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## **THE LONELIEST CANCER: CHARITY CALLS FOR GREATER AWARENESS AND CLARITY TO TACKLE THE TRAGEDIES OF RARE CANCER**

**- *New report exposes the unwarranted obstacles faced by sarcoma patients today***

A comprehensive new report<sup>1</sup> launched today (Tuesday 26<sup>th</sup> November 2019) and commissioned by the charity Sarcoma UK reveals how this little-known and commonly misunderstood cancer has a devastating impact on its patients and their families, from diagnosis through to treatment. And yet, according to a YouGov poll<sup>2</sup> commissioned by the charity, 75% of people “do not know what sarcoma is”.

Sarcomas are tumours that develop in the cells of either the body’s soft tissue or bones and they can appear in almost any part of the body. Over 5,300 people are diagnosed with sarcoma in the UK every year. This is a tenth of those found with breast cancer, meaning that those diagnosed with sarcoma might never meet someone who shares the same type as them; in many ways, sarcoma is the loneliest cancer.

The report explores this rare, easily misdiagnosed cancer that only has a limited number of treatment options available and reveals how it can make the patient journey isolating, frightening and traumatic for many.

The report has found that a lack of awareness of sarcoma among the general public and healthcare professionals - as well as silent symptoms - can lead to late or misdiagnosis, often with heart-breaking consequences. Indeed, only 55% sarcoma patients survive for five or more years after diagnosis. Expert opinion in the report finds that confusion, anxiety and anger are prevalent among

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<sup>1</sup> The report was commissioned by Sarcoma UK and authored by expert health journalist Adrian Monti

<sup>2</sup> The survey for Sarcoma UK was carried out online by YouGov Plc between 28-29 March 2019. Sample: 2,033 adults. The figures have been weighted and are representative of all GB adults (aged 18+)

people diagnosed with sarcoma; they are often bewildered and crushed by the news because for most of them, 'it's a cancer they have never even heard of'.<sup>3</sup>

Sarcoma is so rare, even doctors can sometimes struggle to identify it. According to **Claire Kelleher, Sarcoma UK's Director of Information and Support**, "*Sarcoma presents unique challenges for healthcare professionals not faced when dealing with other cancers, and the consequences of this can make patients feel helpless and alone. It's so uncommon that a GP might only ever see one in their whole career*". In fact, by the time most people are diagnosed, their sarcoma is approximately the size of a large tin of baked beans (10cm).

At present there are 16 specialist sarcoma centres in the UK, and Sarcoma UK runs its own support helpline (which has taken 5,500 calls and 1,500 emails since it was set up in 2016). Over the past two years, the charity has led the work towards collating and improving the quality of the data available around sarcoma incidence in the UK. Unfortunately, the report has underlined that this is proving difficult because it is believed only 37% of NHS data on sarcoma patients' stage is complete. The charity believes that opaque, inaccurate figures on sarcoma can be a catastrophic barrier to improving treatment options. The NHS Long Term Plan, highlighted earlier this year, is calling for 75% of all cancers to be diagnosed at stages I and II in the next ten years. Although a welcome ambition, with only one third of sarcoma patients having their stage of sarcoma recorded, this again highlights how important it is to vastly improve the quality of sarcoma data recording.

As the report underlines, there are over 100 sub-types of sarcoma - there is no one size fits all treatment. Numbers of those diagnosed with each sub-type are relatively small so investment into research is low and recruitment to clinical trials is poor.

Due to the nature of this cancer, aggressive surgery (particularly amputation) is often the first line of treatment alongside radiotherapy and chemotherapy. Usually serious or life-altering, surgery can have a long-term traumatic impact on patients. Even for those who do not need an amputation, surgery can leave their body badly disfigured. The scars from such surgeries are not only physical but can cause long-term if not life-long emotional issues, such as not wanting to socialise or not feeling able to carry on working.

Additional findings from the report include:

- Little progress has been made in recent years in developing successful sarcoma-specific treatments. Often, non-specific cancer drugs are used, and new medications trialled such as olaratumab have been withdrawn due to a lack of discernible clinical benefit.

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<sup>3</sup> Expert opinion from **Sarah Massey, a sarcoma Clinical Nurse Specialist at Royal Liverpool and Broadgreen University Hospitals NHS Trust**, who is directly quoted in the report

- However, there is some cause to be optimistic about the future. Larotrectinib, a new 'tumour-agnostic' drug, was given European approval this autumn and could be a game-changer in terms of improving sarcoma prognosis. A decision on approval for a second drug designed to target changes in cancer cells called entrectinib is also imminent.
- Next year, the UK's second Proton Beam Therapy centre is due to open at University College London Hospital. Alongside The Christie in Manchester, experts are due to see 750 sarcoma patients every year. Its precise high intensity beams make it a particularly viable treatment for children and patients with head and neck tumours.
- Innovative new projects are being funded by Sarcoma UK every year, including research by lead investigator Dr Richard Martin, Deputy Director, Aston Institute of Materials Research at Aston University, Birmingham into bioactive glass (a potentially cancer-killing bone replacement) and a project led by Matthew Allen, Professor of Small Animal Surgery in the Department of Veterinary Medicine at the University of Cambridge which could help improve our understanding of the disease in dogs (in whom sarcoma is ten times more likely) and in humans.

**Richard Davidson, Chief Executive of Sarcoma UK** comments, *"Appallingly, this destructive cancer has maintained a low profile until now even though lives are still being lost or devastated by amputations and invasive treatments. 15 people each day in the UK receive the shattering news that they have sarcoma. Sadly, bone cancers are more common in children and young adults with about 670 cases a year. With greater general awareness, diagnosis could be quicker. Currently, treatments are basic and decades old, and could be more effective. With increased funding for pioneering research survival rates could be improved and the suffering caused by this rare and often cruel cancer would diminish."*

The full report can be found via [sarcoma.org.uk](http://sarcoma.org.uk)

**Sarcoma UK Support Line Specialists are here for every person affected by sarcoma. Monday to Friday, 10am - 3pm. Phone: 0808 801 0401 or email [supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk).**

**ENDS**

**For more information and to request an interview with a patient case study or a sarcoma expert please contact Caroline Beswick, Jo Gulliver or Imogen Daldy on 02071124905 or email / call [caroline.beswick@trinitypr.co.uk](mailto:caroline.beswick@trinitypr.co.uk) / 0770 948 7960.**

- Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma cancer and campaigns for better treatments. It is the only cancer charity in the UK focusing on all types of sarcoma and is one of the largest funders of sarcoma research in the UK, having invested more than £2.6 million into sarcoma research to date.
- [www.sarcoma.org.uk](http://www.sarcoma.org.uk)

- Its mission is to ensure everyone affected by sarcoma receives the best treatment, care, information and support available and to create the treatments of the future.
- Sarcoma UK receives no government funding and relies solely on generous voluntary donations and the energy and imagination of our tireless fundraisers.