MACMILLAN CANCER SUPPORT

Managing the late effects of head and neck cancer treatment

About this booklet

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

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

The booklet explains:

- possible long term and late side effects after treatment
- what can help
- some ways to reduce the risk of certain side effects.

We hope it helps you manage any side 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 .

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

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

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

At the end of the booklet, there are details of other organisations that can help.

Quotes

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

For more information

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

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

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

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

Contents


You Said:
We Did

About late effects

What are late effects?

After treatment for a head and neck cancer, it usually takes several months for side effects to improve. Although the cancer treatment has finished, you will need time to recover and may still be coping with some side effects.

Sometimes side effects do not get better in this time, or they only start after treatment has ended. These are called late effects.

Late effects can start in different ways:

- They may begin during treatment or shortly after it has ended, but late effects last longer than 3 months.
- They may not appear until months, or even years, after cancer treatment has ended. This is a delayed response to treatment.

Your risk of late effects

Different types of cancer treatment cause different side effects. This is the same for late effects. Your cancer team will explain the possible late effects of the treatment you have had.

Your risk of developing late effects depends on:

- the type of treatment you have had
- the extent of your treatment – this means the size of the areas removed during surgery or treated with radiotherapy
- the combination of treatments you had – having more than one type of treatment increases the risk of late effects.

This information is about some of the most common late effects of treatment for head and neck cancer. But there are others.

If you have new or ongoing side effects

After head and neck cancer treatment, you will have regular follow-up appointments with your cancer doctor or specialist nurse. They will check how you are recovering from any side effects.

It is important to tell them if you have a new symptom or side effect that is not getting better. If you notice a new symptom or ongoing side effect between appointments, you do not need to wait. Contact your cancer team at the hospital. Or get advice from your GP or dentist.

"Long-term effects are an issue. I have restricted movement in my neck, swallowing can be difficult and I get a dry mouth. I notice them when they are there and then think about something else. This has become easier to do the further from treatment I am."

Paul, diagnosed with tonsil cancer

Who can help

It can be frustrating to still have side effects from treatment. It may not be easy to adjust to a long term change. But there are usually things that can help.

Your cancer team can often help with late effects. Or they may refer you to another specialist if needed.

The support you need will depend on the problem. The following specialists are often involved with managing head and neck cancer treatment late effects:

- Specialist doctors – including surgeons and cancer specialists (oncologists).
- Specialist nurse – someone who gives information and support on managing side effects.
- Specialist radiographer – someone who gives information and support on managing side effects after radiotherapy.
- Speech and language therapist (SLT) – someone who gives information and support to people who have problems with talking, voice changes or swallowing.
- Dietitian – someone who gives information and advice about food and food supplements.
- Dentist – an expert in treating problems or conditions that affect the teeth and gums.
- Restorative dental consultant – a consultant dentist who restores the teeth. This can include removable prostheses (obturators), removable dentures, bridges and implants to help with your eating, speech, dry mouth and appearance.

- Dental hygienist – someone who cleans teeth and teaches you how to keep your mouth clean, prevent tooth decay and manage gum disease.
- Physiotherapist – someone who provides treatments and exercises to help with reduced movement in the jaw, neck or shoulders, and encourages safe physical activities.
- Occupational therapist – someone who gives information, support and aids to help people with tasks such as washing and dressing.
- Lymphoedema specialist – someone who gives advice and support about coping with lymphoedema (a build-up of fluid in the tissues that can happen after surgery or radiotherapy to the neck).
- Psychologist or counsellor – someone who is trained to listen to people's problems and gives advice about managing feelings and behaviours.


roup Room
Fire exit
Treatment Room 2

Tobacco, alcohol and drugs advice

After head and neck cancer treatment, it is important to avoid things that irritate or affect the health of your mouth. This can:

- help your body recover after treatment
- help improve side effects
- reduce your risk of developing late effects
- reduce your risk of future health problems, including cancer.

It is important to avoid smoking or chewing tobacco. Your team can also give you advice about reducing or stopping:

- drinking alcohol, especially spirits
- recreational drug use.

Your GP or cancer team can tell you about the support available if you are trying to stop or cut down. Do not worry if you have tried to stop before. Breaking a habit is difficult and people often need to try a few times. You are most likely to succeed if you have support from a specialist service. You can ask any healthcare professionals involved in your care for advice.

We have more information about stopping smoking on our website. Visit macmillan.org.uk/stop-smoking

Finding support

Dealing with side effects and changes after head and neck cancer treatment can take a lot of effort and determination. Some people may need to re-learn skills, such as swallowing or speaking. Or you may have ongoing exercises you need to do to prevent mouth, neck or shoulder problems. There may also be other changes in your daily life you are learning to cope with.

Sometimes, you might feel like you are not making progress. It is important to know where to get support or information if you need it.

Your cancer team can help with advice, information and treatment if needed. If you have support from a partner, family or friends, you can also involve them. Take them with you to appointments if possible. This can help them understand what you need to do for your recovery.

Some people find it helpful to talk to someone who is not close to them or involved in their care. This could be a counsellor, or someone from a support group who has been through a similar experience. Some cancer treatment or information centres have health and wellbeing events for people who have had head and neck cancer. These can help you cope with the physical and emotional late effects.

The HOPE programme is a free 6 week self-management course designed to help you develop techniques and strategies when living with or after cancer. Topics include goal setting, fatigue management, and wellbeing.

To find out more about HOPE courses in your area, visit macmillan.org.uk/hope-programme or you can email us at ServiceOpsSupport@macmillan.org.uk

To find more support:

- ask your GP or someone from your cancer team for advice about what is available in your area
- search macmillan.org.uk/in-your-area to find cancer support services near you
- call us free on 0808 808 0000 or talk to us online – our cancer information and support specialists can offer guidance and help you find what you need
- visit our Online Community to talk to people who have been affected by head and neck cancer, share your experience and ask an expert your questions.

Mouth and jaw effects

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

Paul, diagnosed with tonsil cancer

Mouth care and preventing tooth decay

Good mouth care is important for everyone. It is especially important after:

- radiotherapy to the mouth or jaw
- surgery that has changed the shape of your mouth or jaw
- having teeth taken out
- reconstruction to replace teeth or parts of your mouth or jaw.

After these treatments, you may have a higher risk of mouth infections or tooth problems. After radiotherapy you may have a high risk of tooth decay.

Your cancer team will explain how to care for your mouth to prevent problems. You should still follow a good mouth care routine, even if you only have a few or no teeth. Your cancer team or GP can also give you advice about tobacco, alcohol and recreational drugs.

You will need regular check-ups with a dentist or dental hygienist every 3 to 6 months. Most NHS services are free, but you may have to pay for NHS dental care. You may have to pay even though you have had cancer treatment. Your cancer team or dentist can explain how dental charges work in your area.

If you are worried about these costs, you can call us free on 0808 808 00 00 or visit macmillan.org.uk/your-finances You may also find our booklet Planning and managing your finances useful.

Mouth care routine

Follow a regular mouth care routine to protect your teeth and mouth. These tips are useful for most people after head and neck cancer treatment. But always make sure to follow any advice from your cancer team, dentist or dental hygienist.

Checking your mouth and teeth

Check your mouth daily. Get advice from your GP, cancer team or dentist if you have:

- ulcers
- red, white or dark patches
- soreness, or a burning or itching feeling on the tongue
- bad breath
- a new nasty taste.

Sometimes these are symptoms of a fungal infection called thrush. You can get treatment on prescription. Thrush can affect anyone but is more likely if you wear dentures or have ongoing problems with a dry mouth.

Check your teeth daily. Contact your dentist straight away if you have:

- grey, brown or black spots
- holes or pits
- pain or sensitivity.

Brushing your teeth

Brush your teeth, gums and tongue with a small, soft toothbrush in the morning and before bed. You can also brush after meals or rinse your mouth out with water or salty water.

Brush each tooth slowly and gently using small circular movements. Or use an electric toothbrush with a small head that moves in circles. This is called a rotating head. Gently massage the gum around the base of each tooth with your toothbrush. This helps clean plaque from a tooth without hurting your gums.

Move your toothbrush around the mouth, brushing the outside surface of each tooth. Repeat on the inside surface of each tooth. Repeat on the biting surface of each tooth.

After brushing, spit out the toothpaste but do not rinse your mouth with water. The fluoride in the toothpaste stays around your teeth and keeps protecting them, especially at night.

Use the toothpaste and any mouthwashes your dentist and cancer team recommend. Tell them if you are finding them difficult to use.

Use dental floss or interdental brushes to clean between your teeth at least once a day. Move the floss in gentle circles between the teeth, instead of pulling back and forth. Your dentist or dental hygienist can give you advice and support.

Cleaning your dentures

If you wear dentures:

- Use a toothbrush to clean and rinse them after eating, as well as every night and morning.
- Gently brush the inside of your mouth with a different small, soft toothbrush. This is because food may collect between the cheek and gums.
- Remove any denture fixative stuck inside your mouth. A tissue and warm water should help with this.
- Give your mouth a break overnight. Soak your dentures in a closed container. Use cleaning products recommended by your dentist and follow any instructions carefully.
- Get advice from your dentist if your dentures feel uncomfortable.

Cleaning your obturator

An obturator is a special type of denture that seals any gaps in the roof of the mouth. Your cancer team will give you advice about cleaning your obturator if you need one after cancer treatment.

Using fluoride

Fluoride strengthens the hard, outer layer (enamel) on teeth and helps protect them from decay. It can also help reduce tooth sensitivity.

If you have a high risk of tooth decay after head and neck cancer treatment, your dentist or doctor will prescribe a high fluoride toothpaste called Duraphat® 5000ppm.

Your dentist may also recommend other ways to protect your teeth with fluoride:

- Use a fluoride mouthwash at a different time from toothbrushing. For example, use mouthwash 30 minutes before you brush your teeth or at another time of day.
- Wear mouth guards containing fluoride overnight.
- Have fluoride painted on your teeth once every 3 months.
- Use a calcium tooth mousse before brushing your teeth to help fluoride toothpaste work as well as possible. This product is not available on prescription but brands such as GC Tooth Mousse® can be bought online.

Sugary and acidic foods and drinks

When you eat sugary foods, the bacteria in your mouth quickly turn the sugar into acid. Acid breaks down the enamel surface of your teeth. This can make teeth sensitive and cause tooth decay. You can protect your teeth in the following ways.

Avoid or cut down on foods with refined sugar:

- Examples of foods that are high in refined sugar are chocolate, sweets, biscuits, cakes and pastries, fruit pies, dried fruit, sweet sauces, sponge puddings, ice cream, jams, honey and fruit in syrup.
- Some types of breakfast cereals are high in refined sugar but not all. Ask your cancer team or dietitian for advice.
- Check food labels to find out how much sugar they contain. Look out for glucose, sucrose, maltodextrin, dextrose, lactose, caramel, fructose, maltose, toffee, molasses, honey, syrup, corn sugar and hydrolysed starch. These are all alternative names for sugars.

Choose drinks carefully:

- The safest drink for your teeth is still water. Or you could have plain milk, tea or coffee without added sugar.
- Choose sugar free drinks but avoid those with phosphoric acid or citric acid which are harmful to the teeth. Check the list of ingredients to find out if these are in your drink.
- Fizzy drinks are often acidic, even sparkling water and sugar free drinks.

Take care with acidic food and drinks:

- Examples of acidic food and drinks are fizzy drinks, orange juice, oranges, other citrus fruits and tomatoes.
- Avoid or limit these foods and drinks to meal times, no more than 4 times a day. This limits the amount of time your teeth are exposed to acid and gives them time to build up protection again.

If you are trying to gain weight after cancer treatment, high sugar foods may be an important part of your diet for a time. Your dietitian can give advice. A good mouth care routine can help reduce your risk of problems.

Dry mouth and changes in saliva

Saliva helps keep your mouth clean and protects your teeth. It also allows the tongue, lips and cheeks to slide easily over the teeth. Saliva is sometimes called spit.

Radiotherapy to the head or neck can affect your salivary glands. You may not make as much saliva as before and your saliva may be thicker and sticky. This may slowly improve after treatment, but some people have a drier mouth permanently.

Having a dry mouth can be uncomfortable. It can affect eating, speaking and sleeping. You are more likely to get mouth infections, such as thrush. You are also at much higher risk of tooth decay. Remember to keep going with a good mouthcare routine. If you smoke, find out about stopping.

If you have any rough, chipped or sharp teeth or dentures, talk to your dentist about getting them fixed. This prevents them rubbing inside your mouth and causing ulcers to develop.

" Swallowing can be difficult at times. I get a dry mouth and every morning wake with a totally dry mouth. „

Paul, diagnosed with tonsil cancer

Coping with a dry mouth

There are different things you can do to help relieve a dry mouth. It can help to try different things to find out what works for you. Here are some ideas:

- Always carry a bottle of water with you and take regular sips. Or use a water spray. You can buy small spray bottles from most chemists. Some people find it helpful to add a little olive oil to the water in the spray.
- Try sucking ice cubes or sugar free ice lollies.
- If you cannot swallow, it may help to lean over a steaming bowl of hot, but not boiling, water with a towel over your head. You can do this as often as you need for up to 5 minutes at a time. Some people find it really helpful when they wake up, before bed and before eating or drinking. Or your cancer team may give you a nebuliser. This is a machine that turns a liquid medicine into a fine mist or spray to moisten your mouth and throat.
- Avoid drinks that can irritate a dry mouth, such as caffeinated or citrus drinks.
- Ask your cancer team or GP if any medicines you are taking cause a dry mouth. It may be possible to change the drug or reduce the dose.
- Use a lip balm to protect your lips.
- Try using a humidifier in your bedroom at night.
- Ask your dentist for advice on toothpastes. Some contain ingredients that cause mouth dryness.

Saltwater rinse

A warm saltwater 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
- add 1 teaspoon of table salt.

Rinse the salt water gently around your mouth. Then spit it out and rinse your mouth with cold or warm water. Try to do this at least 4 times a day. Make a fresh rinse each day.

Eating tips

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

Artificial saliva

You can use artificial saliva to moisten your mouth and throat. It can come as gels, sprays, mouthwashes, pastilles or tablets. Your doctor or dentist can prescribe artificial saliva, or you can buy it from a chemist. There are lots of different products to try. You may need to try a few to find the ones that work best for you.

Artificial saliva only works for a short time, so it is best to use it just before eating. For longer lasting relief at night, try using a gel product on your tongue and around the inside of your mouth. This may help for up to 5 hours.

If you have dentures, you can use the gel under them to help them feel more comfortable and stay in place.

Always check the ingredients of a product before you use it. Or ask your cancer team, GP or pharmacist for advice. Some brands contain animal products. Some have added fluoride to help protect your teeth. Others are acidic and can cause tooth decay. If you have your own teeth, make sure you use one that is pH-neutral.

Artificial saliva products

Product name (manufacturer)	What form does it come in?	Is it available on the NHS?		Can you buy it from a chemist?	What is the pH value?	Does it contain fluoride?	Does it contain animal ingredients?
AS Saliva Orthana® (AS Pharma)	Oral spray 50ml	Yes		Yes	Neutral	Yes	Pork
	Lozenges (30)	Yes		Yes	Neutral	No	Pork
Biotène Oralbalance® (Haleon UK)	Saliva replacement gel 50g	Yes		Yes	Neutral	No	A protein produced by animals
BioXtra® products (RIS Products)	Dry mouth oral gel 40ml	Yes		Yes	Neutral	No	Cow's milk, egg
	Gel mouth spray 50ml	Yes		Yes	Neutral	Yes	Cow's milk, egg
	Toothpaste 50ml	No		Yes	Neutral	Yes	Cow's milk, egg
	Mouth rinse 250ml	No		Yes	Neutral	Yes	Cow's milk, egg
Glandosane® (Fresenius Kabi)	Saliva spray 50ml (lemon, neutral, peppermint)	Yes		Yes	Acidic – avoid if you have your own teeth	No	No
Oralieve ® Moisturising Mouth	Oral spray	Yes		Yes	Neutral	No	Cow's milk
	Mouth gel 50ml	Yes		Yes	Neutral	No	Cow's milk
Saliveze® (Wyvern)	Oral spray 50ml	Yes		Yes	Neutral	No	No
Salivix® pastilles (Galen)	Lozenges (50)	Yes		Yes	Acidic – avoid if you have your own teeth	No	Beeswax
Xerotin® (SpePharm)	Oral spray 100ml	Yes		Yes	Neutral	No	No

Details correct at time of print – always check the label.

Stimulating saliva

Products that help your mouth make more saliva may help if some of your salivary glands still work, or if the damage to your glands is temporary. Ask your cancer team, GP or pharmacist for advice.

You can buy these products:

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

There are also some treatments available on prescription, such as:

- SST® saliva stimulating tablets
- pilocarpine tablets – this drug can be effective but also causes side effects.

Ask your cancer team for more information.

Coping with thick, sticky saliva

The following tips may help loosen or thin your saliva.

- Gargle and rinse your mouth regularly. Your cancer team can give you advice on what type of mouth rinse to use. A weak solution of salt or bicarbonate of soda and water may help.
- Drink plenty of fluids.
- Lean over a steaming bowl of hot, but not boiling, water with a towel over your head for up to 5 minutes. It is best to do this 4 to 5 times a day.

Sometimes a build-up of thick, sticky saliva can cause coughing, especially at night. If this is a problem, your cancer team or GP may give you drugs to help. These might be capsules or liquid that you take by mouth. Or you may take them as a nebuliser.

A nebuliser is a machine that turns liquid into a fine spray. You breathe the spray in through a mask or mouthpiece. The moisture helps 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.

If you feel you have too much saliva rather than too little, this may be a sign of swallowing difficulties.

Jaw stiffness (trismus)

After radiotherapy or surgery to the head and neck area, the muscles that open and close your mouth may become stiff. This can reduce how far you can open your mouth and is called trismus. If you had both surgery and radiotherapy the risk of trismus is higher.

Your cancer team always plans your cancer treatment to reduce your risk of jaw problems as much as possible. They may have already given you mouth exercises to help prevent problems. The earlier you start jaw exercises, the more successful they are likely to be.

Jaw stiffness can develop a few weeks, or sometimes months, after treatment. The amount of stiffness varies from person to person. There is an easy way to check how wide your mouth can open:

- Open your mouth as wide as you can – it may help to imagine that you are yawning.
- Raise your index finger, middle finger and ring finger on one hand – use your thumb to keep your little finger down.
- Turn your hand so that your fingers are stacked on their sides, one above the other.
- Keeping your fingers straight, point them towards the back of your throat.
- Try to put your fingers in your mouth between your top and bottom front teeth – your index finger should touch your top front teeth and your ring finger should touch your bottom front teeth.

If you can only fit 1 or 2 fingers in your mouth because it cannot open wider, you may have trismus.

Tell your cancer team if you have jaw stiffness or pain, even if it is mild. You will usually meet with a speech and language therapist (SLT) or physiotherapist for assessment and treatment. They will measure how far you can open your jaw at your first appointment. They will repeat this at every appointment. It will help show what progress you are making.

Managing trismus

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 give you advice about:

- jaw stretches you can do
- how long to hold each stretch for
- how many times to repeat the stretches
- other things that may help, such as chewing sugar free gum to keep your jaw moving.

They may give you wooden spatulas or other aids to help you gently stretch the jaw muscles. You put these between your upper and lower front teeth for a certain amount of time each day. You use them to gradually increase the amount they open your mouth over time. This will slowly stretch the jaw muscles.

Your cancer team may also give you advice about diet, dental care and medicines:

- Diet – if it is difficult to chew or swallow, softer foods can be easier to eat. Some people may need supplement drinks until this improves. Your dietitian can give you more advice.
- Dental care – it is important to continue with a regular mouth care routine while your jaw is stiff. A small toothbrush may help. If there are teeth you cannot reach, get advice from your dentist or hygienist.
- Medicines to ease any pain and spasm – muscle relaxants, nerve pain drugs or Botox injections may help.

If pain in your jaw gets worse during jaw exercises, stop and contact your SLT or physiotherapist for advice.

Bone changes (osteoradionecrosis)

Radiotherapy to the head and neck can reduce the blood supply to nearby bones. Sometimes, this leads to bone tissue dying. This condition is called osteoradionecrosis or ORN.

Most people who have radiotherapy will never develop ORN. But if it develops, it is most likely to affect the jawbone. Depending on the area treated, it can sometimes affect bones in the face or neck.

Always contact your cancer team, dentist or GP if you have any of these symptoms:

- pain, numbness or a feeling of heaviness in the jaw
- an area of roughness on your gum
- swelling
- loose teeth
- very tiny parts of bone that can be seen or felt in the gums.

Reducing your risk of ORN

Here are some ways to reduce your risk of osteoradionecrosis:

- Avoid smoking as it affects the blood supply to the bone.
- Look after your mouth and teeth and have a dental check-up every 6 months. If you have an appointment with a new dentist, tell them you have had radiotherapy and have a risk of ORN.
- Get advice from your dentist straight away if you have a broken filling, sore areas in your mouth, or any other mouth problems. Having an infection can increase the risk of ORN.
- If you need to have teeth taken out after radiotherapy, it is important to have this done in hospital. A specialist oral and maxillofacial surgeon or dental oral surgeon will plan your treatment to reduce the risk of ORN.
- If you wear dentures, make sure they fit well. If they rub or are sore, stop wearing them and ask your dentist for advice.

Managing osteoradionecrosis

Treatment depends on whether the osteoradionecrosis is mild or more severe. You may need:

- antibiotics to treat the infection
- painkillers
- advice about improving your mouth health
- advice about diet
- surgery – which is sometimes used to remove any areas of dead bone or, in severe cases, to reconstruct the jaw
- drugs called pentoxifylline, vitamin E (tocopherol) and clodronate – there is not enough evidence yet to say how effective these are, but research is ongoing.

Swallowing and eating effects

Eating and drinking after treatment

Head and neck cancer treatment often affects how easy it is to eat and drink for a time. Many people find this gets easier after treatment finishes. This is because side effects such as pain, swelling, feeling sick, taste changes and tiredness start to get better.

For some people, eating and drinking problems continue for longer. There are things that can help. But it can take a lot of effort and patience to overcome eating difficulties. If you have had to work at this for a while, food might not feel enjoyable anymore. If you have taste changes, you might not enjoy or feel like eating.

Your cancer team will give you support before, during and after your treatment to make sure you are eating and drinking enough. Contact them if you are finding things difficult or a side effect is not improving.

Your speech and language therapist (SLT) can check for chewing and swallowing problems. They may teach you exercises and techniques to help. Your dietitian can give you advice about your diet. They may give you high calorie supplement drinks if you have lost weight.

We have more information about how to increase your weight after cancer treatment in our booklet and audiobook The building up diet. We also have this information on our website. Visit macmillan.org.uk/building-up-diet

Your cancer team may also teach you coping techniques, such as mindful eating. These techniques may help you feel more relaxed at mealtimes and enjoy food again.

If you have a feeding tube

If you had a feeding tube to support eating and drinking during your treatment, this is usually temporary. It can normally be taken out when:

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

A small number of people will have a permanent feeding tube. Your dietitian can help you with any problems or questions about the feeding tube. You may also have a specialist nurse who can help. If you can swallow safely, they will usually encourage you to keep trying to eat and drink, even while you are being fed by tube. This is important as it keeps your swallowing muscles working.

You can find out more about recovering in the days and weeks after surgery or radiotherapy in our booklet Understanding head and neck cancer. We also have this information on our website. Visit:

- macmillan.org.uk/head-neck-surgery
- macmillan.org.uk/head-neck-radiotherapy

Do not worry if you have days when you cannot eat anything. Recovery takes time and it is common to have a setback before things start to get better.

Your SLT will give you advice as you start to eat food again. They will start with food that has a texture that is easier to swallow. Your SLT will then gradually increase the amount and variety of textures. We have more information about feeding tubes on our website. Visit macmillan.org.uk/tube-feeding

Eating and socialising

Many social activities involve eating and drinking. 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, start with something simple, such as going out for a snack. You can start trying other places and foods as your confidence grows.

Do not worry if it takes you longer to eat. It may help to explain to others that you might take longer to eat your meal.

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. This means you are less likely to get tired when eating.

Eating at a friend's house

If you go to someone's house for a meal, let them know about your dietary needs. For example, you could explain in advance that you can only manage certain textures or that you cannot eat spicy food.

People often change meals to suit the needs of their guests, for example if someone does not eat meat or cannot eat gluten. Or you can ask if you can bring your own food to heat up.

Going out to eat

If you are going out to eat in a restaurant, try to check the menu before you go. You can find out if they offer meals that suit you or can be adapted for you. Try contacting them before you go 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. Or you could ask if they will provide a smaller portion size for you.

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

Eating with people you do not know

If you are nervous about how new people will react, you might want to make a plan before you meet them. You may find it helpful to think about what you want to say if they ask about how you eat or drink. Or you might decide you do not want to explain it at all. You could ask someone you already know to tell other guests in advance. Do whatever makes you feel comfortable.

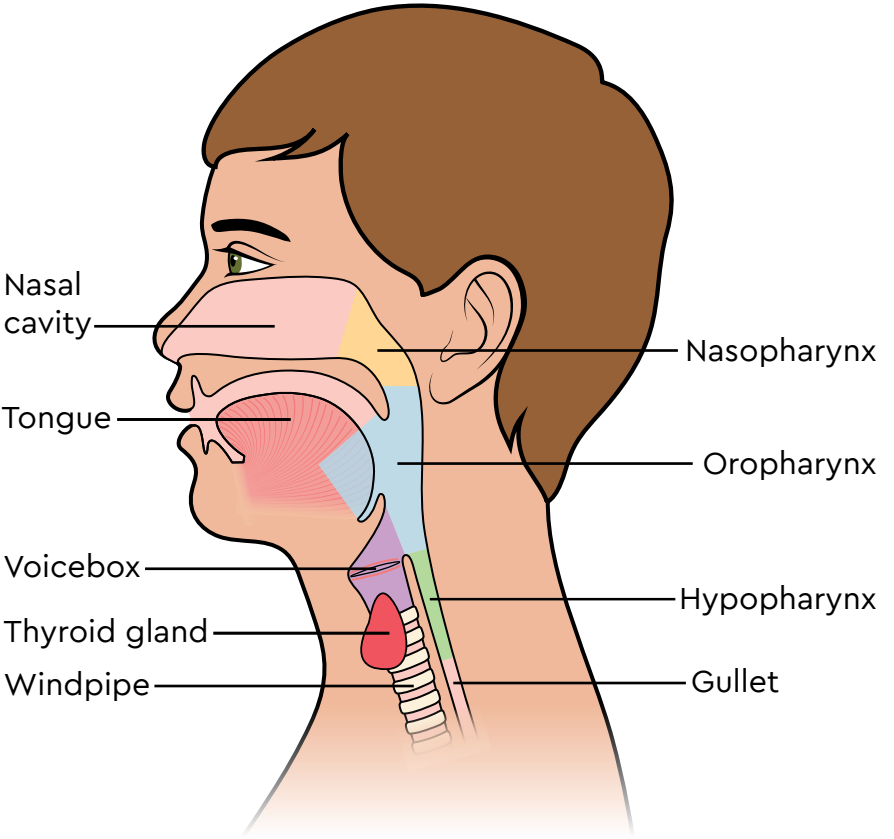
Chewing and swallowing

Treatment for head and neck cancer can affect the way you chew or swallow. Ask your cancer team for advice if you are finding this difficult or if you develop any of the following problems:

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

Your cancer team will check what is causing your symptoms. They will give you advice and treatment if needed. Depending on the cause, you may have appointments with specific team members or other specialists.

The mouth and throat



Chewing and swallowing after surgery

If you had surgery to remove only a small amount of tissue from inside the mouth, you will probably adjust quickly. Any effect on chewing is likely to be small.

You may have longer lasting changes if:

- a lot of tissue was removed
- some or all of your tongue or soft palate was removed
- you had surgery to rebuild the removed tissue.

The shape of your mouth may be different. You may be learning to manage:

- new dentures
- a bridge
- an obturator – a special type of denture that seals any gaps in the roof of the mouth.

If you had teeth removed, your ability to grind food during chewing may change. This can also happen if you have dentures that no longer fit.

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

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

Surgery to areas such as the lower end of the throat (hypopharynx) or the voice box (larynx) can change how you swallow. Sometimes this 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.

Swelling in the throat caused by a build-up of fluid in the tissues (lymphoedema) can also affect swallowing.

Chewing and swallowing after radiotherapy

A common side effect of head and neck radiotherapy is a dry mouth. This can make it difficult to chew food and swallow. Jaw stiffness can also affect how easy it is to chew.

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

If your treatment involved areas of the throat or the tube to the stomach (gullet or oesophagus), the muscles and tissues may become weaker and less stretchy. The upper part of the gullet may become narrower. It may be harder to swallow some foods, or you might find some foods stick in the throat. If the muscles are affected, this can make it difficult to push food down to the stomach.

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.

Some people develop swallowing problems months or years after radiotherapy. There are many reasons for this, including if scar tissue in the throat makes the swallowing muscles tight and hard.

If you notice changes in your swallow over time, contact your cancer team for advice.

Managing chewing problems

The advice and treatment for chewing difficulties depends on what is causing the problem. If dryness or jaw stiffness is making it difficult for you to chew, we have more information you may find helpful.

It is important that chewing problems are assessed by specialists from your cancer team – for example, a surgeon, a restorative dentist or a speech and language therapist (SLT). They may arrange for tests to help find the best way to treat these problems.

If chewing is difficult with new dentures, a bridge, implants or an obturator, contact your dentist, restorative dentist or cancer team for advice.

Chewing exercises

Your SLT may give you exercises:

- to strengthen your lips, tongue and other muscles in your mouth and throat
- to help stimulate parts of the mouth that have lost sensation.

They may give you aids or devices to help you:

- practise biting and chewing
- exercise the lips and tongue.

They may also advise you to eat soft, moist foods. You may find it easier to chew larger or smaller amounts of food. But this may depend on what is causing the chewing difficulties. Your dietitian can also give you advice about this.

Managing swallowing problems

The type of treatment you might have depends on which stage of the swallowing process you are having problems with. You may need to have one of the following tests to find out what happens when you swallow. Your SLT will explain if you need a swallow test and which test is best for you.

Videofluoroscopy

This is a video x-ray to test your swallow. It shows:

- if anything gets stuck in your mouth, throat or gullet
- if any food or drink goes down the wrong way when you swallow
- if any techniques or tips can improve your swallow.

This is usually done in the x-ray department by a radiographer and your SLT. It takes about 30 minutes and is painless. The video x-rays are saved so you and your team can watch and learn from them.

During the test, your SLT may ask you to try different techniques to check if they help when you swallow. They will ask you to swallow different foods of different textures. This might be:

- liquid
- puree
- food with a more solid texture, like a biscuit.

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

Fibreoptic endoscopic evaluation of swallowing (FEES)

Your SLT passes a thin, flexible tube called an endoscope into your nose and down into the throat. A tiny camera in the endoscope shows what is happening in your throat and voicebox (larynx) when you eat and drink. During the test, your SLT may ask you to try different techniques to check if they help when you swallow. The test takes about 20 minutes. The camera video is recorded so you and your team can watch and learn from it.

After a swallowing test

The test results help your SLT understand how they can make swallowing safer and easier for you.

Your SLT may suggest:

- tips and techniques to make swallowing easier
- exercises to strengthen swallowing muscles
- what to eat and drink, for example, thinner or thicker foods and liquids or different tastes and textures
- having a drink between bites of food
- coughing to clear your airway after each swallow
- coping strategies to help you adjust to changes.

It may help to bring someone with you when you get advice from your SLT. They can learn about exercises and techniques you need to use, or changes to food you may need to make.

Stretching the gullet (oesophagus)

After radiotherapy, part of the gullet may narrow. A quick procedure can make swallowing easier. A doctor puts a tube down into the gullet to gently stretch it. This makes more space for food and fluid to pass through.

You can have this done as an outpatient. You usually have sedation and a local anaesthetic for this procedure. Sometimes it is done under general anaesthetic.

Your cancer team will tell you if this procedure might be helpful. They will explain the possible risks and benefits.

Taste changes

Radiotherapy to your mouth, and some cancer drugs, can affect your sense of taste. Some treatments can change your sense of smell, which can affect taste. If your mouth is dry after cancer treatment, this also changes how things taste.

Most foods will likely taste the same, but you may dislike the taste of certain foods. Some people can taste the first few bites of food and then find the taste gets weaker. These changes can lower your desire for food and affect your appetite.

Usually, your sense of taste gradually improves after treatment ends. But sometimes this can take a year or more. If you have taste changes, tell your cancer team. They can offer advice and support.

Looking after your mouth may help improve your sense of taste. Remember to keep a good mouth care routine and avoid smoking. If your mouth is dry, our tips for coping with a dry mouth may help.

Here are some tips for coping with taste changes:

- Eat the food and drinks that you enjoy the most.
- If a food does not taste nice, try it again after a few weeks. Your sense of taste may improve.
- Use your other senses to enjoy food – for example, make your food look and smell as appealing as possible.
- Use sauces and oils to flavour and moisten food.
- If you do not have a sore mouth, you could experiment with strong seasonings and herbs to flavour your food. Try marinating meat in fruit juices, milk or yoghurt.
- Try cold foods. Some people find that cold foods taste better than hot foods.
- Try sweet foods. Some people find they can taste sweet foods better. But be aware that sugary foods can cause tooth decay if you have less saliva after radiotherapy.

Acid reflux

Acid reflux is caused by acid in the stomach coming back up into the throat or gullet. It is quite common after surgery or radiotherapy for head and neck cancers. Saliva helps to neutralise stomach acids. You may find acid reflux is worse if your mouth is dry.

Acid reflux can cause symptoms such as:

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

You should always tell your cancer team if you have any of these symptoms. They can check what is causing the problem. They may give you drugs to reduce acid levels in the stomach.

Acid reflux is often worse when you are lying down. If you notice this, try not to eat or drink for 3 hours before you go to bed. It may also help to raise the head of your bed. For example, you could do this by placing books under your pillows to lift your head up. This means 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.

Speech and hearing effects

Changes to speech and voice

We use our lips, teeth, tongue, mouth, nose and throat when we speak. After surgery or radiotherapy to the head and neck area, your speech or voice may sound different. You may have:

- difficulty making certain sounds or saying some words
- a weak voice or lose your voice easily
- a rough, breathy or hoarse voice.

For some people, these changes are only a small problem. As the area heals, their speech or voice returns to normal, or close to normal. Others may have permanent changes to their voice or to the way they speak. Or they may have changes that make it difficult to communicate.

If you have changes to your speech or voice, there are things that may help. You may have had help from the speech and language therapist (SLT) before and during treatment. Sometimes voice and speech changes develop slowly and only become a problem months or years after treatment. If you need support or notice new or worsening problems after treatment, get advice from your cancer team.

Managing speech and voice changes

Your cancer team can explain any treatments that may be helpful. Your SLT or restorative dentist can help if speech problems are caused by changes in your teeth or shape of your mouth. If your vocal cords have been affected, it may be possible to have surgery or speech and language therapy to improve them.

Keeping your throat and mouth as healthy as possible can improve some speech and voice problems. Avoid smoking and alcohol. Keep a good mouth care routine. If your speech or voice change is worse because you have a dry mouth or thick, sticky saliva, we have more information about ways to improve this.

Speech and language therapy

Your SLT can help you learn to communicate in the clearest and easiest way possible.

They will assess your speech and voice. They can give you advice to help you take care of your throat and use your voice in the best way. They may do this by giving you exercises to:

- help you make your voice heard without straining
- help you make your speech easier to understand.

Speech therapy exercises can be hard work at times. You might find it helpful to make them part of your daily routine. Or you could use a chart to show your exercises and when you do them.

Tips for communicating

It can take time for you, and the people closest to you, to adjust to changes in your speech or voice. The reactions of people you do not know may be harder to get used to. It is normal to feel frustrated if people cannot understand you. But there are things you, and the people you talk with, can do to help.

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

If you are talking to someone new, it can be helpful to explain. You could tell them that your treatment has made it difficult for you to talk. This helps them know what to expect.

Here are some other tips:

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

Phone calls

It is not always possible to communicate face to face.
New technologies can help with things like phone or voice calls. You may be able to adjust the microphone volume on your device so your voice can be heard without straining. There are also apps that convert the text you type into speech. Ask your SLT or occupational therapist for advice.

Hearing changes

Some head and neck cancer treatments can cause hearing changes. This includes:

- some cancer drugs, especially the chemotherapy drug cisplatin
- radiotherapy, if the ear canal or inner ear were in the treated area
- surgery, if it affects the ear canal or inner ear.

Hearing changes may get better as your ears recover from the effects of treatment. But they can sometimes be permanent. They may also develop gradually in the first 2 years after treatment.

Tell your GP or cancer team if you have any hearing loss or ringing in the ears (tinnitus) after cancer treatment. They can refer you to a hearing specialist called an audiologist, or an ENT (ear, nose and throat) doctor for an assessment and tests.

Managing hearing loss

Depending on the type and cause of your hearing loss, you may have one of the following treatments:

- Eustachian tube surgery – the eustachian tube is a small tube between the ear and the throat. It regulates air pressure in the ear. If it becomes blocked, you may have a small operation to clear it.
- Antibiotics – if you have a build-up of fluid in your ear because of an infection, you may have antibiotics to treat it.

Hearing aids may also help with hearing loss. Sometimes a cochlear implant may be an option if hearing loss is severe. This means having an operation to put it in your ear. The implant uses electrical stimulation to provide sound.

Managing tinnitus

Tinnitus is a sound you hear from inside your body rather than outside. It is often described as a ringing sound. But it can include other sounds, such as buzzing, whistling, humming, whooshing or hissing. The sounds can be constant, or they can come and go. It often gets better as your ears recover after treatment. You may be referred to a tinnitus clinic to help you manage it.

Tinnitus is more noticeable when it is quiet. Using sound therapy can help to distract you. For example, having the radio on or using an electric fan. There are devices designed to produce sounds for people with tinnitus. Relaxation techniques can also help as tinnitus is made worse by anxiety. Your tinnitus clinic and Tinnitus UK can give you more information and advice.

Coping with hearing changes

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

Here are some other tips:

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

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

- RNID
- Tinnitus UK.

Face, neck and shoulder effects

Effects on the neck and shoulders

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

Your neck may also feel stiff when you move your head. You may not have feeling in some places, especially around the scar. This often improves over time but does not always get better completely. Some people have pain in their neck or ear that lasts a few seconds before going away. This is known as a spasm.

As the scar heals, you may feel pricking, tingling or numbness on the skin as the nerves repair. Your neck may also be more sensitive to touch or to temperature changes, such as heat or cold. Gentle massage with a non-perfumed cream or oil will keep the skin soft and flexible. This can also help make the scar line smoother.

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

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

If the nerve was only bruised during surgery, it usually recovers within a few months. But if the nerve was removed, the shoulder muscle will gradually get smaller and weaker. This can cause long term changes in the shape and position of your shoulder blade. Surgeons try to avoid damage to this nerve.

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

Coping with neck and shoulder changes

If treatment has affected your neck or shoulders, your doctor may arrange tests. 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 talk to you about:

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

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

Neck and shoulder exercises

Muscles around the head and neck can become overworked and tight after surgery and radiotherapy. Your physiotherapist will assess you and show you exercises that can help.

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

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

There are things you can do to help your posture.

- Look at yourself in the mirror to check the position of your head and shoulders.
- Sit 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 these things until it feels like your normal posture.

Massage

Once the scar tissue has healed, firmly massage the area regularly. Massaging the area around a scar using a non-perfumed oil or cream can help with tightness in the skin.

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

Pain relief

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

"The radical neck dissection made my neck very stiff. After the operation my neck and head movement was very limited. The exercises are so important in getting some movement back. I didn't have much pain in the early days but there was a lot of swelling. "

Jerry, diagnosed with mouth cancer

Swelling of the face or neck (lymphoedema)

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

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

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

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

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

It may help to sleep with some pillows supporting you so you are slightly upright in bed. This can help reduce the fluid build-up and help with drainage during the night.

Always tell your GP or cancer specialist if you notice:

- swelling in your face or neck
- tightness in the muscles.

They can assess you to find out the cause. They can also check if there is anything that may be affecting the lymphoedema, such as any changes to medications.

Lymphoedema is usually treated by a lymphoedema therapist. Your GP, cancer specialist or specialist nurse can refer you.

Coping with lymphoedema

Skincare

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

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 with unperfumed cream or lotion daily.
- If you get any cuts or grazes, wash the area carefully and put antiseptic cream on straight away.
- Protect your face and neck when you are in the sun. Wear a hat and use sun cream with a sun protection factor (SPF) of 50.
- Use insect repellent to prevent bites or stings, as these can make lymphoedema worse.
- Go to your GP straight away if you have any sign of infection in your skin. This includes 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 improves the movement of lymph fluid from the swollen area. NHS lymphoedema treatment clinics often provide MLD. You can also do a version of this at home. This is called simple lymphatic drainage (SLD). Your lymphoedema or MLD therapist can teach you this.

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

Sometimes a type of lymphoedema taping called Kinesio® taping may be used. It lifts the skin to allow lymph fluid to flow more easily.

Rarely, surgery can be used to treat lymphoedema around the eyelids. We have more information about lymphoedema in our booklet and audiobook Understanding lymphoedema.

Lymphoedema can affect how you think and feel about your body. This is known as your body image.

We also have our lymphoedema information on our website. Visit macmillan.org.uk/lymphoedema

Body image

Treatment for head and neck cancers can cause changes to how you look. This can affect your body image. Body image is how you think and feel about your body. If your appearance has changed, you will need time to get used to this.

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

You may find it helpful to talk to others who have been in a similar situation. You might find our Online Community helpful. You can share your experiences, ask questions and get support online. Visit macmillan.org.uk/community

Your feelings about body image

Everyone reacts differently to body changes. You may feel more self-conscious about your body. Some people may feel less confident, anxious, angry or sad. These are normal reactions.

You may feel worried about other people seeing the changes, for example if you have children or a partner.

Talking with people you trust can help. This could be your family, close friends, a partner or your cancer doctor or nurse.

If your body image concerns are difficult to cope with, or you are avoiding social situations, talk to your doctor or nurse. They can refer you to a counsellor or psychologist. They may also prescribe medicines to help.

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

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

Covering up physical changes

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

But try not to focus on hiding areas of your body. This might make you more anxious.

Skin camouflage products

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

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

Managing other people's reactions

You may find that some people look at you for longer. This is often because they are curious and not because they want to upset you. You will probably find that most people notice less than you expect.

Learning how to cope with social situations in advance can build your confidence. You can get more information about how to manage people's reactions from organisations such as Changing Faces.

We have more information about body image and cancer in our booklet and audiobook Body image and cancer. Or visit macmillan.org.uk/body-image

Other late effects

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

Paul, diagnosed with tonsil cancer

Tiredness

Feeling very 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 tasks. It is not unusual for this to last for months after treatment. For some people, tiredness continues for a year or more.

Possible causes of tiredness

Sometimes, tiredness is linked to other problems. Your doctor or nurse can check if there is a cause for your tiredness that can be treated. For example, they may:

- take a blood sample to check for low levels of red blood cells (anaemia)
- check your thyroid is working normally.

These conditions can be treated with medicines. They can also give you advice about helping to manage other causes.

Other causes of tiredness include:

- pain
- depression
- problems eating well
- sleeping problems.

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. Try to 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 and audiobook Coping with fatigue (tiredness). Or visit macmillan.org.uk/fatigue

Underactive thyroid

Radiotherapy for head and neck cancers can sometimes cause the thyroid gland to become underactive (hypothyroid). This can develop months to years after treatment. The thyroid gland is in the front of the neck and makes hormones. Hormones control many different processes in the body.

Symptoms of an underactive thyroid gland can include:

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

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

Pain or numbness

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

Always tell your cancer doctor if you have a new pain or pain that is getting worse. Pain can happen for different reasons. It may be caused by a late effect of treatment such as:

- jaw stiffness (trismus)
- scar tightness
- nerve damage.

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

Managing pain

There are different ways of managing pain. This depends on how bad the pain is and what is causing it. Ways of managing pain include:

- painkillers and other types of drugs
- physiotherapy and massage.

Some people find complementary therapies and talking therapies such as cognitive behaviour therapy helpful. We have more information in our booklet and audiobook Cancer and complementary therapies. Or visit macmillan.org.uk/complementary-therapies

Painkillers

Different painkillers are used for mild, moderate and severe pain. Your doctor or nurse will explain which painkillers may be helpful to manage your pain.

If pain is mild, it can often be controlled with simple painkillers such as:

- paracetamol
- non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen.

Or they may suggest a weak opioid such as codeine. If you need more help to manage pain, your doctor may prescribe opioid drugs such as morphine or fentanyl.

If the pain is difficult to manage, your doctor or nurse can refer you to a pain clinic for expert help. We have more information about pain in our booklet and audiobook Managing cancer pain. Or visit macmillan.org.uk/painkillers

Side effects

Many painkillers can cause constipation. You may need to take laxatives to help. Your doctor or nurse can give you advice. Strong painkillers may make you feel drowsy when you start taking them. This usually improves within a few days once you are used to them.

Taking your painkillers

It is important to take your painkillers as your doctor has prescribed. Taking them regularly helps keep your pain under control. People often think they should delay using painkillers for as long as possible. But this allows the pain to build up, which can make it harder to manage. Tell your doctor or nurse if painkillers are not controlling the pain. Your dose or type of painkiller may need to be changed. Or you may need a combination of painkillers. It may take time to get the right painkiller and dose to manage your pain. Your doctor can refer you to a specialist pain team if your pain is not controlled.

Other types of drugs

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

If muscle spasms are making your pain worse, you may be given a drug to help relax the muscles, such as diazepam. Drugs called steroids may be used to reduce swelling.

Pain caused by nerve damage can be treated with specific drugs that treat nerve pain. These drugs work on the nervous system. The dose is often increased gradually over a few days or weeks. It can take several weeks before you can feel them working.

Exercises and massage

A physiotherapist can show you helpful exercises that stretch the tissues. Try to keep a good posture (body positioning) if you can. This helps to reduce pressure and pulling on the shoulders.

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

Sometimes pain is caused by lymphoedema. Your nurse can refer you to a lymphoedema specialist for treatment which can help with the pain.

Numbness or changes in sensation

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

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

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

Peripheral neuropathy

Some chemotherapy or other anti-cancer drugs can cause numb, tingling or painful hands or feet. This is called peripheral neuropathy. It happens when the nerves that carry messages between the brain, the spinal cord and the rest of the body are damaged. Nerve damage causes symptoms such as pins and needles, numbness or pain in the hands and feet.

These symptoms usually begin to improve gradually a few months after treatment ends. Sometimes damaged nerves do not completely recover so some people have long-term changes. But there are ways to manage the symptoms of peripheral neuropathy.

Managing peripheral neuropathy

There are different drugs to help manage nerve pain. Your doctor can tell you more about the different drugs and how they work.

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

There are other things you can do to help:

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

We have more information about peripheral neuropathy on our website. Visit macmillan.org.uk/peripheral-neuropathy

Other therapies for managing pain

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

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

Sore mouth

After radiotherapy to the head and neck, you may be more likely to get infections or ulcers in your mouth. Your mouth may be more sensitive to spicy, salty, hard or crunchy foods. Alcohol, especially spirits and wine, and smoking can irritate your mouth and make it sore. It is important to continue to look after your mouth even when radiotherapy side effects have improved.

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

Concentration and memory problems

After cancer treatment, some people have difficulty concentrating and remembering things. This is called cancer-related cognitive changes (CRCC) or chemo brain. This is because the symptoms were first linked to chemotherapy.

The causes of CRCC are unclear, but it may be caused by a combination of factors. These may include:

- treatment side effects
- tiredness (fatigue)
- anxiety or depression
- problems eating well
- a side effect of medication
- pain that makes it difficult to concentrate
- menopause.

Changes in memory or concentration are usually mild and often get better within a year of finishing treatment. Sometimes they last longer or have more of an impact on your daily life. These problems may include the following:

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

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

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 or puzzles.
- Get plenty of rest but try to balance this with some physical activity.

We have more information about concentration and memory problems on our website.
Visit macmillan.org.uk/memory-problems

Your sexual wellbeing

The physical and emotional effects of cancer and its treatment may affect your sexual wellbeing.

Treatment for head and neck cancer may affect your body image and self-esteem. This might cause a low sex drive (libido) or sexual difficulties. Some side effects may mean you do not feel like having sex.

Many of the side effects of treatment will gradually improve. For example, tiredness or having a sore mouth. If pain is a problem, getting the pain under control can help. You can ask your cancer team about ways of managing these.

Some treatments may cause long term changes to the face, mouth or neck. For example, some people may have had surgery to remove an area of their mouth. Or have a dry mouth caused by radiotherapy. Physical changes like this may affect how you feel about being intimate, for example how you feel about kissing or oral sex.

You may need time to recover and adapt to changes before you feel comfortable having sex. Partners may also have concerns. Talking openly with each other can have a positive effect on your relationship.

There are often things that can help with these changes. For example, if you have a dry mouth, using artificial saliva before being intimate can help. There are lots of different ways to give and receive pleasure and be affectionate. These are different for everyone, so it can help to explore to find out what you and your partner like.

If difficulties with your sex life do not improve, talk to your cancer doctor or specialist nurse. It may help to talk about how you feel. Try not to feel embarrassed. They are used to giving advice on intimate problems. They can give you information and advice on how to improve sexual difficulties. They can also refer you to other services for more help. We have more information about sex and cancer in our booklet and audiobook Your sex life and cancer. Or visit macmillan.org.uk/sex-and-cancer Our information includes things like coping with erections problems or vaginal dryness.

Menopausal symptoms and sex

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

You can talk to your doctor or nurse about hormone replacement therapy (HRT) or other ways of coping with menopausal symptoms. Managing hot flushes and other symptoms may help to improve your sex drive. Using gels and creams for vaginal dryness can help ease discomfort during sex.

We have more information about menopause on our website. Visit macmillan.org.uk/menopausal-symptoms

Further information

About our information

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

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

Order what you need

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

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

Online information

All our information is also available online at macmillan.org.uk/information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

Find out more at macmillan.org.uk/otherformats

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

The language we use

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

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

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

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

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

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

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

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

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial advice

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

Help accessing benefits

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

Help with work and cancer

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

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Support for head and neck cancer

Cancer Laryngectomee Trust

www.cancerlt.org
Provides support to people who are about to have, or have had, a laryngectomy.

Changing Faces

Support and information line **0300 012 0275**
www.changingfaces.org.uk
Offers support and information for people who have a scar, mark or condition on the face or body that makes them look different. Includes face-to-face skin camouflage service in some areas of the UK.

Mouth Cancer Foundation

Helpline **0192 495 0950**
www.mouthcancerfoundation.org
Raises awareness and provides information and support to people affected by mouth cancer.

Oracle Head and Neck Cancer UK

www.oraclehnc.org.uk
Information and support for people affected by head and neck cancer.

RNID

www.rnid.org.uk
0808 808 0123
A support organisation for people in the UK who are deaf, have hearing loss or tinnitus.

Salivary Gland Cancer UK

www.salivaryglandcancer.uk
Information and support for people affected by salivary gland cancers.

Saving Faces

Expert Patient Helpline **0748 723 5438**
www.savingfaces.co.uk
Support for people with any type of mouth or face disease or injury. Their Expert Patient Helpline puts people in contact with other patients who have the same condition or have had similar surgery.

The Swallows

24/7 Support Line: **0750 472 5059**
www.theswallows.org.uk
Head and neck cancer support group for people affected by cancer, and their carers.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org
Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

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

Cancer Care Map

www.cancercaremap.org
An online resource that aims to help people find cancer support services in their local area across the UK.

Cancer Focus Northern Ireland

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

Cancer Research UK

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

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

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

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

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

General health information

Drinkaware

www.drinkaware.co.uk
Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS 111 Wales

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

NHS Inform

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

Patient UK

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

Tinnitus UK

Tel **0800 018 0527**
www.tinnitus.org.uk
Provides free support to anyone living with or caring for someone with tinnitus.

Stop smoking services

NHS Smokefree Helpline (England)

Tel **0300 123 1044**
www.nhs.uk/better-health/quit-smoking
Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

Quit Your Way (Scotland)

Tel **0800 84 84 84**
www.nhsinform.scot/quit-your-way-scotland
Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

Help Me Quit (Wales)

Tel **0808 278 6119**
Text 'HMQ' to **80818**
www.helpmequit.wales
Offers information, advice and support on stopping smoking in English and Welsh.

Stop Smoking NI (Northern Ireland)

www.stopsmokingni.info
Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.

Counselling

British Association for Counselling and Psychotherapy (BACP)

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

College of Sexual and Relationship Therapists (COSRT)

Tel **0208 106 9635**
www.cosrt.org.uk
Provides information about sexual well-being, including having therapy and finding a therapist. Has a list of professional therapists on the website.

UK Council for Psychotherapy (UKCP)

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

Emotional and mental health support

Mind

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

Samaritans

Helpline **116 123**
Email jo@samaritans.org
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Support for older people

Age UK

Helpline **0800 678 1602**
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.

LGBT-specific support

LGBT Foundation

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

OUTpatients

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

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 Senior Medical Editor, Dr Claire Paterson, Consultant Clinical Oncologist.

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Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

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

Sources

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

Brook, I. Late side effects of radiation treatment for head and neck cancer. Radiation Oncology Journal. 2020. Vol 38(2):84–92. [accessed July 2024].

Homer JJ, Winter SC, editors. Head and Neck Cancer: United Kingdom National Multidisciplinary Guidelines, Sixth Edition. J Laryngol Otol. 2024 Apr;138(S1). [accessed September 2024].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

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

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

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

MACMILLAN CANCER SUPPORT

This booklet is about late effects of treatment for head and neck cancer. It is for anyone who has side effects that last longer than 3 months after treatment, or anyone who has had side effects begin months or years after treatment is over.

The booklet talks about possible side effects. It explains what can help to manage them and what may help to reduce the risk of certain side effects.

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

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

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

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