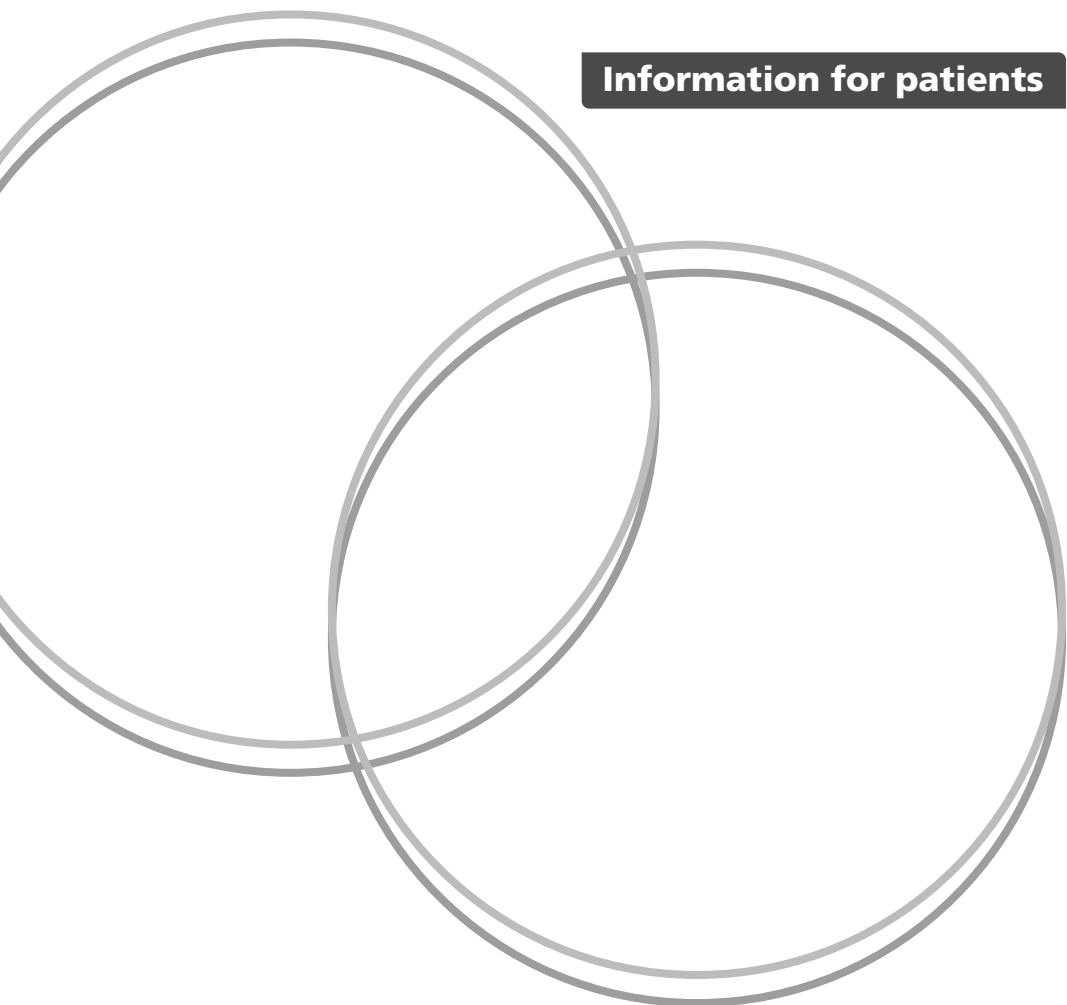




Oxford University Hospitals
NHS Foundation Trust

How to manage pain from head and neck radiotherapy

Information for patients



Who is this leaflet for?

This leaflet is for patients having radiotherapy for head and neck cancer. Radiotherapy uses X-rays and other types of radiation to kill cancer cells.

Head and Neck Radiotherapy have a team of professionals who will see you regularly through your treatment. These include:

- radiographers who deliver the radiotherapy
- nurses and doctors who will plan the treatment and support you during it
- dietitians who will advise you what to eat and drink
- speech therapists who will help you to recover, swallow safely and speak after treatment

The Oxford Cancer Centre Triage team is available 24 hours a day on **01865 572192**. The team will help you cope with the side effects of radiotherapy, such as soreness and pain. We explain these side effects later in this leaflet.

You can manage your symptoms by doing the following:

1. follow instructions and take painkillers regularly
2. use soothing mouthwashes to relieve pain
3. where possible, using distraction techniques like going for a walk, watching TV or practising mindfulness.

How much pain might I have?

This varies hugely between patients. Some people may find the pain is severe and need a mix of painkillers to help control it. This may include the use of morphine. Others may find that it's not that bad. The amount of pain you feel isn't linked to the size of your cancer.

You might not feel pain at the beginning of radiotherapy. It usually starts after a couple of weeks. The pain may get worse over the next few weeks and continues after the treatment has finished. Pain usually peaks 1 or 2 weeks after the end of treatment. It then slowly starts to get better. You should build up the painkillers as the pain increases. As the pain increases you could add a new painkiller or increase the dose for one you are already using. Your medical team will help you with this. When the pain is under control and you are through the worst then you will slowly reduce your painkiller use. The aim is to stop using pain killers as the pain gets better.

Different people experience different levels of pain at different times. It is not possible to predict, but here is an example of how this might work.

During weeks 1 and 2 of radiotherapy:

- You find that mouthwashes are enough to manage your pain

During weeks 3 and 4 of radiotherapy:

- You feel more pain and start using simple analgesia. Analgesia is medicine to ease pain. Simple analgesia includes common painkillers like paracetamol and ibuprofen.
- At the same time, you carry on using the mouthwashes.

During week 5 of radiotherapy:

- You feel more pain and your doctor prescribes codeine-based painkillers.
- At the same time, you carry on using the mouthwashes and simple painkillers.

During week 6 of radiotherapy and 1 week after radiotherapy:

- You feel more pain and your doctor prescribes morphine-based painkillers.
- At the same time, you carry on using the mouthwashes, simple painkillers and codeine.

2 weeks after radiotherapy:

- You notice that you feel less pain now. You are past the peak and you stop using the morphine.
- You carry on using the mouthwashes, simple painkillers and codeine.

3 weeks after radiotherapy:

- You feel less pain and you stop taking the codeine.
- You carry on using the mouthwashes and simple painkillers.

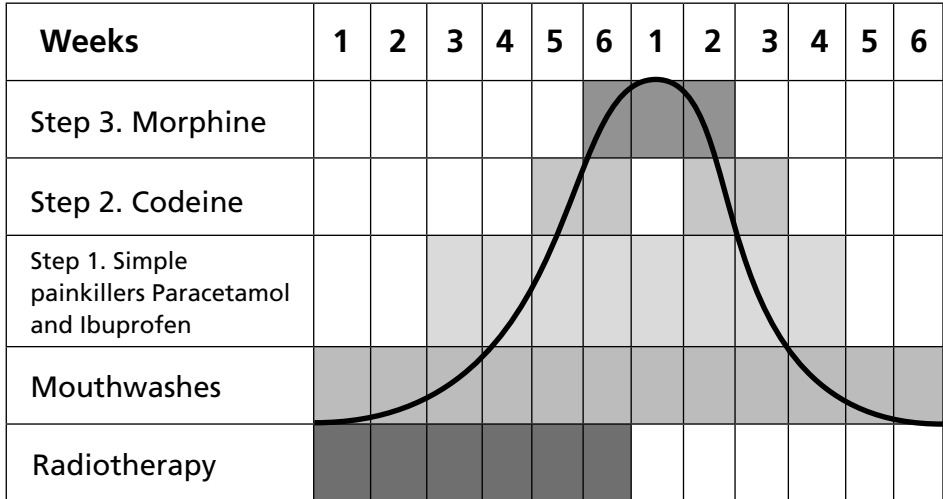
4 weeks after radiotherapy:

- You feel less pain and stop using the simple painkillers.
- Now you are only using the mouthwashes again.

5 and 6 weeks after radiotherapy:

- You feel very little or no pain now and you stop using the mouthwashes.

The diagram below shows this example using a black line to show the pain getting worse and then better again. The grey blocks show when each type of pain management is introduced and then withdrawn.



Different painkillers work in different ways. They can be more powerful when taken together. When the pain gets worse it's important to keep taking simple painkillers like paracetamol and ibuprofen as well as the stronger painkillers.

You need to eat and drink properly so that you stay well. If you take the painkillers this will be easier.

Which painkillers should I take?

Mouthwashes

During treatment, your mouth can become sensitive. Your saliva may become thick and sticky. It can help if you use mild mouthwashes (such as saltwater rinses). We can prescribe mouthwashes like BioXtra, (usually 5-10ml taken four times per day). Be careful as stronger mouthwashes can make your mouth sting. Later, we may suggest you use aspirin dissolved in water as a mouthwash. This must be soluble or dispersible aspirin. You would usually use aspirin 300 mg dissolved in half a glass of water, up to eight times per day. If you use aspirin as a mouthwash, spit it out afterwards and do not swallow it.

Step 1a: Mild pain Use simple analgesia

Product:

Paracetamol. (Taken as tablets, dissolvable tablets or as a drink)

When and how to use:

The maximum dose is 1,000mg or two 500mg tablets which you should take four times a day. Do not take more than eight 500mg tablets in 24 hours. If you have painkillers that you take as a drink, please check the label for the right dose.

Space out the doses evenly through the day.

Take 1g (1000mg) of paracetamol regularly, four times a day, approximately every 6 hours.

For example, at 6am (or when you get up), at 12midday, at 6pm, and at 10pm (or before you go to bed).

It might help you to take paracetamol at least 30mins before meals. This will make eating more comfortable.

Do not take any other medicines that contain paracetamol during step 1. This includes co-codamol and cold and flu products like Lemsip. If your weight is below 50kg, the dose of paracetamol will be reduced – talk to your team.

Step 1b: Mild pain Use further simple analgesia if we advise you to

As well as the paracetamol you should also take ibuprofen unless your health professional tells you not to.

Product:

Ibuprofen. (Taken as tablets or as a drink)

When and how to use:

The recommended dose is 400mg three times a day. The dose may be 1 or 2 tablets depending on the strength of the tablets.

If you have painkillers that you take as a drink, please check the label for the right dose.

Take 400mg of ibuprofen regularly, three times a day, approximately every 8 hours.

For example: 8am (or when you get up), at 2pm, and at 10pm (or before you go to bed)

Do not go above the maximum dose by the end of the day. You should take tablets ideally with or after food so that your stomach reacts to them less. We may prescribe medication to help protect your stomach alongside the ibuprofen. If you get stomach pain after taking ibuprofen, stop taking them and tell your doctor.

Do not take ibuprofen if your health professional tells you not to, or if:

- You have had a gastric ulcer.
- You have asthma and get wheezy after taking ibuprofen, naproxen or diclofenac. This is only a problem for around 1 in 10 asthma patients.
- You have high blood pressure or heart disease.
- You have kidney disease or inflammatory bowel disease. For example, Crohn's disease or ulcerative colitis.
- You are taking aspirin (except as a mouthwash), warfarin or other blood-thinning medication.

Step 2: Moderate or medium pain. Add weak opioid painkillers such as codeine

You will often feel more pain as the radiotherapy continues.

- Keep taking the regular paracetamol.
- Also keep taking the regular ibuprofen if we have agreed on this.
- Then add in codeine as an extra painkiller when you need it.

Product:

Codeine. (Taken as tablets or as a drink)

When and how to use:

The recommended dose is 30mg to 60mg four times a day when you need it for the pain. This will be one or two 30mg tablets. Do not take more than eight tablets in 24 hours. If you take the codeine as a drink, please check the label for the right dose. The liquid medicine comes in different strengths.

Take the codeine as an extra when the pain is bad. You should take the codeine roughly every 6 hours. Do not go above the maximum dose by the end of the day. It might help you to take codeine at the same time as paracetamol, at least 30 minutes before meals. This will make eating more comfortable.

Codeine does not suit everyone so please talk to the specialist team if you get side effects.

Possible side effects of codeine (these are generally less severe than with morphine):

- Constipation. Make sure you drink lots of liquid. You can also buy laxatives in a pharmacy or supermarket to help you to poo.
- Sickness. We may prescribe anti-sickness medication to help with this, which you can take regularly. Sickness often wears off a few days after starting codeine or morphine. Let us know if it doesn't get better.
- Sleepiness. If you feel that the codeine is making you sleepy, try taking a smaller dose first, or stop taking it and talk to your radiotherapy team. Do not drive while taking codeine.
- Slower breathing. Codeine may slow down your breathing if you take too much. There is more risk of this if you are overweight or have sleep apnoea. If you or your carer is worried about your breathing, call 999.

Step 3: Severe pain. Add strong opioid painkillers such as morphine.

You are likely to feel the most pain at the end of radiotherapy treatment and for a few weeks afterwards.

- Keep taking the paracetamol regularly.
- Also keep taking the ibuprofen regularly if we have agreed on this.
- Make sure that you take codeine regularly four times a day. It is helpful to take the regular codeine at the same time as your paracetamol.
- At this stage we will prescribe you morphine liquid for extra pain relief.

Product:

Morphine liquid with the brand name Oramorph®.
(Taken as a drink)

When and how to use:

The recommended dose of morphine liquid varies. Please check the label for the right dose. Your medical team will have told you this.

You should measure out the doses with a medicinal measuring spoon. This will come with your medicine bottle. There are two different measures on the spoon: 2.5ml and 5ml. Take care to use the right end of the spoon to measure your dose.

Use your morphine dose when the pain is very bad, or use it 20 minutes before doing anything you know will be painful, for example eating or drinking. Normally, we will say that you can repeat the dose every 2 or 4 hours.

Keep a record of how much morphine you take and how many doses you need in the day. This will help us to assess your pain and adjust your painkillers if we need to. If you find that you need to use morphine very often, you should get in contact with the specialist team.

Side effects of morphine (these are more likely and can be more severe than with codeine):

- Constipation. Make sure you drink lots of liquid. You can also buy laxatives in a pharmacy or supermarket to help you to poo.
- Sickness. We may prescribe anti-sickness medication to help with this, which you can take regularly. Sickness often wears off a few days after starting codeine or morphine. Let us know if it doesn't get better.
- Sleepiness. If you feel that the morphine is making you sleepy, try taking a smaller dose first, or stop taking it and talk to your radiotherapy team. Do not drive while taking morphine.
- Slower breathing. Morphine may slow down your breathing if you take too much. There is more risk of this if you are overweight or have sleep apnoea. If you or your carer is worried about your breathing, call 999.

Some people find that the pain is still bad even with taking codeine regularly and having extra morphine. Morphine is stronger than codeine so your team may advise you to stop taking the codeine and to take morphine regularly four times a day instead. It is helpful to take the regular morphine at the same time as your paracetamol. The dose will depend on how often and how much of your current pain relief you need to control your symptoms. Keep a diary of your painkiller use to help us get the dose right the first time.

We will usually prescribe a dose of morphine to take regularly four times a day. Check your instructions carefully. Keep taking the regular paracetamol and regular ibuprofen alongside the morphine doses. It might help you to take the morphine at the same time as paracetamol, at least 30 minutes before meals. This will make eating more comfortable.

We will also give you instructions that allow you to take an extra dose of morphine in-between the doses you take regularly. This is often known as breakthrough pain relief. You can use it for pain that your normal dose does not control. You are often allowed to have this extra dose every 2 or 4 hours. As always, check your medication instructions because they are tailored to you.

Is morphine safe and how would I stop?

Morphine is a strong opioid painkiller. It is very useful to treat severe pain during and after radiotherapy. It is safe to use for a few weeks. As the pain gets better you should gradually reduce how much you use. Do not stop it suddenly as it can cause withdrawal symptoms. Most people will have stopped taking morphine a few weeks after the end of radiotherapy. If you use morphine for a long time, it can lead to dependence or even addiction. If you are finding it difficult to stop the morphine, please let us know. Help is available for you.

What happens at the end of treatment?

Your radiotherapy team will see you after your radiotherapy treatment has finished. They will then help you to reduce the painkillers safely. When you have stopped taking the morphine, reduce and stop the codeine over the next few days. Finally, stop taking the ibuprofen and paracetamol.

Important: opioid safety

For drugs such as codeine, morphine, tramadol, and oxycodone.

- Do not drive while taking opioids.
- Store opioids safely and keep them away from children.
- Stop taking opioids as soon as the pain starts getting better.
- Dispose of unused opioids by taking them to a local pharmacy.
- Do not keep leftover drugs at home.
- Do not flush them down the toilet or throw them away

How to get in touch

You can contact the Head and Neck cancer specialist nurses on 01865 234 346 from Monday-Friday (Not bank holidays) 8-4pm, or the triage nurses on 01865 572 192 for evenings, nights, weekends, or bank holidays.

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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Oxford University Hospitals NHS Foundation Trust
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