



No teenager with cancer left out

The impact of cancer on young people's
secondary school education

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Summary

No teenager with cancer left out reports on research which found that a cancer diagnosis can have a significant impact on a young person's secondary school education. It draws on: first hand experiences of young people who have lived with cancer in secondary school; existing research into primary school education and cancer; and the National Foundation for Educational Research (NFER) Teacher Voice survey. The report aims to raise awareness of the impact of cancer on young people's education, highlight existing good practice and suggest ways forward. We would like to thank all the young people who were involved in this research.

About CLIC Sargent

Every day, 10 children and young people in the UK hear the shocking news they have cancer. CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical, financial and emotional support to help them cope with cancer and get the most out of life. We are there from diagnosis onwards and aim to help the whole family deal with the impact of cancer and its treatment, life after treatment and, in some cases, bereavement.

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Introduction

Each year, around 3,600 children and young people are diagnosed with cancer in the UK, of which 2,000 are aged 0 to 18.

School is a huge part of young people's lives. Exam results and decisions made at this time may significantly shape their futures.

This report follows CLIC Sargent's 2012 research report, *No child with cancer left out*, which looked at the impact of cancer on children's primary school education. *No teenager with cancer left out* summarises findings from focus groups and telephone interviews with 22

Young people told us that they need more support to help them reintegrate into school life and reach their potential.

young people aged 13–19 who have or had cancer during their time at secondary school. It explores the specific issues that young people in secondary school face in keeping up with their education when they have cancer, particularly when they return to school during or after treatment.

We've found that lack of awareness about cancer in schools can be a problem. Thankfully, cancer is rare in young people. But this means most teachers and schools may have little or no experience of supporting a pupil who has cancer.

Even if the young person's needs aren't immediately apparent, their learning can be affected, sometimes long-term, by chronic fatigue, as well as attention, concentration, psychological and emotional difficulties.

We found that things work well when schools keep in touch with young people who aren't able to attend – and offer a tailored approach to supporting them when they return. However, in some cases, the social, emotional and practical support young people with cancer receive is not enough. Young people told us that they need more support to help them reintegrate into school life and reach their potential. Many feared falling behind and that their friends would move on.

Both reports deepen our understanding of the impact of cancer on children and young people's education. We will use the information to continue to raise awareness of these issues, share best practice and to help schools and teachers support

children and young people affected by cancer. We will further influence the government on these issues and the research will inform the way that CLIC Sargent health and social care professionals support children and young people with their education.



Key findings

This research has four main findings:

- The education that young people with cancer receive in hospital schools and at home could better meet their needs
- Communication between a young person with cancer, their family and school is important and should start as soon as they are well enough to learn
- Tailored support when a young person first returns to school following a period of illness can make a real difference to their future education and development
- Young people with cancer fear they may have to retake the academic year and will be left behind.

Context

Young people and cancer

Young people face complex issues as they go through secondary school. This time in a person's life, when they move from being a child to a young person, is characterised by biological, psychological and social changes. Having cancer at this time can create even more change and uncertainty.

A cancer diagnosis can significantly disrupt a young person's journey towards becoming independent and achieving their goals and aspirations. It can redefine their life and challenge their sense of identity and how they see themselves. Cancer can threaten a young person's sense of belonging, make them more aware of their body image, and have an impact on their relationships.¹

Previous research

This report builds on our 2012 study, *No child with cancer left out*, which explored the impact of cancer on children's primary school education. For this research, we spoke to children and their parents, hospital school/medical pupil referral unit (PRU) teachers and CLIC Sargent health and social care professionals.

The research found that things work well when:

- A child's primary school teachers and friends keep in regular contact, making them feel involved and valued
- Education, health and social care agencies work together to help children with cancer make smooth transitions through services
- School staff show understanding and consideration when pupils go back to school, by explaining their illness to other pupils and making necessary adjustments to help them participate in school life.

¹ Harvey, N and Finch, A, 'Supportive care for adolescents and young adults during cancer treatment' in Kelly, D and Gibson, F (2008) *Cancer care for adolescents and young adults*. Blackwell, Oxford.



However, some respondents reported:

- Delays in receiving home tuition
- That primary schools didn't keep in touch with children when they were absent
- That children experienced bullying and teasing when they returned to school.

Policy changes

Since our 2012 report, there have been a number of important developments in education policy.

Funding

Hospital and home education services now have a fixed annual budget to cover the costs of all children and young people who receive education in these settings. They no longer have to recoup funding in each case.

Guidance for local authorities

In January 2013, the government published new guidance for local authorities, setting out their legal responsibilities for ensuring that children and young people with medical needs receive a good education. We helped to develop this guidance, called 'Ensuring a good education for children who cannot attend school because of health needs', in collaboration with the National Association for Hospital and Home Teaching (NAHHT), the Council for Disabled Children and other health-focused children's charities.

It includes information for local authorities on:

- Arranging suitable education for children and young people who are too ill to attend their normal school
- Preventing children and young people with medical needs from falling behind their peers in school
- Supporting children and young people to reintegrate successfully back into school as soon as possible
- Naming an officer responsible for the education of children and young people with additional health needs
- Having a written, publicly-accessible policy statement on what arrangements they have to make to comply with their legal duty towards children and young people with additional health needs.



Additional support

Findings from our primary school education report guided our influencing work on reforms to how additional support is provided to children and young people with special educational needs (SEN) and disabilities across the UK. This has included the Children and Families Bill in England, which is currently going through parliament.

Protection under equality legislation

CLIC Sargent recognises that many children and young people with cancer do not define themselves as disabled. However, children and young people who have had a cancer diagnosis are covered by the Equality Act 2010 in England, Scotland and Wales and by the Special Educational Needs and Disability Order 2005 (SEND O) in Northern Ireland.

The Equality Act requires schools to take ‘such steps as it is reasonable to have to take’ to ensure that a disabled pupil, or prospective pupil, is not placed at a substantial disadvantage. This is usually known as the ‘reasonable adjustments’ duty.

A reasonable adjustment is a change a school might make so that a disabled pupil is not disadvantaged. This could be a change to practice, for example allowing a child to have extra time in exams, or a physical adjustment, such as installing an access ramp for a wheelchair user.

Learning in hospital or at home

Hospital school

Local councils are responsible for the education of pupils who are unable to attend school because of their medical needs. Our 2012 primary school report found that hospital schools can play a crucial role in helping ensure children with cancer access the education they are entitled to. They can help children and young people with cancer stay engaged in education and also take their mind off treatment. Most of the young people we spoke to for this secondary school report were offered learning through their hospital school.

Age appropriateness

Our 2012 primary school research found that 61% of parents felt their child was given suitable school work when they were learning in a hospital school. However some young people who took part in our focus groups and telephone interviews as part of our secondary school project, told us that the education they received in hospital school was not age appropriate. A lot of the work they were set was too basic for their ability and it was difficult to learn in an environment where they were the only pupil of their age.

Most of the young people preparing for SATs or GCSEs told us they did not receive the specialist subject support they needed. “The hospital school didn’t really help,” one young person told us. “We did art but not subjects like English and Maths. It was just looking at the books really, not a great deal.”

Communication with the school

Many of the young people we spoke to told us that their school didn't communicate with the hospital school they went to and that there were often delays in sending appropriate work, a finding consistent with our 2012 primary school research.

"They didn't bring me any work. They just gave me a folder and said: 'Just have a go at it, just do it'. I didn't touch most of it."

This lack of communication meant that some young people struggled to complete test papers or work sent to them from their school because they had missed out on the relevant learning. However, a small number said their school did keep in touch with the hospital school and that the work they received was age appropriate. They found this helpful and that it meant they could keep up with their peers:

"It definitely helped that they kept in touch because I was learning at the same pace as the other kids. I was a little bit behind, but generally I was at the same pace as the others."

Secondary schools are likely to be larger than primary schools and pupils may have different teachers for each subject. This can make communication difficult, including coordination between the various teachers involved.

From our previous research, we learnt that primary schools tend to liaise with teachers at the hospital school rather than with pupils directly. We found that young people in secondary schools are more likely to take the lead when communicating with their school. For example, the young people we spoke to who were approaching exams took this communication role on themselves, requesting work from their own school.

"I was quite keen not to fall behind and have to retake the year, so I asked my teachers to send me some work and they were really good at sending it to me."

Consistent with the findings from our 2012 primary school report, this year's research found that technology can play an important role in maintaining communication. A few young people told us that they were able to maintain regular communication with their school by email during their treatment and said this helped with their transition back to school life. One young person's school had an online portal where teachers saved lesson plans and worksheets, a useful way to access work they had missed.



Home tuition

Home tuition is a helpful stepping stone for young people who are not in hospital but are too ill to attend school. For example, some young people told us that they were able to supplement school classes with home tuition to help them catch up.

Young people we spoke to had varied experiences of home tuition. As per the findings of our 2012 research, this often depended on where they lived. Some disliked having a tutor coming to their home and found it difficult to do the work that was set because they had not studied the subject area. Others really valued having a home tutor so that they could focus on certain subjects and did not fall behind. This was particularly common for young people approaching their GCSEs:

“Someone from the hospital school team came to my house and went through the work I’d asked my teachers to send me. It was useful.”

One young person who was having ongoing cancer treatment told us that their home tuition stopped because they could go to school for more than five hours a week. However, they could not attend school for at least one week out of every three because of their treatment. They felt a more flexible approach was needed.

Fay’s story

In 2009, when Fay was 15, she was diagnosed with Hodgkin’s lymphoma. As a result of her cancer treatment, Fay missed out on six months of school.

“When I was well enough, I forced myself to go to school to try and do normal things. I was doing my GCSEs so I needed to do the work. I was quite focused, mainly for everyone else around me. If I could go to school, they would see that I was okay.



I was halfway through my GCSEs and tried to keep up with it as much as I could. Doing drama and music was quite difficult, though, as it’s practical and there was no way for me to be involved if I wasn’t in school.

My German teacher emailed me work to do when I was in hospital. But it was difficult being at the hospital school because it is very much focused on younger children. I could

ask the teachers for help but they did not really know how to.

I ended up dropping one of my GCSEs because I missed too much to carry on.

Then I took a year out after my exams because of all the side effects of my treatment. It had really worn me down.

I think my teachers should have been able to listen to what I wanted. There definitely could have been more support. When I

finished chemotherapy and went back to school, I guess they didn’t really want to approach me with work because I obviously wasn’t very well.

They kind of skated around it and gave me the easy work, which, in the long-run, was really not helpful. They were trying to make it easier, but it didn’t benefit me in terms of my overall education.”

Returning to school during or after treatment

Though the majority of young people with cancer eventually return to school, some find it difficult to reintegrate back into education after their cancer treatment.

Other challenges facing secondary school aged young people include:

- Establishing effective communication across the school workforce
- Negotiating the school environment
- Pressure not to miss exams.

Consistent with our 2012 research findings, almost all the young people we spoke to had a phased return to school. Schools often allowed them to miss classes they did not feel well enough to attend and most were pleased to be consulted about which subjects to prioritise.

Talking about cancer

All young people can feel under pressure at school, for example, about how they look and whether they feel included. These feelings can be exacerbated when a young person has cancer, which is why it's important for schools to support them to reintegrate back into school life.

Health and social care professionals can inform staff, classmates and friends about cancer to correct assumptions they may have about it and help them understand common aspects of treatment and its side effects for children and young people.

CLIC Sargent's role in smoothing reintegration

A young person's reintegration into school is normally coordinated either by their home tutor or an outreach nurse. They will typically go into a school and offer school teachers advice on what to expect from a child or young person undergoing a phased return to school.

CLIC Sargent health and social care professionals often play a key role in maintaining communication between the family and the school at this stage. They may attend or arrange meetings with the school or help develop an individualised health care plan for the school to address the medical and health needs of the child or young person. This can break down a lot of barriers, including anxieties that staff may have about having a child or young person in school who has cancer.

Conducting assemblies

Most of the young people we spoke to told us that a health or social care professional went into their school to conduct an assembly explaining why they had been absent from school and what to expect from the young person concerned on their return. Overall, they felt these assemblies improved their peers' understanding and took the pressure off them because they didn't have to answer so many questions. Some said they weren't involved in the decision to conduct an assembly and wish they had been.

Those who didn't have a professional visit their school to talk about what had happened thought it could have helped stop questions from classmates and prevented or lessened bullying. Others said that meetings with parents and the school helped them reintegrate back into school life.

Maintaining communication

Despite having an assembly at their school, some young people felt that not all teachers were aware of their situation. For example, they were questioned by staff when they left one lesson early in order to have time to get to their next one. One young person told us that their teachers could have been better informed about how cancer can affect a young person's ability to learn:

“They obviously knew that I wasn't very well. But all they knew is that I had cancer. I think they probably could have known more about the treatments and stuff. It was almost as if ‘The cancer is gone now so it's over’ but it doesn't really work that way.”

The young people we spoke to felt that a form teacher's seniority had an impact on how good communication about their situation was amongst teachers within the school. Communication was often better if the headteacher took a personal interest in ensuring all staff knew about a young person's situation.

National Foundation for Educational Research (NFER) Teacher Voice survey

In March 2013, NFER research² found that nearly four out of 10 (38%) secondary school teachers “disagreed” or “strongly disagreed” that enough information resources and guidance are available to teachers to support a pupil with cancer in school. In addition, more than a quarter (27%) of secondary school teachers said they did not know whether enough information, resources and guidance were available.

Additional support with catching up

Young people with cancer can face a number of barriers in keeping up with school work, maintaining friendships and feeling included in school life. Some will need significant or permanent additional support and may not be able to return to previous attainment levels.

In 2010, nearly two thirds (64%) of 16 to 18-year-olds with cancer we spoke to told us that they fell behind with studies or did not do as well as they thought they could have when they went back to school. Around three out of 10 (29%) young people surveyed said they had to leave education altogether.³

2 Pyle, K. (2013). NFER Teacher Voice Omnibus March 2013 Survey: Support for Pupils with Cancer. Slough: NFER. Available: www.clicsargent.org.uk/teenagerwithcancerleftout

A representative panel of 1,587 practising teachers from 1,243 schools in the maintained sector in England completed the survey.

3 CLIC Sargent (2010) More than my illness – delivering quality care for young people with cancer.

Additional learning support

Our 2012 primary school research found that schools can struggle to accommodate the individual needs of children with cancer who have returned after a period of absence. This can contribute to them achieving less than their peers in education.

Most young people we spoke to for this year's report were able to concentrate on selected core subjects like Maths, English and Science. Where things worked well, young people would meet up with a teacher and get information about the work they needed to do or were struggling with. This does not seem to be standard practice though, as a few young people appeared to have a significant lack of support:

"I have my GCSEs coming up and I am really struggling. I have missed loads of subjects and I can't find a way of catching up."

If they have not supported a young person with cancer before, it can be difficult for schools to know how to cater for the learning needs a young person may have acquired as a result of having cancer. Some schools might have separate support units where young people receive targeted learning support. However, several of the young people we spoke to who learnt in these units did not enjoy learning in this environment as it made them feel isolated and vulnerable. Some suggested that tailored or one-to-one support to help fill in the gaps in their learning would have been a better approach.

"You're fighting a losing battle from the day that you go back. There are so many of you in one class that the teacher can't be with you all the time, telling you what to do. You can't hold the class back."

Identifying and meeting needs

Even if a young person has been successfully treated for cancer and has gone into remission, they may experience significant and long-lasting late effects. Studies show that survivors of childhood cancer may perform less well in education compared to their peers, although lower attainment is mostly found among survivors of particular cancers, for example, brain tumours and leukaemia.⁴

A formal assessment of needs on a pupil's return to school would help, suggested two young people. Otherwise, if they appear 'normal' the school assumes they are fine and expects them to pick up where they left off. The question of how effectively young people's needs are assessed on their return to secondary school when they have had cancer is critical to the success of reintegration.

Schools have a legal duty to make changes to the way they function so that a pupil with a disability is not disadvantaged. Our research found that a number of young people were given additional time to complete exams which helped with things like hand fatigue. One was given a laptop because their writing hand had been affected by their cancer. Their Science teacher also helped to type some of their work and they achieved an A in this GCSE subject.

⁴ Lancashire, E et al (2010) Educational attainment among adult survivors of childhood cancer in Great Britain: A population-based cohort study. *Journal of the National Cancer Institute*, 102: 254-270.

One young person, who had a brain tumour, felt they didn't get the extra support they needed. They were told that having someone to help them read their work would be useful but this did not happen. Another left school before they had completed their GCSEs because they became frustrated by the lack of the support they received.

"I wanted some extra help but I wasn't given the option. My mum asked for it but was told it wasn't available because it was a small school. I think if I had had it I may have been more confident in my learning. Maybe I would have put my hand up and not been afraid of getting things wrong."

Catching up

A cancer diagnosis means that young people often experience significant disruption to their education, with treatment sometimes lasting as long as three years. Some may experience difficulties catching up with learning they missed when they were absent. Our research found that some young people were pleased with the amount of support they received when they went back to school. They found that one-to-one support helped them catch up with particular subjects:

"My teachers were more than willing to do whatever it took to make sure that I caught up. I came out of hospital and got two out of 30 in a history test and then, in a few weeks, I did another one and got 19 out of 25."

Others felt that they had to keep requesting support and that if they had not been so persistent, it would not have been provided. "A lot of teachers don't bother or they feel nervous or something," suggested a young person. "So if someone in my position was not proactive about asking, they might end up falling quite far behind. It's probably best to have an official structure so that they can avoid that."

The young people that we spoke to were clear that appropriate additional support at school should be available from the very start. "Cancer can happen to anyone, so I think that all schools should be aware that they must send work home straight away so you don't waste time trying to get hold of the work," one young person told us.

Missing out on school

Fear of being left behind

Young people approaching a pivotal time in their education were most aware of the impact that cancer has had on their ability to achieve at school, and reaching their potential becomes very important to them. This included those approaching examinations for their SATS, GCSEs and A levels.

Some young people we spoke to have been deeply affected by the impact that cancer has had on their ability to achieve the grades they were aiming for.

"I could have been so much better if I didn't have cancer, but now I will never know."



Retaking an academic year

Young people may be encouraged or instructed to retake a year if they miss long periods in education or crucial pieces of work.

However, it was seen as the 'worst case scenario' for some young people in our focus groups, who felt the emotional and social impact of watching their friends' progress and seeing them move on without them. One young person who has retaken a year feared that their new classmates would judge them and think they had to repeat the year because they didn't work hard enough.

Responses suggest that there is a stigma to being put back a year. But two of the young people we spoke to who were about to take their A levels did decide to retake a year. They felt this would help their grades reflect their true potential.

"I want to come out with good grades and if I want to do that then I have to retake the year."

Feeling disempowered

A young person can become more independent in their secondary school years. But having cancer may mean that this independence can be quickly reduced or taken away.

Our research found that some young people felt their school made big decisions about their future education without consulting them. For example, some young people were told they had missed too much education to complete their exams and they felt they had no say in this. Being told they were unable to complete their GCSEs meant that one young person felt they could not demonstrate their achievements at secondary school.

Physical environment

Treatment that a young person receives for cancer can have an impact on their mobility and ability to get around school easily. Some may be chronically fatigued, while others can have poor mobility (for example because of muscle weakness or an amputation), vision or hearing. This can make it difficult to navigate a large secondary school campus.

Our research found that some schools are quick to accommodate any new physical disabilities or needs a young person might have as a result of their illness. One young person's school swapped timetables around so that they could access lessons on ground level. Another moved teachers to different lessons so that the young person had no need to travel to classes. A few young people had used a wheelchair to get about as a result of reduced mobility because of their cancer treatment. They said their school was accessible, with wide doorways, ramps and a lift they had a special key for.

Our focus groups found that some young people had access to a separate room which they could use to receive extra one-to-one support. While some reported circumstances where this worked well, this made a small number of young people feel isolated because they had to stay in a separate part of the school. Their teachers did not know how to meet their needs and they could not access classes that were not on the ground floor.

One young person, whose mobility was affected by their cancer treatment, told us that their school put them in a separate learning area. "There were no lifts and they just kept saying that they didn't have enough staff to put me somewhere else," this young person told us. "It made me give up more because I was in there for the wrong reasons. I was put in there because there was nowhere else." Instead, suggested this young person, the school could have provided more tailored one-to-one support or found a more accessible and appropriate space for them to learn in.

Transition to further and higher education

From this report, we also uncovered some insights about further and higher education.

A number of young people said that their 'special circumstances' had been taken into consideration by colleges so that they could access further education. They were offered a place at colleges even if they didn't have the right results or number of GCSEs.

One young person told us that they had to include a letter from their doctor as part of their university application to explain how cancer had affected their education. The young person had to send the letter with every university application, which they found to be a stressful process. They felt that there could be an easier, more streamlined way for universities to receive this information, for example, by having this letter to be automatically attached to their personal statement.

Another young person told us that they specifically researched universities recognised as being supportive to young people with additional needs and/or special circumstances.



Conclusion

Our research shows that cancer can significantly disrupt a young person's secondary schooling – a crucial time in their education.

It highlights issues young people face in secondary school, including the impact of the physical environment, the importance of effective communication between teachers and the fear of being left behind.

Learning in hospital and at home can be a useful stepping stone back into school after a period of illness. But young people think that the education they receive in these settings should better meet their needs. They also told us about the value of effective communication with their school from the start of their illness, and that tailored support when they first return to school can make a real difference to their future education and development.

We learnt that there is stigma around retaking an academic year and that young people fear that this could mean they would be left behind by friends and peers. They need more support to help them reintegrate into school life and reach their potential.

Our findings complement those from our 2012 report *No child with cancer left out: The impact of cancer on children's primary school education*. We will use them to:

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- **Inform our ongoing policy work.** We want to see secondary education systems that help children and young people diagnosed with cancer receive the support they need quickly, for as long as they need it.

 - **Inspire our influencing.** We think schools need effective guidance on how to support young people with cancer as they move across different educational settings, including in hospital.

 - **Better equip schools to feel confident communicating with young people with cancer, especially those who are absent from school.** We are developing information resources for education professionals that will be published in 2013/2014.

 - **Help improve communication between education professionals, pupils with cancer and their families.** This can help young people with cancer to keep in touch with classmates when they are absent from school, allowing for a smoother transition when they go back to education. It can also help them feel informed and in control.

 - **Raise awareness and build knowledge and understanding of the impact of cancer on young people.** This can help teachers and other pupils to better understand and support a classmate with cancer during and after treatment.

 - **Further explore the impact cancer has on young people's post-16 education, employment, training and skills.** We will be undertaking research into this and a report will be published in December 2013.



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