

Completing Your Radiotherapy Treatment Information for Patients

Introduction

This leaflet aims to let you know what to expect when treatment finishes.

It is important to understand that people can vary a lot in their sensitivity to the treatment and the side effects can be very different for everybody.

The reaction to treatment does not stop when the treatment finishes. Often the first 2 weeks after completing of radiotherapy can be the worst and it can take several weeks before the side effects start to get better.

Some effects can take longer to improve and your doctor may have discussed this with you.

For 6 weeks following radiotherapy you can continue to contact the **Cancer Treatment Helpline** on:

2: 0800 9177711



Pain and Soreness

For some people, the pain can continue and may be worse for the first week or two after treatment. During this period it is you should continue with your regular mouthwash and pain killers. If your pain is getting better you can gradually reduce your pain killers.

Please contact us if you feel that the pain is not manageable. If you have been given Oxetacaine and Antacid, continue to take that regularly for the first few weeks following treatment (Please make sure you have enough to last as this cannot always be given by your GP). You should also continue with your mouth wash regime.

Skin Care

Within the treatment area, your skin may continue to be red and sore. Please clean the area gently with warm water and a clean soft cloth.

Continue with the steroid cream (Betamethasone) and moisturiser (zerobase). When the redness settles, stop using the steroid cream but continue with the moisturiser.

Your skin can become redder for 1 - 2 weeks following treatment and the skin can become broken with some discharge. If your skin is broken please do not apply the steroid cream. Continue to wear loose clothing around your neck.

After finishing radiotherapy you may notice a swollen area under your chin at the front. This should feel soft and is usually a collection of fluid that hasn't drained through the normal system as the nodes/glands that are responsible for this have been treated with radiotherapy. When the skin reaction has improved try gentle massage in an upward motion using some of your moisturiser.

In the long term, you need to protect your skin from strong sunlight by using sun block.

Secretions and Phlegm

If you have been troubled by thick/tacky secretions during your treatment, this can continue for many weeks after treatment has finished. Keep well hydrated by drinking more or taking more fluid via your feeding tube.

If you have been given a nebuliser to loosen secretions you can use this frequently throughout the day, up to every 2 hours.

Dry Mouth and Trismus (Difficulty in Opening Your Mouth)

Radiotherapy can damage saliva function leading to a dry and uncomfortable mouth. It is advisable to continue with your mouth washes and take regular drinks of water, unless advised not to. This dryness often gets better after a few months but for some people this dryness can be a permanent effect of the radiotherapy treatment. Your doctor may have discussed this with you before treatment started. You may find saliva replacement spray or gel helpful.. If you find your mouth opening difficult it is important to continue the exercises given to you by a speech and language therapist (SLT). They will assess you after treatment finishes.

Nutrition

Nutrition is important for recovery. Eating and drinking after treatment can often be challenging. Pain, secretions, taste changes and reduced appetite can all affect your desire and ability to eat. If you are able to swallow it is important to try to eat and drink as much as possible. Start with small amounts (a few teaspoons), a "little and often" approach and try to build up the portions as your side effects settle.

If you have been advised to take oral nutritional supplements (build up drinks) or tube feed, it is important to also continue to take these to boost your nutrition to speed up you recovery.

If you have any nutritional concerns please discuss with a dietitian or your team who will be able to offer advice and support.

Taste Changes

The treatment can affect your sense of taste. Food often doesn't taste how you imagine it will, but it is important that you continue to eat and drink, unless you have been told not to. Try to think of food as medicine.

Taste changes can last for several months but should improve over time.

Swallowing

The Speech and Language therapist (SLT) will continue to monitor your swallowing ability, if required, once your treatment has finished. Carry on doing the swallowing exercises given to you until your side effects have settled, or longer if advised.

If you have been given specific advice regarding your swallowing, eating or drinking, continue to follow this.

If your SLT has advised that it is safe for you to eat and drink, you should try to do so to maximise your swallow recovery.

Voice Changes

If your throat has been treated you may notice that your voice has become hoarse during treatment. This usually improves after a few weeks.

In the meantime stay well hydrated and try not to strain your voice with overuse.

Fatigue (Tiredness)

Unlike many of the other side effects, fatigue can last many months. For some people, it can last even longer. Please try to keep your calorie intake as high as possible as your body uses more calories during the healing process. If you are unable to manage enough calories you may feel weak and tired. It is important to build up your daily activity, however you may need to rest often. We know that gentle exercise can help with your recovery/healing and can also help with low mood.

Macmillan Cancer Support offer a "Move more" Programme and have many other resources available.

Alcohol and Tobacco

It is essential that you do not smoke as this may delay your recovery.

Stopping smoking also reduces the risk of the cancer returning or of a new cancer developing elsewhere.

Initially following your treatment, alcohol will irritate the lining of the mouth and throat and therefore may delay healing. In the long term, you should avoid heavy drinking should as this can also lead to future illness.

If you need help with either of these please do not hesitate to ask us to arrange this for you.

Dental

Initially, after radiotherapy your mouth may be too sore to allow you to clean your teeth and you should follow the advice given to you at your pre radiotherapy dental appointment. This is to minimise the risks of developing decay and gum disease. It is very important that you continue with your mouthwashes frequently throughout the day and if able, to use a high fluoride toothpaste.

A dry mouth and an altered diet, such as supplement drinks can increase your risk of decay so it is important that you follow the mouth care advice you have been given.

You will be offered a dental appointment 4 - 6 weeks after your treatment. This is not for dental treatment but for the dentist to assess your mouth and give you any advice to minimise the risk of developing dental problems.

If you have any concerns about your teeth please inform a member of the Head & Neck team who can contact the dentist on your behalf.

If you had teeth removed prior to radiotherapy or surgery you may need dentures/ implants. If this is the case you may receive an appointment to see a restorative dentist who is a specialist in assessing you for optimum dental health.

Emotions/Feelings

We know that cancer, treatment and side effects can be life changing. For many people this can result in anxiety, fear, low mood, changes in family dynamics or lifestyle and for some, altered body image and decreased libido.

During treatment you are coming to the hospital daily and some people find that they may feel a bit isolated when this stops.

Support is available from a variety of sources including:

Clinical Nurse Specialists (CNS) are experienced nurses who can offer information, support and advice to you and your family. This support can continue long after your treatment is finished. If you have any concerns or questions please get in touch.

Macmillan Cancer Support offers a wide range of physical, emotional and financial advice and you can phone 8am – 8pm on 0800 808 0000 or Email on www.macmillan.org.uk

Maggies Centres offer practical and emotional support for your specific needs and the professional staff can offer advice and information. Your family and friends can also access the centres.

E mail -www.maggiescentres.org

For local support groups please contact your Specialist Nurse who will have information on what is available.

Finances/Return to Work

If cancer and its treatment have impacted on your financial situation, please speak to your CNS who can refer you to Macmillan Benefits Team to assess if you are eligible for financial assistance.

If you need support in returning to work, for example a phased return or need altered duties please speak to your employer first and if you need support please contact your Clinical Nurse Specialist or Macmillan Cancer Support.

Follow up

At the end of the radiotherapy treatment you may be asked to come to the Thursday review clinic at the Western General Hospital a week or two after the treatment has finished so that the Head & Neck team can help with any issues. This may happen for a few weeks until your side effects begin to settle.

If you live in Fife or Dumfries and Galloway you will be seen locally. Your CNS will arrange this for you.

You will then be asked to come to the Tuesday clinic where you were originally seen and you will be seen there every 4-6 weeks for the first year after treatment finishes. Usually, due to the treatment reaction, it isn't possible for the doctor to see how the treatment has worked initially and it can take up to 3 months before an assessment can be made. If you have any questions please speak to your doctor or nurse.

The clinic appointment usually involves the doctor asking how you have been and examining your mouth and neck. The doctor may pass a fine tube down your nose and into your throat to examine the area with a camera.

You will be asked if you have any questions, so feel free to do so.

Some people will require a CT scan but this will be discussed with you.

It is essential that you stop smoking and avoid heavy drinking.

If you have a feeding tube please continue to look after it and make sure you know what to do before finishing treatment.

After radiotherapy you will need to get medication from your GP so it is important to hand in the pink pharmacy sheets that you get with your hospital prescriptions to the GP practice so that they are aware of what you have been getting from the hospital.

Follow up will continue for up to 5 years but as time progresses, if you are well, the clinic appointments will become less frequent.

For further information please contact your Specialist Nursing team on:

Tumfries and Galloway: 01387 241 217

Lothian and Borders: 0131 537 1107 or 01506 524166

Tife: 01383 674 063 or 01383 674 064

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