MACMILLAN
CANCER SUPPORT

MANAGING THE LATE EFFECTS OF HEAD AND NECK CANCER TREATMENT

> My recovery was a slow process. A friend suggested I tried dancing and I've not looked back.

Dave, diagnosed with mouth (jaw) cancer

About this booklet

This booklet is about the possible long-term and late effects of treatment for head and neck cancer. It is for people who are experiencing side effects after treatment has ended.

The booklet explains:

- the possible long-term and late effects of head and neck cancer treatment
- what can help to manage them
- how you can help reduce your risk of developing 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. You can order a free copy from **be.macmillan.org.uk**

How to use this booklet

The 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 to help you.

Some of the information in this booklet may not be relevant for you, depending on the treatment you had. It is fine to skip parts of the booklet if they are not relevant, or if you do not want to read them yet. You can always come back to them when you feel ready.

We have included a notes page at the end of the information about each late effect. You could use these pages to write down your own notes or questions about each late effect you have. You may want to make a note of things you could try, or questions you want to ask your health professionals.

This booklet also comes with a bookmark. You could use it to mark your place, a section of information, a particular late effect or notes you have written that you want to discuss with your healthcare team.

Quotes

Throughout this booklet, we have included quotes from people who have had late effects after treatment for head and neck cancer. Some are from our Online Community (**macmillan.org.uk/community**). The others 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you and your health is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. 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 more information at **macmillan.org.uk/cancerregistry**

Contents

LATE EFFECTS OF HEAD AND NECK CANCER TREATMENT

Long-term and late effects

There are different terms used to describe side effects that develop after treatment, or side effects that you still have after treatment is over. The two most commonly used terms are:

- long-term effects
- late effects.

Long-term effects begin during, or shortly after, treatment and do not go away in the 6 months after treatment. They may go away eventually on their own. Symptoms may slowly get better over 1 or 2 years after treatment ends, or even longer. Sometimes long-term effects are permanent.

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

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

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

Possible late effects of head and neck cancer treatment

The main treatments for head and neck cancer are surgery, radiotherapy and chemotherapy. You may have had a combination of these. When doctors give chemotherapy and radiotherapy together, it is called chemoradiation (chemoradiotherapy).

We have more information about the main treatments for head and neck cancer (see page 132).

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

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

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

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

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

- a dry mouth (see pages 16 to 30)
- taste changes (see page 55)
- a bigger risk of tooth decay and bone damage (see pages 24 to 30)
- difficulty swallowing (see pages 51 to 53)
- changes in hearing (see pages 66 to 72)
- stiffness or pain in the jaw, neck and shoulders (see pages 32 to 37)
- changes in how you look (see pages 108 to 112).

Treatment can also cause changes in how you think and feel generally. You may feel more tired than usual for several months after treatment (see pages 97 to 100). Your sex life may also be affected (see pages 115 to 118). These effects often get better over time as you recover.

After treatment, you may have more time to think and reflect on your illness and what you have been through. You may feel a range of emotions, such as a low mood, anger or anxiety. We have more information on coping with your emotions (see pages 120 to 122).

One of the biggest fears many people have is whether the cancer will come back. As time goes on, most people become less worried. If you still feel very worried, you can get help from your GP, your head and neck cancer team, a counsellor or a psychologist.

We have more information about worrying about cancer coming back in our booklet **Worrying about cancer coming back** (see page 132).

Who can help you manage late effects?

When your treatment has finished, it is natural to want to put the cancer behind you and move forward in your life. Adjusting to changes after treatment takes time. It can be frustrating to still have side effects. But there are often things that can be done to treat and manage them. You specialist doctor will see you regularly in out-patient appointments. You will need to go to appointments less often over time.

As well as specialist doctors and surgeons, there are other specialists who can help. These may include a:

- **restorative dentist** – a dentist who designs prostheses (obturators), implants and dentures to help with eating, speech and appearance
- **dental hygienist** – someone who teaches you how to keep your mouth clean and prevent tooth decay
- **speech and language therapist (SLT)** – a specialist who assesses problems with speech, voice and swallowing and teaches you how to manage and improve them
- **specialist nurse** – a nurse who gives information and support on managing side effects
- **dietitian** – someone who can help you meet your nutritional needs
- **physiotherapist** – someone who offers treatments and exercises to help with reduced movement in the jaw, neck or shoulders and encourages safe physical activities
- **occupational therapist** – someone who can help with ongoing tiredness (fatigue)
- **lymphoedema specialist** – someone who can help manage fluid build-up in the tissues (lymphoedema)
- **psychologist or counsellor** – someone who can help you adjust to changes after treatment.

Other sources of support

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

Dealing with these changes can take a lot of effort and determination. It is normal to have ups and downs, and there may be times when you do not feel you are making progress.

It is important to have people around who can support you. As well as your healthcare team, this may include a partner, family or friends. If possible, take someone with you to your hospital appointments. This may help them understand what you need to do for your recovery so they are in a better position to help you.

Sometimes it is easier to talk to someone who is not close to you or involved in your care. This could be a counsellor or members of a support group who have been through a similar experience.

Many treatment centres have health and well-being events for people who have had head and neck cancer. These help patients who are dealing 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 talk to our cancer support specialists on the Macmillan Support Line on **0808 808 00 00**.

PHYSICAL CHANGES TO THE HEAD AND NECK AFTER TREATMENT

Dry mouth and changes in saliva

Radiotherapy or chemoradiation to the head or neck can affect your salivary glands. This means that 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 finishes, 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 (see pages 41 to 53).

Coping with thick, sticky saliva

Rinsing your mouth regularly can help. Your specialist head and neck team can give you advice on what type of mouth rinse to use. Sometimes a build-up of mucus can cause coughing, especially 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 water (not boiling water) with a towel over your head. This can help loosen thick, sticky saliva. It is best to do this 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. So it is really important to look after your teeth during and after treatment.

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 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. You should make a fresh rinse each day.

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

Relieving dryness

One of the easiest ways to help relieve a dry mouth is to carry a bottle of water with you at all times. You can take frequent sips of water or you could use a water spray instead. You can buy small atomiser spray bottles from most chemists. If you 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.

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

The effect of artificial saliva may only last for a short time. It is best to use it just before eating. For longer-lasting relief at night, try putting the gel on your tongue and around the inside of your mouth. This may relieve dryness for up to 5 hours. If you have dentures, you can use the gel under them. This can help them feel more comfortable and stay in place. Remember to take your dentures out at night to give your mouth a break from them.

Artificial saliva with added fluoride can help to protect your teeth. But some products are acidic and can cause tooth decay. If you have your own teeth, make sure you use one that is pH-neutral. Some brands of artificial saliva may also contain animal products.

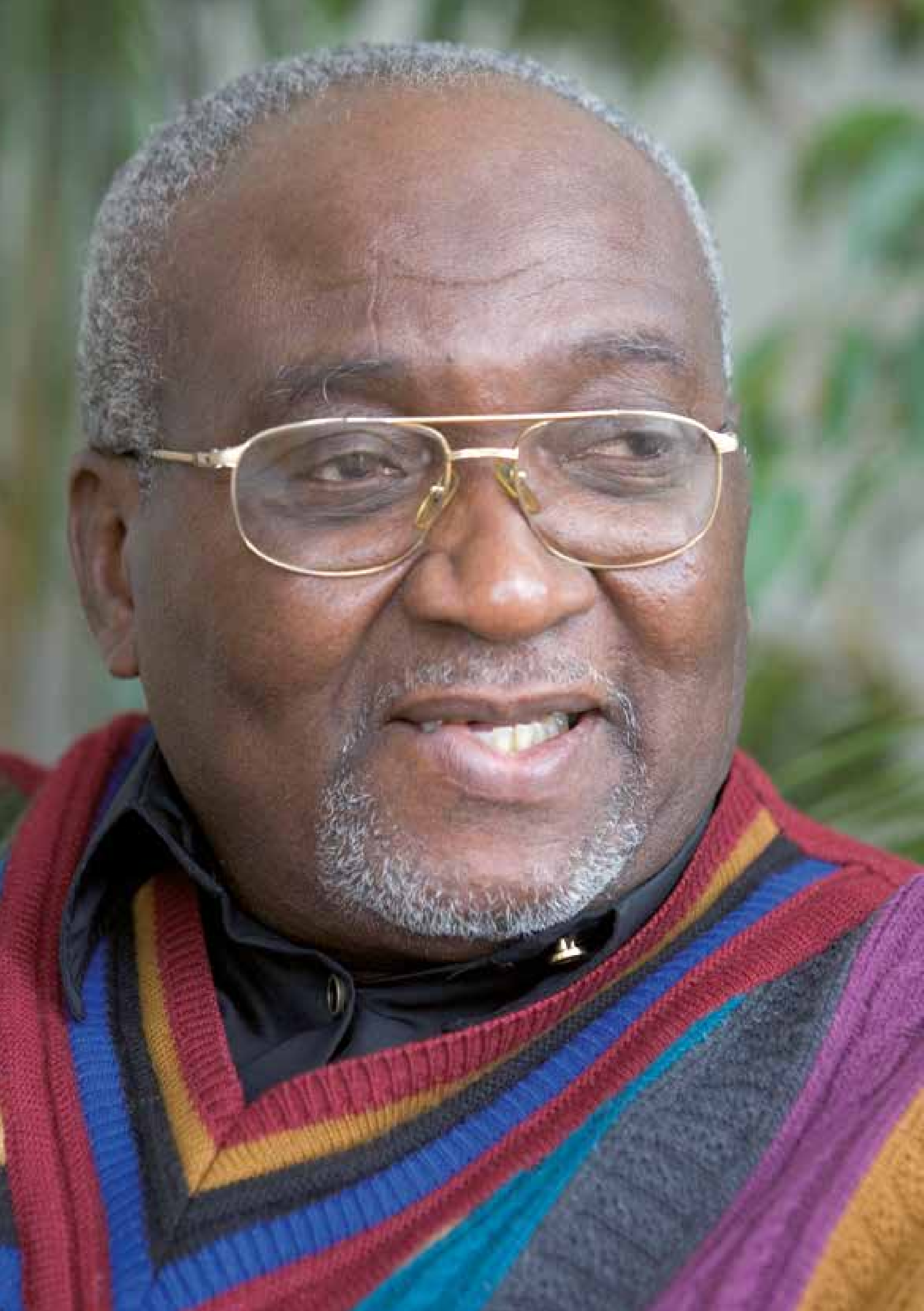
Here are some other things you can do to help ease symptoms of a dry mouth:

- Try to avoid alcohol (especially spirits) and drinks that can irritate a dry mouth. This includes caffeinated drinks or citrus drinks.
- Do not smoke, as smoking dries and irritates the mouth.
- Ask your doctor or nurse whether you are taking any prescribed medicines that can cause a dry mouth. It may be possible to reduce the dosage or change the drug.
- Use a lip salve to protect your lips.
- Try using a humidifier in your bedroom at night.
- Avoid toothpastes with foaming agents in them, as these can make your mouth dry. Foaming agents are usually an ingredient called sodium lauryl sulphate (SLS) – see page 29 for a list of SLS free toothpaste.

If your mouth is dry, it can make eating more difficult. Here are some things you can do to help with eating:

- Try to avoid foods that can irritate a dry mouth. This includes spicy, salty or hard and crunchy foods, or citrus fruits.
- Take sips of water when you are chewing and after swallowing.
- Eat soft, moist foods such as casseroles, soup, melon, grapes and ice cream.
- Add moisture and fat to make food easier to manage, especially with dry and starchy foods like bread, biscuits, crackers and potatoes. For example, you could use gravies, sauces, extra oil, salad dressings, yoghurt and mayonnaise or butter to moisten foods.
- Try rubbing a very small amount of olive or sunflower oil onto your gums just before a meal. This can make it easier to chew and move foods around the mouth.

We have more information on eating and drinking problems in our booklet **Eating problems and cancer** (see page 132).



Stimulating saliva

Treatments that stimulate saliva can help:

- if some of your salivary glands still work
- if the damage to your glands is temporary.

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

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

Table of artificial saliva products for a dry mouth

Artificial saliva products may help moisten your mouth and throat. We have a table of artificial saliva products on the next page.

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

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

Mouth care and preventing tooth decay

When you are coping with the effects of cancer treatments, it can be easy to forget about caring for your teeth. But this is one of the most important things you can do before and after treatment for head and neck cancers.

Saliva helps keep your mouth clean. If you have a dry mouth, you are more likely to get mouth infections, such as thrush. This can cause white patches in the mouth, soreness or a burning feeling on the tongue. It can also cause an unpleasant taste in your mouth. Tell your doctor if you have any of these symptoms. If you have thrush, they can prescribe medicine to help. If you have dentures, you are more likely to get oral thrush (see page 30). You should take them out at night and keep them clean.

Try to fix any rough, chipped or sharp teeth or dentures before your treatment starts. Saliva allows the tongue, lips and cheeks to slide easily over the teeth. Having smooth teeth will prevent them rubbing inside your mouth and causing any sore areas or ulcers to develop.

Saliva is also very important in protecting your teeth against decay. Having a dry mouth means you are at much higher risk of tooth decay. Even if you only have a few teeth, it is important to have a good mouth care routine. This will help keep those teeth in good condition. It will also help to reduce your risk of a rare, serious late effect of radiotherapy called osteoradionecrosis. This can affect the jawbone. We have more information about osteoradionecrosis on our website **macmillan.org.uk**

Here are some things that you can do to help protect your teeth:

- Have regular check-ups with a dentist or dental hygienist every 3 to 6 months.
- Use fluoride products prescribed by your dentist (see page 26).
- Only have sugary and acidic foods and drinks at mealtimes.
- Follow a mouth care routine agreed with your dentist or hygienist.
- Do not smoke.
- Check your mouth daily for ulcers, signs of tooth decay or red, white or dark patches. When you have a dry mouth, decay often happens at the top or bottom of the tooth near the gum line.
- If you notice a change in your mouth or teeth, do not wait for your regular check-up. Go and see your dentist immediately.

Using fluoride

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

You can get toothpastes, mouthwashes and artificial saliva products with added fluoride. The highest fluoride toothpastes are Colgate Duraphat® 2800ppm and Colgate Duraphat® 5000ppm. These have to be prescribed, so ask your dentist or doctor.

Your dentist may also recommend:

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

Cutting down on sugary and acidic foods and drinks

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

Here are some tips that might help:

- Eat and drink fewer acidic things like fizzy drinks, orange juice, oranges and tomatoes, as these can break down tooth enamel. The more times you eat or drink something acidic or sugary, the more acid attacks there are on your teeth. It is important to limit these foods and drinks to mealtimes, no more than 4 times a day.
- Eat fewer foods that contain refined sugar. These include chocolate, sweets, fresh fruit juice, biscuits, cakes and buns, pastries, fruit pies, dried fruit, sweet sauces, sponge puddings, breakfast cereals, ice cream, jams, honey and fruit in syrup.
- Check labels on foods to find out if they contain sugar. Sugar can be called other names on food labels. Look out for glucose, sucrose, maltodextrin, dextrose, lactose, caramel, fructose, maltose, toffee, molasses, honey, syrup, corn sugar and hydrolysed starch. These are all alternative names for sugars.
- Choose sugar-free drinks, but be aware that some can be harmful to the teeth if they contain phosphoric acid or citric acid. Fizzy sugar-free drinks are often acidic. The safest drinks for your teeth are plain milk, still water, and tea and coffee without added sugar. Sparkling water can damage teeth as it contains carbonic acid.

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

We have more information about this in our booklet **The building up diet** (see page 132).

Brushing your teeth

Following a regular mouth care routine can help to protect your teeth. You can agree this with your dentist or dental hygienist. Looking after your mouth and teeth properly is important.

Here are some tips on brushing your teeth:

- Brush your teeth every morning and night.
- Choose a toothbrush with a small head and soft bristles. You could use an electric toothbrush with a small head that moves in circles (a rotating head). Some electric brushes come with a gentle setting, and soft or sensitive brush heads are available.
- Use a high-fluoride toothpaste (see page 26).
- If you have a sore mouth or throat or mouth ulcers, choose toothpaste without an ingredient called sodium lauryl sulphate (SLS), which foams up when you brush. Sensodyne Pronamel®, BioXtra®, Oranurse® Unflavoured Toothpaste and Biotène® Fluoride Toothpaste do not contain SLS.
- Spend 2 to 3 minutes brushing your teeth.
- As you brush, gently massage the gum around the base of each tooth.
- Brush each tooth slowly and gently. Brushing your teeth gently is enough to clean plaque from a tooth without hurting your gums.
- Move around the mouth, brushing the outside surface of each tooth. Repeat on the inside surface of each tooth. Repeat on the biting surface of each tooth.
- After you have brushed your teeth, 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 brushing back and forth. A dentist or 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 you use to brush your teeth to clean your dentures. Also use a denture cleaning cream.
- Clean and rinse your dentures after eating, as well as every night and morning.
- Gently brush the inside of your mouth with a small, soft toothbrush. This is because food may collect between the cheek and gums.
- It is important to remove any denture fixative which has stuck to the inside of the mouth. A tissue and warm water should help remove this.
- Before you go to bed, clean your dentures and soak them in a cleaning solution recommended by your dentist. Then leave them in a glass of water overnight. This will give your mouth a rest and reduce the chance of mouth infections such as thrush.

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.

MY NOTES

About managing a dry mouth and changes in saliva

Effects on the jaw

Jaw stiffness (trismus)

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

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

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

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. Without treatment, jaw stiffness can get more severe. So it is best to start treatment as soon as possible. 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 to see 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 dentist will show you what jaw stretches to do, how long to hold each stretch for and how many times to repeat them. They may also give you aids to help you gently stretch the jaw muscles. Wooden spatulas are often used. You place the spatulas between your upper and lower front teeth for a certain amount of time each day. You increase the number of spatulas you put into your mouth over time. 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.

Other things that may help if you have jaw stiffness

If you are having difficulty chewing or swallowing because of a stiff jaw, softer foods can be easier to eat. You may be referred to a dietitian or given supplement drinks to take until this improves.

We have more information on our website and in our booklet **Eating problems and cancer** (see page 132).

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

Changes to the jawbone (osteoradionecrosis)

After radiotherapy to the head and neck, the blood supply to the jawbone may not be as good as before. Sometimes, this 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
- having a tooth removed
- having an infection
- wearing badly fitting dentures, which can 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.

Always tell your 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. Smoking affects the blood supply to the bone. Find out more about how to give up smoking on our website or in our booklet **Giving up smoking** (see page 132).
- Look after your mouth and teeth and have a dental check-up every 6 months (see pages 24 to 30). Having an infection or a tooth removed can increase the risk of ORN.
- You may need to have one or more teeth taken out after radiotherapy. It is important to see a specialist oral and maxillofacial surgeon or specialist dentist to have this done. They will plan your treatment to reduce the risk of ORN developing.
- Wear well-fitting dentures. If they rub or are sore, do not wear them. See your dentist for advice.

How osteoradionecrosis is treated

- You may have painkillers to relieve pain and antibiotics to treat infection.
- Surgery is sometimes used to remove the affected tissue.
- You may be given medicines that help.
- It is important to continue to look after your mouth and keep your teeth clean.
- Sometimes in severe cases of ORN, jaw reconstruction may be needed.

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

We have more information about osteoradionecrosis on our website **macmillan.org.uk**

MY NOTES

About managing effects on the jaw

> ‘I’ve never had to worry about food because I’ve always been a healthy size. But now, I have a regimen where I have certain fortified drinks, and I have to have soup’.
>
> **Sue**

Eating and drinking

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

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

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.

We have information about what to eat to increase your weight after cancer treatment in our booklets **The building up diet** and **Eating problems and cancer** (see page 132).

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

If you have a feeding tube

Some people have a feeding tube put in before, during or after treatment. A feeding tube may be placed directly through the stomach (a gastrostomy) or through the nose and into your stomach (nasogastric). 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 permanently.

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

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

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

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

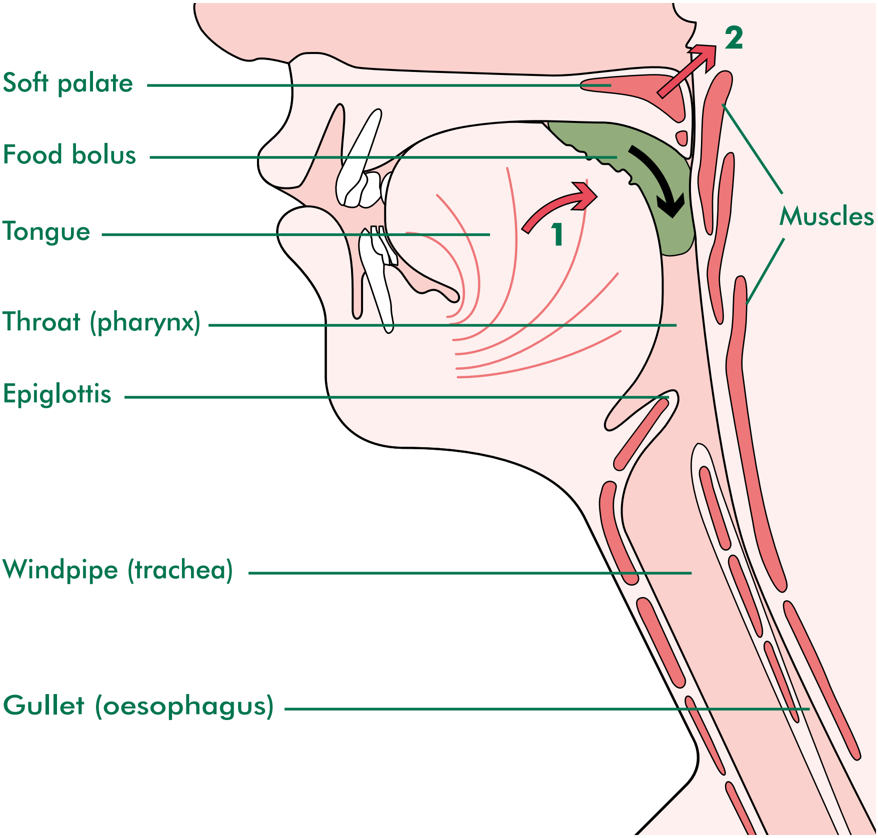
What happens when you chew and swallow?

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

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

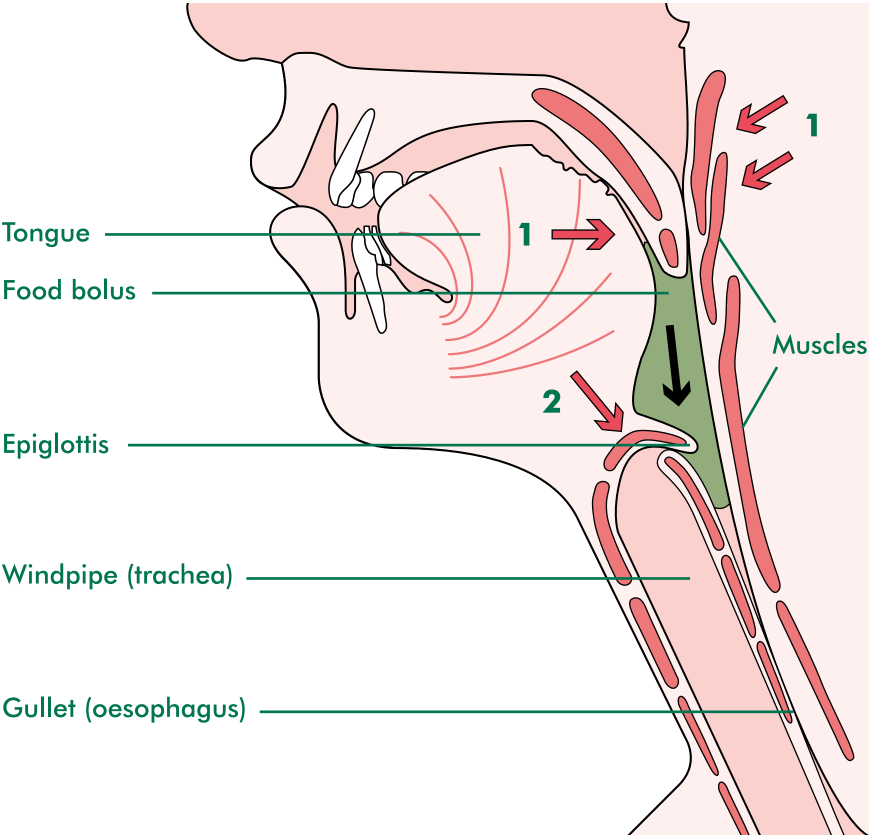
Mouth (oral) stage of swallowing

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



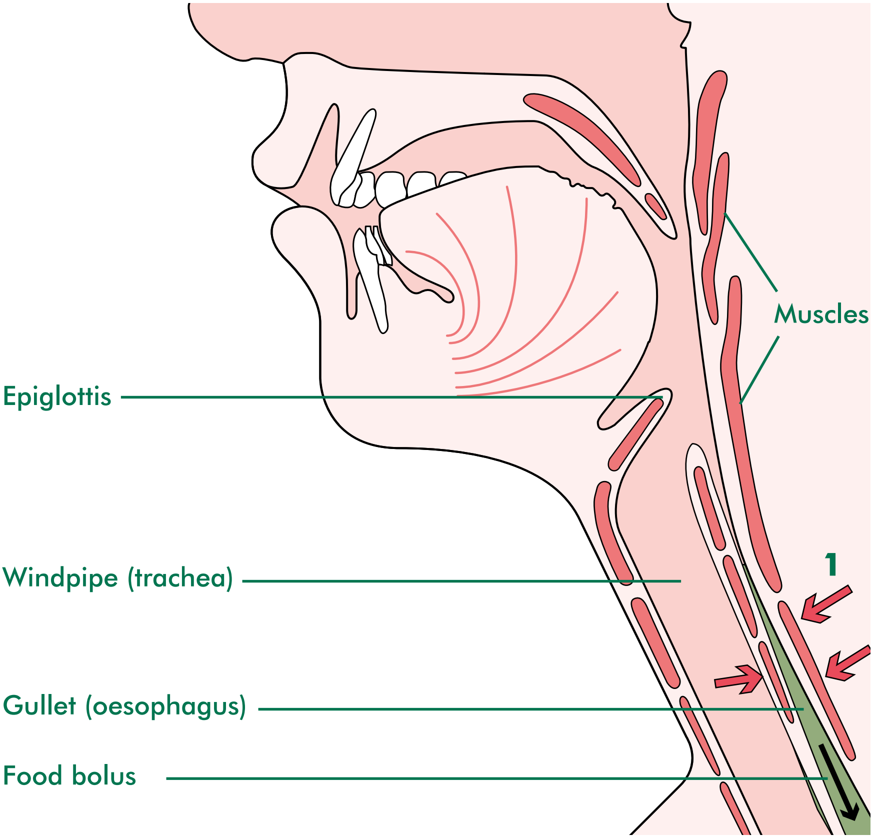
Throat (pharyngeal) stage of swallowing

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



Gullet (oesophageal) stage of swallowing

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



How treatments can affect chewing and swallowing

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

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

Jaw stiffness or a dry mouth also cause difficulties with chewing and swallowing (see pages 41 to 53).

Surgery to the larynx mainly affects the throat stage of swallowing. Swelling in the throat caused by a build-up of fluid in the tissues (lymphoedema) can also affect swallowing (see pages 82 to 84).

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

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

Problems with swallowing can cause food or drink to go down the wrong way into the windpipe. 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.

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 problems. 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 specialist. This could be a surgeon, a restorative dentist or a speech and language therapist (SLT).

Restorative dentistry

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

After surgery to the roof of the mouth (maxilla), some people have an opening between the roof of the mouth and 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 temporary one to begin with. 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, your dentist will make you a permanent obturator.

It is important to let your dentist know if you have any problems with the fit of the obturator. As the tissues in your mouth settle, your hospital dentist may need to adjust the fit from time to time.

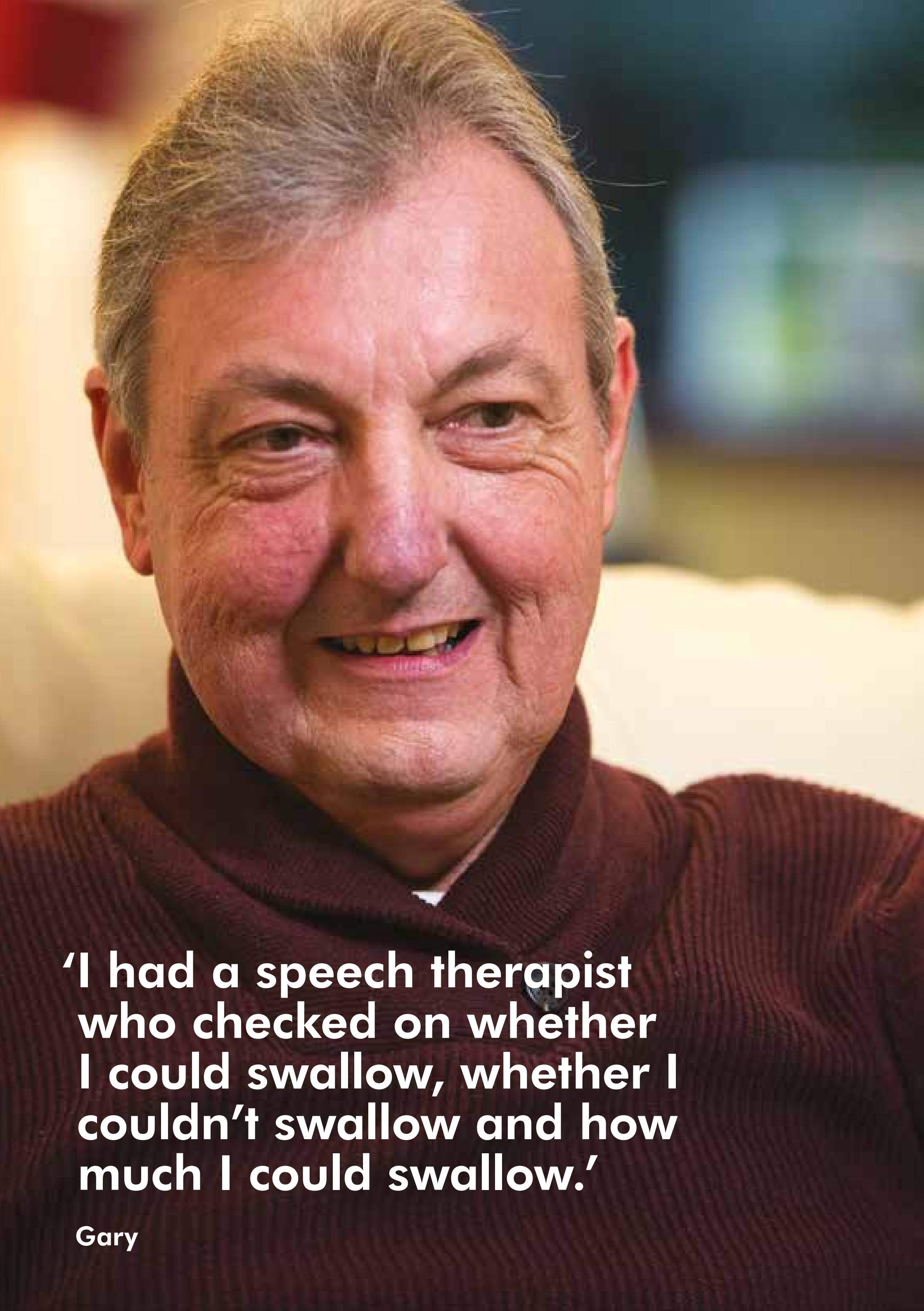
Exercises to improve chewing

Your SLT will assess your chewing to find out which difficulties you have. 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 to help stimulate parts of the mouth that have lost sensation.

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

They may also advise you on changes you can make to the food you eat. For example, this could mean choosing soft, moist foods. You may find it easier to chew with a larger or smaller amount of food in your mouth. This depends on why you are finding it difficult to chew.



> ‘I had a speech therapist who checked on whether I could swallow, whether I couldn’t swallow and how much I could swallow.’
>
> **Gary**

Help with swallowing

The type of treatment you can have depends on which parts of the swallowing process you are having problems with. 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 two tests that can be used to assess swallowing. These are:

- videofluoroscopy (VF)
- fiberoptic 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 what happens in your mouth and throat when you swallow. It can show:

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

This helps your SLT see 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. 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. They may also ask you to try different techniques to see if they help when you swallow. The test takes about 30 minutes and is painless. The x-rays are recorded on video or DVD.

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 your 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 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 on what types of food you can eat. For example, moister foods may be easier to swallow. It may help to bring a partner, family member or friend with you when you see your SLT. This can help them to support you at home when you are eating. 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
- changes to the way you prepare and cook food
- taking time to eat and swallow
- coughing to clear your airway after you swallow
- coping strategies to help you adjust to changes to eating and drinking.

If your SLT gives you swallowing exercises, you 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 it works 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. 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.

‘I do have some long lasting side effects. My taste buds have never quite recovered. I can’t really taste sweetness anymore, so most puddings don’t taste of much.’

James

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.

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 that 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.
- Try marinating meat in fruit juices.
- Try cold foods. Some people find that cold foods taste better than hot foods. Try serving cold meats with pickle or chutney.
- Try sweet foods. Some people find they can taste sweet foods better. But be careful with sugary foods as they can cause serious tooth decay if you have less saliva after radiotherapy.
- Use sauces and oils to flavour and moisten food.

Acid reflux

Acid reflux is caused by acid in the stomach coming 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. So acid reflux may be more noticeable if your mouth is dry. It can usually be treated with drugs to reduce or neutralise acid in the stomach.

Reflux is often worse when you are lying down. If you notice this, try not to eat or drink anything, or have caffeine for three hours before you go to bed. For example, you should avoid coffee, tea and chocolate. 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. Everyone has their own way of dealing with these issues.

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 an ice cream. You can start to do other things as your confidence grows.

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.

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.

If you go to someone’s house for a meal, try not to worry about telling them about your dietary needs. People often make allowances 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 can not eat spicy food. This helps them to prepare food that suits you. Or you can ask if you can bring your own food to be heated up.

If you 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.

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

People who do not know you 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.

Not all of us are good at asking for what we need. If you find it difficult, you may find the information about being assertive helpful (see page 112).

MY NOTES

About managing eating and drinking

Changes in communication

Sometimes, treatment for head and neck cancers can affect your speech, voice or hearing. If your treatment could affect these, your doctor or specialist nurse will talk to you about possible changes.

Changes to speech and voice

We use our lips, teeth, tongue, mouth, nose and throat when we speak. If you have had an operation or radiotherapy to your head and neck area, your speech or voice are likely to sound different. You may have difficulty making certain sounds or saying some words. Changes to your voice may be more severe. People may not be able to easily understand what you are trying to say. Or they may not be able to hear you clearly. Dryness 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 affected area heals. For others, it is more of a problem. It can cause permanent changes to the way they speak.

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

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

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

The sounds you make for speech (your voice) are made by the voicebox (larynx). Treatments that affect the larynx can affect your voice. Your voice may be hoarse, tire more easily or be quieter than normal. If you have had your larynx removed, you will need to learn new ways to communicate (see pages 64 to 65).

We have more information about communicating after an operation to remove the larynx. We also have a video that describes ways of communicating after an operation to remove the larynx (laryngectomy). You can find it at **macmillan.org.uk**

There are things that may help if you have changes to your speech or voice.

Speech therapy

Speech therapy can help you learn to communicate in the clearest and most effective way possible. Your SLT normally assesses and advises you before surgery. Therapy usually begins as soon as possible after surgery and normally continues after you go home.

Your SLT assesses changes in your speech and voice. They can give you advice and treatments to help with any changes. If you have changes to your voice, they can give you advice on how to take care of your throat. They may give you exercises to:

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

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

Apps such as So2Speak® can help guide you through the 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 for free, but you may need to check whether it works on your mobile device.

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. But it will get easier. You can explain that you have had an operation 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 communicate with, can do to help.

> ‘I couldn’t talk. A lot of conversations were done by handwritten notes. It’s made easier by the fact that so many people only text nowadays.’
>
> **Gary**

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 to help with communication:

- Choose a quiet place with no distractions or background noise.
- Find a well-lit place to have your meeting.
- Face the person.
- Tell them you have difficulty with your speech.
- Sit up straight or stand up when speaking. This helps you breathe better.
- Speak slowly and carefully. Try to use short sentences and take a rest between them.
- Keep a pen and paper with you so that you can 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.

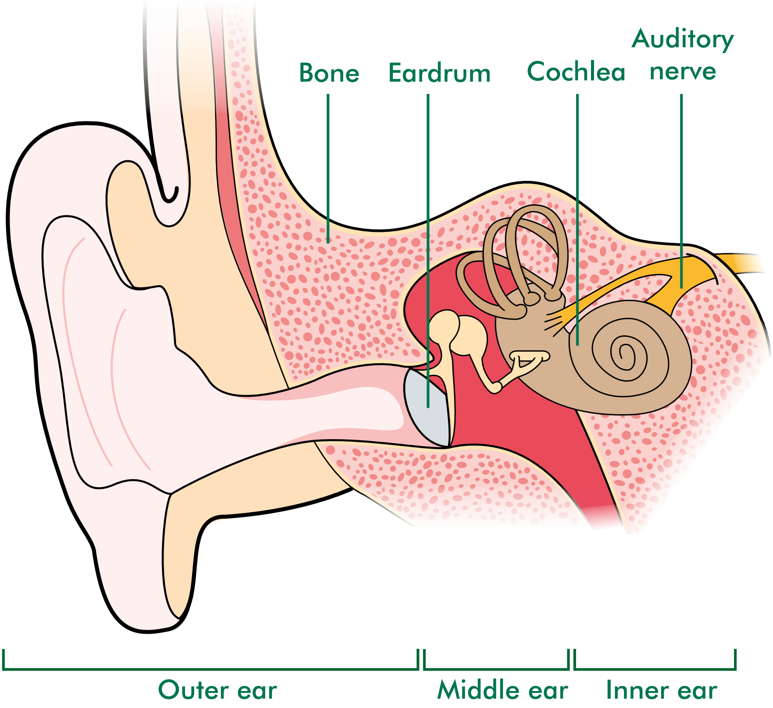
There are also helpful apps that convert the text you type into speech. Your specialist doctor or nurse can tell you more about this. You might also find the Talking Mats® app useful. It uses images to help you communicate quickly. It is free to download and works on some mobile devices. Ask your SLT for more information.

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 (see pages 71 to 72). It often gets better as your ears recover from the effects of treatment. But it can sometimes be permanent. If there is a chance that treatment may affect your hearing, your cancer specialist will explain this beforehand.

The outer, middle and inner ear



Hearing loss

There are two main types of hearing loss:

- **Sensorineural hearing loss (SNHL)** is caused by damage to tiny nerve hairs in the cochlea or to the nerve in the inner ear (auditory nerve). This makes it difficult to hear soft sounds and to tell some sounds apart.
- **Conductive hearing loss** is when sounds cannot pass from your outer ear to your inner ear. This is caused by a blockage in the ear, for example from a build-up of fluid or from earwax.

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

Signs of hearing loss can include:

- difficulty hearing other people clearly and misunderstanding what they say
- missing bits of conversation, especially in groups or when there is background noise
- asking people to repeat something
- listening to music or watching TV at a higher volume than usual
- needing subtitles on films or TV programmes.

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

Treatments for hearing loss

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

Treating fluid in the ear

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

Hearing aids

Hearing aids can help with both types of hearing loss. They work by increasing the volume of sounds. There are many different designs. The audiologist will explain which type is most suitable for you.

They will also show you how to:

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

You can also talk to your doctor about what may help with any hearing loss.

Living with hearing changes

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

Your local authority will have a social services department to support people with hearing loss. They can advise you on specialist equipment like smoke alerts. Hearing Link and Action on Hearing Loss can also give you information about living with hearing changes (see pages 137 to 138).

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

There are also apps to help people with hearing difficulties. Visit **hearinglink.org/living/loops-equipment/useful-apps-for-hearing-loss** for more information.

Support groups can be a good place to share experiences and find out what other people have found helpful. There may be a support group for people with hearing loss and their families in your area. Visit **macmillan.org.uk/selfhelpandsupport** to find out more.

Here are some more tips for communicating if you have hearing loss:

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

Tinnitus

Tinnitus is a sound that you hear from inside your body, rather than from 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. Tinnitus often gets better as your ears recover after treatment.

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

Things that can help include the following:

- **Learning about tinnitus.** You may be referred to a tinnitus clinic to see an expert. They can help you to understand and manage it. Knowing about tinnitus can help you cope. You can learn how to make the tinnitus less noticeable.
- **Wearing a hearing aid (if you have hearing loss).** Tinnitus can be more noticeable if you have hearing loss. This means things that improve your hearing might help, such as hearing aids. External sounds can help your brain to focus on something else.
- **Using other sounds to distract you.** Some people use background noises to distract them. This may be something simple like playing the radio or having an electric fan on. Or it could include using sound recordings of breaking waves, birdsong or white noise (a shushing sound). There are devices specially designed to produce sounds for people with tinnitus.
- **Learning relaxation techniques.** Tinnitus can be made worse by stress and anxiety. Learning ways to help you relax can lower your stress levels. Your specialist nurse, GP or staff at the tinnitus clinic may be able to refer you for therapies that can aid relaxation.

The British Tinnitus Association (BTA), Hearing Link and Action on Hearing Loss have more information on tinnitus (see pages 37 to 138).

MY NOTES

About managing changes in communication

Effects on the neck and shoulders

After surgery for a head and neck cancer, it is important to get to know how the skin on your neck feels now. This is so you can notice any changes in the area. If you feel anything new, you should contact your specialist nurse or consultant to discuss it further.

Surgery to remove lymph nodes in the neck (neck dissection) can cause changes in the neck and shoulder. After your operation, the skin in the area becomes tighter and thicker as the scar heals. Radiotherapy given after surgery can also cause tightness in the skin and tissue in the area that has been treated.

Your neck may feel stiff when you move your head. It may be numb in places, especially around the scar (see pages 87 to 94). This often improves over time but does not always go away completely. Some people have pain in their neck or ear. The pain may last a few seconds before going away. This is known as spasms.

As the scar heals, you may have a feeling of pins and needles 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. This can leading to stiffness and swelling (lymphoedema) – see pages 82 to 84.

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 the shoulder can be painful, more difficult to move 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 heals 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 will 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 as early as possible. This will reduce the risk of developing a frozen shoulder. This is when the tissue around the shoulder becomes inflamed, very stiff and painful.

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.

The physiotherapist may suggest:

- 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. If you are having restorative dental treatment, talk to your dentist about getting into a more comfortable position in the chair. You could also suggest breaking the treatment up into shorter appointments.

Neck and shoulder exercises

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

Your physiotherapist may show you exercises to improve movement and reduce pain. Doing these exercises regularly can help prevent your shoulder becoming stiff. Your physiotherapist 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 (an orthosis). These will 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. Massage the area around a scar, using a non-perfumed oil or cream, to 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 a family member or friend, how to do the massage.

Pain relief

Your doctor can prescribe regular painkillers for you. Tell your doctor if your pain does not get better. They can increase the dose or change your painkillers. If the pain is caused by tightness in your neck or shoulder, physiotherapy and exercise may also help.

MY NOTES

About managing effects on the neck and shoulders

Swelling of the face or neck (lymphoedema)

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

You are at greater risk of developing long-term swelling if:

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

The swelling happens because the lymphatic system, which normally drains fluid away, is not working properly. 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. They can arrange for you to have tests to find what is causing it. 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 have 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 can also help with the symptoms.

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 suncream with a sun protection factor (SPF) of at least 30.
- Use insect repellent to prevent bites or stings, as these can make lymphoedema worse.
- See your GP straight away if you develop any sign of infection in your skin. 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 compression garments to help keep swelling down. They work by stopping fluid from gathering in the affected tissues. You should only wear a compression garment that has been fitted by a lymphoedema specialist. If your garment feels too tight or does not fit properly, it is important to tell your lymphoedema specialist.

Lymphoedema can affect your appearance and how you see yourself (your body image). It is important to get support from professionals and those close to you if you need it.

We have more information in our booklet **Lymphoedema** and on our website **macmillan.org.uk**

We have more information and advice about dealing with body image changes (see pages 108 to 112).

MY NOTES

About managing swelling of the face and neck (lymphoedema)

Pain or numbness

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

Always tell your doctor if you have a new pain or pain that is getting worse. They can arrange tests to find out the cause. Pain can happen for different reasons. It may be caused by a late effect of treatment such as trismus, scar tightness or nerve damage (see page 32). Sometimes it may be a symptom of cancer coming back.

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.

To help your doctor understand your pain, tell them:

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

Managing pain

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

Painkillers

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

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

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. This is not a good idea as it leads to unnecessary pain. It also allows the pain to build up, which can make it harder to control.

Let your doctor know if painkillers are not controlling the pain. Your regular dose may need to be changed or you may need a different painkiller. It sometimes takes time to get the right painkiller and dose to control your pain. You may need a combination of different painkillers to manage your pain. Your doctor can refer you to a specialist pain team if your pain is not well-controlled.

Some painkillers can cause constipation. Constipation means that you are not able to empty your bowels regularly. It can become difficult or painful for you to poo. If the constipation is caused by the painkillers you are taking, it may be possible to change the dose. You may need to take laxatives as well. Your doctor can give you further advice.

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

Mild pain

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

Moderate pain

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

Severe pain

Painkillers used for severe pain include strong opioid painkillers, such as morphine, oxycodone, fentanyl or diamorphin.

Physical therapies

If the pain is caused by tightness from scar tissue in the jaw, neck or shoulder, taking painkillers may help. A physiotherapist can also show you helpful exercises that stretch the tissues (see page 78).

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, always follow the manufacturer's safety instructions. Make sure the pack is warm and not hot, especially if there is 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. Your doctor can refer you for treatment for this. We have more information about lymphoedema (see pages 82 to 84).

Relaxation

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

We have more information about managing pain and complementary therapies (see page 132).

Sore mouth

Radiotherapy to the head and neck often causes a sore mouth. This usually gets better within a few weeks. But you may be more likely to get infections or ulcers in your mouth. Your mouth may be more sensitive to spicy, salty, hard or crunchy foods. Alcohol, especially spirits and wine, may also irritate your mouth and make it sore.

If you have a sore mouth, it is still important to continue with regular mouth care (see pages 24 to 30). Use a small, soft-bristled toothbrush until your mouth recovers. If toothpaste irritates your mouth, try a flavourless toothpaste. Or try a brand that does not contain sodium lauryl sulphate (SLS) – check the ingredients label.

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

Your doctor or dentist can prescribe a mouthwash. This can help prevent or treat a dry mouth, or soreness or ulceration of the lining of the mouth (oral mucositis).

There are also treatments that you can put on the sore, such as Gelclair® and Episil®. They coat the inside of the mouth and protect sore areas. Your doctor may advise you to use them about an hour before eating.

Your doctor or specialist nurse can advise you on the best painkillers for your situation. You can have liquid painkillers, or painkillers that you can dissolve in water (soluble).

Diluted Difflam® mouthwash can help with pain and swelling in the mouth and throat (pharynx). Using a warm salt water rinse can also help. To make the rinse, boil 900ml of water. Let it cool to a warm temperature and then add 1 teaspoon of 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. You should make a fresh rinse of each day.

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.

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

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

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

Peripheral neuropathy

Some chemotherapy drugs can cause changes in sensation to the hands, feet and legs. This is called peripheral neuropathy. 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 month 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 change nerve impulses, which can help relieve pain. These include anti-depressants, anti-convulsants (used to treat epilepsy) or heart drugs. If your pain is difficult to manage, you can ask your doctor to refer you to a pain clinic for expert help.

If you are having 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.

You may be able to get financial help if:

- your symptoms continue for more than 6 months
- you find walking or daily activities difficult.

Call our cancer support specialists on **0800 808 00 00**.

Here are some other things you can do to help yourself:

- Keep your hands and feet warm – wear gloves and warm socks in cold weather.
- Avoid walking around barefoot.
- Check your feet regularly for any problems.
- Wear well-fitting shoes or boots.
- Wear gloves when working with your hands – for example when doing household chores, gardening or DIY.
- Test the temperature of water with your elbow before having a bath or shower, to make sure it is not too hot.
- Turn the temperature control to a lower setting for hot water or have a temperature control (thermostat) fitted.
- Keep areas that you walk through free of clutter and well lit.

We have more information on managing cancer pain and peripheral neuropathy (see page 132).

MY NOTES

About managing pain or numbness

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 pain (see pages 87 to 94). It can also be because of:

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

Depression

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

Talking about your feelings with a professional counsellor can also help. Your GP or specialist doctor can refer you. Some people find that complementary therapies also help to reduce stress and improve tiredness.

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 (see page 132).

Some people find learning relaxation techniques can help. Relaxation CDs and tapes may be available from your local library. Some hospitals, cancer centres and hospices offer breathing control and relaxation sessions. Ask your doctor or nurse whether any are suitable for you.

Pain

Coping with pain can be tiring. If you have effective treatment for your pain, this may improve your energy levels.

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. These hormones control all the cells in our body so that it is able to work normally. If we do not produce enough thyroid hormones, the cells and organs in our body slow down.

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. Your doctor will tell you if they think you may be at risk. If you do develop an underactive thyroid gland, it can be treated with tablets that you take every day.

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 about coping with tiredness in our booklet **Coping with fatigue** (see page 132).

MY NOTES

About managing tiredness


World Radiography Day
NZIMRT - World

Concentration and memory problems

After cancer treatment for a head and neck cancer, some people have difficulty concentrating and remembering things. Doctors call this cognitive impairment. Cognitive means thinking or the way we process information. At the moment, it is not clear if certain treatments cause these problems, or if they are caused by tiredness, stress or depression.

The terms chemo brain or chemo fog are sometimes used to describe these changes. This is because changes in concentration and memory were first noticed in people who had chemotherapy. But these changes can also happen with other cancer treatments.

Changes in memory or concentration are usually mild. They often get better within a year of finishing treatment. Sometimes they can go on for longer, or have more of an impact on your day-to-day life.

Here are some examples of difficulties with concentration and memory that people describe:

- Difficulty in concentrating and focusing (feeling foggy).
- Feeling mentally slower than before and finding it hard to take things in.
- Forgetting details of conversations or events that you would usually have no problem remembering.
- Mixing up dates and appointments.
- 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 will look for any other possible causes for your symptoms. This can include side effects of medicines that you may be taking for tiredness, pain or depression. Treating these things can help. They may arrange for you to have tests, such as blood tests or a scan.

Feeling extremely tired (fatigue) is a common side effect of cancer treatment. It can cause problems with concentration and memory. Managing your fatigue may help improve these problems.

Anxiety, stress and depression can all cause problems with memory and concentration. Pain or other symptoms can also make it difficult to focus on anything else. Treating these symptoms may improve problems with your concentration.

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.

MY NOTES

About managing concentration and memory problems

YOUR FEELINGS AND RELATIONSHIPS

Body image

Treatment for head and neck cancers can cause changes to your body. This can affect your body image. This is the picture you have in your mind of how you look, and how you think and feel about your body. If your appearance has changed, it may take time for you, and the people close to you, to get used to this. You may feel affected by any body image changes before, during or after your treatment.

Sometimes changes in your body image can mean you avoid situations where you may feel uncomfortable. But the more you avoid social situations, the less confident you will feel about going out in future. This can leave you feeling isolated at a time when you need more support.

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

For most people, acceptance takes time. Your specialist team at the hospital can give you support and advice to help you adjust. You may be finding it hard to cope with changes to your body. Ask to see a counsellor to talk about how you are feeling. Changing Faces is a charity that focuses on helping people cope with changes to their appearance (see page 138 for their details). They have a confidential helpline that offers advice and support.

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** You could also ask your specialist nurse about any local support groups that could provide support and practical advice.

Your feelings about body image

Everyone reacts differently to body changes. You may feel more self-conscious about your body but find it manageable. Or you may find that you think about it a lot and find this upsetting.

Body image concerns may make you feel:

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

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

Talking openly with people you trust can be a good way to move forward. This could be your family, close friends, partner or your cancer doctor or nurse. Talking to someone who has been through something similar can also help. There are different types of support to help you cope with your feelings. Talking might help you to feel that people appreciate you for who you are, not for your appearance.

You may also find you come to value how well your body has coped with the cancer and treatment.

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. But 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

Parts of the skin on your face or neck may have been replaced with skin from another part of the body. The colour of the new skin may not match the surrounding skin. You may also have visible scars. Using camouflage products can help to reduce the difference in skin colour and the appearance of scars. Camouflage products can be matched to all skin types and colours.

Some head and neck clinical nurse specialists and organisations offer specialist skin camouflage services (see pages 137 to 143 for contact details). They can give you advice on how to apply it.

Some types of skin camouflage products can be applied to facial prostheses. This can improve the colour to better match your skin tone. It can be useful in the summer when skin tone changes. If you need this, you should take the prosthesis back to the person or organisation that supplied it.

We have more information to help you cope with changes in appearance in our booklet **Body image and cancer** (see page 132).

Managing other people's reactions

You may worry about other people's reactions to changes in your appearance. People may want to ask you how you are feeling. Others may just want to know what has happened to you. It may be helpful to think of possible answers to questions that might make you feel uncomfortable. There is no right or wrong thing to say. You can choose how much you want tell people. You do not have to say anything at all.

Here are some examples of things you could say:

- 'Thank you for asking, but I don't want to talk about it.'
- 'I had an operation.'
- 'I had an operation 6 weeks ago.'
- 'I had an operation to remove an area of cancer and am getting used to the changes, but it will take a while.'

Meeting other people

After treatment, you and the people close to you will start to become more familiar with your changed appearance. As this happens, you may think about seeing other people and going back to work. Avoiding social situations for a long time might make it harder to go out. It is best to start by going somewhere familiar. You may want to take someone with you for support.

Be prepared for mixed reactions. You may find that people take far less notice of you than you expected. But some people may make insensitive remarks or unhelpful suggestions. Children are often openly curious and may ask why you look different. You may want to decide in advance how to answer. Saying that you have had an operation should be enough. You do not have to go into the details.

Being able to cope with social situations will help build your self-confidence. This will increase as you gradually start doing your normal activities. These skills are not difficult to learn, but do need practice. In time, you will gain the confidence to manage social situations.

You can get more information about how to manage people's reactions from organisations such as Changing Faces or Let's Face It (see page 138 for contact details).

Being assertive

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

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

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

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

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

MY NOTES

About managing body image

Your sex life

The physical and emotional effects of cancer and its treatment may affect your sexual confidence or ability to have sex. You may lose interest in sex, feel unattractive or worry that you will never be able to be sexually active. For some people, these problems continue after treatment is over.

After treatment, some people have problems with their body image and self-esteem. Others may be left with a low sex drive (libido) or have sexual difficulties as a result of the physical effects of treatment. Changes to your face, mouth and neck can change how you feel about kissing and having sex. Most difficulties will improve over time.

We have more information in our booklet **Body image and cancer** (see page 132).

Tiredness

You may feel too exhausted to have sex during treatment and for a while afterwards. Most people find that this gradually improves, but occasionally it can last for months or even longer.

You can read more about coping with tiredness on pages 97 to 99.

Discomfort or pain

If you have problems with pain, this may affect your sex drive. Controlling the pain may improve your desire to have sex.

You can read more about managing pain on pages 88 to 90.

Menopausal symptoms in women

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

You are more likely to be affected by the menopause if you were close to the time of having your natural menopause when you had chemotherapy. The menopause can affect your sex drive directly. It can also cause vaginal dryness and hot flushes. This can make having sex difficult.

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

Relationships, sex and intimacy

The physical and emotional effects of cancer and its treatment can:

- cause problems between you and a partner
- stop you from having sex
- affect any new relationships.

It is normal to be worried about your sex life and intimate relationships. 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 will probably need time to recover and adapt to body changes before you feel comfortable about having sex. How long this takes depends on what feels right for you and your partner.

Partners may also have concerns. Talking openly with each other can have a positive effect on your relationship. It can make you feel more comfortable with each other. Sometimes, talking about how you feel about sex may make it easier for your partner to do the same.

Even if you do not feel like having sex, you may still want to be close to your partner. It may help to try and be intimate in other ways. This could include spending more time together, holding hands, hugging, kissing or giving each other a massage. This intimacy may help you slowly get back to having sex again.

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. Some people want to be honest about their experiences from the start of a relationship. Others prefer to wait. If you decide it is the right time to talk to your partner, think about what you want them to understand. For example, you can tell them what worries you and what is important to you.

If difficulties with your sex life do not improve, talk to your 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 can give information and advice on how to improve sexual difficulties. They can also refer you to a sex therapist if needed.

You can also talk to our cancer information specialists on **0808 808 00 00**.

MY NOTES

About managing effects on my sex life

Your feelings

It is normal to find it difficult to cope with some of your feelings months or even years after treatment, especially if you have late effects. These feelings often become easier to cope with over time and with the right support.

Even with ongoing treatment effects, many people find that cancer as helped them focus on what is important in their lives.

Feeling alone

Some late effects can be embarrassing or difficult to talk about. This can make you feel isolated. You may also feel isolated as you start to have less contact with the hospital, or if you do not know anyone else with the same problems. It might help to talk to others who are going through similar experience.

You might find our Online Community helpful. You can share your experiences, ask questions and get support online. Visit **macmillan.org.uk/community** You could also ask your specialist nurse for any local support groups that could provide support and practical advice.

Uncertainty

You may worry that some of your late effects are a sign of the cancer coming back. After cancer treatment, it is also common to feel anxious about aches and pains that you would not have worried about before. It can help to know more about your late effects and where you can get support when you are worried. Our leaflet **Worrying about cancer coming back** has helpful advice (see page 132).

Anger

It is natural to feel angry when you have had cancer, especially if you are coping with the late effects of treatment. Try not to feel bad about feeling this way. It can be a relief to simply tell yourself and people you trust when you are feeling angry. Keeping strong feelings to yourself may make your mood very low (depressed). You can talk to your doctor about seeing a counsellor.

Depression

Coping with the late effects of treatment can be physically and emotionally demanding. This can sometimes make people feel depressed. Signs of depression include:

- feeling low in mood
- having no interest in or enjoyment from the things you would normally enjoy
- feeling helpless or hopeless.

If you think you may be depressed, talk to your doctor. They can refer you to a counsellor or psychologist or prescribe a course of anti-depressant drugs for you.

Our booklet called **Your emotions** has more detailed information that you may find helpful (see page 132).

Negative feelings

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

Most people who have had cancer have times when they feel low or depressed. This happens even in people who seem positive. No one can be positive all of the time. So do not put pressure on yourself when you are finding it tough. It is positive to acknowledge and talk about your feelings.

MY NOTES

About managing my feelings

Relationships

Your experience of cancer may have improved and strengthened your relationships with people close to you. You may feel that you would not have been able to cope as well without the support you have had from family and friends.

However, cancer is stressful and this sometimes affects your relationships. Problems usually improve over time, especially if you can talk openly with each other.

Family and friends

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

Children

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

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness. It can also help to tell school teachers as they can offer support. For more information visit our website **macmillan.org.uk**

Teenagers

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

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk**, which has been developed especially for teenagers who have a parent with cancer (see page 143 for their details).

Your partner

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

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

We have more information in our booklets **Talking about your cancer** and **Talking to children and teenagers when an adult has cancer** (see page 132).

MY NOTES

About managing relationships

Getting help and support

Try to let your family and friends know how you are feeling so that they can support you. Sharing your feelings is not always easy.

Not everyone has people close to them who they can talk to about the cancer and treatment. You could join a local support group to meet other people in a similar situation. You could also use an online social networking site, such as our Online Community (**community.macmillan.org.uk**). Your specialist nurse will have details of cancer support groups and counselling services in your area. Or you can call **0808 808 00 00** to speak to one of our cancer support specialists. They will also be able to give you details.

At your hospital follow-up appointments, your specialist assesses your late effects and how they are being managed. They also check that there are no signs of the cancer coming back.

After having cancer, it is natural for your body to feel different, and for you to feel differently about your body. Aches and pains that you would not have worried about before may make you wonder if the cancer has come back. This is a common reaction. Let your doctor or specialist nurse know as soon as possible if:

- you have symptoms you are worried about
- you are struggling with your emotions.

They can see you earlier than planned, assess your situation and arrange for you to have appropriate help.

We have more information in our booklets **life after cancer treatment** and **Your support and follow-up care** that you may find helpful (see page 132).

FURTHER INFORMATION

About our information

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

Order what you need

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

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

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

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

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

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

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

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

Talk to others

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

Support groups

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

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**

The Macmillan healthcare team

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

Help with work and cancer

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

My Organiser app

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

Other useful organisations

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

Head and neck cancer support organisations

Action on Hearing Loss

Tel 0808 808 0123
Textphone 0808 808 9000
SMS 0780 0000 360
Email informationline@hearingloss.org.uk
www.actiononhearingloss.org.uk

The new name for the Royal National Institute for Deaf People (RNID). Provides support for people with hearing loss and tinnitus.

British Association of Skin Camouflage

Tel 01254 703107
www.skin-camouflage.net

Shows people how to use make-up as skin camouflage. Holds camouflage-awareness presentations and demonstrations for patient support groups. Most creams used by the British Association of Skin Camouflage can be prescribed by GPs.

British Tinnitus Association

Tel 0800 018 0527 (Mon to Fri, 9am to 5pm)
Email info@tinnitus.org.uk
www.tinnitus.org.uk

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

Changing Faces

Tel 0300 0120 275
Email support@changingfaces.org.uk
www.changingfaces.org.uk
Offers support and information for people who have any condition or injury that affects their appearance, and for their families.

Hearing Link

Tel or SMS 07526 123255
(Mon to Fri, 10am to 2pm)
Email helpdesk@hearinglink.org
www.hearinglink.org
Offers information, services and support. Allows people to connect with others to share experiences and advice.

Let's Face It

Tel 01843 491 291
Email chrisletsfaceit@aol.com
www.lets-face-it.org.uk
An international network for people with facial disfigurement. Links patients and their families, friends and professionals for self-help, information and mutual support.

Mouth Cancer Foundation

Helpline 01924 950 950
(Mon to Fri, 9am to 5pm)
Gives information and support to people affected by head and neck cancer.

Skin-camouflage service

Tel 0300 012 0276
Email skincam@changingfaces.org.uk
Changing Faces has a skin-camouflage service. It has skin-camouflage practitioners, who can teach people how to self-apply specialist cover creams.

Skinship UK

Tel 01557 428 504
www.skinshipuk.org
Aims to improve public perception of, and reaction to, skin diseases and disfigurement. Offers a UK-wide network of support groups, a telephone helpline and one-to-one counselling.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK

Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email
info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org
Has a network of centres in various 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.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
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.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk

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

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline 0300 123 3393
Text 86463
Email info@mind.org.uk
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
Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

General health information

Health and Social Care in Northern Ireland

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

Healthtalk

Email
info@healthtalk.org
www.healthtalk.org
www.healthtalk.org/young-peoples-experiences (site for young people)
Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

NHS Choices

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Daily, 8am to 10pm)
www.nhsinform.scot
NHS health information site for Scotland.

NHS Smoking Helpline

Tel 0300 123 1044 (Mon to Fri, 9am to 8pm, Sat and Sun, 11am to 4pm)
www.nhs.uk/smokefree/help-and-advice/support
Offers free information, advice and support to people who are giving up smoking, and those who have given up and do not want to start again.

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- and illness-related websites.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 220 674 (Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
Textphone 028 9031 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 in the phone book or by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline
(England, Scotland, Wales)
0808 808 7777
(Mon to Wed, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

Support for older people

Age UK

Helpline 0800 678 1174
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for younger people

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

YOUR NOTES AND QUESTIONS

Disclaimer

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

Thanks

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

With thanks to: Mr Kavin Andy, Consultant Oral and Maxillofacial / Head and Neck Surgeon; Laura Askins, Dietitian; Dr Shreerang Bhide, Consultant Clinical Oncologist; Tina McClosky, Advanced Practitioner Radiographer; Vicky Poole, Macmillan Head and Neck Clinical Nurse Specialist; Justin Roe, Joint Head of Speech and Language Therapy; Cherith Semple, Macmillan Head and Neck Clinical Nurse Specialist; Iain Soulsby, Dental Surgeon; and the people affected by cancer who reviewed this edition.

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

Sources

If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

American Society of Clinical Oncology Journal. Advances in Supportive Care for Late Effects of Head and Neck Cancer. 2015. http://ascopubs.org/doi/full/10.1200/jco.2015.61.3836 (accessed September 2018).

British Association of Head and Neck Oncologists. Head and Neck Cancer: United Kingdom National Multidisciplinary Guidelines. 2016. http://bahno.org.uk/wp-content/uploads/2014/03/UK-Head-and-Cancer-Guidelines-2016.pdf (accessed September 2018).

National Institute for Health and Care Excellence (NICE). Nutrition Support for Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition. 2006. www.nice.org.uk/guidance/cg32/chapter/1-Guidance#indications-for-nutrition-support-in-hospital-and-the-community (accessed September 2018).

UK Oral Mucositis Cancer Group. Mouth Care Guidance and Support in Cancer and Palliative Care. 2015. www.ukomic.co.uk/pdf/UK_OM_Guidelines.pdf (accessed September 2018).

Can you do something to help?

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

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

5 WAYS
YOU CAN
HELP
SOMEONE
WITH
CANCER

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

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

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

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

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

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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

Issue no

Security number

Signature

Date / /

Don't let the taxman keep your money

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

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

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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

Registered with FUNDRAISING REGULATOR

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

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

This booklet is about the possible long-term and late effects of treatment for head and neck cancer. It is for people who are experiencing side effects after treatment has ended. It is also useful for people caring for someone who is experiencing these late effects.

It has information about possible emotional and physical side effects and how to manage them. It also has information about support that may be available to you.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

What's this logo? Visit **macmillan.org.uk/ourinformation**