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[Logos: NHS
National Institute for Clinical
Excellence]

[Information for the public]

Healthcare services for children and young people with cancer

[Note: this version of the IFP is based on the key recommendations in the second draft for consultation.]

**The paragraphs are numbered for the purposes of consultation.
The final version will not contain numbered paragraphs.**

Understanding NICE guidance – information for the public

Introduction

1. The National Institute for Clinical Excellence (also known as NICE) has issued guidance on organising healthcare services for children and young people with cancer. 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'.

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2. 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.
3. **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 version of *Improving Outcomes in Children and Young People with Cancer*, which is available from the NICE website (www.nice.org.uk) or from the Department of Health Publications Order Line (see page 4). The full report also includes a summary of the evidence, which included evidence from patients and carers, that was considered when the recommendations were being prepared.
4. 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 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 or cancer team.

Caring for children and young people with cancer

5. 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 young people undergo physical changes, and these may affect which type of cancer they have, how it needs to be treated, and how well treatment works for them. Children and young adults also undergo psychological changes, and these may influence how treatment affects them emotionally at the time they are having it as well as in the long term.

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6. 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.
7. 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 [extrapolated from p. 33].

[Above information taken from pp. 6, 9, 10, 12, 32]

Key recommendations

8. ***Care should be coordinated across the whole of the NHS and be available as close to home as possible*** [Para 6, 1st key recommendation]
9. 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 and care appropriate to their age. All local options for treatment should be considered, including hospitals and community-based 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).

[p.105, 136 + 2nd key rec (first bullet point)]

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10. ***Cancer networks should ensure that they meet the needs of children and young people with cancer*** [Para 7, 2nd key recommendation]

11. In the NHS, cancer networks have been set up to organise healthcare for 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.

12. NICE recognises that 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. These recommendations seek to ensure that the needs of children and young people continue to be met as cancer networks develop both at the local level and at the national level.

13. NICE recommends that cancer networks: [pp. 136-8]

- 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, teenagers and young adults
- identify their main centres for treating different types of cancer in children and young people
- make certain that the pathways for referring children and young people 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 the area
- agree arrangements in writing for instances in which 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

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- ensure that the performance of all places in the NHS that offer cancer treatments for children and young people is reviewed by experts working at other hospitals or centres.

14. ***Multidisciplinary teams should provide cancer care*** [Para 8, 3rd key recommendation]

15. A multidisciplinary team (MDT) 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 child or young person with cancer can be complex and require input from a variety of specialist healthcare professionals.

16. The make-up of the MDT will depend on what type of cancer the child or young person has and what type of care he or she needs. For example, if the cancer has already been diagnosed and someone is having treatment, the team may include not only the cancer specialist who is treating the child or young person (called the 'treating oncologist') but also specialist nurses, a specialist pharmacist and a key worker (see next recommendation). There will be many others on the team as well.

17. NICE specifically recommends that centres caring for teenagers ensure that team members understand the communication issues that are specific to patients in this age group.

18. 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 and carers should be involved in decisions about treatment and care at all stages. [from pages 107–11, page 139]

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19. ***Each child or young person with cancer should have a key worker*** [Para 9, 4th key recommendation]
20. 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 ensuring that educational needs are met, for example through liaison with schools and colleges. The key worker should ensure that there is a written care/treatment plan and that the patient and their family and carers have access to it. A key worker may be a nurse, a doctor who specialises in treating children with cancer (known as a 'paediatric oncologist') or another member of staff who is part of the care team. A key worker may change from time to time depending on the stage of treatment and the needs of the child or young person.
21. Treatment for cancer 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. [pp. 114-6; p 139, para 614]
22. ***Care should be appropriate to the child's or young person's age and type of cancer*** [Para 10, 5th key recommendation]
23. NICE recommends that children who may have cancer should undergo tests at a principal treatment centre. 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 or young person's care – although sometimes one of these centres may not be the best place for a child to be seen and he or she will be referred elsewhere. Because there are not many of these centres, the child or

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young person may have to travel some distance to get to one. NICE recommends that when possible, 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.

24. 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 and emotional needs as well as their educational needs.

25. 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. [pp.122–132]

26. ***Time in the operating theatre and a children's anaesthetist should be available when needed*** [Para 11, 6th key recommendation]

27. Children and young people with cancer may need surgery not only to treat the disease itself but also, for example, to diagnose the cancer or to give other types of care. 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. There should also be enough resources to provide an anaesthetist when necessary for a child who is having painful procedures or radiotherapy (treatment with x-rays or similar rays). (For example, a child may not be able to lie still while treatment is going on and so it would not be possible to direct the x-rays accurately at the site being treated.)

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

[pp. 49-50, 37-41, 57 and others]

29. ***Children and young people with cancer should be offered the chance to take part in research trials*** [Para 12, 7th key recommendation]

30. Research trials (or studies) are important for finding out which treatments work best. Good quality clinical 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 clinical trial. NICE also recommends that sufficient resources should be available for the research to be carried out. Sometimes it will not be possible for a child or young person to take part in a research trial – for example, there may not be one looking at their particular form of cancer or for people in their age group – or they may not want to take part.

31. [pp.144–6]

32. ***Treatment should be based on agreed protocols*** [Para 13, 8th key recommendation]

33. 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 sometimes a protocol for children may be better. The doctor should choose the best

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protocol based on the evidence. NICE recommends that the outcomes of treatment and care should be monitored and assessed, so that the data collected can be used to find ways of improving healthcare services for children and young people with cancer. [pp.119–20]

34. ***A register of all cancers in people aged 15–24 should be considered*** [Para 14, 9th key recommendation]

35. 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 older. 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.[pp.13–14, 151]

36. ***Cancer networks should ensure there are sufficient specialist staff*** [Para 15, 10th and 11th key recommendations]

37. When planning services, cancer networks should ensure that there are enough specialist healthcare professionals 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. [p.148-9]

38. Allied health professionals provide services such as physiotherapy, play therapy and speech therapy. They 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 these allied health professionals play in the care of children and young people with cancer should be evaluated. [pp.28-9, 148-9]

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Further information

39. 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 cancer services for children and young people should develop over the coming years.

40. 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).

National Institute for Clinical Excellence
MidCity Place
71 High Holborn
London WC1V 6NA

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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, *Improving Outcomes in Children and Young People with Cancer* (reference [XXX]) and a CD with all documentation including the research evidence on which the guidance is based (reference [XXX]) are also available.

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