

# Changing the sarcoma landscape

Sarcoma UK's  
policy aims



**SarcomaUK**

The bone & soft tissue  
cancer charity

# Sarcoma. Who?

**Sarcomas are uncommon cancers of the soft tissue and bone and can occur anywhere in the body.**

About 5,300 people a year are diagnosed with sarcoma in the UK. Living with sarcoma can be a lonely, isolating experience. We know there are a multitude of issues around sarcoma cancer in the UK that can have a devastating impact on patients and their families, from poor awareness of the cancer, late or incorrect diagnoses, to outdated treatments that are few and far between.

This document outlines the areas that Sarcoma UK is working to improve through our policy and campaigning work.

Over a six-month period, we asked the sarcoma community, including patients, oncologists and carers, what were the problems and issues they faced. As a part of the process, we undertook a nationwide survey of sarcoma patients and interviewed countless members of the patient and clinical communities. Their responses highlighted several important areas that need to be addressed urgently, areas that could be changed through policy levers.

## Earlier and more accurate diagnosis for people with sarcoma

**Anyone with the signs and symptoms of sarcoma needs to be seen as early as possible and referred to services that can quickly and accurately confirm the diagnosis. Doing this can save lives.**

### Why is this important?

- Sarcoma is an uncommon cancer that has vague symptoms, often a growing, possibly painful lump, or bone pain. As these symptoms can be attributed to other things, such as sporting injuries or growing pains, the patient may not think about visiting their doctor.
- Even if they spot something of concern, GPs may not associate the symptoms with sarcoma; most GPs will only see one case of sarcoma in their career.
- The later a sarcoma is diagnosed, the worse the outcome for the patient. Despite time being of the essence, on average sarcomas are diagnosed when they are about the same size as a can of beans.

**“Being left in limbo, not knowing if they have cancer, or what type of sarcoma they have, has a significant emotional toll.”**

- Despite early diagnosis being key, we do not currently have accurate staging data. The NHS Long Term Plan aims that by 2028, the proportion of cancer patients diagnosed at stages 1 and 2 should rise from around half currently to three-quarters. However, since it is estimated that only around a quarter of sarcoma patients are given a stage (compared to over 90% in breast and lung cancers), there is not an accurate picture of the stage at which sarcomas are diagnosed.
- Being left in limbo, not knowing if they have cancer, or what type of sarcoma they have, has a significant emotional toll. The longer it took for people to receive an accurate diagnosis, and the more times they saw a healthcare professional before being diagnosed, the more likely they are to experience anxiety.

# 1 in 4

Awareness is poor. Only 1 in 4 people in the UK know what sarcoma is.

# 35%

More than a third (35%) of sarcoma patients saw a healthcare professional three times or more before being referred for tests.

# 1 in 6

One in 6 people (17%) waited more than a year to receive an accurate diagnosis.

# 22%

A fifth (22%) of sarcoma patients were told their symptom(s) were not serious at their first healthcare appointment.

---

## Our priorities

1. Be the driving force to improve public awareness of sarcoma's signs and symptoms, working alongside the government and arms-length bodies.
  2. Push to improve knowledge and awareness around the signs and symptoms of sarcoma in primary care, such as GPs, community nurses, physiotherapists, pharmacists and emergency department workers.
  3. Lobby the government and arms-length bodies to ensure that there is a well-staffed, diagnostic workforce for sarcoma.
  4. Partner with the clinical community to increase the quantity and quality of staging data for sarcomas in the UK.
- 

**“We know that the routes to diagnoses are complicated and lengthy for sarcoma. For less common cancers where symptoms might be vague, or where they can develop in any part of the body like sarcoma, it makes it even more essential to have any suspicious symptoms looked at as soon as possible.”**

**Richard Davidson, Chief Executive of Sarcoma UK**

# All sarcoma patients have access to the best possible care in the UK

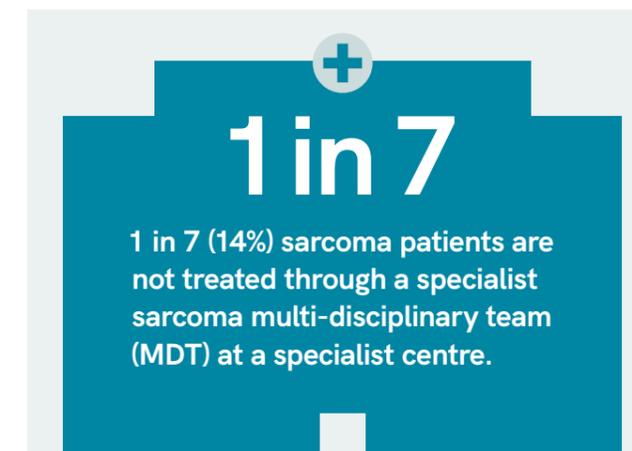
**Getting patients treated by experts who have experience of treating and managing sarcomas is crucial. All patients with suspected or confirmed sarcoma must have their treatment agreed by a specialist multi-disciplinary team (MDT) at a sarcoma centre, sometimes jointly with age-appropriate teams or those that focus on a particular part of the body, to ensure they receive the most appropriate and best possible care.**

### Focus on the drug pazopanib

New treatments rarely come up for sarcoma, so for some soft tissue sarcomas, the results of the PALETTE trial were hugely promising. It considered the effect of a new drug, pazopanib, on survival after previous chemotherapy had failed. This is important, as earlier chemotherapies for these sarcomas have a maximum dose, and can cause severe side-effects. Despite pazopanib being shown to increase the time it takes for sarcoma to progress, the only nation in the UK with routine access is Wales. Specialist sarcoma doctors need access to the full range of clinically-effective treatments to ensure that sarcoma patients get the best possible care.

### Why is this important?

- National guidelines state that patients with suspected or confirmed sarcoma must be cared for and have their treatment agreed by a sarcoma specialist multi-disciplinary team (MDT), yet some sarcoma patients are still seen outside of this specialist setting and receive incorrect care.
- Three reasons why being treated at a sarcoma specialist centre over a non-specialist centre can have life-changing consequences:
  1. Not receiving a diagnosis from a specialist can lead to misdiagnosis and/or receiving the wrong treatment. Research from France shows that diagnoses from non-specialist centres which were later reviewed by expert sarcoma pathologists resulted in a major change in diagnosis in 20-30% of cases.
  2. Being treated by a non-specialised team increases risk of local recurrence. Specialist sarcoma surgeons are trained not to leave the patient with sarcoma cells in the edge of the tissue, reducing the chance of recurrence.
  3. Decisions made about treatment and care by a sarcoma specialist MDT at a specialist centre brings together the experience and knowledge of sarcoma experts to ensure all patients have the most appropriate treatments for their condition. Not having that knowledge could mean that patients who are not referred to a sarcoma specialist centre may not receive the same access to possible future treatments through clinical trials.
- New medicines for sarcoma are scarce, with many medicines currently used having been around for many years. However, even when new medicines do have successful clinical trial results; clinicians are still not able to access them.
- Technology appraisals for new medicines are not adequately set up to consider drugs for less common cancers like sarcoma. Due to the rarity of sarcoma, getting a large enough sample of patients to take part in a trial is problematic. Appraisals systems are not flexible enough to allow for uncertainty, so even when drugs are shown to work, they are not accepted for routine use on the NHS.
- Pharmaceutical companies do not feel incentivised to conduct research into new sarcoma drugs, under fear that even if the drug is successful, they will not recoup the money spent on its development.



---

## Our priorities

1. Actively influence primary care professionals to improve knowledge of sarcoma referral pathways and push for suspected sarcoma to always be referred to a sarcoma specialist centre.
  2. Work with location specific cancer and children's or young adult's teams to ensure sarcoma specialist teams involvement.
  3. Campaign to ensure that patients/doctors have access to the full range of clinically-effective treatments to treat sarcoma.
- 

**“Patients whose care is coordinated by a sarcoma specialist centre by a sarcoma MDT not only get more accurate diagnoses, but receive better care. We want to ensure that every sarcoma patient is recognised and diagnosed as quickly and accurately as possible, and that specialist sarcoma teams have access to the full range of clinically-effective treatments.”**

**Bradley Price, Sarcoma UK's Policy and Public Affairs Manager**

# Push for better access to the appropriate psychological support for sarcoma patients and their carers

Anyone with the signs and symptoms of sarcoma needs to be seen as early as possible and referred to services that can quickly and accurately confirm the diagnosis. Doing this can save lives.

### Why is this important?

- The National Sarcoma Survey 2020 shows that almost all (90%) of sarcoma patients said that their diagnosis or treatment had a negative impact on their mental health or wellbeing.
- In England, the National Cancer Patient Experience Survey questions tens of thousands of patients across all cancer types to monitor experience of cancer care. Consistently over the last seven years, patients with sarcoma have generally reported poorer care experience than those with other diagnoses.
- Counselling and support groups can provide patients with someone to talk to from outside their support network.
- Similarly, the peer network found at support groups allows patients to discuss their concerns and feelings with people who have been through a similar experience; this importantly tries to prevent the rarity of sarcoma making patients feel they are alone. However, only 28% of patients were told about their local sarcoma-specific peer support group.
- Getting the right information at the right time can make a big difference to mental health. It can help people who have been diagnosed with sarcoma to make better informed decisions about their treatment, prepare better for treatment, and help them cope with their mental wellbeing at such a difficult time.
- Having access to the right support can allow patients to better understand sarcoma and ask the right questions for them; this can benefit both their own and their family's quality of life. Despite this, 45% of patients said they were not given enough information at diagnosis.
- The psychological needs of patients and their support networks need to be proactively addressed by specialist sarcoma centres.

**9 in 10**

patients said their diagnosis or treatment had a negative impact on their mental health or wellbeing.

**2 in 5**

patients did not feel they were given enough emotional support by hospital staff throughout their treatment.

**93%**

Almost all (93%) families and carers of sarcoma patients said that they felt either depressed or anxious more often since the diagnosis, or constantly felt depressed or anxious.

---

## Our priorities

1. Encourage sarcoma specialist centres to proactively offer mental health services at regular stages through the diagnosis and treatment of sarcoma.
  2. Improve awareness among healthcare professionals of the psychological support available and their role in sign-posting this to sarcoma patients at every stage of their sarcoma journey.
  3. Increase patient awareness of additional services, such as emotional and financial support from charities, to ensure that they are aware of all their options.
- 

**“The physical care which I received was brilliant but I felt left on my own to deal with the mental side of my diagnosis.”**

Susan Mutch, Sarcoma UK supporter

**“Sarcoma can have a significant negative effect on the mental health and wellbeing of not only patients, but the family and carers around them as well. Having access to psychological support at regular stages through treatment and beyond can certainly help with psychological wellbeing.”**

Helen Stradling, Sarcoma Specialist Nurse and Sarcoma UK's Support Line Manager

# Sarcoma UK's policy priorities:

Sarcoma UK has 10 key policy priorities which look to make an impact on early diagnosis, access to the best possible care and psychological support.

- 1 Be the driving force to improve public awareness of sarcoma's signs and symptoms, working alongside the government and arms-length bodies.
- 2 Push to improve knowledge and awareness around the signs and symptoms of sarcoma in primary care, such as GPs, community nurses, physiotherapists, pharmacists and emergency department workers.
- 3 Lobby the government and arms-length bodies to ensure that there is a well-staffed, diagnostic workforce for sarcoma.
- 4 Partner with the clinical community to increase the quantity and quality of staging data for sarcomas in the UK.
- 5 Actively influence primary care professionals to improve knowledge of sarcoma referral pathways and push for suspected sarcoma to always be referred to a sarcoma specialist centre.
- 6 Work with location specific cancer and children's or young adult's teams to ensure sarcoma specialist teams involvement.
- 7 Campaign to ensure that patients/doctors have access to the full range of clinically-effective treatments to treat sarcoma.
- 8 Encourage sarcoma specialist centres to proactively offer mental health services at regular stages through the diagnosis and treatment of sarcoma.
- 9 Improve awareness among healthcare professionals of the psychological support available and their role in signposting this to sarcoma patients at every stage of their sarcoma journey.
- 10 Increase patient awareness of additional services, such as emotional and financial support from charities, to ensure that they are aware of all their options.

More information around Sarcoma UK's policy and campaigning work at [sarcoma.org.uk/policy](https://sarcoma.org.uk/policy)

You can also contact [policy@sarcoma.org.uk](mailto:policy@sarcoma.org.uk)



**Sarcoma**UK

The bone & soft tissue  
cancer charity