

[Information for the public]

Improving outcomes for people with sarcoma

Cancer service guidance

Understanding NICE guidance – information for the public

The paragraphs are numbered for the purposes of consultation.

The final version will not contain numbered paragraphs.

**The page and paragraph cross references are to the second
consultation draft of the manual**

Introduction

1. The National Institute for Health and Clinical Excellence (also known as NICE) has issued guidance on how healthcare services for people with sarcoma 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’.
2. 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.
3. **The key recommendations from the cancer service guidance on improving outcomes for people with sarcoma are summarised in the following sections.** More information on these and the other recommendations is given in the full manual, *Improving Outcomes for People with Sarcoma*, which is available from the NICE website (www.nice.org.uk) or from the NHS Response Line (see page XX). 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 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 sarcoma can be obtained elsewhere. NHS Direct Online (www.nhsdirect.nhs.uk) is a good starting point, with links to other sources of information on sarcoma. People with concerns about their own health should contact their GP.

Sarcoma

5. Sarcomas are a rare group of cancers that arise in the body's 'connective tissues'. Connective tissues include bone, cartilage, fat, blood vessels, nerves and muscles. Sarcomas can be broadly divided into those of bone and those of soft tissues (tissues such as muscle, fat or blood vessels that support, surround or protect the organs of the body). [para 28]
6. Bone sarcomas include types known as osteosarcoma, chondrosarcoma, Ewing's sarcoma and spindle cell sarcoma.
7. There are many different types of soft tissue sarcoma. Some occur in the limbs and others develop in tissues in the chest, abdomen or pelvis, or, more uncommonly, in the head and neck. [paras 54–58]
8. Although they are related, bone and soft tissue sarcomas require quite different types of treatment. [para 15] In addition, the needs and experiences of people with sarcoma vary widely depending on which part of the body is affected. [para 78]
9. The aim of this guidance is to ensure that people with sarcoma get the best possible care and the care that is most appropriate for their age.
10. 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. NICE recommends that patients should be provided at all stages with information, in a form appropriate to their age and needs.

Key recommendations

Prompt expert diagnosis is crucial [para 4]

11. As with other cancers, the earlier sarcoma is diagnosed the better the chances of successful treatment. NICE believes that the key to improving care is rapid referral for assessment, diagnosis and, if sarcoma is diagnosed, treatment at a specialist sarcoma treatment centre. (There is more about sarcoma treatment centres in the next section.) [para 20]
12. Because sarcoma is so rare, most non-specialist doctors will see only a few cases in their working lifetime. It is particularly important that GPs and non-specialist hospital doctors are aware of the signs of possible sarcoma and of where to send patients for further investigation. [para 141] They should follow the recommendations in the NICE guideline on referral for suspected cancer (see 'Further information' at the end of this document). [para 140, 141]
13. To reduce delays in diagnosis, NICE recommends that people whose symptoms may indicate sarcoma should be seen at designated diagnostic clinics or a sarcoma treatment centre.
14. If a soft tissue sarcoma is suspected, the patient should be referred to a diagnostic clinic at, or linked to, a sarcoma treatment centre. [paras 4, 142] Responsibility for making sure diagnostic centres are available lies with local 'cancer networks'. [para 144] (In the NHS, 'cancer networks' have been set up to organise healthcare for patients with cancer. They bring together the services offered by hospitals and in the community, including those provided by voluntary organisations and local authorities.)
15. If bone sarcoma is suspected, the patient should be referred directly to a bone sarcoma treatment centre for diagnosis, usually after having an X-ray. [para 151]

16. Because sarcoma is sometimes difficult to recognise, NICE recommends that everyone with a provisional diagnosis of sarcoma should have their diagnosis reviewed by a specialist sarcoma pathologist or radiologist (see the next section for more details). [paras 5, 211, 214] It also recommends that organisations commissioning ('buying') healthcare services for diagnosis and treatment of sarcoma should provide funding for a formal system of obtaining second opinions and reviewing difficult cases. [paras 5, 223]

People should be treated by a specialist multidisciplinary team [paras 3, 6, 7, 14]

17. NICE recommends that everyone with a confirmed diagnosis of sarcoma, except children with certain soft tissue sarcomas, should have their care supervised by, or provided in conjunction with, a sarcoma multidisciplinary team (an 'MDT'). [paras 3, 256] An MDT is a group of healthcare professionals who work together to provide the full range of specialist services that patients with a particular condition need. The diagnosis, treatment and care of a person with sarcoma can be very complex, and is best provided by a team with specialist knowledge and experience.

18. It is important that healthcare professionals treating people with sarcoma treat enough patients each year to keep their skills up to date. [para 249] Therefore, NICE recommends that each specialist MDT should see at least 100 new patients with soft tissue sarcoma per year. [paras 6, 257] A sarcoma MDT that treats both bone and soft tissue sarcomas should see at least 50 new patients with bone sarcoma and 100 new patients with soft tissue sarcoma each year. [paras 6, 257]

19. The sarcoma MDT should be based in a sarcoma treatment centre – a single hospital or a group of nearby and closely linked hospitals. [para 259] Because sarcoma is so rare, and members of a sarcoma MDT need to see enough new patients to keep their skills up to date, there

will be quite a small number of sarcoma treatment centres and patients may have to travel long distances to reach one. [para 80]

20. Some types of sarcoma are so rare that not all sarcoma MDTs will have expertise in treating them. NICE recommends that information about the expertise of different MDTs is available within the NHS so that patients can be referred to the best place for treatment. [paras 253, 254]

Who should be in the multidisciplinary team?

21. Each sarcoma MDT should have a named lead doctor (a 'clinical lead') who takes responsibility for the service. [para 260] NICE guidance states that sarcoma MDTs should include at least the following personnel. [tables 5, 6, pages 67–69]

- At least two specialist sarcoma surgeons; these surgeons should spend at least half of their time on sarcoma cases.
- At least two specialist sarcoma radiologists (radiologists are doctors who specialise in the interpretation of images of the body using a variety of imaging techniques).
- At least one (ideally, two) specialist sarcoma pathologist. Pathologists are doctors who analyse samples taken from the suspected sarcoma to determine its type and how advanced it is. Sarcoma pathologists who work alone should have close links with a counterpart at another centre, so that they can get a second opinion on their diagnoses.
- A medical oncologist and a clinical oncologist (at least two). Oncologists are doctors who specialise in treating cancer. Both should spend at least three sessions a week on treating patients with sarcoma.
- For bone sarcoma teams, a paediatric oncologist, because bone sarcoma occurs most often in children.
- Key worker – this can be any member of the MDT but is often a clinical nurse specialising in sarcoma. There should be at least two key workers on the team, but only one needs to be allocated to each patient.

- A palliative care specialist (palliative care is concerned with relieving pain and discomfort to improve a person's quality of life when it is not possible to cure the cancer).
- Support staff to organise the MDT and provide secretarial services.

22. In addition to the core team members listed above, there should be an extended team that includes a physiotherapist specialising in sarcoma and other healthcare professionals such as occupational therapists and orthotists (specialists in medical appliances to help with disability), oncologists and diagnostic specialists from linked cancer centres, and specialist surgeons. There should also be access to counsellors/psychologists and other services such as artificial limb and equipment services.

23. The MDT should meet weekly. They should ensure that each patient has a written care and treatment plan encompassing the whole range of necessary services. The MDT should also make sure that a patient's GP is kept informed about any significant changes to their illness or their treatment. [para 265]

Key workers [para 7]

24. Each person with sarcoma should be allocated a key worker, and should be given the key worker's name and contact details when they are diagnosed [para 92]. The key worker should be a core member of the MDT, often a specialist nurse, and is the contact point for help and support for the person with sarcoma and their carer(s) throughout their treatment. [paras 7, 75, 420, 423] This support should include psychological and spiritual support, access to self-help groups, practical support relating to treatment, and benefits advice. [para 100] The key worker helps coordinate the various aspects of treatment and care, and makes sure the patient has access to the information and advice that they need. Key workers also act as a voice for the patient within the treatment team. If necessary they liaise with care providers in

the patient's local area, such as GPs, community nurses and social services. [para 420]

Making sure MDTs are available for patients [para 14]

25. Primary care trusts (PCTs) in England and local health boards (LHBs) in Wales are responsible for commissioning ('buying') healthcare services for their patients. Because sarcoma is rare, each sarcoma MDT will see people referred to them by doctors working for different PCTs or LHBs. NICE recommends that different PCTs and LHBs should work together to commission MDTs responsible for the diagnosis and treatment of sarcoma. They should do so in close collaboration with cancer networks. NICE also recommends that the Department of Health should consider setting up a national implementation group to ensure the NICE guidance is implemented in England and Wales. [paras 14, 258]

Treatment should be carried out by specialists [paras 8, 9, 13]

26. If sarcoma is diagnosed, the main way of treating it is with surgery (an operation) to remove the tumour. For bone sarcoma, surgery is usually combined with chemotherapy (treatment with drugs). The treatment of soft tissue sarcoma will depend on the type of sarcoma and the part of the body that it is in. As well as surgery, chemotherapy or radiotherapy (treatment with X-rays or other forms of radiation) may be used.

27. NICE recommends that surgery to remove a sarcoma should be carried out by a surgeon who is a member of a sarcoma MDT. Alternatively it should be carried out by a surgeon who specialises in operating on the particular age group of the person with the sarcoma, or the part of the body affected by the sarcoma, working in consultation with the sarcoma team. [para 8]

28. People who need radiotherapy or chemotherapy should receive it at the sarcoma treatment centre or at other designated centres where they

can be treated by appropriate specialists, as recommended by the sarcoma MDT. [paras 9, 309]

29. NICE recommends that the Department of Health's National Specialist Commissioning Advisory Group should consider establishing centres that specialise in treating people with soft tissue sarcomas in the abdomen or pelvis. The National Specialist Commissioning Advisory Group advises the Department of Health about very specialised services needed within the NHS that should be planned and funded nationally. [para 13]

Appropriate support and rehabilitation services should be available to people who are disabled by treatment for sarcoma [para 12]

30. The extent to which sarcoma and its treatment affect people's quality of life varies considerably. For some, its impact can be severe. Surgery for bone sarcoma often leaves the individual with a disability, and in some cases the affected limb has to be amputated. [para 49, 430] The person may need specialist physiotherapy, and may need to be fitted with an artificial (prosthetic) limb or other device. Surgery for soft tissue sarcoma may result in long-term problems such as disfigurement. It is therefore important that sarcoma patients have access to a full range of support and rehabilitation services to help them achieve the best possible quality of life, at the time that most benefits them. These might include: [para 443, 470]

- physiotherapy
- occupational therapy (sometimes called OT; OT helps people to overcome difficulties in carrying out everyday tasks and activities, and to develop the skills to live an independent life)
- provision of prosthetic limbs or other devices
- specialist rehabilitation services for children and young people
- palliative care (relieving pain and discomfort to improve a person's quality of life when it is not possible to cure the cancer).

31. Access to the appropriate support and rehabilitation should be coordinated by the MDT. [para 430] If ongoing services of this kind are required, they should be arranged in the patient's local area wherever possible, in coordination with the patient's key worker on the MDT. [para 435]

Services after amputation

32. People who have needed to have a limb amputated to treat their sarcoma hope to be able to return to normal activity and enjoy the same pursuits as they did before. [para 451] To help them achieve this they should have rapid and easy access to prosthetic services, and be able to choose a prosthetic limb that suits their needs, including special activity limbs if required. NICE recommends that sarcoma MDTs should establish links with a centre that meets the British Society of Rehabilitation's criteria for a Prosthetic and Amputee Rehabilitation Centre (PARC). [paras 453, 454, 455]

Improving knowledge of sarcoma [para 11]

33. Because sarcoma is rare, there is not as much evidence that can be used to make decisions on treatment as there is for some other cancers. [para 534] To help improve the level of knowledge, NICE recommends that all sarcoma teams should participate in nationally organised data collection, training programmes and audits (looking at what has been done and achieved), including patient satisfaction outcomes. [paras 11, 527]

34. Research trials (or studies) are important for finding out which treatments work best and improve quality of life most. Good-quality research trials cannot be carried out successfully if there are not enough patients taking part in them, so NICE recommends that patients with sarcoma should be encouraged to participate in clinical trials. [paras 10, 537, 539] Sarcoma teams should discuss the possibility of participating in a trial with everyone who is eligible. [para

538]The decision about whether or not to take part is entirely up to the patient, who should receive full written information about the purpose of the trial and what it involves (including any risks) before making up his or her mind. Trials that are not being conducted at the patient's own treatment centre should be offered at another centre where possible, and details of all trials should be available at all sarcoma treatment centres.[paras 98, 99] If a patient is not receiving treatment as part of a clinical trial, then the treatment given should be based on local clinical guidelines that have been developed on the basis of research evidence. [para 540]

Further information

35. 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 people with sarcoma should develop over the coming years.
36. If you have any questions about your health or the health of a member of your family or a friend, speak to your GP. Further information on sarcoma is available from NHS Direct (which you can access on the Internet at www.nhsdirect.nhs.uk or by telephone on 0845 46 47).
37. NICE has published a clinical guideline on referral for suspected cancer. This includes information on when someone should be referred urgently for investigation for bone cancer or soft tissue sarcoma. Information is available from www.nice.org.uk/CG027, or for a printed version of the information for the public, telephone the NHS Response Line on 0870 1555 455 and quote reference N0852.
38. NICE has issued guidance on services for children and young people with cancer, which makes recommendations aimed to ensure that children and young people with cancer get the best possible care and the care that is most appropriate for their age. Further information is available from the NICE website (www.nice.org.uk/cs qcyp). Copies of

the information for the public are available from the NHS Response Line (quote reference N0899).

39. 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 (quote reference N0476).

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

Website: www.nice.org.uk

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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 N0xxx). The Guidance manual, *Improving Outcomes for People with Sarcoma* (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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