The Loneliest Cancer

Sarcoma UK
The bone & soft tissue cancer charity

Sarcoma accounts for only 1.3% of cancers in the UK

The current five-year survival rate for sarcoma in the UK is 55%

SARCOMA IN NUMBERS:

On average, 15 people in the UK are diagnosed with sarcoma every day.

Introduction

Sarcoma is a cancer that few have heard of.

Its rarity should not hide the catastrophic effect it can have on those who have experienced sarcoma or their family and friends.

Being little recognised and far from fully understood has led to a plethora of issues which seem unique to sarcoma.

It has more than 100 different sub-types, many with non-specific symptoms. This means it is often misdiagnosed, diagnosed late or treated incorrectly, leading to tumours growing and spreading and further reducing the few treatment options available.

Even those who are successfully treated can suffer life changing after-effects. Many are left facing physical or mental barriers to overcome each day which can be hugely isolating.

Latest statistics show that only 5,300 people each year in the UK are diagnosed with sarcoma — a tenth of those found with breast cancer.

In so many ways, it really can be the loneliest cancer.

What is sarcoma?

If you're not sure what sarcoma is, you're not alone. In a YouGov poll carried out on behalf of Sarcoma UK this year, 75% said they didn't know what sarcoma was.<1>

Put simply, it's a tumour which develops in the cells of the body's soft tissue (the most common type), the bones, or as a gastrointestinal stromal tumour (GIST) anywhere in the tract from the gullet to the anus.

Sarcoma can appear in almost any area of the body. Soft tissue sarcoma, which accounts for seven in ten cases, is found in connective tissue like muscle, blood vessels, fatty tissue and nerves. It appears most commonly in the arms and legs but can also occur on the trunk and female reproductive system. Around 5% of cases occur in the head and neck.

On average, 15 people in the UK are diagnosed with sarcoma every day. Sadly, bone cancers are more common in children and young adults with about 670 cases a year. In these cases, a lump can appear on the bone, destroying it as the tumour grows, with the possibility of it spreading too.

Presently, survival rates for those diagnosed with sarcoma are not as high as many other cancers. Only 55% of sarcoma patients will survive for five or more years. Compare this to testicular cancer which has an estimated five-year survival rate of 98 %.<2>

Richard Davidson, CEO of Sarcoma UK, believes it's time for sarcoma to raise its profile.

He says: "The unfortunate truth is that people only really become aware of what sarcoma is when it touches their life or those in their family. Making both healthcare professionals and the general public more aware of it will help people get a faster diagnosis, obtain better treatment and improve access to any new drugs which will ultimately result in a more positive outcome. By developing a strong national voice while working alongside the NHS and healthcare professionals, our charity aims to achieve these goals."

Diagnosis

Sarcoma creates unique challenges

When we go to the GP, we expect to be told what's wrong with us and what can be done about it. But sarcoma is so rare, even doctors can sometimes struggle to identify it.

"Sarcoma awareness is low, not only with the public but among health care professionals too," says Claire Kelleher, Sarcoma UK's director of information and support.

"It's so uncommon that a GP might only ever see one in their whole career. With more than 100 sub-types, it can develop in people of any age and in any part of their body. This makes a diagnosis very challenging to a non-specialist."

A previous Sarcoma UK awareness campaign aimed at GPs 'red flagged' typical symptoms of the more common soft tissue sarcomas. This reminded GPs to look out for growing lumps anywhere on the body which might require further investigation.

"The rarity of seeing a patient presenting with signs of sarcoma is a big problem," says Claire Kelleher. "It's simply not high up their list of possible reasons to explain a patient's symptoms. For example, bone pain at night — which can be a sign of bone sarcoma — can be explained as growing pains in children, while bumps could be put down as a sporting injury in a young adult. Even an unusual lump in someone older can be diagnosed as a harmless cyst or lipoma — a fatty deposit."

The Sarcoma Patient Survey [3] reported that 27% of patients who visited their GP were started on treatment for another condition or told that their symptoms were not serious.

Early diagnosis is crucial

Awareness is also low among the public. Many of us are aware of key symptoms of common cancers and would visit the GP with a breast lump in case it was a sign of breast cancer, for example. But because so few people know about sarcoma — it only accounts for 1.3% of all diagnosed cancers in the UK — many will have symptoms without knowing the seriousness.

In the Sarcoma UK commissioned YouGov poll, even among people who had heard of sarcoma, 30% didn't know what the symptoms are.

This low awareness among healthcare professionals and the public can lead to late diagnosis.

"If sarcoma is diagnosed when a lump is less than 5cm, the patient has a 20% higher chance of a positive outcome because it's easier to remove," says Claire Kelleher. "A smaller lump is less complicated to extract and has a reduced impact on the area around it."

"Even among people who had heard of sarcoma, 30% didn't know what the symptoms are."

But Sarcoma UK figures show that a lump is typically the size of a tin of baked beans before surgery occurs to remove it. Often sarcoma can develop internally and so not appear as an obvious lump; in such cases symptoms such as shortness of breath, dizziness or pain may only occur later when the growth has been developing unchecked.

Soft tissue sarcomas patients wait on average 92 weeks - almost two years - between spotting symptoms and being referred for investigation. This can be because some of the symptoms, such as those associated with GIST for example, are vague and include feeling sick, abdominal pain or blood in the stool.

100

Sarcoma has more than 100 sub-types

670

Sadly, bone cancers are more common in children and young adults with about 670 cases a year

SARCOMA IN NUMBERS:

"If sarcoma is diagnosed when a lump is less than 5cm, the patient has a 20% higher chance of a positive outcome because it's easier to remove."

“As many as 40% of patients do not receive an initial accurate diagnosis of their sarcoma…”

Patients are misdiagnosed

Another problem is that, often due to its rarity, sarcoma is frequently wrongly diagnosed as something else. Even a lump can be incorrectly assessed. As many as 40% of patients do not receive an initial accurate diagnosis of their sarcoma, according to Sarcoma UK research.

This early mistake can lead to problems further down the line. There have been instances where what is known as a ‘whoops procedure’ is carried out due to misdiagnosis.

“A ‘whoops procedure’ is when a GP or other medic removes a lump believing it’s benign,” says Claire Kelleher. “But later the lump is found to be sarcoma. If it wasn’t fully removed, there can be still signs of cancer in the patient which can spread to other parts of their body. This error can lead to the patient needing more radical surgery and survival less likely.”

A correct assessment is vital

Even if sarcoma is suspected, patients are often sent to the wrong place for treatment. Ideally, they will be referred to their local hospital for an x-ray or ultrasound. Depending on the outcome, they will then be sent to one of the 16 specialist sarcoma centres across the UK. A GP can also refer a patient directly to one of these centres if necessary.

At the specialist centre, the patient will be diagnosed and, if sarcoma is found, treated there too. Some patients are referred there because it’s unclear if they have a sarcoma or not and they need to be expertly assessed. It’s heartening that eight out of ten patients who are sent to these centres with a suspected sarcoma are found not to have one at all. Often the lump or bump turns out to be a benign cyst or lipoma under the skin.

“But not all people do get seen at these specialist centres which are staffed by a multi-disciplinary team of sarcoma experts,” says Claire Kelleher. “Our support helpline was set up in February 2016 and has so far taken 5,500 calls and emails from more than 1,500 members of the public. Twenty of our callers were being treated in the wrong place. Luckily we were able to point them in the direction of a sarcoma specialist centre.”

The main fear with sarcoma is that if it’s not treated quickly, the tumour will spread beyond the original site to other parts of the body. This makes it much harder to treat and frequently surgery — often the first port of call when treating sarcoma — is no longer an option.

Earlier this year, the implementation of NHS England’s Sarcoma Service Specification meant for the first time all sarcoma patients in England must be treated at one of the specialist centres. It’s hoped this will standardise improved treatment and increase survival rates.

It was luck my sarcoma was found — read Liam Harrison’s story, page 17.

An incomplete picture

Sarcoma UK says that despite its best efforts to collate information from the usual go-to sources, accurately tracking all cases of sarcoma has simply proved impossible.

Since sarcoma is uncommon, it can be wrongly ‘coded’ on NHS databases which record diagnosis, treatment and patient outcomes. If sarcoma is not logged properly, statistics become inaccurate. It’s believed that only 37% of data on patients with sarcoma is complete.

This incorrect coding can happen for many reasons. Different hospital trusts use different coding systems so there is no uniformity. Also, if sarcoma is recorded, it can often by very general with no specific detail of where in the body it was found. This can be because the NHS systems do not always allow sub-types to be inputted.

This lack of ‘clean’ data that results in inaccurate figures has a knock-on effect on all aspects of sarcoma treatment. This was highlighted earlier this year with the launch of the NHS Long Term Plan which set out its key goals over the next decade. It’s calling for 75% of all cancers to be diagnosed at stage l and ll. Although Sarcoma UK welcomes this ambitious target, with just over a third of patients having their sarcoma correctly logged, this highlights how important it is to vastly improve the quality of sarcoma data being recorded.

SARCOMA IN NUMBERS:

16

There are 16 specialist sarcoma centres across the UK.

92

Soft tissue sarcoma patients wait an average 92 weeks – almost two years – between spotting symptoms and being referred for investigation.

1,500

Sarcoma UK support helpline has helped more than 1,500 people since February 2016.

5,500

Sarcoma UK support helpline received 5,500 calls and emails since February 2016.

37%

It’s believed that only 37% of data on patients with sarcoma is complete.

Treatment

What are the options?

The sheer number of sarcoma sub-types means there's no 'one size fits all' treatment among the limited number of treatment choices. Patients usually have one or a combination of surgery, chemotherapy and radiotherapy.

Surgery is often part of the early treatment for bone or soft tissue sarcoma in combination with chemotherapy and radiotherapy either before or after treatment depending on the sarcoma and following the assessment of the patient

"By delivering chemotherapy before surgery, it's hoped this will dampen down tumour cell activity and stop the cancer spreading," says Harriet Branford White, senior sarcoma fellow at Oxford's Nuffield Orthopaedic Centre. "After surgery, once the tumour has been removed, chemotherapy is continued repeated to mop up any tumour cells still in the body. Radiotherapy to the original site is sometimes used too.

"Research studies have shown us that surgery alone does not change the outcome of a life. For a bone tumour, what changes an outcome is chemotherapy. The chemotherapy will stop the tumour spreading into the bloodstream and lodging in the lungs, which makes it much more difficult to treat."

Radiotherapy can also treat some sarcoma types particularly in preventing them recurring at the original site of the disease. It is either administered before or after surgery.

The patient's experience

Patients suddenly diagnosed with sarcoma can feel totally overwhelmed says Sarah Massey, a sarcoma clinical nurse specialist at the Royal Liverpool and Broadgreen University Hospitals NHS Trust.

"I've seen confusion, anxiety and anger, with people being totally bewildered and crushed by the news," she says. "Often they say, 'I have a cancer I've never even heard of'. They are then confronted with treatments and surgery which could mean losing a leg.

Even for those who do not have an amputation, they can undergo invasive surgery which can leave their body badly disfigured. The scars from such surgery 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.

"People can see their whole lives falling apart and aren't sure how to cope," Sarah Massey added. "The effects can be devastating so it's important they get the best treatment in the best place possible — a specialist sarcoma centre."

Sarcoma treatment can be problematic

Experts say the rarity of sarcoma has contributed to treatment options barely moving over the years. Many drugs given to sarcoma patients were initially designed for other cancers, before it was found they might benefit sarcoma too.

Other new drugs have offered false dawns. For example, at the start of 2019, the drug olaratumab was withdrawn from being prescribed to new patients with advanced soft tissue tumours. Despite showing great promise following early phase trials, it was said to have no clinical benefit for these patients.

"The big problem for new treatments is the relatively small number of people with sarcoma, with so many sub-types," says Harriet Branford White. "This has led to the need for the sarcoma community to collaborate nationally and internationally with drugs and treatments trials for patients. This allows researchers to gather enough reliable results and thereby improve care for treating patients in the future."

'There are few places to go for treatment' — read Emily Travis's story, page 16.

"Some sarcoma patients could also benefit from proton beam therapy (PBT) which has recently become available in the UK on the NHS."

There's hope for sarcoma patients

Earlier this autumn, a new type of drug which can help some sarcoma patients became the first drug of its type to be given European approval.

This drug called larotrectinib is described as a 'tumour-agnostic drug'. This means it will attack a tumour anywhere — and sarcoma can appear anywhere in the body — if it's carrying a certain genetic abnormality inside its cells. It's being described as a game-changer as it targets the specific defect so can be much more personalised to the patient rather than simply being used against a particular cancer. It's hoped this could mean fewer unpleasant side-effects too.

A decision on approval for a second drug designed to target changes in cancer cells called entrectinib is also imminent.

Richard Davidson, CEO of Sarcoma UK, welcomed the news about larotrectinib. He said it 'highlighted the importance of clinical trials and the need to continue developing new drugs.'

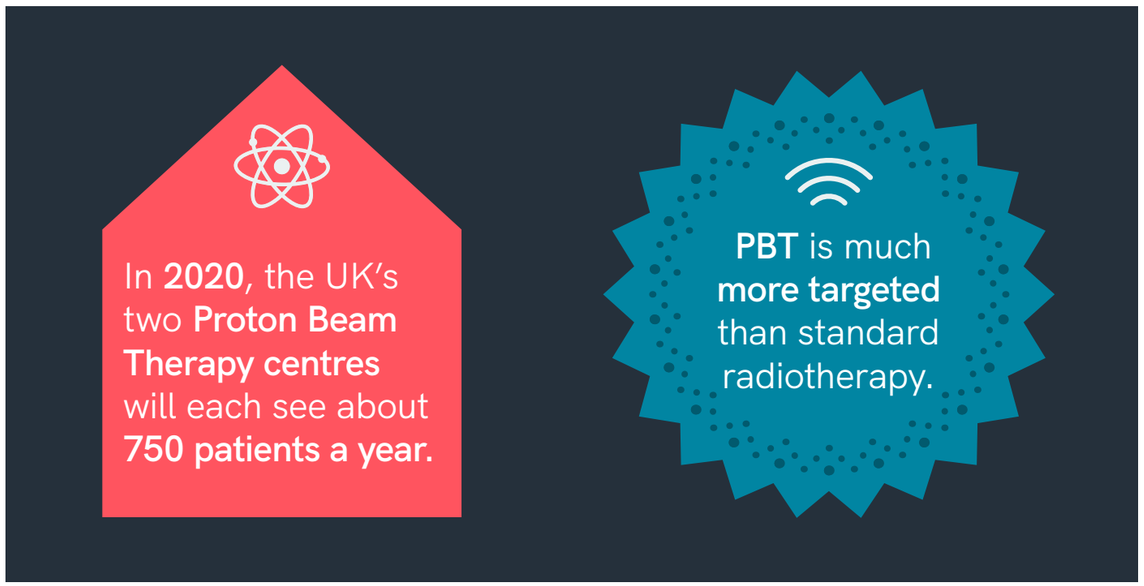
What treatments will be available in the future?

With a fairly limited armoury of treatments for sarcoma at present, there is potential that more could become available in the coming years.

In addition to targeted drug therapies such as larotrectinib and entrectinib, immunotherapy — when the body's own immune system is harnessed to fight cancer — also offers hope to help sarcoma patients in the future.

Sarcoma UK is funding an ongoing study at the Institute of Cancer Research. It is looking at drugs to activate the body's immune system to stop soft tissue sarcomas spreading after their growth has been halted with anti-cancer viruses.

Some sarcoma patients could also benefit from proton beam therapy (PBT) which has recently become available in the UK on the NHS. PBT is much more targeted than standard radiotherapy. By being more precise, a higher intensity of beam can be fired at the tumour without harming so much of the surrounding healthy tissue. This results in less collateral damage and the patient should suffer fewer side-effects.



“PBT is particularly useful for treating children and young people as it’s kinder to a still developing body.”

PBT is particularly useful for treating children and young people as it’s kinder to a still developing body. It could be a viable option for those who have sarcomas in hard to reach places such as the head and neck, which would normally be very risky to treat.

Although radiotherapy – be it conventional or PBT – is standard treatment for some sarcomas such as Ewing’s sarcoma, it’s not used to treat GIST, the most common soft tissue sarcoma. It means it’s not an option for all sarcoma patients.

Last year the UK’s first NHS proton beam therapy centre opened at The Christie in Manchester. In 2020, a second centre at University College London Hospital (UCLH) is due to be ready too. Each will see about 750 patients a year. In the past, some cancer patients –including those with sarcoma – were sent abroad for this treatment because it wasn’t available here.

Sarcoma UK welcomes this treatment. Although PBT is not suitable for all types of sarcoma, it could benefit some patients. Claire Kelleher also believes that for those it can help, being treated in the UK rather than in the United States or Europe is important.

“The impact on people’s wellbeing and quality of life is vastly improved by being able to be treated closer to home,” she says.

Successful treatment isn’t the end of the journey

Those who have been treated for sarcoma can struggle to find the ‘new normal’ Sarcoma UK-funded research has found.

Rachel Taylor, the director of Centre for Nursing, Midwifery and Allied Health Professional Led Research at UCLH and her team of researchers spoke to about 1,000 people in the last two years who have had sarcoma. For many it was a rare opportunity to ‘open up’ to those outside their immediate circle about the physical and emotional impact of sarcoma.

Because many treated for sarcoma need complicated surgery or amputation, it can have a lasting negative effect on their life.

“Patients with sarcoma have ongoing support needs that go beyond the end of treatment,” says Rachel Taylor. “They need physiotherapists, they need help to return to work or school, along with specialist support.”

She helped put together the award-winning Sarcoma Assessment Measure, (SAM), the first qualitative measure of those who have experienced sarcoma. It’s hoped the questionnaire will lead to improved communications between patients and clinicians.

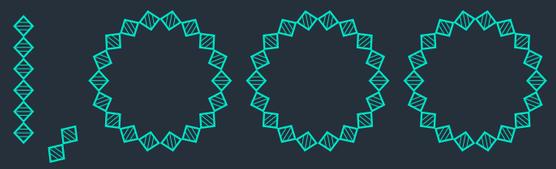
’It’s a lonely cancer’ Read Emma Callanan’s story, see page 16.

Sarcoma UK has so far invested £2.64 million in research across 49 different projects

For 2019/20, a further £870,000 has been committed for research on several projects

SARCOMA IN NUMBERS:

The 100,000 Genomes Project has allowed Sarcoma UK to recruit over 1,000 patients with various sub-types and to undertake in-depth molecular analysis.



Research

With treatment options for sarcoma patients still quite limited, finding effective new ones is clearly a key objective.

Research into sarcoma has been dwarfed by that of more common cancers. Because of the rarity of sarcoma, it's simply not prioritised. Much more has been invested in research and drug development of cancers of the breast, lung, prostate and bowel, for instance.

"If we're honest, for sarcoma patients there aren't a lot of drugs they can be prescribed and there are certainly not a huge number of new drugs on the horizon," says Richard Davidson, CEO of Sarcoma UK.

"Pharmaceutical companies are not investing a lot of money in sarcoma treatment. They are looking to other cancers which are much common. In simple economic terms, the returns are not there with sarcoma because it's so rare."

Meaningful clinical trials into new treatments can harder too. Because sarcoma is rare, trials need to recruit patients from various countries to take part which can prove to be complex to organise effectively.

But there is some cause for optimism. Sarcoma UK continues to invest heavily in ongoing research. The charity, which is one of the biggest funders of sarcoma research, has so far invested £2.64 million in this area. It has supported 49 different projects which has greatly helped increase scientists' understanding of sarcoma. For 2019/20, a further £870,000 has been committed for research on several projects.

"New sarcoma treatment will most likely come from research into other cancers," Richard Davidson believes. "But we need to persist with our own specific research too."

Funding is being spent on a wide range of projects and is also invested in individual researchers. If a researcher can be inspired to study sarcoma, they may devote their entire career — some 40 years or so — to investigating it.

The Big Hope

There's a great deal of optimism that the first research projects of its type will offer a gateway to a better understanding of sarcoma.

Thanks to a £250,000 award from Sarcoma UK, a unique three-year study called the Sarcoma Genomics England Clinical Interpretation Partnership (GeCIP) is now underway. Research is being led by Professor Adrienne Flanagan, who is based at UCL Cancer Institute in London, and involves 35 fellow sarcoma scientists.

They are hoping to discover more about the genomes (which is a complete set of genes found in a healthy cell along with the DNA between those genes) collected from people with different sarcoma sub-types.

The samples being examined were collected for the ground-breaking 100,000 Genomes Project which was launched in 2012 with the promise of providing a greater comprehension of rare diseases.

"More in-depth knowledge of sarcoma could ultimately lead to improved treatment options."

The Sarcoma UK award meant the research experts from around the world were the first to analyse these samples, which otherwise might have not been studied to the degree they now are. The researchers hope to detect trends and patterns that give clues to understanding sarcoma better.

"The 100,000 Genomes Project has allowed us to recruit over 1,000 patients with these various sub-types and to undertake in-depth molecular analysis," explains Professor Adrienne Flanagan.

"This will provide a huge, unprecedented understanding of this rare disease. What is so valuable is that this is the first step in bringing together people with different skills and interests in understanding cancer.

"Sarcoma UK has invested £250,000 in the Sarcoma Genomics England Clinical Interpretation Partnership..."

When you bring people like this together and get them talking, you get new ideas."

More in-depth knowledge of sarcoma could ultimately lead to improved treatment options. If, for example, it could be predicted how a patient will react to radiotherapy by looking at their genome make-up, the amount of radiation they are given could be adjusted accordingly. Treatment could be much more personalised.

Richard Davidson, Sarcoma UK CEO, believes the GeCIP project gives sarcoma a unique chance to be more closely studied.

"This is one of the most important pieces of research looking into a cancer that historically has been frequently overlooked," he said. "The amount we can learn from this piece of research and the impact it could have on thousands of people affected by the cancer in the UK and beyond is vast."

Ongoing research will help sarcoma patients in the future

More research projects are being funded by Sarcoma UK every year. Here are two projects that could benefit patients in the future.

A Cancer-Killing Bone Replacement

Research at Aston University is exploring a new way to tackle the damage caused by sarcomas in the bone while at the same time stopping cancer returning.

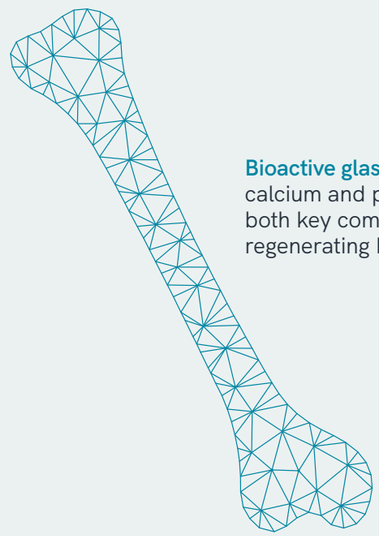
Lead investigator Dr Richard Martin, associate professor in material physics, has been looking at the potential of using bioactive glass as a pioneering way to treat osteosarcomas. This glass will be used to repair small defects caused by the surgical removal of the affected bone and release ions to attack the cancer cells.

The bioactive glass being developed will contain calcium and phosphorous, both key components in regenerating bone. It will also contain the metals gallium and strontium which will be slowly released into the surrounding surgical area. Gallium is known to target and destroy tumour cells while strontium has powerful antimicrobial qualities so will help reduce the infection risk around the surgery site.

It's hoped that the bioactive glass could be put into the patient during a single procedure.

The research, funded with a Sarcoma UK grant of almost £120,000 over three-and-half years, took on its first PhD student this autumn to help carry out further research.

"You have two problems with bone cancer," says Dr Martin. You don't want local recurrence of the cancer, as your survival rate significantly drops. You also want to repair the bone and not suffer an infection. This the first time anyone has really looked at targeting both problems with one solution rather than two procedures."



Bioactive glass will contain calcium and phosphorous, both key components in regenerating bone.

“Osteosarcoma — sarcoma of the bone which occurs mostly in teenagers and young adults — affects dogs too.”

Dogs are taking a lead in research

Our understanding of sarcoma is being furthered by research in dogs as well as humans.

Osteosarcoma — sarcoma of the bone which occurs mostly in teenagers and young adults — affects dogs too. It’s ten times more common in dogs than people and is much more aggressive in dogs too. Without treatment, a dog with sarcoma will usually live around six months; with amputation followed by chemotherapy, the dog’s life expectancy can be more than doubled to about 14 months.

Ongoing research by a team headed up by Matthew Allen, Professor of Small Animal Surgery in the Department of Veterinary Medicine at the University of Cambridge, could help improve our understanding of the disease in dogs and in humans.

Professor Allen says that in both dogs and people, osteosarcoma develops in the bone and then subsequently spreads to other parts of the body, most often the lungs. It’s believed that this spread is the result of tumour cells that get into the patient’s bloodstream, but exactly how and why this comes about is very unclear.

“We know that these “circulating tumour cells” can be found in both dogs and humans, even after the tumour has been removed with surgery,” says Professor Allen. “We want to find out more about these special cells, how they develop and where they hang out. If we knew more about their journey, we would have a much better understanding of how to treat osteosarcoma.”

He believes that using these cells as biomarkers will help doctors better judge what type and degree of chemotherapy would be most effective for their patients.

Conclusion

Sarcoma has been a forgotten cancer up to now. That is demonstrated by the frequency with which GPs fail to recognise the signs, by crucial data being left off NHS statistics and by the lack of new drugs to treat it.

It’s extraordinary that its profile remains so low. Many lives are still being lost to sarcoma and others are blighted due to amputations or invasive treatments. Sarcoma can rip anyone’s normal existence apart — forever — at any time. It does this to about 15 people every day in the UK who are diagnosed with it.

Yet sarcoma doesn’t have to be so bleak. With greater general awareness, diagnosis could be quicker, treatment could be more effective and funding for pioneering research could be increased. These changes would lead to higher survival rates and an easier journey for those diagnosed with sarcoma.

With the media’s help, together we intend to stop sarcoma being the loneliest cancer.

“With greater general awareness, diagnosis could be quicker, treatment couldbe more effective and funding for pioneering research could be increased.”

Case studies

Amelie's story

SIX-YEAR-OLD Amelie Callanan was diagnosed with Ewing's Sarcoma, a rare type of cancer in the bone. She lives in Redhill, Surrey with her parents and younger sister.

Summary

Amelie was diagnosed with Ewing's sarcoma in her left leg in August 2018.

"We were told it was a tumour that was growing in the bone which could mean amputating her leg," says her mum Emma, 41. "The cancer had also spread to both of her lungs. It was the worst news any parent could be given."

Amelie was treated at London's University College Hospital (UCLH) and took part in a clinical trial to improve the treatment outcome. She had 14 rounds of chemotherapy over the next six months. But just before Christmas, doctors said they had no choice but to amputate her left leg above the knee. She had the operation four days after her sixth birthday.

"Amelie's amazing," says Emma. "Two weeks after her amputation, with help she was doing short distances on her scooter. Soon she was back swimming and rushing about."

Amelie had further chemotherapy and radiotherapy. After at first using a prosthetic leg, she now has a bright pink blade. There's no longer any sign of cancer in her lungs.

"When Amelie was first diagnosed it felt isolating, as apart from other children on the hospital ward, we didn't know much about sarcoma," says Emma. "It can be a lonely cancer.

"My biggest fear when we knew she'd lose her leg was we'd also lose the Amelie we knew. But that's not been the case. She's bounced back and everyone has accepted who she is."

Emily's story

MUM-OF-TWO Emily Travis, 43 was diagnosed with sarcoma five years ago. Despite being given a terminal diagnosis four times, Emily, from Marlborough, Wiltshire, has refused to give up.

Summary

Excruciating pain in her abdomen first alerted Emily that something was seriously wrong

But doctors weren't concerned and at one point she was told it was probably constipation. Finally, in 2014, she was diagnosed with leiomyosarcoma in the cavity above her kidney.

"At the time my daughter was about to start primary school," recalls Emily. "They said they would operate to remove the tumour but didn't think they'd be able to get it all out. I was told I was unlikely to see 2015."

Surgery initially appeared successful but at a regular scan in 2016, spots were discovered on her liver. She had three liver tumours removed, but the cancer then spread to her bones.

"Once again the news was devastating," says Emily. "My prognosis was less than a year."

Emily was accepted on to a clinical trial where she would receive double therapy with chemotherapy as well as a new targeted treatment that was being evaluated.

Her treatment at London's Royal Marsden Hospital meant lengthy fortnightly trips including a 5am start and she'd sometimes still be there at 9pm.

Emily underwent treatments including chemotherapy, radiotherapy and immunotherapy as well as the new drug and microwave ablation. But planned surgery has been cancelled as the disease has further progressed. Emily's treatment options are now very limed, but she's trying another chemotherapy drug.

"Sarcoma is a death sentence if it spreads like in my case," she says. "As sarcomas are so rare, there are few places where you can have treatment. If more people were aware of it, perhaps we could improve the patient journey for those living with this life-limiting cancer."

Liam's story

TEACHER Liam Harrison, 33, from Oxford tells how his sarcoma was discovered by chance. He is now based in San Sebastian, Spain.

Summary

In 2006, Liam Harrison was playing football when he suffered a hip injury. He assumed he'd tweaked a muscle. Although he had a slight limp, he hoped the pain would soon ease.

That August he went to a barbecue where his friend Ben playfully launched into him with a rugby tackle, knocking him over. Liam couldn't stand up afterwards and went to hospital where an x-ray suggested something serious. After more tests he was diagnosed with chondrosarcoma — the most common type of bone sarcoma — in his hip.

"Up until I was told I had a sarcoma, I'd never heard of it," says Liam.

Within two weeks, the hip joint which had been damaged by the sarcoma was removed and replaced by a prosthetic hip joint. Liam's made a full recovery.

"When I'm back in England and see Ben, I joke that what he did might have saved my life," says Liam.

The full stories are available on request.

"It's a lonely cancer."

Amelie Callana

"There are few places to go for treatment."

Emily Travis

"Until I had a sarcoma, I'd never heard of it."

Liam Harrison

References

All statistics are sourced from Sarcoma UK unless otherwise stated.

<1> YouGov poll carried out on behalf of Sarcoma UK. Fieldwork carried out between March 28-29 involving 2033 UK adults.

<2> Figures from Cancer Research UK for five-year-survival of testicular cancer in England and Wales for 2010-2011.

<3> This report was published in 2015 by Sarcoma UK.

Sarcoma UK

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.

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At a glance

5,300

Only 5,300 people each year in the UK are diagnosed with sarcoma (compared to 55,000 for breast cancer and 47,700 for prostate cancer for example)

75%

75% of people surveyed said they didn't know what sarcoma was

55%

Only 55% of sarcoma patients will survive for five or more years, compared to 98% for testicular cancer

27%

27% of patients who visited their GP were started on treatment for another condition or told that their symptoms were not serious

40%

40% of sarcoma patients do not receive an initial accurate diagnosis of their cancer

37%

It's believed that only 37% of NHS data on patients with sarcoma is complete

Sarcoma UK

The bone & soft tissue cancer charity