# Supporting someone you know through cancer





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The information contained within this booklet is intended for those wanting to help and support someone experiencing cancer. When reading, please remember that everyone is different. This advice is best used alongside what you know about the person you are supporting and how you think is best to offer help.

If someone you know receives a cancer diagnosis or is going through cancer treatment, you might be wondering how you can support them.

Even though you want to help, sometimes it's hard to know what to say or do.

It's important to remember that there are no set rules, and every relationship is different. Be sure to think about your unique dynamic and let that guide you as you try to support them.

Keep it simple. Often, it's the little things that mean the most.

Every person with cancer has a different experience, so try not to assume how they might be feeling. They may feel happy one day and sad the next. Try to be mindful of their mood and if in doubt, let them lead the way.

# **Prepare yourself**

# Here are some things to think about before talking to someone who has cancer:

Consider your own feelings before making contact.

It can be difficult learning that someone you know has cancer. Take time to acknowledge and cope with your own emotions regarding their diagnosis before you see or talk to them. This way, you can keep the focus on them.

### Do some research

People may not want to talk about their diagnosis for many reasons. It can be physically and emotionally tiring for them to give the same information repeatedly. If possible a partner, relative or friend may be able to tell you more. You might find it helpful to write things down and to repeat information back to be sure you have understood correctly. If there is information that is unknown or not shared, do not push for more. For general research, use reliable sources of information such as:

- Macmillan Cancer Support
- Cancer Research UK
- NHS

# Think about it from your perspective

Recall a time when you were scared or felt sick. Think about what it felt like, whether you felt like talking, how you wanted to be treated, and act accordingly.

You may also want to prepare yourself for changes in the person's appearance and lifestyle such as fatigue, weight-loss and hair-loss. Start any visit to them by saying "it's good to see you" instead of commenting on any physical changes.

# Helpful tips for supporting someone with cancer

Although each person living with cancer is different, here are some general suggestions for showing support:

Ask permission before visiting, giving advice, and asking questions. A cancer diagnosis can make people feel differently from day to day, so make it clear that saying no is perfectly okay.

**Make flexible plans** that give them something to look forward to, especially as cancer treatment can be long and tiring. Be prepared to be flexible with plans, as they may need to change at very short notice.

**Talk about topics other than cancer.** Ask about interests, hobbies, and other topics. People going through treatment will appreciate a break from talking about their disease. Don't be afraid to share a light

conversation or funny story. Laughter is therapeutic so be humorous and fun where appropriate.

### It is ok to not be okay.

Sometimes, sitting in silence or giving a silent hug may be sufficient. Don't feel that the person you're visiting always needs to be made to feel better. Do not ignore uncomfortable topics or feelings and accept that they may feel low or sad.



### Keep in contact with them.

They may often feel isolated, particularly if their immunity is low, so make time for a checkin phone/video call. Be sure to let them know that it's okay to not answer the phone. You could send them messages like "I'm thinking of you".

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### Treat them the same.

Try not to let a person's condition get in the way of your friendship. As much as possible, treat them the same way you always have.

Ask how you can help. Many people find it hard to ask for help. But they may accept practical help if it's offered. However, make sure that if you commit to helping that you follow through on your promise.



**Read their blog, web page, or group emails.** Some people living with cancer choose to write a blog about their experience that they can share with friends and family. Or a family member will post updates to a personal web page or send a group email. Stay current with these updates so that your friend does not have to repeat experiences or information multiple times. These updates are also a great way to start a conversation.

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# **Emotional support**

Research shows that emotional support from family and friends can make a big difference to the quality of life of someone with cancer.

People are often afraid of saying the wrong thing to someone with cancer, however, if you are open, honest, and show your concern then you can be a great support. Here are some tips that might help you.

### Do:

- Say if you feel awkward it acknowledges the situation rather than pretending it's not happening
- Give them a friendly hand squeeze or hug it can go a long way, if that's their thing
- Ring them up, send a card, note, or text to say you're thinking of them
- Let them know that if they want to talk you'll be there to listen then make sure you are available
- Respect their need for privacy
- Offer support throughout the whole diagnosis at the beginning, during treatment and beyond. Cancer recovery can be a long journey
- Share a joke or laugh with them if this seems appropriate
- Keep your relationship as normal and as balanced as possible

### Try not to:

- Say you know how they feel we can't ever know exactly how someone with cancer feels
- Tell them to 'be strong' or 'be positive' it puts pressure on them to behave a certain way
- Take it personally if they seem angry or upset or don't want to talk
- Offer advice that they haven't asked for
- Compare their situation to somebody else you know; each person's experience with cancer is unique

# Being a good listener

A good listener acknowledges someone's thoughts and feelings. You don't need to have all the answers; just listening to a person's concerns or worries can be hugely helpful. Listening is an important part of providing emotional support. Here are some important tips on how to do it well:

- Try to find a setting that's private, relaxed, and with few distractions
- Maintain eye contact but don't stare
- Let the person with cancer lead the conversation and try not to interrupt
- Give your full attention to what they are saying
- If you're finding it difficult or upsetting, don't change the subject say how you feel, this can prevent any awkwardness
- Crying is perfectly reasonable, don't try to cheer them up. Reassure them that it's OK to be sad and that it's a normal response to what's happening to them
- Physical contact such as a friendly touch of the hand can be comforting but if they pull away give them space
- Avoid using humour unless they instigate it themselves
- Become comfortable with silences



# **Emotions they might feel**

You might find that their mood changes from one moment to the next. This is a normal response to a diagnosis of cancer. There are a whole range of emotions that they might experience including:

Fear Frustration
Embarrassment Isolation
Resentment Grief Guilt
Shame Uncertainty

Sadness
Guilt
Loneliness

Acknowledging these emotions can help you to provide support.

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# **Practical support**

### As well as supporting someone emotionally it can help to offer practical support too.

Check in with your friend or loved one and ask if there is anything specific that they need help with.

Some people don't want help, or they may find it hard to accept it. They might want to remain as independent as possible. Try not to take this personally. Respect their decision but let them know, should they change their mind, you're still there.

You could offer to help again in the future or set up a rota so that you and friends can take turns to help out. Make sure you are able to commit to any offers of help that you do make. It's also a good idea to ask before you visit, in case they are feeling too unwell.

# Some of the ways you could offer help:

- Make some meals that they can put in the freezer
- Do some gardening
- Drive them to the hospital for blood tests and appointments
- Help with the cleaning or laundry
- Take pets for a walk or to the vet
- Do the shopping
- Return or pick up library books



- Take the children to and from school
- Bring them lunch and stay for a chat
- Schedule a takeaway and movie night
- Organise a phone chain or support team to check on your friend regularly
- Go for a walk together at their pace and a distance they choose

- Think about the little things your friend enjoys and that make life "normal" for them and find ways to help make these activities easier
- Make any difficult phone calls or gather information they may need
- Find ways to support if they want to fundraise



### What to say

I'm thinking about you.

What are you thinking of doing, and how can I help?

I know staying positive can be hard, how are you really?

I'm here for you if you want to talk.

I'm sorry you're going through this.

I care about you.

can't imagine how you feel.



What not to say!

I know exactly how you feel.

My aunt had that. She died.

Don't worry.

How long do you have?

I'm sure you'll be fine.

# Supporting a colleague with cancer at work

### **Employers and managers offering support**

Managers and employers play an important role in supporting people with cancer and their carers.

If a person has or has had cancer, they are protected by law from unfair treatment at work for the rest of their life. Under equality laws, managers and employers should try to support their employee to return to work.

Exploring making reasonable adjustments to the workplace or working pattern should involve the person with cancer.

# Simple first steps to support your employee could be to:

- Talk to them to understand their needs.
- Provide training for managers
- Check your policies are up to date
- Educate employees
- Raise awareness of cancer

# Supporting a colleague through cancer at work

People will deal with their diagnosis in different ways. Some people will choose to keep the diagnosis private, whereas others will be more open.

Supporting colleagues can be tricky. If it feels appropriate, discretely mentioning that you've noticed a change in them and telling them you are there to talk or support them, without any pressure to explain, is a good place to start. Talking about a cancer diagnosis is a very personal decision, and someone affected should have their wishes respected.

Equally, people will have different ways of working whilst having their treatment. Some people choose to keep working to retain a sense of purpose, whilst others may reduce their working hours or adopt a flexible working "as and when they feel well" policy. Many will stop working temporarily, choosing to concentrate on their treatment and recovery. Being aware of these issues means that you can support a colleague with cancer in a variety of ways, including; keeping them up-to-date with what is going on at work and, if they wish to, making adjustments to overcome side effects of treatment whilst at work.

For someone experiencing cancer, it is helpful for colleagues to be aware of possible side effects they may experience, which will be different

depending on their cancer, their level of fitness, and their treatment. The best source of this information is directly from the person with cancer themselves.

Macmillan offers <u>further</u> <u>training for employers</u> to offer support for people affected by cancer.



# Some of the side effects of a cancer diagnosis and treatment that can affect someone's work life include:

- "chemo fog"
- memory issues
- fatigue
- hair loss (including facial hair, eyebrows, eye lashes)
- loss of smell and/or taste
- nausea/vomiting

- hearing loss
- vision changes
- insomnia
- pain
- neuropathy
- hormonal issues
- toileting changes

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# **After treatment**

For some people, the end of treatment means they are not likely to need any more cancer treatment. For others, treatment is about managing life with cancer over a long period of time.

Many people feel relieved when their treatment ends. However, they may continue to experience side effects for some time.

# There will often be a package of follow-up care. This may consist of:

- Holistic Needs Assessment (HNA). A questionnaire to allow patients to rate their concerns, followed by a conversation about the answers
- Personalised Care and Support Plan. People living with cancer can take an active and empowered role in the way their care is planned and how their support needs are met, with interventions and care tailored around the things that matter most to them
- End of Treatment Summary. A document produced by the clinician at the end of cancer treatment, designed to be shared with the GP and the patient to aid in the delivery of the Cancer Care Review
- Health and well-being education, information and support

These are not standard practice in all hospitals, but gradually, more hospitals are doing them. They may happen formally or in some cases be more informal. Patients will always have the chance to talk to someone from their cancer team before their treatment ends.

Supporting someone after treatment is totally dependent on how they are affected, but it's a lot like helping someone experiencing cancer. Remember to listen carefully to their needs and be respectful of the support they require.

# **Palliative care**

Palliative care is treatment, care, and support for people with a life-limiting illness, plus their family and friends. It's sometimes called 'supportive care'.

Patients can receive palliative care at any stage in their illness. Having palliative care doesn't always mean that they're likely to die soon – some people receive palliative care for years. Patients can also have palliative care alongside treatments, therapies and medicines aimed at controlling their illness, such as chemotherapy or radiotherapy.

The aim of palliative care is to help patients to have a good quality of life – this includes being as well and active as possible in the time they have left.

### It can involve:

- Managing physical symptoms such as pain
- Emotional, spiritual and psychological support
- Social care, including help with things like washing, dressing or eating
- Support for family and friends
- Support with making a will/financial support

Someone receiving palliative care may require help with any of the above. Ask them what you can do to support their care.

# **End of life care**

End of life care involves treatment, care and support for people who are nearing the end of their life. It's an important part of palliative care.

It's for people who are thought to be in the last year of life, but this timeframe can be difficult to predict. Some people might only receive end of life care in their last weeks or days.

End of life care aims to help someone to live as comfortably as possible in the time they have left.



### End of life care includes:

- Managing physical symptoms
- Emotional support for family and friends
- Open discussions about what they expect at the end of life

# Depending on a person's condition, they may require help with practical or emotional tasks, including:

- Washing, dressing, eating, and using the toilet
- Taking medication
- Arranging home visits from healthcare professionals
- Planning visits with family and friends
- Offering reassurance, discussing worries and fears
- Taking care of finances, life admin, or pets

# Bereavement and grief

Bereavement, grief and loss can cause many different symptoms and they affect people in different ways. There is no right or wrong way to feel or deal with loss and grief.

As well as bereavement, there are other types of loss such as the end of a relationship or losing a job or home.

### Some of the most common symptoms include:

- Shock and numbness this is usually the first reaction to loss, and people often talk about "being in a daze"
- Overwhelming sadness, with lots of crying
- Tiredness or exhaustion
- Anger towards the person lost or the reason for a loss
- Guilt for example about feeling angry about something you said or did not say, or about not being able to stop them from dying



# Bereavement and grief

These feelings may not be there all the time and powerful feelings may appear unexpectedly.

It's not always easy to recognise when bereavement, grief or loss are the reason someone is acting or feeling differently.

# The stages of grief

Experts generally accept that we go through four stages of bereavement or grief:

- 1. Accepting that a loss is real
- 2. Experiencing the pain of grief
- 3. Adjusting to life without the person or thing lost
- 4. Putting less emotional energy into grieving and putting it into something new

Most people go through all these stages, but not everyone moves smoothly from one to the next. Grief can feel chaotic and out of control, but these feelings will eventually become less intense over time.



# Tips on how to support people through the grieving process:

- Talk about grief. It can help you and others in feeling less isolated when grieving
- Talk about the person; they are still part of your life
- Find ways to honour and remember the person who died. Start a new tradition that honours their memory
- Allow yourself to feel all of your feelings. Resentment and anger are normal
- Set realistic expectations. If you can't be sad when you've lost someone, when can you?
- Create boundaries with your time. If you need to take some time for you, then do it
- Practice self-care. Check-in with yourself on a regular basis and meet your own needs



The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same. Nor should you be the same nor would you want to.

### - Elizabeth Kubler Ross

# Reliable sources of information and support

## **Local support groups**

**The Humber and North Yorkshire Cancer Alliance** offers a tool for finding local support groups on its website.

**Yorkshire Cancer Community** offers impartial, independent information and a listening ear to those affected by cancer.

<u>Cancer Care Map</u> is a simple, online resource that aims to help you find cancer support services in your local area wherever you are in the UK. You can either search for a service or browse the types of services available.



# **Hospital-based support**

### **Hospital-based support**

Local hospital cancer support services are available not only for people with cancer to access, but also for people affected by a diagnosis (family, friends and work colleagues).

### **York and Scarborough Teaching Hospitals NHS Foundation Trust**

York Hospital – Cancer Care Centre – 01904 721166 Scarborough Hospital – Cancer Information and Support Service – 01723 342606

### **Hull University Teaching Hospitals NHS Trust**

Queens Centre Hull – Macmillan Information Centre 01482 461154 – Monday to Friday from 9.00am-5.00pm. No appointment needed, just drop in.

### **Northern Lincolnshire and Goole NHS Foundation Trust**

Northern Lincolnshire and Goole Macmillan Information Centres 03033 305372

Diana, Princess of Wales Hospital – Amethyst Suite Scunthorpe General Hospital – Ground Floor, Church Lane entrance Goole and District Hospital – Drop-in 10-12 every Friday

## **Cancer tumour specific support**

# National charities are a great source of tumour specific support and information.

- Breast Cancer Now
- <u>CoppaFeel!</u> (breast cancer awareness)
- Bowel Cancer UK
- Asthma + Lung UK
- Roy Castle Lung Cancer Foundation
- Prostate Cancer UK
- Testicular Cancer UK
- Oddballs Foundation (testicular cancer awareness)
- British Skin Foundation
- <u>Skcin</u>

- <u>Target Ovarian Cancer</u>
- Jo's Cervical Cancer Trust
- The Eve Appeal (gynaecological cancers)
- Pancreatic Cancer UK
- Orchid (fighting male cancer)
- Teenage Cancer Trust
- Young Lives vs Cancer (formerly CLIC Sargent cancer care for children)
- <u>Leukaemia UK</u>
- Fight bladder cancer
- Blood cancer UK

# Thank you!

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For more information, please visit **hnycanceralliance.org.uk** or if you have questions, email <a href="mailto:hny.cancerchampions@nhs.net">hny.cancerchampions@nhs.net</a>

