## A practical guide to living with and after cancer

# BE THERE FOR SOMEONE FACING CANCER

A short guide to help make sure no one faces cancer alone

# This information is for you if you are supporting a friend, relative or colleague with cancer.

You probably want to be there for them, but you might not know how you can help. Or you may have trouble finding the right words. Sometimes people are so worried about what to say that they don't say anything at all. This can leave their loved one feeling like they're facing cancer alone.

This leaflet takes you through the different stages of having cancer, from diagnosis through to treatment and beyond, to help you understand what your friend or relative is facing. Each section has:

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# Practical tips on how you can support your friend or relative.

Suggestions for how you can talk to them about what they're going through.

Throughout this leaflet, we've included quotes from people about how they supported a loved one living with cancer. We hope you find their tips useful. Because this is only a short guide, we don't have space to go into detail about everything. However, we do have more in-depth information about the things we mention in this leaflet. To find out about this and the other support Macmillan can offer you and your friend or relative, turn to page 20.

This leaflet is not aimed at carers. A carer is someone who provides unpaid support to a person who couldn't manage without this help. If you're a carer, we have a range of information and support specifically for you. Call us on **0808 808 00 00** to find out more. You can also read our information for carers online at **macmillan.org.uk/carers** 

## Your feelings

Although it's not you who's been diagnosed with cancer, this can be a very difficult time for you too. Remember that you'll need time to come to terms with things, and you may feel a range of emotions. Don't bottle it up. Talk to your family or friends – you may find they want to share their feelings with you too.

The Macmillan Support Line has specialists who can answer your questions or just be there to listen to you – call us on **0808 808 00 00**. You could also get support from the Macmillan Online Community at **macmillan.org.uk/community** And you may want to find out about support or counselling for yourself. Your GP can give you more information.

We also have a website called **The Source** where you can read tips from people who have supported a loved one with cancer. You can also add your own suggestions. Visit **source.macmillan.org.uk** 



# Diagnosis

Cancer is a word that stirs up all sorts of emotions, and a friend or relative being diagnosed with cancer can be frightening. One of the greatest fears you might have is that they'll die. However, many cancers can be cured if they're found early. And when a cancer can't be curable, current treatments often mean it can be controlled for some time.

## How cancer is diagnosed

Most people begin by seeing their GP when they develop symptoms. The GP will investigate the symptoms and refer them to a hospital for further tests. After the diagnosis, a cancer specialist will usually carry out further tests to learn more about the cancer. This helps them decide on the most appropriate treatment.

## How you can help

## Be there

- Visit them especially if they live on their own or you're worried they are feeling isolated.
- Make them a cup of tea and just listen.
- Watch TV or films together to take their mind off things.
- If you can't be there in person, then call, text or message them, write them an email or send a card. And let them know there's no rush to reply.
- If they're not already in contact with Macmillan, suggest that they call us on **0808 808 00 00** to find out how we can support them.

- Help plan for appointments what questions do they have and what do they want to say? Encourage them to write it down to take along on the day.
- Offer to go with them for support and to talk things through.
- Give them a lift especially if they're having a test or scan.
- During the appointment, offer to write the important things down.

## Be there between appointments

- They might find it helps to organise the information they've been given and to keep track of things like their symptoms and mood. You could order them a free Macmillan Organiser from **be.macmillan.org.uk**
- Having more information helps some people feel more in control. You can find our cancer information at macmillan.org.uk/ cancerinformation
- But remember that some people don't want to know all the details and prefer to leave everything to their doctors.

'For me, the trick was getting in touch often. A phone call, a text, perhaps the occasional quirky postcard or visit.'

## Christine

# Talking about it

You may worry about how they'll react if you bring up their diagnosis. You may think you won't know what to do if they cry or get angry, or you might be concerned that talking to them will make it worse. However, the opposite is often true – not talking about a fear or worry can make it bigger.

It can be difficult to know what to say. But there's no magic phrase that's the 'right' thing to say. The important thing isn't what you say – it's that you're there and that you listen. And as a listener, you don't need to have all the answers.

If your friend or relative finds it helps to talk things through, you can help by just listening, letting them talk and not changing the subject. Talking can be a huge relief, so by just listening you will help them feel better.

However, others find that their feelings of shock and disbelief make it difficult for them to talk. They may want to be left alone to work through their thoughts and emotions. This can be hard for you, but they'll talk to you when they're ready.

## What to avoid saying

When someone is diagnosed with cancer, they may be encouraged by other people to 'think positively'. However, this isn't always easy. They may have periods of feeling low, which is a common reaction. Although this may be difficult for you to see, don't feel you have to encourage them to be positive.

You may have heard stories about other people with cancer. Although you mean well, try not to tell your loved one about other people's experiences of cancer, because everyone's experience is different. Try to trust that they'll get the information they need from their healthcare team.



# Treatment

## How cancer is treated

The main cancer treatments are surgery, radiotherapy (using high-energy x-rays to destroy cancer cells) and chemotherapy (using anti-cancer drugs to destroy cancer cells).

Other important treatments include targeted therapies and hormonal therapies. Often a combination of more than one type of treatment is used.

## **Possible side effects**

Different treatments cause different side effects. Side effects can usually be reduced in some way.

Physical side effects can include:

- a lowered immune system, which can make people more likely to get infections
- fatigue (extreme tiredness)
- eating problems, such as a loss of appetite, sore mouth, or problems chewing or swallowing
- changes in appearance, such as hair loss, changes to body shape, and weight changes
- problems with the digestive system, such as nausea, vomiting, diarrhoea or constipation.

Cancer treatment can also affect your emotions. It can cause anxiety, anger, isolation and depression. People can ask their healthcare team about the support available to help them cope.

#### Treatment 10

## How you can help

## If they are in hospital

- If you want to visit, check they're feeling up to it first. And don't visit if you're not feeling well.
- It may be a shock to see them looking unwell. Try to keep your attention on them, not on any medical equipment.
- Make sure you visit during visiting hours, and don't stay too long if they're tired.
- Take them a book or magazine, or check whether the hospital allows flowers.
- Take them an audiobook or some music to listen to.
- Update them on what's happening with other family members, friends or colleagues.
- Find out whether anything needs doing at home that you could help out with.

'Sometimes I just sat with him while his wife went out and had a break. We watched TV, we talked and laughed and sometimes we sat quietly. I took my lead from him and what he could cope with.'

Carrie

## If they are at home during or after treatment

- If they have a carer, offer to visit so the carer can have a break.
- Ask a close member of the family whether there's anything you can do to help. Offer to help out with everyday activities. For example, doing some laundry, picking the children up from school, taking care of any pets, weeding the garden or taking out the rubbish.
- If you offer to do the food shopping or cook a meal, check which foods the person prefers first.
- If they feel up to it, suggest doing some gentle exercise together, like going for a short walk.
- Don't visit if you're not feeling well.
- Take your lead from them about how often to visit they will need time to rest.
- If they have to go to hospital for treatment, offer to give them a lift and sit with them while they have it.
- If they are a colleague, send a card on behalf of yourself and your co-workers.

## Talking about it

Some people with cancer find that changes to how they look or how their body works are some of the hardest parts of having treatment. Your friend or relative may feel less confident and worry that people will treat them differently. They might want to talk to you about how they feel. Try to encourage them when they talk about how they will adjust to any changes.

We all express our feelings in different ways, and sometimes one emotion can cover for another. For example, your friend or relative might feel frightened but express it by being short-tempered or angry with the people around them. Talking about our feelings can help us understand our behaviour and what's behind it. But this isn't always easy.

If you're finding it hard, you could say things like, 'It's hard to talk about this', or even, 'I don't know what to say'. You may worry about saying things like this, but being honest about your own feelings will help build trust between you both. It will also make it easier for your friend or relative to be honest about their feelings.

These conversations can be hard. If you find them very difficult, it's fine to suggest that your friend or relative asks their GP or healthcare team for emotional support.

## After treatment

## What happens now?

Your friend or relative may not need any more treatment because the cancer has been cured. Or they may be living with cancer and the possibility that they will need more treatment in the future. They'll probably have regular check-ups and scans.

This may be a time when they begin to look at getting their life back to the way it was before the cancer. However, it can take time to recover from the effects of treatment, and it's normal to feel tired for several months. Some side effects might be long-lasting, and for some people there may be permanent changes to adjust to. It may also take them time to work through their feelings about everything they've been through and the impact it's had.

> 'We enjoy things like meals out when he is up to eating.'

Katie

## How you can help

- Now treatment is over, they might want to start focusing more on their relationships with family and friends, so suggest visiting or meeting up.
- Remember it will take time for them to recover, so keep up the support ask them how they are and what you can do to help.
- Offer to help with things like gardening, shopping or housework.
- Offer to cook for them sometimes.
- Take them some CDs or DVDs.
- Being more active might help them feel better, so offer to do something gentle like going for a walk together.
- They may get very nervous about check-ups, so offer to go with them for support.
- If you can't be there in person, then call, text or message them, write them an email or send a card. And let them know there's no rush to reply.

## 'I said to her, "Don't cook I'll do it".'

Lynne

## Talking about it

People experience many different emotions after cancer and its treatment. They may be afraid that the cancer will come back and they'll have to go through more treatment. They may wonder whether the cancer has been cured. Some people may feel low or depressed for a while.

## What can help

Talking can help them cope with their emotions. You could encourage them to talk about what's on their mind. Simple things work very well. Try nodding or saying things like, 'Yes', 'I see' or 'What happened next?'. These all sound simple, but during stressful times it's the simple things that help.

Showing empathy is also helpful. If they start to cry as they talk, you could say something like, 'I can see how upsetting that is for you'. If you're very close to them, you could simply sit with them and hold their hand.

You could also repeat back what they've said – partly to check you've got it right, and partly to show you're listening and trying to understand. You could say things like, 'So you mean that ...' or 'If I've understood you, you feel ...'. You may find your own way of saying this, especially if you know each other very well.

## What to avoid saying

Don't be too quick to offer advice – it's fine to just listen. Even if it goes quiet for a bit, try not to be afraid of the silence or feel like you have to fill it.

Try not to use clichés like, 'Things could be worse' or 'Things will work out'. Although you mean well, this can sound like you're ignoring their feelings. Just let them say how they feel. And be mindful of how you use humour. Although it can sometimes help, if it's misjudged it can make things awkward.



# If cancer can't be cured

If cancer comes back or has spread, there may come a time when treatment can't control the cancer and the person is told that they only have a limited time to live.

Some people with cancer that has spread may become ill very slowly over many months. Others may become ill more quickly, within a few weeks. It's not possible to predict accurately when someone with cancer may die.

## Your feelings

Hearing the news that a friend or relative's cancer can't be cured is always very difficult. It can bring up many feelings and emotions. You may have been aware that their cancer was progressing, but you might find it hard to believe what you're hearing. You may feel that it's like a nightmare and you'll wake up and find it's not true. After a few hours or days, the initial shock and disbelief may be replaced by powerful and often overwhelming emotions. These may make it difficult for you to think clearly.

You're likely to need some time on your own or with a partner, relative or close friend to cope with the news. You may want to find out about counselling. Your GP can help with this. The Macmillan Support Line is here to support you. Call us on **0808 808 00 00**. Or visit our online community at any time of the day or night at **macmillan.org.uk/community** 



## How you can help

- You can visit your friend or relative wherever they are – at home, in hospital, or in a hospice or nursing home.
- If they don't want to be on their own, work out a rota so that there's always someone with them.
- If they don't have much energy they may only want to see their close family, so take your lead from them.
- You could read aloud to them, or send them a CD or audiobook to listen to.
- Offer to help with housework, shopping and cooking so their carer (if they have one) can spend more time with them.
- Offer to sit with your friend or relative while their carer has a break.

'On the good days we had some of the best times, and I have some lovely memories.'

Colin

## Talking about it

Most people find it difficult to talk about death and dying. People who are dying sometimes describe being surrounded by a 'conspiracy of silence'. This is where they, and their family and friends, all know what's happening but no one feels able to speak about it freely.

People who are seriously ill, and the people close to them, will sometimes find themselves lost for words. But often simply being with loved ones is enough. A loving look, a hug, or a squeeze of the hand can make words unnecessary. Tears are also very natural – you don't have to put on a brave face. If you try to hide your feelings, you and your friend or relative may not get the chance to say what you want to.

Towards the end, they will get weaker and less able to do things. A lot of the time they may just want to lie quietly and have people sitting nearby. This can be a very intimate and special time. They can tell you whether they'd like to talk, be quiet or listen to music.

There's no 'right' way to cope with the knowledge that a friend or relative is dying. You can only cope in the way that's best for you and come to terms with it in your own way, at your own pace. Many people eventually find a sense of peace and appear to be ready to 'let go' when the time comes.

# Further information and support

We have more information on cancer types, tests, treatments and living with and after cancer. We also have details of other helpful organisations and support groups in your area. You can contact us using the following details:

Macmillan Cancer Support 89 Albert Embankment, London SE1 7UQ Tel 0808 808 00 00 (Mon–Fri, 9am–8pm) macmillan.org.uk

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

To order any of our booklets, visit **be.macmillan.org.uk** or call us on **0808 808 00 00.** 

Braille and large print versions on request

# Other useful organisations

#### Cancer Research UK www.cancerhelp. orq.uk

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

## Health and Social Care in Northern Ireland www.hscni.net

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

## Healthtalk

## www.healthtalk.org www.

## youthhealthtalk.org (site for young people)

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

## NHS Choices (England) www.nhs.uk

The UK's biggest health information website. Has service information for England.

NHS Direct Wales www.nhsdirect.wales. nhs.uk NHS health information site for Wales.

## NHS Inform (Scotland) www.nhsinform.co.uk NHS health information site for Scotland.

## **Patient UK**

**www.patient.co.uk** Provides information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics.

## Disclaimer

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

## Thanks

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## Sources

The information in this leaflet comes from Macmillan's wider range of cancer content. If you'd like further information about the sources we use, please contact us at **bookletfeedback@macmillan.org.uk** 

For more information about anything in this leaflet, please call the Macmillan Support Line on **0808 808 00 00.** 

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** 

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