

MANAGING THE LATE EFFECTS OF HEAD AND NECK CANCER TREATMENT



About this booklet

This booklet is for people who have had treatment for head and neck cancer and are experiencing side effects after treatment has ended.

In this booklet, we describe the possible long-term and late effects of treatment and what can help manage them. We also include information on what you can do to help reduce your risk of developing certain late effects.

We cover a wide range of side effects people may experience after treatment for head and neck cancer. No one will have all of these effects, but some people may have more than one. There will be chapters in the booklet that aren't relevant to you. Feel free to skip these.

You'll also find that some information may only be relevant depending on the treatment you had. We've added icons (see key below) in some sections, to help you find the information that is relevant to you. Use the icons and the contents pages to help guide you.

Key



Chemotherapy



Radiotherapy



Surgery



Chemoradiation

Throughout the booklet we've included quotes from people who have had late effects after treatment for head and neck cancer. Some are from people who have shared their stories with us. Others are from members of our online community. There is a group on the online community that is specifically for people who have been affected by head and neck cancer. You can read more people's experiences or share yours at **macmillan.org.uk/community**

Turn to pages 123–128 for some useful addresses and websites. On page 129 there is space to write down any notes or questions you might have.

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**

We hope that this information helps you get the support you need and understand what you can do to manage side effects. It's important to tell your cancer specialist if you have any new symptoms or ongoing side effects after treatment.

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.

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Long-term and late effects

You may come across different terms to describe side effects that develop after treatment or are still present after treatment is over. There are two commonly used terms:

- long-term effects
- late effects.

Long-term effects begin during or shortly after treatment and don't go away in the six months after treatment. They may go away eventually on their own. Symptoms may gradually get better for one or two years, or even longer, after treatment ends. Sometimes long-term effects are permanent.

Late effects are a delayed response to treatment. They don't appear during treatment, but can happen months or even years later.

In this booklet, we use the term late effects to include both long-term and late effects.

Doctors and researchers are trying to make sure that people get the best treatment, with as few side effects as possible. Treatment for head and neck cancer is constantly developing and people are living for longer because of improved treatments. We're learning more about late effects and how they can be managed.

Possible late effects of head and neck cancer treatments

The main treatments for head and neck cancer are surgery, radiotherapy and chemotherapy. You may have had a combination of these. When doctors give chemotherapy and radiotherapy together, it's called chemoradiation, or chemo-radiotherapy.

We have more information about these treatments for head and neck cancers. Visit [macmillan.org.uk](https://www.macmillan.org.uk) to find out more.

How likely treatment is to cause late effects depends on several things, including:

- the size of the cancer
- where the cancer was
- your general health before treatment started
- the types of treatment used
- how much treatment you had
- whether lymph nodes (lymph glands) in the neck were treated.

Many treatment side effects improve over time. If you have side effects that aren't getting better or if you develop new symptoms, let someone from your cancer specialist team know. They will look at your symptoms and explain if they are likely to be a result of treatment. You may need to have tests to find out the cause.

Remember, you can arrange to see your cancer specialist or specialist nurse between clinic appointments and you can contact your GP at any time.

The most common long term effects of treatment for head and neck cancer are:

- a dry mouth (see pages 14–21)
- a greater risk of tooth decay and bone damage (see pages 22–27)
- difficulty swallowing (see pages 33–47)
- changes in hearing (see pages 59–66)
- stiffness or pain in the jaw, neck and shoulders (see pages 68–72)
- changes in how you look (see pages 92–96).

Treatment can also cause changes in how you think and feel generally. You may feel more tired than usual for several months after treatment (see pages 85–87). Your sex life may also be affected (see pages 98–102). These effects often get better over time as you recover and adjust.

After treatment, you may have more time to think and reflect on your illness and what you've been through. You may feel a range of emotions, such as a low mood, anger or anxiety. Pages 103–105 have more information to help you cope with these kinds of feelings.

One of the biggest fears many people have is whether the cancer will come back. As time goes on, most people become less worried. If you feel that your worries don't get less with time, you can get help from your GP, your head and neck cancer team, a counsellor or a psychologist.

Our free leaflet **Worrying about cancer coming back** has information to help you cope with these feelings. Call us free on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a copy.

Who can help you manage late effects

When your treatment is over, it's natural to want to put the cancer behind you. Adjusting to changes after treatment takes time. It can be frustrating to still have side effects. But there are often things that can be done to treat and manage them. As well as specialist doctors and surgeons, there are other specialists who can help. These may include:

- **restorative dentists**, who design prostheses (obturators), implants and dentures to help with eating, speech and appearance
- **dental hygienists**, who teach you how to keep your mouth clean and prevent tooth decay
- **speech and language therapists (SLTs)**, who assess problems with speech, voice and swallowing and teach you how to manage and improve them
- **specialist nurses**, who give information and support on managing side effects
- **dietitians**, who can help you to meet your nutritional needs
- **physiotherapists**, who offer treatments and exercises to help with reduced movement in the jaw, neck or shoulders and encourage safe physical activities
- **occupational therapists**, who can help with problems with ongoing tiredness (fatigue)
- **lymphoedema specialists**, who manage problems with fluid build-up in the tissues (lymphoedema)
- **psychologists** or **counsellors**, who can help you adjust to changes after treatment.



Other sources of support

As you recover from cancer treatment, you may need to re-learn skills, such as swallowing or speaking. You may need to do regular mouth, jaw, throat, neck or shoulder exercises. There may be changes in your day-to-day life you need to adjust to.

Dealing with all of this can take a lot of effort and determination. The benefits may not be obvious immediately. It's normal to have ups and downs along the way and there may be times when you don't feel you're making progress.

It's important to have people around who can support you. As well as your healthcare team, this may include your partner, family and friends. If possible, take a partner, relative or close friend with you to your hospital appointments. This will help them understand what you need to do, and they will be in a better position to help you.

Sometimes it's easier to talk to someone who is not involved. This could be a counsellor or members of a support group who've been through a similar experience.

Many centres have health and well-being events for head and neck cancer survivors. These help patients who are dealing with the late effects and emotional needs talked about in this booklet. Speak to your nurse specialist about what is available in your local treatment or holistic needs centre.

Social networking sites can help you connect with people, share information, and give and get support. Our online community is a good place to do this ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). You can also talk to our cancer support specialists on the Macmillan Support Line on **0808 808 00 00**.



PHYSICAL CHANGES TO THE HEAD AND NECK AFTER TREATMENT

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Dry mouth and changes in saliva

Radiotherapy or chemoradiation to the head or neck can affect your salivary glands, causing a dry mouth. Your salivary glands may gradually recover after treatment finishes. But you may have less saliva than before and it may be thicker and sticky. Some people have a dry mouth permanently.

If you feel you have too much saliva rather than too little, this may be a sign of swallowing difficulties (see pages 36–47).

'I found the thick, stringy saliva distressing after radiotherapy. But things eventually improved. Although I mostly have a dry mouth, my saliva glands have recovered a little. I no longer need the pints of water during the night, although I can occasionally feel dry depending on the weather.'

Joyce

Coping with thick, sticky saliva

Using a sodium bicarbonate mouthwash may help clear thick saliva. Every three to four hours, rinse it around your mouth and spit it out. You can make the mouthwash by adding one teaspoon of sodium bicarbonate to 550ml (one pint) of cooled, boiled water. Make a fresh mouthwash each day.

The hospital or community team may give you a nebuliser. This is a machine that turns liquid into a fine mist. You can then breathe it in through a mask or mouthpiece. The moisture helps to loosen and break up the saliva. It may be helpful to use the nebuliser throughout your treatment, and for several weeks afterwards, depending on how quickly your symptoms improve.

Alternatively, leaning over a steaming basin of hot water (not boiling water) with a towel over your head can help loosen thick, sticky saliva. It is best to do this four to five times during the day. Using a humidifier may also help to make a room less dry.

Coping with a dry mouth

Having a dry mouth can be uncomfortable and can affect eating, speaking and sleeping. It also makes you much more likely to get tooth decay. So it's really important to care for your teeth during and after treatment (see pages 22–27).

Things that can help include:

- relieving dryness
- treatments that stimulate saliva
- regular mouth care.

Relieving dryness

There are several things you can do to help relieve mouth dryness. One of the simplest is to carry a bottle of water with you at all times. You can take frequent sips of water or you could use a water spray instead. You can buy small atomiser spray bottles from most chemists. If you can't swallow, your nurse or doctor can give you a nebuliser (see page 15) to moisten your mouth and throat.

'I find taking a bottle of water with me everywhere helps. I also chew sugarless gum. And there's an artificial saliva gel you can buy at the chemist, which I use at night.'

Richard

Artificial saliva can also help moisten your mouth and throat. It's designed to be the same consistency and thickness as saliva. It comes as gels, sprays, mouthwashes, pastilles or tablets. It is worth trying different types to find out which one suits you best. Your doctor or dentist can prescribe artificial saliva or you can buy it from a chemist.

The effect of artificial saliva may only last for a short time. It is best to use it just before eating. For longer-lasting relief at night, try putting the gel on your tongue and around the inside of your mouth. This may relieve dryness for up to five hours. If you have dentures, you can use the gel under them. This can help them feel more comfortable and stay in place.

Artificial saliva with added fluoride can help to protect your teeth. But some products are acidic and can cause tooth decay. If you have your own teeth, make sure you use one that is pH-neutral. Some brands of artificial saliva may also contain animal products. The table on pages 20–21 has more information about the different types of artificial saliva.

Here are some other things you can do to help ease symptoms of a dry mouth:

- Be aware of foods and drinks that can irritate a dry mouth, such as spicy, salty or hard and crunchy foods.
- Avoid alcohol (especially spirits) and caffeine, as they can also irritate a dry mouth.
- Don't smoke – smoking dries and irritates the mouth.
- Some prescribed medicines can cause a dry mouth. Ask your doctor or nurse whether you're taking any of these. It may be possible to reduce the dosage or change the drug.
- Use a lip salve to protect your lips.
- Try using a humidifier in your bedroom at night.
- Avoid toothpastes with foaming agents as these can make your mouth dry (see page 25).

If your mouth is dry, it can make eating more difficult. Here are some tips to help:

- Take sips of water when chewing and after swallowing.
- Eat soft, moist foods such as casseroles, soup, melon, grapes and ice cream.
- Use gravies, sauces, extra oil, salad dressings, yoghurt and mayonnaise to moisten foods.
- Add plenty of moisture and fat to make food easier to manage. Dry and starchy foods such as bread, biscuits, crackers and potatoes can be difficult to eat. For example, you could add gravy to potatoes or use lots of butter on toast.

We have more information on eating and drinking problems on pages 33–52.

Stimulating saliva

Treatments that stimulate saliva can help if some of your salivary glands still work or if the damage to your glands is temporary.

Chewing sugar-free gum may help stimulate saliva in some people. Some of these gums, such as Spry[®] gum, contain xylitol, which can reduce tooth decay. XyliMelts[®] also contain xylitol and are designed to slowly release it over a few hours to relieve dryness at night. You can buy these products online.

Some sharp-tasting sweets also stimulate saliva. Choose ones that are sugar-free to help protect your teeth.

Table of artificial saliva products for a dry mouth

Product name (manufacturer)	What form it comes in	Available on NHS?
AS Saliva Orthana® (AS Pharma)	Oral spray 50ml	Yes
	Lozenges (30)	Yes
Biotène® Oralbalance (GSK)	Saliva replacement gel 50g	Yes
BioXtra® products (RIS Products)	Moisturising gel 40ml	Yes
	Gel mouth spray 50ml	Yes
	Toothpaste 50ml	No
	Mouth rinse 250ml	No
Glandosane® (Fresenius Kabi)	Aerosol spray 50ml (lemon, neutral, peppermint)	Yes
Saliveze® (Wyvern)	Oral spray 50ml	Yes
SST® Saliva Stimulating Tablets (Medac)	Tablets (100)	Yes
Xerotin® (SpePharm)	Oral spray 100ml	Yes

	Buy from a chemist?	pH	Contains fluoride?	Animal ingredients?
	Yes	Neutral	Yes	Pork
	Yes	Neutral	No	Pork
	Yes	Neutral	No	Yes – type of animal unknown
	Yes	Neutral	No	Cow's milk
	Yes	Neutral	Yes	Cow's milk
	Yes	Neutral	Yes	Cow's milk
	Yes	Neutral	Yes	Cow's milk
	Yes	Acidic – avoid if you have your own teeth	No	No
	Yes	Neutral	No	No
	Yes	Acidic – avoid if you have your own teeth	No	No
	Yes	Neutral	No	No

Mouth care and preventing tooth decay

Teeth can easily be forgotten when you're coping with the effects of cancer treatments. But looking after your teeth is one of the most important things you can do after treatment for head and neck cancer.

Saliva helps keep your mouth clean. If you have a dry mouth, you're more likely to get mouth infections, such as thrush. This can cause white patches in the mouth, an unpleasant taste, soreness or a burning feeling on the tongue. Tell your doctor if you have any of these symptoms. If you have thrush, they can prescribe medicine to help. If you have dentures, you are more likely to get oral thrush. You must take them out at night and keep them clean.

Saliva is very important in protecting your teeth against decay. A dry mouth means you are at much higher risk of tooth decay. Even if you only have a few teeth, it's important to have a good mouth care routine to help keep those teeth in good condition. This will help to reduce your risk of a rare, serious late effect of radiotherapy called **osteoradionecrosis**. This can affect the jawbone. There's more information about it on pages 31–32.

What you can do to help protect your teeth:

- Have regular check-ups with a dentist or dental hygienist every three to six months.
- Use fluoride products prescribed by your dentist.
- Only have sugary and acidic foods and drinks at mealtimes.
- Follow a mouth care routine agreed with your dentist or hygienist.
- Don't smoke.
- If you notice a change in your mouth or teeth, don't wait for your regular check-up. Go and see your dentist immediately.

Using fluoride

Your dentist or dental hygienist will advise you on how to brush your teeth and keep your gums healthy. They may also prescribe fluoride. This strengthens the hard outer layer (enamel) on your teeth and helps protect them from decay. It can also help reduce tooth sensitivity.

You can get toothpastes, mouthwashes and artificial saliva products with added fluoride. Colgate Duraphat® 2800ppm or Colgate Duraphat® 5000ppm toothpaste is the highest fluoride toothpaste. It has to be prescribed, so ask your dentist about it.

Your dentist may also recommend wearing mouth guards containing fluoride overnight or having fluoride painted on your teeth once every three months.

'I go to the hygienist every three months since the radiotherapy and have fluoride painted on my remaining natural teeth.'

Joyce

Cutting down on sugary and acidic foods and drinks

When you eat sugary foods, the bacteria in your mouth quickly turn the sugar into acid. This damages your teeth and gums by breaking down the enamel on the outside of your teeth. This can make your teeth more sensitive and can cause tooth decay.

- Acidic things like fizzy drinks, oranges and tomatoes can break down tooth enamel. The more times you eat or drink something acidic or sugary, the more acid attacks there are on your teeth. It's important to limit these foods and drinks to mealtimes, no more than four times a day.
- Foods that contain sugar include chocolate, sweets, fresh fruit juice, biscuits, cakes and buns, pastries, fruit pies, dried fruit, sweet sauces, sponge puddings, breakfast cereals, ice cream, jams, honey and fruit in syrup.
- Check the labels on foods to find out if they contain sugar. Sugar can be called other names on food labels. Look out for glucose, sucrose, maltodextrin, dextrose, lactose, caramel, fructose, maltose, toffee, molasses, honey, syrup, corn sugar and hydrolysed starch. These are all alternative names for sugars.
- Choose sugar-free drinks, but be aware that some can be harmful to the teeth if they contain phosphoric acid or citric acid. Fizzy, sugar-free drinks are often acidic. The safest drinks for your teeth are plain milk, still water, and tea and coffee without added sugar. Sparkling water can damage teeth as it contains carbonic acid.

Some people will be trying to regain weight after treatment and may have some of these high-energy foods as part of a build-up diet. This is fine as long as you maintain good oral hygiene to limit any possible damage to your mouth and teeth.

Following a mouth care routine

Following a regular mouth care routine agreed with your dentist or dental hygienist can help to protect your teeth.

Check your mouth daily for ulcers, signs of tooth decay or red, white or dark patches. When you have a dry mouth, decay often happens at the top or bottom of the tooth near the gum line. Contact your dentist or cancer specialist if you notice anything unusual.

Brush your teeth every morning and night (see page 26). Choose a toothbrush with a small head and soft bristles. Gentle brushing is enough to clean plaque from a tooth without hurting your gums. You could use an electric toothbrush with a small, rotating head (it moves in circles). Some electric brushes come with a gentle setting, and soft or sensitive brush heads are available. Spend two to three minutes brushing your teeth.

Use high-fluoride toothpaste (see page 23). Most toothpaste contains an ingredient called sodium lauryl sulphate (SLS), which foams up when you brush. If you have swallowing problems, a sore mouth or mouth ulcers, choose toothpaste without SLS. Sensodyne Pronamel[®], BioXtra[®], Oranurse[®] Unflavoured Toothpaste and Biotène[®] Fluoride Toothpaste don't contain SLS.

It's also important to clean between your teeth with dental floss or interdental brushes at least once a day. Move the floss in gentle circles between the teeth. A dentist or hygienist can show you how and advise you on the best products for you.

Brushing your teeth

- As you brush, gently massage the gum around the base of each tooth.
- Brush each tooth slowly and gently.
- Move around the mouth, brushing the outside surface of each tooth.
- Repeat on the inside surface of each tooth.
- Repeat on the biting surface of each tooth.
- After you've brushed your teeth, spit out any excess but don't rinse. The fluoride in the toothpaste stays around your teeth and keeps protecting them, especially at night.



If you wear dentures

- Use a different brush and a denture cleaning cream to clean your dentures.
- Clean and rinse your dentures after eating, as well as every night and morning.
- Gently brush the inside of your mouth with a small, soft toothbrush. Food may collect between the cheek and gums.
- It is important to remove any denture fixative which has stuck to the inside of the mouth. A tissue and warm water should help remove this.
- Before you go to bed, clean your dentures and soak them in a cleaning solution recommended by your dentist. Then leave them in a glass of water overnight. This will give your mouth a rest and reduce the chance of mouth infections such as thrush.

If you wear a special type of denture called an obturator (see pages 42–43), you may be advised to always keep this in and only take it out to clean it. Follow the advice you're given.

Effects on the jaw

Jaw stiffness (trismus)

After radiotherapy or surgery to the head and neck area, the muscles that open and close your mouth may become stiff. Doctors call this trismus. You may have been given mouth exercises to do to help prevent this.

Jaw stiffness can develop a few weeks or sometimes months after treatment. The amount of stiffness varies from person to person.

An easy way to check how wide your mouth can open is to try to put three fingers vertically between your lower and upper front teeth. If you can only manage one or two fingers, you may have a stiff jaw.

Tell your doctor if you have jaw stiffness or pain, even if it's mild. You'll usually be referred to a speech and language therapist (SLT) or physiotherapist for assessment and treatment. Without treatment, jaw stiffness can get more severe so it's best to start treatment as soon as possible.

How widely you can open your jaw will be measured at your first appointment. This measurement will be repeated at every appointment. It will help you to see what progress you're making.

Jaw exercises

Jaw exercises can help reduce stiffness and pain. They help to stretch the tissues and strengthen the muscles in your jaw. When they are done regularly, they help to increase the amount you can open your mouth.

Your SLT, physiotherapist or restorative dentist will show you what jaw stretches to do, how long to hold each stretch and how many times to repeat them. They may also give you aids to help you gently stretch the jaw muscles. Wooden spatulas are often used. You place the spatulas between your upper and lower front teeth for a certain amount of time each day. You increase the number of spatulas you put into your mouth over time and so gradually stretch the jaw muscles.

There are also hand-operated devices such as TheraBite® or OraStretch® that you put inside your mouth to gently stretch the jaw muscles.

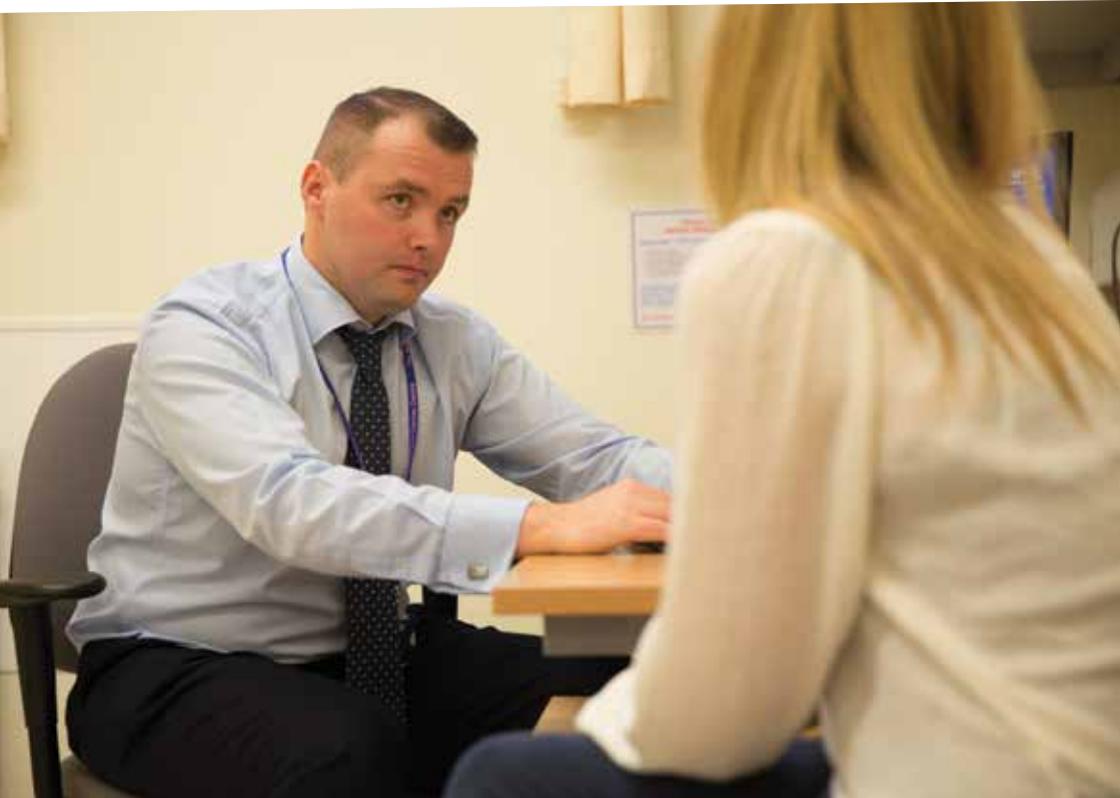
If pain in your jaw gets worse during jaw exercises, don't continue and contact your SLT or physiotherapist for advice.

Your SLT or physiotherapist may also suggest you chew sugar-free gum to keep your jaw moving.

Other things that may help if you have jaw stiffness

If you're having difficulty chewing or swallowing because of a stiff jaw, softer foods can be easier to eat. You may be referred to a dietitian or given supplement drinks to take until you can chew better. You can find more information about eating problems in the next chapter (see pages 33–52).

It's important to continue with a regular mouth care routine while your jaw is stiff. If you find it difficult to reach teeth in the back of your mouth, try using a small toothbrush. Tell your dentist or hygienist if you can't brush your teeth because of a stiff jaw. They can give you more advice.



Changes to the jawbone (osteoradionecrosis)

After radiotherapy to the head and neck, the blood supply to the jawbone may not be as good as before. Sometimes, this may lead to tissue in the jawbone dying. This condition is called osteoradionecrosis or ORN.

Most people who have radiotherapy will never develop ORN. But certain things can increase the risk. These include smoking, wearing badly fitting dentures, having an infection or having a tooth removed.

If tissue in the bone dies, it may cause pain, numbness or a feeling of heaviness in the jaw. You may feel an area of roughness on your gum. Sometimes there is swelling around the gum and teeth may become loose.

Always tell your doctor or dentist if you have any of these symptoms. Don't forget to mention you were treated with radiotherapy. They can check your mouth and arrange for you to have treatment.

Reducing the risk of osteoradionecrosis

Here are some ways to reduce your risk:

- Don't smoke. Smoking affects the blood supply to the bone.
- Look after your mouth and teeth (see pages 22–27). Having an infection or a tooth removed can increase the risk of ORN.
- If you need to have one or more teeth taken out after radiotherapy, it's important to see a specialist oral and maxillofacial surgeon or specialist dentist to have this done. They will plan your treatment to reduce the risk of ORN developing.
- Wear well-fitting dentures. If they rub or are sore, don't wear them. See your dentist for advice.

How osteoradionecrosis is treated

- You may have painkillers to relieve pain and antibiotics to treat infection.
- Surgery is sometimes used to remove the affected tissue.
- You may also be given medicines that help healing.

Research is looking at a treatment using hyperbaric oxygen (HBO) that may help the tissues around the affected area to heal. HBO treatment involves breathing oxygen at higher concentrations than it is found in the air. It is unclear if this treatment is beneficial at the moment and it is only available within clinical trials. Your cancer specialist can discuss it in more detail with you.

Eating and drinking

Surgery or radiotherapy for head and neck cancer can cause changes to how you eat and drink. After treatment, many people find that their ability to eat improves as other side effects get better, such as pain, swelling, feeling sick and tiredness.

'I remember how hard it was to eat a mouthful of yoghurt, thinking that I will never ever manage to eat again. But I did. I forced myself to have one spoonful one day, then two, then three. I had to re-educate my brain into it. It was hard, very hard, but I got there.'

Catherine

If you have eating difficulties, you will usually be supported by a speech and language therapist (SLT). They can teach you exercises and techniques to help you chew and swallow. You may also see a dietitian. They can advise you on how to increase the energy and nutrients in your diet and may give you high-calorie supplements if you have lost weight.

Our information about the building-up diet explains what to eat to increase your weight after cancer treatment. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

It can take a lot of effort and persistence to overcome eating difficulties. If eating has been a struggle for a while, you may no longer associate food with pleasure. Taste changes may reduce your desire for food and affect your appetite (see pages 48–49).

Talk to your SLT if you feel this way. Some SLTs use different coping techniques, such as mindful eating, to help people regain pleasure in food. It helps you to feel more relaxed around food and to find the things about eating you can still enjoy.

If you have a feeding tube

Some people have a feeding tube put in before or during treatment. This is usually temporary. It may be in for a few weeks or for several months or more after treatment. A small number of people will have a feeding tube permanently.

A dietitian will provide support while you have the feeding tube in. They can help you with any problems that you may have. You may also have a specialist nurse to support you.

Wherever possible you will be encouraged to eat and drink, even if you have a feeding tube in place. This is important to keep the swallowing muscles working during radiotherapy and while you are recovering. If you have to stop eating and drinking for any reason, an SLT will help you to try food again. They will start you on the easiest texture for your mouth and throat, and work with you to increase the amount and variety of textures you can manage.

You may have days when you can't eat anything. It's common to have an occasional setback before your eating begins to improve again. When you haven't needed your feeding tube for a few weeks, and you can manage to take enough calories by mouth, it can be taken out.

'At long last I feel like I'm getting somewhere with my eating. It's been a very frustrating business. Finally I've put some weight on and the dietitian has agreed that I may reduce my pump feeds from four to three a day.'

Margaret

What happens when you chew and swallow

Chewing prepares food in the mouth to make it easier to swallow. You put food in your mouth and close your lips to keep it in. The tongue moves the food around in the mouth. Saliva moistens the food and your teeth break it down until it forms a soft, moist ball. This is called a **bolus** and is ready to swallow.

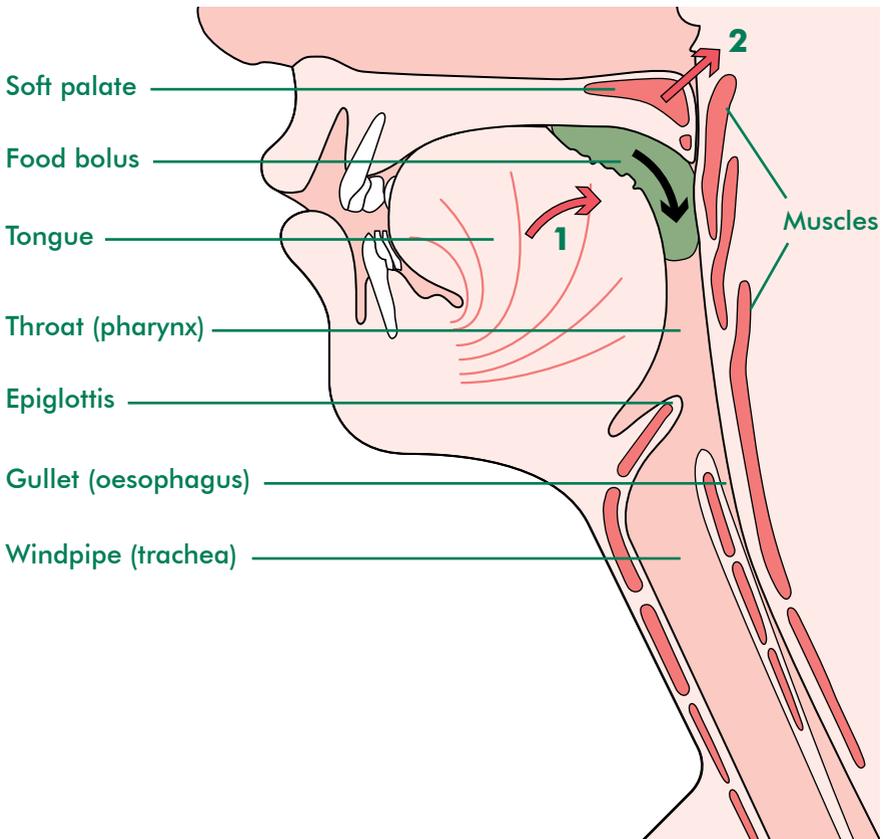
Swallowing happens in three stages. These are shown in the diagrams on the next few pages. We've used numbers to show what happens at each stage. The food bolus is shown as green in the diagrams. Eating difficulties can be caused by problems at one or more of these stages.

'I remember the struggle of learning to eat again after 3–4 months of having no appetite and being fed through the tube. It gets better and better. A year later, I'm still thrilled every time I get pleasure back from eating one more type of food. I can now eat anything, though with a glass of water not too far from me.'

Catherine

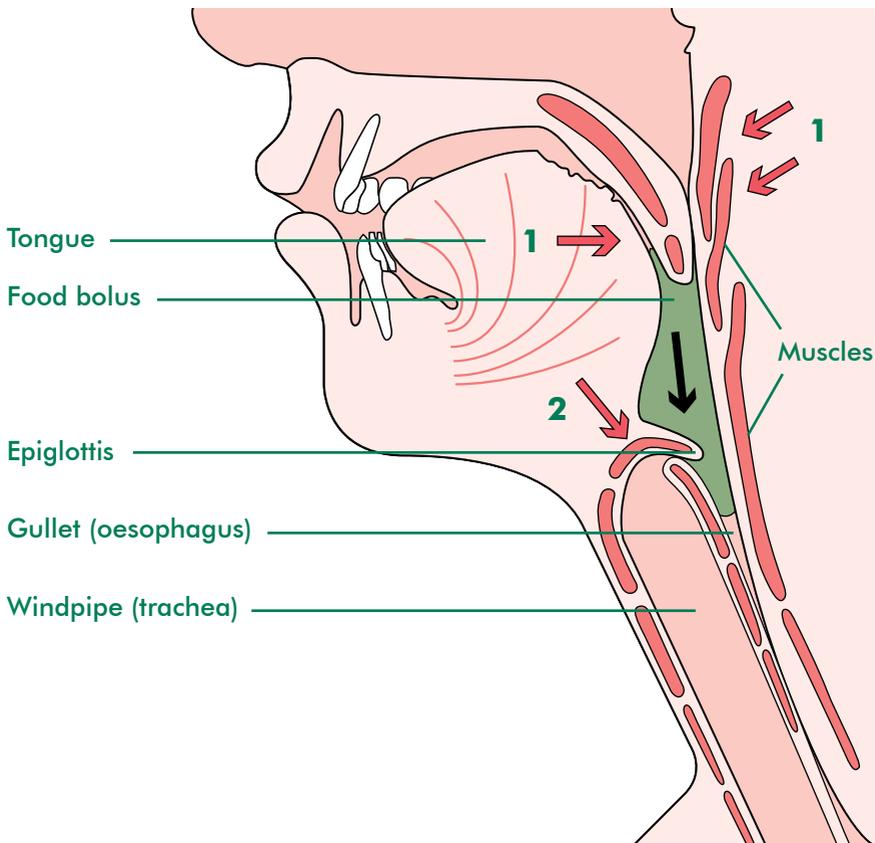
Mouth stage of swallowing

1. When the food bolus (shown in green in the diagram) is ready to be swallowed, the tip of the tongue squeezes against the roof of the mouth. This moves the food to the back of the throat (pharynx).
2. The soft palate moves up, closing the gap between the nose and mouth. This stops food from moving into the nose.



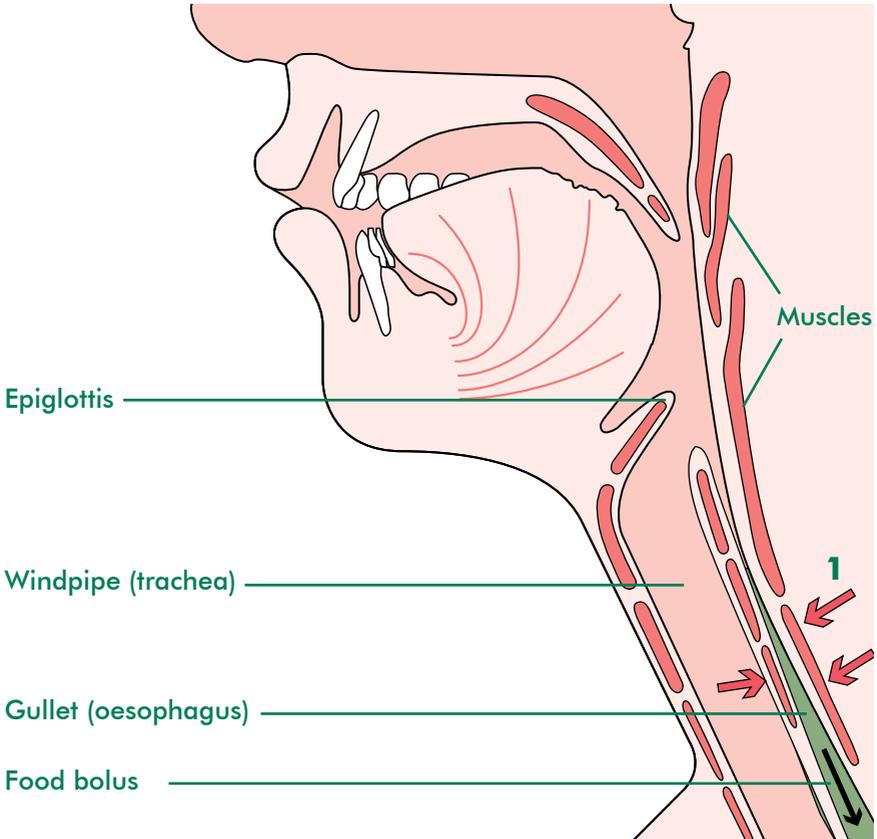
Throat (pharyngeal) stage of swallowing

1. As food moves into the throat, the muscles in the base of the tongue and throat (pharynx) squeeze together. This moves the bolus of food down.
2. Your voice box (the larynx) lifts in your throat and a flap of tissue called the epiglottis moves to close the airway and stop food going into the airways and lungs. The vocal cords close and the voice box moves upwards to further protect the airway. The gullet (oesophagus) opens.



Gullet (oesophageal) stage of swallowing

1. Muscles in the gullet squeeze and relax, pushing food down towards the stomach.



How treatments can affect chewing and swallowing

Surgery for mouth cancer can affect chewing and the mouth stage of swallowing. If only a small amount of tissue is removed, the change may be small and you will probably adjust quite quickly. If a lot of tissue is removed, or if some or all of the tongue or soft palate is removed, you may have longer-lasting changes. If you had teeth removed as part of your treatment, or you have dentures that no longer fit, your ability to grind food during chewing may change.

Muscles and nerves that control the lips, tongue or other parts of your mouth can be affected by surgery or radiotherapy. This can make it difficult to control food and fluid in your mouth. It may also affect your ability to sense where food is in your mouth.

Jaw stiffness (see pages 28–30) or a dry mouth (see pages 14–21) also cause difficulties with chewing and swallowing.

Surgery to the larynx mainly affects the throat stage of swallowing. Swelling in the throat caused by a build-up of fluid in the tissues (lymphoedema) can also affect swallowing (see pages 73–75).

Radiotherapy may make tissues in the throat and gullet weaker and less stretchy. This can make it harder to swallow some types of food or cause some foods to stick in the throat. If nerves that control the muscles in the gullet are affected, this can also weaken the muscles so they're less able to move food downwards.

The upper part of the gullet may be narrower after radiotherapy. It may also be harder for you to know whether there is food in the gullet.

Problems with swallowing can cause food or drink to go 'down the wrong way' into the windpipe (trachea – see page 37). This is called aspiration. It can cause choking and may lead to chest infections.

Sometimes swallowing problems develop months or years after radiotherapy. This can happen if scar tissue in the throat makes the swallowing muscles tight and hard, which is called fibrosis. Tell your SLT, specialist nurse or doctor if you have difficulty swallowing or if you're experiencing any of the following things:

- a deterioration in your ability to swallow
- drooling or dribbling when eating
- food coming down your nose
- food getting trapped in one side of your mouth
- biting your tongue or the inside of your cheeks
- feeling that you have too much saliva
- food sticking in your throat
- choking or coughing when eating or drinking
- a wet- or gurgly-sounding voice
- repeated chest infections
- weight loss.

Help with chewing

The type of treatment you have to improve chewing depends on what is causing the problems. This could be changed mouth shape, tooth loss, jaw stiffness, dry mouth or loss of sensation. It's important you are assessed by a specialist, such as a surgeon, restorative dentist or a speech and language therapist (SLT).

They may suggest:

- restorative dentistry or surgery
- exercises to strengthen and retrain the tongue and mouth muscles
- eating soft, pureed or moist food
- changing the amount of food you put in your mouth
- treatment for jaw stiffness (see pages 28–30)
- ways to relieve mouth dryness (see pages 14–21).

Restorative dentistry **S**

If changes to your bite or to the tissues inside your mouth are affecting your ability to eat or speak, restorative dentists may be able to help.

After surgery to the roof of the mouth (maxilla), some people have an opening between the roof of the mouth and nose. This is covered by a special type of dental plate, called an obturator. It stops food, fluid and air passing between the nose and mouth. Some obturators have a speech bubble at the back to help with speaking.

As the tissues in the mouth heal after surgery, they gradually shrink until they reach their final size and shape. This can take six months or longer. If you need an obturator, you will usually be fitted with a temporary one to begin with. Once your mouth has healed into its final shape, your dentist will make you a permanent one.

It's important to let your dentist know if you have any problems with the fit of the obturator. As the tissues in your mouth are settling, you will probably find that the fit needs adjusting from time to time by your hospital dentist.

'I started with a large plastic obturator, which covered the whole of the roof of my mouth. It had a speech bubble on the back, which went up into the soft palate. The one I have now is much smaller and made of cobalt, but still with the little pink speech bubble at the back. It hurt when I first got it. The best thing I found for the gums was a gel for mouth ulcers that I bought in the chemist.'

Nina

Exercises to improve chewing

An SLT will assess your chewing to find out which difficulties you have. They may arrange for you to have a swallowing test (see below).

They may give you exercises to strengthen your lips, tongue and other muscles in your mouth. There are also exercises to help stimulate parts of the mouth that have lost sensation.

Your SLT may give you chewing aids such as Chewy Tubes® to help you practise biting and chewing. Or they may give you spoon-shaped devices such as Ora-Light® to exercise the lips and tongue.

They may also advise you on changes you can make to the food you eat, for example choosing soft, moist foods. You may find it easier to chew with a larger or smaller amount of food in your mouth. This depends on the cause of your chewing difficulty.

Help with swallowing

The type of treatment you have to improve swallowing depends on which parts of the swallowing process are causing you problems. Your SLT will do an in-depth clinical assessment of your swallowing. You may need to have a swallowing test to show what happens when you swallow. There are two tests that can be used to assess swallowing:

- **videofluoroscopy** (VF)
- **Fibreoptic Endoscopic Evaluation of Swallowing** (FEES).

Your SLT will decide which is best and do the test for you.

A VF uses an x-ray and video to show what happens in your mouth and throat when you swallow. It takes 30 minutes and is done in the radiology department by a radiologist or radiographer and an SLT. You will be given food to swallow, which has had something added to make it show up on the x-ray. You will usually be asked to swallow foods of different textures. This might be something semi-solid such as yoghurt and something solid, such as a biscuit. The moving x-ray images of your swallow will be recorded on video.

A FEES involves passing a thin tube to the back of your throat. You probably had a similar test as part of your routine follow-up. The tube contains a camera to digitally record the test. You will be given small amounts of test foods and a drink to swallow. The test takes about 20 minutes.

Your SLT will explain the results of your swallowing test and use them to plan your treatment. The aim will be to help make swallowing easier and safer for you.

When you go to see the SLT, bring a partner, relative or friend with you if you can. This can help them to support you at home when you're eating. They can learn about techniques you need to use or changes to food you may need to make.

Your SLT may suggest:

- how to position your head and neck when swallowing
- swallowing techniques
- exercises to strengthen swallowing muscles
- eating and drinking thinner or thicker foods or liquids
- changes to the way you prepare and cook food
- taking time to eat and swallow
- coughing to clear your airway after you swallow
- coping strategies to help you adjust to changes to eating and drinking.

If your SLT gives you swallowing exercises, you'll need to do them regularly to get the most benefit. Some people use apps, such as iSwallow[®], to help guide them through swallowing exercises and to keep track of how often they do them. You can download the apps, but check which mobile device they work on. Always talk to your SLT before getting any apps.

Stretching the gullet (oesophagus)



Radiotherapy to the head and neck area can cause the top of your gullet to narrow. This may be identified on a videofluoroscopy. You may be offered a quick procedure to make swallowing easier. A doctor puts a tube down into the gullet to stretch it, to make more space for food and fluid to pass through. You can have this done as an outpatient and usually with a local anaesthetic. But sometimes it is done under general anaesthetic.

'I finished my radiotherapy in May and couldn't get anything down my throat until November. It's a long struggle so don't give up. I set myself targets of six sips of water a day and often didn't reach that. The first food I managed was chicken noodle soup with all the noodles strained out.'

Nina

Taste changes **CR** **R**

Radiotherapy to your mouth can affect your sense of taste. A lack of saliva can also disrupt your taste buds.

Some treatments can also affect your sense of smell, which can affect taste. Everything may taste the same or you may dislike the taste of certain foods. Some people can taste the first few bites of food then find that the taste gets less strong. These changes can reduce your desire for food and affect your appetite.



Usually, your sense of taste gradually improves after treatment ends. Sometimes it can take a year or more. Tell your doctor, dietitian or clinical nurse specialist if you have taste changes. They can offer advice and support.

Here are some tips for coping with taste changes:

- Focus on the food and drinks that you enjoy.
- Use a 'trial and error' approach. If a food you tried did not taste very pleasant, try it again after a few weeks. Your sense of taste may have improved.
- Use your other senses to enjoy food by making your food look and smell as appealing as possible.
- Add spices and herbs to your cooking, as long as they don't irritate your mouth.
- Try marinating meat in fruit juices.
- Try cold foods. Some people find that cold foods taste better than hot foods. Try serving cold meats with pickle or chutney.
- Sometimes people can taste sweet foods better. But be careful with sugary foods as they can cause serious tooth decay if you have less saliva after radiotherapy (see page 24).
- Use sauces and oils to flavour and moisten food.

'For a while, everything tasted like cardboard, but eventually my taste came back. I can taste most things but still find certain foods irritate my throat.'

Joyce

Acid reflux

Acid reflux is caused by acid in the stomach coming up into the throat or gullet. It's quite common after surgery or radiotherapy for head and neck cancer. Acid reflux can cause symptoms such as heartburn, coughing, sore throat, the sensation of 'something in the throat' and a hoarse voice. You should always tell your doctor if you have any of these symptoms.

Saliva helps to neutralise stomach acids, so acid reflux may be more noticeable if your mouth is dry. It can usually be treated with drugs to reduce or neutralise acid in the stomach.

Reflux is often worse when lying down. If you notice this, don't eat or have caffeine for three hours before you go to bed. There is caffeine in coffee, tea and chocolate. It may also help to raise your head with an extra pillow so that you're not lying flat.

Eating and socialising

Many social activities are based around eating and drinking. If you have difficulty chewing or swallowing, you may feel anxious or unsure about social situations. Everyone has their own way of dealing with these issues. This section has some suggestions you may find helpful.

If you feel self-conscious about eating in front of others, first get used to eating at home with people you know. When you feel ready to try eating away from home, do something simple to start with, such as going to a café for an ice cream. You can build from there as your confidence grows.

If you take a long time to eat, try eating smaller portion sizes but increase the number of times you eat each day. Eating small portions means you need to concentrate on eating for a shorter time, so you're less likely to get tired when eating.

If you're worried about keeping family or friends waiting while you eat, talk to them about this. They can reassure you that they don't mind you taking longer. You'll probably find they're more relaxed about it than you think.

When inviting someone over for a meal, people often make allowances for guests with different dietary needs, for example if someone doesn't eat meat or can't eat gluten. Tell your host in advance if you need food of a certain texture or thickness or if you can't eat spicy food. This helps them to prepare food that suits you. Or you can ask if you can bring your own food to be heated up.

If you're going out to eat in a restaurant, try to look at the menu before you go. You can find out if they offer meals that suit you or that can be adapted for you. Try contacting them in advance to ask if they can make changes to a dish, such as adding extra gravy, mayonnaise or butter, leaving out certain spices, or blending your food.

If you take some meals as liquid supplements, ask the restaurant if they can provide you with a cup. This means you can take a liquid supplement meal while your friends order from the menu.

People who don't know you may ask about your eating difficulties when they first share a meal with you. You may find it helpful to think of what you want to say beforehand. Or you might decide you don't want to explain it at all. You could ask your host to tell other guests in advance and add that you'd prefer not to talk about it. Do whatever makes you feel comfortable.

Not all of us are good at asking for what we need. If you find it difficult, you may find the information about being assertive helpful on page 96.



Changes in communication

Sometimes people's speech, voice or hearing can be affected by treatment for cancer in the head or neck. If you had a treatment that could affect these, your doctor or nurse will have talked to you about these possible changes.

Speech and voice

We use our lips, teeth, tongue, mouth, nose and throat when we speak. If you had an operation or radiotherapy to one or more of these areas, your speech may be affected. You may have difficulty making specific sounds or saying certain words. Dryness can make your mouth and throat feel uncomfortable when having longer conversations.

The sounds you make for speech (your voice) are made by the voicebox (larynx). Treatments that affect the larynx can affect your voice. Your voice may be hoarse, tire more easily or be quieter than normal. If you had your larynx removed, you will need to learn new ways to communicate.

We have more information about communicating after an operation to remove the larynx. Visit [macmillan.org.uk](https://www.macmillan.org.uk) to find out more. We also have a video that describes ways of communicating after an operation to remove the larynx (laryngectomy). You can find it at [macmillan.org.uk/voiceresoration](https://www.macmillan.org.uk/voiceresoration)

Changes to speech and voice

Any change to your lips, teeth, tongue, soft palate or voicebox is likely to make your speech or voice sound different. This may mean that you have difficulty making one or two specific sounds or saying some words. Sometimes it may be more severe. People may not be able to easily understand what you are trying to say, or they may not be able to hear you.

For some people, a change in their speech or voice will only be a minor problem and it will return to normal, or near normal, as the tissues heal. For others, it will be more of a problem and will cause permanent changes to the way they speak.

Losing the ability to talk, even for a short time, can be frightening and frustrating. In the first few days after your operation, you could communicate by writing things down. That will allow you to let people know what you need. A speech and language therapist will be involved in your recovery from an early stage. They will be able to give you support and helpful advice.

The following things may help if you have speech or voice changes:

- restorative dentistry – if speech problems are caused by changes in the teeth or shape of the mouth (see pages 42–43)
- speech and language therapy – including exercises to help you strengthen and control muscles used for speech (see next page)
- keeping your throat healthy by not smoking and by drinking plenty of water
- aids to help you communicate.

Speech therapy

Speech therapy can help you learn to communicate in the clearest and most effective way. Therapy usually begins as soon as possible after treatment and normally continues after you go home.

Speech and language therapists (SLTs) assess changes in your speech and voice. They can give you advice and treatments. If you have voice changes, they will give you advice on how to take care of your throat. They may give you exercises to help you make your voice heard without straining and increase stamina.

The exercises may feel like hard work at times, but it's important to keep going with them. It's usually more effective to do them for a few minutes, several times a day, rather than for a longer time less often. You may find it helpful to make a chart of the exercises you need to do and the times you do them.

There are apps you can get to help you manage your exercises. For example, the So2Speak® app is designed to help you do the exercises, remind you when they're due and keep a record of how often you do them. It's free to download, but check whether it works on your mobile device. Always talk to your SLT before trying any apps.

It will take time for you and your family and friends to adjust to your changed speech or voice. The reactions of strangers may be harder to get used to, but will get easier. It often helps if you can put people at ease by simply explaining that you have had treatment that has made it difficult for you to talk.

Tips for communicating

If people can't understand you, it's easy to feel frustrated. But there are things you and the people you communicate with can do to help you express yourself.

Ask your family and friends to give you time to speak and to let you finish what you have to say. Encourage them to tell you if they don't understand anything. If they need to check what you mean, suggest they ask you questions with a yes or no answer.

Here are some general tips:

- Choose a quiet place with no distractions or background noise.
- Find a well-lit place to have your meeting.
- Face the person.
- Tell them you have difficulty with your speech.
- Sit up straight or stand up when speaking. This will help you to use your breath better.
- Speak slowly and carefully. Try to use short sentences and take a rest between them.
- Keep a pen and paper with you so that you can get your message across by writing it down, if the other person can't understand what you are saying.

'My consultant recommended reading aloud to help improve my speech post-treatments. It really does help.'

Joyce

Other ways of communicating

Sometimes, you may need to use other ways to communicate. New technologies can help.

If you're making a phone call, you can increase the volume on some phones so that your voice can be heard without straining.

There are also helpful apps that convert the text you type into speech. The website appsforaac.net has a list of apps available. You might also find the Talking Mats® app useful. It uses images to help you communicate quickly. It's free to download and works on some mobile devices. Ask your SLT for more information.



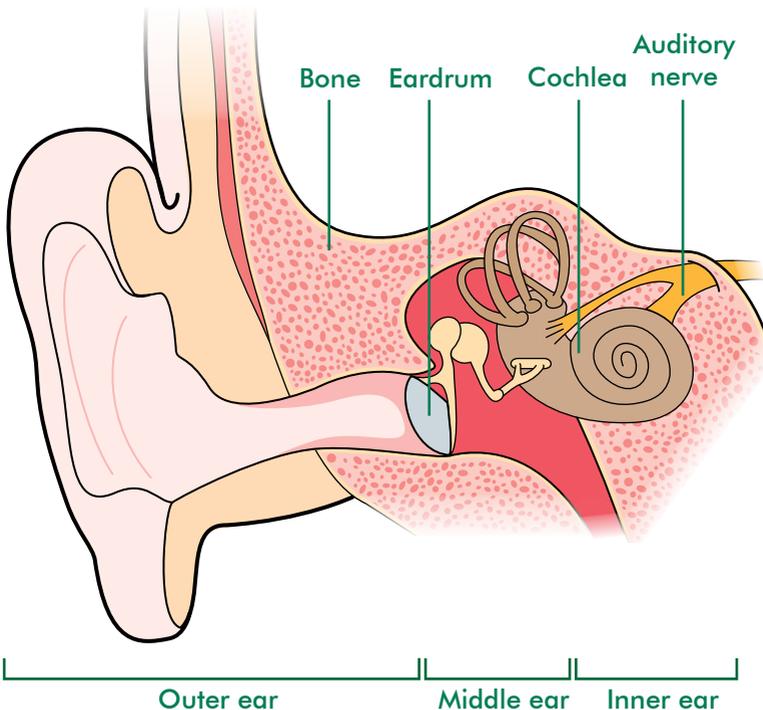
Thomas, who has had a laryngectomy

Hearing changes **C** **R** **CR**

Hearing may sometimes be affected after treatment for some types of head and neck cancer, such as nasopharyngeal cancer. Hearing loss may sometimes come on gradually in the first two years after treatment.

Radiotherapy or the chemotherapy drug cisplatin may cause ringing in the ears. This is called tinnitus (see pages 65–66). It often gets better as the ears recover from the effects of treatment. But it can sometimes be permanent. Your cancer specialist will have told you if the treatment you were given may affect your hearing.

The outer, middle and inner ear



Hearing loss

There are two main types of hearing loss.

Sensorineural hearing loss (SNHL) is caused by damage to tiny nerve hairs in the cochlea or to the nerve in the inner ear (auditory nerve). It makes it difficult to hear soft sounds and to tell some sounds apart.

Conductive hearing loss is when sounds can't pass from your outer ear to your inner ear. This is caused by a blockage in the ear, for example from a build-up of fluid or from earwax.

It's possible to have both these types of hearing loss. This is known as **mixed hearing loss**.

Signs of hearing loss can include:

- difficulty hearing other people clearly and misunderstanding what they say
- missing bits of conversation, especially in groups or when there's background noise
- asking people to repeat something
- listening to music or watching TV with the volume turned up higher than usual
- using subtitles on films or TV programmes.

Tell your GP or specialist if you have problems with your hearing. They can refer you to an audiologist (hearing specialist) or an ENT (ear, nose and throat) surgeon for further tests, including a hearing (audiometry) test.

'I put headphones on and was played a variety of sounds at various volumes. All I had to do was press a button when I heard something. Then it advanced to me hearing hissing noises with beeps and I had to press the button for the beeps. This got very difficult as the hissing noises were made louder.'

Margaret

Treatments for hearing loss

If you have hearing loss, you will be assessed by an ENT surgeon and audiologist. Treatment will depend on the cause of your hearing loss. The surgeon may be able to gently clear away any wax and debris in the ear canal.

Treating fluid in the ear

If you have a build-up of fluid in your ear because of infection, your doctor can prescribe antibiotics to treat it. Sometimes, doctors treat this fluid with a small tube called a grommet. The grommet lets fluid drain from the ear so that it doesn't cause a blockage. It's put in during a small operation, usually under a local anaesthetic.

Hearing aids

Hearing aids can help with both types of hearing loss. They work by increasing the volume of sounds.

There are many different designs. The audiologist will explain which type is most suitable for you. They will also show you how to:

- put the hearing aid in and operate the controls
- change the batteries
- use it in different situations
- clean and check the hearing aid.

'We went out early yesterday morning to collect my hearing aids. I don't think I'd realised how much it had got me down not being able to hear and communicate with people. It was bliss to be able to listen to the radio. I rang my mum for a chat, it was great to be able to use the phone again. Best of all, I can communicate properly with my husband.'

Margaret

Cochlear implants

Some people who have hearing loss because of damage to their cochlea (see diagram on page 59) can be treated with a cochlear implant. This is a small hearing device fitted under the skin behind your ear. It's put in during an operation, under a general anaesthetic.

Your hearing specialist will explain the benefits and disadvantages of each treatment to you.

Living with hearing changes

Adapting to changes in hearing can take time, but support is available. Hearing clinics may have information on social services, support groups and lip-reading classes in your local area.

Your local authority will have a social services department to support people with a hearing disability. They can advise you on specialist equipment like smoke alerts. Hearing Link and Action on Hearing Loss are organisations that can also give you information about living with hearing changes. You can find their contact details on pages 123–124.

There are phones that can make sounds louder and help you to hear callers more easily. There are also systems such as Next Generation Text (NGT), which enable people with hearing loss to communicate through text. Visit [ngts.org.uk](https://www.ngts.org.uk) to find out more.

There are also apps designed to help people with hearing difficulties. Visit [hearinglink.org/apps](https://www.hearinglink.org/apps) for more information.

Support groups can be a good place to share experiences and find out what other people have found helpful. There may be a support group for people with hearing loss and their families in your area. Go to [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport) to find out more.

Here are some more tips for communicating:

- Tell people your hearing is not good.
- Find a well-lit place to have your meeting.
- Ask the person talking to face you and get your attention before beginning to speak.
- Ask them to speak clearly and not too fast.
- Try to get rid of background noise, such as the TV or radio, when talking with people.
- When you're in a group, following the conversation can be more difficult. Asking one person in the group to help you catch up may help.

Tinnitus

Tinnitus is a sound that you hear from inside your body, rather than from outside. It's often described as a ringing sound, but it can include other sounds such as buzzing, whistling, humming, whooshing or hissing. The sounds can be constant, or they can come and go. Tinnitus often gets better as your ears recover after treatment.

Living with tinnitus can be stressful and some people find it affects their concentration or sleep. But there are ways of managing it.

Things that can help include:

- learning about tinnitus
- wearing a hearing aid (if you have hearing loss)
- using other sounds to distract you
- learning relaxation techniques.

'After cisplatin, I had some tinnitus. It's been a year since my treatment finished and the tinnitus has now gone.'

Greg

You may be referred to a tinnitus clinic to see an expert. They can help you to understand and manage it. Knowing more and understanding how you feel about tinnitus can help you cope. You can learn how to tune tinnitus out, so that over time it becomes less troublesome.

Tinnitus can be more noticeable if you have hearing loss. Things that improve your hearing can help, such as hearing aids. External sounds can help your brain to focus on something other than the internal sounds of tinnitus. Some people use background noises to distract them from tinnitus. This may be something simple like having an electric fan on or using sound recordings of breaking waves, birdsong or white noise (a shushing sound). There are devices specially designed to produce sounds for people with tinnitus.

Tinnitus can be made worse by stress and anxiety. Learning ways to help you relax can lower your stress levels. Your clinical nurse specialist, GP or staff at the tinnitus clinic may be able to refer you for therapies that can aid relaxation.

The British Tinnitus Association (BTA), Hearing Link and Action on Hearing Loss have more information on tinnitus. You can find their details on pages 123–124.



Effects on the neck and shoulders **S**

It is good to familiarise yourself with how your neck feels after surgery for head and neck cancers. Skin in this area can feel tighter once it has healed. It can also be uneven and lumpy to the touch. If you feel anything new in this area, you should contact your specialist nurse or consultant to discuss it further.

Neck scars

Surgery to remove lymph nodes in the neck, called a neck dissection, can cause changes in the neck and shoulder. After your operation, as the scar heals, it becomes tighter and thicker. Radiotherapy after surgery can also cause changes to tissue in the treatment area.

'I have an ear-to-ear neck dissection scar and even after almost eight years it can still feel tender and tight (more so in cold weather). The nerves in my face and neck can still 'tingle' too. My district nurse recommended using Bio-Oil on the scars and it does help.'

Joyce

Your neck may feel stiff when you move your head. It may be numb in places, especially around the scar. This often improves over time but doesn't always go away completely. Some people have neck or ear pains. The pain may come as spasms, lasting a few seconds before going away. As the scar heals, you may have some 'pins and needles' sensation as the nerves repair. Your neck may also be more sensitive to touch, heat or cold.

Gentle massage with a non-perfumed cream or oil will keep the skin supple and help with flattening the scar line.

'Nearly three years after the op, my neck often feels very tight. Sometimes it feels like I have cramp in it, especially in cold, windy or wet weather.'

Nina

Removing lymph nodes in the neck can sometimes cause a build-up of fluid in the tissues, leading to stiffness and swelling. This is called lymphoedema. We have more information about it in the next chapter (see pages 73–75).

Sometimes, during surgery to lymph nodes in the neck, the spinal accessory nerve is injured. Normally, this nerve sends messages to the shoulder muscle. If it's damaged, the shoulder may feel stiff, painful or weaker than before.

If the nerve was only bruised, it usually heals within a few months. But if it was removed, the shoulder muscle gradually gets smaller and weaker. This can cause long-term changes in the shape and position of your shoulder blade.

Changes in your neck and shoulders can take up to six months to develop. It is common for stiffness in the neck and shoulders to develop before you have any pain. It's important to get any stiffness checked as early as possible. This will reduce the risk of developing a frozen shoulder. This is when the tissue around the shoulder becomes inflamed, stiff and painful.

If you have neck or shoulder symptoms, your doctor may arrange tests to find out the cause so they can give you the right treatment. They can prescribe painkillers if needed and refer you to a physiotherapist.

The physiotherapist may suggest:

- neck or shoulder exercises
- changes to your posture
- massage
- pain relief
- safe ways of returning to physical activity.

If you are having restorative dental treatment after cancer treatment, you may find long periods of lying flat in the dentist's chair uncomfortable. Talk to your dentist about working in a more comfortable position, or breaking the treatment up into shorter appointments.

Neck and shoulder exercises

Muscles around the head and neck can become overworked and tight after surgery. Your physiotherapist will assess them and show you exercises that can help. Stretches and massage may help to reduce tension and pain. They work best when done regularly. If you have neck stiffness after radiotherapy, you will need to do neck exercises for the rest of your life.

Your physiotherapist may show you shoulder exercises to improve movement and reduce pain. Doing these exercises regularly can help prevent a frozen shoulder. You may be given an elastic tension band or light weights to exercise with. As your strength and movement improves, you can gradually increase the elastic tension or weight. This is called progressive resistance training.

The effects on your shoulder may be more severe if the spinal accessory nerve, which sends messages to the shoulder muscle, was removed or is permanently damaged. A physiotherapist may use specially designed strapping or a brace (an orthosis) to support your arm and hold your shoulder in the right position. This can reduce any pain and help you to use your arm.

'After a month, I was still struggling with roll-on deodorant. I couldn't stretch the left arm enough to flatten the surface of the armpit. Wearing clothing that had to go over my head was impossible. Four months on and the difference is amazing. But my shoulder still feels a bit lopsided and I can't shrug my shoulder up to my ear anymore.'

Margaret

Posture

After your operation, it may feel easier to sit in a slumped position. Try not to do this as it can encourage muscle weakness and tightness. Good posture is important and will help movement in your neck and shoulders.

You can do things to help your posture. Look at yourself in the mirror, to check the position of your head and shoulders. Then sit with your lower back supported, or stand up straight with your shoulders back but relaxed. This will put your joints and soft tissues in a good position. Practise doing this until it feels like your normal posture.

Massage

Once the scar tissue has healed, regular and firm massage will help relieve tightness. Use a non-perfumed oil or cream. Your nurse or physiotherapist can show you, or a relative or friend, how to do the massage.

Pain relief

Your doctor can prescribe regular painkillers for you (see pages 77–78). Tell your doctor if your pain doesn't get better. They can increase the dose or change your painkillers. If the pain is due to tightness in your neck or shoulder, physiotherapy and exercise may also help.

Swelling of the face or neck (lymphoedema) **S**

After surgery, it's common to have some swelling in your face or neck. This usually goes away within a few weeks. But sometimes people who have had an operation to remove lymph nodes from their neck, develop long-term swelling. This is called lymphoedema. It happens because the lymphatic system, which normally drains fluid away, isn't working properly.

Lymphoedema may be worse in the morning and improve as the day goes on. As well as causing swelling you can see in the face or neck, it can also affect tissues inside the neck, such as the throat or larynx (voicebox). This can cause difficulty speaking, swallowing or breathing.

Always tell your GP or cancer specialist if you notice swelling in your face or neck. They can arrange for you to have tests to find what's causing it. Lymphoedema is usually treated by a lymphoedema therapist. Your GP, specialist doctor or health professional at the hospital can refer you to one.

Skincare

It's important to look after the skin on your head, face and neck if you've had any lymph nodes in your neck removed. This can help to reduce the risk of developing lymphoedema. It is also an important way of managing lymphoedema.

Lymphoedema can make your skin dry, itchy and more fragile than before. Any break in the skin increases your risk of infection, which can make swelling worse.

What you can do:

- Use soap-free cleansers that don't dry the skin.
- If you shave, use a clean electric razor.
- Moisturise daily with unperfumed cream or lotion.
- If you get any cuts or grazes, wash the area carefully and put antiseptic cream on straight away.
- Protect your face and neck when you're in the sun. Wear a hat and suncream with a sun protection factor of at least 30 (SPF30).
- Wear insect repellent to prevent bites or stings as these can make lymphoedema worse.
- See your GP straight away if you develop any sign of infection in your skin such as tenderness, redness, heat, discharge or a new area of swelling.

Treating lymphoedema

One of the main treatments for lymphoedema is a type of massage called **manual lymphatic drainage (MLD)**. MLD encourages and improves the movement of lymph fluid from swollen areas. NHS lymphoedema treatment clinics often provide MLD. You can also do a version of MLD, called **simple lymphatic drainage (SLD)**, at home. Your lymphoedema or MLD therapist can teach you this.

Some people are given compression garments to help to keep swelling down. They work by stopping fluid from gathering in the affected tissues. You should only wear a compression garment that has been fitted by a lymphoedema specialist. Poorly fitting garments can do more harm than good.

Lymphoedema can affect your appearance and how you see yourself. It's important to get support from professionals and those close to you if you need it. Pages 92–96 have more information and advice about dealing with changes to your body image.

'My husband was given exercises and massage as well as a compression bandage to wear at night. These worked really well and the swelling went right down and has stayed down.'

Julia

Pain or numbness

If you had pain during treatment, it will usually get better as your tissues heal. Sometimes pain or discomfort lasts for several months or more.

Always tell your doctor if you have a new pain or pain that is getting worse. They can arrange tests to find out the cause. Pain can happen for different reasons. It may be caused by a late effect of treatment such as trismus (see pages 28–30), scar tightness or nerve damage (see pages 82–83). Sometimes it may be a symptom of cancer coming back.

It's natural to feel anxious if you develop pain. But it's important to get it checked out as soon as possible so that you can be given treatment for it.

To help your doctor understand your pain, tell them:

- where it is
- how bad it is, using a scale of 0 to 10
- whether it's constant or comes and goes
- if anything makes it worse or better
- how it affects you, for example when you move, eat or sleep
- if you'd describe the pain as aching, burning, dragging, intense, tender or throbbing.

Managing pain

How pain is managed depends on how severe it is and what is causing it. Painkillers are often used to manage it. Other treatments that may help include physical therapies and relaxation therapies.

Painkillers

Different painkillers are used for mild, moderate and severe pain.

Mild pain

Painkillers used for mild pain include paracetamol and anti-inflammatory drugs such as ibuprofen (Brufen[®], Nurofen[®]).

Moderate pain

Painkillers used for moderate pain include weak opioid painkillers, for example dihydrocodeine (DF118 Forte[®], DHC Continus[®]), codeine phosphate and tramadol.

Severe pain

This pain can be managed using strong opioid painkillers, for example morphine, oxycodone, fentanyl or diamorphine.

Some painkillers work well for muscular pain and others work better for nerve pain. Anti-inflammatory drugs help reduce inflammation and swelling. These are especially good at treating pain in the skin, muscle or bone. They can cause indigestion and may irritate the lining of the stomach, so take them after a meal or snack. If you've had stomach problems, your doctor may advise you not to take them. If muscle spasms are making your pain worse, you may be prescribed a drug to help relax the muscles, such as baclofen (Lioresal[®]).

Drugs that act on the nervous system, such as gabapentin and amitriptyline, are used to treat nerve pain. The dose is often increased gradually over a few days or weeks. It can take a few weeks for them to take effect.

Take your painkillers regularly, as prescribed by your doctor. They aim to make sure pain control is constant. People often think they should put off using painkillers for as long as possible. This isn't a good idea as it leads to unnecessary pain. It also allows the pain to build up, which can make it harder to control.

It's important to let your doctor know if your pain isn't controlled with your painkillers. Your regular dose may need to be changed or you may need a different painkiller. It sometimes takes time to get the right painkiller and dose to control your pain. You may need a combination of different types of painkiller to get the best control for your pain. Your doctor can refer you to a specialist pain team if your pain is not well-controlled.

Some painkillers can cause constipation. Constipation means that you're not able to open your bowels regularly and it can become difficult or painful for you to pass bowel motions. If the constipation is due to the painkillers that you are taking, it may be possible to adjust the dose you take. You may need to take laxatives as well. Talk to your doctor who can give you further advice.

Physical therapies

If the pain is caused by tightness from scar tissue in the jaw, neck or shoulder, taking painkillers and doing exercises to stretch the tissues may help. A physiotherapist can show you these.

Massage and warmth can also ease tightness or muscle cramps in the neck or shoulders. Check with your physiotherapist, doctor or nurse before trying these. Some people use a heat pack that can be put in the microwave to warm the area. If you want to try this, always follow the manufacturer's safety instructions. Make sure the pack is warm and not hot, especially if there is any sensory loss in the area. If you are worried about using a heat pack, check with your therapist.

Sometimes pain is caused by lymphoedema. Your doctor can refer you for treatment for this (see pages 73–75).

Relaxation

Feelings like fear, anxiety, depression and tiredness can make pain worse. Learning to relax and let go of your worries, even if only for a short time each day, can help you manage and control pain.

Sore mouth

After radiotherapy, mouth soreness usually gets better within a few weeks but you may be more likely to get infections or ulcers in your mouth. Your mouth may be more sensitive to spicy, salty, hard or crunchy foods. Alcohol, especially spirits and wine, may also irritate your mouth and make it sore.

If you have a sore mouth, it's still important to continue with regular mouth care. Change to a small, soft-bristled toothbrush until your mouth recovers. If toothpaste irritates your mouth, try a flavourless toothpaste or a brand that doesn't contain sodium lauryl sulphate (check the ingredients label). Page 25 has more information about this.

Always ask your doctor or nurse for advice. They can check for signs of infection and prescribe treatment for you.

Your doctor or dentist may prescribe a mouthwash called Caphosol®. This can be helpful in preventing sore mouth or dryness and treating oral mucositis.

There are also treatments that you can apply directly, such as Gelclair® and Episil®. They work by coating the inside of the mouth and protecting sore areas. Your doctor may advise you to use them about an hour before eating.

Your doctor or specialist nurse can advise you on the best painkillers for your situation. Soluble aspirin is often used to help relieve mouth pain. Dissolve one 300mg aspirin tablet in 100ml water and swish the solution around your mouth before swallowing it. Diluted Difflam® mouthwash can help with pain and inflammation in the mouth and pharynx.

Warm salt water rinses can help. Take 250ml boiled water that has cooled to a warm temperature, and mix in one teaspoon of table salt. Rinse the salt water gently around the mouth then spit it out. Repeat as often as you like.

Numbness

If a nerve was damaged during surgery, you may have a change in sensation or numbness in that area. It can take up to two years for nerves to heal and normal feeling to return.

For a few people, the only way to remove all the cancer is by cutting the nerve. If this happens, sensation changes to that area will be permanent.

Pain can be a useful warning to protect us against injury. If you have numbness or a change in sensation in a part of your head or neck, take extra care to protect it. Sometimes an area that is numb can be injured without you noticing.

If you shave, be careful around skin that's numb. It's safer to use an electric razor. You'll also need to be careful not to expose the numb area to very hot or very cold temperatures.

Peripheral neuropathy

Some chemotherapy drugs can cause changes in sensation to the hands, feet and legs. This is called peripheral neuropathy. This is when there is damage to the nerves that carry messages between the brain, the spinal cord and the rest of the body. Nerve damage causes symptoms such as pins and needles, numbness or pain to the hands and feet.

These symptoms usually begin to improve gradually, a few months after chemotherapy treatment ends. Sometimes damaged nerves don't completely recover and some people have long-term changes. But symptoms may become less troublesome over time if you find ways of coping with them.

Managing peripheral neuropathy

There isn't a drug or treatment that can repair damaged nerves. But nerve pain, sometimes called neuropathic pain, can be treated. Your doctor can prescribe drugs that change nerve impulses and so help to relieve the pain. These include some anti-depressants, anti-convulsants (used to treat epilepsy) and some heart drugs. If your pain is difficult to treat, you can ask your doctor to refer you to a pain clinic for expert help from specialist doctors and nurses.

If nerve damage is affecting your balance or walking, a physiotherapist can give you treatment and advice. If daily tasks are difficult, ask to be referred to an occupational therapist. They can suggest aids and equipment to help.

If your symptoms continue for more than six months and you find walking or daily activities difficult, you may be able to get financial help. Call our cancer support specialists on 0800 808 00 00.

There are also things you can do to help yourself:

- Keep your hands and feet warm. Wear gloves and warm socks in cold weather.
- Avoid walking around barefoot, and check your feet regularly for any problems.
- Wear well-fitting shoes or boots.
- Wear gloves when working with your hands, for example doing household chores, gardening or DIY.
- Before baths or showers, test the temperature of water with your elbow to make sure it isn't too hot.
- Turn the temperature control to a lower setting for hot water or have a temperature control (thermostat) fitted.
- Keep areas that you walk through free of clutter and well lit.

We have more information on controlling cancer pain and peripheral neuropathy. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call **0808 808 00 00** to order free copies.



Tiredness

Feeling extremely tired (fatigue) is one of the most common side effects of head and neck cancer treatment. You may feel like you have no energy so that it's difficult to do simple, everyday things. It's not unusual for this to last for months after treatment. In some people, tiredness may continue for a year or more.

Possible causes

Sometimes, tiredness is linked to pain (see pages 76–79). It can also be because of depression, sleep problems, an underactive thyroid gland or having a low amount of red blood cells (anaemia).

It's important to find out if there's a particular cause for your tiredness, so it can be treated. Tell your doctor or nurse how you're feeling. Be honest with them about how tired you are. They can take blood samples to find out if your thyroid gland is underactive or if you have anaemia. These conditions can be treated with medicines.

Depression

Tiredness can be a common symptom of depression. It's not unusual to feel depressed or anxious after cancer treatment. If you think you may be depressed, talk to your doctor or nurse. Your doctor may be able to prescribe anti-depressants.

Talking about your feelings with a professional counsellor can help. Some people find that complementary therapies also help to reduce stress and may improve tiredness.

Sleep problems

If sleep problems are causing or contributing to tiredness, improving your sleeping pattern will also help you feel better. We have more information about sleeping difficulties.

You may want to learn some relaxation techniques. Relaxation CDs and tapes may be available from your local library. Some hospitals, cancer centres and hospices offer breathing control and relaxation sessions. Ask your doctor or nurse whether any are suitable for you.

Pain

Coping with pain can be tiring. If you have effective treatment for your pain, this may improve your energy levels (see pages 76–79).

An underactive thyroid

Radiotherapy for head and neck cancer can sometimes cause the thyroid gland to become underactive (hypothyroid). This can develop months or years after treatment. The thyroid gland is in the front of the neck. It makes hormones that control the rate that the body works at.

Symptoms of an underactive thyroid gland can include:

- feeling tired and lethargic
- constipation
- slowed thinking
- weight gain
- dry skin and hair.

If your doctor thinks you may be at risk of developing an underactive thyroid, you'll have yearly blood tests to check it's working normally. If you do develop an underactive thyroid gland, it can be treated with daily tablets.

Tips for managing tiredness

Here are some tips for managing tiredness:

- Regular exercise, such as short walks, can help build up energy levels and reduce tiredness. It also helps to reduce stress.
- Develop a routine so that you go to bed and get up at the same time each day. Try not to stay in bed after you wake up.
- Balance activity with regular rest periods.
- Let family, friends and neighbours know how they can help.

Our booklet **Coping with fatigue** has more detailed information and practical advice on how to deal with fatigue. You can order it free from **be.macmillan.org.uk**

Concentration and memory

After treatment for head and neck cancer, some people have difficulty concentrating and remembering things. At the moment, it's not clear which treatments may cause these problems or whether they're caused by tiredness, stress or depression.

Because changes in concentration and memory were first noticed in people who had had chemotherapy, the terms 'chemo-brain' or 'chemo-fog', are sometimes used to describe them. But people with cancer who have never had chemotherapy can also have memory and concentration problems.

Changes in memory or concentration are usually mild and often get better within a year of finishing treatment. Occasionally, they can go on for longer or have more of an effect on your daily activities.

Here are some examples of the difficulties people describe:

- Difficulty in concentrating and focusing (feeling foggy).
- Finding it hard to take things in and forgetting details of conversations.
- Mixing up dates and appointments.
- Not being able to find things easily.

If you're having these problems, talk to your doctor. They will check whether your symptoms are connected to any other causes. This can include the side effects of medicines that you may be taking for tiredness, pain or depression. Treating these things can help.

Managing concentration and memory problems

There are different things you can do to improve your symptoms and help you cope:

- Use a pill box dispenser if you need to take medicines.
- Use planners, calendars, post-it notes or to-do lists.
- Write down anything important.
- Have a daily routine. Try to do one thing at a time and keep things in the same place.
- Try brain exercises like crosswords, word puzzles or sudoku to help improve your concentration.
- Get plenty of rest but try to balance this with some physical activity.



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Body image

Treatment for head and neck cancer can cause changes to your body and affect how you feel about the way you look. If your appearance has changed, it may take time for you and the people close to you to get used to this.

Sometimes changes in how you see yourself can mean you avoid situations where you may feel uncomfortable. But the more you avoid social situations, the less you'll feel like going out in future. This can leave you feeling isolated and cut off from support and companionship when you need it most.

Accepting that you're not going to be exactly the same as you were before having cancer, can be an important step in your recovery. It can help you to focus on what you can do and help you set realistic goals.

For most people, acceptance takes time. Your specialist team at the hospital can give you support and advice to help you adjust. If you're finding it hard to cope with the changes in your body, you can ask to see a counsellor. Changing Faces is a charity that focuses on helping people with any disfigurement find a way to live the life they want. They have a confidential helpline that offers advice and support. See page 123 for contact details.

You may find it helpful to talk to others who have been in a similar situation. You might find our online community helpful. You can share your experiences, ask questions and get support online. Visit [macmillan.org.uk/community](https://www.macmillan.org.uk/community) You could also ask your specialist nurse for any local support groups that could provide support and practical advice.

How concerns about body image may affect you

Body changes may cause you to have concerns about your body image. This may start before or during your treatment, or you may not think about it until later.

Everyone's reaction is different. Some people may feel more self-conscious about their body but find it manageable. Or you may find your concerns are on your mind a lot of the time and find this upsetting.

Body image concerns may make you feel:

- less confident
- anxious about people's reactions to you
- worried about going out and meeting people
- as if you've lost a part of yourself or aren't the person you used to be
- worried about your relationship or about starting a new relationship
- less feminine or less masculine.

You may also feel angry, anxious or sad. These are normal feelings when you are coping with cancer and body changes. You may feel as if you are grieving for what you have lost.

Talking openly with people you trust can be the best way forward. This could be your family or close friends, or your cancer doctor or nurse. Talking to another person who has been through something similar can also help. There are different types of support to help you cope with your feelings.

But you may also find you come to value how your body has coped. Some people see their body changes as signs of their survivorship. It can also be good to know that people appreciate you for who you are, not for your appearance.

Covering up physical changes

Lots of us cover up parts of our body that we are less comfortable with. Some people feel more comfortable wearing scarves or tops with higher necks to cover changes to their face or neck. You might prefer to do this, but try not to become focused on hiding areas. This might make you more anxious and lead you to avoid situations as you're worried that other people will find out about what has changed.

Camouflage make-up

If parts of the skin on your face or neck have been replaced with skin from another part of the body, the skin colour may not match the surrounding skin. You may also have visible scars. It's possible to reduce the differences of skin colour and disguise the appearance of scar tissue by using camouflage make-up. It can be matched to all skin types and colours in both men and women. Some head and neck clinical nurse specialists and organisations offer camouflage make-up services with advice on how to apply it (see pages 123–124).

Some types of camouflage make-up can be applied to facial prostheses to improve the colour match to the skin. This can be useful in the summer when skin tone changes. If you have a prosthesis that needs colouring, you should take it back to the person or organisation that supplied it.

We have more information to help you cope with changes in appearance in our booklet **Body image and cancer**. Call us on **0808 808 00 00** to order it.

Dealing with awkward questions

People may want to ask you how you're feeling. Others may just want to know what has happened to you. It may be helpful to think of possible answers to questions that might make you feel awkward. There is no right or wrong thing to say. You can choose how much you want to say. You don't have to say anything at all.

A short explanation about what's happened is often fine, such as:

- 'I had an operation.'
- 'I had cancer and an operation six weeks ago.'
- 'I had an operation to remove the cancer and am getting used to the changes, but it will take a while.'
- 'Thank you for asking, but I don't want to talk about it.'

Being assertive

Learning how to be assertive can help you cope with body image issues. It can also help you interact better with others. Being assertive is different from being passive or aggressive.

An example of being passive is avoiding situations that worry you. An example of an aggressive response is getting angry with people when you can't do something.

Being assertive means giving your point of view and being able to ask for help. It means knowing that you have the right to:

- say what you need
- be treated with respect
- make a request
- be honest
- make mistakes.

You may be able to get assertiveness coaching on the NHS. Your cancer doctor, specialist nurse or GP can tell you what is available near you.



Your sex life

Sexual difficulties can happen as a result of the physical and emotional effects of cancer and its treatment. You may lose interest in sex, feel unattractive or worry that you'll never be able to be sexually active. For some people, these problems continue after treatment is over.

Bringing sex back into your life can involve a period of adjustment. After treatment, some people have problems with their body image and self-esteem. Others may be left with a low sex drive (libido) or have sexual difficulties as a result of the physical effects of treatment. Changes to your face, mouth and neck can change how you feel about kissing and having sex. Usually, with time, most difficulties can be overcome.

Tiredness

You may feel too exhausted to have sex during treatment and for a while afterwards. Most people find that this gradually improves, but occasionally it can last for months or even longer. You can read more about coping with tiredness on pages 85–87.

Discomfort or pain

If you have problems with pain, this may affect your sex drive. Controlling the pain may improve your desire to have sex. Pages 76–79 have more information on managing pain.

Menopausal symptoms in women



If you were still having periods before your diagnosis, some chemotherapy drugs such as cisplatin, may affect these. Your cancer specialist or nurse can talk to you about this. Often periods return to normal after treatment ends. But in some women, chemotherapy may cause periods to stop permanently. This is called the menopause.

The closer in age you were to your menopause when you had chemotherapy, the more likely you are to be affected. The menopause can affect your sex drive directly. It can also cause vaginal dryness and hot flushes. This can make having sex difficult and reduce your sex drive.

If your periods have become irregular or have stopped, your doctor can do blood tests to check whether you're going through the menopause. You can also discuss hormone replacement therapy (HRT) and other ways of coping with menopausal symptoms. Managing hot flushes and other symptoms may help to improve your sex drive. Using gels and creams to help vaginal dryness can help ease discomfort during sexual activity.

Sex and intimacy

Physical and emotional changes after cancer and its treatment may affect your sexual confidence or ability to have sex. This could cause difficulties with a partner, delay you getting back to having sex or affect any new relationships.

Concerns about your sex life and intimate relationships are normal. If you are in a relationship, you may worry your partner will compare things to how they were before or no longer find you attractive. But your attractiveness to your partner will be linked to lots of different things. It's not about how a part of your body looks.

If you're not in a relationship, you may worry about how a new partner might react to any body changes. People who have cancer do go on to have close and intimate relationships in the future.

You'll probably need time to recover and adapt to body changes before you feel comfortable about having sex. How long this takes depends on what feels right for you and your partner.

Partners may also have concerns. Talking openly with each other can have a positive effect on your relationship and make you feel more comfortable with each other.

Even if you don't feel like having sex, you may still want to be close to your partner. Focusing on being intimate can take the pressure off. This could be spending more time together, holding hands, hugging, kissing or giving each other a massage. This intimacy can help you slowly get back to having sex again.

If difficulties with your sex life don't improve, talk to your doctor or specialist nurse. Try not to feel embarrassed – they're used to giving advice on intimate problems. They can give information on how to improve sexual difficulties and advice on different ways of looking at problems. They can also refer you to a sex therapist if needed.

Ways of releasing feelings

Sexual self-esteem is often directly related to overall feelings of well-being. If you feel unsure about yourself and lack confidence as a result of the cancer, you may also lack confidence sexually. It can help to talk about and express these difficult feelings.

You could share your feelings with someone who will listen and not judge you or tell you what to do – perhaps a close friend or family member. If you have feelings that are hard to discuss, you could always talk to our cancer information specialists on **0808 808 00 00**.

Sexual contact can be a good outlet for some people. Anger may subside in a healthy way after intercourse. Sexual contact can also distract people from feelings that are bothering them.

If you have a partner, you may find it best to talk directly with them. Share your rage, anger and other feelings. Many couples use such times to start being more honest with one another, perhaps after many years of avoiding sensitive issues. Keeping old feelings hidden won't help you or your relationship to heal. By talking openly you may find that you can overcome the problems in communication that are common in matters of sex and cancer.

We have more information to help you deal with the physical and emotional changes that cancer treatment can cause. Call us on **0808 808 00 00** to find out more. We also have a video on our website that may help, at **[macmillan.org.uk/sexuality](https://www.macmillan.org.uk/sexuality)**

Your feelings

It's normal to have difficult feelings to cope with months or even years after cancer treatment, especially if you have ongoing effects to deal with. We've covered some of the feelings you may have, along with suggestions for what might help. Some people only experience a few of these emotions and may be able to deal with them easily. For other people, they may be harder to cope with. Most people find that they get better over time.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have and has advice on coping with them. Call **0808 808 00 00** to order a free copy.

Even with ongoing treatment effects, many people find that cancer has helped them focus on what's important in their lives. Some people feel that although they wouldn't have chosen to go through this experience, it's changed them in positive ways.

Uncertainty

It's natural to worry about the cancer coming back. After finishing treatment for head and neck cancer, many people say this is their main concern. People often find that this feeling gets better over time as they focus on other things besides the cancer. Taking control of the things you can change in your life, such as your lifestyle, can help.

Remember, you don't have to wait until your follow-up appointment if anything is worrying you. You can contact your specialist nurse with any concerns. We have more information you might find helpful in our leaflet **Worrying about cancer coming back**.

There are ways that you can build up your support network, such as by joining a support group or social networking site. You can visit our online community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community) There, you can chat to other people who are experiencing the same things, or just read through the posts or blogs other people have written.

If your fears are becoming overwhelming, talk to your GP or cancer specialist. They can refer you to a counsellor for expert help.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

Negative feelings

You may worry that having negative feelings or feeling stressed may slow your recovery or increase the risk of the cancer coming back. But there's no evidence that negative feelings or stress increase the risk of cancer coming back.

Most people who have had cancer, even the most optimistic, have times when they feel low or depressed. No one can be positive all of the time. Don't put pressure on yourself to stay on top of things when you're finding it tough. It's positive to acknowledge and talk about your feelings.

Anger

It's natural to feel angry when you've had cancer, especially if you're coping with late effects. Don't feel bad about feeling this way. Simply telling yourself and people you trust when you're feeling angry, can be a relief. Bottling up strong feelings may make you feel depressed. If there's no one you feel able to talk to, you can talk to your doctor about seeing a counsellor.

Depression

Coping with the late effects of treatment can be physically and emotionally demanding. This can sometimes cause people to feel depressed. Some signs of depression are feeling low in mood, having no interest or enjoyment from the things you'd normally enjoy and feeling helpless or hopeless. If you think you may be depressed, talk to your doctor. They can refer you to a counsellor or psychologist and prescribe a short course of anti-depressant drugs for you if necessary.

There are other ways that you can help yourself. Some people find using complementary therapies or doing regular exercise helpful. Talking to other people who are facing similar challenges by joining a support group or using social networking sites may also be helpful.



Relationships

Your experience of cancer may have improved and strengthened your relationships with people close to you. You may feel that you wouldn't have been able to cope so well without the support you've had from family and friends.

However, cancer is stressful and this sometimes has an effect on your relationships. Problems usually improve over time, especially if you can talk openly with each other. We've listed some of the issues that can arise in relationships and some ways of coping with these.

Family and friends

You may sometimes feel that your family and friends don't understand if you aren't feeling positive about getting on with things. You may feel they don't realise how much the effects of treatment are interfering with your life. Talking openly about how you're feeling will help them to understand you better and give you the support you need.

Children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

Your partner

Some couples become closer as a result of sharing the experience of cancer. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between close and loving couples who've been together for a long time.

Talking openly about your feelings and listening to each other can help you to understand each other's point of view.

Our booklets **Talking about your cancer** and **Talking to children and teenagers when an adult has cancer** have some useful tips about talking to your family, friends or partner. You can order these for free on be.macmillan.org.uk or by calling our support line on **0808 808 00 00**.



Getting help and support

Try to let your family and friends know how you're feeling so that they can support you. Talking about your feelings isn't always easy.

Not everyone has people close to them who they can talk to about their cancer and its treatment. You can talk to other people facing similar challenges by joining a support group or by using social networking sites. Your specialist nurse will have details of cancer support groups and counselling services in your area. Or you can call **0808 808 00 00** to speak to one of our cancer support specialists, who will also be able to give you details.

At your hospital follow-up visits, your specialist will be assessing your late effects and how they're being managed. They will also check that there are no signs of the cancer coming back.

After going through cancer, it's natural for your body to feel different, and for you to feel differently about your body. Aches and pains that you would previously have shrugged off may make you wonder if the cancer has come back again. This is a common reaction. If you have symptoms you're worried about or are struggling with your emotions, let your doctor or specialist nurse know as soon as possible. They can see you earlier than planned, assess your situation and arrange for you to have appropriate help.

You can read more in our booklet **Life after cancer treatment**, which has information about getting help and support after you've had treatment. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Work

For most people, returning to work is a big step in their recovery. Many companies have an occupational health service for their employees, which can offer support in various ways to people returning to work. Occupational health departments may also offer counselling, before and after your return to work, which is completely confidential.

Late effects such as tiredness, changes in memory or concentration, or changes in the way you communicate, may make work more difficult for you. There are laws protecting the rights of workers who are affected by illnesses such as cancer. Your employer has a duty to make 'reasonable adjustments' to your workplace and working practices to ensure that you aren't at a disadvantage compared with others. These may include:

- assistance with a phased return to work
- allowing time off for medical appointments without it being taken off holiday allowance or sick pay
- creating more flexibility in working hours
- changing a job description to take away tasks that might be physically challenging – either temporarily or permanently (depending on your preference)
- allowing some or all work to be done from home
- providing a support worker (such as a hearing assistant)
- providing facilities appropriate for your disability
- allowing extra breaks to help you cope with tiredness.

Where adjustments may be more costly, a government-funded scheme called Access to Work may help your employer with financial and practical support.

Our booklets **Work and cancer** and **Self-employment and cancer** have more information that may be helpful. We also have a guide for employers that are supporting staff affected by cancer called **Managing cancer in the workplace**.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living.

You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 127). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

Financial support

If you've had problems getting back to work, you may be having some financial difficulties. Our cancer support specialists can help with checking the benefits you may be entitled to, filling in forms, accessing grants and giving general financial information. They may be able to put you in touch with a benefits adviser in your area.

We also have a booklet called **Help with the cost of cancer**, which you may find useful. Visit **be.macmillan.org.uk** or call **0808 808 00 00** to order a free copy.

Insurance

After having cancer treatment, it can be more difficult to get certain types of insurance, including life and travel insurance. An independent financial adviser (IFA) can help you assess your financial needs and find the best deal for you. You can find an IFA through one of the organisations listed on page 127.

We have more information about getting insurance that you might find helpful.



Leading a healthy lifestyle

After having cancer treatment, leading a healthy lifestyle can help improve well-being. Some changes, such as stopping smoking if you smoke and drinking less alcohol, may also help to reduce your risk of cancer coming back or of developing a new cancer.

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. Smoking increases your risk of the cancer coming back and is a major risk factor for other smoking-related cancers and heart disease. It can make some late effects, such as mouth problems, worse. It can also increase the risk of osteoradionecrosis (see pages 28–30).

Our leaflet **Giving up smoking** has more information and tips to help you quit.

Alcohol

Drinking alcohol and smoking will greatly increase your risk of developing another head and neck cancer. Cutting back on alcohol will help reduce this risk.

Get physically active

Being active helps increase your energy levels and reduces stress.

Eat a well-balanced diet

Eating a balanced diet with lots of fruit and vegetables and less saturated fat and sugar will help your body to recover and heal. If you have changes to the way you eat, this may be a challenge. You may need support and advice from a dietitian. Your cancer team at the hospital can arrange this for you.

Reducing stress in your life and making time to relax

It's also a good idea to look at reducing stress in your life, relaxing more and having some fun.

We have more information on the benefits of doing regular exercise at [macmillan.org.uk/physicalactivity](https://www.macmillan.org.uk/physicalactivity) You can also order booklets on physical activity at [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or by calling **0808 808 00 00**.



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About our information

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

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available online at **macmillan.org.uk/cancerinformation**

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

Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**

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

Help us improve our information

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres.

There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

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

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

Online community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

Help with work and cancer

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



Macmillan's My Organiser app

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

Other useful organisations

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

Action on Hearing Loss

19–23 Featherstone Street,
London EC1Y 8SL

Email informationline@hearingloss.org.uk

www.

actiononhearingloss.org.uk

Tel 0808 808 0123

Textphone 0808 808 9000

SMS 0780 0000 360

The new name for the RNID.
Provides support for people with hearing loss and tinnitus.

British Association of Skin Camouflage

PO Box 3671,
Chester CH1 9QH

Tel 01254 703107

www.skin-camouflage.net

Shows people how to use make-up as skin camouflage. Holds camouflage awareness presentations and demonstrations for patient support groups.

British Tinnitus Association

Ground Floor, Unit 5,
Acorn Business Park,
Woodseats Close,
Sheffield S8 0TB

Tel 0800 018 0527

Email info@tinnitus.org.uk

www.tinnitus.org.uk

Support and information for people with tinnitus and their carers in the UK.

Changing Faces

The Squire Centre,
33–37 University Street,
London WC1E 6JN

Tel 0300 0120 275

Email

support@changingfaces.org.uk

www.changingfaces.org.uk

Offers support for people who have any sort of disfigurement, and their families. Also works with healthcare professionals, schools and employers to promote awareness about disfigurement.

Hearing Link

27–28 The Waterfront,
Eastbourne,
East Sussex BN23 5UZ

Tel 0300 111 1113

Email

helpdesk@hearinglink.org

www.hearinglink.org

Offers information, services and support. Allows people to connect with others to share experiences and advice.

Let's Face It

72 Victoria Avenue,
Westgate-on-Sea,
Kent CT8 8BH

Tel 01843 833724

Email chrisletsfaceit@aol.com

www.lets-face-it.org.uk

An international network for people with facial disfigurement. Links together patients, their families, friends and professionals for self-help, information and mutual support.

Skinship UK

Tel 01387 760567

www.skinshipuk.org

Aims to improve current public perception of, and reaction to, skin diseases and disfigurement. Offers a UK-wide network of support groups, telephone helpline and one-to-one counselling.

General cancer support organisations

Cancer Focus

Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX

Tel 0800 783 3339

(Mon–Fri, 9am–1pm)

Email hello@cancerfocusni.org

www.cancerfocusni.org

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

Cancer Research UK **www.cancerresearch.org**

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

Cancer Support Scotland

Cancer Support
Scotland Centre,
75 Shelley Road,
Glasgow G12 0ZE
Tel 0800 652 4531

Email info@cancersupportscotland.org

www.
cancersupportscotland.org

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

Macmillan Cancer Voices **www.macmillan.org.uk/cancervoices**

A UK-wide network that enables people who have or have had cancer and those close to them to speak out about their experience of cancer.

Maggie's Centres

The Gatehouse,
10 Dumbarton Road,
Glasgow G11 6PA
Tel 0300 123 1801

Email

enquiries@maggiescentres.org

www.maggiescentres.org

Information about cancer, benefits advice, and emotional or psychological support.

Riprap

www.riprap.org.uk

Developed especially for teenagers who have a parent with cancer.

Tenovus

Gleider House, Ty Glas Road,
Cardiff CF14 5BD
Tel 0808 808 1010

(Mon–Sun, 8am–8pm)

www.tenovus.org.uk

Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

General health information

Health and Social Care in Northern Ireland

www.hscni.net

Provides information about health and social care services in Northern Ireland.

Healthtalk

www.healthtalk.org

www.youthhealthtalk.org

Has information about cancer, and videos and audio clips of people's experiences.

NHS Choices

www.nhs.uk

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

www.nhsinform.co.uk

NHS health information site for Scotland.

Patient UK

www.patient.info

Provides people in the UK with information on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Support for older people

Age UK

Tavis House,
1–6 Tavistock Square,
London WC1H 9NA

Tel (England and Wales)

0800 169 2081

Tel (Scotland)

0800 4 70 80 90

Tel (Northern Ireland)

0808 808 7575

(Mon–Sun, 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.

Financial or legal information

Benefit Enquiry Line

Northern Ireland

Tel 0800 220 674

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

Textphone 0800 243 787

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

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

Citizens Advice

Provides advice on 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

Department for Work and Pensions (DWP) Disability Benefits Helpline

08457 123 456

Textphone 0845 722 4433

Personal Independence Payment Helpline

0845 850 3322

Textphone 0845 601 6677

Carer's Allowance Unit

0845 608 4321

Textphone 0845 604 5312

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

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

GOV.UK

www.gov.uk

Has comprehensive information about social security benefits and public services.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

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

Tel 01455 883 300

Email bacp@bacp.co.uk

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

Samaritans

Freepost RSRB-KKBY-CYJK,
PO Box 9090,
Stirling FK8 2SA

Tel 116 123

Email jo@samaritans.org

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

UK Council for Psychotherapy (UKCP)

2nd 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.



You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Chris Alcock, Consultant Clinical Oncologist.

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Sources

We've listed a sample of the sources used in this publication below. If you'd like further information about the sources we use, please contact us at bookletfeedback@macmillan.org.uk

British Association of Head and Neck Oncologists (BAHNO). *Head and Neck Cancer: Multidisciplinary Management Guidelines*. 4th edition. 2011.

The Royal College of Surgeons of England/The British Society for Disability and Oral Health. *The Oral Management of Oncology Patients Requiring Radiotherapy, Chemotherapy and/or Bone Marrow Transplantation*. Clinical Guidelines. 2012.

UK Oral Mucositis in Cancer Group (UKOMiC). *Mouth Care Guidance and Support in Cancer and Palliative Care*. 2nd edition. 2015.

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

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Security number

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Signature _____

Date / / _____

Don't let the taxman keep your money

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

- I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand 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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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CANCER SUPPORT**