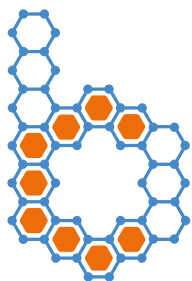


LIVING WITH, AND BEYOND, PRIMARY BONE CANCER

Uncovering the impact of primary bone cancer



**BONE
CANCER**
RESEARCH TRUST
UNTIL THERE'S A CURE

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The Bone Cancer Research Trust

The future: we need your help

Since the Bone Cancer Research Trust began in 2006, we have become the leading charity dedicated to fighting primary bone cancer. With the support of our community we've invested in pioneering research and created award-winning information for patients and their families.

Despite advances in scientific knowledge and patient information, the reality is that primary bone cancer remains a rare and brutal disease that is not widely known - either amongst the general public or the healthcare profession.

This means that many patients aren't correctly diagnosed until their cancer is already quite advanced. And it also means that primary bone cancer doesn't receive the levels of attention and funding needed to develop better, more effective and kinder treatments.

'Living with, and beyond, primary bone cancer' will help us promote better awareness and understanding of this disease.

Our vision is a future where primary bone cancer is cured. To achieve this we need to support, engage, and listen to those who are affected by it.

Thank you to the hundreds of people who took the time to contribute their stories, experiences and views to this research project. It will help us work together to achieve a more positive, hopeful future for everyone affected by primary bone cancer.



John Dealey

Founder & Trustee



Gill Johnston

Founder & Trustee

ABOUT THE PROJECT

This research project was commissioned by the Bone Cancer Research Trust and delivered in partnership with Alterline, an independent research agency. The project was an in-depth examination of the impact of primary bone cancer on patients and their loved ones.

Our national survey covered many aspects of people's lives and was open to people who have or had primary bone cancer, and their family and friends.


In total, 321 people took part in the national survey: 101 people who have or have had primary bone cancer; and 220 family members or friends of people who have or have had primary bone cancer.

In this publication, where statistics are reported on, they include the responses of both people who have, or had, primary bone cancer and their friends or family reporting on their behalf.

The survey was completed between 4th August and 20th September 2015. It was distributed to the Bone Cancer Research Trust's network of patients, families, supporters, volunteers, fundraisers, researchers, and healthcare professionals.

Alterline also used social media and online advertisements to reach out to people who may not have previously come into contact with the Bone Cancer Research Trust.

Following the survey, 19 people completed a daily online diary for one week to tell us more about their experience with primary bone cancer. A further 5 volunteers shared their experiences with us in more depth to help us produce this report along with a series of short videos.



The Bone Cancer Research Trust thanks everyone who took the time to contribute their stories, experiences and views to this project.

WHAT IS PRIMARY BONE CANCER?

Primary bone cancer is a rare type of cancer that can have a devastating impact. Most members of the public and most healthcare professionals simply don't know enough about it.

A lack of awareness about this brutal disease leads to a lack of support for those who are affected by it. Not only do patients and their loved ones feel there is a lack of public awareness, they also feel that the NHS and healthcare professionals don't see primary bone cancer as a significant priority.

This needs to change.



Only 28%
of survey participants
felt that the NHS
gives primary bone
cancer the attention
it deserves



Only 55%
felt that healthcare
professionals
understand what life
is like with primary
bone cancer

**PRIMARY BONE
CANCER**
AFFECTS PEOPLE
OF ALL AGES
BUT IS MOST OFTEN
SEEN IN TWO GROUPS

 **10-25 YEARS**
AND
OVER 50 YEARS

1 ALMOST
600
PEOPLE
IN THE UK & IRELAND
DEVELOP
PRIMARY BONE CANCER
EVERY YEAR

Bones give the body structure, and may be considered as one of the strongest parts of the human body. Few of us think of our bones undergoing change – especially once we’ve stopped growing and reached adulthood. However, bones are made of different types of living cells just like any other part of the body. This means any one of our bones can develop cancer, just like any other part of the body.

‘Primary bone cancer’ is the name given to cancer that starts in a cell in a bone.

Cancer is a disease of the body’s cells. It causes uncontrolled growth of abnormal cells. A group of abnormal cells is known as a ‘tumour’.

**Altogether there are 9 different types of primary bone cancer.
85% of all cases diagnosed are caused by the four most common types²**

Osteosarcoma

is the most common type in children and young people. It tends to begin in long bones like the arms and legs.

Chondrosarcoma

is the most common type in adults. It tends to begin in the pelvis, ribs, arms, shoulder blades and legs.

Ewing sarcoma

is most commonly seen in 10-20 year olds. It tends to begin in the arms, legs, ribs, pelvis or spine.

Chordoma

is most common in those aged 60+.
It occurs in the spine.

1. Cancer Research UK (2013) Bone sarcoma statistics, www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bone-sarcoma (Accessed: April 2016).

2. Public Health England (2014): PHE Knowledge and Intelligence Team (West Midlands).



01

A DIFFICULT DIAGNOSIS

“

My son was fobbed off with various reasons for his excruciating pain, and had at least 12 visits to the GP.

From the parent of a child who died following a diagnosis of Ewing sarcoma at age 22

Primary bone cancer is difficult to identify, both for patients and for healthcare professionals. Recognising bone cancer at earlier stages is a crucial factor in improving the chance of survival.

SYMPTOMS EXPERIENCED BEFORE DIAGNOSIS

58% pain at night time

55% lump or swelling

54% problems with mobility

37% tiredness



21% weight loss

18% fever or sweating

14% loss of muscle tone

The symptoms of primary bone cancer can be very general, and are often mistaken for other common health conditions. Many people taking part in our research said before receiving their diagnosis they did not even know that cancer could develop in bones.

Low awareness and understanding meant they didn't consider the possibility that their symptoms could be due to cancer. Many waited months - or even years - before seeking help.



After noticing their symptoms, 1 in 5 people waited 6 months or more before going to visit a healthcare professional.

When patients take steps to seek help, medical professionals are not always able to provide a quick diagnosis. The people in our study reported making multiple visits to different types of healthcare professional.

Some patients reported that their doctor had never dealt with a case of primary bone cancer before theirs. Some doctors had never even heard of primary bone cancer.

This low level of awareness makes it especially difficult for patients to receive a timely diagnosis.

We heard how symptoms are often overlooked, not given enough attention, or are mistaken for other conditions such as growing pains, sports injuries, a slipped disc, or bursitis.

This leaves patients feeling distressed, unheard, and alone.

“
My son was wrongly diagnosed on three occasions; he even had physio on the tumour! His doctor had to look up in the medical dictionary what Ewing sarcoma was.

From the parent of a child who died following a diagnosis of Ewing sarcoma at age 9

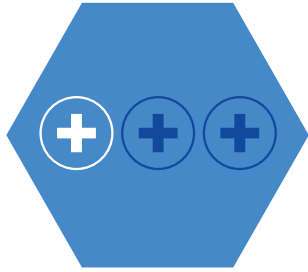
The difficulties experienced with gaining a diagnosis meant that people visited healthcare professionals multiple times:

- 87% visited their GP once or more, with nearly a quarter going five or more times.
- 44% visited an Accident & Emergency department at least once, due to the severity of their symptoms.

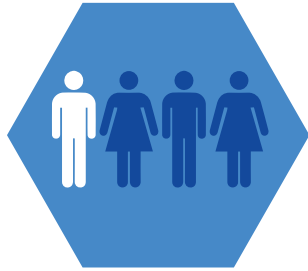
Patients also visited walk-in centres, physiotherapists, bone specialists and other consultants when seeking a diagnosis.

“
The pain was dismissed as a likely slipped disc and despite several visits to the GP, no scans were offered until five months after the pain was first reported.

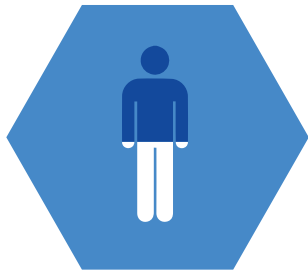
From the spouse of person who died following a diagnosis of osteosarcoma at age 45



Just over **1 in 3** visited **three or more** types of health care professional prior to diagnosis



Nearly **1 in 4** visited their GP **more than 5 times**



Almost **half** visited A&E at least once



A GP's PERSPECTIVE

As GPs, on average we will only see a few cases of sarcoma in our life time, and we will literally see thousands of cases of musculoskeletal cases in between. The biggest challenge is to sort out those that are high risk from those with very low risk symptoms.

- Dr Tom Kirk

“

I didn't know you could get cancer in the bone. You've got breast cancer, and all these different cancers, but you never hear about them in a bone.

It started with some swelling on my right thigh and knee. It was more like a sprain or a sports injury, but when it got bigger and more painful my Mum dragged me to see someone. We kept going backwards and forwards between the GP and the out of hours' doctors, but every time I went they would just tell me it was something different – too much exercise, too little exercise, housemaid's knee.

They even told me it was all in my head. My family kept fighting to get somewhere – we knew something was wrong. I couldn't use my leg, I'd lost weight and I was so exhausted that I kept falling asleep at school. My Dad gave up his appointment with his GP one day because I was so bad; she had seen osteosarcoma before and immediately sent me for an X-ray and blood tests. It took over five months to get to the point where someone believed me.

When I was finally diagnosed, I didn't know if I could go through the treatment. We had fought so long I didn't know if I had any fight left in me. I was watching my brother, who was four at the time, running round and I just thought 'how can I not fight?'. I wanted to see him grow up. That really gave me the strength to carry on.

Coleen, a past patient, diagnosed with osteosarcoma at age 14



02 A LONELY JOURNEY

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Cancer is devastating for any individual, but when there is no-one to turn to the devastation turns to isolation as well.

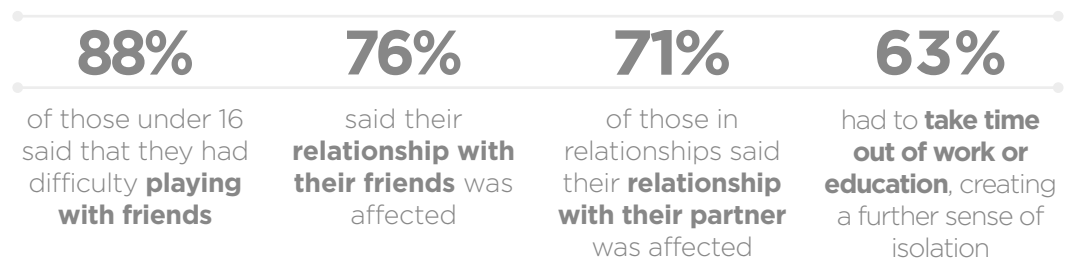
From a current patient who was diagnosed with Chordoma at age 46



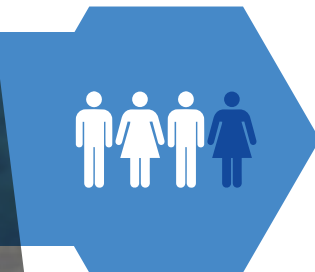
Many people with primary bone cancer feel alone at a time when they are most in need of support. Patients are unlikely to meet others with the same type of cancer, and say it is difficult to find suitable information about what to expect. There is also a huge impact on personal and social relationships.

Patients reported lacking the confidence to take part in their usual social activities. Feeling ill from symptoms or side effects also affected people's ability to socialise or play with friends. They also told us how they felt close family and loved ones were drifting away from them because of their illness.

Patients and past patients who completed our week-long research diaries also described the difficulties they experienced with making new relationships and dating, and maintaining intimacy in their relationships.



Nearly 3 in 4 people who had primary bone cancer said they felt socially isolated



A LACK OF SUPPORT IS FELT THROUGHOUT THE BONE CANCER JOURNEY

Some bone cancer patients can often feel their condition is neglected when compared with the support available for other types of cancer.

1. DIAGNOSIS

People in our study recalled feeling as if their world had fallen apart. They often felt they lacked personal, accessible, and supportive information about bone cancer at this early stage.

2. TREATMENT

There are only a small number of specialist bone cancer centres in the UK and Ireland. Patients reported that being separated from friends and family caused further emotional distress at an already difficult time.

“

I felt devastated. All we were told was that we had no option but to undergo treatment – there was nobody in the same position to talk to.

From the parent of a child who died following a diagnosis of Ewing sarcoma at age 9



3. AFTERCARE

People told us they missed having the close contact with their treatment centre, and needed somewhere to turn to for advice. This left some with feelings of anger and a concern for what the future holds.



“

I spent a lot of time in isolation for treatment, and no-one understood what I was going through at the time. I felt utterly lost and confused.

From a past patient who was diagnosed with Ewing sarcoma at age 8

“

I began to miss the support... that came with my cancer, and visiting hospital became worse because I was no longer a very important patient. I felt a bit forgotten and lost.

From a past patient who was diagnosed with Ewing sarcoma at age 8

03

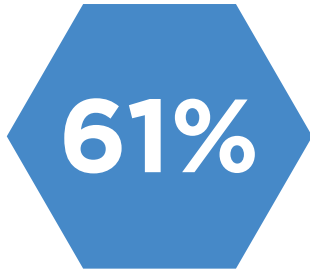
WHAT BONE CANCER TAKES AWAY

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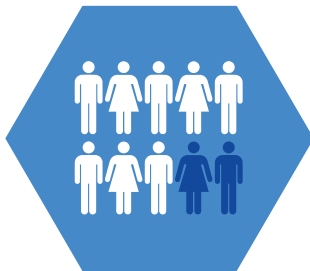
It makes every day difficult. I wake up tired and fatigued and always in pain. My brain doesn't work; my memory and cognition are severely affected making carrying out tasks very difficult. My mobility is limited due to anxiety and fear of falling. I struggle going out alone.

From a past patient who was diagnosed with osteosarcoma at age 14

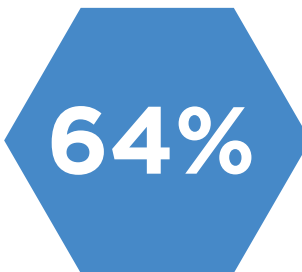




experienced some sort of pain



Nearly **8 in 10** of those who experience symptoms have had problems with mobility or movement



of those who experience symptoms said they experience tiredness

Primary bone cancer brings a burden of symptoms and restrictions that impacts patients on a daily basis.

Living with primary bone cancer can mean experiencing a range of debilitating symptoms. Pain, tiredness, and mobility problems take away the ability to do even the simplest every-day activities, affecting all aspects of life.

Over half reported at least moderate difficulty with day-to-day activities in the house along with almost 2 in 3 patients reporting at least moderate difficulty with day-to-day activities outside their home.

Bone pain is often viewed as one of the most severe types of physical pain that people can experience. We heard how pain was incredibly debilitating, and how difficult it is to control with medications.

HOW BONE PAIN WAS DESCRIBED



TOOTHACHE IN YOUR BONES



HORRENDOUS



EXCRUCIATING



LIKE A METAL VICE SQUEEZING YOUR BONE



LIKE ELECTRIC SHOCKS



TROBBING

We heard how people had to give up doing the things they love: from travelling and dancing, to simply lifting up their children.

My friends are off to Thailand soon to go on safari I feel envious and overlooked.

From a past patient who was diagnosed with spindle cell sarcoma at age 59

It stopped him from doing things he loved like playing football, being active.

From a bereaved sibling of a person who was diagnosed with osteosarcoma at age 17

I'm finding as our baby gets bigger, holding him for long periods puts a huge strain on my body.

From a current patient who was diagnosed with chondrosarcoma at age 34



Had to resign from a rambling club I was actively involved in, so my social side went completely.

From a past patient who was diagnosed with spindle cell sarcoma at age 57

I used to be out every weekend with my girlfriends, drinking and dancing. I miss dancing.

From a past patient who was diagnosed with Ewing sarcoma at age 40

Sometimes he's too tired to dry himself after having a bath so needs help and feels he's lost his independence.

From a parent of a current patient who was diagnosed with osteosarcoma at age 15

“

There is a lot you give up and there is a lot you learn to get around

Life is much harder now. I'm in pain from the limb sparing surgery and I constantly have back ache from walking with a limp for twenty-five years. I rely on painkillers to get through the day. I'm constantly tired and I don't sleep at night. Most days my daughter will go to school and I will go back to bed.

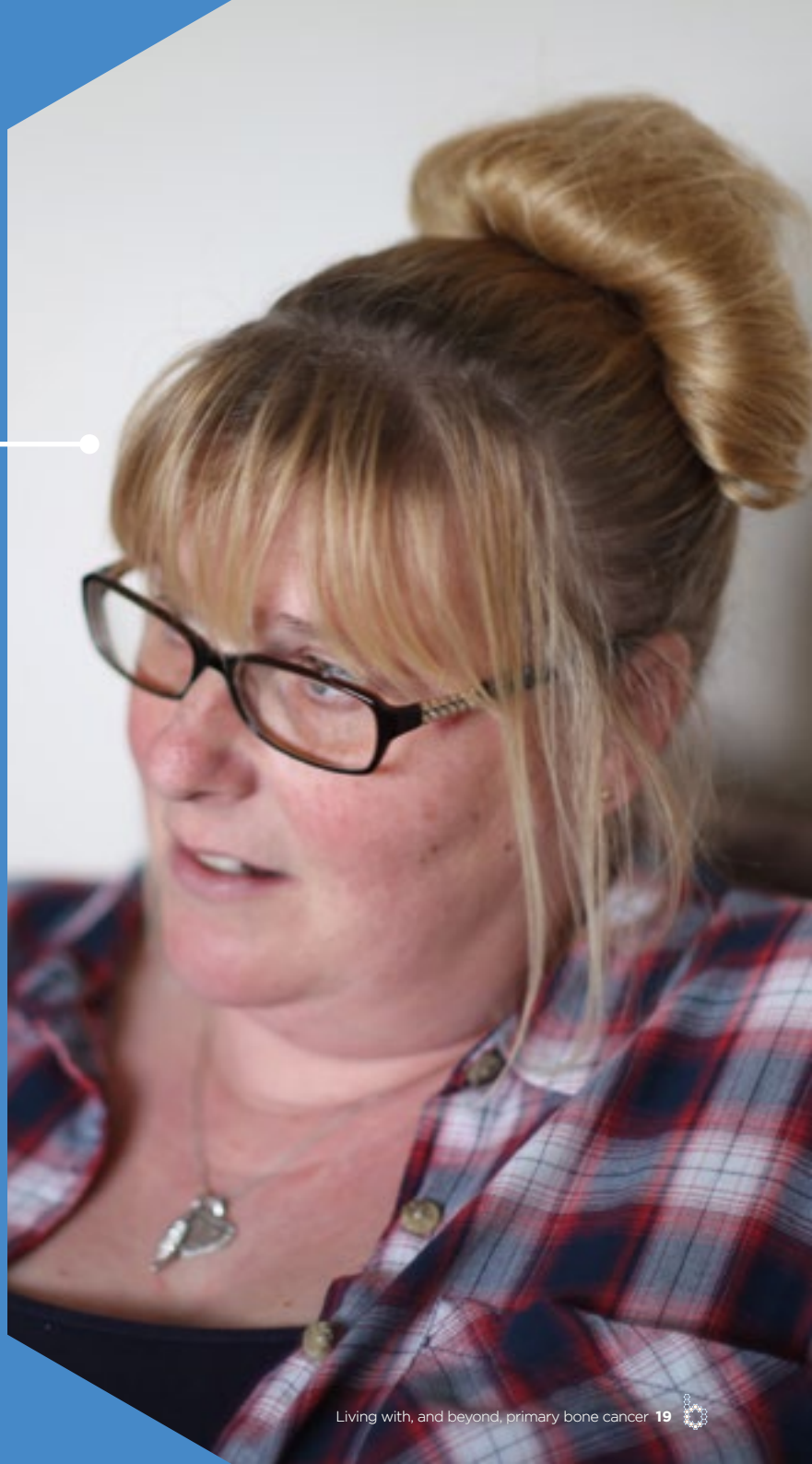
On a bad day, I'm snappy and my oldest son will say "you're in pain because you're shouting at us Mum". It's because I want to do the things I can't do.

I take the dog for a walk in the car and once I get to the park I sit in the boot throwing the ball. That upsets me because I used to like taking the dog for a walk.

Even round the house I find things difficult. Cooking is a nightmare because I can't stand there for long periods of time. I wash pots in stages so I can have a break and sit down. I don't go out, I don't go anywhere, my partner is always saying let's go to the pictures, but it hurts me sitting in an uncomfortable chair, it hurts my back, it hurts my knee.

I get so depressed sometimes. But then I remember that I've had this longer than I haven't. This is my way of life and it's made me who I am today.

Kelly, a past patient who was diagnosed with Ewing sarcoma at age 15



04 LIFE- ALTERING TREATMENT

“

Frankly, my daughter's life is suspended. No school, friends have disappeared, hair gone, gained 40 pounds, leg amputated, in and out of the hospital all the time. It's a nightmare.

Fom a parent of a current patient who was diagnosed with osteosarcoma at age 14



As primary bone cancer is rare, it doesn't receive the levels of attention and funding needed to develop better, more effective and kinder treatments. Currently, patients face aggressive chemotherapy, radiotherapy, and life-altering surgery.

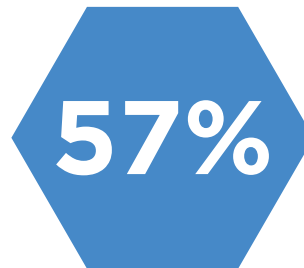
LIFE-CHANGING SURGERY

Many feel surgery is a major part of their treatment. As well as removing the tumour itself, 54% had surgery to remove the affected part of their bone, 35% had limb-sparing surgery and 23% needed to have a limb amputated. Over half of the people we spoke to underwent two or more types of surgery.



The operation to remove the tumour and some of the bones in her leg (and the plastic surgery to heal it up) took her over 2 months to recover from, and she had to get physio to learn how to walk again.

From the sibling of a person who died following a diagnosis of osteosarcoma at age 22

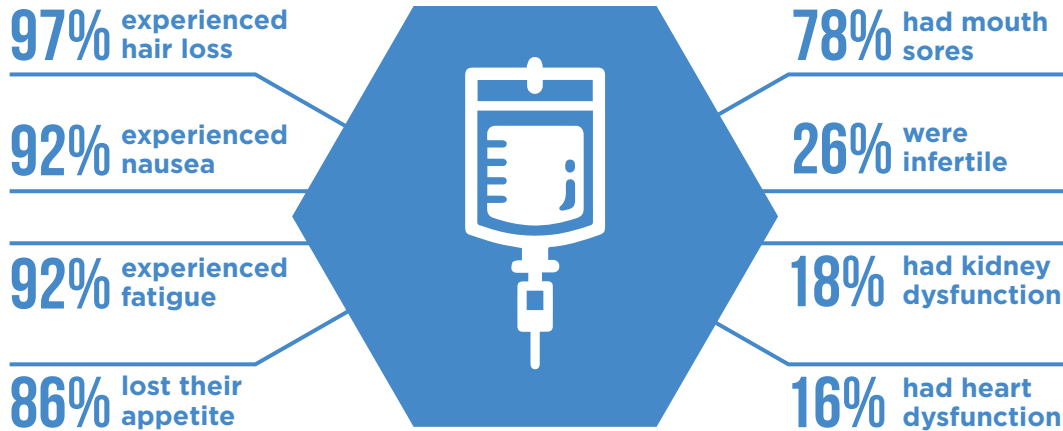


had **2 or more** types of surgery during their treatment

AGGRESSIVE CHEMOTHERAPY

Chemotherapy drugs and the doses used to treat primary bone cancer are particularly powerful. Many patients told us they found the side effects difficult to bear, recalling a significant impact on their quality of life.

THE SIDE-EFFECTS OF CHEMOTHERAPY



Compared with many other cancers, chemotherapy for bone cancer has a long duration of treatment. Patients can undergo up to 12 weeks of chemotherapy before surgery, then up to 30 weeks afterwards. Surgery is often followed by physiotherapy, extending the length of the hospital stay. It was common for people to say that they had long hospital stays, up to a year or eighteen months, making it almost impossible to maintain a normal life.

“

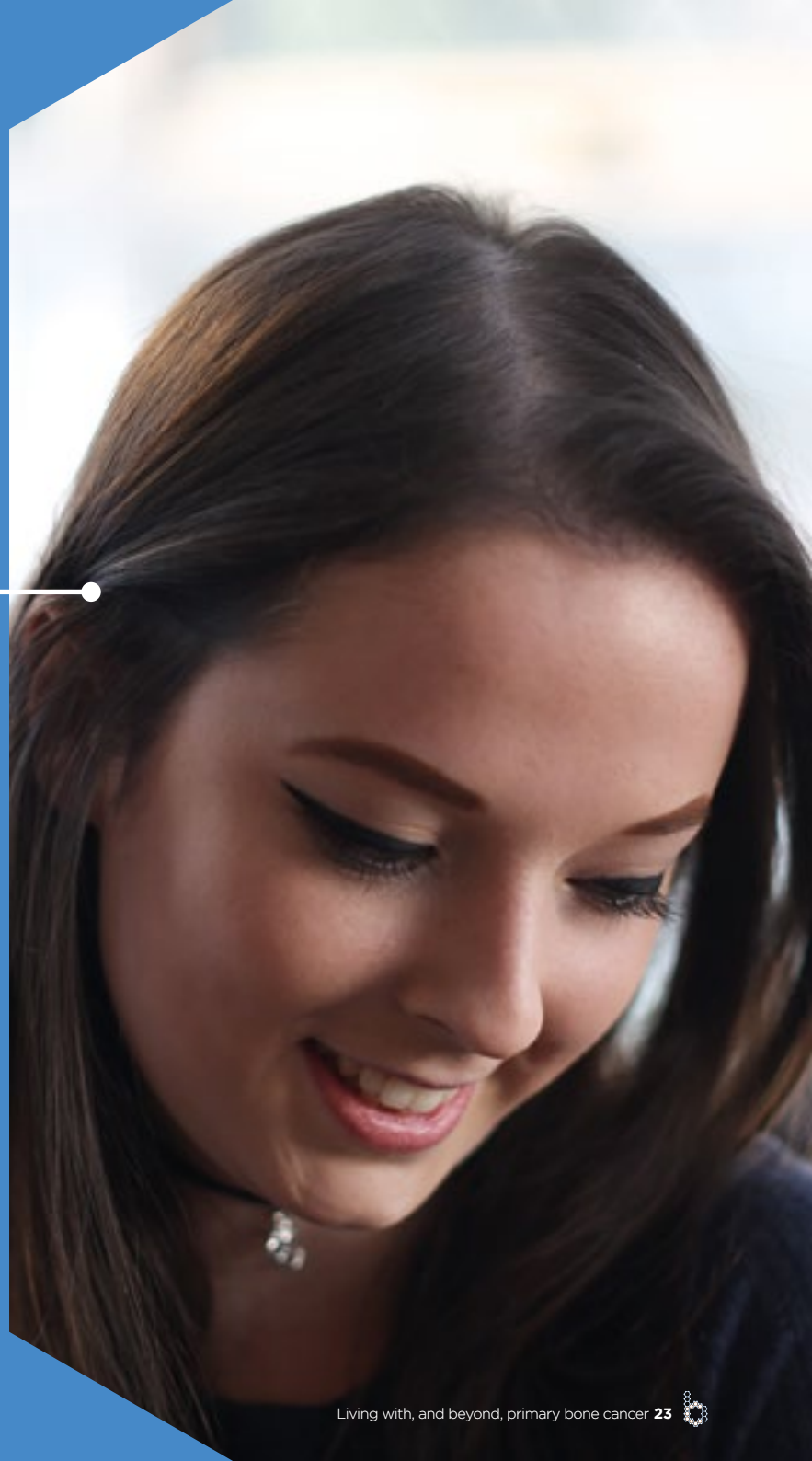
You just lose who you are during chemotherapy. You might as well be in a coma.

I was 8 years old when I was diagnosed, and I had both chemotherapy and a knee replacement to treat my bone cancer. The whole thing took a year. The chemo was the strongest kind as I was so young at the time. It was horrible.

My mouth and throat were full of ulcers and I had to be fed through a tube. I weighed around three stone at this time; I was really frail. It was the emotional impact that really took its toll. I don't remember getting a lot of support and I coped by not coping. At the time I was very resentful and angry. I felt so isolated. I'd spend days in bed and then switch to going to school, but no-one there really understood what I was going through.

For years later I had surgeries. I had a lot of keyhole surgery to extend my metal leg whilst the other was growing and had a cage on the bad leg where I turned screws each day to extend it. It just became routine. All this treatment lasted eight years, it's only just really over.

Sophie, a past patient who was diagnosed with Ewing sarcoma at age 8



05

A LIFE-LONG IMPACT

“

The old me died when I received my diagnosis.

From a past patient who was diagnosed with osteosarcoma at age 14



The impact of primary bone cancer doesn't end when treatment finishes. The physical effects of treatment and surgery can persist for years after remission. Those who shared their story with us also spoke of an emotional burden that has stayed with them beyond the primary bone cancer journey.

The on-going impact of treatment was strongly apparent in many patients we spoke to. Many – especially those who had undergone surgery – did not anticipate that their quality of life and overall health would be affected indefinitely.

“

I was not prepared for the size of the scar and how it would affect me afterwards... I understand the tumour had to be removed, but I should have been warned about nerve damage, how it would affect my life.

From a past patient who was diagnosed with chondrosarcoma at age 35

80% of people in remission who still experience symptoms reported problems with mobility. Some told us about the adaptations they needed to make to do the things they normally would, such as planning rest breaks into their day-to-day activities.

Some have also had to learn how to do everyday activities again.

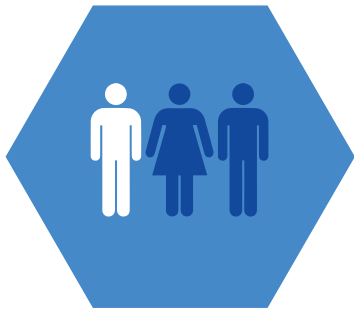
“

My child had her leg amputated. This has seriously impacted her ability to be independent in almost every way, including toileting and showering. She is learning how to do almost everything in a new way.

From a parent of a current patient who was diagnosed with osteosarcoma at age 14

93%

of friends and family are concerned about the effects on the long-term health of loved ones who have primary bone cancer



1 in 3 people whose education was affected had to reassess their education or career aspirations

Primary bone cancer also leaves patients with long-term emotional difficulties, including low self-esteem, anxiety about the cancer returning, and social and psychological impairments. Issues of anxiety and depression tend to be worse for those patients who have felt unsupported during and after treatment.

Primary bone cancer can alter the course of people's lives, and force patients to find a new identity for themselves. It affects patients' ability to work, affects the type of work they can do, and often means reassessing education and career aspirations.

“

I still feel tired and moody, and sometimes don't have much drive to do things. I had to quit my job more than a year ago and the situation is very depressing. I feel like I can't catch up with all the tasks I should be performing. The “new normal” sucks big time.

From a current patient who was diagnosed with osteosarcoma at age 29

“

I didn't have the energy to work full time. It restricted the jobs I could do and made other jobs that I would have liked to have done inaccessible.

From a past patient who was diagnosed with osteosarcoma at age 17

“

Years later people say ‘well, you’re alright now’. But you’re never alright with one arm.

I was first diagnosed with bone cancer in 1969 and to this day, it is still with me. The obvious effect is that I had my left arm amputated in 2004 so I’ve had to make so many changes to get by.

I can dress myself, but it’s not easy. Getting a shirt over my prosthesis is difficult and it takes time. I have clip-on ties and slip-on shoes so I can get dressed independently. I love bird watching and use special binoculars that I can hold in one hand so I can still do this.

I developed mild anxiety after my first tumour so I live my life based around ‘comfort zones’. I prefer to avoid public transport, but luckily my wife and I find our way around this. I still get frustrated sometimes, and I sometimes shout at myself when I’m at home if I can’t do things as quickly as I used to. But I’ve got to bear in mind, I’m still here. Mentally and physically I’m still strong. I am determined to carry on.

Peter, a past patient who was diagnosed with Ewing sarcoma at age 27



“

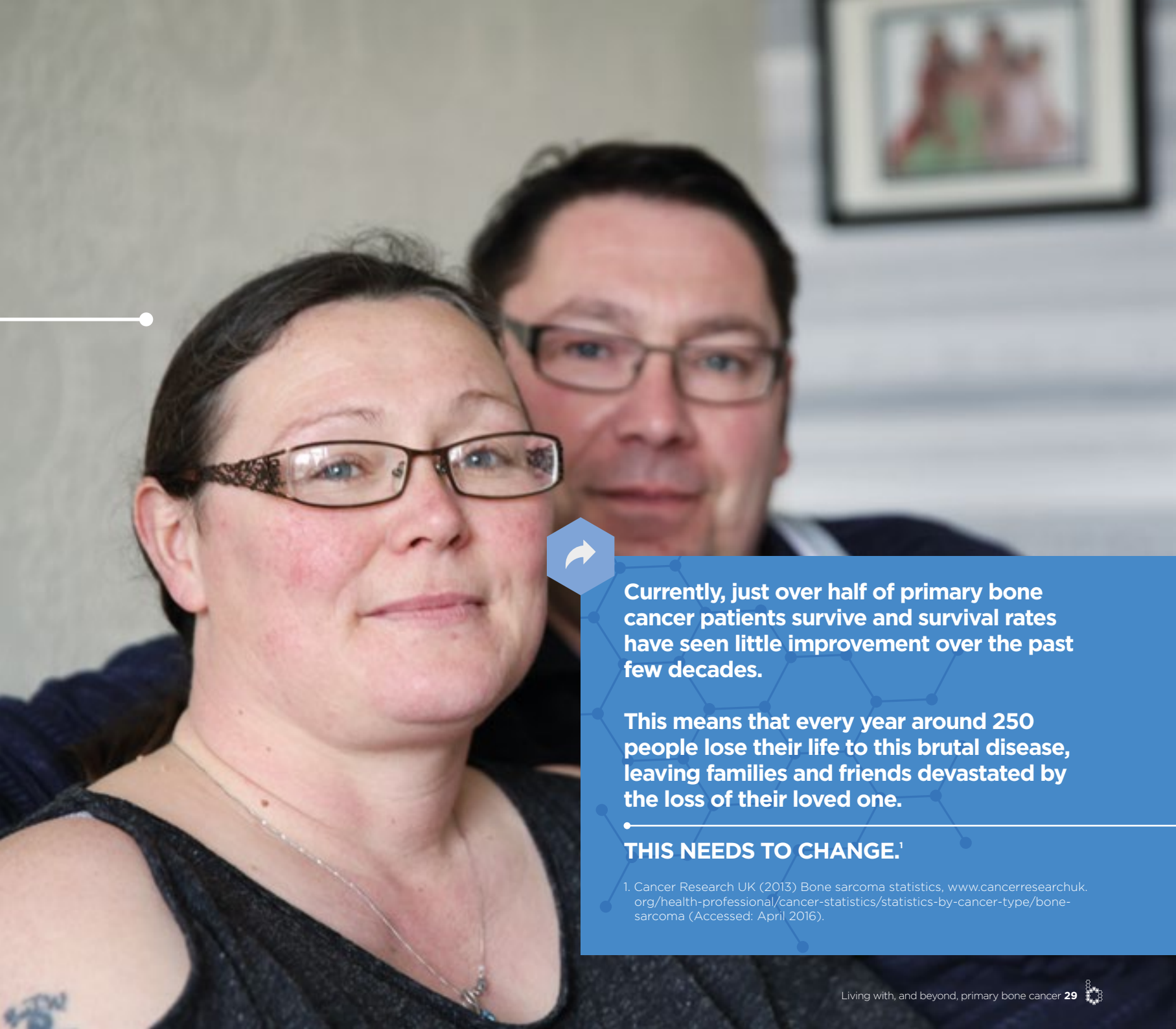
You've got this new life you don't want. Life is never going to be the same again.

We lost our daughter two years ago. The day Lucy died I didn't just lose my daughter, my whole routine changed. We had to learn to live again. But you just don't want to move on because your child is not supposed to pass away before you. We wish she was still here, even despite the horrors she went through fighting bone cancer.

In the last few months of Lucy's life, it was hard. She would talk about the presents she wanted next Christmas, next birthday. The difficult thing was knowing that she wouldn't see another birthday, she won't see another Christmas. It's been so tough for Lucy's sister to cope too. She still says goodnight to Lucy and blows her a kiss before she goes to bed. For everybody else life moves on, but we have to deal with this constantly, this sense of emptiness and loss. Little things can just remind us of Lucy at any point. This year all her friends are going to secondary school, and it's a constant reminder that she won't.

We decided to go to a bereavement camp to get us through this. It's really helped us to celebrate Lucy's life and has given us time to reflect. With their help, we're starting to rebuild our family back up. It will never be the same but it allows life to start again.

Tony and Catrina, parents of Lucy, who was diagnosed with osteosarcoma at age 5



Currently, just over half of primary bone cancer patients survive and survival rates have seen little improvement over the past few decades.

This means that every year around 250 people lose their life to this brutal disease, leaving families and friends devastated by the loss of their loved one.

THIS NEEDS TO CHANGE.¹

1. Cancer Research UK (2013) Bone sarcoma statistics, www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bone-sarcoma (Accessed: April 2016).



THE BONE CANCER RESEARCH TRUST

We are the leading national charity dedicated to fighting primary bone cancer

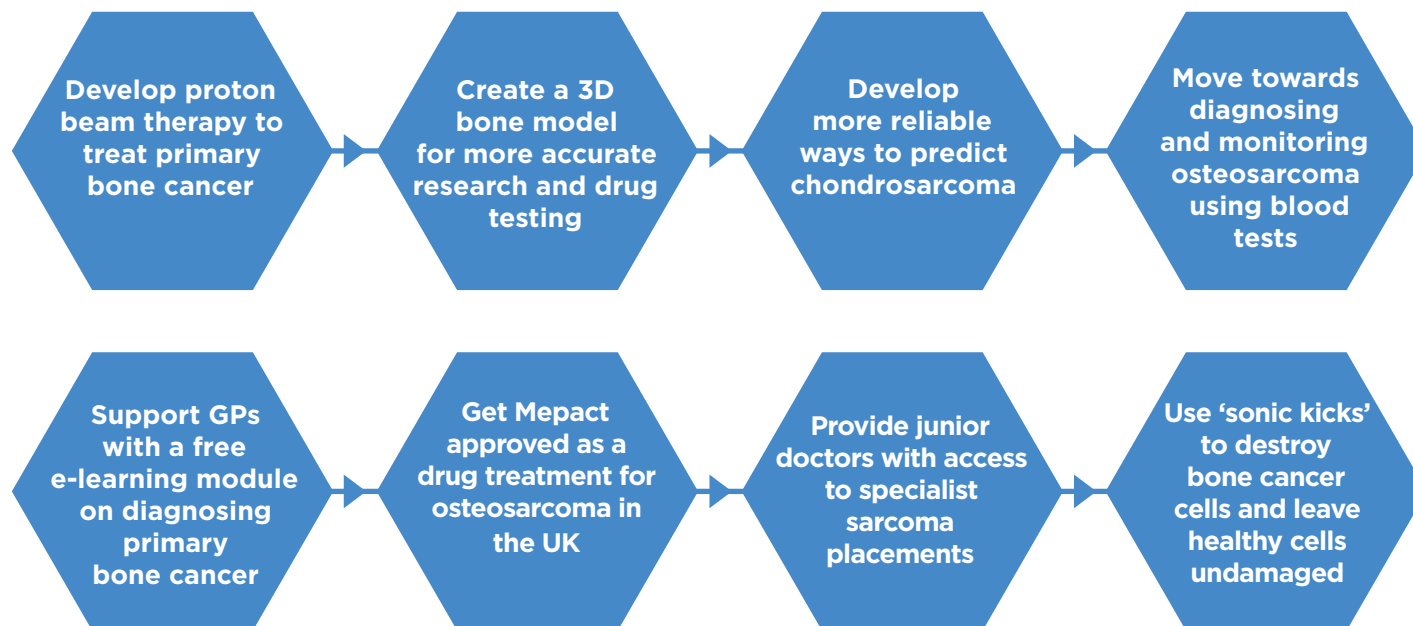
Research | Information | Awareness | Support

We are uniquely placed to make a difference through research, and our vision is for a future where primary bone cancer is cured. For those affected by the disease right now, our supportive network and top-quality information mean no-one should have to feel alone or isolated.

We are the voice of the primary bone cancer community.

JUST SOME OF WHAT WE'VE ACHIEVED SINCE 2006

With the support of our community we've funded the research, campaigning and training needed to:





THE FUTURE: WE NEED YOUR HELP

54% of all cancer deaths in the UK are from the rarer types of cancer - this includes primary bone cancer.³

We will keep fighting for primary bone cancer to get the levels of attention and funding needed to develop better, more effective and kinder treatments.

Until there's a cure, we need your help.

HOW CAN YOU HELP?

SHARE YOUR STORY

Sharing your experiences of primary bone cancer will help us raise awareness amongst the public, healthcare professionals, researchers and policy makers.

JOIN OUR SUPPORTIVE COMMUNITY

Visit our social media pages for updates and news from other people affected by primary bone cancer. Find high-quality, reliable information on our website.

HELP FUND PIONEERING RESEARCH

We rely entirely on donations and fundraising to support our vital work. Join one of our fantastic challenge events - from half marathons to sky dives - or work with our fundraising team to organise your own.

 **FOR MORE INFORMATION VISIT WWW.BCRT.ORG.UK**

³ National Cancer Intelligence Network (2013) Rare and less common cancers, Available at: http://www.ncin.org.uk/publications/rare_and_less_common_cancers (Accessed: April 2016).





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