

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.

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.

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.

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.
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“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