THE GOOD, THE BAD, THE UGLY

OUR IMPACT AND ACCOUNTABILITY REPORT 2019

YOUNG LIVES vs CANCER
CLIC SARGENT
From the moment the doctor says cancer, life is never the same again. It’s shocking, overwhelming, isolating... and completely unfair. Especially when you’re young. It’s bad enough having to go through gruelling treatment, but then cancer takes over your life. Your ambitions for the future – education, relationships, career, travel – suddenly seem very far away.

We understand how devastating cancer is, not just for the child or young person but for the whole family. That’s why CLIC Sargent fights tirelessly to stop cancer destroying young lives. We help families navigate the complicated and frightening world they’ve been dropped in to. We provide financial grants and free accommodation close to hospital to help with spiralling costs. And we lobby the government to make sure families get the support they’re entitled to. We’re here to make sure young cancer patients get through treatment and can focus on getting their lives back on track.
A lot of impact reports are an opportunity for an organisation to boast about all the great things they’ve done. But at CLIC Sargent, we don’t think you care first and foremost what we have to say. The reason you support us is because you want to help children, young people and their families get through the devastating effects of cancer.

That’s what matters most to us, too. So in this year’s impact and accountability report, we’ve given priority to children and young people with stories about the difference you’ve made to young lives, directly from them. Because as much as we like to talk (and we do), we know that our big mouth is nothing without the voices of children and young people with cancer.

The rest is designed to give you a snapshot of things you’ve helped us to achieve, highlight some tricky topics, and be honest about where we weren’t at our best. We include that type of content because you keep the charity running, so we know we’re accountable to you.
Diagnosed with a brain tumour aged seven.
"After my diagnosis, everything changed. Because of my brain tumour I had to start all over again. I had to learn how to walk, talk and even interact with people."

"I used to be very popular at school, but I think my friends found it hard when I changed and sometimes didn’t understand my behaviour. Coming to CLIC Sargent’s Children’s Advisory Group meant I met other children like me, going through similar problems. And because we didn’t look at our disabilities we made good friends. Thanks to CLIC Sargent, I don’t feel isolated anymore."

Dawid’s mum Aleksandra says: "Having support from CLIC Sargent has been extremely important. They helped us access support that we either didn’t know about or didn’t feel we had the authority to ask ourselves. Having an expert friend like Louise, our CLIC Sargent Specialist Nurse, in our corner was invaluable. After Dawid’s treatment, Louise took the time to speak to teachers about his special needs, and how to best enable him to return to school. You can’t really put value on that."
ABIGAIL, AGED 8
Diagnosed with acute lymphoblastic leukaemia aged three.

I wouldn’t have got the mental health support I needed in time.

Debbie, Abigail’s Mum
“When the doctor broke the news that Abbey had leukaemia, it was a hell of a shock,” says Mum, Debbie. “Life was a whirlwind after that. Abbey’s health started to go downhill really quickly.

“Our CLIC Sargent Social Worker, Sam, was great throughout. When we were first diagnosed he came in for a chat and offered to help us, and also befriended Abbey. Having a child in hospital costs a lot of money, such as parking at the hospital which can become really expensive. Sam explained about the Disability Living Allowance and how it could help with some of those extra costs. The forms were horrific, they were so long and complicated. Our heads were totally shot, we were like rabbits in headlights at that stage, but he sorted it out for us.

“Before her cancer, Abbey had never had her hair cut. It was right down her back, and we were worried about how she’d cope with losing her hair. Sam bought a Barbie doll for her that had wigs and headscarves and that helped a lot. She still has it now. After two months of treatment, Abbey’s hair did start to fall out, but she dealt with it like she dealt with everything else thrown at her – she just adjusted.

“At the beginning of 2016 everything got on top of me. I suffered a lot with anxiety and depression and I really struggled to get help. I tried every avenue and felt like there was nowhere to turn. The GP suggested getting in touch with CLIC Sargent because they’d supported us before. The next thing, Sam was on the phone to the hospital, advocating for me so I was seen as a priority to get therapy. That experience has driven me on to set up my own support group for other parents of children with cancer.

“Abbey is now back at school full time. She’s got pigtails for the first time which she is thrilled about.”
Diagnosed with leukaemia aged 20.

“When I met my CLIC Sargent Social Worker, Sarah, shortly after my diagnosis, it really made my day. After having loads of tests done in two different hospitals to find out what was wrong with me, it was a relief to meet someone who didn’t give me medication or more bad news.

“With cancer, it’s not just the treatment and the chemo you have to go through, it’s all the side effects. I got an infection in my spleen. I had nurses putting in needles and taking fluids out from my back. I couldn’t walk so had to use crutches. I was 21, I should have been at uni and fit and healthy, but instead I was stuck in this little hospital room. Sometimes I found myself thinking, ‘Can I carry on? Do I want to carry on?’

“Sarah and the rest of the CLIC Sargent team were such a help. They gained my trust and I felt confident opening up and confiding in them. Sarah sat and listened to my fears, anxiety and anger, and then gave her expert input. I can drop them a text and they will pop in to see me; it feels good to know there is someone there to help me. Even now as an outpatient, I can text Sarah saying I’ll be coming into hospital and she’ll come and see me and catch up.

“Without CLIC Sargent, I would have been really stressed out. I wouldn’t have been able to share my problems and talk to someone, I wouldn’t have known anything that I was entitled to. CLIC Sargent has been my foundation. They’ve given me something I can build on after my cancer.”
“Cancer devastated our finances,” says Mum, Debbie. “Every single bit of our savings was wiped out and we were selling belongings to get more money.

“Before all of this we thought we were comfortable, but your finances can be devastated so quickly. The level of stress was so high all of the time. You’re already going through the worst time imaginable with your child getting a cancer diagnosis. To then face financial problems too, it was unbearable.

“I honestly don’t think we would’ve survived without CLIC Sargent. My CLIC Sargent Social Worker Claire couldn’t have been more helpful. We were able to get a room at CLIC Haven [one of the CLIC Sargent Homes from Home]. It was brilliant; we could get out of the hospital, have a shower and be out of that clinical atmosphere. Our actual home was a two-hour drive away, so CLIC Haven gave us somewhere to be together as a family.

“Claire also helped us get a grant which was a huge boost for us. She helped us with our benefit forms, something we wouldn’t have been able to navigate on our own because they are so complex. It’s impossible to deal with applying for benefits and every-day chores when your child is having treatment for cancer, so Claire’s help was a huge weight off our shoulders.”
Diagnosed with leukaemia
aged three
HAYLEY, AGED 16

Diagnosed with acute myeloid leukaemia at 14 months old.
“While I was in hospital, CLIC Sargent put my mum up in a CLIC Sargent Home from Home really nearby, which made it so much easier for my parents to come visit me and support me.

“It also meant they could look after my brother at home, making life normal for him. It was invaluable.

“As I’ve grown older, I’ve learned more about what I had and how it could have potentially affected me. I still have some physical reminders of that period in my life but I have always been determined not to let it define me. I feel so grateful and indebted to CLIC Sargent for their support and, as a result, I really wanted to give something back. I can’t bake a cake or run a marathon, but I can write a song! So I thought, ‘OK, I’ll write a song about empowerment’, and that’s where my song, Mars, came from. The song means a lot to me.”

Hayley’s mum Renee says: “When your child has cancer, you don’t really have a choice but to cope. If Hayley was going to get through this, we had to be positive and proactive and try to understand the process as much as possible. Thankfully, we had CLIC Sargent’s resources – they were from a trusted source, which was really important. It saved us from Googling and worrying ourselves with the amount of misinformation out there. We never saw ourselves as victims and we felt more powerful due to CLIC Sargent’s support.”
There’s no two ways about it, it has been a great 12 months, from campaigning to fundraising and most importantly, limiting the damage cancer causes to young lives beyond their health. We finally got the Government to launch the Children’s Funeral Fund, so we can all sleep a little easier knowing families will no longer risk going into further debt if their child dies. From a fundraising perspective, we raised more than ever before. This was helped by a bumper contribution from our amazing partner, Morrisons, who have agreed to be part of Team Young Lives for another year. And we’ve had thousands of other fundraisers baking, skydiving, hiking, head shaving and more. We rely on donations, both big and small, because without them our service doesn’t exist, and we spend every single penny conscious of the energy you put into raising it.

Our success relies on people of course, and I want to say a big thank you to our volunteers and staff for everything they’ve done in the last 12 months. Their determination never ceases to amaze me and they have certainly done young lives with cancer proud this year.

But there are two even bigger thank yous. The first, of course, is to every child and young person with cancer and their families. We’re privileged that you continue to allow us to support and advocate for you, and that you continue to encourage and challenge us to do better – we wouldn’t have it any other way. The second massive thank you is to our supporters. In short, you keep CLIC Sargent running. Simply saying thank you doesn’t do that justice, but until I can personally meet each of you and give you a big hug, high five, or firm handshake, then writing ‘thank you’ will have to do.

Despite our successes, there is a ‘but’ (you knew it was coming, because you know I am never satisfied where young lives with cancer are at stake). People are increasingly sceptical about how charities operate and the impact they have. As CEO I have to make tough decisions every day to balance the competing demands we face. I want CLIC Sargent to step up and be a charity that supporters know they can trust. We have promised to be honest with you. In the following pages we celebrate our successes but don’t shy away from areas we need to improve. I hope it shows we’re trying our best in tough times, because I believe that is true – every member of CLIC Sargent is a good person trying their very best. I want charities to be judged on the number of people reached, the impact on those people, and the money spent doing it, so we’ve tried to make that clear for you in this report.

Last year I talked about the importance of reaching the ‘missing third’ – the 31% of young lives diagnosed with cancer we don’t currently reach. As we’ve delved deeper into how to do this we’ve been reminded just how complex it’s going to be. That’s covered elsewhere (pages 26-27), but I want to reassure you we will not stop in our mission to get there, because it is way too important. This challenge will form the backbone of our new strategy.
Accountable to you

Last year I listed four specific projects we were working on, to make sure we’d be accountable to you in 12 months’ time. I’m sure you haven’t thought about anything else all year, but just in case you need a reminder:

1. **Call on Government to create a Young Cancer Patient Travel Fund to stop the unacceptable costs families face travelling to and from hospital for treatment.** You’ll see on page 26 that we’ve made strong progress, but despite 30,000 people signing a petition to set up the fund and getting cross-party support from MPs, we’re still waiting. Trust me when I say we’ll continue to fight for this.

2. **Complete the build of two new Homes from Home.** I’m delighted to say we did this, and we’ve got more in the pipeline. See page 23.

3. **Launch a new website with better information easily accessed as part expanding our digital services.** We did this too! Furthermore we launched a Live Chat service and benefits calculator on the website. See page 23.

4. **Complete the first two phases of developing our 2020 to 2025 strategy.** Also done, and it’s shaping up nicely for launch in late 2019.

I hope you agree it’s been an outstanding year but as always, there’s way more to do. Thank you for being an essential part of Team Young Lives. I hope this report helps you see what you achieved and encourages you to stick with us. If this is the first time you’ve heard about us… **come join our fight.**

Kate Lee, CEO
THE DIFFERENCE WE MAKE

You’ve heard some big things from five amazing people about the impact CLIC Sargent had on their lives. But we know what you’re thinking: what about the rest? We’re glad you asked! Here’s the difference we made across the UK last year.

THE NUMBER OF CHILDREN AND YOUNG PEOPLE WITH CANCER WE REACHED

That’s 66% of everyone under 25 diagnosed with cancer

We know the lives of family members are also often wrecked because of a young person’s cancer diagnosis, so the total number of people we reached last year was around

6,733

23,500
THE IMPACT WE HAD

Our bottom line is making sure young cancer patients and their families get the support they need during cancer treatment to give them the best possible chance of having their relationships, finances, mental health and education still intact once they’re through it.

As a direct result of CLIC Sargent’s work:

- 72% of young people said CLIC Sargent’s support helped them get their life back on track after cancer.
- 67% of parents said CLIC Sargent’s support helped them adjust to life after their child’s cancer treatment.

WHAT WE SPENT TO MAKE THAT IMPACT

£14.6m

Things to know

Percentages are respondents who agreed or strongly agreed with the statement.

Results are based on the 126 young people or parents who responded to the survey (of a population of 4,962 who came to the end of their service with us between 1 October 2017 and 31 March 2019).
HERE'S HOW WE DID IT

- 34,000 campaign actions taken by our supporters
- 1,336 visits to schools, colleges and universities to deliver care to students, stopping them missing classes
- 1,220 families welcomed in our Homes from Home
- 5,802 grants given to help families, totalling over £1.2 million
- 1,109 opportunities for young people and families to get involved in shaping CLIC Sargent’s work
- 373 individual school healthcare plans created to ease the transition back into education
- 2 new grants launched for young cancer patients
We ask young cancer patients and their families to tell us how our work makes a difference to them. We’re proud of these results. You should be too, because without you they wouldn’t happen.

75% of young people and parents said CLIC Sargent helped them feel less isolated during cancer.

77% of young people and parents said CLIC Sargent helped them to manage the financial challenges of cancer.

59% of young people and parents said CLIC Sargent helped to manage the emotional and mental health impact of cancer.

57% of young people and parents said CLIC Sargent helped them to maintain positive relationships with family and friends.*

The two stats below have got us thinking: the results are good, but we want them to be higher because they are integral to our mission of limiting the damage cancer causes beyond health. We’re working on it, so watch this space.

*Unlike other statements, this response saw a noticeable difference between young people (69%) and parents (51%).
Thanks to you, we raised £29.5 million last year to limit the damage a cancer diagnosis causes to young lives.

This is how you did it:
WHAT DID YOU DO WITH MY POUND?

The amazing donations we get go one of two places. They either go directly on our service (see the table below) or they go towards generating the next pound. We don’t receive government funding for our services and that means everything we spend to help young cancer patients and their families has to be generated the hard way. In short, it costs money to raise money. Last year for every pound we spent on fundraising, we turned it into £2.27, and we’re constantly striving to increase that figure.

How much we spent on raising income:

<table>
<thead>
<tr>
<th>Donations and legacies:</th>
<th>£9,637,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retail trading:</td>
<td>£2,719,000</td>
</tr>
<tr>
<td>Fundraising events trading:</td>
<td>£613,000</td>
</tr>
</tbody>
</table>

How we spent it on young lives against cancer:

<table>
<thead>
<tr>
<th>When the doctor says cancer:</th>
<th>£2,468,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>There’s no place like home:</td>
<td>£5,104,000</td>
</tr>
<tr>
<td>Helping young lives thrive, not just survive:</td>
<td>£1,748,000</td>
</tr>
<tr>
<td>Cancer costs:</td>
<td>£3,849,000</td>
</tr>
<tr>
<td>When a child dies:</td>
<td>£723,000</td>
</tr>
<tr>
<td>Making change happen:</td>
<td>£763,000</td>
</tr>
</tbody>
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| TOTAL: | £14,655,000 |

The remaining gap between our income and expenditure is £1.8 million. Of this, £1.6 million from our Morrisons partnership was set aside to spend in 2019/2020. We also spent a further net £800,000 on our Homes from Home and other assets. This means that despite a record fundraising year, we have had to use £600,000 from our free reserves (savings).

These summary financial statements have been extracted from the full Annual Report and Accounts which were approved by the Board of Trustees on 25 July 2019. However these summary statements have not been separately audited.
We’re proud of what we achieved last year, but you should be even more proud, because we can’t do anything without your support. The impact we have on young cancer patients only happens because of you. There are so many examples of Team Young Lives working together to achieve great things. Here are just a few. If it looks like too little, don’t worry – the rest are here: clicsargent.org.uk/impact2019

Getting young lives back on track

Cancer shatters young people’s dreams and ambitions. So we launched our ‘Thrive Not Just Survive’ grant in partnership with Societe Generale, to help young cancer patients get their ambitions back on track. 43 grants were given out last year, totalling £72,000.

Knowledge is power

To limit disruption to their lives, children and young people with cancer need to get the best care close to home, but local healthcare professionals don’t always have the necessary specialist knowledge. We helped by launching an Outreach Nurse Educator programme thanks to funding from Morrisons and the Stavros Niarchos Foundation.

Our nurse educators deliver best practice training on childhood cancer to healthcare professionals in local services. After the first year, 95% of participants said it would help improve the care they could provide in local services, in collaboration with the cancer centres.
Faster help with cancer costs

When cancer strikes, costs can spiral quickly and we give a registration grant to help families cope with the unexpected costs. Previously, we paid the grants by cheque, but to get payments out more quickly, we implemented a new social care database integrated with our grants system. This means we’re able to start paying grants directly into bank accounts, helping with cancer costs more quickly.

Children’s Funeral Fund is here

After three years of tireless campaigning, Government has launched a Children’s Funeral Fund. This is a huge victory for us and everyone who campaigned with us, as it means that when a child dies, parents will no longer be forced into debt to pay for the funeral.

There’s no place like home

Treatment for young cancer patients often happens many miles away from home, so our free Homes from Home close to hospital are refuges for families when their child is going through treatment. Last year, we relocated two of our homes in Edinburgh and Southampton. We’re also in the process of buying two new properties in Manchester (opening in 2021) and Newcastle (2023), based on renovation schedules.

From the bottom of our art

This World Cancer Day, thousands of you proudly wore our Bands Against Cancer or donated online, and 460 volunteers banded together to support our charity partner Morrisons with 250 bucket collections at local stores. We also held three art shows, where young cancer patients showed their ‘change’-themed art. Together we smashed it, raising an incredible £690,000!

There when it matters most

We issued 1,287 financial hardship grants for families who face even greater financial difficulties than others when cancer strikes: for example, a family’s car breaks down and the parents can’t afford to fix it because their income’s already taken a hit due to their child’s cancer. The grant was funded by a generous £350,000 donation from Children with Cancer UK.

Digital service to reach more

To help reach all children and young people with cancer who need us, we launched Live Chat on our website, giving young cancer patients and their families another way to connect with us and to get faster support when and where they need it. In the first six months, we’ve had 241 conversations with parents, young people and wider family and friends, covering topics from the care we provide to queries around money and education.

Oh, and the day-to-day stuff

You’ll notice these achievements are mainly focused on new initiatives, but we think our work supporting thousands of people year after year is a massive achievement too. This wouldn’t happen without the ongoing long-term support from key partners such as People’s Postcode Lottery, JD Wetherspoon and Signet, and the thousands of individuals who continue to give what they can for young lives against cancer. You are all legends.
You complained, we acted

Nobody likes getting a complaint. We certainly don’t, and although we know every organisation gets them, we work hard to limit the number we receive. Last year we had 99. Two-thirds of these related to door-to-door fundraising.

Like many charities, we use agencies to fundraise on our behalf by visiting people’s homes to share our vital work and ask them to help young cancer patients. Last year, door-to-door fundraising raised around £600,000, so it’s a big part of our income. And 11,347 people started a direct debit last year after speaking to a door-to-door fundraiser, so the ratio of complaints is small. However, it is important to us that we fundraise with integrity, and door-to-door is no exception. We put a number of procedures in place when we’re fundraising in this way to ensure we get it right, and the majority of supporters also receive a follow-up call to check they are still happy with the amount they have agreed to donate.

Of the remaining complaints, we had eight relating to how clearly we communicate our service. These included giving families
information about the breadth of our service, helping families understand our eligibility criteria and signposting to other organisations when a request falls outside the service we can provide. We don’t want families to have any uncertainty about our service – they have enough to worry about – and we’ve used these complaints to improve the way we communicate our work.

Giving young lives more control

We’ve always been well respected for involving young cancer patients and their families in shaping CLIC Sargent. And for good reason – they are involved in a variety of ways from advisory panels and reference groups to helping us recruit and induct our staff.

But we think we need to raise the bar to be able to genuinely say the charity is shaped by what young cancer patients and their families tell us. We’ve noticed that too often we develop ideas for our services, campaigns and projects and then ask for approval, which puts pressure on them to tell us it’s great because they know the time and effort that’s already gone into it. We need to work differently across the board to ensure we genuinely co-design our work alongside children, young people and parents, right from the outset.

That’s going to take a shift in culture, but it’s a culture we must have because young cancer patients and their families know what it’s like to go through cancer better than anyone else.

Are we supporting fewer people?

Last year we supported 2,818 newly diagnosed young cancer patients. The eagle-eyed among you will see that’s a lower figure than previous years.

We’ve looked into this and there may have been fewer children diagnosed with cancer due to a drop in birth rates, but we won’t know for sure until the full data is released by Cancer Research UK in 2021. But we know the decrease, which was primarily within the 0–15 age group, was partly down to changes we made to comply with new data protection laws (GDPR) which launched in May 2018. We introduced new referral guidelines for our staff, including a form for clinicians to complete, to establish a structured and consistent process for our teams across the UK and to ensure the NHS gets consent before passing on patient details to us.

Implementing a new process into business as usual initially slowed down the number of referrals. We sorted it pretty quickly by simplifying the process and being on hand to support clinicians with the form, and the new process is now running smoothly. We also enabled self referral through Live Chat and supporter services. However the experience served as a reminder of how vital it is for our referrals to be straightforward, because when it isn’t, young cancer patients lose out.

It gets better (or should that be worse?). We got members of our executive team in a room to talk about the things they wished we had done better last year. It’s the sort of conversation that organisations keep behind closed doors, but we filmed it because we’re accountable to you, so you have a right to know. Take a look at clicsargent.org.uk/impact2019
The travel costs scandal

Last year we campaigned for a Young Cancer Patient Travel Fund to help ease the financial burden families face when travelling for treatment. When treatment is at its most intense, travel costs on average £180 every month, and sometimes treatment can go on for years, plunging families into debt. The campaign went well. We had 30,000 people sign a petition to set up the fund and we got cross-party support from MPs. But nothing has actually happened in terms of the fund itself. And in the 12 months since, we estimate that 4,450 young cancer patients have spent around £5 million travelling for cancer treatment. That’s unacceptable. Now has to be the end of the road for travel costs.

Supporting the missing third

Last year we told you we support 69% of children and young people diagnosed with cancer. We believe that’s the largest specialist reach of any organisation for this age group. But it makes us uncomfortable because it’s not enough. Last year we made a commitment to you to sort it, so what have we done since?

Is this more stuff we got wrong? Thankfully not. The Ugly is a collection of things we’re angry about – things that make life harder for children and young people with cancer. We’re fighting hard to solve them, but we need others to do their bit too.
Two significant areas of work have been investigating the data, and then conducting detailed insight with key groups, including former cancer patients we hadn’t supported, to understand how they were missed. Analysing the data told us that we’re missing 19 to 24-year-olds more than younger age groups. It also told us the majority of those we’re not reaching have one of eight disease types. The insight identified some complex issues. You can read the detail at: clicsargent.org.uk/what-about-me but in short there are a number of things for us to do, and areas where we need others to step up.

We need to be clearer about the vital support we offer, and invest further in areas to promote self-referral, such as SEO (search engine optimisation). We need to collaborate better with other charities to ensure young cancer patients get the most holistic service possible. We also need the NHS to do their bit. We found some clinicians are not following NICE guidance to refer young people with cancer for age-appropriate support. That might be because clinicians don’t know the specialist support out there for young people, or believe there’s already sufficient support within the NHS. We also found some clinicians don’t always tell young people they have cancer, which creates obstacles from the start. Influencing such a large complex system will be hard and it will take time, but we love a challenge, and this one is well worth fighting.

**The pence-in-the-pound debate**

We know many people make a judgement of whether to support a charity based on how much money goes on their frontline service. We think that’s a shame because it is a flawed formula and, for us, means it is costing young cancer patients getting the support they need. Why is it flawed? Well seeing as you ask, you can read our CEO Kate Lee’s challenge on the ACEVO website (acevo.org.uk/a-golden-formula). But if you’re in a hurry, here are a few factors which influence the pence-in-the-pound figure and show the problems of using it to compare charities.

Charities who don’t receive substantial statutory funding (like CLIC Sargent) have to invest more in fundraising activities, which eats into the pound ratio. Charities who get a large chunk of their income from lots of people raising relatively small amounts (like CLIC Sargent) have to spend more in facilitating, processing and thanking those wonderful donors. Charities whose service includes bricks and mortar (like CLIC Sargent’s Homes from Home) may need to save up for years before they buy or build a property to deliver that service. For each year when they’re saving, the pence-in-the-pound ratio suffers, and ironically is over-inflated in the year the money is spent. We’re hoping people move away from this easy pence-in-the-pound comparison, and instead draw conclusions from how many people a charity reaches, the impact on those beneficiaries, and how much the charity spends doing it.
We try to be brave and honest. Always. This year, we asked our staff and the wider public what burning questions they really wanted answered, particularly the difficult ones that other charities might avoid. We promised to reply to them. So here goes...
Your fundraising costs are high. Why do you invest more in fundraising than other charities?

We think it’s really important that supporters feel able to trust that their donations are being used wisely. But we believe comparing charities’ fundraising costs is flawed because there are many variables which influence the figure. We go into this in more detail on page 27.

We don’t get government funding for our core service in the ways some charities do. That means we have no choice but to invest in fundraising. In 2016 we developed a new income generation strategy called ‘One Team, One Target’. At the heart of it is moving away from a model where we treat donors as paying customers, and more towards building long-term relationships. We haven’t done this because we want donors to say nice things about the charity; we’ve done it because we believe it will keep donors supporting young cancer patients for longer. So far it has been working well, but we have to continue to invest in fundraising – especially in the uncertain economic times we’re facing – to ensure we can raise the income needed for young lives against cancer.

Do you have any plans for focusing on the emotional trauma siblings go through and post treatment?

This is an area families say is largely unmet during their cancer experience. Last year we talked about how we are determined to reach all children and young people diagnosed with cancer. Part of this work has been reviewing what services we will realistically be able to provide to ensure we do not compromise the safety and quality as we increase the numbers of people we support. We think it makes more sense to work with a partner organisation to deliver that type of care. For example, last year we provided social work support to Ellen MacArthur Trust on their siblings sailing trip, which enables siblings to be with others facing similar worries.

Why do you use fighting language? Isn’t it a bit insensitive?

Cancer doesn’t care about children and young people – their friends or family, education or work, mental health, or their hopes for the future. We don’t like that. In fact it makes us angry. And that’s why the fight we talk about is our fight. We fight on behalf of every child or young person diagnosed with cancer. It’s what we do every day. This question has reminded us we need to be clear about whose fight we’re talking about.
We have great ambitions for young lives against cancer – to limit the isolation, debt and fear of the future cancer can cause. But we can't do any of it without you.

Join our fight.