

How to cope with side effects and symptoms that affect how you eat, drink and speak when your cancer cannot be cured

Department of Nutrition and Dietetics

Information for patients with head and neck cancer

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Introduction

You have been given this information as you have been diagnosed with a cancer in the head and neck region that cannot be cured.

Any treatment you now have will be aimed at easing the side effects caused by the tumour and improving your quality of life. Not everyone will have these symptoms approaching the end of their life.

Not all of the information will be applicable to you at this time.

It is difficult to know what will happen, but knowing some of the possibilities provides a chance to think ahead and prepare.

Who is responsible for your care?

Within the hospital you are supported by a team of health professionals that work alongside your consultant.

This includes the Clinical Nurse Specialist (CNS), the Speech and Language Therapist (SLT) and the dietitian. They see patients at diagnosis, through treatment and in follow up clinics to support your recovery from treatment.

Once this has finished, your care is handed over to the community teams. This is led by your GP but can include community nurses, dietitians and hospice care, depending upon your needs. If it is felt you need more help once you are discharged from hospital the CNS will refer you to the right team.

If your needs change once you are home, you will need to talk to your GP and they will refer you as necessary.

Do not be afraid to ask if you would like more information or help. The community nurses and your GP are there to help.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

Possible side effects

When head and neck cancers grow they can cause side effects and symptoms, which can make eating, drinking and speaking difficult.

The symptoms you may have might depend on the position of your cancer. Not everyone will have these symptoms as they can depend on your general health and wellbeing and treatments you have had or are having.

The aim of this leaflet is to provide you with a basic understanding of these side effects and symptoms and how to manage them.

Pain

- Pain around the area of the tumour is very common and it can greatly affect your quality of life, but particularly your ability to eat, drink and speak.
- With the right treatment and support your pain can usually be managed. You can discuss this with your GP or community nurse. They will look at your medicines or other ways to help you manage the pain.
- Most pain can be kept under control with prescribed medicines, taken regularly. You are also advised to take medicines 20 to 30 minutes before you eat or before doing speech and language exercises.
- If you find that the pain medicines are not easing your pain, you will need to contact your GP or community nurse. They can then assess your pain and look at other medicines that may help you.
- Some medicines for pain relief can cause side effects such as constipation. This can be managed if you tell your GP or community nurse as soon as you are having problems.

Swallowing

- Swallowing is a common problem that can affect how you eat, drink and take medicines and may become more difficult for you as you approach the end of your life.
- It may become more difficult to chew food, moving your tongue, controlling your saliva, moving food to the back of your mouth, coughing/choking when swallowing, food or fluid coming up in to your nose and or not being able to get food or fluid down.
- Swallowing difficulties can sometimes be caused by pain. If your pain under control you will find it easier to eat and drink. Make sure you follow the advice for managing your pain. If the pain is still causing you problems with swallowing please talk to your GP or community nurse.
- Making changes to your diet will make swallowing easier. Naturally smooth foods will help to stop choking and most foods can be made smooth in a blender. Smaller portions, little and often will help you tolerate food/drink better.
- The dietitian can tell you what levels of food and drink are right for you and explain what this means. They can send information out to you.

Swallowing continued

- If fluids are particularly difficult, then the SLT may do a swallowing assessment to see if using thickening powders would be helpful. The SLT will give you further information about thickening powders as appropriate.
- Having difficulty swallowing can lead to food and/or drink going 'down the wrong way' and into your lungs and this can cause a chest infection. If you begin to feel chesty go to your GP who can review you and offer antibiotics if needed.
- Not eating enough will cause weight loss which will reduce how much of your normal daily tasks you are able to do. It is important that you try to eat as much and as often as you can.
- If you find your diet is greatly reduced, you may need nutritional supplements. Your GP or community nurse can arrange these if needed. They can also refer you to a community dietitian.
- Some people choose to have a feeding tube which will make sure their diet and fluid needs are met. This is called enteral feeding. Your community nurse will talk to you about this as appropriate.

Fatigue (Tiredness)

- This is a feeling of extreme tiredness. It can have a big impact on your daily life, making your meals and maintain your weight.
- Try to have small, regular meals and snacks.
- Have your 'main meal' of the day when you feel you can. This may not be your usual time to eat your main meal.
- More details and practical ideas on how to do this can be found in the dietary information included in this pack. If you need another copy, please visit www.linds.nhs.uk to look at or print one out. If you would prefer, please contact the dietitian on the contacts page and one can be sent out to you.

Lack of appetite

- Your illness, treatments and medicines might cause you to lose your appetite. Your appetite may also depend on how you are feeling. It is common for low mood, feeling worried or depressed to cause a poor appetite.
- There are things you can do to help if you have lost your appetite. Eat small, regular meals and snacks even if you don't feel hungry. Aim for three small meals and three snacks a day.
- Use ready prepared meals or cook a few meals and freeze them so you are not needing to prepare food each time.
- Use a small plate and only have small portions. You can always have a second helping if you want.
- Try to eat with other people, even if you are having a different meal or a liquid supplement to drink. Eating is a very social activity and it can become lonely if you stop having meals and drinks with your family and friends.

Weight loss

- It is common to lose weight in this situation as many of the side effects can cause you to lose your appetite and not want to eat or drink.
- Changes in appearance can be upsetting as you lose weight.
- It can be very difficult to be able to gain weight. It is more important to try and maintain your current weight or to reduce weight loss, to maintain your quality of life.
- Please see the dietary information included in this pack for practical ways to prevent weight loss.
- Nutritional supplement drinks are often used to increase nutritional intake when eating is difficult. You can ask your GP or community nurse to prescribe these.
- If it is expected that eating is likely to become very difficult, some people choose to have a feeding tube to ensure they are meeting their nutritional and fluid needs. You can discuss this with your consultant, GP or dietitian if you would like more information on this.

Communication

- As head and neck cancers progress they can have an impact on speech and voice depending on where your cancer is situated.
- People sometimes find that their speech is likely to sound different and they can become more hoarse or breathy. Moving the tongue and lips can also become more difficult making speech become less clear.
- Slowing speech down can be helpful, as well as regular steaming to help dampen the voice box. The SLT will explain more about steaming if appropriate.
- In extreme situations you may require support with communication with a communication device such as an Ipad with a text-to-speech app. The SLT team can support you with this if you feel it would benefit you.
- Pain can also be a barrier to clear communication and making sure pain is managed is important.
- There is specialist SLT support available in the community and visits can be arranged at home if necessary. If you feel you would benefit from this service please ask your GP or consultant to refer you.

Managing secretions

If you are finding that managing your saliva is difficult then the GP may be able to prescribe some medication that can dry up your saliva or alternatively thin it down .

If you have any further questions or any problems please see contact details on back page.

Contact details

Specialist Head and Neck Cancer Dietitian

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0116 2585400

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk