



Healthcare services for children and young people with cancer

Understanding NICE guidance – information for the public

Introduction

The National Institute for Health and Clinical Excellence (also known as NICE) has issued guidance on how healthcare services for children and young people with cancer should be organised. 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 is important to remember that many service guidance recommendations made by NICE require large-scale changes in the way that sections of the NHS work. Although such changes cannot be made overnight, the NHS is working to put all the NICE guidance recommendations into practice.

The key recommendations from the guidance on improving care for children and young people with cancer are summarised in the following sections. More information on these and the other recommendations is given in the full manual, *Improving Outcomes in Children and Young People with Cancer*, which is available from the NICE website (www.nice.org.uk) or from the NHS Response Line (see page 4). This also includes a summary of the evidence, which included evidence from patients and carers, that was considered when the recommendations were being prepared.

Although NICE cancer 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 different kinds of cancer in children and young people can be obtained elsewhere. NHS Direct Online (www.nhsdirect.nhs.uk) is a good starting point, with links to other sources of information on cancer in children and young people. People with concerns about their own or their child's health should contact their GP.

Caring for children and young people with cancer

NICE has developed guidance on the healthcare that should be provided to children and young people with cancer. NICE recognises that the needs of children and young people with cancer are different from those of older adults with cancer. For example, during childhood and adolescence, physical changes occur that may affect the type of cancer present, how it needs to be treated, and how well the treatment works. Children and young people also undergo psychological changes that may influence their emotional response during and after treatment.

The aim of this guidance is to ensure that children and young people with cancer get the best possible care and the care that is most appropriate for their age.

Good communication between patients, their families and healthcare professionals is important: it can promote better care and support and reduce stress for patients and families.

It is rare for children and young people to get cancer. Many of the symptoms of cancer in young people are non-specific; this means that they could be caused by a number of different conditions. However, if you are concerned about your own or your child's health, talk to your GP.

Key recommendations

Care should be coordinated across the whole of the NHS and be available as close to the patient's home as possible

Services should be organised across the whole healthcare system to ensure that all children and young people with cancer have access to the safest and most effective treatments as close to their home as possible. Facilities and support should be appropriate to the child's or young person's age. All local options for treatment provision should be considered, including hospitals and community-based healthcare services. However, the best treatment may not be at the nearest hospital but in a cancer centre that has the facilities and expertise that are needed. Cancer networks should play a key role in organising the services (see below).

Cancer networks should ensure that they meet the needs of children and young people with cancer

In the NHS, cancer networks have been set up to organise healthcare for adult patients with cancer. These networks bring together the services offered by hospitals and in the community, including those provided by voluntary organisations and local authorities.

Many of these networks have not yet addressed the special needs of children and young people with cancer. So NICE has made recommendations about how cancer networks can better serve this group of patients throughout their treatment and long-term follow-up. As cancer networks develop at both the local and national level, NICE recommends that they should work in partnership with services for children and young people to ensure that the needs of this group of patients continue to be met.

NICE recommends that cancer networks should do the following.

- Make sure the way services are organised is clear, and that each cancer network has someone (called a 'network lead') who is responsible for the services for children and someone who is responsible for the services for young people.
- Identify their main centres, such as hospitals or clinics, for treating different types of cancer in children and young people.
- Ensure that the ways children and young people are referred to treatment centres are clear.
- Ensure that all aspects of care are carried out by staff who have had appropriate training.

- Ensure that there are guidelines for referring children and young people to centres outside the local area, if appropriate treatment is not available within their area.
- Agree arrangements in writing when more than one centre cares for a child or young person with cancer (this type of arrangement is known as 'shared care').
- Ensure that all relevant national guidance is followed; this includes guidance issued by NICE, the Department of Health and other organisations.
- Ensure that all places that offer NHS cancer treatment for children and young people have their performance reviewed by experts working at other hospitals or centres.

Multidisciplinary teams should provide cancer care

A multidisciplinary team (MDT) consists of healthcare professionals with all the relevant skills, knowledge and experience related to a particular area of healthcare. An MDT is needed because the diagnosis, treatment and care of a child or young person with cancer can be complex and require input from a variety of specialist healthcare professionals.

The make-up of the MDT will depend on what type of cancer the child or young person has, what type of care he or she needs, and what stage of treatment he or she is at. For example, if the cancer has already been diagnosed and someone is having treatment, the team may include the cancer specialist doctor who is treating the child or young person (also called a 'paediatric oncologist' or 'paediatric haematologist'), specialist nurses, a specialist pharmacist and a key worker (see next recommendation). There will be many others on the team as well.

NICE specifically recommends that centres caring for teenagers ensure that team members understand some of the particular difficulties that can arise when communicating with patients in this age group.

NICE also recommends that the role of each member of the team is clearly defined and that decisions about treatment are written down and made available to all team members. If more than one team is involved in a child's or young person's care, information should be shared regularly.

Patients, families and carers should be involved in decisions about treatment and care for children and young people at all stages and should have access to the information they need to share in decision-making. Information should be provided in a format that suits their needs. Patients, families and carers who are able and want to contribute to the patient's care should receive appropriate support and training.

Each child or young person with cancer should have a key worker

Each child or young person with cancer and their family should have a key worker to coordinate care, provide information, assess their needs and provide emotional and practical support. This support should include liaison with organisations that provide social care and rehabilitation and with schools and colleges to ensure that educational needs are met. The key worker should ensure that there is a written care/treatment plan that the patient and their family and carers have agreed to and have access to.

A key worker may be a nurse, a doctor who specialises in treating children with cancer or another member of the care team. The key worker may change from time to time, depending on the stage of treatment and the needs of the child or young person.

Treatment for cancer and follow-up care may last a long time, over which a child's or young person's physical and emotional states may change, not only as a result of having cancer but also as a natural part of growing up. Key workers should be able to help the child or young person and their family adjust to these changes and access appropriate support services and follow-up care.

Care should be appropriate to the child's or young person's age and type of cancer

NICE recommends that children and young people who may have cancer should have their care managed by a principal treatment centre that can provide the range of healthcare services they need.

For children, the principal treatment centre should usually be one of the specialist centres known as the 'United Kingdom Children's Cancer Study Group' treatment centres. A multidisciplinary team from the principal treatment centre should organise the child's care.

For teenagers and young adults, NICE recommends that there should be designated principal treatment centres. Young people should be cared for by teams that not only have expertise in treating the cancer but also have the experience necessary to respond to the needs of teenagers and those of their families.

Because there are not many principal treatment centres, the child or young person may have to travel some distance to get to one. NICE recommends that, when appropriate, children or young people should be seen for some treatment and follow-up visits at a centre close to their home, such as a local hospital (this is known as shared care).

All health professionals at centres that care for children or young people with cancer must understand the specific needs of this group of patients. These include their social, developmental and emotional needs as well as their educational needs.

Sometimes a child or young person will have to be referred for some of their treatment to a specialist unit that has expertise in treating a particular type of cancer or providing a particular type of treatment, but that does not specialise in treating children or young people. If this happens, it is important that the specialist unit works in partnership with a centre that can provide care appropriate for the age of the child or young person.

Time in the operating theatre and a children's anaesthetist should be available when needed

Children and young people with cancer may need surgery (for example, to diagnose the type of cancer or to treat it). There should be enough resources at a centre treating children or young people to provide all of the types of operations or anaesthetic services that may be needed, although some specialised operations may need to be done elsewhere. There should also be enough resources to provide a specialist children's anaesthetist when necessary for a child who is having painful procedures or radiotherapy (treatment with X-rays or similar rays). (For example, without anaesthesia a child may not be able to lie still enough for radiotherapy to be delivered accurately to a specific site.)

Most of the time, emergency surgery is not needed but, when necessary, a surgeon who specialises in caring for children or young people with cancer should have access to an operating theatre to carry out an emergency operation during normal working hours.

Children and young people with cancer should be offered the chance to take part in research trials

Research trials (or studies) are important for finding out which treatments work best. Good-quality research trials cannot be carried out successfully if there are not enough patients taking part in them, so NICE recommends that all children and young people should be offered the opportunity to take part in research trials that are appropriate for them. All new treatments should be offered as part of a research trial. Patients should be given appropriate information so that they can choose whether or not to take part in a research trial. NICE also recommends that sufficient resources should be available for the research to be carried out.

Treatment should be based on agreed protocols

If a child or young person is not receiving treatment as part of a clinical trial, then the treatment given should be based on agreed 'protocols' (agreed procedures and methods of providing treatment and care). These protocols set out the best way of caring for children or young people with different types of cancer. Sometimes a doctor may choose to treat a teenager or young adult using a protocol for adults, but at other times a protocol for children may be better. The doctor should involve the patient in the decision-making process and choose the best protocol based on the evidence. NICE recommends that the outcome of treatment and care should be monitored and assessed, so that the information collected can be used to find ways of improving healthcare services for children and young people with cancer.

A register of all cancers in people aged 15–24 should be urgently considered

One way in which the NHS can improve services and make better plans for treating patients is by collecting information on cases of cancer in children and young people. This process is known as 'registration of a disease'. At the moment, there is a national registry of cases of cancer that occur in people aged under 15, but there is no similar registry for young people aged 15 and over. NICE recommends that national experts should be asked to consider whether a special register of cases of cancer in people aged 15–24 should be set up.

Cancer networks should ensure there are sufficient specialist staff

When planning services, cancer networks should ensure that enough specialist healthcare professionals are available to provide the care needed by children and young people with cancer. Appropriate education and training should be available for staff working with children and young people and their families.

Allied health professionals, who provide services such as physiotherapy, play therapy and speech and language therapy, can have an important role in a child's or young person's care. However, there is a shortage of staff in some of these fields and NICE says that steps must be taken to remedy this. NICE also recommends that the part that allied health professionals play in the care of children and young people with cancer should be evaluated.

Further information

It is 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 cancer services for children and young people 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 child or young person in your family has cancer and you have questions about the information here, or about treatment and healthcare in general, talk to a member of your cancer team. In addition, further information on cancer in children and young people (including the signs or symptoms of 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).

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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 N0899). The Guidance manual, *Improving Outcomes in Children and Young People with Cancer* (reference N0897), and a CD with all documentation including the research evidence on which the guidance is based (reference N0898) are also available.