



Healthcare services for haematological cancers

Introduction

The National Institute for Clinical Excellence (known as NICE) has issued guidance for the NHS in England and Wales on the organisation of healthcare for people with haematological cancers (cancers of blood cells).

This type of guidance is called ‘service guidance’. It recommends which healthcare professionals should be involved in treatment and care, and the facilities such as hospitals best suited to provide that healthcare. It’s important to appreciate 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 six key recommendations from the haematological 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 Haematological Cancers (the Manual)*, and this is available from the NICE website (www.nice.org.uk). The full report also includes a summary of the evidence that was considered when the recommendations were being prepared. The full research evidence is also available.

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 haematological 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 haematological cancers). People with concerns

about their own health should contact their GP or cancer team.

Haematological cancer

Haematological cancer (cancer of blood cells) is a general name for three main types of cancer:

- leukaemia
- lymphoma
- myeloma.

There is great variation in the way these diseases show themselves, and in their severity. Some haematological cancers quickly produce unpleasant symptoms; others cause few or no symptoms and are found only by chance, for example following a blood test. Haematological cancers can affect people of all ages, but most become more common as people get older. Specific symptoms can include: lumps (often in the neck), which are typical of lymphomas; bone pain, often in the back, and kidney problems, which are characteristics of myeloma; and fatigue and vulnerability to infection, which can result from most types of haematological cancer but are particularly severe in acute leukaemia.

Key recommendations

People should be treated by a multidisciplinary team

The NICE cancer service guidance recommends that every patient with leukaemia, lymphoma or myeloma should be cared for by doctors and nurses

who are part of an appropriate multidisciplinary team. This brings together people with all the necessary skills, knowledge and experience. A multidisciplinary team is necessary because the diagnosis, treatment and care of a person with haematological cancer can be very complex. There are many sub-types of the diseases (this is particularly so for the leukaemias and lymphomas) and each patient must receive care tailored to suit his or her particular condition.

Where the teams should be based

It is very important to have the right combination of skills in the haematological cancer teams, and for them to see enough patients with the different disease types to keep these skills up-to-date. Each team should serve an area that has at least 500,000 people in it. If a hospital serves an area with a smaller number of people, or does not have the right specialists to form a particular type of team, then it may combine with other hospitals to form the multidisciplinary teams. All hospitals contributing to a multidisciplinary team are likely to provide outpatient treatments (treatment patients can receive and then go home), and some inpatient care (for which patients need to stay in hospital). However, not all the hospitals covered by the team will provide the most intensive types of inpatient treatment. So some patients may need to visit more than one hospital to receive the right care.

The teams should hold regular meetings to discuss the treatment and care of each patient for whom they are responsible.

Who should be in the teams

The NICE guidance says that the multidisciplinary teams should include enough core members for the following people to be present at every meeting to discuss an individual patient's care.

- **Haemato-oncologists** (doctors who specialise in investigating and treating cancer of blood cells and bone marrow) – at least two should specialise in the tumour type being discussed at the meeting (for example, leukaemia or lymphoma); when hospitals combine to form a team, at least one haemato-oncologist from each hospital should be present at the meeting.

- A **haematopathologist** (a doctor who specialises in diagnosing diseases of the blood and bone marrow by looking at samples of body tissues).
- **Nurses** – including at least one clinical nurse specialist who has been trained to provide support and information for people with haematological cancer.
- A **palliative care specialist** (palliative care is concerned with relieving pain and discomfort).
- **Support staff** – to organise team meetings and provide secretarial support.

As well as the people listed above, a team treating people with lymphoma or myeloma should include a radiologist (a doctor who examines pictures of the body taken using X-rays and other special techniques). And a team treating people with lymphoma should also include a clinical oncologist (who can treat cancer using radiotherapy and with anticancer drugs such as chemotherapy). All of the professionals in a haematological cancer team should regularly diagnose or treat people with the type of haematological cancer the team specialises in. People with haematological cancer sometimes need additional care that will mean other specialists join the team as required.

The roles of the teams

Haematological cancer teams diagnose the precise type of cancer the person has and are responsible for making decisions, with the patient, about the most appropriate treatment and care. These teams also provide most of the treatment. They are responsible for providing ongoing information, advice and support to patients and their families or carers. It is important that the team communicates with the patient's GP and other professionals involved in providing care for that patient, such as doctors who care for elderly people, and voluntary organisations like hospices. This ensures that patients are always cared for by someone who knows their diagnosis and history.

A multidisciplinary team should include a clinical nurse specialist and a palliative care specialist

The role of the clinical nurse specialist

When asked about their care, patients often say that healthcare professionals haven't given them some of the information they want, and do not always explain clearly the likely effects of treatment on people's lives. Clinical nurse specialists can improve this situation by making sure that support and information are available for people with haematological cancer. They have special training in how to communicate effectively with people about their cancer. NICE recommends that from the time of diagnosis, each patient should be able to talk to a specific clinical nurse specialist who can give support and counselling and help to ensure that the patient receives good continuity of care.

NICE also recommends that a clinical nurse specialist should be a full member of each haematological cancer team, to encourage other members of the multidisciplinary team to think about treatment from the patient's point of view.

The role of the palliative care specialist

Throughout a person's illness and treatment for haematological cancer, one of the important aspects of care and support is controlling the symptoms – such as discomfort or pain – that may be caused by the disease or its treatment. This is called palliative care. For some patients the time may come when trying to cure the cancer is no longer helpful (and may cause greater distress), and supportive and palliative care becomes the main option. Quality of life for a person with haematological cancer can be greatly improved by making this decision to move to supportive and palliative care at the right time, although patients, their families or carers, and their doctors may find this difficult.

To make sure that people with haematological cancer benefit as much as possible from palliative care, NICE recommends that a palliative care specialist (doctor or nurse) should be a full member of all haematological cancer teams. Palliative care teams should also be organised in local hospitals and in the community, so that they can easily help people with all types of cancer, including haematological cancer, who are at home, in a hospice, or in hospital.

Each diagnosis of haematological cancer should be reviewed by experts

Because an accurate and full diagnosis is so important to the teams treating patients with haematological cancers special arrangements are proposed. To confirm a diagnosis of haematological cancer, further specialist tests often have to be carried out. They can be technically very complicated and difficult to do reliably, and errors are possible. In order to avoid errors, NICE recommends that pathology tests (tests on samples of body tissue) to confirm a diagnosis of haematological cancer should be examined by staff who specialise in these methods. These experts are usually based in recognised centres where they can look at the results of the specialist tests, together with information from the initial tests, and reach a clear diagnosis. Studies have shown that expert review of pathology test results increases the number of accurate diagnoses and provides a better guide as to how the cancer should be treated.

People with neck lumps should have rapid access to diagnostic services

Lumps in the neck, armpit or groin are common and are often caused by an infection. Only a few people with such lumps have cancer, so GPs may not always refer patients with these symptoms quickly. NICE recommends that anyone with an unexplained lump that has lasted for more than 6 weeks, and that is not obviously due to an infection, should have a sample of blood sent to a laboratory for testing and be referred to a doctor who specialises in investigating such lumps (usually a haematologist), or to a lump clinic (see below), within 2 weeks.

A lump clinic is a one-stop clinic that investigates isolated lumps in the neck or armpit (and sometimes lumps that occur in other places in the body). These clinics may be staffed by haematologists, ear, nose and throat specialists, head and neck cancer specialists, and surgeons. Where lump clinics already exist, patients and GPs say that they are happy with this service, which allows all the initial investigations to be carried out in a short time. Studies suggest that referral to a lump clinic results in a diagnosis being reached more quickly.

Once people are diagnosed as having haematological cancer, they should be referred without delay to the right multidisciplinary team.

Complex chemotherapy for acute leukaemia should be carried out by specialist teams

Treatment for acute leukaemia is often complicated and demanding for staff as well as patients. People with acute leukaemia require intensive treatment and support and may need to stay in hospital for several weeks or months. Both the treatment and the disease reduce a person's resistance to infection, which puts patients at serious risk. Some complications need very rapid care and attention. Because of this, NICE recommends that this type of intensive treatment for acute leukaemia should be given only in hospitals that are large enough to form their own leukaemia team, and have the right facilities and skilled staff available day and night. Facilities should include special measures to reduce the risk of infection. Specialist units that treat five or fewer new patients with acute leukaemia each year are unlikely to be able to provide all the facilities and expertise needed.

High-dose therapy and transplantation should be carried out in accredited centres

In order to treat particular types of disease, a small number of people with haematological cancer need very high doses of drugs – doses that would stop the bone marrow making new blood cells. This type of treatment puts the patient's life at risk from complications such as bleeding and infection.

The risk of these complications can be reduced if patients are given a bone marrow transplant so that they can make healthy blood cells again.

NICE recommends that high-dose therapy and bone marrow transplantation should be carried out only in specialised centres that meet very strict accreditation standards. These include the necessary staffing and facilities suitable for this work. The accreditation standards are described in full on the website of the European Group for Bone Marrow Transplantation (www.ebmt.org). Successful transplantation needs skill and experience, and the standards state that a bone marrow transplant centre must carry out at least ten bone marrow transplants each year.

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 that the haematological cancer services should develop over a number of years. Implementing these changes will take time.

If you have any questions about your health, or the health of a friend or relative, speak to your GP. If you or a friend or relative has a haematological cancer and you have questions about the information here, or about treatment and healthcare in general, talk to a member of the haematological cancer team. Further information is also available from NHS Direct (call 0845 46 47 or go to the NHS Direct website, www.nhsdirect.nhs.uk).

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Copies of this document can be obtained from the NHS Response Line by telephoning 0870 1555 455 and quoting reference N0328. The full guidance, reference N0327, has also been published and a CD with all documentation including the research evidence on which the guidance is based is available, reference N0329

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