NHS

National Institute for
Clinical Excellence

Healthcare services for head and neck cancers

Understanding NICE guidance – information for the public

Introduction

The National Institute for Clinical Excellence (also known as NICE) has issued guidance on the organisation of healthcare for adults with head and neck cancers. The guidance recommends which healthcare professionals should be involved in treatment and care, and the types of hospital or cancer centre that are best suited to provide that healthcare – this type of guidance is called 'service guidance'.

It's important to remember that many service guidance recommendations require large-scale changes in the way that a section of the NHS works. Although such changes can't be made overnight, the NHS is working to put all the guidance recommendations into practice.

The key recommendations from the head and neck cancer service guidance are summarised in the following sections. More information on these and the other recommendations is given in the full version of *Improving Outcomes in Head and Neck Cancers*, which is available from the NICE website (www.nice.org.uk) or from the NHS Response Line (see page 4). The full report also includes a summary of the evidence that was considered when the recommendations were being prepared.

Although service guidance does sometimes refer to appropriate forms of investigation and treatment, it doesn't provide detailed information on these areas. More detailed information on investigations and treatment for head and neck cancers can be obtained elsewhere (NHS Direct Online, www.nhsdirect.nhs.uk, is a good starting point, with links to other sources of information on head and neck cancer). People with concerns about their own health should contact their GP or cancer team.

Head and neck cancer

Head and neck cancer is a general name for many different, but uncommon forms of cancers. They include cancers of the mouth, lip or tongue (oral cancers), or the upper parts of the throat (larynx and pharynx). Head and neck cancers also include some rare forms of cancer such as cancers of the salivary gland, nose, sinuses, and middle ear, and cancers of the nerves and bones of the head and neck.

The guidance also covers cancer of the thyroid (a gland in the neck that produces hormones that regulate metabolism). Cancer of the thyroid is quite rare and is unlike the other cancers discussed, so it is considered separately in some parts of this document.

Skin cancers, sarcomas and brain tumours are not covered by the head and neck cancer guidance (NICE is developing separate guidance for these). Likewise, the guidance does not cover lymphoma, a cancer of the lymph nodes that can cause lumps in the neck, because NICE has made separate recommendations for services for this type of cancer *(Improving Outcomes in Haematological Cancers*[1]*).*

Treatment for head and neck cancers is most successful if they are diagnosed and treated early. Most head and neck cancers are treated with surgery to remove the tumour, or with radiotherapy (treatment using x-rays), or both. Chemotherapy (treatment using cancer medicines) isn't usually used alone for these cancers but may sometimes be used in combination with radiotherapy (this is called chemo-radiation).

Patients may need plastic or reconstructive surgery for damaged areas, or specialised dentistry after the tumour has been treated. After radiotherapy and/or surgery, people may have difficulty with eating, drinking and talking, and some may also need to cope with facial disfigurement. Treatment

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[1] Available on the NICE website (www.nice.org.uk).

for some types of head and neck cancer may involve removing the voice box (larynx); if this is the case, the person has to breathe through an opening in the neck (stoma) and may need to learn to communicate in new ways.

Key recommendations

Cancer networks should decide which hospitals will diagnose, treat and care for patients

National Health Service (NHS) cancer services in hospitals and the community are organised into networks (called cancer networks). These bring together various health services, voluntary organisations and local authorities.

NICE recommends that the cancer networks should decide which hospitals in their area should diagnose, treat and care for patients with different types of head and neck cancer. In the future, most patients with head and neck cancer will be assessed and treated in specialist cancer centres, which will each serve a population of over 1 million.

Multidisciplinary teams should be responsible for every patient

A multidisciplinary team consists of healthcare professionals with all the relevant skills, knowledge and experience related to a particular area of healthcare. A multidisciplinary team is needed because the diagnosis, treatment and care of a person with head and neck cancer can be complex and requires input from a variety of specialist healthcare professionals.

NICE recommends that everyone with head and neck cancer should be cared for by a multidisciplinary team. These teams will be responsible for assessing patients, for planning treatment, and for the patients' care. Specialised teams should care for people with thyroid tumours, or other tumours that are rare or difficult to treat (see right).

For the more common forms of head and neck cancer, each multidisciplinary team should care for at least 100 new patients each year. For less common forms such as thyroid cancer or other rare cancers, multidisciplinary teams will serve a population of over 1 million. This is so that the team members treat enough patients each year to keep their skills up to date.

Specialised multidisciplinary teams should care for people with some rare or difficult tumours and with thyroid cancer

There should also be special multidisciplinary teams to provide treatment for patients whose cancers are rare or present particularly challenging problems, such as salivary gland tumours and tumours at the base of the skull. The specialists needed in these teams will depend on the type of cancer.

People with thyroid cancer should be cared for by thyroid cancer multidisciplinary teams. These should be either:

- head and neck cancer teams that include experts in endocrine medicine (treatment of disorders of hormones and the glands that secrete them), **or**
- specialised endocrine cancer teams.

The roles of the teams

The multidisciplinary teams are responsible for assessing patients' needs and working with them to plan their treatment and care. They also provide support and advice to local healthcare professionals caring for patients away from the centre where the multidisciplinary team is based.

Surgery should be performed by surgeons who are members of the multidisciplinary team and carried out in a hospital that has a specialised head and neck ward. But for patients with small, localised mouth or throat tumours, surgery may be done by surgeons who are part of the multidisciplinary team in hospitals that do not have a specialised ward.

Who should be in the teams

The NICE guidance gives details of the types of healthcare professionals that should be included in all head and neck multidisciplinary teams and all thyroid cancer multidisciplinary teams. These include surgeons and doctors who specialise in treating cancer with drugs or radiotherapy, specialist nurses and dentists, and support staff to organise team meetings and keep records. Patients with rare head and neck tumours or other problems may require care from additional specialists who should join the team when necessary.

In each thyroid cancer team there should be one member who is qualified to give treatment with radioiodine (radioactive iodine), which may be used after the thyroid gland is removed to destroy any remaining cancer cells.

The teams should normally meet every week to discuss the treatment and care of their patients.

Clear systems should be in place for patients to be seen quickly by specialists

When patients first see their doctor, it is not usually obvious that they have cancer. Most patients are first referred to a local hospital or clinic. If cancer is found or strongly suspected, which occurs in the minority of patients, the patient should be referred from there to a specialist cancer centre.

Patients with head and neck cancer tend to do better if they are treated as soon as possible, so clear systems should be in place within each cancer network for patients to be seen quickly by specialists. Doctors, dentists and other healthcare professionals who may see patients with symptoms that could be caused by head and neck cancer should understand these arrangements.

Patients with certain defined symptoms of head and neck cancer should be referred urgently to a specialist head and neck doctor at a local district hospital. Patients with a neck lump should be referred to a lump assessment clinic, which should be made available by cancer networks for rapid diagnosis and referral. If cancer is found then the patient should be referred straight to the appropriate multidisciplinary team. Patients with certain defined symptoms of thyroid cancer should be referred directly to the thyroid multidisciplinary team.

Support services should be available to all patients who need them

Staff providing specialist services have a crucial role in the care and support of patients. Nurses, speech and language therapists, dietitians, and specialist dentists can provide information and discuss treatment options with patients. This can help patients to participate fully in their care and decision-making. Other specialist services needed during patients' assessment, treatment and rehabilitation, such as psychological, psychiatric and counselling services, should be provided.

Clinical nurse specialists

A clinical nurse specialist (CNS) is a nurse with specialist training and experience in a particular area. They can provide psychological and social support for patients and their families, and are involved in the coordination of the patient's care.

The CNS should also work closely with the other members of the multidisciplinary team to ensure that the patient's individual situation and concerns are considered in the planning and management of their care.

NICE recommends that patients should have access to a named head and neck CNS throughout the course of their disease, and all patients should be offered the opportunity to see a CNS before decisions about their treatment and care are made. Patients and carers should be able to contact their CNS if they have questions, or need help coping with their disease or its consequences. The CNS should be available to provide support when necessary, which may be for some time after a patient leaves hospital.

Speech and language therapists

Treatment for head and neck cancer can cause difficulties with speaking, eating or swallowing. These difficulties may occur following radiotherapy, or after face or mouth surgery such as the removal of the voice box (larynx). Patients who have these difficulties should have access to a speech and language therapist and to specialist equipment when it is needed.

Dental services

During their care, many people with head and neck cancer have problems with their teeth, face and mouth. This may be a result of the cancer itself or of the surgery or radiotherapy used to treat it. Specialist dental services may be required before or after treatment, especially when radiotherapy is involved, and should be available to patients if they need them. A consultant with appropriate experience should coordinate the dental care of patients.

Nutrition and dietetic services

Patients who need information about their diet before, during and after treatment should have access to a dietitian with specific expertise in dealing with head and neck cancer. The dietitian can provide patients with support and advice about how to maintain a good diet while coping with the after-effects of treatment. Sometimes the effects of the cancer or the treatment mean that the person has to be fed through a tube. If this happens, dietitians have an important role in providing information and support.

Local support teams should provide long-term support in the community

Every cancer unit or cancer centre should set up local support teams to manage the care of patients after they have left hospital. Depending on the needs of the individual patient, members of the local support team may include: a clinical nurse specialist, a speech and language therapist, a dietitian, a dental hygienist, a physiotherapist, an occupational therapist, a social worker, a psychologist, a psychiatrist, and a counsellor. Other local patients who have experience of cancer services and who are willing to provide support may also be a part of the team.

Local support teams should work closely with the other services involved at every level of patients' care. They should have access to local services necessary to provide long-term support and address the rehabilitation needs of the patient. A specific member of the local support team should coordinate the care of each patient.

Patients and their carers should be given information about wound, mouth and tooth care. Those who have surgery should be shown how to live with any changes that result from the procedure. This may include the management of stomas that have been added during surgery to assist with eating and breathing. They should be given contact numbers for the local support team who can help them with any problems.

Information should be collected

Multidisciplinary teams should make sure that information about patients' disease, treatments and outcomes is recorded. This information is needed to evaluate and improve services for patients with head and neck cancer.

More research should be done

More research is urgently needed on the management of head and neck cancers to improve the care of patients. The multidisciplinary teams should be involved in relevant studies, and where appropriate patients will be invited to take part in clinical trials using new treatments.

Further information

It's important to remember that your local services may be a little different from those described here – the NICE guidance sets out the way in which the head and neck cancer services should develop over the coming years.

If you have any questions about your health or the health of a member of your family or a friend, speak to your GP. If you, or a friend or relative, have a head or neck cancer and you have questions about the information here, or about treatment and healthcare in general, talk to a member of your head and neck cancer team. In addition, further information on head and neck cancer (including the signs or symptoms of head and neck cancer) and support groups is available from NHS Direct (which you can access on the Internet at www.nhsdirect.nhs.uk or by telephone on 0845 46 47).

NICE has also issued guidance on supportive and palliative care services for adults with cancer, which includes recommendations about issues such as communication and the types of support services people should be offered. Further information is available from the NICE website (www.nice.org.uk); copies of the information for the public are available from the NHS Response Line (telephone 0870 1555 455 and quote reference number N0476).

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Copies of this document are available from the NICE website or from the NHS Response Line (telephone 0870 1555 455 and quote reference N0745). The Guidance manual, *Guidance on Cancer Services – Improving Outcomes in Head and Neck Cancer: Manual Update* (reference N0758) and a CD with all documentation including the research evidence on which the guidance is based (reference N0759) are also available.

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