

The best cancer information for everyone

Cancerbackup has merged with Macmillan Cancer Support. We will be providing the same high-quality, expertly developed information about cancer, and now we can make it available to everyone who needs it.

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support, and push for better cancer care. One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

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

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Helping you cope with the
emotional effects of cancer



**WE ARE
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The best cancer
information
for everyone
from Cancerbackup
and Macmillan
Cancer Support

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MACMILLAN.
CANCER SUPPORT**



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This booklet is part of Macmillan Cancer Support's **Living with cancer** series. To order any of the series call **0800 500 800** or go to www.be.macmillan.org.uk. For more information about how Macmillan can help you, see page 41.

01

A diagnosis of cancer is a devastating experience for most people

When you are first told that you have cancer you may feel shocked, numb, and unable to believe what's going on. You may feel as though the situation is happening to someone else, and that you're watching yourself from the outside.

Cancer can have a huge effect on your emotions, as well as on the practical aspects of your life. You may experience shock, fear, anger, sadness or depression. These feelings may occur at the time of diagnosis, during treatment, or when you're recovering and adjusting to life after cancer treatment.

Many people feel lonely and isolated at times during their illness. Sometimes the loneliness is all too real. Your partner, family and friends may find it difficult to

cope – they may not know what to say, or how they can help. It may seem that they are distancing themselves from you. For many, the sense of isolation is made worse if they find it difficult to talk about how they feel and what they are going through.

Whatever your situation – whether it's you who has cancer, or a friend or relative, you don't have to face it alone. This booklet discusses the loneliness and isolation that may accompany cancer and suggests ways you can help yourself. It also tells you about other organisations which can provide help and support.



Cancer and your feelings

'Being told I had cancer was like someone had swiped the world from beneath my feet.'

Most people feel overwhelmed when they are told that they have cancer. Many different emotions arise, which can cause confusion and frequent mood swings. These emotions are part of the process that many people go through in dealing with their illness. Partners, family members and friends often have similar feelings and may also need support and guidance in coping with their feelings.

There's no right or wrong way to feel. Reactions vary and people have different emotions at different times.

Shock

Even if you thought your symptoms might be cancer, it's still a shock to be given the news. You may feel panicky, and that you can only take in a small amount of information, so you have to keep asking the same questions over and over again. You may need to be told the same bits of information repeatedly. This is a common reaction to shock.

Some people find that their feelings of disbelief make it difficult for them to talk about their illness with family and friends. Others may feel a strong urge to discuss it with those around them.

Anxiety

When you or someone close to you has been diagnosed with cancer, it's natural to worry about what will happen. Fear and anxiety are normal reactions to stressful situations and can feel very uncomfortable.

The fear and anxiety that occur with cancer may be there all of the time or may come and go. Sometimes the feelings can be very strong and difficult to cope with. You may find that you can't concentrate, are irritable and easily distracted, sleep badly and get tired easily.

Loss of control

One of the hardest things to cope with can be the feeling that cancer and its treatment have taken over your life and that you've lost control. This is a common feeling and is partly true, but over time, people usually find things they can do that help them to cope.

There may be times when you feel too tired and helpless even to think about what could help. It's not unusual to feel like this when you have cancer. You'll have good and bad days, and it's important for you and your family to realise this.

Anger and resentment

Understandably you may be very upset by many aspects of the illness. You may feel resentful that you or someone you care for has cancer while other people are well. These feelings are a common reaction when cancer is diagnosed and there's no need to feel guilty about having such thoughts or feelings.

Guilt

You might feel guilty and blame yourself (or someone else) for getting cancer. This may be because we often feel better if we know why something has happened. In most cases it's impossible to know exactly what has caused a person's cancer, so there's no reason for you to feel that anyone is to blame. Cancer isn't a punishment for something you have done.

Sorrow and sadness

It's common to feel sad after cancer has been diagnosed. The sadness may come and go, or may be present a lot of the time. There are often many changes to be made and you may feel grief as a result of these changes, and at the thought that your future may not be as you had planned.

Denial

Some people cope by carrying on as normally as possible and trying not to think or talk about the cancer and its impact on their lives. This is just another way of coping with the situation and can be a good way of dealing with

cancer for many people. If that's how you feel, you can say quite firmly to the people around you that you'd prefer not to talk about your situation, at least for the time being. It may be difficult for your family or friends to understand that you need some time to deal with what has happened.

However, continuing to avoid the situation may lead to problems later. In the long run, it can help you to acknowledge the changes the cancer has caused in your life, and think about what will help you cope with these changes.

Withdrawal

There may be times when you want to be left alone to sort out your thoughts and emotions. This is a very normal reaction for some people. However, if you find that you would rather be on your own for most of the time and often avoid talking to other people, this may be a sign that you are depressed. Sometimes depression can stop you wanting to talk.

There are different ways to help you manage depression – see page 30 for more information.

'I know that my family and friends worry about me, that I am not telling them everything, and this can sometimes make me feel pressured.'

Loneliness and isolation

'I was alone and not receiving any support whatsoever. Many people have partners to care for them but I had no-one at all. There was no-one there for me.'

One of the most common feelings people have is loneliness and a sense of being on their own. This isolation can affect people at different times in their illness – when they are diagnosed, during treatment and afterwards. Anyone affected by cancer may experience loneliness and isolation.

There can be many reasons why people feel alone. Coping with the feelings and changes cancer brings can be a lonely experience. Having to cope with changes to your appearance, such as losing your hair or losing weight, may add to the sense of isolation. Feeling different to other people can be very hard.

You may feel lonely even if you're surrounded by family, because you feel that no-one really understands what you're going through. People react differently. Some people respond by wanting to fight and

not let cancer 'take them over'; others allow the doctors to take control. Some people prefer to feel in charge of their own wellbeing and support themselves in a variety of ways. Everyone's different and there is no 'right' way of behaving.

Often the sense of isolation is made worse if you find it difficult to talk about how you feel and what you are going through. It can be hard to talk to friends and family about how you really feel; you tell them that you're fine, when you feel very different inside. You may find yourself giving people other reasons for not being yourself, such as, 'I'm just feeling tired'.

If you can find the courage to talk to just one person about how you feel, it can be the first step towards helping you to feel better. The less you talk about it, the more cancer may become all you think about. And the more alone you might feel.



Difficulties in talking

There are several reasons why it can be difficult to talk about cancer:

- you may not want to talk about it because you might get upset
- you may feel you shouldn't talk about it – it may be a taboo subject
- you don't know who to talk to, or who might understand
- you don't know how to talk about it or what people will want to know
- you don't want to upset other people, or to be a burden to them
- you might want to protect other people from the difficulties you are facing
- you're concerned about how other people will react; they might not want to talk about your illness or they might find your illness difficult to cope with, so they may keep their distance.

Losing control of your feelings:

How you feel may make you want to be alone and not talk. You may be unsure about how you will react when you talk to other people – you may be afraid that you will cry and not be able to stop. You may feel that you want to stay strong when you talk to people and that it's not good to cry.

A taboo subject: In the past, cancer was a taboo subject and many people felt that it shouldn't be discussed. But things have changed and now cancer is talked about much more. Many people have written or talked about their cancer experiences, and cancer is discussed in magazines, and on radio and TV.

Many people are aware of the improvements in cancer treatments and know that many cancers can be treated and cured. So it's perhaps not such a frightening subject as it used to be.

Will people understand?: You may worry that people will feel uncomfortable talking about cancer. Some people do find it difficult. Your friends and family

may feel that they ought to know what to say and yet have no idea. Sometimes, because people don't know what to say, they may avoid you altogether, and this can be hurtful.

Pretending things are OK:

Some people go into denial and pretend that the cancer is not happening. Again, this can be very upsetting when you need their support. Sometimes, after a while, their feelings will change and they will be able to talk to you. However, if they can't, you may have to accept that this is their way of dealing with things.

Lack of experience: Some people have no experience to help them in supporting and talking to you. They may not have had a serious illness themselves or not have known anyone else with one. They may be unsure of what you want and need, and not know how to ask you.

It's not your friends' or family's fault if they feel uncomfortable or unable to talk to you. It may just be that they find the subject very difficult and they are afraid of making things harder for you.

Fear of your reaction: Your friends or family may also be worried about how you will react if they bring up the subject of cancer. They may think that they won't know what to do if you cry or get upset.

It can be difficult to talk about cancer for all the reasons given above. But if you are open and talk about your situation and feelings, you can let people know what support you may need. You can learn to judge reactions, and see who is willing to talk to you and able to be supportive.

You and your partner

If you have a partner, a cancer diagnosis may cause your relationship to change. The effect on your relationship can depend on the level of commitment between you, how long you've been together, how long you have been living with the diagnosis and how it affects your day-to-day life.

When someone has an illness that affects their relationship, it can help to think about what things were like before. If the relationship was difficult before the cancer was diagnosed, it probably won't be any better after the diagnosis. However, some couples come to a new understanding and love for one another as a result of overcoming a shared challenge like cancer.

Communication plays a big part in any relationship. When someone is diagnosed with cancer, both they and their partner will experience a range of different emotions. Talking about the illness and the impact it's having can be an important way to help you both cope with it. But remember, you or your partner might not always want, or feel able, to talk.

'My husband couldn't cope at all... he pretended it wasn't happening.'

If you live alone

If you live by yourself, you can feel even more alone and unsure of who to turn to. You may have many concerns. You might have practical things to sort out, like who will look after your pet when you are in hospital, or who will care for you at home, as well as who'll be there to support you.

Some people have busy lives, and family and friends close by. But if you don't have people near, it may be hard to know where to get help. You may like to join a cancer support group where you can meet with other people in a similar situation (see 'Support groups' on page 14).

Cancer often causes people to think about their lives and their priorities. Some people make significant changes to their lives, such as changing their job. It may be a good time to think about joining a local hobby group so you can meet people. Doing something new may also help you feel better.

The internet is becoming a common way of socialising, keeping in touch and making new friends. There are a number of internet-based groups for people affected by cancer (see 'Internet support' on page 15).

Young people

Cancer in young people is uncommon. It can be difficult to meet other people who have been through it. It can also be difficult for friends and family to know what it is like to have cancer if they haven't been through it themselves.

This can make you feel lonely and as if no-one understands what you are going through. It's worth remembering your friends may be frightened by the news of your illness and not know how best to respond. There are groups, especially on the internet, specifically for teenagers with cancer, where you can get support and information.

The benefits of talking

It can be so difficult to talk about cancer that you may think, 'Why should I bother?' Why is it worth talking about what's going on if it makes you and your friends feel uncomfortable?

Talking can help you cope with the uncertainties or difficulties that may lie ahead. It can give you support, and help you have some control over your situation.

Generally, people often get comfort from talking to each other. Discussing fears or concerns can help put them into perspective. Sometimes, you may find it difficult to make decisions or know how you feel. Talking about it can help.

Talking about a fear or a worry often stops it from growing in our minds. If we're thinking about something all the time, the worry just gets bigger and bigger. Once the fear is out in the open and being discussed, this process often stops.

Also, talking about something important or personal produces a bond between people. This is valuable in itself and can help you feel appreciated and supported.

Who can you talk to?

Some people have a close circle of friends and family that can give them a lot of support. Others don't have many people to support them. But even with a supportive family and a wide circle of friends, it can, at times, be difficult to talk about cancer. There can be a deep feeling of isolation and a sense that only people who have experienced cancer themselves can understand your thoughts and feelings.

Family and friends: Family and friends who you trust and feel safe with are the people you're likely to feel comfortable talking to. They know you best and may have been through difficult things with you in the past, so can hopefully give you the support that you need.

However, sometimes people with cancer find it difficult to talk to close family or friends, and find it easier to speak to someone they don't know so well.

Organisations and counselling:

If you can't find anyone to talk to, you can contact one of the organisations listed at the back of this booklet (see page 46). You can also ask your doctor or nurse, or someone else in your medical team, to tell you about any counselling services available.

Support groups: Most areas have cancer support groups. Sometimes these groups are led by a healthcare professional. Other members of the group may be in a similar position to you, or they may not. It's quite usual for a group to include people with different types of cancer at different stages. You may find this wider experience helps you to see your own problems from a different perspective. See page 43 for information about how to find a support group in your area.

Internet support: There are a number of internet groups for various cancers. You can 'chat' online (anonymously) or, if you prefer, just read other people's entries. This can be very supportive, and help ease feelings of isolation. Other people's experiences can help you learn how to cope with the treatment and how to live with cancer.

Internet groups, such as Macmillan's Share discussion forum www.macmillan.org.uk/share, are easy to join and also easy to leave, without any need for personal contact or explanations.

We also have a cancer social network called What Now? www.whatnow.org.uk where people affected by cancer can chat to each other online. You can also write blogs, upload and share photos, share videos and recipes and organise events.

'For me, on Share, I didn't feel alone anymore. I could talk to people in exactly the same position as me. I could also be very open and say I'm tired of worrying and that I'm scared. Outside of Share, I had to be the strong one.'

'With What Now? you have created a fab place for people like me to find reassurance even on the darkest days.'



How to talk

'I personally found it very hard to talk openly about things to friends and family, especially to my father-in-law and mother-in-law.'

How you talk to people about your cancer will depend very much on your own personality and how you usually talk to the people around you. When you have identified people who can help and support you, you can try the following:

- at first, just talk about day-to-day things if you want to. Simply because you have been affected by cancer doesn't mean you're not allowed to talk about anything else. Talking about everyday things may help you feel more comfortable about discussing difficult topics later
- if you've been worrying about something a lot, it is good to say so. This lets the person listening to you know how important the issue is to you
- when you're talking, it's a good idea to check every now and then that the other person understands what you are saying
- towards the end of the conversation, it may help to summarise what you've said, especially if you've decided on a particular course of action, or you've asked for help with something.

Humour

If joking about things has been part of the way you have coped with frightening things in the past, it might help you now. Humour has to be used carefully, but it can be a good way of coping with difficult issues – it can help to make situations less frightening.

- it will help to tell the person that you want to talk about your cancer experience and how you feel
- you could start talking about awkward subjects by saying something general, perhaps about how worried you are generally; and then it's easier to talk about something more specific, such as your uncertainty about what the future holds

How are you feeling?

Listening

Listening is an important part of communication – we all like to feel we've been heard, especially when talking about a serious issue. Making sure you're comfortable and that you have enough time is important. Don't be afraid to express your feelings and concerns. It's quite normal to be sad and upset – this is a natural reaction to bad news.

Silences need not be awkward as they give you a chance to focus your thoughts. And remember that touch can sometimes express what you mean more than words.

There is no 'magic formula' or 'right thing' to say. Listening and talking will help you both understand, as much as you can, what the other person is feeling. The more you understand each other, the better the communication will be.



'I soon found out who my friends were. Some people just couldn't cope and ignored me..., while others I hardly knew offered all sorts of help.'

Uncertainty

'When I was first diagnosed with breast cancer I thought I was going to die within months because no-one explained the concept of "living with cancer" to me at the time – this was something I had to find out for myself.'

Cancer can lead to uncertainty in many areas of your life. Feeling that we have some control over our lives gives us a sense of security and allows us to enjoy things that we do. It's natural to want to know what's likely to happen to us, so that we can plan for our future.

Often it's difficult to know whether treatment will be successful and whether the cancer can be cured. Even after the treatment has ended, you may still be left wondering whether it will come back. This uncertainty can make it very difficult to plan ahead and you may wish that you could know for sure what will happen.

When cancer is diagnosed, it can take away your sense of security and control and this can be very frightening. Uncertainty can be one of the hardest things to deal with and can cause a lot of tension. You may find that you feel irritable, angry and frightened.

Sometimes, it can help to find out as much as possible about the illness and what may happen. It is best to discuss this with the doctors and nurses who know your situation and are involved in the treatment.

You may find that your doctors and nurses can't answer your questions fully or that their answers sound vague. Many people find this uncertainty very hard to live with.

Taking control of your situation

'I am pleased with the help I received and feel more in control of the situation as a cancer patient.'

Finding out about the cancer and its treatment can help give you back some feeling of control and help you to feel more confident about the future. You can ask your doctor or nurse to tell you about your cancer and its treatment, or you can get information from some of the organisations listed on page 46.

Reliable sources of information

Sometimes, it's difficult to get all the information that you need from your doctor or nurses. Your own healthcare team is in the best position to help you and answer your questions, because they have the most information about your situation.

However, there are lots of other sources of support and information. It's important to get information from a reliable source, as many people still believe myths about cancer.

You can get reliable information from the organisations listed on page 46. These organisations often provide helplines, booklets, videos and audiotapes.

Some people want to know everything possible about the illness. This understanding can increase their confidence and can also help them during talks with their doctor, as well as with family and friends. With more information, some people feel more involved in their care, and, therefore, they feel more in control generally.

If you can tell your healthcare team what you really think and feel, this can help them to understand the issues that are important to you.



Self help

'I felt very alone and even though family and friends were incredibly kind, I was unable to share all my feelings with them. It was at the Macmillan information centre that they suggested I have some counselling. I had five sessions with Don. He taught me about the nature of fatigue and how I should allow for it into my daily life.'

There are lots of things you can do that will help you to feel less alone and more able to cope with the cancer and its effects.

When you're living with cancer, it's important to look after yourself:

- eat well every day
- if you feel unwell, get some extra rest and don't put off seeing your doctor
- accept offers of help or turn to others for help
- keep to a regular sleeping pattern if you can
- try to have some regular

exercise; it can help you relax and boost your energy

- try to share your feelings
- try to keep your social life active by staying in contact with your friends
- recognise when you are feeling 'run down' and stressed (headaches, trouble sleeping, tummy upsets, and colds that don't go away) and see your doctor for advice.



If you can, try to make plans to do things you enjoy. You could try to book things a few weeks ahead – this will give you something to look forward to.

Some people find that they lose motivation and begin to limit the amount that they do – this of course can add to the feeling of being alone. If you want to be on your own, it helps if the rooms you are in are light and airy. Try not to sit still in one place for long periods of time. Listening to music or radio programmes may also help you feel better.

It can help to know that your feelings are a common reaction to cancer and its treatment.

Releasing tension

Sometimes, you may feel as if it is all getting too much for you, and you need to let off steam before you explode. If this happens, try thumping a cushion or pillow, turning the radio or CD player up very loud, or screaming. Exercise can help release pent-up tension, even gentle exercise such as walking. Having a good cry can also help to release emotions.

These will not do anyone any harm and they may leave you feeling much better. Some people find that it helps to write down how they feel. Keeping a diary or journal may be a way of allowing you to express your fears and worries, without having to talk them through with other people.

Complementary therapies

People often speak of feeling that they have lost control of their life when they have cancer. Anyone affected by cancer may experience strong emotions at times. A complementary therapist who listens and cares may help you cope with some of those difficult feelings, which can be an effective way of getting back some control.

Complementary therapists usually work with the person as a whole. This is called a holistic approach. Some hospitals and hospices provide complementary therapies alongside conventional cancer treatments, such as chemotherapy or radiotherapy.

Complementary therapies may:

- help you feel better and improve your quality of life
- improve your general health
- give you a sense of control over what is happening to you
- reduce stress, tension, sleeplessness, anxiety and depression, and make you feel more relaxed
- help to reduce the symptoms of cancer, such as pain, feeling sick, breathlessness, constipation, diarrhoea, tiredness and poor appetite
- help to reduce some of the side effects of cancer treatment.

Self help groups

Joining a self help group can give you many benefits. However, not everyone finds talking in a group

easy. It might help to go along to see what the group is like and then make a decision.

Self help and support groups offer a chance to talk to other people who may be in a similar situation and facing the same challenges (see page 43 for more information).

Alcohol and recreational drugs

It may feel good at first to have a few drinks or try some recreational drugs to help you forget how you may be feeling. However, this is only a short-term solution. Too much alcohol can cause problems and damage relationships with family and friends, which are particularly important at this time.

Taking recreational drugs may make you feel better for a short time, but can seriously damage your health in the long term.

'Men come to our group devastated, but what they soon realise is that everyone around them is in the same boat. The change you see after a few meetings is incredible. Speaking about their illnesses to others takes them from negative to positive.'

Depression

'I feel frustrated... and tired and sometimes I don't feel like doing anything.'

Depression may be triggered by the diagnosis of cancer, other issues related to the cancer or its treatment, or the impact of the cancer on a person's life.

Depression can develop slowly, making it very difficult for either you or your family to recognise when it started. In other cases, it can seem to hit you suddenly – one day you wake up and realise that you feel hopeless and helpless and are engulfed in a 'black cloud' of depression.

Depression is not a sign of personal failure or inability to cope. It can usually be successfully treated when it occurs. The first step to feeling better is getting appropriate help.

When you're feeling alone and that no-one understands, you can feel low, confused and frightened. It's not unusual to have times when you feel very low. However, for some people affected by cancer, their low mood may continue or get worse and they may need

specialist help or treatment. Some people find that their sadness and loneliness gives way to a situation where their mood is low most of the time for several weeks or more, and they are depressed.

Some of the symptoms of depression are:

- waking up early, having difficulty sleeping, or sleeping more
- smoking or drinking more alcohol than usual
- crying a lot
- having difficulty remembering things
- feeling low-spirited for much of the time, every day
- being unusually irritable or impatient
- getting no pleasure out of life or what you usually enjoy
- feeling a loss of affection or desire to make love
- finding it hard to concentrate or make decisions.



Depression can also cause physical symptoms, such as tiredness, loss or increase of appetite and physical aches and pains, though these can also be caused by the illness and its treatment.

Loss of self-esteem

You may feel as though you have lost your independence and no longer have control over your life. It may also seem as though things you used to do and find easy are now much more difficult. This might cause you to lose some confidence in yourself.

Fatigue

Fatigue is very common in people who are anxious or depressed. If your tiredness is due to anxiety or depression, some of the self-help ideas listed here may help you to feel less tired.

Dealing with depression

There's no need for you to feel guilty about feeling depressed or not feeling positive all the time. There are things you can do to help yourself. If you think you need professional help, you can talk to

your doctor or nurse. They may refer you to a specialist or may prescribe medication.

There are organisations that deal with depression and they will have more information. See page 46 for more details.

Antidepressant medicine:

Some people will be prescribed an antidepressant to help lift their mood. It's thought that antidepressants work by affecting certain chemicals in the brain. They work slowly, so you will not usually notice any improvement in your symptoms until about two weeks after you start treatment.

Antidepressants are not addictive, and most people only need to take them for about six months to help them through their depression. Like all other medicines, antidepressants have side effects. However, these are usually mild, and tend to be more of a problem during the first few weeks of treatment.

St John's Wort: St John's Wort is a herbal treatment, which some research has shown to be effective in treating depression for some people. It may cause fewer side effects than antidepressants. Other research has shown that it is not as effective. You should talk to your doctor if you plan to try taking St John's Wort as it can react with other medicines. As with other treatments for depression, it may take several weeks to get the full benefits.

Referral to a psychiatrist or clinical psychologist:

If you are very depressed, you may find it helpful to be referred to a psychiatrist or clinical psychologist. They have special expertise in helping people who are depressed.

Although recovery from depression may seem unlikely when you are depressed, remember that it won't continue forever. Even if you have no treatment, there's a good chance that eventually your mood will improve. Self help suggestions, talking therapies or antidepressant medication can all help to speed up your recovery.

Sleep problems

Many people have trouble sleeping at some time. This may be because of general anxiety, worry about treatment or fears about the future. Actually getting to sleep may be the most difficult part. Some of the suggestions here may help you to get a better night's sleep:

- try to establish a regular routine at bedtime and go to bed at the same time each night
- try a warm milky drink before bed
- have a warm bath with a few drops of lavender or geranium oil to soothe you, or sprinkle a couple of drops of lavender oil on your pillow
- if you can't sleep, or wake up early, don't try so hard to sleep; instead, try to relax and rest your body. You could listen to music or the radio, watch TV or read a book
- relaxation tapes, or audio tapes with stories, are also very useful for helping you get to sleep.

Professional help

'I was struggling to cope and the support worker helped me through. She is very understanding and I felt that I had a friend and a counsellor and an expert in a situation that I found extremely hard to cope with.'

If you find that your feelings and emotions are overwhelming and are stopping you from being able to carry on normally with your life, or if you are becoming depressed, then it may be time to get professional help.

Working with your GP and healthcare team

Appointments are usually short, so try to plan what you want to say before you see the doctor. It can help to write things down before the appointment. When you are with the doctor, try to tell them how you really feel – focus on what concerns you most of all. This will help your doctor to give the most helpful advice or treatment for you.

Consider taking a friend or partner along to help remind you of everything you want to discuss. Taking someone along with you

also means that they can remind you what the doctor said. Some GPs are happy for the discussion to be recorded, so you can listen to it later.

Many people find that during their treatment they get a lot of support from the hospital team looking after them. People who are having treatment for cancer will often be assigned a clinical nurse specialist. These specialist nurses are often the point of contact at the hospital. They can provide further information and support to people with cancer and their families.

They will often help with all sorts of other concerns, like worries over holidays, finances, or work, which people may feel they can't talk about with their consultant. They are likely to have details of local support groups and other organisations that may be able to help.

There are many other members of the wider healthcare team who may be able to help you cope with your feelings and emotions. Each has a different role to play, but usually you will only need the help of one or two:

Counsellors: Trained to listen and help people talk through their problems. They will not give advice or provide answers, but will help you find your own answers. This can be very helpful, particularly if you don't feel able to discuss your feelings and emotions with people close to you.

Clinical psychologists: Trained to understand what people think and feel, and how they behave, particularly in stressful situations, such as coping with cancer. If you're depressed or anxious, a clinical psychologist can help you reduce distress by changing your ways of thinking or the things that you do to help you to feel better.

Talking therapies

There are many different types of talking therapy available, including psychological therapy and counselling. These have all been shown to benefit people who have anxiety or depression, and can be useful for people affected by cancer. Although a few specific types of talking therapies are mentioned here, there are many others to choose from:

Counselling: Many people can get support by talking to close family members or friends. However, it can sometimes help to talk to someone from outside your circle of family and friends, who has been trained to listen and help you explore your feelings. The emotions you feel may be very tangled and confused. You may find them difficult to talk about with your friends or family.

Talking one-to-one with a trained counsellor in a more focused way, can help you sort out your feelings and find ways of coping with them. Some GPs have counsellors within their practice, or they can refer you to a counsellor. You may need to pay for counselling.

Group therapy: You may be given the opportunity to take part in group therapy. A trained therapist (counsellor or other professional) encourages a group of individuals to share their feelings and experiences with each other.

Problem-solving therapy: When people feel that they are not coping well with life or circumstances, they can feel anxious and depressed. It can be hard to believe that things can change or that there's anything that they can do that may help. One way of learning to cope better is using a method called problem solving.

The therapist will help you list all your concerns and difficulties. Together, you will choose one problem to work on. They will then help you to think of your own ways of solving the problem and look at all the pros and cons of each solution. In the time between sessions you will be encouraged to try out a solution of your choice. This is an important part of the treatment. Satisfaction in achieving your goal is the beginning of overcoming the bigger problems.

Cognitive behavioural therapy (CBT): The way we think about things – ourselves, our world, the future – has a powerful effect on how we feel. People who are anxious or depressed often have negative patterns of thinking and behaviour, which keep them feeling low in spirit. Cognitive behavioural therapy is designed to break this cycle.

When people are depressed, they often stop doing the things they used to enjoy. This loss of pleasurable activities adds to depression. Part of the treatment is designed to help you find out what you can do that gives you a sense of satisfaction and pleasure.

Even when nothing else changes, the way you think about things can affect how you feel. The therapist will help you recognise the negative thoughts that are making you feel low, and will help you find effective ways to challenge them.

Being positive

'I was diagnosed with endometrial cancer two years ago. It has been a life-changing experience but there have been positives: I have a new outlook on life, I try not to get stressed over minor things, I relax more and appreciate life.'

Many people affected by cancer feel that they should 'be positive'. If you or someone you know has been diagnosed with cancer, you may be advised by other people to 'think positively'. However, it's not always easy – a lot of people have periods of feeling low at some time in their lives.

What is being positive?

Positive thinking means different things to different people. However, generally it's about facing up to the situation, and finding ways of coping with it. People do this in different ways. What works for one person may not work for another.

When you talk to people who have cancer, even the most positive of them will admit to low times when they felt depressed and anxious. No-one can be positive 100% of the time. It's important that you don't feel that

you must always stay on top of things. Being positive doesn't mean having to feel happy and cheerful all the time. It's a positive thing to acknowledge and talk about your feelings – even when you're feeling tired, worried, depressed or angry.

There may be times when you want to talk about a difficult topic, like the chance of the cancer being cured or making a Will. At such times, comments about being positive are then not always helpful – in fact, they can be very upsetting.

The impact of cancer on life

A diagnosis of cancer means you'll have to deal with issues and situations that may be very frightening and challenging. When life feels uncertain, it can help to talk things through – both your hopes and your fears.



Fears and thoughts surrounding cancer include:

- cancer can be a life-threatening disease
- you may lose some independence and freedom
- you may lose friends who can't face up to the illness
- you may lose important work contacts
- you may have to make big changes to your life.

These are very real concerns and will obviously have an effect on you, and those close to you. It is OK to worry about and be upset by them. And it is OK to cry and say how you feel when things get tough. Crying is a natural response to distress, and not a sign of weakness. It can be a very important release and often you will feel better afterwards.

Do my feelings affect my cancer?

Feeling sad or having negative feelings doesn't delay a person's recovery from treatment, make the cancer grow faster, or make it more likely to come back.

Research studies have tried to find out whether 'positive thinking' can make treatment more successful or prevent cancer coming back. This is a very difficult issue to research and studies have shown different results.

Although cancer may be influenced by our thoughts, feelings and attitudes, the process is not well understood. There's no convincing evidence that 'positive thinking' can make treatments more effective or prevent cancer coming back. And it's important to remember that cancer is also influenced by other things, such as our environment, diet, and our genetic and physical make-up.

However you feel, it's important that you are able to talk honestly, and cry if you need to. This can help to release tension and stress and can even bring you closer to the person you are talking to. It is important to remember that all feelings and thoughts pass, and you'll feel better at some time in the future.

If you find it hard to talk openly to people in your family it may help to find someone from outside to talk to, such as one of our nurses, the specialist nurse at the hospital, a counsellor, or one of the organisations listed on page 46.

'My father was initially reluctant to open up, but I saw what a difference it made when his Macmillan nurse got him to talk about his feelings and ask questions that he couldn't ask his family.'

You are not alone

On the following pages we have listed resources, organisations and groups that can help you to cope with any feelings of loneliness and isolation that may accompany your cancer diagnosis, treatment and beyond.

These support networks mean that you do not have to go through this experience alone. Indeed, however low you get and however isolated or lonely you may feel, it is important to remember that you are not alone.

Macmillan services

Concerns or questions about living with cancer?

We can provide you with emotional and practical help, and put you in touch with other sources of support. Call our freephone on **0808 808 2020** (Monday to Friday 9am-9pm). If you are deaf or hard of hearing, you can use textphone **0808 808 0121**, or RNID Typetalk.

We have dedicated phonelines for Hindi, Urdu and Punjabi speakers, and interpreting services are available for other languages (see next page).

You can also email us for emotional and practical support at cancerline@macmillan.org.uk

Questions about cancer types, treatments or what to expect?

Call our cancer information nurse specialists on freephone **0808 800 1234** (Monday to Friday 9am-8pm). They can help you with up-to-date information on diagnosis, symptoms, treatments, clinical trials and more. If you are deaf or hard of hearing, you can use textphone **18001 0808 800 1234**, or RNID Typetalk.

Interpreters are available in over 200 languages.

You can also email a question, using the form 'Email a Nurse' on www.cancerbackup.org.uk

Prefer to communicate in a language other than English?

We have dedicated Hindi, Urdu and Punjabi speakers who can offer **emotional and practical support** for people living with cancer. Please call:

Hindi - 0808 808 0100

Punjabi - 0808 808 0101

Urdu - 0808 808 0102

For cancer information in other languages you can also call our team of **specialist nurses** using a dedicated freephone number listed below. For information and support in languages not listed here, please call **0808 800 1234** and ask for an interpreter.

Arabic - 0808 800 0130
 Bengali - 0808 800 0131
 Cantonese - 0808 800 0132
 French - 0808 800 0133
 Greek - 0808 800 0134
 Gujarati - 0808 800 0135
 Hindi - 0808 800 0136
 Polish - 0808 800 0137
 Punjabi - 0808 800 0138
 Turkish - 0808 800 0139
 Urdu - 0808 800 0140
 Vietnamese - 0808 800 0141

Please note we can only give information about healthcare and support services available in the UK.

Are you a young person affected by cancer?

If you are between 12 and 21 years old and have any questions or concerns about cancer then call the free Macmillan YouthLine on **0808 808 0800** (Monday to Friday 9am-9pm). Find out more

about the Youthline by visiting www.macmillan.org.uk/youthline

You can also:

- email: youthline@macmillan.org.uk
- find out more on the 'Why bother?' website for young people concerned about cancer (www.whybother.org.uk) and the 'Teen Info in cancer' website for teenagers with cancer (www.click4tic.org.uk)

If you are a teacher please see our 'CancerTalk' website www.cancertalk.org.uk

Need out-of-hours support?

All our phone lines are open Monday to Friday, but hours vary.

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

The following organisations can offer immediate information and support:

NHS Direct
 0845 4647
www.nhsdirect.nhs.uk

NHS Scotland
 0845 242 424
www.nhs24.com/content

The Samaritans
 0845 790 9090
www.samaritans.org.uk

Want to talk to others in a similar situation? You can:

Meet people online

Thousands of people meet every day to support each other, make new friends and share experiences in our online communities. Visit our online discussion forum at 'Share' (www.macmillan.org.uk/share), or chat to people, read blogs and view videos on 'What Now?' (www.whatnow.org.uk).

Find support face-to-face

At our local cancer information centres trained staff can answer your questions about cancer. Our centres also hold booklets, leaflets, videos and other sources of information about cancer. To find your nearest centre, call **0800 500 800** or visit www.macmillan.org.uk/map type in your postcode or town and click 'search'.

Join a cancer self help and support group

We support over 800 independent cancer self help and support groups and organisations across the UK. By joining a group you can spend time with people who share and understand your experience, or who have dealt with it in the past. This simple act of sharing can make an enormous difference to the way you feel.

To find your nearest support group, visit www.macmillan.org.uk/selfhelpandsupport, or call us on **0800 500 800**. We also publish a directory of cancer self help and support groups. You can order this by calling **0800 500 800**, or on our website www.be.macmillan.org.uk

Macmillan publications

Cancerbackup and Macmillan have merged, so we now offer a wider range of booklets and leaflets. You can view these at www.be.macmillan.org.uk. You can order the materials from this website or by calling **0800 500 800**. You can also order Macmillan publications,

and search for other cancer publications, at

www.macmillan.org.uk/publications

Cancer Voices

Cancer Voices are people affected by cancer who choose to use their experience to improve cancer services. They are involved in a wide range of activities with various organisations, including Macmillan.

These activities include: reviewing leaflets; supporting other people affected by cancer; helping to plan activities and sitting on policymaking groups.

To find out more about Cancer Voices go to www.macmillan.org.uk/cancervoices, or email cancervoices@macmillan.org.uk. You can also call 0800 500 800.

Macmillan training courses

Macmillan offers a range of free training and development opportunities for people affected by cancer. You can find out more at www.learnzone.macmillan.org.uk

Living with Cancer Course:

A six-week course for people affected by cancer, run by people who have had cancer themselves. The course can help people regain their confidence and enjoy a better quality of life.

Cancer Support Course:

An accredited course for those supporting people living with cancer, focusing on the skills they need. The course, which lasts one year, is split into five units:

- Effective communication skills to support people affected by cancer
- Introduction to counselling skills
- Working with loss and bereavement
- Cancer awareness
- Health and wellbeing

In addition, there are three more units which can be taken as options:

- Support for people affected by cancer
- Good practice for cancer support groups
- Skills for user involvement

Macmillan workshops

Macmillan runs a number of one- and two-day workshops that help people affected by cancer develop themselves and their coping skills.

Be good to yourself:

A one-day workshop that gives you a taste of the different ways in which you can look after yourself physically and emotionally when you are affected by cancer.

Listening and responding:

Develop your listening skills so you can support people affected by cancer.

Relaxation and visualisation:

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

Close relationships and cancer:

Find out how cancer affects relationships and develop strategies for changing and

improving relationships that have been affected by cancer.

Cancer and its treatments:

Increase your knowledge of cancer and its treatments in order to be able to support others who are affected by cancer.

Making a difference workshops:

These one-day workshops are for people who have experienced cancer and want to use this experience to influence and improve cancer care.

Macmillan can also provide training around interpersonal skills, which covers topics such as Assertiveness and Dealing with anger.

For further information about the above courses, call the training administrator on 020 7091 2010 or email workshops@macmillan.org.uk

'I feel that since coming on the course I can try and be more positive about my illness. I feel that I am not alone anymore.'

Attendee at Living with Cancer Course, June 2008

Useful organisations

British Association for Counselling and Psychotherapy

BACP House
15 St John's Business Park
Lutterworth
Leicester LE17 4HB
Tel: 01455 883300
Email: bacp@bacp.co.uk
www.bacp.co.uk

Aims to promote awareness of counselling and increase availability. Can refer people to a local counsellor, and there is also a searchable list on their website. They can also provide an information sheet for those seeking help.

British Complementary Medicine Association

PO Box 5122
Bournemouth BH8 0WG
Tel: 0845 345 5977
Email: office@bcma.co.uk
www.bcma.co.uk

Has a code of conduct, and a list of registered practitioners who belong to member organisations. Can provide practitioners' telephone numbers.

Cancer Counselling Trust

1 Noel Road
London N1 8HQ
Tel: 020 7704 1137
Email: support@cctrust.org.uk
www.cancercounselling.org.uk

Qualified counsellors and psychotherapists offer free, confidential counselling to cancer patients, as well as couples or families affected by cancer.

Face-to-face counselling is provided at the London office, and phone counselling is available for people unable to visit. Although counselling is free, donations are welcomed if people are able to do so.

Cruse Bereavement Care

PO Box 800
Richmond
Surrey TW9 1RG
Helpline: 0844 477 9400
(Monday to Friday, 9.30am-5pm)
Helpline email:
helpline@cruse.org.uk
Young person's freephone helpline: 0808 808 1677
Young person's helpline email:
info@rd4u.org.uk
www.crusebereavementcare.org.uk

Provides bereavement counselling, help, information and support to anyone who has been bereaved. Has a network of branches across the UK.

Cruse Bereavement Care Scotland

Riverview House
Friarton Road
Perth PH2 8DF
Tel: 01738 444 178
Email: info@crusescotland.org.uk
www.crusescotland.org.uk

Exists to promote the wellbeing of bereaved people and to enable anyone bereaved by death to understand their grief and cope with their loss. The organisation provides counselling and support through branches located in all parts of Scotland.

Depression Alliance

212 Spiffire Studios
63-71 Collier Street
London N1 9BE
Tel: 0845 123 2320
Email: information@depressionalliance.org
www.depressionalliance.org

Supports people with depression. Has a national network of self help groups and a range of free publications which offer advice and information on depression and related topics.

Depression Alliance Scotland

11 Alva Street
Edinburgh EH2 4PH
Tel: 0845 123 2320 (Weekdays
10am-2pm except Wednesdays)
Email: info@dascot.org
www.dascot.org

Depression Alliance Scotland is a national charity for people with depression in Scotland. They provide information, support and understanding to those affected by, and working with, depression. They offer a network of self help groups where people with depression can share their experiences and coping strategies with others, as well as an information service by phone, post and email.

Journeys

120-122 Broadway

Roath

Cardiff CF24 2NJ

Tel: 02920 692 891

www.journeysonline.org.uk

Journeys (formerly the Depression Alliance Cymru) is the only organisation with the sole purpose of supporting people affected by depression in Wales, and their family and friends. The charity takes a holistic approach to overcoming depression through guided self help, building the foundations for sustainable and long-term wellbeing.

Journeys provides information, practical resources, services and training that promote the development of skills and strategies to help people find their own route to recovery. They also coordinate a network of self help groups.

MIND (National Association for Mental Health)

15-19 Broadway

London E15 4BQ

Tel: 020 8519 2122

Fax: 020 8522 1725

Information line: 0845 766 0163

Email: contact@mind.org.uk
www.mind.org.uk

MIND works for a better life for everyone with experience of mental distress. They provide information on all aspects of mental health, including legal matters, to service users, carers, family and friends, service providers and the public. MIND also campaigns for greater understanding in the wider community and offers mental health services through a network of local MIND associations.

Royal College of Psychiatrists

17 Belgrave Square

London SW1X 8PG

Tel: 020 7235 2351

The professional and educational body for psychiatrists in the UK and the Republic of Ireland. Produces information leaflets for the public which can be downloaded from the website at www.rcpsych.ac.uk/mentalhealthinformation.aspx

Samaritans

Tel: 0845 790 9090

Email: jo@samaritans.org

Write to: 'Chris' at PO Box 9090, Stirling, FK8 2SA

www.samaritans.org.uk

Confidential emotional support from trained volunteers for people in emotional crisis, not only those who are suicidal. Available 24-hours a day, seven days a week.

Saneline

Tel: 0845 767 8000 (Seven days a week, 6-11pm)

Email: sanemail@sane.org.uk
www.sane.org.uk

Helpline offering information and advice on all aspects of mental health for people with mental illness, or their families or friends.

Scottish Association for Mental Health

Cumbræ House

15 Carlton Court

Glasgow G5 9JP

Tel: 0141 568 7000

Email: enquire@samh.org.uk
www.samh.org.uk

Support, information and advice on various aspects of mental health.

Youth Access

1-2 Taylors Yard

67 Alderbrook Road

London SW12 8AD

Tel: 020 8772 9900

Fax: 020 8772 9746

Email: admin@youthaccess.org.uk
www.youthaccess.org.uk

An information and counselling service for young people. Provides referral to local services including information, advice, counselling and support.

General cancer organisations

Irish Cancer Society

43-45 Northumberland Road
Dublin 4
Ireland

Cancer helpline: 1 800 200 700
(Weekdays 9am-5pm, Tuesdays
9am-9pm)

Email: helpline@irishcancer.ie
www.cancer.ie

Operates Ireland's only freephone cancer helpline, which is staffed by qualified nurses trained in cancer care.

Maggie's Centres

The Stables
Western General Hospital
Crewe Road South
Edinburgh EH4 2XU

Tel: 0131 537 3131

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

maggiescentres.org

www.maggiescentres.org

For anyone affected by cancer.

The aim of Maggie's Centres is to help people with cancer to be as healthy in mind and body as possible and enable them to make their own contribution to their medical treatment and recovery.

Maggie's programme of support is designed to give people the tools they need to cope with the major upheaval cancer causes in their lives. All services are free of charge and work in partnership with local NHS Trusts. Maggie's Centres can be found in the following locations: London, Edinburgh, Dundee, Highlands (Inverness), Fife (Kirkcaldy), Oxford and South West Wales (Swansea), with many more centres planned throughout the country.

Penny Brohn Cancer Care

Chapel Pill Lane

Pill

Bristol BS20 0HH

Tel: 0845 123 2310

Tel (Switchboard): 01275 370 100

Email: helpline@pennybrohn.org

www.pennybrohncancercare.org

Penny Brohn Cancer Care

(formerly Bristol Cancer Help

Centre) provides complementary

care, The Bristol Approach, to

people with cancer and their loved

ones. Working alongside medical

treatment, this complementary

approach attempts to transform

lives, giving people practical tools

to improve their daily quality of life and helping to take the fear out of cancer.

Tak Tent Cancer Support

Flat 5, 30 Shelley Court

Gartnavel Complex

Glasgow G12 0YN

Tel: 0141 211 0122

Email: tak.tent@care4free.net

www.taktent.org

Offers information and support for cancer patients, families, friends and health professionals. Runs a network of support groups across Scotland, meeting monthly in the evening. Also provides counselling and complementary therapies.

Teenage Cancer Trust

3rd floor, 93 Warren Street

London W1T 3EZ

Tel: 020 7612 0370

Email: tct@teenagecancertrust.org

www.teenagecancertrust.org

Focuses on the particular needs of UK teenagers and young adults with cancer, leukaemia, Hodgkin's and related diseases.

Tenovus

43 The Parade

Cardiff CF24 3AB

Helpline: 0808 808 1010

(Monday to Friday, 9am-4.30pm,
except Wednesday pm)

Tel: 02920 482 000

www.tenovus.com

Funds patient care, counselling and a freephone cancer helpline.

Has over a total of 30 health professionals in several hospitals in England and Wales. Offers support, information and counselling to anyone affected by cancer.

The Ulster Cancer Foundation

40-42 Eglantine Avenue

Belfast BT9 6DX

Helpline: 0800 783 3339

Tel: 02890 663 281

Email: infocis@ulstercancer.org

www.ulstercancer.org

Offers a free telephone and call in service, where information is available on all aspects of cancer. The service is provided by specially trained nurses with experience in cancer care.

Support for carers

Carers UK

32-36 Loman Street
Southwark

London SE1 0EE

Carers line: 0808 808 7777
(Wednesday and Thursday,
10am-12pm and 2-4pm)

Email: info@carersuk.org
www.carersuk.org

Offers information and support to carers. Can put people in contact with support groups for carers in their area. Carers UK have national offices for Scotland, Wales and Northern Ireland – these contact details are below:

Carers Scotland

91 Mitchell Street

Glasgow G1 3LN

Tel: 0141 221 9141

Email: info@carerscotland.org
www.carerscotland.org

Carers Wales

River House

Ynsbridge Court

Gwaelod-y-Garth

Cardiff CF15 9SS

Tel: 02920 811 370

Email: info@carerswales.org
www.carerswales.org

Carers Northern Ireland

58 Howard Street

Belfast BT1 6PJ

Tel: 02890 439 843

Email: info@carersni.org
www.carersni.org

Crossroads – Caring for Carers

10 Regent Place

Rugby

Warwickshire CV21 2PN

Tel: 0845 450 0350

Email: communications@crossroads.org.uk
www.crossroads.org.uk

Over 200 schemes across England and Wales which provide a range of services for carers, including in the home (by paid, trained care workers) to enable the carer to have a break. Several Crossroads branches are working in partnership with Macmillan to provide a specialist service for patients with a cancer diagnosis, their carers and families.

Crossroads Caring for Carers

Northern Ireland

7 Regent Street

Newtownards BT23 4AB

Tel: 02891 814 455

www.crossroadcare.co.uk

Crossroads Caring for Carers

Scotland

24 George Square

Glasgow

Lanarkshire G2 1EG

Tel: 0141 226 3793

Email: info@crossroads-scotland.co.uk

www.crossroads-scotland.co.uk

The Princess Royal Trust for Carers

142 Minorities

London EC3N 1LB

London office: 020 7480 7788

help@carers.org

Glasgow office: 0141 221 5066

infoscotland@carers.org

Northern office: 01257 234 070

infochorley@carers.org

www.carers.org

Provides information, advice and support services to carers through a network of over 100 independently managed carers centres across the UK. Local centres can be found on the website or by phoning your nearest office.

Support for young carers

www.youngcarers.net

An online service for young carers from The Princess Royal Trust for Carers. The site allows you to search for young carers projects and support groups by postcode.

www.youngcarer.com

A site for young carers, their families and those who work to support them across the UK. The site was created as part of The Children's Society National Young Carers Initiative.

How are you feeling?

General information and advice

Benefits Enquiry Line

Tel: 0800 882200 (Free)
Text: 0800 243355 (Free)
www.dwp.gov.uk

Provides advice about benefits, and can also provide help with the completion of some disability related claim packs.

Citizens Advice Bureau

Contact details for your local office can be found in the phone book or at www.citizensadvice.org.uk

Find advice online, in a range of languages and for each UK country, at www.adviceguide.org.uk

Citizens Advice Bureaus provide free, confidential, independent advice on a variety of issues including financial, legal, housing and employment.

**WE ARE
MACMILLAN.
CANCER SUPPORT**



Have cancer? Had cancer?

Care for someone with cancer?
Use your cancer experience to help improve the future of cancer care.

Talk to us.

Visit www.macmillan.org.uk/cancervoices
email cancervoices@macmillan.org.uk
or call 020 7091 2007 and please mention where you saw this advert.

