person with cancer while you have some time to yourself)
- equipment and adaptations to your home
- benefits advice
- meals on wheels
- laundry service – for people with incontinence
- holidays
- respite care (see pages 46–47).

Some services will be paid for by the NHS, so they will be free of charge. In other cases, social services will carry out a financial assessment to calculate if you have to make a financial contribution.

The section on financial help (see pages 59–63) has more information on this.

Your social worker will stay in touch with you once the various services have been arranged. They will check that the services are working and that your needs haven't changed.

If you're providing ongoing care for someone, you can ask the social worker for an assessment of your needs. This can be an opportunity to discuss with social services any help you need. It is important to keep yourself healthy, and to balance caring with your life, work and family commitments. You can get more information about carer's assessments on the Carers UK website **carersuk.org**

If you have been assessed as having a need for social services, you may be entitled to get direct payments from your local authority. This means that you are given payments to organise care services yourself, rather than the local social services organising and paying for them directly. You can get information about direct payments from the NHS Choices website at **nhs.uk**, **direct.gov.uk** or from your local council.

As well as arranging services to meet your needs, many social workers are trained in counselling skills and can offer emotional support.

### **Home care**

You can get help in the home to support you and the person you are caring for. This can give you a break and help you feel less tired.

**Care attendants/carers** come to the home to help in various ways. This may be with either jobs around the house, such as cleaning, washing and cooking, or just to sit with your relative or friend. They can also give some physical care with tasks such as washing and dressing. Some care attendant schemes provide someone to be there at night. Your local social services department or the Carers Trust (see page 86) will be able to tell you about schemes in your area.

**Home helps** offer a variety of services including domestic help, cleaning, washing, cooking and shopping. Home helps are available in some parts of the UK. Other parts, unfortunately, provide no service at all. Your local social services department, social worker, community nurse or GP will know the situation in your area.

If you can afford it, you can get private domestic help by contacting a cleaning agency or by putting an advertisement in a local paper or shop window. If you organise domestic help yourself, make sure you check the person's references before employing them.

### **Meals on wheels**

If you're out at work in the day and the person you're caring for has difficulty preparing a meal themselves, it may be possible for them to have meals provided at home. This is often known as meals on wheels. These may be provided by a commercial organisation or your local authority. You'll probably have to pay for this service.

You will probably be offered frozen meals that can be put in the freezer to eat later, instead of hot meals. You may be able to borrow equipment to reheat the meals and a small freezer if you need it. Daily hot meals are usually only provided if your relative or friend can't manage the frozen meals service.

A range of meals is usually available. If the person you are looking after has particular cultural or religious dietary needs, this can usually be provided. For example, they may need a kosher or vegetarian meal, or a very soft diet.

Your social worker can arrange meals on wheels.

## Laundry service

If you're caring for someone who is incontinent and you have to do a lot of washing, your local social services department may be able to help by providing a laundry service. Alternatively, you may be able to get a grant for laundry charges. Ask the district nurse, GP or social worker about this.

## Voluntary organisations and charities

Voluntary organisations and charities play an important role in providing help and support to people who are ill, and their carers. They may offer:

- information
- loans and grants for aids and equipment
- holiday schemes
- financial help
- counselling
- transport
- befriending
- respite care at home
- a good neighbour scheme.

A good neighbour scheme is where local people provide practical help, usually for people who live alone. This help may include shopping, picking up prescriptions and offering transport.

Some voluntary organisations also run local self-help and support groups where you can meet other carers in a similar situation (see also pages 78–79). You may find you can talk with them more openly because they understand what you're going through. Local support groups often provide information and some have newsletters.

Many voluntary organisations and charities, including Macmillan, have helplines you can call for information and support. We've listed details of other voluntary organisations and charities most likely to be able to help you on pages 86–92.

To find out what help is available in your area, call our cancer support specialists on freephone **0808 808 00 00**. You can also contact your local Volunteer Centre. Their details should be in the phone book or online.

Carers' centres also provide a range of support for carers including information, advice and training. You can find your local carer centre by searching **carers.org** or by calling Carers Trust (see page 86).



# 3

## CARING AT HOME

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**There are many ways you may be involved in caring for your relative or friend at home. Here we've outlined some ways you can help manage their everyday practical needs and symptoms.**

## **Managing everyday practical needs**

### **Washing and bathing**

Having a regular wash can help someone feel more comfortable and lift their mood. Many people who are bed-bound get sticky and hot, as some cancers can cause heavy sweating.

The person you are looking after may need help with a bath, shower or wash. Your district nurse or social worker may be able to arrange for a carer to come in each day to help with this. If you prefer to do it yourself, the carer can show you how to shower or wash the person you are caring for. Change the bed sheets as often as you can. Ask the district nurse or carer to show you how to do this if the person you are caring for can't get out of bed.

If your relative or friend is attending the local hospice day centre (see page 47), it may be possible for them to have a bath while they are there. The specialist palliative care nurse can usually arrange this.

### **Clothing**

Loose, comfortable clothing, such as tracksuits, skirts or trousers with elastic waistbands, are easy to get on and off. It's also a good idea to choose clothes that are easy to wash and need little or no ironing. The person you are caring for may want to stay in their night clothes. This is fine if they are more comfortable or if it is easier for them.

Someone with cancer may feel colder than usual. Warm clothes, such as socks or woollen stockings, a jumper or dressing gown can help to keep them warm. If necessary, keep a hot water bottle, electric heat pad or wheat bag close to them. Make sure they are not too hot.

Your relative or friend may be having hot flushes because of their treatment. It may be better to use layers of clothing that can be easily taken off and put on again.

### **Hair care**

Your relative or friend may feel better if their hair is washed regularly. If the person you are caring for can't get to the sink, you could buy a plastic hair-washing tray from a disabled aids supplier (see page 89). You could try using a rinse-free waterless shampoo (or cap) that can be put directly on to their hair and removed by drying off with a towel. Ask at your local chemist for information about these products or search online.

Some hairdressers and barbers provide a mobile service and will visit the home so the person you are caring for can get a haircut.

If the person you are caring for is a man, he may need help with shaving. You could always ask a male friend or family member to help with this.

If the person's hair has fallen out because of chemotherapy or radiotherapy, their scalp may become dry and itchy. This can be helped by gently rubbing in some moisturising cream. It's important to check with the hospital, GP or district nurse before you apply anything to the skin.



We have a booklet called *Coping with hair loss*, which has helpful tips on coping with a dry scalp.

## **Nails**

It may be possible for someone from a voluntary group to come in to do a manicure or pedicure. Chiropodists or podiatrists will often make home visits, but this service isn't always free so check first. If the person you care for is diabetic, always ask a chiropodist to cut their toe nails.

## **Toilet needs**

If your relative or friend is very weak, you may need to help them go to the toilet or use a commode, bedpan or urinal. This can be one of the most difficult aspects of caring and you may both be embarrassed at first. The district nurse can give you some advice and, if necessary, arrange for someone to come in and help with getting them to the toilet once or twice a day.

## **Incontinence**

If the person you care for has lost some or all control of their bladder and bowels, ask the district nurse for advice. You may also be able to get support from a continence adviser (see page 22).

It's a good idea to try to make sure the bedroom isn't far from the toilet. Or, keep a commode, bedpan or urinal nearby.

The district nurse can give you information about using incontinence sheets, pads and pants, as well as protective bed covers. These may help to keep the bed clean and improve the person's comfort.

If these aren't effective, the nurse may suggest a catheter. This is a tube that is inserted into the bladder so that the urine can be drained away into a special bag. A catheter is simple and painless. Bags and tubes can easily be hidden by bedclothes and blankets. For men, it's also possible to drain urine using a tube connected to a sheath that fits over the penis.

If necessary, your district nurse may organise a visit from a continence adviser to give you advice and information. You can also find out more from the Bladder and Bowel Foundation (see page 90).

### **Moisturising and massage**

Many people who are in bed for a long time find it very soothing to have their limbs and back gently massaged. You may use a light moisturising cream such as aqueous cream or almond or vegetable oil. This also stops their skin from drying out. Head massage or gentle rubbing can also be very soothing and relaxing. If their face is dry, you can apply a moisturising cream. Lip balm can be used for dry or cracked lips.

You shouldn't massage areas that are swollen, sore, inflamed or have broken skin, including areas of lymphoedema. If you're unsure, always ask the nurse or doctor before doing any massage. If the person's skin has been exposed to radiotherapy, check with the hospital, GP or district nurse before you apply anything to the treated area.

### **Moving and turning**

If the person you're looking after needs help to get out of bed, you will need to be taught how to move them safely. Ask the district nurse or occupational therapist (OT) to show you the best way to do this. Take great care when you do it, as it's easy to injure your back. You may be able to have a hoist or sling to help you to move them.

People who are bed-bound, especially those who are very ill or very thin, are at risk of getting pressure sores. These are very uncomfortable and can become infected. To avoid getting sores, the person who is ill will need to turn from one side to their back and then to the other side about every two hours.

If they can't turn themselves, ask the district nurse to show you the best way of turning them. A pressure-relieving mattress and ankle or elbow pads will help to reduce the risk of pressure sores.

## **Managing falls**

If the person you care for is very weak, they may have an unexpected fall. If this happens, don't struggle to move them as you may risk injuring them further and yourself. Contact the ambulance service. They will come and assess them for any injuries and will help to move them back to a chair or bed.

## **Managing symptoms**

### **Sore mouth**

A sore mouth is a common side effect of cancer treatment or the effects of advanced cancer. It can make someone feel very unwell and uncomfortable.

If your relative or friend's mouth is too sore to use an ordinary toothpaste and toothbrush, try using a soft toothbrush and mouth rinses. If their lips are dry, a lip balm can be useful.

Mouth ulcers and thrush are common. If their mouth becomes very sore or coated, tell the GP, specialist palliative care team or district nurse. It is very important these symptoms are treated. There are mouthwashes, tablets, gels or pellets that can help relieve the symptoms. If dental treatment is needed, ask the dentist if they can do a home visit. You may need to pay for this.

### **Constipation**

People who have advanced cancer are more likely to become constipated. There are various reasons for this. Some people get constipated because they have lost their appetite and aren't eating enough, or because they can't move around much.

Painkillers can cause constipation and if they are being taken regularly, laxatives may be necessary. A laxative is a medicine that helps people to go to the toilet. The GP can prescribe suitable laxatives.

If the person you're caring for has constipation, tell the GP, district nurse or palliative care nurse. They will probably suggest that the person increases the amount of fluids they drink and may recommend laxatives, suppositories or enemas. These should help relieve the constipation.

If the person you are caring for has no problems with eating, then it's helpful to add more fruit and high-fibre foods to their diet.

### **A poor appetite and eating difficulties**

People who are very ill often don't feel like eating. Cancer, its treatments and medicines can all affect appetite. Feeling sick and having diarrhoea or constipation can stop them eating. They may feel too tired to eat, have a sore or dry throat or mouth, or find chewing and swallowing difficult.

Cancer can also change the way the body uses food, so it's possible to lose weight even if they are eating normally. If your relative or friend is having trouble eating, it may help to ask the GP or district nurse for advice, or ask to speak to a dietitian.

The amount they can eat may change from day to day and their likes and dislikes may also change. Take time to ask them what they would like to eat. Try to give them small meals often, whenever the person feels like eating, rather than at set times of the day. Small meals and snacks can also help if the person is feeling sick.

You may find it helpful to keep a range of different foods in the house so that you can offer them something at any time of the day. You may want to keep tinned foods and pre-prepared frozen meals ready for when they feel able to eat. These foods can be as good for them as a meal that takes a long time to prepare.

If they can't manage solid food, try soft foods such as porridge, bananas, custard, soup, yoghurt or milk-based foods such as rice pudding. You may try liquidised food or a nourishing drink, such as a smoothie. You can buy ready-made supplement drinks like Complian® or Build-Up® from your chemist and from some supermarkets. Other supplements are available on prescription.

Your GP, specialist palliative care nurse or the dietitian may give you a supply of supplements before the person you care for comes home.

Moist food is often easier to cope with, and will help to prevent a dry mouth. A glass of crushed ice chips (flavoured or plain), or a bowl of ice cream can be refreshing and help to keep the person's mouth moist. If their mouth or tongue is sore, drinking through a straw may help.

People with advanced cancer often take a long time to eat. Allow them plenty of time so they don't feel rushed. You may find yourself wanting to watch them eat if you're concerned they're not eating enough. This is understandable but it can be off-putting to have someone watch how much you eat. If they prefer, let them eat on their own. They can then eat what they want in their own time. If you have to feed them, make sure you're sitting comfortably in a chair that gives proper support and allows you to reach them without stretching.

Eating in bed is often uncomfortable. If possible, make sure your relative or friend is supported with pillows, or in a chair next to the bed.

A table that goes across the bed can make eating easier. You may be able to hire one through the OT or home care team. Cushioned trays that sit safely on the lap or knees are another good way to make eating in bed easier and can be bought in a large home-store. A two-handed cup or a child's feeder cup with a lid may be helpful for someone who finds it an effort to sit up or if their hands are weak or shake when they drink.

Mealtimes are often an enjoyable and important part of family and social life. It can be frustrating and worrying when someone you're caring for can't eat very much and is losing weight. It's normal for someone with advanced cancer to eat less and lose weight. Try not to worry if they can't always eat what you've cooked, and don't urge or nag them to eat as this can be unhelpful.



We can send you our booklets *Eating problems and cancer* and *Recipes for people affected by cancer*.

## Nausea and vomiting

Some people with advanced cancer feel sick (nausea) or are sick (vomit). This may be due to the cancer or it may be a side effect of medicines or treatment. It's important to let the doctor or nurse know if the person feels sick. There are anti-sickness medicines that may help. Here are some other tips to help relieve sickness:

- avoid fatty and fried foods
- eat cold foods as the smell from cooking and hot food can often increase feelings of nausea
- eat small meals and snacks, and drink small amounts of fizzy drinks, such as ginger beer
- suck peppermint sweets.



## Controlling pain

People with advanced cancer are often worried that they are going to be in severe pain. But not everyone with advanced cancer will have pain. Of those who do, the pain can usually be well controlled with painkillers. Occasionally, some people may have pain that's more difficult to control. In this situation, a combination of different medicines or other treatments may be needed.

The hospital doctor or GP will probably already have prescribed some painkillers. They are usually given as tablets or capsules that are taken by mouth. Some types of painkiller can be given as a patch stuck onto the skin (rather like a nicotine or hormone replacement patch). It's also possible to give painkillers by injection just under the skin. Injections of painkillers are more likely to be used if a person can't swallow or absorb tablets or capsules, perhaps because they are being sick or are very drowsy.

If your relative or friend's painkillers don't seem to be working, contact their GP, district nurse or specialist palliative care nurse. An adjustment of dose or change of medicine may be all that's needed.

Some painkillers can make people feel drowsy or light-headed at first, but usually this wears off after a day or so. If it doesn't, tell their GP, district nurse or specialist palliative care nurse. It's often possible to change to a painkiller that suits them better.

You may be able to help relieve pain and discomfort with simple things. These include:

- changing the person's position
- a heat pad or hot-water bottle wrapped in a towel to prevent burns

- wheat packs that you can warm in a microwave
- ice packs
- massage.

Sometimes, just listening to the fears and worries of the person who is ill can help them cope better with pain.

If pain and other symptoms are very troublesome and distressing, a short stay in a hospice may help (see page 49). In a hospice, the doctors and nurses will be able to assess their pain and symptoms. They can adjust the dose of medicines or add in new ones to control symptoms more quickly than if they were at home. Once their symptoms are controlled, they will be able to go home again.

Some types of pain can be controlled with more specialised techniques, such as a nerve block. If the hospice doctor thinks that a nerve block will help your relative or friend, they can refer them a pain control specialist.



We have more detailed information about pain in our booklet *Controlling cancer pain*.

## Sleep problems

Your relative or friend may have problems sleeping at night. If they are in pain, it can be very difficult to sleep well and their pain control may need to be adjusted slightly (see previous page).

They may be sleeping a lot during the day. If they are drowsy during the day and can't sleep at night, ask the GP to check their medicines. The GP may change their medicines to help them sleep better.

The person you care for may be anxious and find it difficult to relax. Reading, listening to music, meditating, or having a warm, milky drink or herbal tea in the late evening may help them to relax and fall asleep. Anything containing caffeine, such as coffee, tea and cola drinks should be avoided. The GP can prescribe sleeping tablets, if necessary.

Make sure that their mattress and pillows are comfortable, especially if they are spending a lot of time in bed. Ask the district nurse or OT if the person you are caring for needs a pressure relieving mattress. You may be eligible for a Macmillan grant to help with the costs of buying a new mattress and pillows – see page 62 for more details.

Here are some other ideas to improve your relative or friend's sleep:

- make sure that the room is at the right temperature – cool with fresh air, but not too cold
- have blankets available if needed
- make sure there isn't too much light – you could consider replacing the curtains for darker ones or putting up a blind behind the curtains to shut out more light
- try to minimise noise distractions, such as a ticking clock
- soft music may be soothing.



We have a booklet with more detailed information about managing the symptoms of cancer called *Controlling the symptoms of cancer*.

## Spiritual and religious support

Some people find that they become more aware of spiritual or religious feelings during stressful times. This may cause them to question their faith, values and beliefs.

If you or the person you're caring for already have a strong faith, this may give you a lot of comfort and support, but it can also be a source of uncertainty.

If you think that it might help you both to talk to someone, such as the hospital or hospice chaplain or a religious leader, don't be put off because you aren't sure what you believe or haven't worshipped regularly. Spiritual and religious leaders are used to dealing with uncertainty. They are usually happy to talk and to give whatever support and comfort they can.



# 4

## OTHER CARE OPTIONS

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## **When you're caring for someone full-time or for long periods, you may need to have breaks otherwise you may start to feel stressed, resentful or even unwell.**

A number of different care options are available to give you time off. To access some of them you need to be referred to your social services or local authority for an assessment. They will assess the needs of the person you care for and your needs as a carer. They will then be able to tell you about the services they can provide to meet your needs. Local authorities charge for some care services and they will give you information about how the care will be funded.

### **Respite care**

Respite care allows you to get a short break for a few hours, an evening or a week or two. Ask your social worker, GP or specialist palliative nurse about the ways you may be able to have a short break. Talking over your situation with someone else can be helpful. They may suggest some of these care services.

### **Sitting services**

Sometimes it can be arranged for someone to sit with the person you look after to give you a break for a few hours in the day, or an evening off. Occasionally, sitters can stay overnight. Some sitters will also help with light housework or personal care, such as bathing and dressing.

## Day centres

Your local hospice or hospital may run a day centre for people with cancer. The day centre may be able to look after your relative or friend for a short time. The centre may provide lunch and some centres offer other services, such as bathing and complementary therapies. Usually transport is provided.

## Short stays

There will be times when you need more than a few hours off or an evening's break. Recognising when this is needed can be very important. If you need a break, the district nurse or specialist palliative nurse may be able to arrange for the person you're caring for to go into a hospice (see page 49), hospital, residential home or care home with nursing (see page 48) for a short while.

This is a decision you will have to make with the person you are caring for. They may even be the one to suggest it if you're getting very tired. Both of you might enjoy a short break. After this, you may both feel rested and better able to manage again.

Before you make a decision, you, the person you're looking after and perhaps other members of the family or friends, might find it reassuring to go and see the hospice, hospital or home and talk to the staff.

To find out what is available in the area, ask your healthcare team or a local support group. You can also contact the Carers Trust or Carers UK for more information about services local to you (see page 86 for contact details).



## Care in residential homes or care homes with nursing (nursing homes)

They offer short- or long-term accommodation and care. Residential care homes or care homes with nursing provide different levels of care. Your social worker or healthcare team can explain the difference and give you more information about:

- local care homes
- the care provided by the care homes
- things to think about when choosing a care home
- funding arrangements.

They can also help to arrange this type of care but it may take some time.

Lists of local care homes are available from your local social services department. Care homes may not be available in all parts of the UK.

The standard of care provided by care homes and care agencies is monitored across the four UK nations by specific organisations (see page 95). Before choosing a care home or agency you may want to check its standard of care with one of these organisations. You can also ask your healthcare worker or social worker to provide you with this information. They may be able to help you get a report on the care home or agency so that you both feel confident about the standard of care provided.

## Hospice care

If the person you are caring for becomes more unwell as their illness develops, they may want to be looked after in a hospice or in a palliative care unit of the local hospital. You may have already discussed this with them and they may have written down their wishes in a Preferred Priorities for Care (PPC) document (see pages 52–53).

The GP, district nurse, specialist palliative care nurse or social worker may suggest a short stay in a hospice or the hospital. They may suggest it because your relative or friend has symptoms that would be easier to control if they had specialist care. They may also suggest it to give you a rest as caring for someone can be very tiring.

It's often difficult to accept that moving them is the best solution, especially if you've put all your time and energy into caring for them at home. You may both feel very upset that they might not be able to come home again. However, it's common for someone to go into a hospice for a short time so that their symptoms can be closely assessed and managed, and then return home.

Care in a hospice is always free. They specialise in managing symptoms including pain. They are generally smaller and quieter than hospitals and they work at a much gentler pace. Many have sitting rooms and are able to provide a place for relatives to stay overnight.

Sometimes there is a waiting list to go into a hospice but this is usually short. If you're not sure about the idea of hospice care you can ask to visit before making a decision. You can then talk to staff about your concerns. Many hospices also have specialist palliative care community nursing teams (see page 22) and day centres for people living at home. Your palliative care nurse can tell you more about these services.



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## PLANNING AHEAD

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**The person you're caring for may want to talk to you about where they want to be cared for when they die or what treatments they don't want to have. This is known as advance care planning. This section includes information about this as well as making a will and planning a funeral.**

If you live in England and Wales, you may also find it helpful to read Macmillan's publication *Your Life and your choices: plan ahead*.

## **Advance care planning**

Advance care planning is an opportunity for the person you're caring for to talk about what they would and wouldn't like as they approach the end of their life. Planning for their future care is important in case they become unable to make choices themselves, for example if they become unconscious or lose the ability to make decisions about treatment. If you know what your relative's wishes are in advance, you will be able to carry them out even if they can no longer tell you themselves.

There are several ways a person can plan ahead:

### **Preferred Priorities for Care**

They may like to write down their choices for care in a Preferred Priorities for Care (PPC) document, which is a type of advance care plan. As well as information about where your relative or friend would like to be cared for, the PPC can also include details about other wishes they may have about their care, so that everyone knows what is important to them.

The PPC document can be kept with your relative or friend and used to tell health professionals and other carers what their wishes are. The information about their wishes can be helpful if, in the future, they become unable to make decisions about their care. Although the PPC isn't a legal document, any wishes that are written in the document should be taken into account.

We can send you a copy of the National End of Life Care Preferred Priorities for Care document (see page 93). This document may not be used in all parts of the UK so check with your healthcare professionals if they have a specific document they recommend.

### **Power of attorney**

The person you're caring for may want to appoint a Power of Attorney. They will need to put in writing the name of someone they trust to make decisions or manage their financial and health affairs in the future if they are no longer able to do so. The person they appoint to make decisions on their behalf is known as an attorney. A Power of Attorney must be made while the person is able to understand what it is and what it means.

In England and Wales, Power of Attorney is known as Lasting Power of Attorney (LPA). There are two types of LPA:

- A **Property and Financial affairs LPA** allows one or more person to make decisions about things such as paying bills, dealing with the bank and selling a house.
- A **Health and Welfare LPA** allows one or more person to make decisions about things such as treatment, care, medication and where you live.

In Scotland, there are also two types of Power of Attorney:

- A **Continuing Power of Attorney (CPA)** allows someone to be appointed to manage your finances.
- A **Welfare Power of Attorney (WPA)** allows someone to be appointed to make decisions about your health.

In Northern Ireland, someone can be appointed to manage your property and finances. This is known as **Enduring Power of Attorney**. But it's currently not possible for you to give other people the power to make decisions about the care and treatment of someone else.

There is a fee to register Powers of Attorney. If the person you're caring for is receiving certain benefits or has a low income, you may be exempt from paying the registration fee or you may only have to pay part of it.

You can get more information about Powers of Attorney and how to register them from a social worker. Or you can speak to The Office of the Public Guardian if you live in England, Wales or Scotland or The Office of Care and Protection if you live in Northern Ireland.

### **Advance Decision to Refuse Treatment (Advance Decision, Advance Directive, Living Will)**

Your relative or friend may want to make an Advance Decision to Refuse Treatment (ADRT). This allows them to refuse certain treatments, such as resuscitation and other life-sustaining therapies.

In England and Wales, an Advance Decision to refuse treatment is legally binding. This means it must be followed by your healthcare team, provided they know about it. It must also meet certain criteria set out in the Mental Capacity Act (2005). Your healthcare team will be able to tell you more about this.

In Northern Ireland and Scotland, an Advanced Decision to Refuse Treatment is legally binding, although it's governed by common law instead of an act and similar criteria apply.



We have more information about Advance Decisions to Refuse Treatment that we can send you.

You can get further information about advance care planning from your relative or friend's doctors and nurses.

## Making or updating a will

If the person you're caring for hasn't made a will or kept it up-to-date, try to tactfully encourage them to do so. If someone dies without making a will, their property will be divided up under legal rules that don't take account of individual circumstances. For example, when two people live together but aren't married, and there isn't a will, the surviving partner will not inherit anything. The estate (including the house they had jointly lived in) would go to the dead partner's next of kin. This situation can cause enormous distress and possibly lengthy (and expensive) legal proceedings at a time when people are already upset.

If the person you're caring for is your spouse or partner, it may also be worth transferring bank or building society accounts or tenancies into both your names. This makes it a lot easier to transfer the responsibility to you.

These arrangements may be very hard for you to bring up with the person you are caring for. You may feel that you will seem grasping or uncaring if you try to talk about how their property will be divided up after their death. It may also be very painful for you to plan together for a time when they are no longer there.



If this is too hard for you to do yourself, you might try to see if someone from outside can talk about it. For example you could speak to the doctor, the district or palliative care nurse, or the social worker.

If a will already exists, it can be updated or altered very easily by adding a Codicil, which is an extra instruction to a will that can be added at any stage. It's a good idea to get the advice of a solicitor, as a will or Codicil is a legal document.

You can find a solicitor by asking a friend for a recommendation or by telephoning The Law Society (see page 92). Get quotes from a few solicitors before deciding which is best for you. Sometimes they will make home visits.

## **Funeral planning**

Some people like to make plans for their own funeral, such as choosing what music they would like to be played, or who they would like to attend. They may decide whether they would prefer a cremation or burial. If possible, discuss this with them. Sometimes talking about the funeral can help you begin to come to terms with their death and give you both peace of mind.

## **Listing important documents**

It's important that your relative or friend keeps their documents in a safe place. This should include their will, their Advance Decision to Refuse Treatment, their Power of Attorney and their funeral plan if they have one.

Make sure you also keep a list of where other important documents are kept. These could include:

- the deeds of the house
- the person with cancer's passport and driving licence
- any birth, marriage and divorce certificates
- details of bank or building society accounts
- insurance and pension policies
- tax and national insurance numbers.

You might also want to list the names and telephone numbers of various people who would need to be told about the death. For example, executors of the will, the bank manager, employer, landlord, solicitor, accountant and doctor. You might also want to think about family members and friends who would need to be told.



# 6

## FINANCIAL HELP

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**This may be a difficult time financially. The person you're looking after might have provided the main income for your household before they became ill. You may have decided together that you should give up work or work part-time so you can be at home. You may have to find the money for other expenses such as extra heating, laundry charges, special equipment or dietary needs.**

## **Benefits and allowances**

You or your relative or friend may be entitled to a number of different benefits and allowances. Try to claim as soon as possible. Payments are usually paid directly into an account of your choice.

Some benefits and allowances are listed in this section. For more information, you can contact the Benefit Enquiry Line, your local Jobcentre Plus office or call one of our welfare rights advisers on freephone **0808 808 00 00**. If you have internet access, you can also visit the website **gov.uk**

**Disability Living Allowance (DLA)** This is for people under 65 who need help or have difficulty with personal care (the care component) and/or getting around (the mobility component). As part of the Welfare Reform Act 2012, DLA will gradually be replaced by Personal Independence Payment for people of working age from April 2013.

**Personal Independence Payment (PIP)** This is for people aged 16–64 who need help or have difficulty with personal care (the daily living component) and/or getting around (the mobility component). PIP has many similarities to DLA but there are also differences. For example, the eligibility criteria are different and PIP payments will be reviewed more regularly. Contact our welfare rights advisers on **0808 808 00 00** to find out more.

**Attendance Allowance (AA)** This is for people aged 65 or over who have difficulty looking after themselves. There is no mobility component. The amount of benefit paid will depend on how much support and care the person needs.

Anyone who is not expected to live longer than six months because of an illness can apply for DLA/PIP or AA under special rules. Under these rules, the claim will be given priority and will be dealt with more quickly.

**Carer's Allowance (CA)** This is paid each week if you are 16 or over and spend at least 35 hours a week caring for someone. You can't claim CA if you are studying for 21 hours a week or more, or if you earn more than £100 a week (after certain deductions). For you to receive CA, the person you care for must be receiving AA, DLA care component (middle or higher rates) or PIP daily living component.

**Employment and Support Allowance (ESA)** This benefit gives financial help to people who are unable to work due to illness or disability. It also provides some support to those who can work. There are two types of ESA: contributory-based (dependent on national insurance contributions) and income-related (means-tested). People may get either or both depending on their national insurance contribution record and their income and savings.

From October 2013, income-related Employment and Support Allowance will be replaced by Universal Credit. Contributory-based Employment and Support Allowance will stay the same.



Because the benefits system is changing significantly over the next few years, the benefits and allowances you may be entitled to could change. So it's important to always check the current situation and whether you are eligible.

## Macmillan grants

These are small, mostly one-off grants, to help people meet expenses that have arisen from, or are associated with, their cancer.

Everyone's practical needs are different, so grants are available for a variety of different cancer-related expenses. For more information, please call us on **0808 808 0000** or visit **[macmillan.org.uk/grants](http://macmillan.org.uk/grants)**

## Other sources of financial help

You may be able to get some financial help from charities. A Guide to Grants for Individuals in Need lists all the charities and what they provide. It's published by the Directory of Social Change (visit **[dsc.org.uk](http://dsc.org.uk)**) and you can find a copy in most libraries. Many trade unions and professional organisations also have benevolent funds, which can provide financial help and advice. Details are in The Charities Digest (published by Waterlow), which is held in most libraries.

The Association of Charity Officers (visit [aco.uk.net](http://aco.uk.net)) tries to help people find charities that may be able to offer some financial assistance. Using information about your relative or friend, such as their occupation, religion and where they live, the association can usually find relevant charities to help.

Turn2us helps people find specific charities that may be able to offer financial assistance. Visit [turn2us.org.uk](http://turn2us.org.uk) or call **0808 802 2000**.

If you, and/or the person you are caring for, are employed, the human resources, personnel or welfare officer at your workplace can also be an important source of information and help.

### Help with your mortgage

If you are having difficulty paying your mortgage, contact the manager of the building society or lender as soon as possible and explain what has happened. They may agree to suspend payments for a while to give you time to sort your finances out, or suggest that you pay only the interest on the loan for a while. Another solution is to extend the term of the mortgage so that you have less to pay each month.

Your local Department for Work and Pensions office, social worker or a Citizens Advice Bureau can also advise on help with paying your mortgage.



You may find it helpful to read our publication *Help with the cost of cancer*. It has more detailed information about financial help.





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## YOUR FEELINGS AND EMOTIONS

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**Looking after someone you care about can cause you to have many different feelings and emotions. Some people find that coming to terms with advanced cancer together brings them closer. You may find it easier to talk to each other and share your feelings. This can help support you both through your anxieties, sadness, fear and uncertainty.**

Others may find looking after someone is not always easy or satisfying. Many carers lie awake at night worrying about what's going to happen in the future and how they're going to cope. Some people feel frustrated or worried because the person they are caring for can no longer share responsibility with them for running a home or looking after a family.

Nearly everyone feels angry and resentful at some point. You may feel guilty about having these emotions and worry that you have them. You might think you don't love the person you're caring for enough. Many carers are often very tired and short of sleep. The main thing to remember is that these feelings are normal. You're probably going through one of the most stressful times of your life and it's natural to have strong emotions.

It's normal for some carers to ask for help. This may be from your family and friends, a counsellor or a health care professional such as your GP or nurse. Some of the organisations listed on pages 86–92 can help you to find someone to talk to.



You may also find it helpful to read our booklet *How are you feeling? The emotional effects of cancer*.

Although everyone's experience is different, we've included some feelings and emotions that most carers say they have felt at some times.

## Resentment

'We have good days and bad days. I've learned to take each day as it comes. Sometimes he's in pain or hasn't slept much and he gets quite irritated with me if I'm a bit clumsy lifting him or the food doesn't turn out quite right. It's difficult not to feel hurt when you're doing so much for him all the time.'

**Deb**

Most carers have times when they feel resentful. It's natural to feel like this. You may not have much time to enjoy hobbies or go out and see your friends. The person you're caring for may sometimes be moody, self-centred and withdrawn. They may have become more irritable since they became ill, especially if they're in pain. They may not always seem to appreciate what you're doing for them. Many people take out their fear, anxiety or frustration on the person closest to them. If this is happening to you, you may sometimes feel unwanted and resentful. Trying to talk about this may help, perhaps find a time when you're both having a better day.

You may find it easier to talk about your feelings with someone else. Sometimes feelings of anger and guilt can build up, especially if you're not able to talk about them. Give yourselves a chance to try to understand how the other person feels and you may be able to avoid your anger and irritation building into an argument.

## Fear

'I lie awake at night panicking. I know she's often awake at night too, and I wonder what's going through her mind. But in the day, there's so much to do, I don't have time to think about it. She does though.'

**John**

Cancer can be very frightening. You may feel that you don't know enough about it and that you don't have any control over what's happening or what's going to happen. The person you're caring for is probably afraid too. You may both be hiding what you really feel so you don't upset each other.

It can help to find a sympathetic person to talk to about your fears and worries. Just talking and getting your concerns out into the open might be enough. You may then find that you're better able to help your relative or friend talk about their fears.

## Depression

'Some days I feel terrible. I can't even go into his room in case I break down in front of him. I feel I should be stronger for him, but I can't be.'

**Victoria**

You're bound to have times when you feel low, usually when you are very tired or anxious. Or when the person you're caring for is unhappy or needs a lot of help. Usually, these low times don't last long and within a few days you'll start to cope with your normal routine again. But if you find that you're always feeling low or tearful or often feel desperate or panic-stricken, you could be depressed.

Don't feel you're letting yourself down if you admit to feeling depressed. No-one is going to think any worse of you. Your family and friends may not realise how much strain you're under. Talk to them if you can, and ask them to help. They may be able to sit with your friend or relative while you have some time off.

Talk to your GP if you think you are depressed. A family member or friend may have mentioned that they are worried about you. No-one will be surprised you feel this way. Your GP may refer you to a counsellor or give you some antidepressants.

## Anger

'Sometimes I feel so angry – not with anyone in particular, just with the situation we are in. I keep thinking, why me?'

**Pippa**

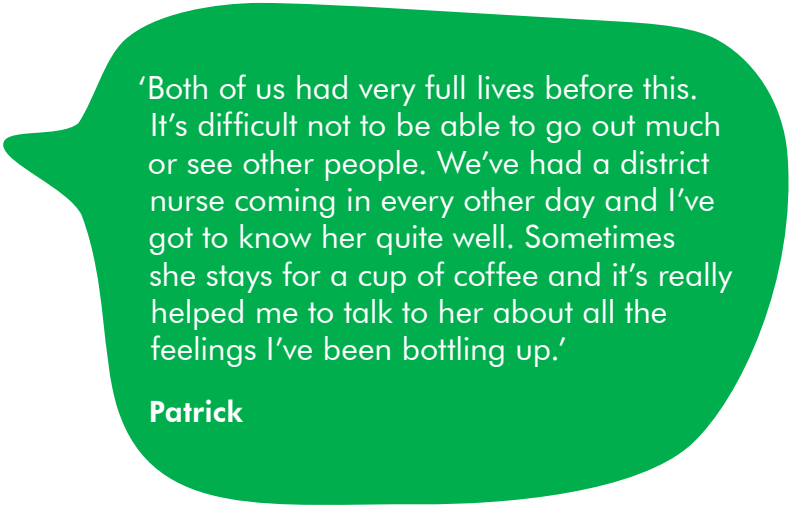
Many people say that after they've got over the shock of being told that someone close to them has advanced cancer, they start to feel very bitter or angry. It may seem very unfair that illness has got in the way of your plans.

You may have to cope with feelings of anger towards both the illness and towards the person you're caring for. You might find that you start to lose your temper with them, especially if they have become irritable or depressed.

Feeling angry with each other is to be expected and there's no reason to feel guilty about it. However, it's important to find a way of dealing with your anger before it builds up too much. It might help if you can talk about it to a relative, good friend, or someone else who has been through the same experience, such as a member of a local carers' group. Some people find that writing about their anger helps them to release some of the emotion.

For information about local carers' groups, contact Carers UK, or the Carers Trust (see page 86 for contact details).

## Frustration



'Both of us had very full lives before this. It's difficult not to be able to go out much or see other people. We've had a district nurse coming in every other day and I've got to know her quite well. Sometimes she stays for a cup of coffee and it's really helped me to talk to her about all the feelings I've been bottling up.'

**Patrick**

Caring for someone can be very frustrating and being cared for can be frustrating too. Between you, you need to work out a way of getting along where you both feel that you have some control over your own lives.

As a carer, you need to make sure that you have some time to yourself when you can do something that you enjoy and find satisfying.

If the person you're caring for is also very frustrated, try to think of ways that they can have some independence and freedom. If they are bed-bound, you could arrange for them to have a phone, radio or TV remote in easy reach. Maybe they could help with some everyday jobs. Most importantly, make sure that they are fully involved in decisions about their treatment and care.

## Loneliness and isolation

'I sometimes wonder if the world is still out there. People ring me and call in from time to time, but some days I feel so cut off.'

**Jacqui**

If you're at home looking after someone full-time, you may not have much opportunity to go out and socialise. It's often easier to stay at home all the time, especially if the person you are caring for is not feeling well and needs a lot of attention. You might begin to believe that only you can do the caring required.

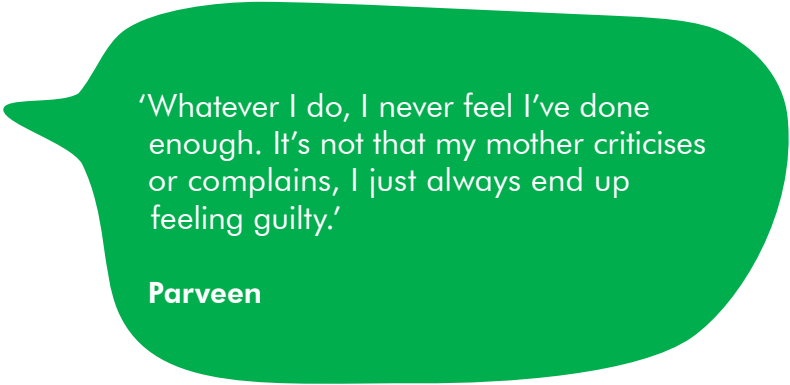
But it's very important to see other people, even if it's only once or twice a week. Once you get used to not seeing other people, it becomes more and more difficult to make contact. Also, other people may eventually stop seeing you if you don't accept their offers of help or company.





If you find you are losing touch with other people, try to make the effort to ring one of your relatives or friends and tell them you're lonely and that you need to see someone. You might be surprised by how much support and company they can offer. You could also contact a local carers' or cancer support group (see pages 78–79). Sharing your experiences with other people in the same situation can really help you feel less alone.

## Guilt



'Whatever I do, I never feel I've done enough. It's not that my mother criticises or complains, I just always end up feeling guilty.'

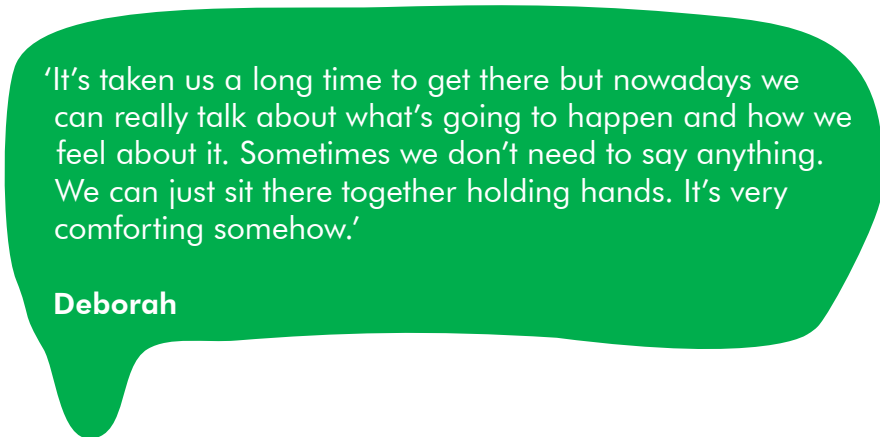
**Parveen**

Most of us have feelings of guilt. We all sometimes feel that we could have done more or that something we did was wrong. Sometimes, these feelings can get out of control and you may forget about how much you have done. You may not feel good about yourself and you start to believe that you can't do anything right. The person you're caring for may also feel guilty, perhaps about how much work and stress the illness is causing you and the rest of the family.

## Coping with feelings and emotions

### Talking together

The feelings that you have when someone close to you is very ill can be very strong and hard to deal with. Trying to be open about the way you're feeling may help you to feel more in control. If you can't do this with the person you're caring for, try talking with someone else, like a friend or relative. Your feelings may be easier to deal with once you have talked about them.



'It's taken us a long time to get there but nowadays we can really talk about what's going to happen and how we feel about it. Sometimes we don't need to say anything. We can just sit there together holding hands. It's very comforting somehow.'

**Deborah**

Many people find it very difficult to be open together in this way, especially when they're faced with a new and stressful situation. Some carers are uncomfortable about discussing their own feelings with the person with cancer because they don't want to upset them. Others can't bear to talk about it because they don't think they'll be able to comfort their friend or loved one, or because they're worried about breaking down and crying in front of them.

Some people are simply not used to talking with each other about their feelings.

There are no right or wrong ways of communicating and often just being there, perhaps giving a hug or holding hands, is enough to show someone that you care. Be prepared for them to talk about their illness if they want to. Often they won't expect you to provide answers but just want you to listen and understand so they don't feel so alone.

If you both find it hard to talk about your feelings, it may be easier to bring in a third person to help you. This could be a trusted friend, a religious leader, a counsellor or one of the health professionals you've got to know and trust.

## **Counselling**

The emotions you feel may be very tangled and confused. You may find them difficult to talk about and hard to share with your family or friends. Talking to a trained counsellor gives you an opportunity to talk to someone who is outside your situation. They will listen carefully to what you say. They have the skill and understanding to help you explore your feelings and find ways of coping with them.

Your GP will be able to refer you to a counsellor. You could also contact your local support group or hospital support centre as they may be able to put you in touch with a counsellor.

## Looking after yourself

It's important that you look after yourself as well as the person you care for. There are many ways you can do this.

### Take breaks

Having some time for yourself can help you to relax and feel able to cope better, which can also help the person you're caring for.

You may be able to arrange for someone to come in regularly so that you can have some time to yourself, even if it's only a few hours a week. If there isn't a relative or friend who can take over for a few hours, there are other ways of getting this help (see pages 18–29).

### Make time for you

When you get time off, it's important that you relax or enjoy yourself doing something different. You may feel tempted to spend time off clearing up the house or doing the washing so that you can get ahead on the chores. But this is unlikely to help you feel better in the long run.

However short it is, a regular and complete break doing something you enjoy is likely to make you feel much better.

It might just be an hour looking round the shops, having a coffee with a friend, going to the cinema or taking a grandchild to the swings. The main thing is to do something that you want to do and switch off for a while.

## **Eat well**

Try to eat healthily. If you can, make time to prepare and sit down for a cooked meal every day. If you don't have time to prepare a meal, perhaps you could ask a friend to prepare you one. Remember to treat yourself to your favourite foods sometimes.

## **Get some fresh air and exercise**

Try to get some fresh air and exercise every day, even if it's only to go for a short walk. This will help keep you more mentally alert, and may help to reduce tiredness and stress.

## **Use relaxation techniques**

Using techniques, such as relaxation and massage, help to reduce stress and feel better able to care. You may also like to learn a relaxation technique using relaxation CDs, DVDs or podcasts.

Some people find having a massage particularly helpful and a great way for them to switch off for a short time. It may be that you have a close friend or relative who would like to go with you for a massage at the same time.

## **Releasing tension**

Sometimes your feelings may get overwhelming and, if you can't cope, it may help to thump a cushion. This doesn't harm anyone and can leave you feeling a lot better.

Practicing deep breathing may help to reduce stress. Fill your whole lungs with air and breathe in and out slowly at regular intervals.

It can also sometimes help to write down your feelings. This gives you an opportunity to express your emotions rather than bottling them up.

## Sleep

Many people say that when they're caring for someone who is very ill they find it difficult to relax at night. You may be thinking and worrying about the person who's ill and this can keep you awake. It may be that the person you're caring for is having a bad night, which then keeps you awake. Here are some tips that may help you to have a better night's sleep:

- Read a book before you go to sleep. It will focus your mind on something other than cancer.
- Have a relaxing bath. You could add lavender oil or bath soak to help you relax.
- Have a warm drink.
- Listen to a relaxation CD or your favourite piece of relaxing music.
- Write a diary. If you get all your thoughts out on paper they won't be quite so busy in your head.

## Join a support group

Support groups are a really good way to talk to others who are in a similar situation. Some groups are specifically for people who are caring for someone with cancer. They give you a chance to talk to and meet up with other carers who understand what you're experiencing. Even if you can't go to their meetings, you might find it helpful to talk on the phone.

You can find more information about what support groups may be available in your local area from your local council.

Not everyone who's caring has the time to go to a support group. So another way to get support and to share your feelings is to join an online forum. Online forums are good because you can get in touch with lots of people who are in the same situation as you. The best things about forums are that you:

- can be anonymous
- can dip in and out when you want
- don't have to tell people anything you don't want to
- can make online friends.

There are plenty of forums for carers and for people affected by cancer. For example, Macmillan's online community has a forum for carers ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). Choose one that best suits you and your situation.



We have two publications for carers, which you may find useful:

- *Hello, and how are you?* tells you about getting help and support as a carer.
- *Let's talk about you* is for young carers and talks about the support they can get to help with their needs.

Our cancer support specialists on **0808 808 00 00** can send you this information or visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk)





# 8

## FURTHER INFORMATION

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# How we can help you

**Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.**

## Get in touch

### Macmillan Cancer Support

89 Albert Embankment,  
London SE1 7UQ

### Questions about cancer?

Call free on **0808 808 00 00**

(Mon–Fri, 9am–8pm)

**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

### Hard of hearing?

Use textphone 0808 808 0121  
or Text Relay.

### Non-English speaker?

Interpreters are available.

## Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

## Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](http://macmillan.org.uk/talktous)**

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at **[macmillan.org.uk/informationcentres](http://macmillan.org.uk/informationcentres)**

## Publications

We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free booklets, leaflets, and fact sheets.

## Other formats

We have a small range of information in other languages and formats. Our translations are for people who don't speak English and our Easy Read booklets are useful for anyone who can't read our information. We also produce a range of audiobooks. Find out more at [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats)

Please email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) if you'd like us to produce our information for you in Braille or large print.

You can find all of our information, along with several videos, online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)

## Review our information

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

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk)

## Need out-of-hours support?

You can find a lot of information on our website, [macmillan.org.uk](https://www.macmillan.org.uk)

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

## Someone to talk to

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

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

## Professional help

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

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

## Support for each other

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

### Support groups

You can find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

### Online community

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

## Financial and work-related support

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

If you've been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee and help you find further support.

### Macmillan Grants

Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much needed break.

Find out more about the financial and work-related support we can offer at [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)

## Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) – which offers a variety of e-learning courses and workshops. There's also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.

## Other useful organisations

### Support for carers

#### **Carers Trust (Princess Royal Trust for Carers in Scotland)**

**Tel (England)** 0844 800 4361

**Tel (Scotland)** 0141 221 5066

**Tel (Wales)** 0292 009 0087

**Email** [info@carers.org](mailto:info@carers.org)

**www.carers.org** and

**www.youngcarers.net**

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

#### **Carers UK**

**Tel (England, Scotland, Wales)** 0808 808 7777

**Tel (Northern Ireland)**  
028 9043 9843

(Wed–Thu, 10am–12pm  
and 2–4pm)

#### **Email**

[advice@carersuk.org](mailto:advice@carersuk.org)

**www.carersuk.org**

Offers information and support to carers across the UK.

Can put people in contact

with support groups for carers in their area.

#### **Young Carers Initiative**

The Children's Society,  
Edward Rudolf House,  
Margery Street,  
London WC1X 0JL

**Tel** 0845 300 1128

**Email** [supportercare@childrenssociety.org.uk](mailto:supportercare@childrenssociety.org.uk)

**www.youngcarer.com**

Works nationally to promote good practice for young carers and their families. From the website you can search for local young carers projects and find information about health, school, the internet, being heard, who's who and The Purple News young carers newsletter.

#### **Young Carers Net (YCNet)**

Princess Royal Trust for Carers,  
Unit 14, Bourne Court,  
Southend Road,  
Woodford Green IG8 8HD

**Tel** 0844 800 4361

**Email** [youngcarers@carers.org](mailto:youngcarers@carers.org)

**www.youngcarers.net**

Website and online support service for young people aged 18 and under in the UK, who help to look after someone in their family who has an illness, disability, drug/alcohol addiction or mental health condition.

## **Advanced cancer and end-of-life care**

### **Help the Hospices**

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

**Tel** 020 7520 8200

#### **Email**

[info@helpthehospices.org.uk](mailto:info@helpthehospices.org.uk)

**[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)**

#### **org.uk**

Provides information about living with advanced illness. Has a directory of hospice services and practical booklets available free from the website.

### **Marie Curie Cancer Care**

89 Albert Embankment,  
London SE1 7TP

**Tel** 0800 716 146

(Mon–Fri, 9am–5.30pm)

**Email** [supporter.services@mariecurie.org.uk](mailto:supporter.services@mariecurie.org.uk)

**[www.mariecurie.org.uk](http://www.mariecurie.org.uk)**

Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

## **Bereavement support**

### **Cruse Bereavement Care**

PO Box 800,  
Richmond TW9 1RG

**Tel** 0844 477 9400

(Mon–Fri, 9.30am–5pm)

**Email** [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

**[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)**

Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website, at **[crusebereavementcare.org.uk/LocalCruse.html](http://crusebereavementcare.org.uk/LocalCruse.html)**



## **RD4U**

Cruse Bereavement Care,  
PO Box 800, Richmond  
TW9 1RG

**Tel** 0808 808 1677

(Mon–Fri, 9.30am–5pm)

**Email** [info@rd4u.org.uk](mailto:info@rd4u.org.uk)

**[www.rd4u.org.uk](http://www.rd4u.org.uk)**

Designed for young people by young people, RD4U is part of Cruse Bereavement Care.

It supports young people after the death of someone close.

Offers a private message service from the website.

## **Counselling and emotional support**

### **British Association for Counselling and Psychotherapy (BACP)**

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

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

**[www.bacp.co.uk](http://www.bacp.co.uk)**

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)**

## **Samaritans**

Freepost RSRB-KKBY-CYJK,  
Chris, PO Box 9090,  
Stirling FK8 2SA

**Tel** 08457 90 90 90

**Email** [jo@samaritans.org](mailto:jo@samaritans.org)

**[www.samaritans.org](http://www.samaritans.org)**

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## **UK Council for Psychotherapy (UKCP)**

2<sup>nd</sup> Floor, Edward House,  
2 Wakley Street,  
London EC1V 7LT

**Tel** 020 7014 9955

**Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk)

**[www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## Equipment and advice on living with a disability

### Assist UK

Redbank House,  
4 St Chad's Street,  
Manchester M8 8QA

**Tel** 0161 832 9757

#### Email

[general.info@assist-uk.org](mailto:general.info@assist-uk.org)

**[www.assist-uk.org](http://www.assist-uk.org)**

A UK-wide network of Disabled Living Centres. Staff can give advice about the products, which are designed to make life easier for people who have difficulty with daily activities.

### British Red Cross

UK Office,  
44 Moorfields,  
London EC2Y 9AL

**Tel** 0844 871 11 11

#### Email

[information@redcross.org.uk](mailto:information@redcross.org.uk)

**[www.redcross.org.uk](http://www.redcross.org.uk)**

Offers a range of health and social care services such as care in the home, a medical equipment loan service and a transport service.

### Disability Rights UK

12 City Forum,  
250 City Road,  
London EC1V 8AF

**Tel** 020 7250 3222

**Email** [enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

**[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)**

Provides information on social security benefits and disability rights.

Has a number of helplines for specific support, including information on returning to work, direct payments, human rights issues, and advice for disabled students.

### Disabled Living Foundation (DLF)

380–384 Harrow Road,  
London W9 2HU

**Tel** 0845 130 9177

(Mon–Fri, 10am–4pm)

**Email** [helpline@dlf.org.uk](mailto:helpline@dlf.org.uk)

**[www.dlf.org.uk](http://www.dlf.org.uk)**

Provides free, impartial advice about all types of disability equipment and mobility products.

## General cancer support organisations

### Bladder and Bowel Foundation

SATRA Innovation Park,  
Rockingham Road,  
Kettering NN16 9JH

**Tel** 0845 345 0165

**Email** [info@bladderandbowel  
foundation.org](mailto:info@bladderandbowelfoundation.org)

**[www.bladderand  
bowelfoundation.org](http://www.bladderandbowelfoundation.org)**

Provides information and advice on a range of symptoms and conditions related to the bladder and bowel.

### Cancer Black Care

79 Acton Lane,  
London NW10 8UT

**Tel** 020 8961 4151

**Email**

[info@cancerblackcare.org.uk](mailto:info@cancerblackcare.org.uk)

**[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)**

Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

## Cancer Focus Northern Ireland

40–44 Eglantine Avenue,  
Belfast BT9 6DX

**Tel** 0800 783 3339

(Mon–Fri, 9am–1pm)

**Email** [hello@cancerfocusni.org](mailto:hello@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

## Cancer Support Scotland

Calman Cancer Support  
Centre, 75 Shelley Road,  
Glasgow G12 0ZE

**Tel** 0800 652 4531

**Email**

[info@cancersupport  
scotland.org](mailto:info@cancersupportscotland.org)

**[www.cancersupport  
scotland.org](http://www.cancersupportscotland.org)**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### **Irish Cancer Society**

43–45 Northumberland Road,  
Dublin 4, Ireland

**Tel** 1800 200 700 (Mon–Thu,  
9am–7pm, Fri, 9am–5pm)

**Email** [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)  
**www.cancer.ie**

National cancer charity offering information, support and care to people affected by cancer. Has a helpline staffed by specialist cancer nurses. You can also chat to a nurse online and use the site's message board.

### **Maggie's Centres**

1<sup>st</sup> Floor, One Waterloo Street,  
Glasgow G2 6AY

**Tel** 0300 123 1801

**Email** [enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**www.maggiescentres.org**

Maggie's Centres provide information about cancer, benefits advice, and emotional or psychological support.

### **Tenovus**

Head Office, Gleider House,  
Ty Glas Road, Cardiff CF14 5BD

**Tel** 0808 808 1010  
(Mon–Sun, 8am–8pm)

**www.tenovus.org.uk**

Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

## **Financial or legal advice and information**

### **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

#### **England and Wales**

**www.citizensadvice.org.uk**

#### **Scotland**

**www.cas.org.uk**

#### **Northern Ireland**

**www.citizensadvice.co.uk**

You can also find advice online in a range of languages at [adviceguide.org.uk](http://adviceguide.org.uk)

### **Gov.uk**

[www.gov.uk](http://www.gov.uk)

Has comprehensive information about social security benefits and public services.

### **The Law Society**

113 Chancery Lane,  
London WC2A 1PL

**Tel** 020 7242 1222

#### **Email**

[info.services@lawsociety.org.uk](mailto:info.services@lawsociety.org.uk)

[www.lawsociety.org.uk](http://www.lawsociety.org.uk)

Represents solicitors in England and Wales and can provide details of local solicitors.

### **Law Society of Scotland**

26 Drumsheugh Gardens,  
Edinburgh EH3 7YR

**Tel** 0131 226 7411

#### **Email**

[lawscot@lawscot.org.uk](mailto:lawscot@lawscot.org.uk)

[www.lawscot.org.uk](http://www.lawscot.org.uk)

### **Law Society of Northern Ireland**

96 Victoria Street,  
Belfast BT1 3GN

**Tel** 028 9023 1614

**Email** [info@lawsoc-ni.org](mailto:info@lawsoc-ni.org)

[www.lawsoc-ni.org](http://www.lawsoc-ni.org)

### **Personal Finance Society – ‘Find an Adviser’ service**

[www.findanadviser.org](http://www.findanadviser.org)

Use the website to find qualified financial advisers in your area.

### **Unbiased.co.uk**

**Email** [contact@unbiased.co.uk](mailto:contact@unbiased.co.uk)

[www.unbiased.co.uk](http://www.unbiased.co.uk)

On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.



You can search for more organisations on our website at [macmillan.org.uk/organisations](http://macmillan.org.uk/organisations), or call us on 0808 808 00 00.

# Further resources

## Related Macmillan information

You may want to order some of the resources mentioned in this booklet. These include:

- *An advance decision to refuse treatment*
- *Controlling cancer pain*
- *Coping with hair loss*
- *Eating problems and cancer*
- *End of life: a guide*
- *Hello, and how are you?*
- *Help with the cost of cancer*
- *How are you feeling? The emotional effects of cancer*
- *Let's talk about you*
- *Lost for words – how to talk to someone with cancer*
- *National End of Life Care Preferred Priorities for Care document*

- *Recipes for people affected by cancer*

- *Your life and your choices: plan ahead*

To order a booklet, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

All of our information is also available online at **macmillan.org.uk/cancerinformation**

We have fact sheets about surgery and radiotherapy in Bengali, Gujarati, Hindi, Polish, Punjabi, Russian, Traditional Chinese and Urdu. We also have Easy Read books about cancer. Visit **macmillan.org.uk/other formats** to find out more.

## Helpful books and leaflets

### **A guide to grants for individuals in need 2011–2012**

Directory of social change. 11<sup>th</sup> edition. 2009. £75.

A directory of a wide range of charities and

trusts that provide financial assistance to people in need. Most public libraries will have a copy.

## Macmillan audiobooks

Our high-quality audiobooks, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer. To order your free CD, visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call **0808 808 00 00**.

## Macmillan videos

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

## Useful websites

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

## Macmillan Cancer Support [www.macmillan.org.uk](http://www.macmillan.org.uk)

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

- all the information from our 150+ booklets and 360+ fact sheets
- videos featuring real-life stories from people affected by cancer and information from professionals
- how Macmillan can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form for sending your questions
- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

### **American Cancer Society** **www.cancer.org**

Nationwide community-based health organisation dedicated to eliminating cancer. It aims to do this through research, education and advocacy.

### **Cancer Research UK** **www.cancerhelp.org.uk**

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

### **Care Quality Commission (CQC)** **www.cqc.org.uk**

In England, this is an independent regulator of all health and social care. It makes sure standards of care and safety are being met in places where care is provided. This includes the NHS, local authorities, private companies or voluntary organisations. You can check if standards are being met on the Care Quality Commission websites:

#### **www.carecommission.com**

In Scotland, adult and independent healthcare services are regulated by the Scottish Commission for the regulation of social care.

### **www.cssiw.org.uk**

The Care and Social Inspectorate for Wales encourages the improvement of social care and services in Wales.

### **www.rqia.org.uk**

In Northern Ireland, the Regulation and Quality Improvement Authority encourages the improvement of health and social care.

### **Healthtalkonline**

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

Contains information about some cancers and has video and audio clips of people talking about their experiences of cancer and its treatments.

### **Macmillan Cancer Voices** **www.macmillan.org.uk/cancervoices**

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.



**National Cancer Institute –  
National Institute of Health  
– USA**

**[www.cancer.gov](http://www.cancer.gov)**

Gives information on cancer and treatments.

**NHS Choices**

**[www.nhs.uk](http://www.nhs.uk)**

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

**NHS Direct Online**

**[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)**

NHS health information site for England.

**NHS 24 in Scotland**

**[www.nhs24.com](http://www.nhs24.com)**

NHS health information site for Scotland.

**NHS Direct Wales**

**[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

NHS health information site for Wales.

**Health and Social Care  
in Northern Ireland**

**[www.n-i.nhs.uk](http://www.n-i.nhs.uk)**

The official gateway to health and social care services in Northern Ireland.

**Patient UK**

**[www.patient.co.uk](http://www.patient.co.uk)**

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

**Riprap**

**[www.riprap.org.uk](http://www.riprap.org.uk)**

Developed especially for teenagers who have a parent with cancer.



## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photographs are of models.

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our medical editor, Dr Tim Iveson, Consultant Medical Oncologist and Macmillan Chief Medical Editor.

With thanks to: Charlotte Argyle, Carers Support Programme Manager Macmillan; Ben Bowers, District Nursing Charge Nurse; Fiona Gilmour, Macmillan Service Improvement Lead; Imelda King, Macmillan Palliative Care Clinical Nurse Specialist; and the people affected by cancer who reviewed this edition.

## Sources

**We've listed a sample of the sources used in this publication below. If you'd like further information about the sources we use, please contact us at [bookletfeedback@macmillan.org.uk](mailto:bookletfeedback@macmillan.org.uk)**

Advance Decisions to Refuse Treatment. [www.adrt.nhs.uk/index.html](http://www.adrt.nhs.uk/index.html) (accessed June 2013).

National Institute for Health and Care Excellence (NICE). *Improving Supportive and Palliative Care for Adults with Cancer: The Manual*. March 2004.

NHS Choices. [www.nhs.uk](http://www.nhs.uk) (accessed April 2013).

NHS End of Life Care Programme. *Advance Care Planning: A Guide for Health and Social Care Staff*. August 2008.

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



## **Share your cancer experience**

Support people living with cancer by telling your story, online, in the media or face to face.

## **Campaign for change**

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

## **Help someone in your community**

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

## **Raise money**

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

## **Give money**

Big or small, every penny helps. To make a one-off donation see over.

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

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Signature

Date / /

## Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

- I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

Please cut out this form and return it in an envelope (no stamp required) to:  
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,  
89 Albert Embankment, London SE1 7UQ

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

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

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit [macmillan.org.uk](http://macmillan.org.uk)

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.  
Non-English speaker? Interpreters available.  
Braille and large print versions on request.

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Next planned review 2016. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).



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