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CANCER SUPPORT

A guide for carers

# CARING FOR SOMEONE WITH ADVANCED CANCER



# About this booklet

## This information is for anyone caring for someone with advanced cancer.

A carer is someone who gives unpaid support to a family member or friend who could not manage without this help. You may not live with the person you care for, and you may have a job or children to look after as well. You may be a young carer looking after an older relative.

You may not think of yourself as a carer. You may think you're just a partner, relative or friend doing their bit to help. But the support you give is very important. From helping with shopping, to being there when they need to talk. The person who spends the most time looking after someone is usually called their **main carer**. But some people have more than one carer.

When someone has advanced cancer, it means that the cancer has come back or spread. 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 will be a shorter time.

Your person you care for may begin to need more help with their everyday needs, such as bathing, dressing and cooking. You may want to plan how best to look after them and make them comfortable. You may worry that you won't have the physical or emotional strength to cope, or that it will be difficult to get the support you need to make life at home easier. This booklet gives information to help you cope with these issues.



## How to use this booklet

This booklet is divided into sections to help you find the information you need. You may find some sections useful now and other sections more helpful in the future.

There are details of other organisations you might like to contact on pages 89–95. There’s also space to write any notes or questions you have for health and social care professionals on pages 96–97.

We’ve included some comments from other carers which we hope you find useful. Some are from **healthtalk.org** and some are from people who have chosen to share their story with us. Some names have been changed.

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 and friends. They may also want information to help them support you and the person you are caring for.

## More information

We have more booklets you might want to read:

- **Coping with advanced cancer** may help you understand what the person you are caring for is coping with.
- **Looking after someone with cancer** gives lots of practical advice on caring and how to get support.
- **A guide for young people looking after someone with cancer** has information to help young carers under 18.
- **Your life and your choices: plan ahead** explains how people can think about their future care by advance care planning.
- **End of life: a guide** explains what happens at the end of someone's life, how to plan for it and what to do after they have died.



To order these, or any others mentioned throughout this booklet, call us for free on **0808 808 00 00** or visit **[be.macmillan.org.uk](https://www.be.macmillan.org.uk)**

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# GETTING READY FOR COMING HOME

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This section is about the things you may want to think about before the person you are caring for is 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 their needs have changed and they are more unwell now, you may find some of the information here useful.



# Talking about it

Before the person you're caring for comes home, it's a good idea to talk to them about how they want to be looked after and how you can help 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 feel valued and loved.

If other family members and friends are sharing the care, it's useful to involve them in discussions early on too. You will then be able to find out how each person can help, and where you may need further help.

You may find that you're asked to keep everyone updated 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 could think about asking another family member or a friend to help you do this.

# Organising help and services

All the practical help and services needed should already be set up before your family member or friend comes home. This is usually done by the hospital or hospice staff, with a **social worker**. See pages 23–33 for more information about the professionals you may meet. All hospitals and organisations have policies to make sure a person is safely discharged and the care they need at home has been organised.

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

If there are a lot of things to discuss before discharge, the ward or hospice staff may arrange a meeting. This may involve:

- the person with cancer and their main carer
- the doctor in charge of the person's care
- specialist nurses
- an occupational therapist (OT)
- a social worker.

If you are the main carer, you should be involved in any discharge planning. You should never be left to take the person home without the right help and support in place. If you aren't sure of the plans that are being made, talk to the nurses or ward manager. They can discuss it with you and arrange for you to see the social worker. This is so you can talk about any help you may need, called a **carers assessment** (see page 31). If you're not happy with anything that has been arranged, say so.

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. As well as giving you support, they can remind you of anything you may have forgotten.

Remember that plans can be changed later if the situation changes. For example, when the person first goes home, you may not need any help looking after them. But if they begin to get weaker, you may need help with their personal care – such as washing, dressing and eating.

The person you're caring for should be given information from the hospital or hospice to take home. This may tell you what medication and type of diet they need, and where to get more support. 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're 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. You can talk to the pharmacist about this.

## GP and community services

The GP and community nursing team should be told that the person you're caring for is being sent home soon. You can ring the GP to explain what is happening. 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 GP 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 23–24.

# 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 in the home. They can arrange for an **occupational therapist** (OT – see page 27) to visit and assess your home. Some hospitals and hospices are able to supply some equipment a day or so before discharge.

You can also hire equipment from voluntary organisations and charities, such as the British Red Cross (see page 91).

## Beds

Being comfortable in bed can be very important for anyone who is unwell because they may need to spend a lot of time there. The district nurse (see page 25) can arrange equipment for the bedroom. They may lend you a pressure-relieving mattress or a hospital bed. Once the person you're caring for is home, you can ask them what would make them comfortable. The district nurse should be able to give you advice on the best way to do this.

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

## Chairs

If the person you're looking after is able to sit in a chair, it's important that they are well supported and comfortable. An OT or **physiotherapist** (see page 28) can give you advice on this. The district nurse can usually arrange for the loan of a pressure-relieving cushion.

## Commodes, bedpans and urinals

If the person you're 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 look like chairs and some have wheels.

## Bathing equipment

It may also be difficult for them to have a bath or shower. Using a bath chair, bath board or shower stool may help. An OT or physiotherapist will assess the person's needs and talk to you both about what equipment would work best for your situation.

## Breathing equipment

If the person you're caring for has breathing problems, their healthcare team can arrange equipment such as a nebuliser, oxygen concentrator or cylinder.

## Wheelchairs and walking aids

They may have difficulty walking and need a wheelchair, walking stick or walking frame. An OT or a member of the healthcare team should be able to arrange this.

## 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.

There are shops and organisations that sell or hire out aids and equipment. Try looking under 'Disabled' in the Yellow Pages or by searching online. You can also ask your local pharmacist what they have available.

Some people may be able to get a Macmillan grant to help pay for equipment (see page 81).

The person's health and social care teams should be able to give you advice about how to get the equipment you need. Organisations that provide equipment and advice on living with a disability are listed on pages 91–92.

## Blue Badge scheme

This scheme allows people with mobility problems to park closer to where they want to go. To apply for a badge, contact the local council. A healthcare professional, welfare rights adviser or social worker will be able to help with the application.

A close-up, low-angle shot of a person's legs as they ascend a staircase. The person is wearing dark blue denim jeans and brown, well-worn shoes. The stairs are covered in a thick, brown carpet. To the right, a white, turned wooden banister is visible, providing support. The lighting is warm and indoor, highlighting the textures of the fabric and wood.

**'The district nurse suggested putting an extra banister on the stairs. By the time it was installed it was a godsend. It helped Katy get up the stairs independently.'**

Ciarán

# Preparing your home

Before the person you're caring for arrives, you may need to make some changes to your home. These can make life easier for you both.

## Home adaptations

An occupational therapist (OT) can give you advice about the safety of the house and making minor changes. For example, you may need handrails in the bathroom, or need the bed moved downstairs.

Major changes might be possible too, such as putting in a toilet or shower downstairs, or installing a stair lift. But these can take several months of planning and may not be possible before the person comes home. It also involves building work which can be disturbing. You will need to discuss whether you want to make these changes.

If you live in a council or housing association house or flat, changes like these are usually paid for by the local authority. But this 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 (see page 30). You should make any claims for financial help before you start any building work.

## Organising their room

One of the most important things to do is to get their room ready. They may spend a lot of time there so it's important they are happy in it and it feels welcoming. Talk about which room they'd prefer and, if you have more than one floor, would they like to be upstairs or downstairs. If they can't get around easily, they may want to be in the room nearest the bathroom.

Put their bed or chair in a good position, preferably with a view out of a window. If possible, position it so you're able to get around both sides of the bed. You could put a small table next to the bed, and a chair for visitors if there's space.

Ask them if there's anything they'd like in the room. You could hang up their favourite pictures or photos. Or they may want a computer, TV or phone nearby. You may want to think about getting an intercom so they can talk to you when you're somewhere else in the house.

If their room has, or is near, a gas appliance such as a gas heater, it's a good idea to have a carbon monoxide detector fitted.

## Sleep arrangements

It's important that you get plenty of sleep and rest. If you're caring for a partner and usually share a bed, you may need to think about whether to keep doing this. Sleeping apart may allow you both to get the rest you need. But sleeping together and feeling close may be important to you too. Talk to your partner so you can both decide what is best.

## Food

If the person you care for has a poor appetite or is having trouble eating, ask them what foods they enjoy and stock up on these before they come home. The hospital dietitian and ward or community nurses can give you advice and may be able to supply supplement foods and drinks.

As the carer, you may also have to change the way you think about food and eating.

We have more information on pages 46–48 about the types of foods you could stock up on, and things you can do to help with eating problems.



# WHO CAN HELP YOU?

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# 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 make a big difference.

Some people may want to help with things like 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 and will let you talk about your worries.

If you're feeling a bit overwhelmed, try making a list of things that you need help with. You could then ask people what they would be able to do. Some people may be able to help regularly, this could be a couple of hours a week. Others may prefer to help every now and again.

It's important that you know who you can turn to and how they'll be able to help. You could try identifying a few key people. They could be parents, close friends, or someone from a local support group (see page 69).

If you always seem to be good at coping with everything, your family and friends may not realise how much you need help. Or they may be waiting for you to ask for help.

You may find our website **The Source** helpful. It's where people affected by cancer, and their families and friends can share their experiences and give practical tips about living with cancer. Visit [source.macmillan.org.uk](http://source.macmillan.org.uk)

# Health and social care professionals

There are a number of community health and social care professionals who can support you. The type and amount of support you get will depend on where you live and how the services are organised in your area.

## GP (family doctor)

A GP has overall responsibility for the healthcare of people who are unwell and being looked after at home. For the person you're caring for, they can:

- assess their changing health
- give them information and support
- prescribe drugs
- organise nursing help if needed – for example, visits from a district or specialist palliative care nurse
- refer them to a physiotherapist or occupational therapist (OT)
- arrange for them to go into a hospital, hospice or nursing home, if needed – this may be to give you a break, known as **respite care** (see pages 56–57).

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

Contact the GP if you are worried about something. This may be if the person you're caring for has new symptoms or some that are getting worse, 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 tell you about local support services.

GP surgeries must provide a 24-hour service. If you call for a doctor when the surgery is closed or at weekends, you'll probably be put through to an out-of-hours doctor.

People with cancer in the UK can get free prescriptions. In England, the person with cancer first 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 involved in the care of someone who is ill at home. They have overall responsibility for the nursing help you're given and will talk to you about the care that will be provided. This care may include:

- assessing the person's nursing needs
- giving support and advice
- giving injections
- changing dressings
- advising on nutrition, pressure area care, bowel problems and incontinence
- arranging for any special equipment to be delivered.

They can also show you how to do everyday nursing tasks, such as washing or moving the person.

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. After that, the district nurse usually organises for other nurses who work in their team (also known as **community nurses**) 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. This may vary depending on the services available in your area. District and community nurses will deal with the more complicated needs of the person you are caring for.

## 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. You may also be able to get help with laundry services (see page 33).

The Bladder and Bowel Foundation has more information and advice on bladder and bowel problems (see page 92).

## Community specialist palliative care team

Palliative care teams include specialist nurses and doctors. These teams specialise in controlling pain and symptoms, as well as offering emotional support. They are usually based in hospices and can visit people who are being cared for at home.

Community specialist palliative care nurses will work closely with the person's GP, district nurse and other hospital services. They will tell you more about their services, how to contact them and when they are available.

## 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 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 (see page 90 for contact details). 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 and cooking. They help people with advanced cancer learn how to save energy while doing these tasks.

OTs can suggest and arrange minor changes to your home (see page 17). They can also help you by ordering a wheelchair, equipment to make bathing or showering easier, or specially adapted cutlery.

Your social worker (see page 30) 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.

They may need to see the physiotherapist as an outpatient at either the hospice or local hospital. Some physiotherapy teams may visit people at home.

## Private nurses (agency nurses)

You can also get help from a private nurse. This can be very expensive and may only be practical as a short-term solution. But it can be useful if you're working and you need a nurse 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 (see page 30) or a support group (see page 69) for advice. You can still ask for advice even if the person with cancer is not eligible for care provided by social services.

Look in your local phone book under 'Nursing Agencies' or search online. Page 95 has details of organisations that check the standards of care a nursing agency provides.



## Social services

A **social worker** (sometimes called a care manager) is responsible for assessing what practical and social help you and the person with cancer needs. If you don't already have a social worker, the GP or a nurse involved in the person's care 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** or needs assessment. Each local authority has its own eligibility criteria, so the services that are provided will vary from area to area.

If the person with cancer fits the criteria, your local authority has a duty to provide services to meet their needs. These can be provided by social services or arranged to be given by other organisations, such as charities. Services include:

- home care (see page 32)
- sitting services (see page 56)
- equipment and adaptations to your home (see pages 13–17)
- information and benefits advice
- meals on wheels (see page 33)
- laundry services for people with incontinence (see page 33)
- holidays
- respite care (see pages 56–57).

Some services will be paid for by the NHS, so they will be free. In other cases, social services will do a financial assessment to calculate whether you have to pay something. You may be able to get **Continuing Health Care** (CHC) provided by the NHS. Ask any health or social care professional how to apply for this.

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

### **Carer's assessment**

As a carer, you can ask the social worker for an assessment of your needs, called a carer's assessment. This is an opportunity to talk about any help you need. You can still ask for this assessment even if the person you are caring for has been assessed as not eligible for support. It is important to keep healthy, and to balance caring with your life, work and family commitments.

You can get more information about a carer's assessment at **macmillan.org.uk/carers** or from our booklet for carers, **Looking after someone with cancer**.

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

## Home care

You may be able to get help in the home to support you and the person you're caring for. This can give you a break and help you feel less tired.

Care attendants, carers or personal assistants come to the home to help. This may be to do some jobs around the house, or to sit with the person you're caring for. They can also give some personal care, such as washing and dressing the person. Some care attendant schemes arrange for someone to be there at night. Your local social services department or the Carers Trust (see page 89) will be able to tell you about schemes in your area.

**Home helps** offer a variety of services including cleaning, washing, cooking and shopping. Home helps are only available in some parts of the UK. Your local social services department, social worker, community nurse or GP will know what's available in your area.

You can also get help around the home by contacting a cleaning agency. Ask friends or neighbours for a recommendation. Or you could search adverts in a local paper or online. Agencies can be expensive so try shopping around for the best deal.

If you organise the help yourself, make sure you check references before employing anyone. You may have to explain that you are caring for someone and any particular needs that either of you have. And find out what you have to do to end the arrangement if it's not working.

## 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. 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 the person you're looking after can't manage the frozen meals service.

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

A social worker can arrange meals on wheels. Or you can visit **gov.uk** to see what services they provide.

## 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 provide a laundry service. Or 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 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. 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 more information and support. We've listed details of some of these on pages 89–95.

To find out what help is available in your area, call our cancer support specialists for free on **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 at **carers.org** or by calling the Carers Trust (see page 89).



# CARING AT HOME

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# 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 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 what to do.

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 can't get out of bed.

If the person goes to the local hospice day centre, it may be possible for them to have a bath while they are there. The specialist palliative care nurse can usually arrange this.

## Clothing

Choose loose, comfortable clothes because they are easy to get on and off. For example tracksuits, and skirts or trousers with elastic waistbands. And clothes that are easy to wash and don't need a lot of 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's easier for them.

Someone with cancer may feel colder than usual. Warm clothes, such as socks or wool tights, 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.

They 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

The person you're looking after may feel better if their hair is washed regularly. If they can't get to the sink, you could buy a plastic hair-washing tray from a disabled aids supplier (see pages 91–92). You could try using a rinse-free, waterless shampoo (or cap) that you put directly on their hair and remove by drying off with a towel. Ask at your local pharmacy for information about these products or search online.

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

If the person you're caring for is a man, he may need help with shaving. If you are a female carer and not sure what to do, you could ask a male friend or family member to help with this.

If the person's hair has fallen out because of treatment, their scalp may become dry and itchy. It can help to gently rub moisturising cream into their scalp. 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 to the home to give a manicure or pedicure.

Chiropodists or podiatrists will also often make home visits. 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 the person you're looking after 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 parts 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 26).

It's a good idea to make sure their bedroom is near a toilet. Or keep a commode, bedpan or urinal nearby.

The district nurse can give you information about using incontinence sheets, pads and pants, and protective bed covers. These may help to keep the bed clean and make the person more comfortable.

If these don't help, the nurse may suggest a catheter. This is a tube that is put into the bladder so 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 possible to use a tube connected to a sheath that fits over the penis.

*'My role as a carer was sometimes to help Katy walk, dress and get into the wheelchair. You end up doing all the driving and the household chores as well. So you have a full-time job. And then it gets into the nursing side, the bandages, sorting out the catheter and so on. So you end up in many, many roles as a carer, all of which you have to try to do as best you can. It's a huge learning curve.'*

**Ciarán**

## 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.

A head massage or gentle rubbing can also be soothing and relaxing. If their face is dry, you can use a moisturising cream. And use lip balm 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 anything. If the person's skin has been treated with radiotherapy, check with the hospital, GP or district nurse before you put anything on the treated area.

## Moving and turning

If the person you're looking after needs help getting 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. It's easy to injure your back so be very careful. You may be able to use a hoist or sling to help you.

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 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 try to move them as you may risk injuring them further and yourself. Call an ambulance. The paramedics will check them for any injuries and will help move them back to a chair or bed.



# Managing side effects and symptoms

## Sore mouth

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

If their 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's 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. 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 them.

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 drinks more fluids and may recommend laxatives, suppositories or enemas. These should help relieve the constipation.

If they're not having trouble eating, then it's helpful to add more fruit and high-fibre foods to their diet.

## Poor appetite and eating problems

People who are very ill often don't feel like eating. Cancer and its treatments can affect their 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
- find that food tastes different
- find chewing and swallowing difficult.

## How you can help

- The amount they can eat and their likes and dislikes may change from day to day. 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.

- 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 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 rice pudding. You could try liquidised food, or a nourishing drink such as a smoothie.
- You can buy ready-made supplement drinks like Complam<sup>®</sup> or Build-Up<sup>®</sup> from your local pharmacy and some supermarkets. You can get other supplements on prescription. The GP, specialist palliative care nurse or 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 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.
- Give them plenty of time to eat so they don't feel rushed. People with advanced cancer often take longer to eat. It's normal for them to eat less and lose weight. You may want to watch them if you're worried that they're not eating enough. This is understandable but can be off-putting. Let them eat on their own if they prefer. They can then eat what they want in their own time.
- Eating in bed is often uncomfortable. If possible, make sure they are supported with pillows, or in a chair next to the bed. A table that goes across the bed can help. You may be able to hire one through the OT or home care team. They could also try using a cushioned tray, or a two-handed cup if their hands are weak or shake when they drink.

If you help feed them, make sure you're sitting comfortably in a chair that gives proper support and allows you to reach them without stretching.

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



**You may want to read our booklets *Eating problems and cancer* and *Recipes for people affected by cancer*. To order free copies, call our support line on 0808 808 00 00 or visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk)**

## Nausea and vomiting

Some people with advanced cancer feel sick (nausea) or are sick (vomit). This may be due to the cancer or its treatment. It's important to let the doctor or nurse know if the person feels sick. There are anti-sickness medicines that may help.

There are things you can do to help the person you care for. You can encourage them to:

- avoid fatty and fried foods
- eat cold foods – the smell from cooking and hot food can often make them feel more sick
- eat small meals and snacks
- drink small amounts of fizzy drinks, such as ginger beer
- suck peppermint sweets.

## Pain

People with advanced cancer are often worried that they are going to be in severe pain. Not everyone with advanced cancer will have pain. If the person you're caring for is in pain, it can usually be well controlled with painkillers. Sometimes, the pain may be 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 painkillers. They are usually given as tablets or capsules to swallow. Some types of painkiller can be given as a patch stuck on to the skin (like a nicotine or hormone replacement patch). It's also possible to inject painkillers just under the skin. Injections are more likely to be used if a person can't swallow tablets or capsules, or absorb medicine from a patch. This might be because they are being sick or are very drowsy.

If the person's painkillers don't seem to be working, contact their GP, district nurse or specialist palliative care nurse. The dose or medicine may need to be changed.

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

Sometimes just listening to their fears and worries can help them cope better with pain.

If their pain or other symptoms are very severe and distressing, a short stay in a hospice may help (see page 57). The doctors and nurses there will be able to assess the pain and symptoms. They can adjust the dose of medicines or add 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 this will help, they can refer them to a specialist in pain control.

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

## Breathlessness

The person you're looking after may be breathless at times. They may feel short of breath or their chest may feel tight. This can be very scary for both of you. Breathlessness can be difficult to live with, but there are ways you can help the person you care for to manage it:

- Help them to use breathing and relaxation techniques. This involves using your diaphragm and lower chest muscles to breathe. It's important to breathe gently and to relax your upper chest and shoulder muscles.
- Use a Borg scale so they can show you how breathless they feel at different times. A Borg scale uses numbers 0–10, with 10 being severe breathlessness. Keep a diary of their breathlessness. This may help you both to know what makes it worse so you can manage your activities together.
- Help them find their most comfortable seating and standing positions when they feel breathless.
- Speak to their GP about any medicines that may help them.
- Have a small handheld fan ready to blow cool air towards their nose and mouth. Sitting in front of an open window may also help.

Our booklet **Managing breathlessness** has more detailed information to help the person you're caring for.

## Sleep problems

They 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 (see pages 50–51).

If they are drowsy during the day and can't sleep at night, ask the GP to check their medicines. They may be able to adjust it or prescribe sleeping tablets.

The person 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 evening may help. They should avoid anything with caffeine in, such as coffee, tea and cola drinks.

Make sure their mattress and pillows are comfortable, especially if they're spending a lot of time in bed. Ask the district nurse or OT if they need a pressure-relieving mattress. You may be able to get a Macmillan Grant to help with the cost if you need to buy a new mattress and pillows (see page 81).

Here are some tips to help with sleep problems:

- Make sure the room is at the right temperature – cool with fresh air, but not too cold.
- Have blankets to hand.
- Make sure there isn't too much light – you could think about getting darker curtains or putting up a blind behind the curtains. Light from phones and clocks can also disturb sleep.
- Try to minimise noise distractions, such as a ticking clock.
- Soft music may be soothing.

A person wearing a green and white striped shirt is watering plants in a garden. They are holding a white watering can and pouring water into a grey metal bucket. The background features a brick wall, a yellow frog-shaped garden ornament, and various potted plants, including purple flowers and green foliage.

**‘Respite care was essential really. I thought it would be a nice break for Mum but as it turned out, it was a very good break for me. I wish I’d organised that sooner.’**

**Fiona**

# OTHER CARE OPTIONS

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# Respite care

A number of different care options are available to give you time off from caring. 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. Local authorities charge for some care services and they will give you information about how the care will be funded.

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

## Sitting services

Sometimes it's possible to arrange for someone to sit with the person you look after for a few hours in the day, or for an evening. Occasionally, sitters can stay overnight.

Some sitters will also help with light housework or personal care, such as washing 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 the person you're caring for, for a short time. The centre may provide lunch and some centres offer other services, such as 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 59), hospital, residential home or care home with nursing (see page 58) 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, and afterwards feel rested and better able to manage again.

Before you make a decision, you both might find it reassuring to go and see the hospice, hospital or home, and talk to the staff. You could also take along other members of the family or friends.

To find out what's available in the area, ask your health or social care teams, or a local support group. You can also contact Carers Trust or Carers UK for more information about services local to you (see page 89 for contact details).

# Care in residential homes or nursing homes

They offer short- or long-term accommodation and care. Residential care homes or care homes with nursing (nursing homes) provide different levels of care. A social worker or member of the healthcare team can explain the difference. They can 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 UK by specific organisations (see page 95 for their contact details). 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 give you 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're 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. This is known as **advance care planning** (see page 4).

The GP, district nurse, specialist palliative care nurse or social worker may suggest a short stay in a hospice or hospital. This may be because the person has symptoms that would be easier to control if they had specialist care. This may also be to give you a rest.

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 to have their symptoms closely assessed and managed, and then go back home.

Care in a hospice is always free. They specialise in managing symptoms including pain. They are generally smaller and quieter than hospitals and work at a much gentler pace. Many have sitting rooms and space for family 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 worries.

**'I felt that we actually grew closer to each other. We began to talk much more about what we meant to each other and the things that we'd really enjoyed doing together – so that was a positive thing.'**

**Darren**



# YOUR FEELINGS AND EMOTIONS

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# Emotional effects of caring

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. Others find looking after someone is not always easy or satisfying. Everyone's experiences are different, but we've included some feelings and emotions that most carers say they have felt at some point.

## Resentment

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 their fear, anxiety or frustration out on the person closest to them. If this is happening, 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. This can help prevent your anger and irritation building into an argument.

## Fear

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 the person you're caring for talk about their own fears.

## Depression

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. 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. No one will be surprised you feel this way. They may be able to sit with the person you're caring for while you have some time off.

Talk to your GP if you think you are depressed. They may refer you to a counsellor (see page 69) or give you some anti-depressants.

## Anger

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 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. But it's important to find a way of dealing with it before it builds up too much.

Some people find that writing about their anger helps them release some of it. Or you might find it helpful to talk about it with a relative, good friend, or someone else who has been through a similar experience. This could be someone from a local support group (see page 69).

## Frustration

Caring for someone can be very frustrating. 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 to do things you enjoy and find satisfying.

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

## Loneliness and isolation

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're caring for is not feeling well and needs a lot of attention.

You might start to think that you're the only one who can care for the person.

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 can become more difficult to make contact. And they may eventually stop asking to see you if you don't accept their offers of help or company.

If you find you're losing touch with friends or family, try to make the effort to ring one of them. 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 support group (see page 69). Sharing your experiences with other people in the same situation can really help you feel less alone.

## Guilt

Most of us feel guilty about something. 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 to help. You may not feel good about yourself and 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.

'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**



# Talking about your feelings

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 to a close friend or family member.

Your feelings may be easier to deal with once you have talked about them.

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 they're caring for 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. 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 talk to someone you don't know. This could be a close friend, religious leader, counsellor or health professional.

## Counselling

If you find it difficult to talk to your family or friends, it may help to talk to a trained counsellor. 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. Your local support group or hospital support centre may be able to put you in touch with one. The British Association for Counselling and Psychotherapy can also give you details of counsellors in your area (see page 90).

## Support groups and online support

Support groups can be a good way to talk to other people in a similar situation. Some groups are specifically for people who are caring for someone with cancer. You can meet other carers who may understand what you're going through.

You can find more information about local support groups from your local council or visit [macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)

If you use the internet, you may want to join an online support group or chat room. This can be a helpful way of getting in touch with lots of people who may be in a similar situation to you. They're easy to join and you can stay anonymous if you prefer.

Our online community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community) lets you talk to people in our chat rooms, blog your experiences and make friends. It has a specific group just for carers.

# 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 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 happy to talk and give whatever support and comfort they can.

# Looking after yourself

It's important that you look after yourself as well as the person you care for.

## Take breaks

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

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 (see page 56).

## 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 cleaning the house or doing the washing. 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 drink with a friend or going to the cinema. 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, perhaps you could ask a friend to help you. And remember to treat yourself to your favourite foods sometimes too.

## Be active

Try to be active and get some fresh air every day. This could just mean a short walk. This will help keep you more mentally alert, and may help you feel less tired and stressed.

## Use relaxation techniques

Practising deep breathing may help to reduce stress. Fill your lungs with air and breathe in and out slowly, at regular intervals. You may want to learn relaxation techniques using relaxation CDs, DVDs or podcasts. These may be available at your local library. You may also find it helpful to listen to our CD **Relax and breathe**, which you can order from [be.macmillan.org.uk](http://be.macmillan.org.uk)

Some people find having a massage very relaxing and a great way to switch off for a short time. Your local carers' centre or Macmillan information centre may offer free complementary therapies for carers.

Sometimes it helps to release tension. If your feelings overwhelm you and you feel you can't cope, it may help to punch a cushion. This doesn't harm anyone and can leave you feeling a lot better.

It may also help to write down your feelings. This gives you the chance to express your emotions rather than bottling them up.

## Get enough 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 them and this can keep you awake. Or the person you're caring for may be 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 or magazine 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 may not be quite so busy in your head.

'I committed myself to going to the gym, to practicing meditation and joining a support group. By doing this, it brought me to a sense that I was not alone, there were other people in the same position. Of course, that doesn't ease your pain but it helps you cope a little bit better.'

**Joe**



# WORK AND FINANCES

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# Working and caring

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.

Finding a balance between work and caring can be difficult, but it is definitely not impossible.

You may find it helpful to read our booklets **Working while caring for someone with cancer** and **Work it out for carers**. They give helpful advice on flexible working, getting support at work and talking about cancer in the workplace.

We also have videos of carers talking about their experiences of working while caring. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

Remember you can ask your local social services for a carer's assessment (see page 31). This is a chance to talk about any support that would help you balance work and caring, as well as other issues.

# Benefits and financial support

## Carer's Allowance

Carer's Allowance is the main benefit for carers.

You may be able to get this if you care for someone who is getting one of the following disability benefits:

- Attendance Allowance
- the care component of Disability Living Allowance at the middle or higher rate
- the daily living component of Personal Independence Payment of either rate.

To qualify for Carer's Allowance you need to care for someone for at least 35 hours a week. It's handy to keep a diary of all the time you spend caring, as this can help with your application. If you qualify, you may be able to get other benefits.

You can find out whether you are entitled to Carer's Allowance and make an application online. Visit [gov.uk/carers-allowance](https://www.gov.uk/carers-allowance) if you live in England, Scotland or Wales, or [nidirect.gov.uk/carersallowance](https://www.nidirect.gov.uk/carersallowance) if you live in Northern Ireland.

## Carer's Credit

There is also a national insurance credit called Carer's Credit. You may be able to get this if you are not eligible for Carer's Allowance. Anyone who gets Carer's Allowance automatically receives Carer's Credit too.

Carer's Credit enables carers to build up qualifying years for the basic State Pension, the additional State Pension and Bereavement benefits.

For more information, visit [gov.uk/carers-credit](https://www.gov.uk/carers-credit) if you live in England, Scotland or Wales, or [nidirect.gov.uk/carers-credit](https://nidirect.gov.uk/carers-credit) if you live in Northern Ireland.

## If your caring role ends

If your caring role ends, it's important to let the relevant benefits offices know.

If you live in England, Scotland or Wales, contact the Carer's Allowance Unit. Visit [gov.uk/carers-allowance-report-change](https://www.gov.uk/carers-allowance-report-change) or call **0345 608 4321**.

If you live in Northern Ireland, contact the Disability and Carers Service on **028 9090 6186**.

Letting the relevant office know will help you to avoid problems later. If you have a low income once your carer's benefits stop, you may be able to claim other benefits.

## Benefits for the person you look after

The person you're caring for may be able to get certain benefits. This could include Personal Independence Payment in England, Scotland or Wales, or Disability Living Allowance in Northern Ireland. These benefits are for people aged under 65 who have difficulty looking after themselves or moving around. People aged 65 or above can claim Attendance Allowance instead.

People who are not expected to live longer than six months can make a 'special rules' claim for these disability benefits. This would mean they would receive payments quickly. Speak to our welfare rights advisers on **0808 808 00 00** for more information.

## Disabled parking badge and free tax disc

The person you care for may be entitled to a disabled parking badge for your car, which you can use when you are taking them out. See page 15 for more information on the Blue Badge scheme.

You may also be entitled to a free tax disc (vehicle tax exemption). If you live in England, Scotland or Wales, you can find out by calling the Driver and Vehicle Licensing Agency (DVLA) on **0300 790 6801**. If you live in Northern Ireland, call the Driver and Vehicle Agency on **0845 402 4000**.

## Tax refund

If you, or the person you care for, has to give up work and your income falls, you may be able to get a tax refund. To find out, contact HM Revenue & Customs on **0300 200 3300**. If your circumstances change, it's also worth asking whether you are paying the right amount of tax. Look in the phone book or visit **hmrc.gov.uk**

## Insurance

Some life insurance policies pay out when someone is diagnosed. Have a look through your policies, and those of the person you care for. You may find that you are covered for loss of income, medical treatment, credit cards, mortgage payments or other expenses.

Contact our welfare rights advisers on **0808 808 00 00** for advice or help accessing benefits and other kinds of financial support.

## Grants

You may be able to get some financial help from charities. Macmillan provides small, mostly one-off grants, to help people pay expenses that are 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 00 00** or visit **[macmillan.org.uk/grants](https://www.macmillan.org.uk/grants)**

## 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.

Our booklet **Help with the cost of cancer** has more detailed information about financial help. You can call our support line on **0808 808 00 00** to order a copy, or go to **[be.macmillan.org.uk](https://www.be.macmillan.org.uk)**



# YOUR RIGHTS AND TREATMENT

# CANCER

# UNDERSTANDING THYROID CANCER (DUCULAR AND PAPILLARY)

# SEX AND RELATIONSHIPS

# SIDE EFFECTS OF CANCER TREATMENT

# FURTHER INFORMATION

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# About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

## Order what you need

You may want to order more leaflets or booklets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

All of our information is also available online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)

[macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- ebooks
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats)

If you'd like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk) You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

## Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

### Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence. Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

## Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. 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

Thousands of people use our online community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

### Financial advice

Our financial guidance team can give you advice on mortgages, pensions, insurance, borrowing and savings.

### Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)



### Macmillan's My Organiser app

This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

There are lots of other organisations that can give you information or support.

## Support for carers

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

32–36 Loman Street,  
London SE1 0EH

#### **Tel (England)**

0844 800 4361

#### **Tel (Scotland)**

0300 123 2008

#### **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.

## Advanced cancer and end-of-life care

### Hospice UK

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

**Tel** 020 7520 8200

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

**www.hospiceuk.org**

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

### Marie Curie

89 Albert Embankment,  
London SE1 7TP

**Tel** 0800 716 146

(Mon–Fri, 9am–5pm)

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

**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.

## Counselling, bereavement and emotional support

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

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

**Tel** 01455 883 300

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

**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)

### 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.cruse.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 [cruse.org.uk/cruse-areas-and-branches](http://cruse.org.uk/cruse-areas-and-branches)

### **London Friend LGBT Bereavement Helpline**

86 Caledonian Road,  
London N1 9DN

**Helpline** 020 7837 3337  
(Mon–Wed, 7.30pm–9.30pm)

#### **Email**

office@londonfriend.org.uk  
**www.londonfriend.org.uk/  
get-support/helpline/**

A helpline for lesbian, gay, bisexual and transgendered callers. Also welcomes calls from affected family, friends, colleagues and carers.

### **Ruby Care Foundation**

Westfield, Maesycrugiau,  
Pencader, Carms SA39 9DH

**Email** info@rubycare.org

**www.rubycare.org**

An international educational charity dedicated to the care of the terminally ill, companionship of the dying, and support and counselling for the bereaved.

### **TCF (formerly The Compassionate Friends)**

14 New King Street,  
Deptford, London SE8 3HS

**Helpline** 0845 123 2304  
(open every day of the year,  
10am–4pm and 7pm–10pm)

**Email** helpline@tcf.org.uk

**www.tcf.org.uk**

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

### **Equipment and advice on living with a disability**

#### **British Red Cross**

UK Office,  
44 Moorfields,  
London EC2Y 9AL

**Tel** 0844 871 11 11

#### **Email**

information@redcross.org.uk

**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**

Ground Floor,  
CAN Mezzanine,  
49–51 East Road,  
London N1 6AH  
**Tel** 0300 555 1525

**Email** enquiries@  
disabilityrightsuk.org  
**www.disabilityrightsuk.org.uk**

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.

### **General cancer and support organisations**

#### **Bladder and Bowel Foundation**

SATRA Innovation Park,  
Rockingham Road, Kettering,  
Northants, NN16 9JH

**Helpline** 0845 345 0165  
**Email** info@bladderand  
bowelfoundation.org  
**www.bladderand  
bowelfoundation.org**

The Bladder and Bowel Foundation (B&BF) is a UK-wide charity that provides information and advice on a range of symptoms and conditions related to the bladder and bowel. Provides support for a range of bladder and bowel problems.

#### **Cancer Black Care**

79 Acton Lane,  
London NW10 8UT  
**Tel** 020 8961 4151

**Email** info@cancer  
blackcare.org.uk  
**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  
**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**

The Calman Centre,  
75 Shelley Road,  
Glasgow G12 0ZE

**Tel** 0800 652 4531

**Email** info@

cancersupportscotland.org

**www.cancersupport  
scotland.org**

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

### **Maggie's Centres**

20 St. James Street,  
London W6 9RW

**Tel** 0300 123 1801

**Email** enquiries@

maggiescentres.org

**www.maggiescentres.org**

Provides 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)

**Email** info@

tenovuscancercare.org.uk

**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.

## Money or legal advice and information

### Benefit Enquiry Line

#### Northern Ireland

Tel 0800 220 674

(Mon–Wed and Fri, 9am–5pm,  
Thu, 10am–5pm)

Textphone 0800 243 787

[www.nidirect.gov.uk/  
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)

Provides information and advice about disability benefits and carers' benefits.

### 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 these websites:

#### England and Wales

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

#### Scotland

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

#### Northern Ireland

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

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

### Department for Work and Pensions (DWP)

#### Disability Living Allowance

Helpline 0345 712 3456

Textphone 0345 722 4433

#### Personal Independence Payment Helpline

0345 850 3322

Textphone 0345 601 6677

#### Carer's Allowance Unit

0345 608 4321

Textphone 0345 604 5312

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

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

## Organisations to check care standards

### Care Quality Commission (CQC) [www.cqc.org.uk](http://www.cqc.org.uk)

An independent regulator of all health and social care in **England**. 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.

### Care Inspectorate [www.careinspectorate.com](http://www.careinspectorate.com)

The independent scrutiny and improvement body for care services in **Scotland**.

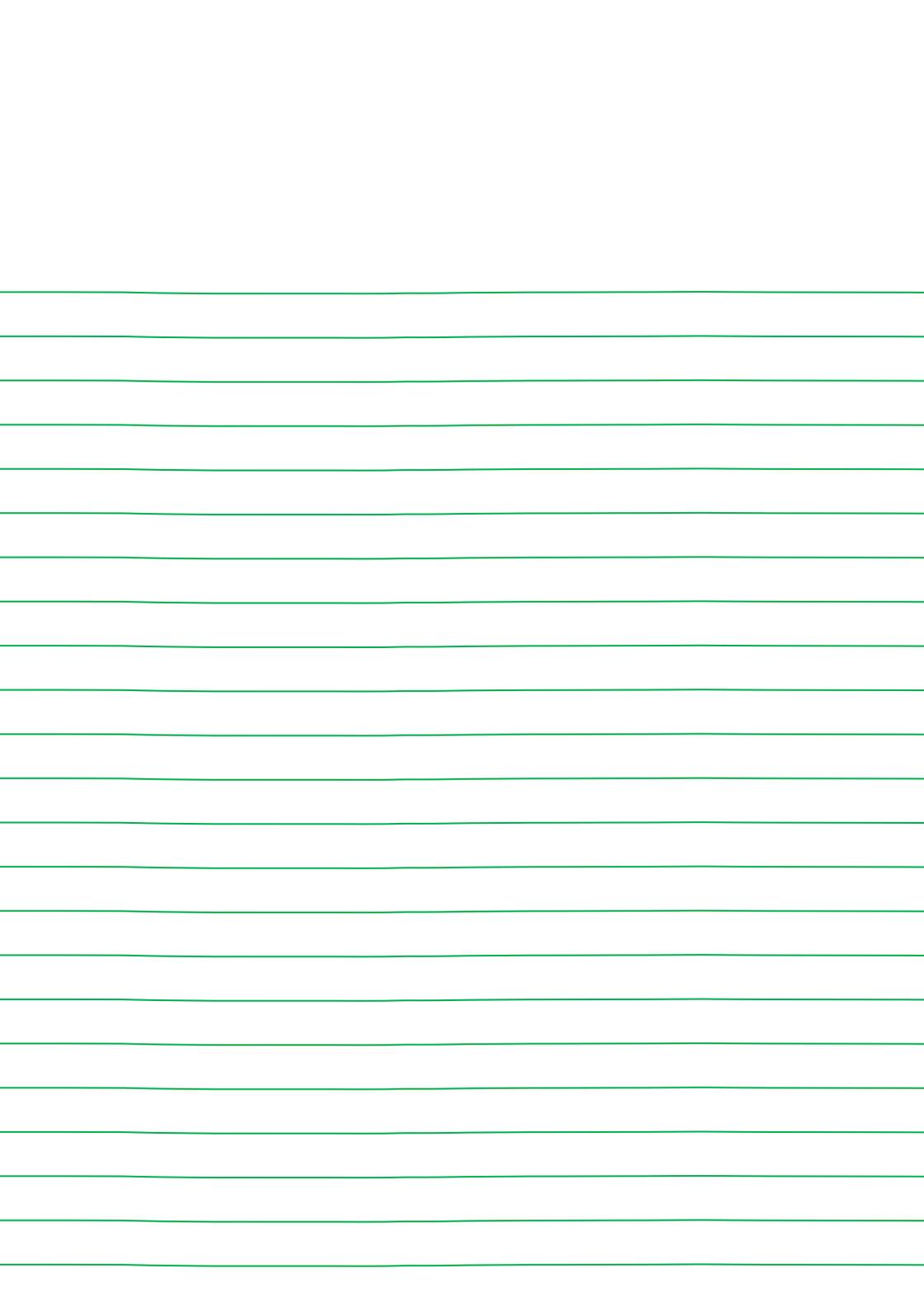
### The Care and Social Inspectorate for Wales [www.cssiw.org.uk](http://www.cssiw.org.uk)

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

### Regulation and Quality Improvement Authority [www.rqia.org.uk](http://www.rqia.org.uk)

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





## 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 photos are of models.

## Thanks

This booklet has been written, revised and edited by Macmillan's Cancer Information Development team. It has been approved by Dr Sara Booth, Macmillan Consultant in Palliative Medicine and our Chief Medical Editor, Dr Tim Iveson, Consultant Medical Oncologist.

With thanks to: Charlotte Argyle, Macmillan Carer Support Programme Manager; Ann Brennan, Macmillan Lead Nurse Specialist Palliative Care; Alison Foster, Macmillan Associate for Palliative and End of Life Care (Wales); Anna Grady, Community Palliative Care Clinical Nurse Specialist; Elizabeth Grew, Macmillan Carers Support Project Officer; Brigette Gwynne, Macmillan GP Adviser; Dinah Hickish, Senior Advanced Nurse Practitioner/Matron; Fiona Smith, Macmillan Social Care Project Manager; Eileen Sweeny, NI Partner Development Support Worker; and Adline Warwick Thompson, Oncology Counsellor. Thanks also to the people affected by cancer who reviewed this booklet and shared their stories.

## 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)**

Carers UK. [www.carersuk.org](http://www.carersuk.org) (accessed April 2015).

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

NHS Choices. [www.nhs.uk](http://www.nhs.uk) (accessed April 2015).

Quality standard for end of life care for adults: NICE quality standard 13: 2011.

# 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

Card number

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Valid from

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Expiry date

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Issue no

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Security number

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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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CANCER SUPPORT**