



**“FIGHTING
CANCER
ISN'T JUST
ABOUT
SURVIVING”**

OUR IMPACT 2018

**YOUNG LIVES
vs CANCER
CLIC SARGENT**



OUR PROMISE

When cancer strikes young lives CLIC Sargent helps families limit the damage it causes beyond their health.

CLIC Sargent will fight tirelessly for children and young people with cancer, often when they feel they can't. We do this individually, locally and nationally, so that they can focus on the important things, like getting well.

We understand everyone is different, so we work hard to help when each child and young person needs it most. We shape the work we do around six core principles:

1

When the doctor says cancer, we are there and ready to help.

2

Cancer costs. A lot. We give grants and help people access benefits.

3

There's no place like home, so we offer free accommodation near hospitals and give expert cancer care close to home.

4

Cancer shatters young cancer patients' educations, social lives and future prospects. We help them thrive, not just survive.

5

When a child dies we help families find a way to cope. We also help families prepare in case the unthinkable happens.

6

The NHS and government have the biggest impact on young lives with cancer but often don't provide what is needed. Our campaigning challenges and supports them to do better.

**THEIR
VOICE
OVER
OURS**



We believe the voices of young cancer patients, and their families, are much more valuable than our own corporate spiel. So, we asked three of them – Seren, Kaiser and Vicky – to share their stories, and how we've made a difference to their cancer experience. So, without further ado:



Kaiser
24, from Birmingham, England

I started to get really itchy skin. I went to the doctor's and they said it was just eczema. I went to specialists to get an answer but everyone said the same thing, apart from one professor in hospital who sent me for a scan. When I went for the results they told me I had a tumour on my chest which was days away from spreading to my heart.



Seren
22, from North Wales

I was diagnosed at 19, during my first year at uni. At first, I thought it was just uni life taking its toll. But it didn't seem to be getting better, so I went to the doctor's for a blood test. Four months after I'd noticed something was wrong, they told me it was cancer.



Vicky
(Isabel's mum) from Christchurch, England

When Isabel was just a few days old, my partner and I took her to the doctor because she had an enlarged stomach. The doctor dismissed it as constipation but now we know it was an enlarged liver due to leukaemia. A few days later she started showing random bruises over her body. They weren't the type of bruises that you get when you hurt yourself, they were grey. At just 22 days old, Isabel was diagnosed with a rare type of blood cancer, called Infantile Acute Lymphoblastic Leukaemia.



When the doctor says cancer

**“I only had a
couple of days
until it spread
to my heart.”**

Kaiser



My diagnosis came out of the blue. I kept being told it was asthma or eczema. Then they said it was cancer and I only had a couple of days until it spread to my heart. I met Orlando and Sam from CLIC Sargent, and they just made me feel at home. The role they played from the start was really good.



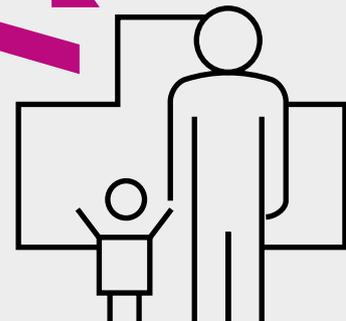
I can't really remember anything about when I was told I had cancer – it's like I was in a little bubble. One minute I was normal Seren. Five minutes later, everything changed. Then my CLIC Sargent Social Worker, James, came over. He took me, my mum and my dad into a room and talked us through the PIP [Personal Independence Payment] benefit paperwork, so we got all that sorted. Then he made my mum and dad leave the room and had a chat with me on my own, which I thought was nice, because I was overwhelmed. I mean, I tell my mum and dad everything, but it was nice he gave me the option to ask any questions, to just speak to him on my own.



I didn't even know kids could get cancer. When we got the results back from the blood test, it was horrendous. Isabel began chemotherapy a couple of days later and Becca, our CLIC Sargent Social Worker, was amazing. I don't know what I would have done without her.

7,010

Last year we helped 7,010 children and young people with cancer, and their families, cope with the impact of a cancer diagnosis.



“I don’t think people understand how much it costs.”

Seren



I don’t think people understand how much it costs, not just to live and have no job when you’re young but also when your family can’t always support you. You spend a lot of money. You’re getting buses to hospital, then you’re getting taxis when you’re not well enough to get on a bus – you can’t because of your immune system. I had to get a new bed at home because I only had a single bed and my parents wanted me to have enough room because I was ill. During treatment I lost two stone, so I also needed a new wardrobe because I couldn’t fit in my old clothes. It’s all these things that people don’t think about.



You don’t think about money when your child has cancer. It’s the last thing on your mind. Me and Luke had worked all our lives, so we didn’t know anything about benefits – how the system works, what we could claim for. Becca got us through all the paperwork to apply for benefits, and made sure we got the grant provided by CLIC Sargent, which made a massive difference at the beginning.



I didn’t know much about PIP. But Sam and Orlando talked me through it and helped me fill out the forms. I was really, really badly ill. It did take quite a while to get PIP so CLIC Sargent’s grant helped at the start.

OVER 5,300 GRANTS PROVIDED

In 2017/18, we provided over 5,300 grants totalling £1,075,962 to help children and young people with cancer, and their families.

We provide grants when they're most needed. For example, cancer costs from the moment of diagnosis, but there's no financial support sitting there waiting for you. So to help with these immediate costs, we give a grant of £170.

Last year, we also launched a new Home Essentials grant, funded by Morrisons. This grant will help us better support families and young people with cancer in dire financial need, who simply don't have the money for home essentials, like heating, food or nappies.



There's no place like home

“We were just amazed that this support was offered.”

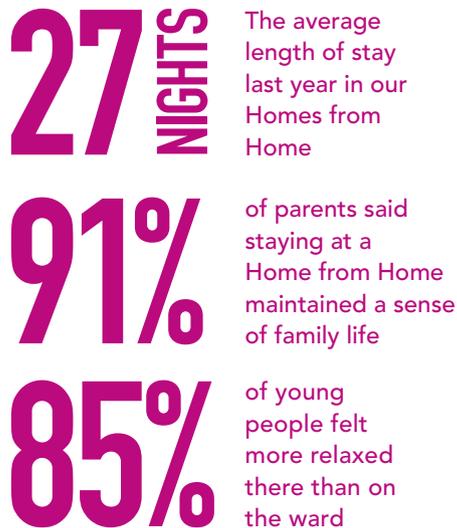
Vicky



When Isabel was receiving regular treatment in Southampton, we stayed at CLIC Haven right next to hospital. We were there for weeks at a time and were just amazed that this support was offered. It felt homely and it gave us a nice and safe place to sleep. We could rest and stay near Isabel, it made such a difference. Without the Home from Home, it would have been a 45-minute drive one way.



Our Homes from Home reduce a family's travel and accommodation costs, and allow them to stay together close to hospital during their child's treatment. Last year, 1,213 families stayed in our 10 homes, completely free of charge, for days, weeks or months at a time depending on treatment.



Demand for our Homes from Home continues to grow, so we're doing something about it. Last year, we started building a new home in Southampton, Jean's House. With nine new rooms, this will offer 3,285 nights for families going through their child's cancer treatment. We also began moving our Home from Home in Edinburgh, alongside the relocation

of the Royal Hospital for Sick Children, to make sure families remain close to the hospital during treatment. We also increased the reach of our Homes from Home offer, by giving parents staying on hospital wards access to basic home comforts in our properties, like washing machines, a kitchen to cook in and a quiet area to sit and have a cup of coffee. This 'Home Comforts' service will be rolled out across all our Homes from Home next year, with the support of our charity partner, Morrisons.

Our nurse educators

To make sure as many children and young people with cancer can get the best care close to home, we recruited three Outreach Nurse Educators to deliver best practice for childhood cancers to healthcare professionals supporting children with cancer in local services. Linda Sanderson, our nurse educator for north England, delivered 50 specialist education sessions to 308 health, social care and educational professionals.

Our nurse educators are vital in making sure young cancer patients and their families get the best care close to home, so they can get on with their lives.

We're extremely grateful to the Stavros Niarchos Foundation for funding Linda's post for the last two years.

Helping them thrive, not just survive

“My journey with CLIC Sargent has changed me.” Seren



While I was on treatment my uncle was also really ill, he had throat cancer. We lost him one month after I finished treatment. I was getting loads of support from my social workers Sam and Orlando, talking to them and them trying to help me keep my mind away from it. My mental state was horrific. Whenever I used to speak about what I was going through I'd just break down. But thanks to CLIC Sargent's Young Person's Reference Group (YPRG), meeting people in a similar situation, now I can actually speak in front of a crowd. I've got to the stage where I'm ready to just go full steam ahead.





I joined CLIC Sargent's YPRG a year after treatment. Rachel [CLIC Sargent Social Worker] said I should join. I got to meet young people who'd been through similar experiences, and got presenting opportunities which I could put on my CV. None of my friends have had the chance to have that experience or build up their confidence in that way. I did my dissertation about the language people use to talk about their cancer. I don't think I ever would have done that if I hadn't been able to turn this into a positive experience because of the support CLIC Sargent has given me.

In April, I ran the London Marathon. I never thought I'd be able to do that after my cancer diagnosis. And I didn't even have to think about who to race for;

CLIC Sargent were the first there to help me through everything and gave me so much support.

Young Lives Pathway

We launched Young Lives Pathway, a comprehensive insight project with parents and young people to better understand their experience of cancer and our role in their journey. Listening to what is most important to people, where they feel supported and when they don't, is crucial in helping us to develop our services.

Music programme

Our music programme continues to help young lives thrive, using music to help people through their experience with cancer. Last year, we ran a workshop for 20 young musicians delivered by music industry professionals, with the final performance aired live across the UK.

When a child dies

**“It’s so important that
someone’s there
for you during the
whole journey.”**

Vicky





When the chemo stopped working and Isabel relapsed, we brought her home to begin palliative care. Isabel had a big party for her first birthday with all of our family and friends. She passed away eight days later.

By this stage I had lost my job because I needed to focus on Isabel and I was diagnosed with post-traumatic stress disorder after Isabel passed away. It was so hard to get back to work, a lot of parents like us struggle to get life back on track.

My CLIC Sargent Social Worker Becca was there for me through it all, she kept checking up on me. It's so important that someone's there for you during the whole journey, where you don't have to explain everything all the time.

466

families received compassionate grants totalling £140,100, to help them pay for funeral costs.

350

home visits were provided for bereavement support, helping parents begin to come to terms with the loss of their child.

Making change happen

“I was so overwhelmed
when I found out
we did it.” Vicky

WE DID IT!

A woman with long, wavy blonde hair is smiling and looking towards the camera. She is wearing a black top under a red and black plaid shirt. She is holding a white sign that says "WE DID IT!" in purple, bold, sans-serif capital letters. The background is a textured, yellowish-brown brick wall.



I know how it feels to lose your child, your job, your home. It's so hard. So

when Carolyn Harris MP and CLIC Sargent campaigned last year to end funeral costs for parents who've lost their child to cancer, I spoke on their behalf in parliament. MPs would come in during the day and speak to us, find out what it was all about. I think they hadn't really thought about it before. They don't think about children dying of cancer and the costs, so it was quite thought-provoking for them.

I was so overwhelmed and emotional when I found out that we did it, that government was setting up a Children's Funeral Fund. Now families going through this in the future will have fewer financial worries.

We listen to young cancer patients and their families, making change happen in the system through our research and campaigning.

Two in three parents are already in debt as a result of their child's cancer diagnosis. It's simply not right they should also have to worry about funeral costs, if the unthinkable happens. This is why we've been campaigning for government to create a Children's Funeral Fund. And we did it! In April 2018, the Prime Minister announced that parents in England will no longer have to pay for burial or cremation costs for their child. This follows our work in getting child burial fees scrapped in Wales and Scotland last year.

But that's not all we did to make change happen last year. We launched our *Hidden Costs* report, highlighting the emotional costs of cancer for young people. Two young people presented on our research at external conferences. And we ran campaign masterclasses to equip parents and young people to get campaigning. 14 young people also spoke at parliamentary events, met politicians, gave evidence to a select committee and met with the Financial Conduct Authority to call for changes in the system.

WITHOUT YOU, WE ARE NOTHING

Our work wouldn't be possible without everyone in Team Young Lives – our legendary supporters, partners, staff and volunteers. It's time to celebrate just a few of the things we achieved together last year.

Banding together for World Cancer Day

Last year was our best World Cancer Day yet, raising £560,000, six times more than 2016/17. Our charity partner Morrisons led the way, raising an incredible £325,000 of this through bucket collections and World Cancer Day band sales.

The Sun appeal

We secured a newspaper partnership with The Sun, raising over £130,000 with The Sun *Smiles at Christmas* appeal. The Sun ran 21 stories – the equivalent of £1 million in free editorial coverage – with 60 million readers hearing about our vital work.

#NoFilter4Cancer

In June we launched #NoFilter4Cancer, a month-long campaign giving young cancer patients a voice to share the unique challenges they face around mental health and body image. Activities included a range of innovative digital content such as a virtual choir made up of young cancer patients. We also produced a new policy report on the hidden costs of cancer, and launched a new information resource including 17 videos by young people offering tips and advice for other young people.

We know the impact we have on young lives against cancer isn't just down to big partnerships. In 2017/18, 38,000 regular givers raised £4 million. That's the equivalent of 160,000 social work hours, or maintaining the grants we give to families for four years!

2,773 challengers ran, cycled and skydived for Team Young Lives

Worth their weight in gold

Last year, our long-standing partner Signet Jewelers supported our Jean's House appeal to build a bigger, better Home from Home in Southampton. They also donated engagement and wedding rings to help young people and families struggling financially. The jeweller has now raised over £650,000 since getting on board in 2014.

J D Wetherspoon passes the £15million mark (and played Santa!)

In 2017/18 our 16-year partnership with J D Wetherspoon reached an incredible £15 million! Staff and customers from the nationwide pub chain have fundraised tirelessly for young lives against cancer, raising £1.8 million alone last year. The partnership is more than just fundraising though – last year they surprised families staying in Paul's House (one of our Homes from Home) at Christmas with hampers full of luxury goodies.

Morrisons makes it

Our three-year partnership with Morrisons enjoyed its first full year in 2017/18 and exceeded all expectations. In just 17 months the partnership has raised £5m, and they've now pushed their target to £10m by March 2020. Their incredible fundraising prowess has seen a direct impact on young lives in many ways, including:

- A new Home Essentials grant to support those struggling to pay for even the most basic provisions like food and nappies
- Creating an online grants system so families can access grants money immediately rather than having to cash in cheques
- A team of nurse educators, working in local and community healthcare settings, to deliver the most up-to-date cancer care education to relevant staff, so families can feel confident accessing safe cancer care closer to home.

1,397 volunteers
joined
our fight

People's Postcode Lottery

Last year, the People's Postcode Lottery raised £2.3 million, taking the total raised to support young cancer patients to a spectacular £6,750,000 since 2016.

Empowering Young People

Big Lottery Fund Northern Ireland supported our social work team in Northern Ireland for the sixth year in a row. Thanks to the Fund, young people accessed group work sessions around health, fitness, emotional and peer support, and education and employment.

Peter Sowerby Foundation

Last year, the Peter Sowerby Foundation gave a three-year grant of £214,345 towards our work in Yorkshire. As a direct result, our care teams in Leeds and Sheffield are making a difference to 600 young cancer patients every year.

The James Tudor Foundation

The James Tudor Foundation is a key supporter of our services in the South West. To date the Foundation has donated £207,000, with a particular focus on our nursing programme, supporting families with clinical and practical care.

Garfield Weston Foundation and Fidelity UK Foundation

The Garfield Weston Foundation and the Fidelity UK Foundation have provided £175,000 towards a new social care database. The system will be used across CLIC Sargent, enabling better access to information to enhance our one-to-one support for children and young people across the UK.

Events and committees

Through the St Nicholas Party, Windsor Race Night and CLIC Sargent Golf Day, dedicated committees and supporters raised over £700,000 to provide vital support for young cancer patients and their families.

HANDS UP, WE'RE NOT PERFECT

We're proud of our achievements. But we didn't get everything right. There, we said it. We're telling you because your support keeps the charity running, so you have a right to know. It also helps us improve, and that's important because young lives are depending on us.

Key things we didn't achieve last year:

- Children and young people regularly tell us wifi is poor in hospitals. We wanted to do something about it in 2017/18 but it's proved harder than we thought. We're working on it
- We know the diversity of our staff needs to get better. For example, only 8.2% identify as Black and Minority Ethnic. We've started looking at ways to improve diversity throughout our next strategy
- Even though we raised more money than ever before, we didn't quite reach our income target, which we're stretching to invest more in services
- We support 69% of all children and young people diagnosed with cancer, consisting of 87% of children (0–14) and 56% of young people (15–24). That's good, but not good enough.

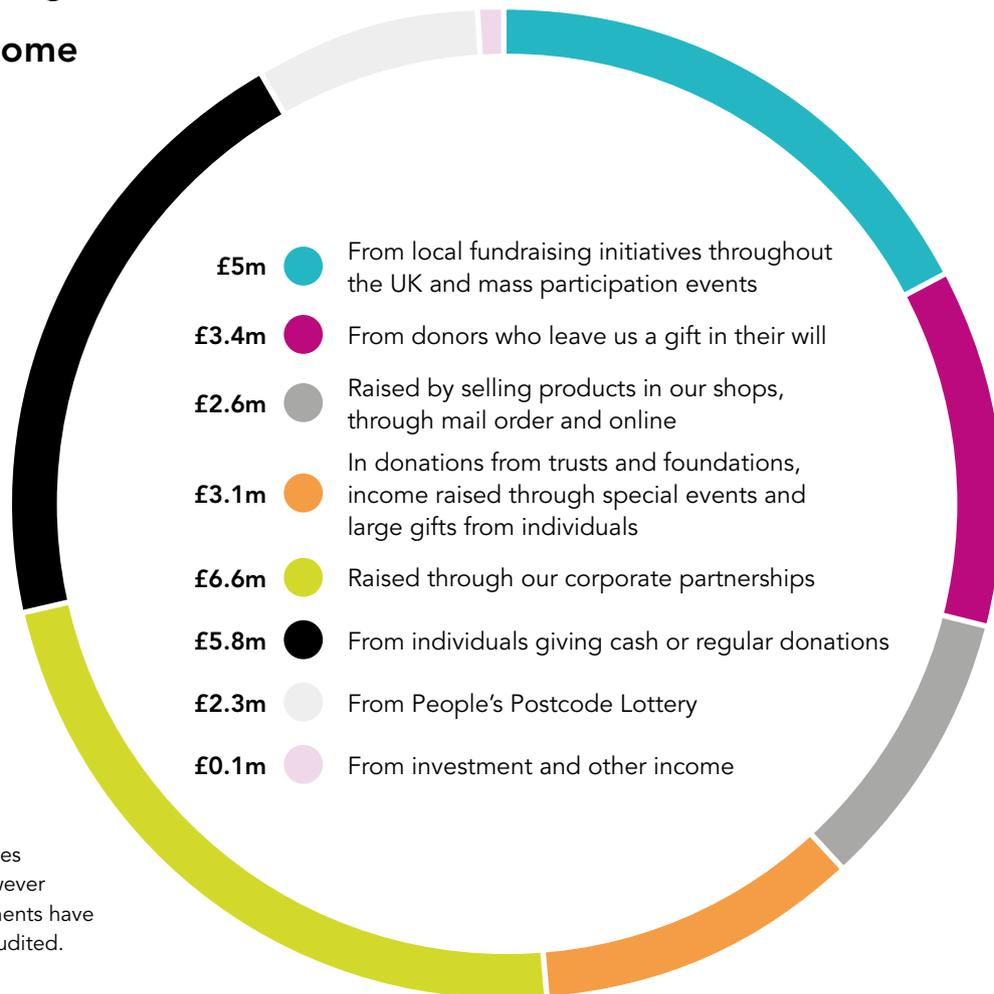
We also learned a lot from the Young Lives Pathway. Looking at parents' and young people's experiences of cancer has highlighted many areas where we're having a positive impact. But it has also flagged areas where they don't feel as supported as they'd like. They told us we need to consider how to:

- Provide more support after treatment ends, emotionally, mentally and practically
- Offer more practical and emotional support for dads, and a young cancer patient's brothers and sisters
- Provide or signpost to accurate info on clinical trials and treatment
- Help young people find the words to tell their friends they have cancer.

THE FIGURES

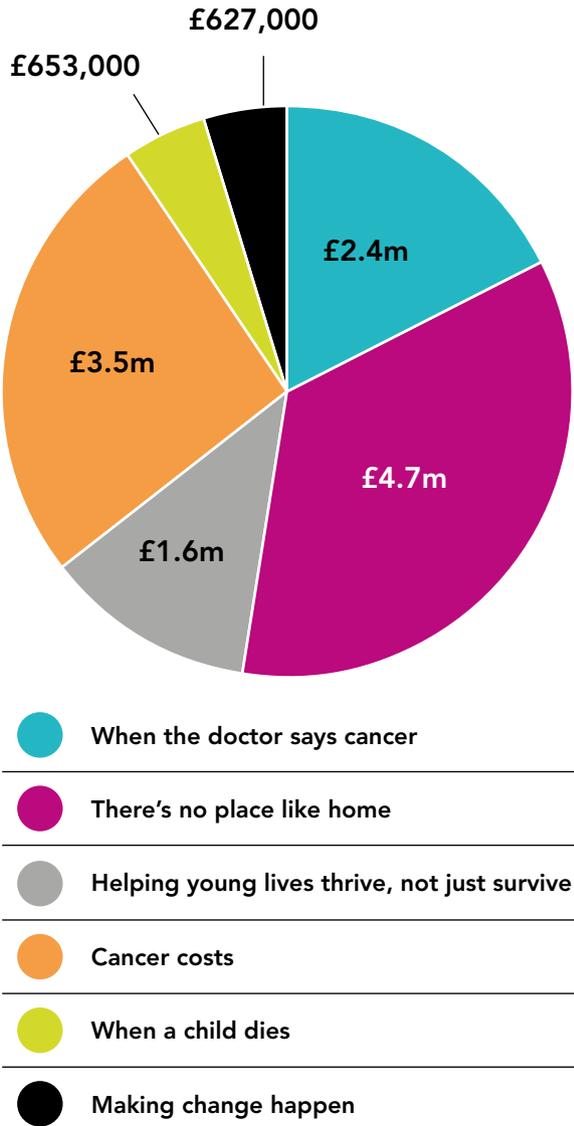
Thanks to you, we raised £28.9 million this year to limit the damage a cancer diagnosis causes to young lives.

2017/18 income



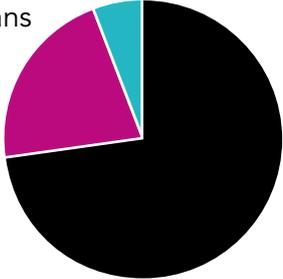
These summary financial statements have been extracted from the full Annual Report and Accounts which were approved by the Board of Trustees on 26 June 2018. However these summary statements have not been separately audited.

How we spent it for young lives against cancer:



The cost of raising income

At CLIC Sargent we don't receive government funding for our core services. That means everything we spend on our services has to be generated the hard way, and raising money costs money.



- Donations and legacies : £8,691,000

- Retail trading : £2,543,000

- Fundraising trading : £667,000

During 2017/18, for every £1 we spent on fundraising we raised £2.42. That isn't quite as good as we would like but we have been investing in increasing the number of regular givers. That provides long-term financial sustainability but is expensive in the short term.

The remaining gap between our income and expenditure is £3.3 million. £2.2m raised by Morrisons has been set aside for specific charitable activities in 2018/19, and £1.1m has been used on construction work on our new Homes from Home.

If you want more info on how charities raise and spend money, try this helpful guide from NCVO: howcharitieswork.com

100

SUPPORTED

CHILDREN AND
YOUNG PEOPLE
WITH CANCER,
AND THEIR FAMILIES

5,303

grants given to help families
totalling over £1 million

OUR IMPACT
IN NUMBERS

3

government policies changed, helping families get the support they deserve

Welcomed

1,213

families in our Homes from Home



1,400

opportunities for young people and families to get involved in shaping CLIC Sargent's work

294

individual school healthcare plans created to provide a smoother transition back into education



1,288

visits to schools, colleges and universities to deliver care to students to stop them missing classes

TEAM YOUNG LIVES: THE FUTURE



By getting to this point of the Impact Report, I'm sure you'll understand why I'm so proud to do my job.

Across CLIC Sargent, I see dedicated and passionate staff working tirelessly to support children, young people and their families through the devastation of cancer. Whether it's social workers helping families navigate through the turmoil of a diagnosis, to housekeepers keeping our free Homes from Home spotless, to fundraisers raising the money to make the work possible, every day I'm in awe of the work we do. This year we've made progress in rebuilding our financial stability, and we're investing more into our services than ever before. But I'm not going to repeat the impact already covered in this report. I lost out to Kaiser, Seren and Vicky for that job, and rightly so. They demonstrate the way we stop cancer destroying young lives far better than I could.

Instead, I'm going to share with you a tough reality we must face.

We currently reach two thirds of children and young people with cancer in the UK. That's an achievement in itself because it's the largest specialist reach from any organisation into this group. But it means there are people – over 1,000 – struggling with the devastating impact of cancer, who may not know we even exist. And that simply isn't good enough. People like my amazing friend, Kris Hallenga, Founder of CoppaFeel!. She was diagnosed with incurable breast cancer at 23. Throughout that horrific time Kris was never once pointed in the direction of CLIC Sargent. She wasn't offered our financial support or benefits guidance; we didn't offer her advice on fertility or relationships. Our expert shoulder, the one that professionally and instinctively knows why getting cancer under 25 is going to be particularly challenging, wasn't there for her, or her family to cry on. I find that hard to swallow.



I also want you to be aware of some specific objectives for 2018/19. Please hold us accountable to these this time next year.

I honestly believe we have the team, the support and the determination to crack this problem. So I have issued a challenge across CLIC Sargent, without compromising the depth and quality of our amazing delivery, to reach every child and young person diagnosed with cancer who needs us and wants our help. It is going to be hard and exhausting, but so is cancer when you are 23. This year we are establishing seven dedicated workstreams to tackle this, from identifying and understanding the missing group, to determining what supporting them will look like, to getting the word out there and then delivering it.

We won't stop until we've got there, but we need you to continue to be as committed as we are.

Kate Lee

- We'll continue to challenge government about how much cancer costs until the message hits home. In 2018/19, we're focusing on travel costs. Young cancer patients travel an average of 60 miles to and from hospital. And when treatment is at its most intense, it costs them £180 a month on top of everything else. This is unacceptable. We're calling on government to create a Young Cancer Patient Travel Fund.
- As part of the expansion of our vital Homes from Home service, we'll complete the build of Jean's House (Southampton) and Ciaran's House (Edinburgh), plus finalise plans for the refurbishment of Paul's House (London). We're also going to fully roll out Home Comforts.
- We'll continue to expand our services through digital innovation, as we believe that's a key part of reaching everyone who needs us. In 2018/19 we'll launch a new website with better information more easily accessed, and delivered in a way to better suit young people.
- Complete the first two phases of developing our 2020–2025 strategy to make sure it's focused on delivering services that stop cancer destroying young lives for every child and young person.



YOUNG LIVES
vs CANCER
CLIC SARGENT