A practical guide to living with and after cancer

## BODY IMAGE AND CANCER



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### About this booklet

Learning that you have cancer can be one of the hardest things you ever have to face. Everyone has their own experience of cancer and how it affects their life.

For some people, cancer and its treatment can have a big impact on their body. Treatments like surgery, chemotherapy, radiotherapy and hormonal therapy can change the way your body looks, works or feels.

This booklet explains how cancer and its treatment can affect your body and the way you see it (see pages 5–9). It also suggests ways of dealing with these thoughts and feelings (see pages 11–48). Not all the information will be relevant to you, so you may just want to read certain sections.

We developed this booklet with the help of people who have experienced body changes due to cancer and its treatment. We've included information about how they felt, what they found useful and examples from their experiences. Some names have been changed or removed.

We also suggest exercises for you to complete, which you may find helpful.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**  Turn to pages 54–63 for some useful addresses and websites, and page 64 to write down any notes or questions for your doctor or nurse.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

### **Body image**

Changes to your body can be a constant reminder of your cancer diagnosis and treatment. They can sometimes affect your body image, which is the picture you have in your mind of how you look (your size, shape and form), and how you feel about your body.

Research has found that 3 out of 4 people that have a body change due to cancer or its treatment feel embarrassed about it at some stage. Concerns about body image can affect both women and men at any age.

Thoughts and feelings about your body image can be difficult to deal with. You may find that you go through many different emotions. This experience will be unique to you, but you may meet other people who have similar thoughts and feelings.

# The pressure on how you look

These days, there's a lot of emphasis on how we look, and we are surrounded by images of attractive, healthy and perfect bodies. But the pictures we see in newspapers, magazines, on television and on the internet are often not realistic. Many celebrity photographs are 'airbrushed' to make them look better. This 'ideal' image is usually not possible for anyone, whether they have a cancer diagnosis or not.

It's common for women – even from a young age – and it's becoming more and more common for men, to be unhappy with the way they look. More people are trying to improve things they don't like through plastic surgery, weight loss, intense exercise programmes or by buying products.

It's natural to have concerns about your body image from time to time, but you may feel more sensitive after cancer treatment that has caused a change to your body:

- You may be embarrassed about the change and don't want people to make a fuss about it.
- You may worry about how it will affect your relationships with your partner, family, friends or work colleagues.
- You may worry about how it will influence meeting new people, starting a relationship or getting a new job.
- You may be concerned about questions other people might ask.

These feelings are quite normal when coming to terms with changes to your body. However for some people, these concerns may cause anxiety and even depression (see pages 19–20).

There is professional support available to help you adjust to and live with permanent body changes, if you need it. It may also help to share your experience with other people who are affected in a similar way (see pages 21–22). We have an online community where people can share their worries and thoughts at any time. Visit at **macmillan.org.uk/community** 

How we look is important to many of us. But our character and personality are just as important and are part of our attractiveness to other people.

### Physical body changes and cancer

Cancer and its treatment can cause a number of different physical changes to your body. If you experience a change that's not mentioned here, you should discuss it with your doctor or nurse.

Changes brought on by cancer or its treatment can affect:

- Appearance the way you look For example, surgery can cause scarring or a change in shape to your body. A part of your body may have been removed, such as a breast or limb. Some people may have a scar on their face. Other changes might include hair loss, weight loss/gain, skin changes or a swelling to a limb or area of the body (lymphoedema).
- Function the way your body works For example, some people may need a colostomy. This is a surgically made opening on the surface of the tummy (abdomen), called a stoma. Bowel motions are passed through the opening and into a bag. Other examples include changes to your senses, movement, speech, swallowing and fertility. Young women may have menopausal symptoms after certain treatments. Other treatments can affect memory or concentration.
- Sensation the way your body feels For example, after surgery, the area can feel different, with areas of numbness.

Other effects include changes in hearing or tingling, numbness and pain in the hands and feet. People that have lost a limb due to cancer treatment may have 'phantom pain' sensations of the limb, even though it's been removed. Radiotherapy can sometimes change the way the skin feels over the treated area.

Body changes can occur quickly or over a long period of time. These changes may be temporary or permanent, visible or hidden from other people.

Concerns about your body can occur at any time. Some people will focus on just getting through their treatment and won't think about its impact until much later.

The effect on someone isn't always related to the size, severity or visibility of the change. For example, a small hidden scar can still affect a person's mood, confidence or sexuality.

'I have always valued my strength and ability to do things myself but there are things that I can't do for myself now.'

Changes to your body may seem more important after you leave hospital, at the start of another type of treatment or after finishing treatment. Some people may feel that they 'don't recognise themselves' or that they 'lose themselves'.



### Your feelings

At first, body changes can seem overwhelming. The feelings around 'losing a part of yourself' after a physical change to your body can be similar to the feelings of losing a loved one. You may have feelings of anger, anxiety, sadness and depression.

Feelings and emotions can come and go quickly. At times you may feel fine, but then suddenly you can feel overwhelmed, tearful or frightened. It's perfectly natural to feel like this after a major change to your body, and it's part of adapting to the way you see yourself after treatment.

There's no set time or method for this process of adapting; everyone does it at their own pace and in their own way. For some people it may take weeks, for others it may take months or even years.

However, for some people, getting to grips with a physical change to their body can feel overwhelming. They may feel that they will never be able to come to terms with what has happened. If this is the case, it may be helpful to look at your feelings and to share them. Perhaps write them down or speak to family or friends about how difficult you're finding it. There's more information about how to do this on pages 21–22.

You may experience many different emotions. We mention some of them here.

### Anger

'All of a sudden I felt like a wreck, I was not looking the best and that made me angry. I liked my long hair and wearing push-up bras and making the best of myself. I didn't feel like me.'

It's natural to feel angry when coming to terms with a loss such as a permanent physical change to your body. Even though it can feel uncomfortable, talking about it can often help people accept changes.

You may feel angry about the unfairness of your cancer and the change treatment has caused to your body. You can sometimes feel angry towards your doctor or nurse for what has happened.

We all have our own ways of dealing with anger. If you struggle to talk about anger, it might help to explore different ways of dealing with it:

- You may want to go to a space where you feel able to scream, shout and cry as loud and as much as you want.
- Some people take up boxing or exercise classes to get anger out of their system.

• Music or other creative activities like painting, drama or dancing can also be useful to allow feelings of anger to be expressed.

### Anxiety

We often feel anxious about situations that we think are unpredictable or dangerous. This causes the release of the hormone adrenaline, which results in a 'fight or flight' response to help us tackle or escape from the perceived danger.

When coming to terms with a body change, you might experience either the change itself or talking to other people about it, as a 'perceived danger'. You may worry that people will laugh at you or comment on your appearance when you go out in public. This can make you feel anxious. Anxiety is one of the most common emotions felt by people with body changes.

Although some anxiety can improve our performance at times, such as during a job interview, too much anxiety is unhelpful. It can be an unpleasant feeling and can cause physical effects, such as:

- over-breathing (hyperventilating)
- a sensation of your heart beating too fast (palpitations)
- dizziness
- sweating
- dry mouth

- needing to use the toilet more often
- feeling sick.

These unpleasant effects can cause you to avoid anything that you think will make you anxious. For example, if someone's anxious about their appearance, they might avoid looking at a scar after an operation or in a mirror after they've lost their hair. When you start to wear a wig, going to the supermarket or meeting new people may be frightening. Some people may avoid anything to do with their colostomy bags.

#### Avoidance

This is a normal response for some people when they feel anxious about something. There is no set time for facing a physical change to your body. You will know when you feel ready to do it.

However, family, friends or healthcare professionals may confront you if they feel you may be avoiding the change in your body, which can be upsetting. It may be helpful to tell them how you feel about the change.

One way of dealing with avoidance, is to face the change in your body gradually. This is often done best with someone you trust, such as a relative, friend or healthcare professional, at a time when you feel ready. For example, someone that had a mastectomy may first want to become comfortable with the idea of having lost a breast. Once they're okay with this idea, they may want to touch the area where the breast was. And when they are comfortable doing this, they may want to remove the dressing next time and look at the scar. This can happen over a period of time that is acceptable to you and in as many sessions as you need.

Fear is often bigger than the reality and you may find that your fear was completely unnecessary as the following example shows:

Anita's hair was growing back after treatment. She planned to meet a friend for lunch, but she was anxious about going out for the first time without her wig. She chose a quiet hotel and agreed to meet her friend in the hotel lobby. However, Anita didn't know that the hotel was holding a big event that day and people she knew were going.

When Anita saw lots of people in the hotel, her initial response was to leave as she was worried about their reaction to her short hair. But she didn't want to let her friend down so she waited in the lobby. She noticed that her feelings of anxiety quickly passed as everyone she knew was so glad to see her, they didn't appear to notice her hair. Other people she didn't know just seemed to go about their business. This experience increased Anita's self-confidence. It might also help to think about the advice you were given as a child: 'if you fall off your bike, get straight back on'. This positive approach lets you confront your fears, which usually reduce or go away.

There are many other things you can do to help you manage your anxiety and to get back in control:

- Talk about how you feel with someone you trust.
- Keep a diary to express your feelings and worries.
- Use visualisation for example, put together a picture in your mind of a place you like and where you feel relaxed, safe and comfortable. Take the time to think about this picture when you feel anxious.
- Try meditation, which helps to calm your mind and be more focused.
- Use complementary therapies such as aromatherapy, reflexology, acupuncture or massage.
- Practice abdominal breathing see below.

### Abdominal breathing exercises

These exercises are very useful as they can be done anywhere. They work quickly and can help control feelings of anxiety. At first, you should practise them regularly when you aren't anxious. They can be performed lying down, in a chair or standing up.

Breathing should be slow and gentle but not 'deep' as this can result in light-headedness.

**Step 1** – make sure that your shoulders, head and neck are relaxed, and supported if you're sitting or lying down.

**Step 2** – place one hand on your chest and one hand just below your ribcage.

**Step 3** – slowly and gently breathe in (inhale) through your nose and feel your stomach and diaphragm move out.

**Step 4** – when you have taken in a full breath, pause for a moment. Slowly and gently breathe out (exhale) through your pursed lips or nose.

Repeat this process for five minutes, three times a day for a few weeks.

Our booklet Cancer and complementary therapies describes breathing techniques in more detail. You can also speak to an occupational therapist at the hospital who can show you breathing techniques to help you relax. They can often provide a DVD or CD to help guide you at home.

Problem solving (see pages 36–37), thinking about awkward questions (see pages 24–25) and setting goals (see pages 32–35) can also help you manage anxiety.



### Sadness and depression

When something unpleasant or difficult happens that changes our lives, it's natural to feel sad or low at times. But if this low mood continues or gets worse, then it may mean that you're depressed. Sometimes, it can be difficult to know if you're depressed or not. It may be other people who notice symptoms and suggest that you might need help. Symptoms of depression can include:

- a low mood that's worse in the mornings and gets better during the day
- feeling tearful (but sometimes finding it difficult to cry)
- a sense of guilt
- feeling like you're a burden to other people
- losing interest in things around you
- unable to feel pleasure
- finding it hard to concentrate
- feeling that you want to hide away from other people.

Occasionally, people may have thoughts about taking their own life. Samaritans has a 24-hour confidential helpline on **08457 90 90 90** that provides support to anyone in emotional crisis. You may also have physical symptoms of depression like weight loss, poor appetite, trouble sleeping or waking up early in the morning, tiredness and even pain.

If you find any of these feelings particularly difficult to deal with, speak to your GP, specialist doctor, nurse or other healthcare professional at the hospital. They can listen and offer advice or refer you for professional support with a counsellor. There are also organisations that can help (see pages 57–58).

You may also find it helpful to read how your thoughts can affect the way you feel about yourself – see the section on Taking control (pages 30–48).

## Talking about your body changes

People often feel they have to appear to cope well and put on a brave face. They might worry that they can't let people know how they really feel about the changes to their body as they may appear ungrateful. This can mean that the real impact of the changes, such as anger, anxiety and sadness isn't talked about.

Sometimes people think more about other people's needs than their own and this can also stop them from talking about their own experiences.

'It's the core of who I am. It's the fact that it always looks as if I'm coping and I'm on top of things. I'm awfully good at that, but underneath...'

We usually keep our thoughts and feelings about our bodies private and we don't discuss them openly with other people. You may feel too embarrassed and awkward to say how you really feel. But keeping your feelings to yourself can stop you doing things you enjoy or getting the right help. It can help to talk about your feelings with someone you feel comfortable with and can trust. One way to start a conversation may be to write down your questions or concerns and show them to your healthcare professional. It can also help to write down their answers, as it can be difficult to remember everything discussed. You could use page 64 of this booklet to do this.

You may find it useful to speak to someone who has had a similar experience to you. Many areas offer 'buddy systems' or have support groups. Or you may prefer to share your experiences, ask questions and get support from others through the internet.

Visit healthtalkonline.org or Macmillan's own community at macmillan.org.uk/community to talk about your experiences with other people.



### **Awkward questions**

'People ask questions like "What have you done to your arm?".'

We are often curious about things that are different and that we haven't experienced. People may want to talk to you to see how you are, but some may just want to know what has happened to you.

It can feel uncomfortable and awkward answering their questions. And you may worry about how they will react to your answers.

Sometimes you may be conscious of a change yourself, but it may not be noticeable to other people. What you want to tell others can depend on:

- how you feel in general and about your body change
- your relationship with the other person
- where you are and whether other people are present.

It may be helpful to think in advance about possible questions that may make you feel awkward and possible ways of answering them. There is no right or wrong thing to say. You can come up with different responses, which will help to prepare you for different situations. For example:

- 'I had an operation.'
- 'I had cancer and had an operation six weeks ago.'
- 'I had my operation to remove the cancer and am getting used to the changes, but it will take a while.'
- 'I had a cancer removed. I am going for more surgery in a few weeks. I can tell you more if you're interested.'
- 'Thank you for asking, but I don't want to talk about it.'

You can choose how much you want to say. Most people will be happy with a short explanation of what happened.



### Sexuality and intimacy

Changes to your body caused by cancer or its treatment, can make you feel less masculine or feminine. Treatment may affect your ability to have sex because it can change how your sexual organs work. It can also change how you feel about sex. You may worry that sex will be painful, impossible or embarrassing.

You may have no desire for sex. This may leave you feeling sexually unattractive and can also affect your self-esteem and self-confidence. You may feel you want to withdraw from your partner. Some people avoid having sex.

Some people also worry that they may lose their husband, wife or partner if they can't fulfil their sexual needs. Talking to your partner about sex can be difficult. But discussing your fears and worries can help you both feel more comfortable with each other. Your partner may have concerns as well.

Being open with each other can often have a positive effect on a relationship and intimacy. If having sex is a worry, it may help to agree to avoid it for a while. This can take the pressure off and allow you to concentrate on rebuilding intimacy. For example, you can focus on spending time together and going out, holding hands or kissing and cuddling.

When both of you feel ready, you can move on to caressing non-intimate areas, then intimate areas and finally, sexual intercourse. If you're not in an intimate relationship with someone, the thought of starting one may seem daunting or impossible. Or you may worry about what or when to tell a new partner about body changes. We often make assumptions about what others think or feel about us and fear rejection.

Sexuality can be difficult to talk about for most people, but healthcare professionals, such as nurse specialists, can give you help and advice. Your healthcare team can also refer you to a sexual health specialist if that would help. These are experts in dealing with issues around intimacy and relationships, and they can give you confidential advice and practical help.

Our booklets Sexuality and cancer and Cancer, you and your partner have further advice on how to deal with the physical and emotional changes that can affect your sexuality and intimacy. You may also find it helpful to look at our section on Taking control (see pages 30–48). There are a number of ways of dealing with concerns about relationships. Here's an example, which you might find useful:

Tanya was diagnosed with cervical cancer and had to have a hysterectomy (removal of the womb) as part of her treatment. This left her feeling like less of a woman. Tanya had two children but was concerned that she could no longer have children but her partner still could. This made her feel that the balance in their relationship had changed.

Tanya spoke about her concerns with her healthcare team. They helped her to question her thoughts to see if there was another way of looking at things. At first, Tanya was helped by looking at all aspects of her femininity. She involved her partner in this process. This led to them understanding that while Tanya thought that being able to have children was an important part of being a woman, this was low down on her partner's list of what makes her an attractive woman.

### **Taking control**

It can be easy to focus on change in a negative way. However, you can take control and find ways and people to help you adapt. Sometimes this starts when you feel ready to look after yourself again, see or touch the affected area, or socialise with family and friends. There are various things that can help at different times and in different situations, so having a range of approaches is useful.

We have listed some ideas on the following pages. You might have used some of these before.

### **Getting information**

At the hospital, you'll probably be given lots of information about your cancer and its treatment. This can help to prepare you for what may happen due to the cancer and its treatment. It can also help you make decisions about treatment options, such as reconstruction.

Many people benefit from taking someone they trust with them to appointments. They can help you ask important questions and remember what you've been told.

'The amount of information was overwhelming. My daughter came with me to the next appointment and helped me to think about my options.' Healthcare professionals can:

- give you information for example, they might tell you about a possible side effect and what may help, such as a cold cap treatment for hair loss
- refer you to other members of the team for example, occupational therapists can help with problems caused by tiredness
- refer you to other services, such as counselling, if you agree that would be helpful
- refer you to another healthcare professional for a second opinion about your care if you feel this would be useful.

Although information can be helpful, it doesn't always prepare you for how you're going to feel.

### **Family and friends**

Your family and friends can help you feel confident and valued. They can also encourage you when you're trying new ways of adapting to body changes.

However, while you may appreciate their offers of support, you may feel:

- they don't understand how you feel
- frustrated as they are doing things that you're unable to do
- upset or irritated if you feel they're trying to protect you.

Talking to your family and friends can let them know how you really feel. It also lets them know what you would like them to do to help you. For example, they can go out with you and tell you their view of a situation.

They may also find it helpful to read this booklet or any sections that you thought were useful.

### Setting goals

Many people stop doing things they enjoy while having cancer treatment. When you have a body change after treatment, you may continue to avoid social activities because of anxiety. However, this may mean that you miss out on things you really like doing. So, it's important to think about things you know you'd like to do or achieve. Setting goals can help. Your goal(s) should be:

- **Personal** find something important to you, not others.
- **Realistic** think about goals you feel ready or able to deal with.
- Achievable choose something that is realistically possible.
- **Measurable** think about how you will know you have achieved your goal.
- Specific think about details that will help you achieve it.

If your overall goal is quite difficult, then it's better to identify short-, mid- and long-term goals. You can break these down further into a series of steps if you need to.



John had become anxious about going out in public and had been avoiding his friends. But he wanted to attend a wedding in six months' time. So he identified a short- and mid-term goal to help him work towards his overall goal.

- short-term goal go out for a coffee with a friend
- mid-term goal go out for a meal with friends
- long-term goal attend a wedding in six months' time.

Initially, John focused on smaller steps to help him achieve his short-term goal:

#### Step 1

- Phone a few friends to see if anyone is available for a coffee.
- Ask them to come to his house and they will walk to the coffee shop together.
- Go at 10am when the coffee shop is usually quiet.

John keeps repeating each step until his anxiety reduces and he feels comfortable and able to move to the next step.

#### Step 2

Walk to the coffee shop alone at 10am and meet a friend outside.

#### Step 3

Walk to the coffee shop alone at 10am and meet a friend inside.

#### Step 4

Walk to the coffee shop alone at a busy time and meet a friend inside.

Repeating each step lets you gain confidence in your ability to manage any feelings of anxiety.

You may want to write down a goal and the steps that can help you achieve it.

#### Goal:

#### Steps:

#### **Problem solving**

Worries or problems can sometimes seem overwhelming. For example, you may worry about going out after a body change and wonder if you'll ever be able to enjoy a normal social life again. It can be hard to believe that things can change or that anything can help. Problem solving can help you break down problems into something more manageable. This is done through a series of steps:

#### Step 1 – Identify the problem

Try to be as specific as possible. Work on a single problem which has an achievable goal. Write down the problem in one sentence. If you can't do this then the problem is too big. You will need to break the problem down further. You may wish to speak to a relative or close friend to help you do this.

## Step 2 – Think about any solution that may help your problem

Step 3 – Think about the pros and cons of each possible solution

Step 4 – Think about the solutions that are most likely to solve your problem

Step 5 – Try it out

#### Step 6 – Review the problem

Consider if the problem has been solved. Has a different problem been identified? Would another solution have been better?

Dealing with one problem in a successful way will help you overcome bigger problems.

An example is given below:

Fred had problems swallowing due to a dry mouth caused by radiotherapy. He was concerned about not being able to eat at a restaurant. Rather than avoid going out, Fred thought about different solutions and decided to phone the restaurant to check the menu. He realised there were things on the menu that he could eat. He also asked if he could have a smaller portion and extra sauce. After learning this would be okay, he felt less anxious and more confident about going out with his family for a meal. He also got an information card from a healthcare professional that explained why he needed small portions.

You may want to try jotting down a problem and following the steps above.

**Problem:** 

**Possible solutions:** 

**Best solutions:** 

**Review:** 

#### Being aware of your thoughts

Thoughts go through our minds constantly. They can be about many things, including:

- our environment
- what's happening around us
- what's going on in our lives
- ourselves
- others
- the future.

Usually we barely notice our thoughts. However, when we become aware of them, we can check to make sure that they're as helpful as possible. For example, when reading information about cancer you may think: 'I don't understand any of it'. You might go on to question this thought to see if it's right and then realise that: 'there are some bits I understand and I can re-read the other parts'.

Some people find it useful to keep a diary of their thoughts. Others prefer just to think about them regularly. This can help you identify their effect on your feelings and behaviour. It can also help you see unhelpful thinking patterns. Questioning your thoughts can help you change them, if needed. There are a number of different unhelpful thinking patterns:

Over-generalising

This involves the use of key words, such as never, always, nobody and everyone: 'Everyone will stare at me if I go to the pub.'

#### Personalising

This is thinking everything is related to your appearance or body changes: 'I didn't get the job because of my appearance.'

#### **Mental filtering**

This is paying attention to the negative and ignoring the positive: 'The lady in the newspaper shop didn't understand what I was saying as my speech is so poor now.'

#### **Mind-reading**

This is when someone thinks they know what someone else is thinking without checking that their thoughts are correct: 'My husband/wife will think I am ugly because of the changes in my body.'

#### All-or-nothing thinking

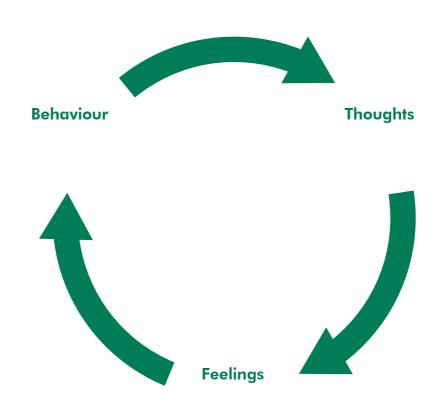
This is when someone thinks in terms of extremes, for example either/or and all/nothing: 'If I can't eat a full meal then I can't go to the restaurant with my family.'

#### Negative thinking – a vicious circle

When faced with a big change in life, like a permanent body change, people can sometimes develop unhelpful ways of thinking. These negative thoughts can then affect how they feel and behave. This vicious circle is shown below:



You may want to consider your thoughts, feelings and behaviour in relation to a recent situation using the blank circle on the opposite page.





You may realise that you have unhelpful thoughts about your body changes. It may help to ask yourself the following five questions:



What is the evidence? Is what I'm thinking definitely right? Can I prove that? What evidence do I have for and against my thoughts?



What alternative views are there? How might someone else view this situation? How would I see it if my friend was talking about it? How would I have looked at this situation before I had cancer?



What is the effect of thinking the way I do? Does it help or hinder me from doing and getting what I want? How? What would be the effect of thinking of things less negatively?



Am I making it a habit to jump to a particular conclusion? Am I only seeing the negative side of things and forgetting the positives? Am I blowing things out of proportion?



What action can I take? What can I do to change my situation? Am I overlooking solutions to problems?

By questioning your thoughts you can start to think in a more positive, balanced way. The table on the next page shows how you can change negative thoughts into more balanced, positive thoughts.

Negative thoughts	More balanced and positive thoughts
'Everyone will stare at me if I go to the pub.'	'Some people will stare but it will probably be due to curiosity.'
'I didn't get the job because of my appearance.'	'I didn't get the job because there was someone who was better suited to it.'
'The lady in the newspaper shop didn't understand what I was saying as my speech is so poor now.'	'Although the lady in the newspaper shop did not understand what I was saying the first time, she understood it when I repeated myself – so I can make myself understood.'
'My husband/wife will think I'm ugly because of the changes in my body.'	'Although I am aware of my body change, my husband/ wife may not notice it so much. Anyway, I have other attractive qualities.'
'If I can't eat a full meal, then I can't go to the restaurant with my family.'	'It would be nice to go out with my family. I can ask for a small portion of food.'

There are many self-help books and internet resources to help you understand your ways of thinking. However, some of these may not be suitable for you when struggling with feelings around body image changes. If you feel that your mood is affected by the way you think and you're struggling with it, you may want to speak to your GP or any other healthcare professional. They can refer you to a counsellor for further support.

#### Developing your social skills

Sometimes people may stare, make comments, ask questions or avoid people with body changes. This can be upsetting and hard to deal with. Social skills focus on how to communicate well and can help you manage social gatherings and the reactions of other people. You may find it helpful to try out new approaches and see if they work for you. We are all different and different things will work for each of us.

You may wish to think about:

- Presentation The way you present yourself overall is important, for example, dress and accessories. It conveys a message to other people about how you feel about yourself.
- **Posture** Communication involves the whole body. Standing with your shoulders back and head up makes you look confident and assertive.
- **Engaging with people** Making eye contact, smiling and nodding tells others that you're approachable.

- Taking the initiative You may wish to talk about your body changes at an appropriate point in a conversation. This can reduce your anxiety and help you maintain control. For example, you could say to someone you've not seen for a while: 'I've not seen you for ages. You look well. You might notice I've lost a lot of weight. I had cancer treatment but I'm slowly getting better.'
- **Staring/negative comments** Stares or comments can be distressing. You can let the person know that you're aware of it and want it to stop. This can be done through non-verbal signals such as an assertive look, smiling, nodding or frowning. Or you can use verbal responses, for example, 'Please don't stare at me. It's only a scar.'

It takes time for these approaches to feel natural. As you go through different experiences, they can help you change your approach for the future.

#### **Covering up changes**

There are a number of different ways to cover up changes. Your healthcare team may be able to:

- advise you about clothing and accessories, for example, using a scarf to cover up hair loss
- make sure you use the most relevant and discreet product, for example, a speaking valve, after surgery to remove the voicebox (larynx)
- refer you to Changing Faces for advice about camouflage make-up – see page 54

• refer you for a replacement part (prosthesis), for example, a breast prosthesis.

Many of us cover up parts of our body that we are less comfortable with. It can be useful to camouflage a change but some people may become focused on hiding it. This can make them anxious and may lead them to avoid situations, as they're frightened that other people will find out about the change. For example, someone with weight and muscle loss may not go swimming for fear of it being seen.

Sometimes attempting to hide a change can draw more attention to it. For example, wearing a high neck jumper to cover scarring in the summer can draw attention, whereas a silk scarf would be less obvious.

Another approach is to enhance other areas of your body, as this can draw attention away from an area of concern. For example, wearing lipstick or blusher may detract from the loss of eyelashes.

Some hospitals and support groups run programmes such as Look Good...Feel Better, which is an organisation that gives women expert advice on make-up and skincare. You can ask your specialist nurse what services like this are available in your area. Many people find it useful to have a range of ways to help adapt to changes.

You may want to take a few minutes to write down how you might cover up any changes you may have. Think about how this is useful and what else might help.

#### Exercising

Some areas run exercise programmes for people with cancer. Regular exercise can improve your body image and release chemicals that make you feel good. Evidence shows that exercise may help reduce the risk of some cancers coming back or of developing a new cancer.

There are also living with cancer programmes, which can help you move on after cancer and treatment. The members of your healthcare team should be able to tell you about local services.

We have information about physical activity and weight management, which you may find helpful.



## How we can help you

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

#### Get in touch

Macmillan Cancer Support 89 Albert Embankment, London SE1 7UQ Questions about cancer? Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm) www.macmillan.org.uk Hard of hearing? Use textphone 0808 808 0121 or Text Relay. Non-English speaker? Interpreters are available.

## Clear, reliable information about cancer

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

#### **Macmillan Support Line**

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

#### Information centres

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

#### **Publications**

We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, fact sheets, and audiobooks. We can also provide information in Braille and large print.

You can find all of our information, along with several videos, online at **macmillan.** org.uk/cancerinformation

**Review our information** 

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

If you'd like to hear more about becoming a reviewer, email **reviewing@ macmillan.org.uk** 

#### Need out-of-hours support?

You can find a lot of information on our website, **macmillan.org.uk** For medical attention out of

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

#### Someone to talk to

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

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

#### **Professional help**

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

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

#### Support for each other

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

#### Support groups

You can find out about support groups in your area by calling us or by visiting **macmillan**. org.uk/selfhelpandsupport

#### **Online community**

You can also share your experiences, ask questions, get and give support to others in our online community at **macmillan**. **org.uk/community** 

#### Financial and work-related support

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

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

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

#### **Macmillan Grants**

Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much needed break. Find out more about the financial and work-related support we can offer at macmillan.org.uk/ financialsupport

#### Learning about cancer

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

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

# Other useful organisations

There are many useful cancer organisations that mention body changes in their general information booklets.

#### British Association of Skin Camouflage

PO Box 3671, Chester CH1 9QH **Tel** 01254 703 107 **www.skin-camouflage.net** Members are trained by the association in all aspects of skin camouflage. Services are sometimes available through NHS clinics and creams can be prescribed by GPs.

#### **Changing Faces**

The Squire Centre, 33–37 University Street, London WC1E 6JN **Helpline** 0300 012 0275 **www.changingfaces.org.uk** and **www.iface.org.uk** (for young people aged 11–21) Offers support and information for adults and children who have any sort of disfigurement, and their families, with the aim of building effective coping strategies and self-confidence.

#### **Colostomy Association**

2 London Court, East Street, Reading RG1 4QL Helpline 0800 328 4257 (24 hours a day, 7 days a week) Email cass@ colostomyassociation.org.uk www.colostomyassociation. org.uk

Offers support, reassurance and information to anyone who has had a colostomy or is facing one. Produces a range of free literature with useful guidance. Offers home and hospital visits by experienced colostomates, and telephone advice and support.

#### Let's Face It

72 Victoria Avenue, Westgate on Sea CT8 8BH **Tel** 01843 833 724 **Email** chrisletsfaceit@aol.com **www.lets-face-it.org.uk** Self-help organisation for people with facial disfigurement that provides telephone support, social activities, dietary and medical advice, and information about camouflage make-up.

#### Look Good...Feel Better

West Hill House, 32 West Hill, Epsom KT19 8JD Tel 01372 747 500 Email info@lgfb.co.uk www.lookgoodfeelbetter. co.uk

A free cancer support service for women living with cancer. Holds free skincare and make-up workshops to help combat the visible side effects of cancer treatment and boost confidence and well-being.

## The National Association of Laryngectomee Clubs

Lower Ground Floor, 152 Buckingham Palace Road, London SW1W 9TR Tel 020 7730 8585 Email

#### info@laryngectomy.org.uk www.laryngectomy.org.uk

Aids rehabilitation of people who have had laryngectomy surgery. Provides pre- and post-surgery support, information, and speech and language therapy.

#### **Saving Faces**

St Bartholomew's Hospital, West Smithfield, London EC1A 7BE **Helpline** 07792 357 972 (Mon–Fri, 9am–5pm) **Email** 

helpline@savingfaces.co.uk www.savingfaces.co.uk Gives information about facial surgery research and links new patients with former patients who can provide advice and support.

# General cancer support organisations

#### **Cancer Black Care**

79 Acton Lane, London NW10 8UT Tel 020 8961 4151 Email info@cancerblackcare.org.uk www.cancerblackcare.

## org.uk

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

#### Cancer Focus Northern Ireland

40–44 Eglantine Avenue, Belfast BT9 6DX **Tel** 0800 783 3339 (Mon–Fri, 9am–1pm) **Email** 

helpline@cancerfocusni.org www.cancerfocusni.org

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

#### **Cancer Support Scotland**

Calman Cancer Support Centre, 75 Shelley Road Glasgow G12 0ZE **Tel** 0141 211 0122 **Email** info@ cancersupportscotland.org **www.cancersupport scotland.org** Offers information

and support to people affected by cancer. Also runs support groups, and provides counselling and complementary therapies.

#### **Irish Cancer Society**

43–45 Northumberland Road, Dublin 4, Ireland **Tel** 1800 200 700 (Mon–Thu, 9am–7pm, Fri, 9am–5pm) **Email** helpline@irishcancer.ie **www.cancer.ie** Has a freephone cancer helpline staffed by nurses trained in cancer care. You can also chat to a nurse online and use the site's message board.

#### **Maggie's Centres**

1<sup>st</sup> Floor, One Waterloo Street, Glasgow G2 6AY **Tel** 0300 123 1801 **Email** enquiries@ maggiescentres.org **www.maggiescentres.org** Maggie's Centres provide information about cancer, benefits advice, and emotional or psychological support.

#### Penny Brohn Cancer Care

Chapel Pill Lane, Pill, Bristol BS20 0HH **Tel** 0845 123 2310 (Mon–Fri, 9.30am–5pm) **Email** helpline@pennybrohn.org **www. pennybrohncancercare.org** Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

#### Tenovus

Head Office, Gleider House, Ty Glas Road, Cardiff CF14 5BD **Tel** 0808 808 1010 **www.tenovus.org.uk** Provides a range of services to people with cancer

and their families, including counselling and a freephone helpline.

# Counselling and emotional support

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

BACP House, 15 St John's Business Park, Lutterworth LE17 4HB Tel 01455 883 300 Email bacp@bacp.co.uk www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk**. **org.uk** 

#### UK Council for Psychotherapy (UKCP)

2<sup>nd</sup> Floor, Edward House, 2 Wakley Street, London EC1V 7LT **Tel** 020 7014 9955 **Email** info@ukcp.org.uk **www.psychotherapy.org.uk** Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

# Financial or legal advice and information

#### Benefit Enquiry Line (England, Wales, Scotland)

Tel 0800 882 200 (Mon–Fri, 8.30am–6.30pm) Email BEL-Customer-Services@dwp.gsi.gov.uk www.gov.uk/ benefit-enquiry-line Provides advice and information for disabled

people and carers on the range of benefits available.

#### NI Direct (Northern Ireland) Tel 0800 220 674 (Mon, Tue, Wed, Fri, 9am– 5pm, Thu, 10am–5pm) Textphone 0800 243 787

www.nidirect.gov.uk/ money-tax-and-benefits

#### **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing and employment issues.

Find details for your local office in the phone book or on one of the following websites:

#### England and Wales www.citizensadvice. org.uk

Scotland www.cas.org.uk

#### Northern Ireland www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk** 

#### **GOV.UK**

www.gov.uk Has comprehensive information about social security benefits and public services.

#### The Money Advice Service

Holborn Centre, 120 Holborn, London EC1N 2TD **Tel** 0300 500 5000 **Email** enquiries@ moneyadviceservice.org.uk **www.moneyadvice service.org.uk** Runs a free financial health check service and gives advice about all types of

#### **Money Advice Scotland**

Tel 0141 572 0237 www.moneyadvice scotland.org.uk

financial matters.

#### National Debtline (England, Wales and Scotland)

Tricorn House, 51–53 Hagley Road, Edgbaston, Birmingham B16 8TP **Tel** 0808 808 4000 (Mon–Fri, 9am–9pm, Sat, 9.30am–1pm) **www.nationaldebtline.co.uk** A national helpline for people with debt problems. The service is free, confidential and independent.

#### Personal Finance Society – 'Find an Adviser' service

42–48 High Road, South Woodford, London E18 2JP Tel 020 8530 0852 www.findanadviser.org

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

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

#### **Disability Rights UK**

12 City Forum, 250 City Road, London EC1V 8AF **Tel** 020 7250 3222 **Email** enquiries@ disabilityrightsuk.org **www.disabilityrightsuk.org** Provides information on social security benefits and disability rights.

#### Disabled Living Foundation (DLF)

380–384 Harrow Road, London W9 2HU **Tel** 0845 130 9177 (Mon–Fri, 10am–4pm) **Email** helpline@dlf.org.uk www.dlf.org.uk

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

#### **Limbless Association**

Unit 16, Waterhouse Business Centre, 2 Cromar Way, Chelmsford CM1 2QE **Helpline** 0800 644 0185 **Email** enquiries@limblessassociation.org **www.limblessassociation.org** Offers support and information to people who are about to have an amputation or those who are already living with limb-loss.

#### Support for older people

Age UK

Tavis House, 1-6 Tavistock Square, London WC1H 9NA **Tel (England and Wales)** 0800 169 6565 Tel (Scotland) 0845 125 9732 **Tel (Northern Ireland)** 0808 808 7575 (Daily, 8am-7pm) www.ageuk.org.uk Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

# Further resources

## Related Macmillan information

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

- Cancer and complementary therapies
- Cancer, you and your partner
- Physical activity and cancer treatment
- Sexuality and cancer
- Weight management after cancer treatment

To order, visit **be.macmillan.** org.uk or call **0808 808 00 00**. All of our information is also available online at macmillan.org.uk/ cancerinformation

#### Macmillan audiobooks

Our high-quality audiobooks, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer.

To order your free CD, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

#### **Useful websites**

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information.

The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

#### Macmillan Cancer Support www.macmillan.org.uk

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

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

www.cancer.gov (National Cancer Institute – National Institute of Health – USA) Gives comprehensive information on cancer and treatments.

#### www.cancerhelp.org.uk (Cancer Research UK)

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

#### www.healthtalkonline.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.

#### www.macmillan.org. uk/cancerinformation/ teensandyoungadults (Macmillan Cancer Support)

Macmillan's cancer information site written specifically for young people.

#### www.macmillan.org.uk/ cancervoices (Macmillan Cancer Voices)

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

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

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

#### www.nhsdirect.nhs.uk (NHS Direct Online)

NHS health information site for England – covers all aspects of health, illness and treatments.

www.nhs24.com (NHS 24 in Scotland)

www.nhsdirect.wales. nhs.uk (NHS Direct Wales)

#### www.n-i.nhs.uk (Health and Social Care in Northern Ireland)

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

#### www.patient.co.uk (Patient UK)

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

#### www.riprap.org.uk (Riprap)

Developed especially for teenagers who have a parent with cancer.

## Your notes and questions

You could use this page to write down any notes or questions you want to ask your doctor or nurse.

#### 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

The original text of this booklet was written by Caroline Hood, Macmillan Clinical Project Lead – Body Image and Cancer. The current edition has been reviewed by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our medical editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Tania Hawthorn and her colleagues, Consultant in Liaison Psychiatry; Vanessa Linton, Macmillan Head & Neck Advanced Nurse Practitioner; and the people affected by cancer who reviewed this edition.

#### Sources

Barraclough J. Cancer and emotion. 3<sup>rd</sup> edition. Chichester. John Wiley and Sons Ltd. 1999.

Bessell A, Moss T. Evaluating the effectiveness of psychosocial interventions for individuals with visible differences: a systematic review of the empirical literature. Body Image. 2007. 4: 227–238.

Cash T, Pruzinsky T. Body image: a handbook of theory, research and clinical practice. London. The Guilford Press. 2004.

Diagnostic and statistical manual of mental disorders. 4<sup>th</sup> edition. Washington DC. American Psychiatric Association. 2011. Harcourt D, Rumsey N. Altered body image. Nursing Patients with Cancer: Principles and Practice. 2006.

Hood C. Project to improve care for people coping with changes in body image. Cancer Nursing Practice. 2010. 9:26–32.

Rankin J, et al. Rehabilitation in cancer care. 1<sup>st</sup> edition. Oxford. Wiley-Blackwell. 2008.

## Can you do something to help?

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

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



#### Share your cancer experience

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

#### Campaign for change

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

#### Help someone in your community

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

#### **Raise money**

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

#### **Give money**

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

### Call us to find out more 0300 1000 200 macmillan.org.uk/getinvolved

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

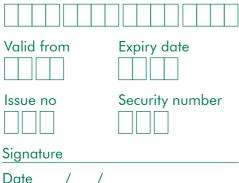
Email

Please accept my gift of £

(Please delete as appropriate) I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number



# Don't let the taxman keep your money

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

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

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

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

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



#### If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.

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 supporting you online, any time. The fundraisers who make it all possible.

You don't have to face cancer alone. We can give you the strength to get through it. We are Macmillan Cancer Support.

Questions about living with cancer? Call free on 0808 808 00 00 (Mon-Fri, 9am-8pm) Alternatively, visit macmillan.org.uk

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

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