

Head and Neck Aftercare Service

A Patient's Personalised Care Plan for the Aftercare Service at Lister Hospital

This leaflet provides information for when you have completed your treatment for head and neck cancer and includes your personalised care plan. It aims to answer some of your questions about the team who will be seeing you, where they will see you and how often you will be seen by the Head and Neck Team. It also has details of the contact numbers you should use if you have any concerns between hospital visits.

Please keep this leaflet handy to refer to, but if you have any additional questions, please speak to a member of the team/your keyworker.

We hope the Aftercare Service (After Treatment Review Clinic) will help you to adapt to the changes caused by your cancer and its treatments so you can achieve the best quality of life after treatment.

Contents

Page

3	Your personalised care plan
4	Why do I need to attend the After Treatment Review Clinic?
4	Who will I see at the After Treatment Review Clinic?
4	Can I bring someone with me to the After Treatment Review Clinic?
4	After Treatment Review Clinic appointments
5	Will my GP be informed about my appointments?
5	Taste and dry mouth – Helpful hints
6	Lymphoedema
6	Restricted mouth opening (Trismus)
6	When should I see my dentist?
6	Physiotherapy
7	Exercising after cancer treatment
7	What other services are available?
7	Emotions
8	What Concerns or symptoms should I contact the hospital about?
9	Recording any side effects you may have
10	Notes page
11	Further information and support
11	Useful contacts

Your Personalised Care Plan

Name: _____

Date of Birth: _____

Hospital number: _____

Diagnosis: _____

Treatment received: _____

Treatment completion date: _____

Any other information: _____

Why do I need to attend the After Treatment Review Clinic?

The review clinic can help you to improve the quality of your life after having had treatment. At your review:

- you can discuss any ongoing side effects from your treatment and receive advice on how these might be best managed.
- we will monitor any signs of recurrence of your cancer. You may need some tests from time to time; these will be discussed with you if they are necessary.
- we will provide an opportunity for you to discuss how you are feeling after your treatment, and we can give advice and support if you are finding adjusting to life after cancer difficult.
- you can receive support to stop smoking if needed.
- we can give support to help you control your alcohol intake if required and discuss any possible further referrals.

Who will I see for review at the After Treatment Review Clinic?

On some occasions it will be appropriate for you to be reviewed by your clinician, and at other times you may be seen by the clinical nurse specialist and/or other health professionals. Many members of the Head and Neck Team can be part of your after treatment reviews, depending on your needs. This includes surgeons and oncologists, specialist nurses, dietitians and speech and language therapists. In addition, you can be referred to a lymphoedema nurse therapist or physiotherapist if needed.

Can I bring someone with me to the After Treatment Review Clinic?

We encourage you to bring a family member, friend or carer with you and welcome their attendance at the clinic; your loved one is just as important as you. Addressing their concerns and need for information, as well as yours, is an important part of the clinic's aim. Please do let us know if they would like advice or support.

After Treatment Review Clinic appointments

How often you are seen depends on your type of cancer and your individual needs. In the first year you will usually be reviewed every 4-6 weeks. These will become less frequent over the next 5 years until you are well enough to be discharged. Should you feel you need a more urgent appointment, we would be happy to give you an earlier appointment (usually within 1-2 weeks).

You can also have telephone advice and support between visits by telephoning your keyworker; this is normally the Macmillan head and neck cancer nurse specialist, and the head and neck support nurse.

Keyworker: _____

Telephone: _____

You may be offered an electronic Holistic Needs Assessment. This is a questionnaire for you to complete, which aims to tell us your concerns.

The Head, Neck and Thyroid Cancer Clinics take place at the Lister Hospital every Thursday. **Thyroid Telephone Clinics** take place on a Tuesday. Your consultant or a member of their team will be present.

Dietitian - The Macmillan specialist head and neck dietitian is available at the clinic to offer tailored advice for your nutritional needs when you are undergoing treatment and when it is completed.

Speech and Swallowing Therapist - The speech and swallowing therapists will continue to see you in clinic if you require any speech therapy sessions or advice about any new or ongoing swallowing problems.

Will my GP be informed about the appointments?

After you attend clinic, your GP will be sent a letter to update them on how you are. You can also receive copies of your clinic letters (please request this if you wish to receive them).

Taste and dry mouth

Head and neck cancer treatment can cause taste changes and for your mouth to become dry. This can affect the pleasure you get when eating. Your GP or cancer doctor can give you saliva replacement products to help your mouth feel moist. There are a range of different products available from gels to toothpaste and sprays. A simple water spray or sips of water can also be effective. Please let your doctor or nurse know if a dry mouth is causing you concern.

If the soreness in your mouth has settled, the helpful hints on dry mouth and taste changes below may be useful. For some people these changes may be permanent and no recovery in saliva production is expected. For others, it may be at about 2 years after treatment that you notice your mouth becomes more moist and your taste improves.

Please discuss any concerns with your Head and Neck Team at your aftercare review.

Helpful hints on taste and dry mouth

When mouth soreness has settled:

- Try rinsing your mouth with fizzy water before meals.
- Gently clean your mouth and teeth after meals; good mouth care is essential.
- Avoid mouthwashes containing alcohol or strong flavours which may alter the taste of foods.
- Tell your doctor if you notice white patches in your mouth, or if you have a consistent 'bad taste' in your mouth which may indicate an infection.
- If food tastes bitter, it may be helpful to avoid red meat, sour juices, coffee, tea, tomatoes and chocolate.
- If food tastes too sweet, try cooking with lemon juice, herbs, vinegar or mint, although they may not be advisable if you have a sore mouth, or are receiving radiotherapy to the mouth or throat.
- Use marinades, soy sauce or readymade sauces to enhance flavour.
- Sweet flavoured drinks, carbonated drinks and ice lollies can all help you cope with a change in taste, although remember to brush your teeth afterwards.
- Add lots of seasoning, or other flavourings to meals.
- Try leaving food to cool for five minutes, as cooler foods may taste better.
- Try different flavours, or foods you may not have previously enjoyed.
- Try eating small pieces of fresh pineapple which can be very refreshing.
- Concentrate on foods which taste good to you.
- You may lose your sense of smell, if so please let us know.

Remember: Your doctor can prescribe artificial saliva gel or spray.

Further information can be obtained from:

- Macmillan Cancer Support Publication - Eating Problems and Cancer
- Lynda Jackson Macmillan leaflet - Managing Taste Changes (HHC244)

Lymphoedema

At about 6-8 weeks after radiotherapy, you may notice a soft swelling around your neck, chin or face. This swelling can fluctuate in size and can appear bigger in the mornings. This is a side effect of having surgery and/or radiotherapy to your neck and it is called lymphoedema. If you notice this, please inform your key worker and they can refer you to the Lymphoedema Service, where they will use special massage techniques to help drain this fluid away from the face and neck area. You will be taught self-massage techniques that you can use at home. For most people, this swelling will decrease slowly over the next 12 months following treatment.

Restricted mouth opening (Trismus)

During and after radiotherapy/surgical treatment, you may experience some discomfort and tightness when opening your mouth to yawn or eat. This may happen because the muscles around the jaw have become more stiff and less elastic.

It is helpful to keep stretching the mouth open for short periods regularly for at least 3-6 months after treatment. Continue to use the muscles responsible for chewing, talking and yawning as frequently as you are able. This is not only important for eating, but also for dental hygiene and dental treatment.

If you feel that your mouth opening is becoming restricted, please contact your Speech and Language Therapist who will be able to measure your mouth-opening and advise on an appropriate treatment plan to maximise your jaw function.

When should I see my dentist?

Regular dental care is an important part of your aftercare. You should make an appointment to see your dentist about 6 months after you have completed your treatment. If you were seen by the Oral/Maxillofacial Department before treatment, you should receive a follow-up appointment.

If you need dentures, we recommend that they are not made until 6 months after you have completed treatment. This is because the lining of your mouth needs time to completely recover from treatment and the shape of your gums may still be changing.

If your dentist advises any extractions in the future, it is important this is discussed with your Key Worker or Oncology Team.

If you are experiencing a dry mouth due to your treatment, we would advise you to start using fluoride supplement products. These can be obtained from your dentist. Dental implants are suitable for some patients. Please ask your Oral and Maxillofacial Team.

Physiotherapy

If you have had surgery to your neck area, you may have been given exercises by the physiotherapists to improve your neck and shoulder movement and to decrease any tightness of the scars. If you have any difficulties with this movement or concerns about your scars, please discuss this with your team at your review clinic. They will refer you to the community physiotherapist, if needed.

Exercising after cancer treatment

You may feel you don't have the energy or willpower to do exercise, or you don't know where to start. You may feel you need guidance with what you should or shouldn't do.

"Inactivity causes our muscles to lose strength and work less well. It can also increase feelings of extreme tiredness (fatigue), stress and anxiety. Even a little regular exercise can build up your energy levels (stamina) and help you feel better. Exercise also helps people cope with treatment side effects and cancer symptoms". Exercise after treatment can include walking, gardening and even doing light housework.

Further information can be obtained from:

- Macmillan Cancer Support Publication - Physical activity and cancer.

There may be an exercise group near you specifically for people with cancer or other health conditions. For more information, discuss this with your keyworker or Macmillan Information and Support Centre (please see contact details on page 11)

What other services are available?

One of the most difficult things to cope with after treatment is the feeling that cancer and its treatment have taken control over your life. There are many small things that can help to make each day easier, but there may be times when you are too tired to think about them.

Recovering from head and neck cancer can be a slow process. Getting a better understanding of head and neck cancer, its treatment, and ways to manage side effects can lead to an improvement of your quality of life after treatment.

Over time, side effects will lessen and become easier to manage. However, if you are feeling overwhelmed by thoughts or fears for the future it is important to let your doctor or keyworker know. It may be that you are experiencing depression or anxiety which may need further intervention.

We also have a designated team, **Macmillan Personalised Care Team**, who help us with assessing your needs and concerns, so you get the help you need.

Please discuss any concerns with your keyworker to see which services are available.

Emotions

Your key worker will talk to you about how you are feeling before, during and after your treatment. We can signpost you for emotional and psychological help, if you need this. Services available include:

- Head and Neck Support Group
- Thyroid Support Group
- Moving on from Head and Neck Cancer Workshop
- Macmillan Information and Support Centre, Lister Hospital
- Patient Self-management Programme - HOPE
- Lynda Jackson Macmillan Service, Mount Vernon Cancer Centre - Counselling Services

What concerns or symptoms should I contact the hospital about?

Some symptoms and changes are expected after treatment. The table below is a guide to help you in managing expected symptoms. It will also help you to identify unusual symptoms that you will need to contact your Head and Neck Team about.

Symptom	Who should I contact?	When to contact them
Difficulty with swallowing, or coughing with liquids or foods.	Head and Neck Nurses, Dietitian or Speech and Language Therapists.	Within usual working hours, Monday to Friday, 9-5pm. However, if this happens over the weekend, please attend your local Emergency Department.
Change in breathing. Feeling short of breath or breathing becomes noisy.	Head and Neck Nurses - If unable to contact them, attend your local Emergency Department.	Within usual working hours, Monday to Friday, 9-5pm. However, if this happens over the weekend or during the night, attend your local Emergency Department.
Shoulder stiffness.	Head and Neck Nurses.	Within usual working hours, Monday to Friday, 9-5pm.
Feeling low in mood.	Head and Neck Nurses.	Within usual working hours, Monday to Friday, 9-5pm.
Change in voice.	Head and Neck Nurses or Speech Therapists (if known to their service).	Within usual working hours, Monday to Friday, 9-5pm.
Unexplained rapid weight loss.	Head and Neck Nurses, Dietitian.	Within usual working hours, Monday to Friday, 9-5pm.
Swelling under chin and around neck and face.	Head and Neck Nurses.	Within usual working hours, Monday to Friday, 9-5pm.
Lump in neck that feels hard.	Head and Neck Nurses.	Within usual working hours, Monday to Friday, 9-5pm.
Persistent pain in neck, ear or mouth.	Head and Neck Nurses.	Within usual working hours, Monday to Friday, 9-5pm.
Feeding tube becomes blocked.	District Nurse, Dietitian or Nutrition Nurse for telephone advice.	Within usual working hours, Monday to Friday, 9-5pm. However, if it happens at the weekend, please attend your local Emergency Department.
Tiredness and fatigue.	Head and Neck Nurses.	Within usual working hours, Monday to Friday, 9-5pm.
Bleeding post-surgery or from a wound.	If new, continuous bleeding phone 999 or attend your nearest Emergency Department. If the blood is dark blood or a small amount, please call the Head and Neck Nurses for advice.	Open every day, 24 hours a day, 365 days a year. Within usual working hours, Monday to Friday, 9-5pm.

Recording any side effects you may have

You may find it helpful to fill out this chart each day, and then bring this information leaflet with you each time you see the doctor and nurses at your review clinic. It will help you to remember accurately how you felt and enable the team treating you to try to ease your side effects.

(1) **Not at all** (2) **A little** (3) **Quite a lot** (4) **Very much**

	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun
Date														
Best days (please tick)														
Worst days (please tick)														
Side effect - Low mood														
Side effect - Face swelling														
Side effect - Fatigue														
Side effect - Dry mouth														
Side effect - Shoulder stiffness														

(1) **Not at all** (2) **A little** (3) **Quite a lot** (4) **Very much**

	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun
Date														
Best days (please tick)														
Worst days (please tick)														
Side effect - Low mood														
Side effect - Face swelling														
Side effect - Fatigue														
Side effect - Dry mouth														
Side effect - Shoulder stiffness														

Please use this space to write down any notes or any questions you may like to ask:

Further information and support

- **Macmillan Cancer Information and Support Centre, Lister Hospital**
Situated at the main entrance to the Lister Hospital.
Drop-in centre and telephone helpline for any questions relating to cancer:
Telephone 01438 284657 (Monday to Friday, 10am - 4pm, excluding Bank Holidays)
Email - macmillaninfosupport.enh-tr@nhs.net
- **Macmillan Cancer Support** www.macmillan.org.uk
Specialist advice and support, and financial grants for people with cancer and their families:
Telephone 0808 808 0000
- **Changing Faces** www.changingfaces.org.uk
To support people with visible differences and disfigurements
Telephone 0300 012 0275
- **Mouth Cancer Foundation** www.mouthcancerfoundation.org
Telephone 01924 950950
- **The National Association of Laryngectomee Clubs (NALC)** www.laryngectomy.org.uk
Advice and Support for laryngectomies and their families and friends.
Telephone 0207 730 8585
- **Butterfly Thyroid Cancer Trust** www.butterfly.org.uk
Advice and support for patients with thyroid cancer.
Telephone 0739 9564 463
- **British Thyroid Foundation** www.btf-thyroid.org
Information and support for people affected by thyroid disorders
Telephone 01423 810093
- **The Swallows Head and Neck Cancer Support Group**
2c Sycamore Trading Estate, Squires Gate Lane, Blackpool FY4 3RL
Telephone 01253 428940 or
Telephone 07504 725059 - 24/7 Patient/Carer Support Line
Email - info@theswallows.org.uk

Useful contact details

East and North Hertfordshire NHS Trust:

- Website www.enherts-tr.nhs.uk
- Telephone 01438 314333

Macmillan Cancer Information and Support Centre, Lister Hospital:

- Telephone 01438 284657 (Monday to Friday, 10am - 4pm, excluding Bank Holidays)
- Email - macmillaninfosupport.enh-tr@nhs.net

Leaflet information

**You can request this information in a different format or another language;
please speak to your doctor or nurse.**

This leaflet has been written in collaboration with oncologists, health professionals, patients and carers within Cancer Services.

Date of publication: March 2025

Version number: 01

Author: Jackie Jones

Reference: Cancer Services

Review Date: March 2028

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