YOUNG VOICES
TRANSFORMING THE LIVES OF YOUNG PEOPLE WITH CANCER
There’s never a good time to get cancer, but for a teenager the timing seems particularly cruel. Young people can get some of the most rare and aggressive forms of cancer. Their rapidly growing bodies work against them, enabling cancer to grow faster. The emotional upheaval of adolescence can make a cancer diagnosis even harder to cope with.

Every day in the UK, six young people aged between 13 and 24 years old will have to face that diagnosis. Yet, as this only represents 0.6% of all cancers they are often misdiagnosed initially and lack access to specialist services tailored to their specific needs.

This report is a collection of messages from teenagers and young adults about their experiences of having cancer, the issues important to them and their views on Government policy on health services in the UK.

These messages were collected in a variety of ways - video messages which have been transcribed; handwritten and emailed messages. They come from young people across the UK and their families. Selected messages highlighting key themes make up the body of the report; the appendix contains all of the messages.

Teenage Cancer Trust believes young people’s lives shouldn’t stop because they have cancer, so we treat them as young people first, cancer patients second.

We exist to improve the quality of life and chances of survival for the six young people aged between 13 and 24 diagnosed with cancer every day in the UK. We want to make sure every one of them has access to the best possible care and professional support from the point of diagnosis.

• We fund and develop specialist units within NHS hospitals that bring young people together to be treated by teenage cancer experts in an environment tailored to meet their needs.

• By educating young people about cancer and working with health professionals to improve their knowledge, we work to significantly improve their diagnosis experience.

• And through our own research and by working with our partners in the NHS, across the UK governments and organisations both nationally and internationally, we strive to improve survival rates.

Teenage Cancer Trust aims to build enough specialist units so that all young people needing hospital treatment for cancer across the UK have access to the dedicated, specialist support we provide.

We lead the world in the care of young people with cancer. Together with these young people, their families and the passion of our supporters, we’re challenging healthcare to meet the needs of young people with cancer and in doing so, we’re transforming lives.
Health services in the UK are currently facing some of the biggest financial and structural challenges ever. The economic crisis is having a huge impact, with unprecedented cuts and efficiency savings being demanded. As a devolved responsibility, health services are now controlled by different political parties. The ageing population and increasing numbers of people surviving and living with cancer are also having a significant impact on cancer services. These economic, political and social issues are dominating decisions about health services across the UK. It is important, against this changing background, that the improved recognition, services and outcomes for teenagers and young adult cancers are not forgotten or reversed. The UK is leading the world in services for teenagers and young adults with cancer, but there is still more to do.

The NICE Children and Young People’s Improving Outcomes Guidance (2005) (NICE CYP IOG) helped to secure a step change in the recognition of the specific needs of the 13 - 24 year old age group, and design of services to meet these needs. Teenage Cancer Trust is supporting the delivery of the recommendations in the NICE CYP IOG. This guidance is recognised in England and Wales, and similar framework for Scotland and Northern Ireland would help improve services across the UK.

Teenage Cancer Trust’s strategic priorities were born out of consultation with young people with cancer, their families, health professionals, experts in teenage and young adult cancers, and trustees and staff. These priorities reflect our experience and understanding of the challenges faced in delivering services for teenagers and young adults with cancer and their families over the last 21 years:

QUALITY & ACCESS
• Funding and developing specialist facilities for young people with cancer across the UK, including specially trained staff

DIAGNOSIS & SURVIVAL
• Significantly improving the diagnosis experience and outcomes for young people with cancer
Teenage Cancer Trust units aren’t like ordinary cancer wards. Everything about them has been designed to give teenagers the very best chance of a positive outcome. This is backed up by our Nurse Consultants who provide clinical care, develop research, deliver professional education and ensure that standards remain as high as possible.

We know how damaging it is to take a young person away from their normal life - their friends, their environment, and put them in a cancer ward with small children or older people.

Quality is about making sure the staff and environment are specialised and tailored to benefit the specific needs of young people. We are calling for national standards across the UK setting out expected service standards including staffing and age appropriate units and services.

**STAFFING**

Teenagers and young adults face a range of challenges associated with their age and stage in life. These challenges don’t disappear with a cancer diagnosis, which is why professionals trained in the needs of teenagers and young adults are so valued:

**QUALITY**

“Staffing levels in one hospital were very low and I was regularly made to feel like a nuisance. My mum and my sister (who is a student nurse) did most things for me i.e. changing my bed, dressing my Hickman line, helping me shower. The nurses administered my chemo and gave me drugs (which were always late). I understand they were very short staffed but I do not think this is an excuse... On a positive note, I found the care at the beatson (West of Scotland Cancer Centre) outstanding and found the nurses lovely... It was the little things like having a microwave in the Teenage Cancer Trust room or a nurse having a chat in the middle of the night.”

Nilani, 20, from Glasgow, diagnosed with germ cell tumour.

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“I feel it is very important that every teenager and their entire family are given psychological support whilst facing cancer. It is simply impossible to expect a young person, who has so many things to worry about including academic work, the carelessness of friends’ comments, to try to cope on their own.”

Niall, 16, from Ireland, diagnosed with Adrenal Tumour.

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“I found having to be treated with adults, mainly OAPs, a lot worse to handle than the cancer diagnosis itself... the only thing that made it bearable was having the Teenage Cancer Trust team bringing me things to do and having a friendly face. To make it as normal as possible. I had to sleep next to old people who were incontinent; who were planning funerals... My whole experience would have been a completely different story if I was on an age appropriate ward, with people I can relate to, and with staff who wanted to work with the teenage and young adult age group.”

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Stephanie, 16, diagnosed aged 17, from Northumberland, diagnosed with Ewings Sarcoma (right pelvis).
Yet, being with people of the same age makes the world of difference, transforming the experience:

“Babies screaming at 3am along with drip stands bleeping equals unhappy and tired teenagers.”

“I’d never really met other teenagers until coming to Teenage Cancer Trust or having the hospital meeting.”

“My experience of the NHS is a good one - the care and support I have received is second to none. I hope that this will continue, not just for me but all other young cancer patients I have met and who are still undergoing treatment.”

“The treatment that I am allowed to access through Teenage Cancer Trust is the best kind of treatment I could ever imagine and it’s unlike anything anywhere else in terms of getting ill, so keep it in the NHS.”

“I hope you understand the need to allow the age limit of the Teenage Cancer Trust to remain at 25, because if it is lowered to 19, she would lose out on all of the benefits that Teenage Cancer Trust bring, and the support they deliver, not just to patients, but to families as a whole.”

“I want the NHS to be more focused to people’s needs. When I was having chemo and radiotherapy I was never being treated with anyone that was even similar to my age and what I was going through, and every week I went into chemo someone else had died. It was just too hard to deal with. There was no one really specialised in young people.”

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“I would like to open your eyes to ‘God’s waiting room’ which is my clinic and being the youngest person by about 40 years as I have ‘old man’s leukaemia’... I want you to know how amazing us ‘Cancer Kids’ are, and the importance of looking after us properly.”

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Food is another factor that if improved would provide a better quality experience. In Teenage Cancer Trust units we encourage healthy eating to support recovery, and we provide opportunities to have some control over food whilst in hospital through providing kitchen facilities. Those who do experience regular hospital food have reported bad experiences:

*You should come on a date with me to hospital and experience life as an inpatient for a young adult yourself. Seriously, you want to try the baked potatoes because you won’t believe it, it’s shocking.*

*Get the food sorted out, how difficult can it be to sort out food. Why can’t people see that food should be used as a medicine and not just for the sake of it, instead of giving us slop that’s disgusting, that isn’t going to make anybody feel better? Do something worthwhile. It can’t be that difficult, surely.*

“Over the past 18 months I’ve been in five different hospitals and the food has been abysmal. I was always encouraged to eat well and good and nutritious food—however no good food was available. A lot of it was very stodgy and not pleasant to eat.”
Less than half of teenagers and young adults with cancer are getting access to specialist age-appropriate services - more is needed to improve outcomes for this age group.

We want every young person with cancer in this country to have that chance, and in order to achieve this we believe there needs to be appropriate funding to develop and deliver services.

"More teenage wards."
"More specialist help for young people."
"Teenage Cancer Trust wards for everyone, everywhere please."
"Teenage Cancer Trust and what it does should be available for everyone."
"Please make sure that all young people from the ages of 13-24 have some kind of access to appropriate services for young people."
"Just develop more wards for younger people instead of being on adult wards."
"Please build more hospitals for other kids that can’t get into them."

"Transition into adult services needs to be a lot smoother; it is difficult when you have been in children’s services for so long to move into adults. Doctors and nurses from adult services need to be more understanding."

There should be more services available for people like me and our age group.

"How many teenagers and young adults with cancer are being referred to specialist care in England?" O’Hara C et al. The North West Cancer Intelligence Service, Manchester (2011)

Teenage Cancer Trust units bring teenagers with cancer together with loads of new friends of their own age so they can support each other. This is an important part of maintaining some normality to life and integrating back into life after treatment. Access to these specialised units are valued by young people.
Every Principal Treatment Centre, or equivalent across the UK, should have a specialised unit for teenagers and young adults with cancer which can treat young people and provide expert advice to other hospitals. The experience of not being able to access a specialist service, knowing that there are some out there is incomprehensible to young people.

"I am 17 years old and from Somerset. I was diagnosed with Hodgkin’s lymphoma. At first my family and I had to travel to Bristol for my first cycle of chemotherapy. Fortunately I was able to have my further three cycles locally, to avoid the tiring travel to and from Bristol, which didn’t allow us to continue with our lives as normal. I found that once I had decided to be treated at my local hospital, the information and support decreased.

In the South West in general I feel like there is not a lot of support for young people with cancer, and the lack of a unit in the region makes me feel as though we are somewhat forgotten, as we have nowhere to go specifically.”

Lucy, 17, from Somerset, diagnosed with Hodgkin’s Lymphoma

“I have undergone two courses of radioactive iodine treatment. Unfortunately my local hospital doesn’t offer this treatment to children, but does to adults. If I was much younger I could probably understand the decision more, but I generally would say being 16 I feel grown up enough to have treatment in a local hospital. I ended up having to travel 102 miles to London. Even though I know it’s in my best interest to be sent for my treatment in London, I couldn’t help but wonder there must have been some way I could have had treatment close to home. Leicester hasn’t got a Teenage Cancer Trust unit and the hospital in London does.”

Paris, 16, from Leicester, diagnosed with Papillary Thyroid cancer

“The availability of teenage specific cancer units: they need to be available all over the country which are big enough to hold all the teenagers and young adults diagnosed. They are a vital part of the hospital just like separate wards for children, why should teenagers be any different!”

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Young people with cancer are clear that specialised services need to be protected so they can access them:

**“With regard to the NHS, I personally think those cuts should be made elsewhere. Maybe in regards to military spending or not military because I know those guys are doing a tough job. But you can make cuts. You’re building 5 new war ships, what’s the point of that? I just don’t think the NHS is the place to make cuts.”**

James, 18, diagnosed with Anaplastic Large Cell Lymphoma

**“The only way to make progress in something as complex and frustrating as oncology is to find the solution. Why isn’t more money being pumped into cancer research? Although the political theatre is somewhat entertaining on a Wednesday afternoon, I find the soundbite “we inherited from the party opposite” wearing rather thin. Increased government spending, that is done effectively, is the only way to improve cancer care.”**

Mr Cameron, £168 billion is a lot of money that needs cutting, or needs to be paid back. If I was in debt myself, I would reduce my lifestyle. I’d stop drinking and start paying back my debts. That’s what you need to do for the country. People don’t seem to understand that, and I know you’re getting a lot of bad press, but stick at it.

One thing I will say is that cancer, particularly among young people, is something where if cuts to the NHS need to be made in that area, then maybe in paperwork or in bureaucracy, something that won’t affect the patients themselves.
Teenagers and young adults too often experience delays in diagnosis. In a survey we carried out in 2011 with young people with cancer, one in four young people reported that they visited their GP four times or more before they were diagnosed.¹

We know that young people can ignore their symptoms or be too scared to speak to their doctor immediately so it’s vital that when they do, GPs listen to them and take appropriate action. Two week referral for suspected cancer is a major breakthrough for cancer patients, but it won’t benefit young people until GPs think about cancer when they see young people with symptoms.

We advocate for a three strikes approach - where GPs automatically refer young people presenting with the same symptoms after three repeat visits. We are also calling for better understanding of cancer in young people and access to diagnostics to improve diagnosis for GPs.

Young people also need education about cancer to increase their confidence in knowing when something is wrong with their health and approaching health professionals, we believe this should form part of the curriculum in schools across the UK.

¹ Find Your Sense of Tumour Conference, Teenage Cancer Trust (2011)
After noticing I had a huge lump on my throat I went to the doctors. The Doctor told me I had adult croup and to go home to inhale steam. So I did, but it did not improve my breathing. I was practically struggling for breath walking up a couple of stairs! My parents were still concerned, so the next day my dad took me to Nottingham Queen Medicals centre’s A and E.

Continued: “Again the Doctors didn’t seem bothered about the lump, this time diagnosing me with ASTHMA! So I went home, began using the inhalers I had been equipped with. They seemed pointless; they did not help at all! That night I went to bed relatively early. A couple of hours later, I jumped up gasping for air! I literally could not breathe, my dad ran upstairs trying to help me and I just collapsed outside my bedroom.

I stopped breathing, my heart stopped. My dad knew First Aid and luckily bought me round after my heart stopped several times. If it was not for him, I would not be here to tell this story. If the doctor had simply sent me for an x-ray then I would not be mentally scarred as much as I am. Something needs to change to see a quicker diagnostic; no-one deserves to go through what me and my family did that night.”

Danielle, 21, diagnosed with Non-Hodgkin’s Lymphoma six years ago, now studying at Nottingham Trent University

Me celebrating my 21st birthday in London recently
Studies have shown that five year survival statistics for teenage and young adults with cancer are approximately 69% for males and 73% for females. However due to the spectrum of tumour arising in teenagers and young adults this ranges from 89% for male germ cell tumours (e.g. testicular), to 42% for males with leukaemia and 46% for bone sarcoma. These survival rates have not improved for over 20 years.

We know that young people have a much better experience and chance of survival if they are diagnosed early and treated by teenage cancer experts, in an environment tailored to meet their needs. We need better data about teenage and young adults with cancer, and their support needs to improve their quality of life during and after treatment.

**LATE EFFECTS**

"I think more aftercare could be provided by the NHS. During my treatment I had to take steroids to shrink the tumour. This increased my weight horrendously, I began my treatment at 66kg by the end of my steroids I was 94kg. It has taken blood, sweat and tears to finally shed all this weight! I have spent a ridiculous amount of time at the gym, controlling my eating and basically changing my whole lifestyle. I endured all this by myself, no help. I feel I would of benefited from advice on how to lose the weight, what type of exercises and what food I should eat.*

Danielle, 21, diagnosed with Non-Hodgkin's Lymphoma six years ago now studying at Birmingham Trent University.

"I will have permanent struggles for the rest of my life. My mobility has been made a lot more difficult relying on walking aids, wheelchairs, other people, lifts and downstairs accommodation for the rest of my life. Now due to the chemotherapy and radiotherapy I have become infertile so that is another huge step for me and my partner to come to terms with and we can only hope the funding will be there for us when we are ready to have IVF. Having children has always been my dream and I did everything possible in the time I had to protect my fertility but it failed. I hope you can help put something in place for myself and many over man and woman like me!"

Stephanie, 19, diagnosed aged 17, diagnosed with Ewings Sarcoma (right pelvis).

"I can say I have survived Cancer which is amazing but sadly I have had friends who have not. Though I survived Cancer this has come at a price. Late effects. If growing up in your teens isn't hard enough I had to deal with the late effects of my treatment, the hardest part being told that I most likely will not be able to have children this I am still unsure of today. I would probably look different if I had never had Cancer been taller and had bigger assets but at the same time it would have not made me the person I am today."

Hannah, 20, from Devon but currently living in Aldershot studying to be a children’s nurse. Diagnosed with Acute Myeloid Leukaemia.
Finishing treatment means the welcome, but daunting, task of returning to everyday life. Whilst cancer is clearly defined as a disability in law, we know that young people with cancer are often not getting access to the support they need including benefits, and support to resume their education and/or employment:

“This as a teacher of a student who was a cancer survivor and as a mother of a teenager who has just finished treatment - it is really important that David Cameron waives further education fees for students who go over 18 years of age and lose out on education and then return to college to face high fees.”

Anne, Teacher

“I think schools need to be more equipped with handling pupils with cancer. I was tormented, name-called and basically laughed at for having the C word. Pupils need to be taught, even though we are going through this treatment we are still normal and should be treated the right way.”

Danielle, 21, diagnosed with Non-Hodgkin’s Lymphoma six years ago, now studying at Nottingham Trent University

Keep Mifamurtide funded - it could be saving my life!

Ruth, 20, diagnosed aged 18 with Osteosarcoma

Investment in research and medicines is important to young people with cancer, who know that access to clinical trials and developing best care and treatment can save lives.

There is a significant lack of trials for the types of cancers that affect teenagers and young adults, but for the ones that do exist, often the age range excludes them.

In medicine the gold standard for identifying the best options comes from randomised clinical trials. So through missing out on clinical trials, young people are missing the opportunity to have improved treatments and outcomes.

“David Cameron’s being silly with the way he chooses to spend his money about some cancer drugs and that he should rethink the way he treats teenagers across the country.”

“There needs to be, in my opinion, more money spent on the research especially for people that are relapsed like myself, instead of focusing on the majority percentage of people that are cured. You need to look at ways of saving more people.”

“David Cameron, generally I’m not into politics much myself but here’s one thing I do have to say. I think in order for you to be a great Prime Minister, and be remembered, you need to stick by cancer patients, stick by the charities for cancer, and find a cure. Because then, if you put enough money into it hopefully you’ll be able to save a million lives, and I will be eternally grateful. So support us because we need you.”

“Keep Mifamurtide funded - it could be saving my life!”

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RESEARCH AND MEDICINES

WORK, EDUCATION AND BENEFITS

“I’d like to bring to your attention the direct impact on my career that my cancer had. I was aware of there being a lump in my neck around May/June 2010 when as level exams are taken and due to the severe fatigue I suffered (and still suffer from today as a result of my chemotherapy and radiotherapy treatments) caused me much trouble during my exams. Therefore my exam results did not fulfil my full potential and I feel that this should be more acknowledged by people such as yourself as this would lead to universities considering this when, as you know, university places are much more difficult to obtain.

I would very much like to become a primary school teacher as I love to work with, help and shape the minds of children and I wouldn’t want my cancer diagnosis to result in this not being able to happen.”

Abbie (Abi), 21, diagnosed aged 17 with Hodgkin’s lymphoma

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“Raise disabled living allowance.”

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CONCLUSIONS

The views of teenagers and young adults with cancer and their families in this report show that they are concerned about misdiagnosis, the kind of services they will have access to, and the impact of cancer on their lives when they try to resume life as normally as possible.

They deserve the assurance that all that is possible is being done to address their concerns and bad experiences.

We call on the UK Governments to work with us to improve the outcomes and lives of teenagers and young adults with cancer and their families.

In the next three years we want to see:

1. High quality services, specialised for teenagers and young adults
   • Every country in the UK to have national standards of the specialised care for teenagers and young adults, and that these are monitored and implemented.
   • Patient reported outcomes measures (PROMs) are developed and implemented for this group so services are meeting the needs of patients.

2. More specialised services for teenagers and young adults with cancer across the UK
   • Clear guidance and protected financial investment in developing the services needed to ensure every young person with cancer has access to specialised care.
   • Every Principal Treatment Centre or equivalent across the UK has a teenage and young adult unit.

3. Early recognition and investigation of the signs and symptoms of cancer in teenagers and young adults
   • Introduction of a three strikes approach – a GP will automatically refer on a case if a young person has visited three times with the same unresolved symptoms.
   • Training and information for GPs and health professionals to improve awareness and understanding of cancer in young people.
   • Availability of effective diagnostics for GPs to speed up investigation of symptoms.
   • Education for all young people about cancer, forming part of the National Curriculum and the Curriculum for Excellence to ensure all young people are empowered to speak up about health issues.

4. High rates of survival and support for teenagers and young adults surviving cancer
   • Accurate recording of teenagers and young adults with cancer, including late effects and ongoing needs.
   • Research on the impact of having cancer on education and work experiences, developing support models to best support young people surviving cancer continue their lives.
APPENDIX

FIND YOUR SENSE OF TUMOUR MESSAGES ON WHITEBOARD, APRIL 2011

- Hospital Food x 5 ‘it’s terrible’ - ‘not nice’
- We need fun and good food
- Badly staffed wards not enough trained nurses
- Hey Mr Cameron - honestly pour some money into cancer research for young people - lost too many friends
- More teenage wards
- Babies screaming at 3am along with drip stands bleeping = unhappy and tired teenagers
- Raise disabled living allowance
- More specialist help for young people
- More help for carers
- We need more financial support for students who want to continue their studies while not at uni.
- Teenage Cancer Trust wards for everyone, everywhere please
- If you don’t have health, you don’t have life
- Parliament should respect our rights
- We need to know more about cancer before and after treatment
- Teenage Cancer Trust and what it does should be available for everyone and soon
- Petrol costs too much
- Get out of the EU
- What is more important, fighting cancer and having a healthy life or budget deficit?
• Jadi, 23, diagnosed with Breast Cancer
All I wanted to stress is that I hope all the cuts being made to the NHS are the right ones and that this won’t cause any interruption to the treatment and care that is given. My experience of the NHS is a good one - the care and support I have received is second to none. I hope that this will continue, not just for me but all the other young cancer patients I have met and who are still undergoing treatment - like me.
I would love to see the government supporting causes like Teenage Cancer Trust and Clic Sargent as their support and care, like the NHS is invaluable. Thank you.

• Jacque, 15, diagnosed with Leukaemia
Please sort out school taxes. Parents are going through bankruptcy.
You are a capitalist that does not stand for social mobility, together that is a paradox. Efficiency savings and money goals have no place in public services that is business philosophy.

• Ruth, 20, diagnosed aged 18 with Osteosarcoma
Keep Mifamurtide funded - it could be saving my life!

• James, 18, diagnosed with Anaplastic Large Cell Lymphoma
The only way to make progress in something as complex and frustrating as oncology is to find the solution. Why isn’t more money being pumped into cancer research? Although the political theatre is somewhat entertaining on a Wednesday afternoon, I find the soundbite “we inherited from the party opposite” wearing rather thin. Increased government spending, that is done effectively, is the only way to improve cancer care. Cancer is a terrible outcome for any adult, let alone a child. More so, than a banker who looked at the balance books in 2009! Cancer is a fight you don’t want, need or deserve! I just wish more money would come from the government, maybe my voice won’t be heard, and maybe you will carry on not listening but one thing that I will carry on doing is fundraising for cancer charities. I hope you will too.

• Hollie, 18, diagnosed with Nasopharyngeal Carcinoma
I think current travel insurance prices are ridiculous. I am going on holiday soon and have been quoted on average £3,500. I think if an insurance group came together and gave insurance at a price, then if the patient didn’t claim gave back half the money, there would be a lot more people getting the right insurance for their illness. I have had to just go for normal insurance and hope I don’t get poorly as I simply can’t afford it. I think this is a great idea and would go far!

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• Ruth, 20, diagnosed aged 18 with Osteosarcoma
Keep Mifamurtide funded - it could be saving my life!

• Dear David Cameron
My message to you is a complaint about recent NHS and education cuts. People in the country you run depend on the NHS so cutting funds makes no sense - you may have the money for private care. But most of us don’t especially with higher VAT and £9,000 for uni and cutting ESA is just wrong.
You’re greedy, you take from the poor and give to the rich.

• Wow, what a question, I have no idea off the top of my head and would have to think about it for a while. I would like to definitely open his eyes to ‘god’s waiting room’ which is my clinic and being the youngest person by about 40 years as I have ‘Old Mans Leukaemia’, being made to pay for IVF and the battles in education I’ve had since my diagnosis. I would also let him know how amazing us ‘Cancer Kids’ are, and the importance of looking after us properly.

• In the future please ensure that all young people from the ages of 13-24 have some kind of access to appropriate services for young people and receive the right emotional support both during and after treatment. Please implement the survivorship guidance that the NCSI is working on. It is time to stop young people getting “lost in the system”, it’s not all about treatment, people have to live with the physical and emotional effects of it too.
From what I’ve read about the GP thing, considering I wasn’t diagnosed by a GP I think it’s a load of rubbish. Yes they should perhaps do a bit more but I don’t think I’d be here today if someone hadn’t diagnosed me, that wasn’t my GP. But I think you can only reform so much, and if it cuts too much and things change too much and it just will go back to an awful state. I think you’ve just got to be careful that’s all. I just called David Cameron that’s all. Just don’t do anything you’re going to regret later on and then complain about it. And stop blaming the other government, seriously.

Please don’t cut nursing staff because it’s so important. Publicise charities like Teenage Cancer Trust and Samaritans more because it’s a needed thing and shouldn’t be run by a charity. Please build more hospitals for other kids that can’t get into them. More funding.

The most important thing to me in the NHS is the blood bank because without access to that I would not be here, dead. And the treatment that the NHS provides that I am allowed to access through Teenage Cancer Trust does so keep it in the NHS. Please build more hospitals for other kids that can’t get into them. Better hospital food.

I think there should be more Teenage Cancer Trust wards, instead of if you’re either with old people or in a paediatric ward with really young people. So yeah, that would be quite cool Mr Cameron, and apart from that, that’s it for now.

I think as well that emphasising on the money side of things that the cuts that are being made at the moment to the NHS that they the cuts being made for the right reasons. That it’s not going to jeopardise the quality of care and support that’s given, because it’s second to none like where I’ve been treated at City Hospital in Nottingham and I just hope that it’s going to carry on and that it won’t affect the quality of care and support given.

FIND YOUR SENSE OF TUMOUR VIDEO MESSAGES, APRIL 2011

I think the NHS is working fine, there’s nothing that I’d rather want to be there.

Better people you can interact with, better nurses, better units making you feel like home rather than feeling in hospital. Better people you can interact with, better nurses, better units making you feel like home rather than feeling in hospital. Better people you can interact with, better nurses, better units making you feel like home rather than feeling in hospital. I think the NHS is working fine, there’s nothing that I’d rather want to be there.

To Mr David Cameron, I would say you can’t cut the NHS services for treatment of cancer generally as a start. There needs to be in my opinion more money spent on the research especially for people that are relapsed like myself, instead of focusing on the majority percentage of people that are cured. You need to look at ways of saving more people.

Get the food sorted out, how difficult can it be to sort out food. Why can’t people see that food should be used as a medicine and not just for the sake of it. Instead of giving us slop that’s disgusting, that isn’t going to make anybody feel better. Do something worthwhile. It can’t be that difficult, surely.

Also don’t cut youth wards, Teenage Cancer Trust wards, don’t stop installing those units. Give people the opportunity to spend time together instead of sticking young people on an old persons ward. It doesn’t work, we need to be around like minded people. Give us the opportunity to do that. Don’t cut cancer research, science, taking away nurses that can have the one on one with patients is not the way to do it. Please don’t do that, please help to save more people. That’s what Teenage Cancer Trust are trying to do. Please join us in doing that.

I think there’s just a really small thing that is not the best of company and it needs to be sorted. I think there should be more Teenage Cancer Trust wards, instead of if you’re either with old people or in a paediatric ward with really young people. So yeah, that would be quite cool Mr Cameron, and apart from that, that’s it for now.

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I'd say I wanted to be treated more at home rather than at a hospital. It doesn't make you feel as normal as everyone else and the same as everyone else. Just because you have an illness doesn't mean you're any different to anyone else.

Better GPs.

For less people getting diagnosed and for more cures.

I want the NHS to be more focused to people's needs. Because when I was having chemo and radiotherapy I was never being treated with anyone that was even similar to my age and what I was going through. Everyone who was having chemo at the same time I was having chemo that were like 40 or 50 years older than me. And every week I went into chemo someone else had died, like old fellas on the same ward as me. It was just too hard to deal with, everyone else's emotions when I was trying to deal with my own emotions, but it just wasn't happening. There was no one really specialised in young people. I was being treated like I was 50 or 60 years old which obviously I'm not.

David Cameron, generally I'm not into politics much myself but here's one thing I do have to say. I think in order for you to be a great Prime Minister, and be remembered, you need to stick by cancer patients, stick by the charities for cancer, and find a cure. Because then, if you put enough money into it hopefully you'll be able to save a million lives, and I will be eternally grateful.

David Cameron, what I want to say to you is I hope you never have to go through what we've had to go through. I hope no one in your family has to go through what we've been through. But let me tell you it's something that really needs support and it's something that is beyond anything. You know to have your life threatened like this, to have such horrible treatment, and to have such terrible things. And I think Sam sums it up by saying, you know, you'd make yourself a great Prime Minister if you support Teenage Cancer Trust or any sort of cancer charity because it's a horrible horrible disease. To take on something as nasty as that and win, it's in your hands and I think you can do it.

So support us because we need you.

I think David Cameron should do more for Teenage Cancer Trust. Buy more new equipment to save people's lives. Get more scientists. Get cures for cancer. And everyone to completely stop cancer.

I feel David Cameron should put more money into the Teenage Cancer Trust, and just develop more wards for younger people instead of being on adult wards; I know it can feel a bit intimidating. Get more drugs, and not cut back. People need these drugs to get better, no matter how much effort and time and money it takes. Because money's not everything you need. You need life is more important than money.

Mr Cameron, first of all I appreciate the very hard job you've got to do. £68 billion is a lot of money that needs cutting, or needs to be paid back. If I was in debt myself I would reduce my lifestyle. I'd stop drinking this stuff, and start paying back my debts. That's what you need to do for the country. People don't seem to understand that, and I know you're getting a lot of bad press, but stick at it. One thing I will say is that cancer, particularly among young people, is something where if cuts to the NHS need to be made in that area, then maybe in paperwork or in bureaucracy, something that won't affect the patients themselves. Because they really value what they have already and people like George really do find that children's ward just really weren't suitable.

They weren't suitable because I was being kept up all night by babies screaming or constant beeping of the drip machine. And it just wasn't good and I'd never really met other teenagers until coming to Teenage Cancer Trust or having the hospital meeting. We've got 10 seconds so we have to say goodbye, I'm sorry. There's more I'd like to say but, oh well.

Congratulations, I hope you do a good job. Take care.

Hi David, I think that the way young people with cancer were treated under the Labour government before you, I think that worked just perfectly. With regard to the NHS, I personally think those cuts should be made elsewhere. Maybe in regards to military spending, or not military because I know those guys are doing a tough job. But you can make cuts, you're like building 5 new war ships what's the point of that. Like we don't need them, you know. I mean the... is just rubbish at the moment and we could do with a lot better situation.

Hi David, I think that the way young people with cancer were treated under the Labour government before you, I think that worked just perfectly. With regard to the NHS, I personally think those cuts should be made elsewhere. Maybe in regards to military spending, or not military because I know those guys are doing a tough job. But you can make cuts, you're like building 5 new war ships what's the point of that. Like we don't need them, you know. I mean the... is just rubbish at the moment and we could do with a lot better situation. I just don't think the NHS is the place to make cuts, the NHS has done fantastic for me, like. I was treated between the switchover and I think that the way the Labour government handled the NHS was very children's very good and I can't see many improvements you can make. Thanks.

We need better food.

Raise the rate of DLA and decent hospitals.

We want you to help parents more.
Dear Teenage Cancer Trust,
As a teacher of a student who was a cancer survivor and as a mother of a teenager who has just finished treatment - it is really important that David Cameron waives further education fees for students who go over 19 years of age and lose out on education and then return to college to face high fees.

Yours
Anne Lean

Danielle, 21, studying at Nottingham Trent University, diagnosed with Non-Hodgkin’s Lymphoma 6 years ago

Hello
I was diagnosed with Non-Hodgkin’s Lymphoma in February 2005. I was treated at the Queens Medical Centre in Nottingham and my treatment lasted 2 years.

The way I was diagnosed could be viewed as quite unique. After noticing I had a huge lump on my throat I went to the doctors. The doctors eventually sent me to have my throat X-rayed. So I did, but it did not improve my breathing. I was practically struggling for breath walking up a couple of stairs! My parents still concerned, so the next day my dad took me to Nottingham Queen Medicals centres A and E. Again the doctors didn’t seem bothered about the lump, this time diagnosing me with asthma!

So I went home, began using the inhalers I had been equipped with. They seem pointless; they did not help at all! That night I went to bed relatively early, I woke up a couple of hours later and went downstairs. I remember I had just had a very weird nightmare which was very abnormal for me (to this day I remember this nightmare). My Dad said I would be fine so I went back to bed as I had school in the morning. A couple of hours later I jumped up gasping for air! I literally could not breathe, my dad ran upstairs trying to help me and I just collapsed outside my bedroom. I stopped breathing, my heart stopped. My sister who was 12 at the time could see this from her bedroom. My dad knew First Aid and luckily bought me round after my heart stopped several times. If it was not for him, I would not be here to tell this story. I was rushed to hospital and spent 5 days in P.I.C.U, where after being admitted on a children’s cancer ward was told the worse news possible.

The team at the Queens Medical Centre were amazing and my Professor David Walker enabled me to fight this horrific disease. However, despite this I should not have gone through the horrific ordeal before my diagnostic. If the doctor had simply sent me for an x-ray then I would not be mentally scarred as much as I am. Something needs to change to see a quicker diagnostic; no-one deserves to go through what me and my family did that night.

Also I think schools need to more equipped with handling pupils with cancer. I was bullied, name-called and basically laughed at for having the C word.
Pupils need to be taught, even though we are going through this treatment we are still normal and should be treated the right way.

Furthermore, I think more aftercare could be provided by the NHS. During my treatment I had to take steroids to shrink the tumour. This increased my weight horrendously, I began my treatment at 66kg by the end of my steroids I was 94kg. It has taken blood, sweat and tears to finally shed all this weight! I have spent a ridiculous amount of time at the gym, controlling my eating and basically changing my whole lifestyle. I endured all this by myself, no help. I feel I would of benefited from advice on how to lose the weight, what time of exercises and what food I should eat. At the end of the day I did not put on weight because of the reasons most people do. My weight increased because if I did not take the steroids I would have died.

Hannah, 20, Devon (currently living in Aldershot studying to be a children’s nurse). Diagnosed with Acute Myeloid Leukaemia in 1999.

Cancer, whether you have a tumour or a blood cancer like me, it was never something you expected to get, I was young but I can remember so much. The treatment is evil. I can say I have survived cancer which is great but I am still unsure of today. I would probably look different if I had never had cancer been taller and had bigger busts but at the same time it would have not made me the person I am today. I feel there needs to be better care for people like me who had cancer when they were younger but now suffer from the late effects of the treatment these last longer than people think and though they do not always show on the outside like the treatment for cancer it can hurt on the inside and I feel this is forgotten. Transition into adult services needs to be a lot smoother, it is difficult when you have been in children’s services for so long to move into adults. Doctors and nurses from adult services need to be more understanding, there should be more services available for people like me and our age group.
Kirsty, 15, East Kilbride, South Lanarkshire

Dear Mr Cameron,

My name is Kirsty McDonald. I am 15 and I live in East Kilbride, South Lanarkshire. I am writing to emphasise the importance of the Teenage Cancer Trust in the lives of teenagers and young adults who have been diagnosed with cancer.

I am not a patient myself but my older sister, Morvern McDonald, believe you are acquainted, has ovarian cancer. It has been an extremely long, hard and trying journey for her but also for us, as a family. In the beginning, when she was having her operations, she was in the Royal Alexandra Hospital in Paisley and Glasgow’s Royal Infirmary in the gynaecological wards which are mostly populated by older women, and, as she is only 24, I found it very hard to be in their company 24/7. I felt that the other, older, patients’ conversations were of subjects irrelevant to her, so, imaginably, she felt very isolated and out-of-place.

The Teenage Cancer Trust allows her to meet other people her age and socialise during treatment, and makes the time she spends in hospital less daunting. Currently she is being treated at the Beatson Oncology Centre in Glasgow, and, because of the Teenage Cancer Trust, she doesn’t feel as nervous or anxious as the nurses are extremely friendly and understand how important it is to make patients’ time in hospital as normal and ‘homely’ as possible.

I hope you understand the need to allow the age limit of the Teenage Cancer Trust to remain at 25 to remain so, because if it is lowered to 19, she would loose out on all of the benefits that the Teenage Cancer Trust bring, and the support the deliver, not just to patients, but to families as a whole.

Regards,
Kirsty

Nilani, 14, Bromley, Kent, diagnosed with an Adrenal Tumour

Dear Mr Cameron,

I was diagnosed with cancer in December 2010. It’s been a very difficult 9 months for me and my family. I felt we were supported very well by the NHS and the charities that helped us during this hard time; CLIC Sargent, Teenage Cancer Trust and Teens Unite Fighting Cancer.

The general awareness of cancer needs to be improved as well, it can be very difficult for the friends of a patient to know how to deal with the situation, one way this can be done would be to discuss it in PSHCE lessons which take place in all schools.

I hope you can help us.

Thank you,
Nilani

Karen, Mother

My beautiful daughter died in June this year from cancer after a two year hard and difficult battle which involved over a year of chemotherapy and numerous operations. She was looked after in a Teenage Cancer Trust unit.

Prior to diagnosis it took over 10 months for her to get the appropriate treatment as at the beginning her GP refused an simple xray request. She was then seen on numerous occasions by different health professionals who did not think to do one either. These young people are not listened to. The fact that she had never attended her GP apart from routine childhood vaccinations, should have been more for someone to realise this was a person who didn’t complain for the sake of it. I would urge that early diagnosis and treatment is essential and that needs to come from the GP. Late diagnosis and allowing young people to suffer is a terrible injustice. I feel my daughter doesn’t feel as nervous or anxious as the nurses are extremely friendly and understand how important it is to make patients’ time in hospital as normal and ‘homely’ as possible.

I hope you understand the need to allow the age limit of the Teenage Cancer Trust to remain at 25 to remain so, because if it is lowered to 19, she would lose out on all of the benefits that the Teenage Cancer Trust bring, and the support the deliver, not just to patients, but to families as a whole.

Regards,
Kirsty


My name is Lucy. I am 17 years old and from Somerset. I was diagnosed with Hodgkin’s Lymphoma in March last year, and treated at Musgrove Park Hospital in Taunton. At first my family and I had to travel to Bristol for my first cycle of chemotherapy as they were unsure whether my local hospital could participate in the medical trial. Fortuitously I was able to have my further three cycles of chemotherapy and numerous sessions of radiotherapy at Musgrove Park, to avoid the tiring travel to a city from Bristol, which didn’t allow us to continue with our lives as normal.

I found that once I had decided to be treated at my local hospital, the information and support decreased. Although I can’t fault the support I received from my local hospital, by comparing my experiences to those who were treated at Bristol Children’s Hospital, I seem to have missed out on some things. In the South West in general I feel like there is not a lot of support for young people with cancer, and the lack of a Unit in the region makes me feel as though we are somewhat forgotten, as we have nowhere to go specifically. I was treated on a children’s ward, which was not always suitable.

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Regards,
Kirsty

EMAIL MESSAGES, SEPTEMBER 2011
A lot of the nurses I encountered were amazing particularly in the Beatson. However, when I was in Charing Cross hospital over Christmas I did not have a good experience. Staffing levels were very low and I was regularly made to feel like a nuisance. My mum and my sister (who is a student nurse) did most things for me including changing my bed, dressing my Hickman line, helping me shower.

The nurses administered my chemo and gave me my drugs (which were very much and unable to go to the bathroom and they kept sending me off with laxatives. My mum is a GP and it wasn’t until she got involved that they decided to scan me. I felt they were just fobbing me off and couldn’t be bothered listening to me.

My tumour produced the HCG tumour marker which meant I tested positive on a pregnancy test. I knew there was no possibility that I could be pregnant and nobody believed me. It was so frustrating.

I was treated for a germ cell tumour (had mets in liver). I was treated for a germ cell tumour (had mets in liver). I was treated for a germ cell tumour (had mets in liver). I was treated for a germ cell tumour (had mets in liver). My tumour produced the HCG tumour marker which meant I tested positive on a pregnancy test. I knew there was no possibility that I could be pregnant and nobody believed me. It was so frustrating. First of all, I would like to raise the issue of delays in diagnosis. I went to my GP five times before they started taking me seriously. I wasn’t eating very much and unable to go to the bathroom and they kept sending me off with laxatives. My mum is a GP and it wasn’t until she got involved that they decided to scan me. I felt they were just fobbing me off and couldn’t be bothered listening to me.

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EMAIL MESSAGES, SEPTEMBER 2011

Stephanie, 19, diagnosed aged 17, Hertfordshire, diagnosed with Ewings Sarcoma (right pelvis)

Teenage specific cancer units need to be available all over the country which are big enough to hold all the teenage and young adult age group. Me and my family both feel that these wards should be made compulsory in hospitals just like children’s wards. Positive attitudes are everything when you get diagnosed and it is made a lot harder when the facilities you are in are not designed for you. It took me around 6 months to get diagnosed with going back to the GP every week they kept on saying it’s growing pains or you must of pulled a muscle the pains in your imagination, they wouldn’t send me for an X ray because they’re too expensive. They also didn’t realise that my age group would be at such high risk of getting cancer, GPs need to have a regular 3-5 year training in new discoveries in teenager cancers in particular because there is the stigma saying this age group puts things off the雷达 because they think they are too young, so that is another huge step for me and my partner to come to terms with and we can only hope the funding will be there for us when we are ready to have IVF. Having children has always been my dream and I did everything possible in the time I had to protect my fertility but it failed. This is another huge step for me and my partner to come to terms with and we can only hope the funding will be there for us when we are ready to have IVF. Having children has always been my dream and I did everything possible in the time I had to protect my fertility but it failed. So I hope you can help put something in place for myself and many other young adults who are even more teens with cancer in need of this great organisation.

Sarah, 16, USA Atlanta, Georgia

Through befriending Roger Daltrey, I have become active in trying to help get Teenage Cancer Trust started in the United States, because it is something we desperately need here. I was treated in an excellent Children’s Hospital, but it was just that - a Children’s Hospital. Sixteen year olds don’t want to watch cartoons all day and have blocks on the internet. I absolutely love what Teenage Cancer Trust is doing in the UK and I am doing everything I can to raise money so that once it finishes its work there that it can finally move it overseas to the US where there are even more teens with cancer in need of this great organisation.

Furthermore, I’d like to bring to your attention the direct impact on my career that my cancer had. I was aware of there being a lump in my neck around May/June 2000 when all level exams are taken and due to the severe fatigue I suffered (and still suffer from today as a result of my chemotherapy and radiotherapy treatments) caused me much trouble during my exams and therefore my exam results did not fulfil my full potential and I feel that this should be more acknowledged by people such as yourself as this would lead to universities considering this when, as you know, university places are much more difficult to obtain. I would very much like to become a primary school teacher as I love to work with, help and shape the minds of children and I wouldn’t want my cancer diagnosis to result in this not being able to happen.

I was treated on an adult oncology ward and it was the hardest thing as we were on different wards, rooms, or in different cycles. It was hard to meet people my own age going through the same thing as we where on different wards, rooms, or in different cycles. So with out the help of the teenage cancer trust the experience would of been a lot harder! My whole experience would of been a completely different story if I was on an age appropriate ward, with people I can relate to. And with staff who wanted to work with the teenager and young adult age group. Me and my family both feel that these wards should be made compulsory in hospitals just like children’s wards.

Positive attitudes are everything when you get diagnosed and it is made a lot harder when the facilities you are in are not designed for you.

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QUALITY
ACCESS
DIAGNOSIS
SURVIVAL

VISIT  www.teenagecancertrust.org
EMAIL  hello@teenagecancertrust.org
OR CALL  020 7612 0370

FACEBOOK  www.facebook.com/teenagecancertrust
TWITTER  @TeenageCancer

Teenage Cancer Trust is a registered charity: 1062559 (England & Wales); SC039757 (Scotland)