Managing the late effects of head and neck cancer treatment

About this booklet

This booklet is about the possible long-term and late effects of treatment for head and neck cancer. It is for anyone who has side effects that:

- last longer than 3 months after treatment
- begin months or years after treatment is over.

There is also information for carers, family members and friends.

The booklet explains:

- the possible long-term and late effects of head and neck cancer treatment
- what can help to manage them
- what may help to reduce the risk of certain late effects.

We hope it helps you manage any late effects, and deal with some of the questions or feelings you may have.

Our booklet **Understanding head and neck cancer** has more detailed information about head and neck cancer and its treatment (page 98).

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 104 to 112, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had late effects after treatment for head and neck cancer, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk**/other formats or call **0808 808 00 00**.

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Long-term and late effects

Sometimes side effects do not go away, or they start months or years after treatment has ended. These side effects are called:

- long-term effects – if they begin during treatment, or shortly after treatment has ended, and last longer than 3 months
- late effects – if they begin months or even years later, as a delayed response to treatment.

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

Doctors aim to provide the best treatment with as few side effects as possible. With improved treatment for head and neck cancer people are living for longer. Newer ways of giving radiotherapy, such as intensity-modulated radiotherapy (IMRT), may also help to reduce the risk of some late effects, such as dry mouth.

Doctors and nurses are also learning more about how to manage late effects.

Possible late effects

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

- the size and location of the cancer
- the type and amount of treatment you had
- whether lymph nodes (glands) in the neck were treated
- your general health before treatment started.

Some side effects of treatment improve over time. Tell your specialist doctor or nurse if your side effects are not getting better, or you develop new symptoms. They will talk to you about your symptoms and explain if they are likely to be linked to treatment. Sometimes you may have tests to find out the cause.

You can contact and sometimes meet with your cancer specialist doctor or nurse between clinic appointments. You can usually contact your GP or dentist if you are concerned.

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

- a dry mouth
- difficulty swallowing
- taste changes
- increased risk of tooth decay and bone damage
- changes in hearing
- stiffness or pain in the jaw, neck and shoulders
- changes in how you look.

You may also have other general effects such as tiredness for several months after treatment. Your sex life may also be affected. These effects often get better over time as you recover.

You may still be coping with difficult feelings, such as a low mood, anger or anxiety. We have more information on coping with your emotions in our booklet **Your feelings after cancer treatment**.

After treatment, people often worry about the cancer coming back. As time goes on and you get back to daily life this may affect you less. But if the anxiety does not improve, talk to your head and neck cancer team, or GP. They may be able to refer you to a counsellor or a psychologist for specialised help.

We have more information in our booklet **Worrying about cancer coming back**.

You can order our booklets and leaflets for free.
Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

Who can help

After treatment has finished you may want to do the same things that you did before treatment. But adjusting to changes takes time. It can be frustrating to still have treatment side effects. There are usually things that can be done to treat and manage them. Your specialist doctor and nurse will monitor your side effects at your appointments.

There are different specialists who can help with late effects. These may include the following:

- Specialist doctor – this could be a surgeon, cancer specialist (oncologist), plastic surgeon.
- Specialist nurse – someone who gives information and support on managing side effects.
- Speech and language therapist (SLT) – someone who gives information and support to people who have problems talking and swallowing.
- Dietitian – someone who gives information and advice about food and food supplements.
- Dentist – an expert in treating problems or conditions that affect the teeth and gums.
- Restorative dental consultant – a consultant dentist who rehabilitates the teeth. This can include removable prostheses (obturators), removable dentures, bridges and implants to help with your eating, speech, dry mouth and appearance.
- Physiotherapist – someone who gives treatments and exercises to help with reduced movement in the jaw, neck or shoulders and encourages safe physical activities.

- Dental hygienist – someone who cleans teeth and teaches you how to keep your mouth clean and prevent tooth decay, manage gum disease.
- Occupational therapist – someone who gives information, support and aids to help people with tasks such as washing and dressing.
- Lymphoedema specialist – someone who gives advice and support about coping with lymphoedema.
- Psychologist or counsellor – someone who is trained to listen to people's problems and help them find ways to cope.

As you recover from 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 also be other changes in your daily life you need to adjust to.

Dealing with these changes can take a lot of effort and determination. It is normal to have emotional and physical changes. There may be times when you do not feel you are making progress. Talk to your head and neck team about your concerns so they can support you in your recovery.

If you have support from a partner, family or friends, take them with you to your hospital appointments if possible. This can help them understand what you need to do for your recovery.

Some people do not have support networks or find it easier to talk to someone who is not close to you or involved in your care. This could be a counsellor, or someone from a support group who has been through a similar experience.

Many treatment centres have health and well-being events for people who have had head and neck cancer. These can help you to cope with the physical and emotional late effects. Speak to your specialist nurse about what is available in your local 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. Visit **macmillan.org.uk/community**

You can also call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm. ☎

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected by a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

You can find details of the cancer registries on page 112.


Way Out

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Mouth care and preventing tooth decay

Looking after your mouth and teeth is very important to protect yourself from dental problems. You may be at higher risk of dental problems because of your treatment.

Even if you only have a few teeth, it is important to have a good mouth care routine. You need regular check-ups with a dentist or dental hygienist every 3 to 6 months (page 11). This will help find early signs or tooth decay and look after your gums. It also reduces the risk of developing a serious problem of the jawbone.

Saliva is important in keeping your mouth clean. If you have a dry mouth, you are more likely to get mouth infections, such as thrush. Saliva also protects your teeth against decay. A dry mouth also means you are at much higher risk of tooth decay.

Saliva allows the tongue, lips and cheeks to slide easily over the teeth. If you have any rough, chipped or sharp teeth or dentures it is important to get them fixed. This prevents them rubbing inside your mouth and causing ulcers to develop. We have more information and advice about dry mouth (pages 25 to 31).

Protecting your teeth

Things you can do to help protect your teeth include the following:

- Follow a mouth care routine agreed with your dentist or dental hygienist.
- Do not smoke.
- Use fluoride products prescribed by your dentist (pages 18 to 19).
- Avoid sugary drinks.
- Only have acidic foods or drinks at mealtimes.
- Check your mouth daily for ulcers, red, white or dark patches or signs of tooth decay. When you have a dry mouth, decay is often at the top or bottom of the tooth near the gum line.
- If you notice a change in your mouth or teeth, contact your dentist straight away.

> **"I hate dental treatment so have been extremely diligent in tooth and oral care since my treatment. I don't want any fillings, crowns or implants."**
>
> Paul, diagnosed with tonsil cancer

Thrush

Thrush is a fungal infection which causes redness and white patches in the mouth. Other symptoms include:

- a sore mouth or a burning feeling on the tongue
- an unpleasant taste in your mouth
- difficulty eating or drinking.

Tell your doctor if you have any of these symptoms. They can prescribe medicine to help. If you have dentures (page 22), you are more likely to get oral thrush. Take them out at night and brush your dentures every day.

Using fluoride

Your dentist or dental hygienist will advise you on how to brush your teeth and keep your gums healthy. They will also prescribe a specialised fluoride toothpaste called Duraphat® 5000ppm. This strengthens the hard, outer layer (enamel) on your teeth and helps protect them from decay. It can also help reduce tooth sensitivity. This toothpaste is not available over the counter. Your dentist or doctor will prescribe this for you to use if you have any of your own teeth.

You can use a fluoride mouthwash at a different time to toothbrushing. For example, you can use mouthwash 30 minutes before you brush your teeth or another time of day.

Your dentist may also recommend:

- wearing mouth guards containing fluoride overnight
- having fluoride painted on your teeth once every 3 months.

Some dentists may also advise using a calcium tooth mousse to use before brushing your teeth. After cancer treatment, you may not have enough calcium in your mouth to help fluoride toothpaste work as well as possible. This product is not available on prescription but can be bought online.

Reduce sugary and acidic foods and drinks

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

Here are some tips to reduce tooth decay:

- Eat and drink fewer acidic things like fizzy drinks, orange juice, oranges, other citrus fruits and tomatoes. The more times you eat or drink something acidic or sugary, the more acid attacks there are on your teeth. Limit these foods and drinks to meal times, no more than 4 times a day.
- Choose sugar-free drinks but avoid those with phosphoric acid or citric acid which are harmful to the teeth. Check the list of ingredients to find out if these are in your drink. Fizzy sugar-free drinks are often acidic. Sparkling water can damage teeth as it contains carbonic acid. The safest drink for your teeth is still water. Or you could have plain milk, tea or coffee without added sugar.
- Try to avoid or reduce foods with refined sugar such as chocolate, sweets, biscuits, cakes and pastries, fruit pies, dried fruit, sweet sauces, sponge puddings, breakfast cereals, ice cream, jams, honey and fruit in syrup.
- Check food labels to find out how much sugar they contain. 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.

If you need to gain weight after treatment you may need some high-energy foods as part of your diet. You can meet with a dietitian for further advice. Try to make sure you look after your mouth and teeth to limit any possible damage.

We also have more information about weight gain in our booklet **The building-up diet** (page 98).

Brushing your teeth

Following a regular mouth care routine is very important to protect your teeth. You can agree this with your dentist or dental hygienist.

Here are some tips:

- Brush your teeth for 2 to 3 minutes every morning and night before going to sleep, using a high-fluoride toothpaste (pages 18 to 19).
- Choose a toothbrush with a small head and soft bristles. Or use an electric toothbrush with a small head that moves in circles. This is called a rotating head. Some electric brushes have a gentle setting and use a soft or sensitive brush head.
- Brush each tooth slowly and gently. This is enough to clean plaque from a tooth without hurting your gums. Gently massage the gum around the base of each tooth with your toothbrush.
- Move your toothbrush 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 brushing spit out any excess but do not rinse with mouthwash or water. The fluoride in the toothpaste stays around your teeth and keeps protecting them, especially at night.

It is 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, instead of pulling back and forth. A dentist or dental hygienist can show you how to do this and advise you on the best products for you.

If you wear dentures

Here are some tips to help with mouth care if you wear dentures:

- Use a different toothbrush from the one to brush your teeth and use a denture cleaning cream.
- Clean and rinse your dentures after eating, as well as every night and morning.
- Remove any denture fixative which has stuck to the inside of the mouth. A tissue and warm water should help with this.
- Remove and clean your dentures at night. Soak them in a cleaning solution recommended by your dentist. This gives your mouth a rest and reduces the chance of mouth infections such as thrush.
- Gently brush the inside of your mouth with a small, soft toothbrush. This is because food may collect between the cheek and gums.

You may wear a special type of denture called an obturator. Your dentist may advise you to keep it in and only take it out to clean it. You should follow the advice you are given.

Dry mouth and changes in saliva

Radiotherapy or chemoradiation to the head or neck can affect your salivary glands. This means you may not make as much spit (saliva) as before and so your mouth may become dry. Your salivary glands may gradually recover after treatment, but your saliva 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.

> **"If I talk or lean forward I have too much saliva, at times it can be quite thick. If I lean backwards, I have an incredibly dry mouth. It feels like my throat is sticking together and I have difficulty in breathing."**
>
> Elise, diagnosed with jaw cancer

Coping with thick, sticky saliva

Rinsing your mouth regularly and gargling can help with thick saliva. Your head and neck team can give you advice on what type of mouth rinse to use (page 38). Rinsing with a weak solution of salt and water may help to loosen thick saliva. Drinking plenty of fluids can also help.

Sometimes a build-up of mucus can cause coughing. This may happen more at night. The hospital or your GP may give you a nebuliser. This is a machine that turns liquid into a fine spray. You can then breathe it in through a mask or mouthpiece. The moisture helps to loosen and break up the saliva. It may help to use the nebuliser throughout your treatment, and for several weeks afterwards. This will depend on how quickly your symptoms improve.

You could also try leaning over a steaming bowl of hot, but not boiling, water with a towel over your head. This can help loosen thick, sticky saliva. It is best to do these 4 to 5 times a day. Using a humidifier may also help 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. Smoking will dry and irritate your mouth. They also increase your risk of dental problems. If you smoke, it is important to try to stop. Your GP or hospital team can tell you about the support that is available to help you. Avoid alcohol, especially spirits, which are very irritating to the mouth.

There are different things you can do to help relieve a dry mouth. Always carry a bottle of water with you and take frequent sips. Or, use a water spray instead. You can buy small atomiser spray bottles from most chemists.

If you cannot swallow, your nurse or doctor can give you a nebuliser (a machine that turns a liquid medicine into a fine mist or spray) to moisten your mouth and throat.

> **"Swallowing can be difficult at times as I get a dry mouth. Every morning, I wake with a totally dry mouth."**
>
> Paul, diagnosed with tonsil cancer

Salt water rinse

A warm salt water rinse can be soothing if you have a dry mouth. To make the rinse, boil 900ml of water. Let it cool to a warm temperature and then add 1 teaspoon of table salt. Rinse the salt water gently around your mouth. Then spit it out and rinse your mouth with cold or warm water. Try to do this at least 4 times a day. Make a fresh rinse each day.

There are other things you can do to help with a dry mouth.

Other tips to relieve dryness

- Try sucking ice cubes or sugar-free ice lollies.
- Avoid drinks that can irritate a dry mouth, such as caffeinated or citrus drinks.
- Ask your doctor or nurse if any medicines you are taking cause a dry mouth. It may be possible to change the drug or reduce the dose.
- Use a lip salve to protect your lips.
- Try using a humidifier in your bedroom at night.
- Ask your dentist for advice on toothpastes as some contain foaming agents, usually an ingredient called sodium lauryl sulphate (SLS). This can make your mouth dry. But some SLS-free toothpastes are fluoride-free so are less effective against tooth decay and gum disease.

Eating tips

- Avoid foods that irritate a dry mouth, such as hard and crunchy foods, spicy, salty foods and citrus fruits.
- Take sips of water before you take a bite of food. This lubricates the mouth before you start chewing.
- Eat soft, moist foods with sauces and gravies, such as casseroles and soups.
- Add moisture and fat to make dry, starchy foods such as bread, biscuits and crackers easier to eat. Use extra oil, salad dressings, yoghurt and mayonnaise or butter to moisten foods.
- Try rubbing a small amount of olive or sunflower oil onto your gums before a meal. This can make it easier to chew and move foods around the mouth.

Using artificial saliva

You can use artificial saliva to moisten your mouth and throat. It comes in different forms, such as gels, sprays, mouthwashes, pastilles or tablets. Try different types to find out the best for you. Your doctor or dentist can prescribe artificial saliva, or you can buy it from a chemist.

The effect may only last for a short time, so it is best to use it just before eating. For longer-lasting relief at night, try using the gel on your tongue and around the inside of your mouth. This may relieve dryness for up to 5 hours.

If you have dentures, you can use the gel under them to help them feel more comfortable and stay in place. Take your dentures out at night to give your mouth a break from them.

Artificial saliva with added fluoride can also help to protect your teeth. But some saliva products are acidic and can cause tooth decay. If you have your own teeth, make sure you use one that is pH-neutral (pages 30 to 31).

Some brands of artificial saliva may also contain animal products. You can check this with the person prescribing the artificial saliva.

Stimulating saliva

Treatments that stimulate saliva may help if some of your salivary glands still work or the damage to your glands is temporary. You can buy these products online.

- Sugar-free gum may help stimulate saliva. Some gums (such as Spry® gum) contain xylitol, a low-calorie sweetener, which can also help reduce tooth decay.
- XyliMelts® (discs you stick to your gums, teeth or dentures) slowly release xylitol which helps stimulate saliva to relieve dryness.

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

Product name (manufacturer)	What form does it come in?	Is it available on the 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
Oralieve Moisturising Mouth	Oral spray	Yes
	Mouth gel	Yes

Can you buy it from a chemist?	What is the pH value?	Does it contain fluoride?	Does it contain animal ingredients?
Yes	Neutral	Yes	Pork
Yes	Neutral	No	Pork
Yes	Neutral	No	A protein produced by animals
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
Yes	Neutral	No	Cow's milk
Yes	Neutral	No	Cow's milk


Speech
&
Language Therapy

Effects on the jaw

Jaw stiffness and reduced mouth opening (trismus)

After radiotherapy or surgery to the head and neck area, the muscles that open and close your mouth may become stiff. This can reduce how wide you can open your mouth. Doctors call this trismus. You may have been given mouth exercises to do to help prevent this. If you had surgery and radiotherapy the risk of trismus is greater. Techniques such as intensity-modulated radiotherapy (IMRT) help to reduce the risk of late effects such as trismus.

Jaw stiffness can develop a few weeks or sometimes months after treatment. The amount of stiffness varies from person to person. The earlier you start jaw exercises the more successful they are. The muscles become tight, making it more difficult to open your mouth once stiffness has set in.

An easy way to check how wide your mouth can open is to try to put 3 fingers vertically between your lower and upper front teeth. If you can only manage 1 or 2 fingers, you may have trismus.

Tell your doctor if you have jaw stiffness or pain, even if it is mild. You will usually be referred to a speech and language therapist (SLT) or physiotherapist for assessment and treatment (page 38). Your SLT or physiotherapist will measure how wide you can open your jaw at your first appointment. They will repeat this measurement at every appointment. It will help you track what progress you are 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 you do them regularly, they help to increase the amount you can open your mouth.

Your SLT, physiotherapist or restorative dental consultant will show you:

- jaw stretches you can do
- how long to hold each stretch for
- how many times to repeat the stretches.

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. This will gradually stretch the jaw muscles.

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

If pain in your jaw gets worse during jaw exercises, you should stop 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.

Eating

If you are having difficulty chewing or swallowing because of a stiff jaw, softer foods can be easier to eat. Your dietitian can give you more advice. Some people may need supplement drinks to take until this improves. We have more information in our booklet **Eating problems and cancer** (page 98).

Dental care

It is important to continue with a regular mouth care routine while your jaw is stiff (pages 16 to 22). If it is difficult to reach teeth in the back of your mouth, try a small toothbrush. Tell your dentist or hygienist if you cannot brush your teeth because of a stiff jaw. They can give you more advice.

Drugs to improve symptoms

Your doctor may prescribe different drugs such as muscle relaxants or drugs to treat nerve pain to ease any pain and spasm. Botox injections may also help improve muscle pain and spasm.

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 leads 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
- surgery
- having a tooth removed
- having a dental infection
- having a broken filling or sharp tooth which is injuring the gum
- badly fitting dentures, which cause an ulcer in the gum.

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. Or some very tiny parts of the bone may become loose and can be seen in your mouth.

Always tell your GP, hospital doctor or dentist if you have any of these symptoms. Remember to let them know that you have had radiotherapy to your head and neck area. 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 of osteoradionecrosis (ORN):

- Do not smoke, because it affects the blood supply to the bone.
- Look after your mouth and teeth and have a dental check-up every 6 months. Having an infection or a tooth removed can increase the risk of ORN.
- You may need to have 1 or more teeth taken out after radiotherapy. It is important to meet with a specialist oral and maxillofacial surgeon or dental oral surgeon to have this done in hospital. They will plan your treatment to reduce the risk of ORN developing.
- Wear well-fitting dentures. If they rub or are sore, do not wear them. Contact your dentist for advice.

How osteoradionecrosis is treated

Treatment depends on whether the osteoradionecrosis is mild or more severe. Different treatments can include:

- antibiotics to treat the infection
- surgery, which is sometimes used to remove the dead bone.
- an antibiotic called doxycycline
- a drug called pentoxifylline given with vitamin E (tocopheral), although there is not enough evidence to say how effective this is
- jaw reconstruction, which may be necessary in severe cases
- hyperbaric oxygen (HBO), which involves breathing in oxygen at very high concentrations to help the affected tissue to heal. This has been researched for many years, but doctors are still unsure about any benefits of this treatment.

Eating and drinking

Surgery or radiotherapy for head and neck cancers can change how you eat and drink. Many people find this gets easier after treatment finishes. This is because side effects such as pain, swelling, feeling sick and tiredness start to get better.

Who can help

If you have eating problems, you will usually be supported by a speech and language therapist (SLT) – page 10. They can teach you exercises and techniques to help you chew and swallow.

You may also meet with a dietitian who can advise you on how to increase the nutrients and calories in your diet (page 10). They may give you high-calorie supplement drinks if you have lost weight. Supplement drinks are high in sugar and are usually only used for a short period of time. This is to avoid long-term damage to teeth and jaws.

It can take a lot of effort and patience to overcome eating difficulties. If you have found eating difficult for a while, you may no longer associate food with pleasure. Taste changes may reduce your desire for food and affect your appetite.

Talk to your SLT or dietician if you feel this way. They may use different coping techniques, such as mindful eating, to help you enjoy their food again. These techniques can help you to feel more relaxed at meal times and find things about eating you can still enjoy.

We have information about what to eat to increase your weight after cancer treatment in our booklet **The building-up diet** (page 98).

If you have a feeding tube

Some people have a feeding tube put in before, during or after treatment. The tube 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 in permanently.

A feeding tube may be placed either:

- directly through the stomach, called a PEG (percutaneous endoscopic gastrostomy) or RIG (radiologically inserted gastrostomy) feeding tube
- through the nose and into your stomach (nasogastric) and used only for a short while.

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

You will be encouraged to continue to eat and drink, even if you have a feeding tube in. This is important as it keeps the swallowing muscles working during radiotherapy and while you are recovering. Your SLT will help you to try to eat food again. They will start you with food with a texture that is easier to swallow, and then gradually increase the amount and variety of textures.

You may have days when you cannot eat anything. It is common to have a setback before your eating begins to get better. The feeding tube can normally be taken out when:

- you have not needed to use it for a few weeks
- you can get enough calories by eating and drinking normally.

Chewing and swallowing

Treatment for head and neck cancer can change the way you chew and swallow. The effects can depend on where in the head and neck the cancer started, the stage, and type of treatment.

Chewing prepares food in the mouth to make it easier to swallow. 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 (bolus) that is ready to swallow.

Swallowing happens in 3 stages:

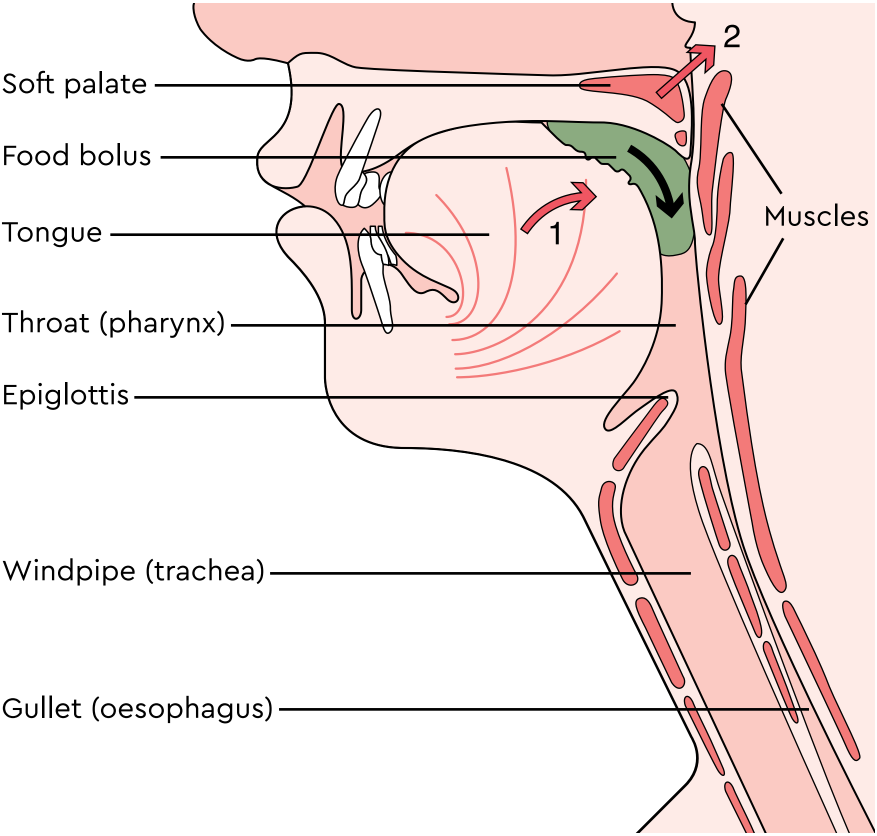
- the mouth stage (page opposite)
- the throat stage (page 42)
- the gullet stage (page 43).

Eating difficulties can be caused by problems at 1 or more of these stages.

Mouth stage of swallowing

1. When food 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 passing into the nose.

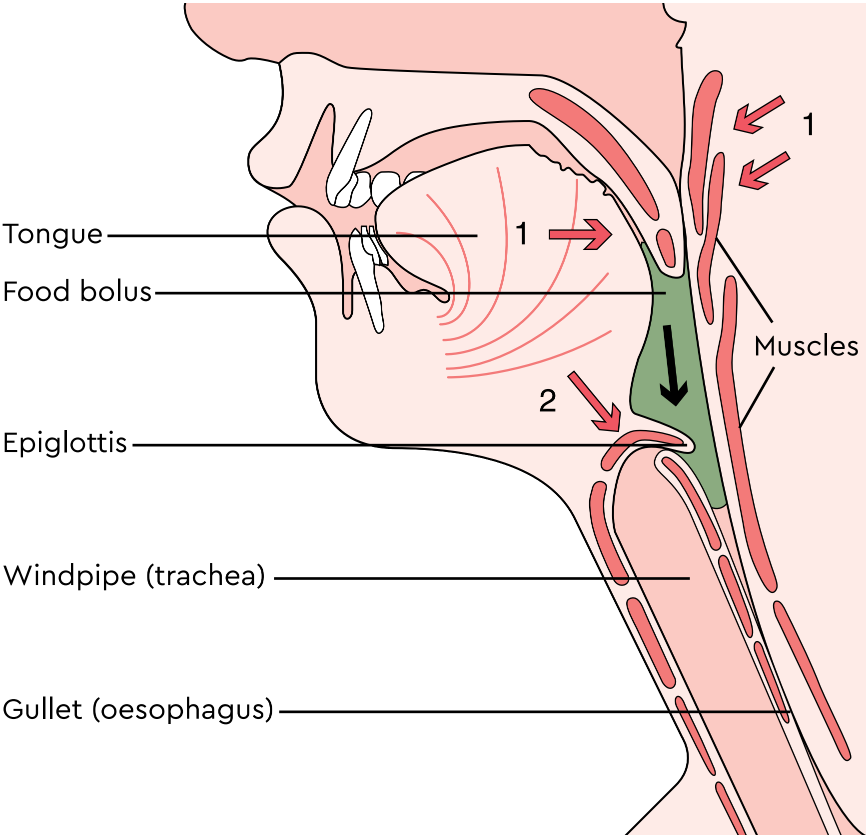
Mouth (oral) stage of swallowing



Throat 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 food down.
2. Your voice box (larynx) lifts in your throat. A flap of tissue called the epiglottis closes the airway and stops food going into the lungs. The gullet (oesophagus) then opens.

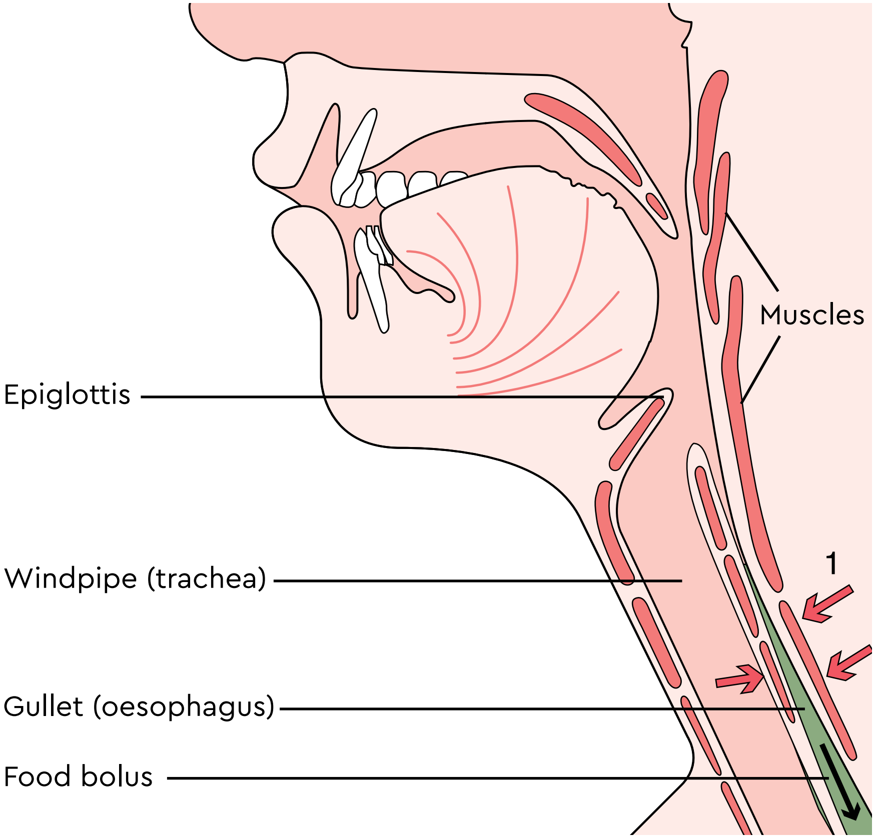
Throat (pharyngeal) stage of swallowing



Gullet (oesophageal) stage of swallowing

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

Gullet (oesophageal) stage of swallowing



How treatments can affect chewing and swallowing

Mouth stage

Surgery for mouth cancer can affect chewing and swallowing. If only a small amount of tissue is removed, the effect on chewing may be small. 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, your ability to grind food during chewing may change. This can also happen if you have dentures that no longer fit.

Surgery or radiotherapy can affect the muscles and nerves that control the lips, tongue or other parts of your mouth. This may make it difficult to control food and fluid in your mouth or sense where food is in your mouth.

Jaw stiffness or a dry mouth also cause difficulties with chewing and swallowing.

Throat stage

Surgery to the voicebox (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 – pages 71 to 73.

Radiotherapy may make muscles and tissues in the throat and gullet weaker and less stretchy. This can make it harder to swallow some foods or cause certain foods to stick in the throat. If nerves that control the muscles in the gullet are affected, they may be less able to move food downwards.

The upper part of the gullet may become narrower after radiotherapy. Any nerve damage may make it 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. 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. This is called fibrosis.

When to contact your speech and language therapist or dietician

Tell your speech and language therapist (SLT), specialist nurse or doctor if you have difficulty swallowing or if you are experiencing:

- 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
- a 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

You may be able to have treatment to help with chewing. The type of treatment you have depends on what is causing the problem. Problems could be caused by:

- a change in the shape of your mouth
- tooth loss
- jaw stiffness
- dry mouth
- loss of sensation.

It is important you are assessed by a either a surgeon, a restorative dentist or a speech and language therapist (SLT) – page 10.

Restorative dentistry

Changes to your bite or to the tissues inside your mouth may affect your ability to eat or speak. Restorative dental consultants (restorative dentists) may be able to help.

Obturators

After surgery to the roof of the mouth (maxilla), some people have an opening between the roof of the mouth and the nose. You may be able to have restorative surgery to help with this. A restorative dentist can cover the opening with a special type of dental plate called an obturator. This stops food, fluid and air passing between the nose and mouth. Some obturators have a speech bubble at the back to help with speaking.

If you need an obturator, you will usually be fitted with a surgical obturator at the time of your cancer surgery. It is replaced with a temporary obturator a few weeks after your operation. This is because as the tissues in the mouth heal after surgery, they get smaller until they reach their final size and shape. This can take 6 months or longer.

Once your mouth has healed into its final shape, the restorative dentist will make you a longer-term obturator. Your mouth will continue to change shape over the years. Your obturator will need replacing when it starts to feel uncomfortable.

You will have regular appointments to check the obturator fits well and feels comfortable.

It is important to let your restorative dentist know if you have any problems with how well the obturator fits between these appointments. As the tissues in your mouth settle, they may need to adjust the fit from time to time.

Dental rehabilitation

If you had any teeth removed before surgery or radiotherapy, the restorative dental consultant will assess you for follow up dental care. You may need to be managed for gum disease. Or you may need removable dentures, bridges or implants. This will depend on the needs of your mouth and the type of cancer treatment you have had.

Exercises to improve chewing

Your SLT will assess the problems you have with your chewing. They may arrange for you to have tests to help find out the best way to treat any problems.

They may give you exercises to strengthen your lips, tongue and other muscles in your mouth. There are also exercises you can do 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 to eat soft, moist foods. Depending on what is causing the chewing difficulties, you may find it easier to chew larger or smaller amounts of food. Your dietician can also give you more advice on this.

Help with swallowing

The type of treatment you have depends on which parts of the swallowing process you are having problems with (pages 40 to 43). Your speech and language therapist (SLT) will do a clinical assessment of your swallowing. You may need to have a swallowing test to show what happens when you swallow. There are 2 tests that can be used to assess swallowing. These are:

- videofluoroscopy (VF)
- fibreoptic endoscopic evaluation of swallowing (FEES).

Your SLT will decide which test is best for you.

Videofluoroscopy (VF)

A VF is a special x-ray test which shows:

- if anything gets stuck in your throat
- if any food or drink goes down the wrong way when you swallow.

This helps your SLT understand how they can make swallowing safer and easier for you.

This test is done in the x-ray department by a radiographer and your SLT. It takes about 30 minutes and is painless. The x-rays are recorded on video or DVD.

They may also ask you to try different techniques to find out if they help when you swallow.

They will ask you to swallow different foods of different textures. This might be:

- liquid or food with a semi-solid texture, like yoghurt
- food with a solid texture, like a biscuit.

A special substance is added to the food to make it show up on the x-ray.

Fiberoptic endoscopic evaluation of swallowing (FEES)

A FEES is another test to show what happens in your mouth and throat when you swallow. Your SLT passes a thin, flexible tube through the nose to look at the back of the throat. The tube contains a small camera which records your swallowing while you eat and drink. The test takes about 10 to 20 minutes.

After having a swallowing test

After your tests, your SLT will meet with you to discuss the results of the tests. The tests help them to recommend exercises and other ways to make swallowing easier for you. They will also advise you eat moister foods, which may be easier to swallow.

It may help to bring a partner, family member or friend with you when you meet with your SLT. They can learn about exercises and 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
- changing 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 will need to do them regularly to get the most benefit. Apps such as iSwallow® can help guide you through swallowing exercises, remind you when to do them and keep track of how often you do them. Always talk to your SLT before using any apps. You can download the apps, but you may need to check whether they work on your mobile device.

Stretching the gullet (oesophagus)

Radiotherapy to the head and neck area can cause the top of your gullet to narrow. This may be shown on a videofluoroscopy (VF). You may be offered a quick procedure to make swallowing easier. A doctor puts a tube down into the gullet to stretch it. This makes more space for food and fluid to pass through. You can have this done as an outpatient.

You usually have a local anaesthetic for this procedure. But it is sometimes done under general anaesthetic. Your doctor can tell you what the possible benefits and risks are.

Taste changes

Radiotherapy to your mouth can affect your sense of taste. A lack of saliva can also affect your taste buds. Some treatments can change your sense of smell, which can affect taste.

Most foods may taste the same or you may dislike the taste of certain foods. Some people can taste the first few bites of food and then find the taste gets weaker. These changes can lower 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. If you have taste changes, tell your doctor, dietitian or specialist nurse. They can offer advice and support.

Here are some tips for coping with taste changes:

- Eat the food and drinks that you enjoy the most.
- If a food did not taste very nice, try it again after a few weeks. Your sense of taste may improve.
- Use your other senses to enjoy food, for example by making your food look and smell as appealing as possible.
- Use marinades or strongly flavoured seasonings and herbs to flavour your food. Only use these once your mouth is no longer sore after treatment.
- If you do not have a sore mouth, try marinating meat in fruit juices.
- Try cold foods. Some people find that cold foods taste better than hot foods.
- Try sweet foods. Some people find they can taste sweet foods better. But be aware that sugary foods can cause serious tooth decay if you have less saliva after radiotherapy.
- Use sauces and oils to flavour and moisten food.

Acid reflux

Acid reflux is caused by acid in the stomach coming back up into the throat or gullet. It is quite common after surgery or radiotherapy for head and neck cancers. Acid reflux can cause symptoms such as:

- heartburn
- coughing
- a sore throat
- the sensation of having something in the throat
- a hoarse voice.

You should always tell your doctor if you have any of these symptoms.

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

Reflux is often worse when you are lying down. If you notice this, try not to eat or drink anything or have caffeine for 3 hours before you go to bed. It may also help to raise your head with an extra pillow so that you are not lying flat.

Eating smaller meals often can also help reduce acid reflux. If you are having food through a tube, having it at a slower rate can help.

Eating and socialising

Many social activities involve eating and drinking. If you have difficulty chewing or swallowing, you may feel anxious or unsure about eating in front of other people.

Feeling self-conscious

If you feel self-conscious about eating in front of others, it may help to get used to eating at home with people you know first. When you feel ready to try eating away from home, do something simple to start with, such as going for ice cream. You can start to go out to eat other things as your confidence grows.

Taking a long time to eat

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

Worrying about keeping people waiting

If you are worried about keeping family or friends waiting while you eat, talk to them about this. They can reassure you that they do not mind you taking longer. You will probably find they are more relaxed about it than you think.

Eating at a friend's house

If you go to someone's house for a meal, try not to worry about telling them about your dietary needs. People often adapt meals for guests, for example if someone does not eat meat or cannot eat gluten. Tell your host in advance if you need food of a certain texture or thickness or if you cannot 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.

Going out to eat

If you are 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. For example, you could ask them to add extra gravy, mayonnaise or butter, leave out certain spices or blend your food.

Using liquid supplements

If part of your meal is a liquid supplement, ask the restaurant if they can provide you with a cup. This means you can take a liquid supplement meal with you and still order something from the menu.

Eating with people you do not know

People you do not know may ask about your eating difficulties when they first have a meal with you. You may find it helpful to think about what you want to say beforehand. Or you might decide you do not want to explain it at all. You could ask the people you know to tell other guests in advance and add that you would prefer not to talk about it. Do whatever makes you feel comfortable.

If you find it difficult to ask for what you need, you may find the information about being assertive helpful. We have more information in our booklet **Eating problems and cancer** (page 98).

Changes in communication

Sometimes, treatment for head and neck cancers can affect your speech, voice or hearing. Your doctor, speech and language therapist (SLT) or specialist nurse will explain any possible changes before your treatment starts.

Changes to speech and voice

We use our lips, teeth, tongue, mouth, nose and throat when we speak. If you had surgery or radiotherapy to your head and neck area, your speech or voice may sound different. You may have difficulty making certain sounds or saying some words. Sometimes changes to your speech or voice may be more severe. This can mean people may not be able to easily understand you.

Thick, sticky saliva may make it difficult for you to speak (page 24). Reduced saliva causes a dry mouth (pages 25 to 31). This can also make your mouth and throat feel uncomfortable when having longer conversations.

For some people, these changes are only a minor problem. Their speech or voice returns to normal, or near normal, as the area heals. For others, it may involve permanent changes to the way they speak or to their voice.

If you have speech or voice changes, the following things may help:

- Do the exercises the SLT suggests. These can help you to strengthen and control the muscles used for speech and voice.
- Keep your throat healthy by not smoking and by drinking plenty of water.
- If speech problems are caused by changes in your teeth or shape of your mouth, a restorative dentist can help.

Your voice is the sound of your speech made at the level of your voicebox (larynx). Treatments that affect the larynx can affect your voice. The quality of your voice may become rougher (hoarse) more breathy, strained or quiet and may tire more easily.

If you have changes to your speech or voice there are things that may help. Sometimes surgery to the vocal cords may be possible to improve your speech or any voice changes. Your SLT and specialist doctor will explain any treatments that may be helpful.

Speech therapy

Speech therapists can advise you how to communicate in the clearest and most effective way possible.

Your SLT assesses changes in your speech and voice. They can give you advice and speech therapy exercises on how to use your voice in the best way and take care of your throat. They may give you exercises to:

- help you make your voice heard without straining
- increase how long you can easily talk for.

The exercises may feel like hard work at times, but it is important to follow the advice of your SLT and do the exercises they gave you. It can be helpful to make them part of your daily routine. You may find it helpful to make a chart of the exercises you need to do and the times you do them.

Your SLT can usually recommend useful apps that are free and suited to your needs. They can help you to download them onto your phone, if you have one. Always talk to your SLT before using any apps.

It can take time for you, and your family and friends, to adjust to changes in your speech or voice. The reactions of people you do not know may be harder to get used to. It can be helpful to explain that you have had treatment that has made it difficult for you to talk. This can help put yourself and other people at ease.

Tips for communicating

If people cannot understand you, it is normal to feel frustrated. But there are things you and the people you talk with can do to help.

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 do not understand anything. If they need to check what you mean, suggest they ask you questions with a yes or no answer.

Here are some tips:

- Choose a quiet place without distractions or background noise.
- Find a well-lit place.
- Face the person.
- Tell them you have difficulty with your speech.
- Sit up straight or stand up when speaking. This helps you breathe better.
- Speak slowly and carefully. Try to use short sentences and take a rest between them.
- Have a pen and paper with you so you can communicate by writing things down if you need to.

Other ways of communicating

Sometimes, you may need to communicate in other ways. New technologies can help with this. If you are 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. Your SLT or occupational therapist can advise you about this.

Hearing changes

Treatment for some types of head and neck cancer, such as nasopharyngeal cancer, can sometimes affect your hearing. Hearing loss may sometimes come on gradually in the first 2 years after treatment.

Radiotherapy or the chemotherapy drug cisplatin may cause ringing in the ears. This is called tinnitus. It often gets better as your ears recover from the effects of treatment. But it can sometimes be permanent.

Tell your cancer doctor or nurse if you have problems with your hearing. They can refer you to a hearing specialist called an audiologist, or an ENT (ear, nose and throat) doctor for an assessment and tests.

Treatments for hearing loss

Treatment will depend on the type and cause of your hearing loss.

The small tube between the ear and the throat is known as the eustachian tube. This tube regulates air pressure in the ear. Sometimes it can become blocked after treatment. There are different ways to manage this. You may need a small operation.

If you have a build-up of fluid in your ear because of infection, your doctor can prescribe antibiotics to treat it.

Hearing loss may also be helped with hearing aids. Sometimes a cochlear implant may be an option if hearing loss is severe. You need an operation to put it in your ear. It uses electrical stimulation to provide sound.

Tinnitus

Tinnitus is a sound you hear from inside your body rather than outside. It is 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. It often gets better as your ears recover after treatment. You may be referred to a tinnitus clinic to help you to manage it.

Tinnitus is more noticeable when it is quiet. Using sound therapy can help to distract you. This could be having the radio on or an electric fan. There are devices specially designed to produce sounds for people with tinnitus. Relaxation techniques can also help as tinnitus is made worse by anxiety. Your tinnitus clinic and The British Tinnitus Association (page 104) can give you more information and advice.

Living with hearing changes

Getting used to changes in your hearing can take time, but there is support is available. Your hearing clinic can give you practical advice. There are also phones that can make sounds louder and help you to hear callers more easily. There are also apps to help people with hearing difficulties.

Some tips if you have hearing loss include the following:

- Avoid background noise, such as TV or radio, when talking with people.
- Find a well-lit place to have your conversation.
- Tell people your hearing is not good.
- Ask the person talking to you to face you, speak clearly and not too fast.
- If in a group conversation, asking one person to tell you what has been said may help.

The following organisations provide information about living with hearing changes and tinnitus:

- Royal National Institute for Deaf People (RNID) — page 105
- The British Tinnitus Association — page 104.

Effects on the neck and shoulders

Surgery to remove lymph nodes in the neck is called neck dissection. It can cause changes in the neck and shoulder. After surgery, the skin in the area becomes tighter and thicker as the scar heals. Radiotherapy, especially after surgery, can also cause tightness in the skin and tissue in the treated area. It is important to get to know how the skin on your neck feels. If you notice anything new or it feels different, contact your specialist doctor or nurse or consultant.

Your neck may also feel stiff when you move your head. It may be numb in places, especially around the scar. This often improves over time but does not always recover completely. Some people have pain in their neck or ear that lasts a few seconds before going away. These are known as spasms.

As the scar heals, you may feel pricking, tingling or numbness on the skin 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. This can also help make the scar line smoother.

Removing lymph nodes in the neck can sometimes cause a build-up of fluid in the tissues called lymphoedema. This can lead to stiffness and swelling.

During surgery to lymph nodes in the neck, the spinal accessory nerve is sometimes injured. This nerve usually sends messages to the shoulder muscle. If it is damaged, the shoulder may feel stiff. Some people find that shoulder movement can be painful, more difficult or weaker than before. Others find that they cannot move their arm as much as before.

If the nerve was only bruised during surgery, it usually recovers within a few months. But if the nerve 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. Surgeons try to avoid damage to the nerve.

Changes in your neck and shoulders can take up to 6 months to develop. It is common for stiffness in the neck and shoulders to develop before you have any pain. It is important to get any stiffness checked and treated as early as possible. This reduces the risk of developing a frozen shoulder. This is where the tissue around the shoulder becomes inflamed, stiff and painful.

> **"When I get a cold now, it affects my chest badly. The nerve damage goes as far down as my chest and with the tightness of the scars on my neck, coughing is a real challenge."**
>
> Elise, diagnosed with jaw cancer

Coping with neck and shoulder changes

If treatment has affected your neck or shoulders, your doctor may arrange tests to find out why. This is so they can give you the right treatment. If needed, they can prescribe painkillers and refer you to a physiotherapist (page 10).

The physiotherapist may talk to you about:

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

If you have changes in your neck and shoulders, you may find lying down for long periods of time uncomfortable.

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 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 will show you exercises to improve movement and reduce pain. Doing these regularly can help prevent your shoulder becoming stiff. They may give you 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.

If the spinal accessory nerve was removed or is permanently damaged, the effects on your shoulder will be more severe. A physiotherapist may use specially designed strapping or a brace called an orthosis. These support your arm and hold your shoulder in the right position. This can reduce any pain and help you to use your arm.

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 helps with 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. Sit up or stand up straight with your shoulders back but relaxed. When you sit, make sure your lower back is supported. This puts 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, firmly massage the area regularly. Massaging the area around a scar using a non-perfumed oil or cream, can help relieve tightness in the skin.

Always check with your physiotherapist, doctor or nurse before massaging the affected area. Your nurse or physiotherapist can show you, or someone you are close to, how to do the massage.

Pain relief

Your doctor can prescribe regular painkillers for you. Tell them if the pain does not get better. They can increase the dose or change your painkillers.

Swelling of the face or neck (lymphoedema)

After surgery and radiotherapy, it is common to have some swelling in your face or neck. This usually goes away within a few weeks.

You may have more risk of developing long-term swelling if:

- you had surgery to remove lymph nodes from your neck
- you had radiotherapy after surgery.

The swelling happens because the lymphatic system, which normally drains fluid away, has been damaged by treatment. This is called lymphoedema.

Lymphoedema can also affect tissues inside the neck, such as the throat or larynx (voicebox). This can cause problems with speaking, swallowing or breathing. Lymphoedema may be worse in the morning and improve as the day goes on.

Always tell your GP or cancer specialist if you notice swelling in your face or neck or tightness in the muscles. They can assess you to find out the cause. Lymphoedema is usually treated by a lymphoedema therapist. Your GP, cancer specialist or specialist nurse can refer you to one.

Coping with lymphoedema

Skincare

It is important to look after the skin on your head, face and neck if you had any lymph nodes in your neck removed. This can help to reduce the risk of developing lymphoedema. If you have been diagnosed with lymphoedema, looking after your skin is important in managing it.

Lymphoedema can make your skin dry, itchy and more fragile than before. This can cause the affected area of skin to break more easily. This increases your risk of infection, which can make swelling worse.

Here are some other things you can do to look after your skin if you have, or are at risk of, lymphoedema:

- Use soap-free cleansers that do not dry the skin.
- If you shave, use a clean electric razor.
- Moisturise gently 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 are in the sun. Wear a hat and use sun cream with a sun protection factor (SPF) of at least 30.
- Use insect repellent to prevent bites or stings, as these can make lymphoedema worse.
- Contact your GP straight away if you develop any sign of infection in your skin. This could be tenderness, redness, heat, discharge or swelling in a new area.

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 the swollen area. NHS lymphoedema treatment clinics often provide MLD. You can also do a version of MLD at home. This is called simple lymphatic drainage (SLD). Your lymphoedema or MLD therapist can teach you this.

Some people are given low pressure compression garments to help keep swelling down. They work by preventing fluid from gathering in the affected tissues. But you should never have compression to the neck area. You should only wear a compression garment that has been measured and fitted by a lymphoedema specialist. If your garment feels too tight or does not fit properly, it is important to tell your lymphoedema specialist.

Sometimes a type of lymphoedema taping called Kinesio® taping may be used. It lifts the skin to allow lymph fluid to flow more easily. Rarely, surgery can be used to treat lymphoedema around the eyelids. We have more information in our booklet **Understanding lymphoedema** (page 98).

Lymphoedema can affect how you think and feel about your body. This is known as your body image. We have more information and advice about dealing with body image changes (pages 90 to 93).

Pain or numbness

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

Always tell your cancer doctor if you have a new pain or pain that is getting worse. Pain can happen for different reasons. It may be caused by a late effect of treatment such as trismus, scar tightness or nerve damage (pages 78 to 79).

It is natural to feel anxious if you develop pain. But it is important to get it checked out as soon as possible so that you can have treatment for it. Your doctor can arrange tests to find out the cause of the pain and make sure it is not linked to the cancer.

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 drugs may also be used depending on the type of pain you have. Physiotherapy and massage may also help to ease pain.

Some people find complementary therapies like meditation, massage, acupuncture or relaxation helpful. Ask your doctor or nurse for advice if you are thinking about using a complementary therapy. We have more information in our booklet **Cancer and complementary therapies** (page 98).

A talking therapy called cognitive behavioural therapy (CBT) may also be used to help manage pain. We have more information on managing cancer pain in our booklet **Managing cancer pain** (page 98).

Painkillers

If pain is mild, it can often be controlled with simple painkillers such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs) – for example, ibuprofen. Anti-inflammatory drugs can irritate the stomach, so you take them after a meal or snack. If you have had stomach problems, your doctor may advise you not to take them.

Different painkillers are used for mild, moderate and severe pain. Mild to moderate pain is controlled by opioid drugs such as morphine in a liquid form. Moderate to severe pain is treated with stronger opioids such as morphine or fentanyl. If the pain is difficult to manage, your doctor can refer you to a pain clinic for expert help.

Side effects

Many painkillers can cause constipation. You may need to take laxatives as well. Your doctor can give you further advice. Strong painkillers may make you feel drowsy when you first start taking them. This usually improves within a few days once you are used to the dose.

Taking your painkillers

It is important to take your painkillers regularly, as prescribed by your doctor. This is to maintain a constant level of pain control. People often think they should delay using painkillers for as long as possible. But this allows the pain to build up, which can make it harder to control. Tell your doctor or nurse if painkillers are not controlling the pain. Your dose may need to be changed or you may need a different painkiller. It may take time to get the right painkiller and dose to control your pain. You may need a combination of different painkillers to manage your pain. Your doctor can refer you to a specialist pain team if your pain is not well-controlled.

Other types of drugs

Your doctor or nurse may prescribe other drugs to help control the pain. You may take these with painkillers or on their own.

If muscle spasms are making your pain worse, you may be prescribed a drug to help relax the muscles. You may be prescribed drugs such as diazepam or baclofen (Lioresal®). Drugs called steroids may be used to reduce swelling.

Pain caused by nerve damage can be treated with specific drugs that treat nerve pain. Drugs that work on the nervous system, for example, gabapentin and amitriptyline, can be used. The dose is often increased gradually over a few days or weeks. It can take several weeks for them to take effect.

Physical therapies

A physiotherapist can also show you helpful exercises that stretch the tissues (page 10).

Massage and warmth can also ease tightness or muscle cramps in the neck or shoulders. Some people use a heat pack to warm the area. If you want to try this, it is very important to follow the manufacturer's safety instructions. Make sure the pack is warm and not hot, especially if you have any loss of sensation in the area. Always check with your physiotherapist, doctor or nurse before using a heat pack or massaging the affected area.

Sometimes pain is caused by lymphoedema (pages 71 to 73). Your nurse can refer you to a lymphoedema specialist for treatment which will improve the pain.

Other therapies

Cognitive behavioural therapy (CBT) is a talking therapy that may help you.

Feelings like fear, anxiety, depression and tiredness can make pain worse. Learning to relax, even if only for a short time each day, may help to manage and control pain. Ask your doctor if there is a healthcare professional who can help you. This might be an occupational therapist, physiotherapist or psychologist (pages 10 to 11).

Sore mouth

After radiotherapy to the head and neck 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, and smoking can irritate your mouth and make it sore. It is important to continue to look after your mouth even when radiotherapy side effects have improved.

Always ask your doctor or nurse for advice. They can check for signs of infection and prescribe treatment for you. Diluted Difflam® mouthwash can help with pain and swelling in the mouth and throat (pharynx). Using a warm saltwater rinse can also help (page 26). Treatments, such as Gelclair® and Episil® are used to coat the inside of the mouth and protect sore areas. Your doctor may advise you to use them about an hour before eating.

Numbness or changes in sensation

If a nerve was damaged during surgery, this may cause a change in sensation or numbness in that area. It can take up to 2 years for nerves to heal and normal feeling to return. But if the nerve was cut during surgery to remove the cancer changes in sensation will be permanent.

Pain can be a 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 is numb. It is safer to use an electric razor. Be careful not to expose the numb area to very hot or very cold temperatures.

Peripheral neuropathy

Some chemotherapy drugs can cause numb, tingling or painful hands or feet. This is called peripheral neuropathy. It happens when the nerves that carry messages between the brain, the spinal cord and the rest of the body are damaged. 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 do not completely recover, and some people have long-term changes. But there are ways to manage the symptoms of peripheral neuropathy.

Managing peripheral neuropathy

There is not 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 help treat nerve pain.

If you have problems with balance or walking because of nerve damage, a physiotherapist can give you treatment and advice. If you are finding it hard to do daily tasks, ask to be referred to an occupational therapist. They can suggest aids and equipment to help. There may be financial help available and also support at work.

Other things you can do to help include the following

- Keep your hands and feet warm with gloves and warm socks.
- Avoid walking around barefoot.
- Check your feet regularly for any problems.
- Wear well-fitting shoes or boots.
- Wear gloves when doing household chores, gardening or DIY.
- Turn the temperature control to a lower setting for hot water or have a temperature control (thermostat) fitted. Check the temperature with your elbow before a shower or bath.
- Keep areas free of clutter and well-lit.

> **"Fatigue is ongoing and is probably the most frustrating long-term effect."**

Paul, diagnosed with tonsil cancer

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 and find it difficult to do simple, everyday things. It is not unusual for this to last for months after treatment. In some people, tiredness continues for a year or more.

Possible causes of tiredness

Sometimes, tiredness is linked to other problems such as:

- pain
- depression
- sleep problems
- an underactive thyroid gland
- having a low number of red blood cells (anaemia).

It is important to find out if there is a treatable cause for your tiredness. Tell your doctor or nurse how you are feeling. They can take blood samples to find out if your thyroid gland is underactive or if you have anaemia (low levels of red blood cells). These conditions can be treated with medicines.

Pain

Coping with pain can be tiring. Having effective treatment for your pain may improve your energy levels.

Depression

Tiredness can be a common symptom of depression. It is not unusual to feel depressed or anxious after cancer treatment.

If you find that your mood is low most of the time, you may have depression. If you have depression, your GP will discuss possible treatments with you. They can refer you to a counsellor and prescribe medicines to help if necessary.

Some people find complementary therapies and mindfulness help to reduce stress and improve tiredness. We have more information in our booklet **Cancer and complementary therapies**.

Eating problems

Our bodies get energy from the food we eat. Fatigue can happen if the body does not get enough food, or if there are changes to the way the body is able to use the food. If you are having difficulties eating, talk to your nurse or dietitian. Try having regular, small amounts of food or snacks, rather than a big meal. Ready-made, high-calorie drinks are available from any chemist and some on prescription. We have more information about coping with eating difficulties in our booklet **Eating problems and cancer**.

You can order our booklets and leaflets for free.
Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

Sleep problems

If sleep problems are causing tiredness or making it worse, improving your sleeping pattern will help you feel better. We have more information about sleeping difficulties. Visit **macmillan.org.uk/trouble-sleeping**

Simple breathing and relaxation exercises may help reduce anxiety and stress and improve sleeping. They can also reduce muscle tension. You can learn them as part of a group, or at home using a CD or podcast. You could ask your doctor or nurse if relaxation sessions are provided at your hospital.

Underactive thyroid

Radiotherapy for head and neck cancers 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 and makes hormones. Hormones control many different processes in the body.

Symptoms of an underactive thyroid gland can include:

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

If you are at risk of developing an underactive thyroid, you will have yearly blood tests to check it is working normally. An underactive thyroid gland can be treated with daily tablets.

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.
- Try to go to bed and get up at the same time each day. Try not to stay in bed after you wake up.
- Pace yourself. Balance activity with regular rest periods.
- Let family, friends and neighbours know how they can help.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 98.

Concentration and memory problems

After cancer treatment some people have difficulty concentrating and remembering things. Doctors call this cancer-related cognitive changes (CRCC) or chemo brain because the symptoms were first linked to chemotherapy. The causes are unclear, but it may be caused by a combination of factors. For example, chemo brain may be caused by treatment side effects, anxiety or depression, menopause or poor nutrition.

Changes in memory or concentration are usually mild and often better within a year of finishing treatment. Sometimes they go on for longer or have more of an impact on your daily life. You may experience:

- difficulty in concentrating and focusing (feeling foggy)
- feeling mentally slower than before and finding it hard to take things in
- mixing up dates or forgetting appointments or events
- not being able to find things
- difficulty doing more than one thing at a time (multi-tasking)
- struggling to remember everyday words or phrases.

If you are having these problems, talk to your doctor. They may arrange for you to have tests, such as blood tests or a scan.

Feeling extremely tired (fatigue) or having anxiety and depression can affect concentration and memory. Pain or other symptoms can also make it difficult to focus. Your doctor can check for any other possible causes for your symptoms, such as depression or side effects of medicines that you may be taking. Finding ways to manage these symptoms may help to improve problems with your concentration and memory.

Managing concentration and memory problems

Here are some things you can do to improve your memory and concentration 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 cancers can cause changes to how you look. This can affect your body image. Body image is how you think and feel about your body. If your appearance has changed, you will need time to get used to this and to adapt.

Your specialist team at the hospital can give you support and advice to help you adjust. Changing Faces is a charity that helps people cope with changes to their appearance (page 105).

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**

Your feelings about body image

Everyone reacts differently to body changes. You may feel more self-conscious about your body but find it easy to cope with. Or body image concerns may make you feel less confident, anxious, angry, anxious or sad. These are normal reactions.

Talking with people you trust can be a good way to move forward. This could be your family, close friends, a partner or your cancer doctor or nurse. If your body image concerns are difficult to cope with, or you are avoiding social situations, talk to your doctor or nurse.

Your cancer doctor or specialist nurse can refer you to a counsellor or psychologist for talking therapies. They may also prescribe medicines to help. Cognitive behavioural therapy (CBT) is a talking therapy that helps you to challenge unhelpful thinking patterns and behaviours. It can be a helpful therapy for people with body image concerns.

Taking care of yourself and your body may help you develop a more positive body image. Even if your body looks or feels different, you can feel proud about it getting you through treatment.

Be kind to yourself and take time regularly to do nice things for yourself. Eating healthily, getting enough sleep and being more physically active are other ways of taking care of your body.

Covering up physical changes

It is normal to want to cover up parts of your body that you are less comfortable with. You might feel more comfortable wearing scarves or tops with higher necks to cover changes to your face or neck.

Try not to focus on hiding areas of your body. This might make you more anxious. You might avoid social situations because you are worried about how other people may react to the changes in your appearance.

Skin camouflage products

If you have had skin grafts, the colour of the new skin may not match the surrounding skin. Or you may have visible scars you would like to cover up. Using camouflage makeup can help.

Some head and neck clinical nurse specialists and organisations, such as Changing Faces (page 105), offer specialist skin camouflage services. They can give you advice on how to apply it. If you wear a prosthesis and it does not match your camouflage make-up, go back and meet with the person who supplied it. They can match the colour to your camouflage makeup.

Managing other people's reactions

You may find that some people look at you for longer. Usually this is because they are curious and not because they want to upset you. You will probably find that most people take much less notice than you might expect. Learning how to cope with social situations in advance can build your confidence. You can get more information about how to manage people's reactions from organisations such as Changing Faces (page 105).

It may help to think of different responses to prepare you. Or you can tell them you do not want to talk about it.

You do not need to give long explanations. For example, you could say:

- 'I had an operation to remove a cancer a few weeks ago and I'm recovering well.'
- 'Thank you for asking, but I would rather not talk about it at the moment. Don't worry, I'm doing fine.'
- 'I had my operation to remove the cancer and I'm getting used to the changes, but it will take a while.'

We have more information in our booklet **Body image and cancer** (page 98).

Your sex life

The physical and emotional effects of cancer and its treatment may affect your sexual confidence. It may also affect your ability to have sex or intimate relationships.

After treatment, you may have problems with your body image and self-esteem. You may be left with a low sex drive (libido) or have sexual difficulties because of the physical effects of treatment. Symptoms like tiredness or pain may mean you do not feel like having sex. Tiredness usually gradually improves and having the pain controlled may also improve things.

Changes to your face, mouth and neck can change how you feel about kissing and having sex. If you are not comfortable with kissing or using your mouth during sex, tell your partner. There are other ways to give and receive pleasure. A sex therapist may be able to help if you need advice. Most difficulties will improve over time.

Relationships, sex and intimacy

It is not unusual to have concerns about your sex life and intimate relationships after treatment for head and neck cancer. If you have a partner, you may worry they will compare things to how they were before. Or you may worry they will no longer find you attractive. But there will be lots of reasons why your partner finds you attractive. It is not just about how a part of your body looks.

You may need time to recover and adapt to body changes before you feel comfortable about having sex. Partners may also have concerns. Talking openly with each other can have a positive effect on your relationship. It can make you feel more comfortable with each other. We have more information in our booklet **Cancer and your sex life** (page 98).

If you are with a partner, it might help to just spend time being close and intimate without having sex. Sometimes this can lead to sex. But it is also a way to build trust and confidence together.

If you are not in a relationship, you may worry about how a new partner might react to any physical changes. You may be unsure what to tell a new partner. People who have cancer do go on to have close and intimate relationships. It is your decision how, when and what you tell a new partner.

If difficulties with your sex life do not improve, talk to your hospital doctor or specialist nurse. It may help to talk about and express how you feel. Try not to feel embarrassed. They are used to giving advice on intimate problems. They may be able to give you information and advice on how to improve sexual difficulties. They can also refer you to a sex therapist if needed.

Menopausal symptoms

Chemotherapy may cause periods to stop temporarily. Depending on your age, your periods may stop permanently. This is more likely if you are closer to your natural menopause. Menopause can reduce your sex drive and cause vaginal dryness and hot flushes. This can make having sex difficult.

Your doctor can do blood tests to check if you are menopausal. You can talk to them about hormone replacement therapy (HRT) or other ways of coping with menopausal symptoms. Managing hot flushes and other symptoms may help to improve your sex drive. Using gels and creams for vaginal dryness can help ease discomfort during sex. We have more information about menopause. Visit **macmillan.org.uk/menopausal-symptoms**

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About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

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

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

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring 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
- interactive PDFs
- large print
- translations.

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

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

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

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 support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide information to help you manage cancer at work. Visit **macmillan.org.uk/work**

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 is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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**

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**

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Head and neck cancer support organisations

British Tinnitus Association

Tel **0800 018 0527**
www.tinnitus.org.uk
Offers support and information for people with tinnitus and their carers in the UK.

Changing Faces

Tel **0300 012 0275**
www.changingfaces.org.uk
www.changingfaces.org.uk/skin-camouflage
Offers support and information for people who have any condition or injury that affects their appearance, and for their families. It has skin camouflage practitioners, who can teach people how to self-apply specialist cover creams.

Royal National Institute for Deaf People (RNID)

Helpline **0808 808 0123**
SMS **07360 268 988**
www.rnid.org.uk
Offers support and practical advice to people in the UK with hearing loss and tinnitus.

Saving Faces

Tel **0203 417 7757**
www.savingfaces.co.uk
Reducing the incidence of facial injuries, disorders and diseases including oral cancer. Funds and leads research to improve treatments.

General cancer support organisations

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

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 such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

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

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

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

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the therapist directory page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **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.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
www.phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr/AboutUs/Registry

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 Dr Chris Alcock, Consultant Clinical Oncologist.

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We welcome feedback on our information. If you have any, please contact **informationproductionteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our head and neck cancer information. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

Nilsen M L, Belsky MA et al. Late and long-term treatment-related effects and survivorship for head and neck cancer patients. Current treatment options in oncology. 2020. Volume 21. Issue 12.

Machiels J.-P, Leemans C. R. et al. Squamous cell carcinoma of the oral cavity, larynx, oropharynx and hypopharynx. EHNS-ESMO-ESTRO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology, 2020. Volume 31, Issue 11, Pages 1462–1475.

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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.

5 ways you can help someone with cancer

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

2. **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.

3. **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?

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

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

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
☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Valid from
☐☐ ☐☐

Expiry date
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Issue no
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Security number
☐☐☐

Signature

Date / /

Do not 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 would rather donate online go to **macmillan.org.uk/donate**

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FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

This booklet is about the possible long-term and late effects of treatment for head and neck cancer. There is also information for carers, family members and friends.

The booklet talks about different late effects and what can be done to help to manage them.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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