



No child with cancer left out

The impact of cancer on children's
primary school education





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Summary

No child with cancer left out summarises research which shows that a cancer diagnosis can have a significant impact on a child's primary school education. This report aims to raise awareness of the impact of cancer on children's primary school education, highlight existing good practice and suggest ways forward.

About CLIC Sargent

Every day, 10 children and young people in the UK hear the shocking news that they have cancer. Treatment normally starts straightaway and can last for up to three years. CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical and emotional support to help them cope with cancer and get the most out of life.



Foreword

When a child is diagnosed with cancer, treatment normally starts straightaway, is often given many miles from home at specialist children's cancer centres, and can last up to three years. During treatment and beyond, a child's education may be significantly disrupted, together with their ability to make and maintain friendships at school. A cancer diagnosis and its treatment also has a profound effect on family life, including on siblings and other family members.

CLIC Sargent aims to be there from diagnosis onwards providing clinical, practical and emotional support to help the whole family deal with the impact of cancer and its treatment, life after treatment and sadly, in some cases, bereavement.

We undertook this research to better understand the support that currently exists for primary school age children with cancer and their families; to highlight what works well, and to help to change those things that don't. We looked at the support children receive in hospital schools, when they are tutored at home, and as they reintegrate back into full-time school. The findings are set out in this report, *No child with cancer left out*, which we hope will raise awareness of the issues and help inform policy and practice.

Our research found that cancer can significantly disrupt a child's education – in fact nine in 10 (90%) children told us that their cancer diagnosis and treatment made a difference to their school life.

Communication was a key issue – communication between hospital and primary school, as well as between teachers and parents. Where communication worked well, parents said they felt their child received

the educational and emotional support they needed; where communication was poor, parents often said they felt let down by the system. In many cases we found that schools and local authorities apply policies and practices in different ways, which can make navigating the system a real challenge. For example while 56% of parents told us that they were approached by a professional about their child's education within the first month, 16% reported that they were not approached at all.

Awareness and understanding of the impact of cancer on a child also helped teachers and other pupils to better comprehend and support a classmate with cancer during and after cancer treatment.

Some of the children we spoke to told us they welcomed the extra attention when they returned to school, but many found their friends had 'moved on' and they felt

left out as a result. Over a third of the parents who responded to our survey reported that their child had experienced teasing or bullying as a result of the effects of their treatment. These effects might include hair loss or weight gain due to steroids.

"Over a third of the parents who responded to our survey reported that their child had experienced teasing or bullying as a result of the effects of their treatment."

Our research illustrates a number of good practice examples of how to support children learning in hospital, at home and when they return to primary school. We will share these ways of working with policy makers and education professionals to help them gain new insights and inspiration.

We are extremely grateful to the 221 parents, 60 children, 18 hospital schools and 68 CLIC Sargent health and social care professionals who have contributed to this report. In return, CLIC Sargent promises to work with policy makers and politicians, schools and teachers, and children and

families themselves to ensure that children with cancer receive the support they need in hospital, and at school, to get the most out of life during and after their cancer treatment.

Lorraine Clifton
Chief Executive



December 2012





Introduction

Each year, around 1,600 children aged 0-14 are diagnosed with cancer in the UK. Many of these children are at a critical stage in their development – at a point in their primary school education where they are laying down the fundamentals of literacy and numeracy and building their emotional intelligence through friendships. In a 2010 CLIC Sargent study,¹ children told us that the disruption to their education is one of the most devastating impacts of cancer on their world, second only to the impact on their physical health.

Attending school is a huge part of a child's life. It provides structure and stability, as well as helping children develop crucial social, emotional and behavioural skills. While many academic studies have looked at the impact of cancer on a child's educational attainment, the social and emotional impact of cancer on a child's experience of school is less well-known. This is why CLIC Sargent decided to undertake this study, which aims to:

- Raise awareness of the challenges children with cancer experience in keeping up with their education when they face often lengthy periods of cancer treatment
- Highlight good practice of supporting children with cancer in education
- Improve the support children receive to continue their education during treatment, and get back to 'normal' life at school when their treatment has finished.

In the research that underpins this report, nine out of 10 of the primary school age children we spoke to said that being diagnosed with cancer had made a difference to their school life. However, many of the children and parents who responded had relatively positive experiences of hospital schools, local authority-provided home tuition, and reintegration back into primary school.

Where the system works well, the child's primary school teachers and schoolmates keep in regular contact and make them feel involved and valued; education, health and social care agencies work together seamlessly to ensure that children can make the necessary transitions without any trouble; and primary schools show understanding and consideration when pupils re-enter their classes, explaining their condition to fellow pupils and making necessary adjustments to help them participate as much as they can in primary school life.

However, many of our respondents reported delays in securing home tuition, primary schools that didn't maintain contact with children when they were absent for more than a few weeks, and bullying and teasing when they returned to school.

Our findings highlight many examples of good practice which we will now aim to share more widely with education professionals and policy makers. They also illustrate the impact that financial pressures on local authorities could have on some of the most vulnerable children in our society.

1 CLIC Sargent (2010) *The impact of cancer on a child's world*

Key findings

Learning in hospital or at home

- Over two in three (70%) parents reported that their child had received some form of education away from their primary school during their treatment, mostly through hospital schools
- All of the hospital schools we spoke to told us that the level of communication varies considerably from one primary school to another
- More than one in three (36%) parents said their child's primary school was in regular contact with their child's hospital school during their time in hospital – but the majority of families did not feel they were kept well-informed about their child's education when their child was taught in hospital
- Some children with cancer found it difficult to access home tuition, and some never managed to access it at all. Almost all the hospital schools we spoke to reported problems with home tuition
- Just over half (56%) of parents said they were satisfied that their child was given suitable school work when they were being taught at home

Returning to school

- Almost two in three (63%) parents told us they felt well-informed about their child's education at their primary school following their cancer diagnosis
- Almost two in three (64%) parents said they were consulted about how their child's diagnosis should be communicated to other teachers and school children – although one in three were not consulted on the matter
- Just over half (56%) of parents of children who have returned to school felt that their child had received sufficient support to enable them to resume as normal an education as possible

Social impact and support

- More than one in three (35%) parents said their child had experienced bullying or teasing from their peers because of their cancer diagnosis and treatment
- Almost half (47%) of parents said that their child had grown apart from friends because of their cancer diagnosis and treatment
- Almost half (47%) of parents said their child's school did not help to maintain contact with peers and friends during their absence from school.





Policy context

Education provision in the UK is in a period of transition. Policy change has led to a significant increase in the number of academies, an increase in the age to which all young people in England are required to continue in education and ongoing changes to special educational needs (SEN) and disability provision in England, Wales and Northern Ireland.

CLIC Sargent works to influence policy so that children and young people with cancer are not negatively affected by such changes, and that they receive the support they need in education. For example, we are currently working with the Department for Education, along with hospital schools and other children's health and disability charities, to develop new guidance² for children and young people with medical needs in education. Fundamental to CLIC Sargent's work is the belief that children and young people with cancer should be enabled to achieve their potential and that quality support in education is a crucial part of achieving this.

Below is a brief guide to the main rules which apply to primary school age children with cancer and how they are changing.

Funding

Local authorities in England, Scotland and Wales currently invoice for the cost of each child's hospital schooling in a process called recoupment. It has been proposed that, in future, there will be one single national fund to pay for hospital schooling in England. This will be allocated to local authorities according to the number of projected hospital school places in their area. In Northern Ireland, Education and Library Boards currently fund hospital and home education provision for children within and from outside the local authority area. However, there are proposals to change this so that money is recouped from the local authority where the child lives, as currently happens in England, Scotland and Wales.

The rules on funding

Local authorities are allowed to claim back the cost of providing education in hospitals in their area for children who normally live in another borough. The amount they can claim back isn't fixed – it's agreed between authorities. However, local authorities can't refuse to make payments on behalf of children they are responsible for, even if they didn't give their prior agreement to the arrangement. Only the amount they pay is negotiable.

The six day policy

The law doesn't specify at what point local authorities should step in to offer education to children with medical needs who can't attend their primary school. However, where it is clear that an absence is likely to be more than 15 days the local authority should arrange education by the sixth day. All local

authorities should have freely-accessible written policies setting out what they will do for pupils unable to attend school because of a medical condition, and they should be flexible enough to meet the needs of individual pupils, whatever those needs are.

² This new guidance will replace *Access to Education – for children and young people with Medical needs* which was published by the then Department for Education and Skills in 2001



Hours of education

The law in England, Scotland and Wales doesn't specify how many hours of schooling a child with medical needs should receive, as long as the end result is equivalent to what they would have had in their primary school. The government states that a child receiving home tuition may need fewer hours because the one-to-one tuition they receive will be concentrated.

Coordination between services

All the agencies involved in supporting a primary school age child with cancer – including their primary school, hospital school and local education authority – are expected to collaborate effectively to ensure that the child experiences a joined-up service. The government recommends working in partnership to ensure this happens. However, it is not prescriptive about how this should work – it's up to local areas to set their own policies.

Assessment

The assessment of children's needs when they return to school – and whether they require a statement of SEN – is a major issue for many of the parents and children we spoke to.

In September 2012 the Department for Education published draft legislation³ aimed at reforming the SEN and disability framework in England. The provisions include a proposal to replace statements of SEN with education, health and care plans for 0 to 25-year-olds; to set out a 'local offer' of services available to parents and young people; and provisions to require joint commissioning between local authorities and clinical commissioning groups. While CLIC Sargent supports the intentions behind many of these proposals, we are concerned that children with cancer in England could lose out as a result of these changes.

The Welsh Assembly Government is also proposing to change the current statutory framework⁴ for the assessment and planning of provision for children and young people with SEN. The aim is to bring in a simpler, more person-centred and integrated system focusing on 'additional needs', with a more multi-agency approach to addressing need – moving away from an approach where education is in the lead to one of full partnership between education, health and social services. Individual development plans will replace the existing statements of SEN, and the concept of additional needs will be given legal force. The new system will also cover everyone up to the age of 25 who needs additional support.

There are no plans to change the system in Scotland, where the concept of SEN was broadened to 'additional support needs' in 2004 and includes factors affecting a child's learning, such as bullying and bereavement. Local authorities must prepare a coordinated support plan for children where appropriate, to ensure the support provided by different agencies is joined up.

The Northern Ireland Executive also has its own code of practice on assessing SEN and is currently reviewing SEN and inclusion provision. The policy intention for the new SEN framework is to ensure that the child is placed firmly at the centre of the processes for identification, assessment, provision and review of the support they may require.

Reasonable adjustments

While CLIC Sargent recognises that many children and young people with cancer do not define themselves as disabled, 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

3 Draft legislation on the reform of provision for children and young people with special educational needs was published in September 2012. This will form part of the Children and Families Bill 2013

4 The consultation document *Forward in partnership for children and young people with additional needs* was published in June 2012

Disability Order 2005 (SENDO) 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 change, for example installing an access ramp for a wheelchair user.

This reasonable adjustments duty includes a new requirement to provide auxiliary aids or services – the definition of which is very broad. The Equality and Human Rights Commission's draft Code of Practice for schools states that it is 'anything which provides additional support or assistance to a disabled pupil.'⁵

Under the new duty, schools will need to consider whether a disabled pupil may need an auxiliary aid or service to prevent them being at a substantial disadvantage. The group who are most likely to benefit from the duty are disabled children who do not have SEN – including children with a medical condition such as cancer.

In Northern Ireland, SENDO places duties on agencies responsible for the provision of education and associated services. For schools, there is a duty to work towards making the education experience more accessible to disabled pupils and prospective pupils in terms of premises, the curriculum and information. To assist with this particular duty the Northern Ireland Education and Library Boards produce accessibility guidance and strategies.⁶

5 www.equalityhumanrights.com

6 www.equalityni.org



Our research methodology

Our research looked at the experiences of children who were diagnosed with cancer between the ages of four and 11, parents of children diagnosed with cancer at this age, hospital school staff and CLIC Sargent health and social care professionals. We used the following research methods:

Children

► Children's questionnaire

A children's questionnaire featured in *Shout Out!*, CLIC Sargent's magazine for children with cancer. Children were asked to complete a number of questions and return their answers to us. 31 children submitted responses.

► Children's activity workshops

Three children's activity workshops, themed around the children's questionnaire, were held in Birmingham, Bristol and Manchester. In total, 29 children attended the workshops.

Parents

► Survey of parents

An online and paper survey was promoted to parents of children who were diagnosed with cancer between the ages of four and 11. A total of 204 parents completed the survey, of which 21 were bereaved.

► Parent focus groups

Three parent focus groups based on the parent survey were held in Birmingham, Bristol and Manchester. In total 17 parents attended.

CLIC Sargent health and social care professionals

► Survey of CLIC Sargent Nurses and Social Workers

An online survey was distributed to CLIC Sargent Nurses and Social Workers. A total of 12 nurses and 27 social workers completed the survey.

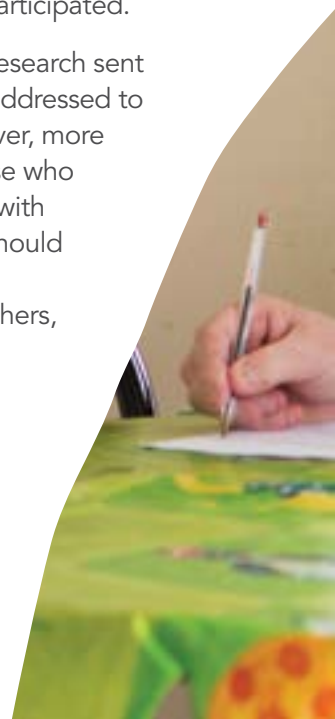
► Focus groups

Two focus groups, based on the CLIC Sargent Nurses and Social Workers survey, took place with a total of 20 social workers from London and nine nurses from the South West.

Hospital school staff

All of the hospital schools within the 18 principal treatment centres across the UK were invited to take part in a 30-minute interview. 17 hospital schools took part in either a telephone or face-to-face interview. One hospital school based at a shared care centre also participated.

All invites to take part in the research sent to the hospital schools were addressed to the head/lead teacher. However, more often it was decided that those who directly worked with children with cancer within the classroom should take part in the interview. We spoke with six head/lead teachers,



16 teachers, one special educational needs coordinator and one school secretary.

In total, 221 parents, 60 children, 68 CLIC Sargent health and social care professionals and 18 hospital schools took part in the research. Consulting with primary school staff was outside the scope of this project.

We asked parents, children, CLIC Sargent professionals and hospital schools to consider the impact of cancer on children's primary school education in terms of:

- Learning in hospital or at home
- Returning to school during or after treatment
- Social needs and support.



Learning in hospital or at home

Continued learning – whether it’s in a primary school, a hospital school or through home tuition – is the right of all children with cancer. Our research has identified some excellent examples of good practice, from joined-up working between health, social care and education professionals to detailed learning plans which can help children keep up with their primary school education. However, we’ve also highlighted some significant areas of concern, including delays in providing home tuition and increasing pressure for cost savings, which could have serious consequences for the education of children with cancer.

Learning in hospital

Hospital schools can play a critical role in ensuring that children with cancer access the education they are entitled to. One parent told us that the hospital school on their day unit is

“fantastic”. They said it keeps normality going, distracts children from cancer and gives them something to look forward to.

What the law says

Section 19 of the Education Act 1996 requires every local education authority to make arrangements for the provision of suitable education at school or ‘otherwise than at school’ for all school age children who might be denied an education because of illness.

The Act defines ‘suitable education’ as ‘efficient education to the age, ability, and aptitude and to any SEN the child may have.’

This right to a full-time education applies to all school age children, regardless of whether they are on the roll of a school or not, and it applies to pupils in academies and independent schools as well as in traditional state schools. However, the law doesn’t specify what ‘full-time education’ means in terms of hours; it’s taken to mean an education equivalent to what the child would have received if they were attending school.

Education for pupils who are unable to attend school because of medical needs can be provided in a variety of ways, for example through the provision of a hospital teaching service, home tuition, or an integrated hospital/home education service.

Seven out of 10 (70%) parents we surveyed said their child had had some education in hospital since they were first diagnosed, and the vast majority of those parents (70%) said this education was delivered in a hospital

school classroom. The remaining 30% said their child received education at their bedside. The children we spoke to confirmed this: over three-quarters (77%) told us that they had spent some time learning in a hospital school. More would like to attend hospital schools if they could. One nine-year-old girl told us: “There is a hospital school in the hospital but you can’t go if you’re on a drip – and I am always on a drip. This really annoys me.”

“When I was in hospital I always looked forward to school time. It gave me something else to do other than just sit in bed watching telly. Most of the time I was barriered, meaning I had one-to-one lessons. When I was barriered, having lessons also meant that I could see and talk to someone other than Mum or Dad.”

School girl, age 12

Good practice

Working in partnership with Arts for Health, an arts and health organisation, Alder Hey Children’s Hospital has established activity sessions for children on the wards. As explained by a hospital school teacher, “Arts for Health is great. We have a storyteller that visits from a gallery in the city. He’s able to engage children of all ages.”

Securing hospital education

The hospital schools we spoke to told us that they identify new oncology patients either by visiting each of the wards every morning to see whether any new children have been admitted, or by attending a multi-disciplinary team meeting which includes all the different specialists who work with children. Hospital school staff told us that they would always confirm with a medical professional that the children are well enough before they began teaching them.

Most hospital schools said that the hospital generally provides education to children who are in hospital for five days or longer. However, the time between being admitted to hospital as an inpatient and receiving education appears to vary between hospital schools. Some told us that they start making provision straight away for cancer patients who they know are going to be in hospital for a long time.

One hospital school teacher told us: “The trigger is when the child has been out of education for five days or more. Oncology patients are automatically contacted and referred to us on the first day of their hospital stay.”

The six day policy

The law doesn’t specify at exactly what point in a pupil’s illness he or she becomes the responsibility of the local authority rather than their own school. Broadly speaking, if it’s a short absence, schools are expected to support their pupils, but after anything more than 15 days’ absence due to illness it becomes the home local authority’s responsibility to ensure that the pupil receives an education.

Similarly, there’s no deadline in law by which local authorities have to start providing education for children who miss school due to illness – unlike excluded children, who have to be back in education by the sixth day following their exclusion. In some cases, it won’t be clear from the outset that a sickness-related absence will last more than 15 days, so the local authority won’t get involved until the length of the absence becomes apparent.

However, where it is clear from the start that an absence is likely to last more than 15 days, the local authority should arrange provision by the sixth day, or earlier wherever possible. If the pupil’s absence from school is planned in advance, the local authority should aim to get suitable alternative education in place from the first day of their absence.

Another hospital school teacher told us that their hospital has a three day rule rather than a five day one. They aim to start working with children on the third day following their admission, and if they then leave the hospital and later return, the hospital school reconnects with them on their first day back.

Some hospital schools told us that they've experienced problems with local authorities being reluctant to pay for children to be educated until the child has been in hospital for five days or more. However, most hospital schools emphasised that teaching begins when the child is ready. Once enrolled, a child is registered at both their primary school and the hospital school.

All of the hospital schools we spoke to told us that once they know about a new oncology patient they will introduce themselves to the parents, assess whether the child is well enough to be taught and establish whether the parents are happy for this to go ahead.

"The parents come to the school room and we have an in-depth meeting about what they need to get out of education while they are here, what stage their child is at back at home, what their particular needs are, and then we begin to make contact with their home school."

Head of hospital education

Good practice

As part of the East Specialist Inclusive Learning Centre, the Leeds Hospital and Home Teaching Service has produced a comprehensive resource detailing the service they offer to children unable to attend school because of their medical needs. It includes forms for parents and schools to complete, and clear information about education that can be offered in hospital or at home. Their website⁷ is equally informative, and includes a video detailing their service which could be of great use to parents, children and primary schools alike.

Hospital schools will also ask the parents' permission to contact their child's primary school to let them know that the child is in hospital, and that they will be taught in the hospital school. They will ask the school about the child's level of learning, what they enjoy and whether they have any additional support needs or are on the SEN register. Most hospital schools told us that they would also ask the primary school to send work for the child to complete so they are able to keep up with their classmates. Our interviews show that the amount of information hospital schools receive varies considerably.

While waiting for this information, hospital schools will often provide children with age-appropriate activities and assess their

level of learning. Most hospital schools said that each child would have an Individual Education Plan following their admission – a plan drawn up by a teacher to help parents and the school identify the child's needs and target areas of particular difficulty.

Three hospital schools told us that they send schools an information pack including guidance on what the hospital school does, why they teach children in hospital, what they will teach and what is expected from the primary school. One hospital school head said: "We send out a handbook for schools which tells them about what we do on the ward. The booklet gives the school information about us, what we do, how we work, and what we will do if the child is too unwell, as well as asking for work from

7 Leeds Hospital and Home Teaching Service www.eastsilc.org

the school. It is sometimes a little bit hit and miss what type of information we get from schools – some are better than others – but schools are very busy and we understand that.”

Just over half (56%) of parents we surveyed told us that they were approached by a professional (a teacher, nurse or social worker) about their child’s education within four weeks of first receiving a diagnosis, with almost one in four (23%) reporting that they had been approached within the first week. However, 16% of parents reported that they were not approached at all. Three out of five (61%) parents reported that their child was given suitable schoolwork when they were learning in a hospital school, although 17% felt that their child was not given sufficient work when learning in hospital.

“The work they gave her wasn’t particularly appropriate for her age group, and she came back one day in tears. And when I looked at it, they’d given her GCSE work, and she was eight at the time. But they did try.”

Parent of a child with cancer

Funding

The number of educational sessions in which children take part is recorded by the hospital school teacher. In the case of children from outside the local authority area in which the hospital school is based, a letter asking for payment is then sent to the child’s home local authority. Hospital schools told us that most local authorities pay without any reluctance. However, some have a strict six day policy; they will not pay for a child’s education until they have been an inpatient for six days. Others have been known to ask for extensive notes or query the number of learning sessions a child has received.

A small number of hospital schools told us that the current financial climate has made it more difficult to recoup funding from some children’s home local authorities. Three hospital schools said that funding for hospital schools in their area had recently been reduced, as a result of which they have had to review how they deliver education.

The current financial climate makes it even more important for hospital schools to account for all the education that a child receives. Some told us that it is not a problem; others said that it is a labour-intensive and onerous task.

The Department for Education is currently developing a new model of hospital school funding. Proposals include funding hospital schools through dedicated school grants⁸ administered by local authorities, thereby removing the need for recoupment. One hospital school told us they believe the proposed changes will give them more flexibility in providing education. At the moment hospital schools can only deliver what they can claim back for, but the new approach will mean that they will be able to plan ahead.

“At the moment it’s like bums on seats for schools,” one hospital school head told us. “I have to see as many children as I can so we have enough of a figure on the roll to justify the income we are getting from the local authority. I shouldn’t have to do that; I should have a fixed budget which means I can deploy people according to the children’s needs – especially children with cancer.”

However, some of the hospital schools we spoke to were concerned that if they have a large number of children registered at the school at one time, the set amount they get from the dedicated school grant may not cover the costs of teaching all children. It will be important to monitor the impact the funding reforms will have on hospital schools and home tuition provision.

8 The principle source of funding for schools in England from central government to local authorities

Siblings learning in hospital

Our research found that 8% of brothers and sisters of children with cancer are taught in a hospital school at some stage, as a result of their sibling's cancer diagnosis and treatment. Hospital schools have no formal or legal responsibility for providing education for siblings. However, four hospital schools told us that they do teach siblings while their brother or sister is in hospital, usually when the whole family has temporarily moved near the hospital while their child is an inpatient.

Of those hospital schools that mentioned siblings, eight said that they do not provide any education for them. The main reason for not doing so was lack of resources, as teaching siblings reduces the amount of time that teachers are able to work with inpatients. One hospital school told us that they have recently been asked to stop supporting siblings. Another told us that they recoup funding from the siblings' home local authority and that recently more local authorities have been questioning whether they should fund such provision.

"We used to teach siblings with no problem whatsoever, but because of internal change we're not allowed to teach them any longer. So we often have situations where we have the siblings of patients rattling around in the hospital, sometimes for weeks on end. Either because they have been uprooted from far away to be in the hospital, or there are no other systems in place for them. So everybody in the hospital will logically think 'There's a child of school age...where should they go? They should go to the school room, obviously'. We are perfectly happy to teach them, but we can't put them on our register."

Hospital school lead teacher

In England, advice on the education of siblings in this situation is that the local authority to which they've moved (ie the one where the hospital school is located) should try to find them a place in a local primary school for as long as it's needed. A number of hospital schools told us that they have helped families find places in this way. To determine the most appropriate education provision for siblings, teaching staff should endeavour to undertake a holistic assessment of their needs.

Communication with the school

Just over a third (36%) of parents reported that their child's primary school was in regular contact with teaching staff in their child's hospital school during their time in hospital. In another CLIC Sargent survey,⁹ three in five (61%) parents told us that they felt they were kept well-informed about their child's education when their child was taught in hospital.

In England, statutory guidance,¹⁰ which will shortly be updated, sets out how schools should support children with medical needs. This states that schools should have a policy in place for dealing with these situations, and a designated member of staff responsible for dealing with pupils who can't attend school for medical reasons. When we asked hospital schools who they would contact at a child's primary school to talk about their educational needs, answers varied from class teacher to head teacher, SEN coordinator and school inclusion manager. Most hospital schools relied on parents' advice in deciding who to contact.

All of the hospital schools we spoke to told us that the level of communication varies hugely from one primary school to another. Many said that primary schools are much better at maintaining regular communication than secondary schools, which tend to be bigger and where pupils have many teachers for different lessons. A large number of hospital schools

9 2012 User Feedback Survey – 76% of parents/carers who responded also told us that they felt that they had received some support and advice from their CLIC Sargent care professional in communicating with school about their child's illness. CLIC Sargent's annual User Feedback Survey enables us to capture the experiences of those who use our services

10 Currently *Access to Education 2001* which is to be superseded by new guidance in 2013

also told us that they often have to chase the primary schools for work and information. One suggested that it might be because so few primary schools have any experience of having a pupil with cancer, and are therefore unsure of what to do and what their role should be.

Three hospital schools told us that they maintain regular communication with pupils' primary schools by sending end-of-term reports detailing the child's level of learning and their achievements. One hospital school suggested that successful communication often depends on the parents – if the parents insist on getting support and are in regular contact with the primary school, then the school is more likely to engage with the hospital school.

Some hospital schools told us that they thought that email had improved communications. However, one told us that they did not have internet access, and as a result they found communication with children's primary schools very difficult.





Kieran's story

In 2009, when Kieran was eight, he was diagnosed with a rare type of cancer, Philadelphia positive acute lymphoblastic leukaemia. He underwent intensive chemotherapy and a stem cell transplant, spent 15 weeks in hospital, and was off school for a total of eight months.

His mum, Clare, told us: "Kieran went to the school room at the hospital and he loved going there – they never gave him too much work when he was unwell.

Kieran's school was not supportive. I had to contact them or nothing happened. It would have been helpful if the teacher had called weekly to find out how he was. The class did send him cards but that was a one-off. The school did not explain to the children what had happened to him and how it would affect him.

Kieran was above average at school before he was diagnosed. He went back in and worked very hard to catch up after missing Year 4. Kieran had no extra help when he went back to school, he would have benefited from some one-to-one tuition, particularly in maths. Basically, he worked very hard to catch up having missed most of Year 4."

"It would have been helpful if the teacher had called weekly to find out how he was."



Learning at home

Almost two-thirds (62%) of parents who responded to our survey said their child had been taught at home after receiving a diagnosis of cancer. Just over half the children we surveyed (51%) told us that a teacher gave them lessons at home when they were not in hospital but were not well enough to go to school.

The law and home tuition

Local authorities are responsible for pupils who are unable to attend school because of their medical needs. Statutory guidance¹¹ says they should ensure that:

- Pupils are not at home without access to education for more than 15 working days
- Pupils who have a condition which is likely to lead to prolonged or recurring periods of absence from school, whether at home or in hospital, have access to education, so far as possible, from day one
- Pupils receive an education of similar quality to that available in school, including a broad and balanced curriculum
- Pupils educated at home receive at least five hours teaching each week. This is a minimum and should be increased where necessary to enable a pupil to keep up with their studies.

Whether the child is able to access this entitlement will depend on medical advice and perhaps, more importantly, whether they feel able to cope with it. The right balance must be struck between encouraging pupils to study and recognising when they are not well enough to benefit from teaching. This must be kept under regular review.

"The overwhelming success was the home tutor that our local council provided. They were just wonderful. We received incredible support and every family should have that as standard."

Parent of a child with cancer

In order for a child to receive home tuition, teaching staff¹² require a referral from a health or education professional, stating that the child would benefit from home tuition for medical reasons. This referral is sent to the child's home local authority, which is responsible for providing home tuition for that child.

In all, 14 of the 18 hospital schools we surveyed reported problems with home tuition for children with cancer. One of the main issues we found concerned children who live in one authority but receive their

hospital treatment in a different one. In these cases the local authorities were frequently slow to provide home education, or in some cases did not provide it at all.

Once a referral has been sent to the child's home local authority and the child has left the hospital, the staff of the hospital school they've been attending have no control over, or responsibility for, their future education. Some hospital schools teach children from a large geographic area, which increases the difficulties of working with multiple local authorities to secure home tuition.

Hospital schools reported huge variation in local authorities' approach to setting up home tuition. Some local authorities are reportedly quicker than others when it comes to putting home tuition in place. One hospital school told us that when they

11 Currently *Access to Education 2001* which to be superseded by new guidance in 2013

12 Whether from the hospital school or child's primary school

anticipate that a local authority will delay setting up home tuition, they make a referral earlier than required so it's in place when a child is ready to leave hospital. Another told us that children are often on a waiting list for home tuition once they leave hospital.

"When my son was at home after treatment and unable to attend school, it took a very long time for his local authority to agree to home tuition. At times when we asked for work from his school, it never came."

Parent of a child with cancer

If the hospital the child has been learning in is in the same local authority as where the child lives, the process of setting up home tuition appears to be much smoother. However, some children clearly don't receive this level of support. For example, one CLIC Sargent Nurse told us: "It can be very frustrating for children outside the city, as processes can be long and not always very successful." In total, more than three in five (63%) CLIC Sargent health and social care professionals said there is insufficient educational support for primary school aged children with cancer when learning from home.

Communication with parents

Almost half (48%) of the parents surveyed told us they felt they were kept well-informed about their child's education when their child was taught at home. Two out of five (40%) parents said their child's primary school kept in regular contact with home tutoring staff.

Just over half (56%) of parents said they were satisfied that their child was given suitable school work when they were being taught at home, while 17% were not satisfied with the amount of work their child was given.

The government is now looking to promote greater use of electronic media in home education. The use of electronic media,

'virtual classrooms', learning platforms etc, can provide access to a broader curriculum but this should generally be used to complement face-to-face education, rather than as the sole form of provision. One CLIC Sargent Social Worker told us: "I cover two different local authorities. One provides individual home tuition, the other online learning. Most children prefer individual tuition, and this helps smooth their return to school. It is also more flexible and better able to meet the child's needs, as it is individually-tailored rather than with a small group." Face-to-face education can be particularly important for pupils who have missed out on time in primary school and socialising with classmates.

Five hour entitlement

The entitlement to home tuition is not defined in law in terms of hours. Most local authorities set the minimum time at five hours home education per week. This is the least children should receive, and should be increased where necessary to enable a pupil to keep up with their studies. A number of CLIC Sargent Social Workers told us that five hours home education is not enough for some children with cancer and that other groups of children might receive more. "Home tuition in my local authority area is for only five hours a week, although excluded children receive more than this," a CLIC Sargent Social Worker told us.

It seems some local authorities find it difficult to budget for home tuition. One pupil referral unit which covers both home and hospital education told us that home tuition is prohibitively expensive, and that it is difficult to provide more than five hours a week. A CLIC Sargent Nurse told us their local authority had recently increased the number of hours of home tuition it provides from five to 10 hours a week to match the provision it provides for excluded children.

"We waited nearly a year for a home teacher who was brilliant, but it really should not have taken so long. Five hours a week home teaching is too little for a child in Year 6."

Parent of a child with cancer

Our research suggests that home tuition is a fundamental element of a child's right to education while they are receiving treatment for cancer, and access to it needs to be addressed in order to ensure there is a consistent approach.

Reduced resources

One hospital school teacher told us that there is very sparse provision for home tuition in the local authorities surrounding her hospital. She finds this very frustrating as, with so little support available, children can wait months for provision to be put in place. This was just one of a number of hospital schools which told us that funding for home tuition is being cut. One hospital teacher we spoke to suspects that this is because home tuition budgets are seen as 'soft targets' for funding reductions. Hospital school and home tuition funding arrangements must ensure that there is a fair, transparent system in place to enable hospital schools to deliver flexible and sufficient education.

"The economic climate and the strain on resources means things get squeezed; more and more children who are in need of teaching at home don't fall under home tuition protocols."

Hospital school teacher

Four hospital school teachers told us that some local authorities delay payment for home tuition sessions, and that children in need of home tuition were missing out as a result. We found that in some cases, hospital schools are informed by parents that home tuition has not been put in place, and they then have to chase the child's home local authority. A number of them told us that it's often up to the parents to fight for home education, and one suggested that parents should be provided with clear information detailing what their child is entitled to and the responsibilities of their local authority/primary school. One parent of a child with cancer told us: "You've had to deal with something very traumatic – you don't want to go fighting to find something, it should be coming to you."

"There was one child who needed home teaching, but her local authority advised her family that the child should return to school because there was no provision for home teaching in her area. In the end the parents kept her at home because they didn't feel that she was ready to be back at school at that time."

Hospital school lead teacher

Home tuition can be a valuable stepping stone between hospital education and primary school and a child may need to access both simultaneously. This can be difficult for some local authorities to fund and a number of hospital schools told us that it tends to be an either/or service.



Partnership working

Some hospital schools have ways of working to minimise the number of children who fall through the gap. A number of schools told us that CLIC Sargent Nurses link up with the child's primary school to tell them that home tuition has been recommended.

41% of CLIC Sargent health and social care professionals told us they had directly supported a child learning at home. For most, this involved liaising with home tuition services, the child's primary school, hospital staff and the child themselves. One social worker told us she chases up home tuition requests and arranges school meetings to ensure that home education is put in place. Likewise, a nurse told us that she liaises with the local authority's Education Other Than At School team¹³ to ensure home tuition is running smoothly and the number of hours of provision is appropriate for the child's needs. "Our paediatric oncology team liaises closely with the local Education Other Than At School officer and meets with her at least once every term," a CLIC Sargent Nurse told us. "We are able to contact her at any time if we feel a child needs home tuition."

One hospital school told us that an officer from the hospital's own local authority attends regular home tuition meetings at the hospital school to ensure that the link between hospital and home tuition is seamless. A hospital school teacher from a pupil referral unit explained that because their home tuition service is part of the hospital school, children will often have the same teacher at home as they did in hospital – which helps with continuity.

"Some local authorities manage it better than others," a hospital school teacher told us. "Some are slower to get going, and some don't provide very much, so it's very variable. But we're fortunate because we operate the outreach teaching ourselves, which gives us more control."

12 hospital schools told us that they liaise with other professionals involved in a child's cancer journey through regular multi-disciplinary team (MDT) meetings. Professionals involved in a MDT usually include doctors, psychologists, social workers and ward and outreach nurses. A number of hospital school staff told us that they found the meetings helpful in gaining a holistic understanding of a child's needs.

One teacher said: "I attend the MDT meetings on the ward, so there is always that opportunity for me to raise or discuss children with both the CLIC Sargent Social Workers and the outreach nurses. I also know the children's key workers¹⁴, so we can contact each other directly. They often get in touch if they have been visiting children at home. If their home tuition hasn't started yet they come back to me to see if it's been set up. There is a good line of communication between us."

However, two hospital schools told us that lack of capacity can restrict their involvement in MDT meetings. One also told us that the MDT meetings in their hospital are not very accessible for teaching staff, and that there is a lot of medical jargon used which means that teachers feel less able to engage.

13 Local authorities should have a team which provides services and support for pupils unable to attend primary school

14 This could be a CLIC Sargent health and social care professional, or another healthcare professional

Returning to school during and after treatment

The vast majority of children of primary school age with cancer do eventually return to primary school. In all, 82% of parents told us that their child had returned to school since their cancer diagnosis, and 60% of bereaved parents told us that their child had returned to school while receiving palliative care.

Our research shows that the majority of parents were satisfied with the communication they received from their child's primary school, the way the needs of their child were assessed, and the additional support their child received to help

them catch up. However, this is by no means everyone's experience. Our research highlighted some concerning stories, and opportunities for good practice to be shared more widely.

Bradley's story

Bradley was diagnosed with acute myeloid leukaemia in March 2006, aged three, and was on treatment for a number of years. When he started school he found it very difficult to catch up with work and his mum worked hard to get him all the support he needed from the school, eventually hiring a private tutor for Bradley.

His mum, Anita, told us: "Bradley wasn't of school age when he entered hospital for treatment, so he didn't receive school education in hospital. He needed to have a bone marrow transplant in August 2007 and he was due to start school one month later, in September. After having the transplant Bradley couldn't go to school for six months, so he completely missed the first half of his first primary school year.

I was told about home tuition in the hospital and I spoke to the head teacher at the primary school he was due to start at about getting it organised. She was then able to organise a teaching assistant to come to our house five hours a week; that's all we could manage with the hospital visits we had to attend. The teaching assistant would cover with Bradley what was being taught to his class at school and tried to make him feel like he wouldn't be too far behind."

Because Bradley missed almost all of his first year and only attended three days a week in

his second year, he was very behind by the end of Year 2. Anita asked the school if he could have extra help and, as a result, he did get an Individual Education Plan although he did not get one-to-one assistance. Anita wrote to the school to inform them of his cancer, the transplant and his condition, outlining her concerns for him and explaining he was prone to infection. However, when she met with his teacher for the first time she says it was clear his teacher hadn't been informed that Bradley had cancer, and was unaware that he had very different needs to the other children.

Anita said: "I had to ask his teacher for extra work for him, and felt I had to be very proactive to ensure the school were providing the support he needed. I think the situation would have been a lot worse for Bradley had I not pushed. I felt that I really couldn't back down or Bradley would have been forgotten about."

Phased transition

Many of the children who return to primary school do so on a phased basis, building up to full-time attendance. Of those parents whose children returned to school, 88% said their child was able to return on a part-time basis at first.

One parent of a child who returned told us: "Being able to work with the school to return on a flexible basis – even if just for a couple of hours initially to keep up regular contact with the class – worked well for my daughter. She was gradually able to build up the amount of time she spent in school as her treatment progressed."

Fear of returning

Almost one in five (18%) parents who provided information about the social issues their child faced because of their cancer diagnosis and treatment told us that their child lost confidence or was anxious about returning to school. There were various reasons for this, including infection control, obtrusive Hickman lines (used for administering medication), the child's changed appearance and nervousness about rough playtimes.

This anxiety applies to parents too. A number of CLIC Sargent Nurses told us that they often help families overcome anxiety and support them when their child goes back to school. We asked parents how they felt about their child returning to school: more than half (56%) said that they were anxious or concerned about this.

"Due to his weight gain, his self-esteem was low and I didn't want him to mix with other people. My son does not attend any birthday parties because he's always isolated from other children."

Parent of a child with cancer

Other parents felt more comfortable about their child's return. Some mentioned the emotional and social benefits of going back to school and being around friends. "My son returned to school throughout his treatment and I was very glad it allowed him to be 'normal' again," a bereaved parent told us. "Keeping in touch with his friends was incredibly important to him psychologically, and it was important for his morale and keeping his mind off the cancer."

A child's return to school can have a significant impact on their family in other ways, such as enabling parents to return to work. In 2011 a CLIC Sargent study¹⁵ found that two-thirds of parents lost earnings and three-fifths cut their working hours following a child's diagnosis with cancer.

Schools might also have concerns about having children with cancer return. One parent told us: "My son's school was very worried about him getting hurt in the playground, and insisted he wear head protection like rugby players wear – which he hated."

"I can't go to school if there is a virus like a tummy bug, cough or cold as it could mean I would go into hospital. If it was measles or chicken pox, it could be fatal for me."

School girl, age nine

Infection is a significant cause of concern for children, parents and schools when planning a return to education. Cancer treatment can compromise a child's immune system, so infections which are often prevalent at schools, such as chicken pox or measles, are major worries.

15 CLIC Sargent (2011) *Counting the costs of cancer*



Keeping parents informed

Good quality communication can help build parents' confidence when they are preparing for their child's return to school. Almost two-thirds (63%) of parents told us they felt well-informed about their child's education at their primary school following their cancer diagnosis.

One parent told us: "My daughter's school was amazing. We had a great support network throughout the school. We felt very confident when she returned that they were all looking out for her. The school contacted me immediately if anyone had chickenpox etc. From the head teacher to the janitor I knew everyone was watching out for her."

However, this wasn't everyone's experience. Another parent said: "It's been a complete battle from the start with the school. I feel very bitter at the lack of understanding and support we've received. We had to suggest solutions every step of the way. Even when we asked about whether the local authority could supply a home teacher they denied any knowledge of such a service."

Almost two-thirds (64%) of parents said they were consulted about how their child's diagnosis should be communicated to other teachers and pupils – although one in three (36%) were not given any say in the matter. One parent told us that had she been given the chance, her daughter would have liked to talk about her illness at a school assembly.

CLIC Sargent's role in smoothing reintegration

A child's reintegration into school is normally coordinated either by their home tutor, or by an outreach nurse, who will typically go into a school and give the school teachers advice on what to expect from a child undergoing a phased return. CLIC Sargent health and social care professionals often play a key role in maintaining communication between the family and the school at this stage.

Over half of the CLIC Sargent health and social care professionals we surveyed told us that they had directly supported a child's reintegration into their primary school, most commonly by attending or arranging meetings to be held with the school. Two-thirds said they thought communication worked well in these cases. A large number reported regular liaison between the child's primary school and other agencies and professionals, and 72% told us that they liaised closely with the child's primary school to support their reintegration into education.

A number of CLIC Sargent Nurses told us they develop an individualised health care plan for the school to address the medical and health needs of the child. They said that a meeting between the nurse and the school can break down a lot of barriers, including anxieties that staff may have about having a child in school who has cancer. The plan also asks the school to contact them if the child is not attending.

"I formulated a health care plan for a child who was returning to school who needed supervision as a result of his brain tumour," one CLIC Sargent Nurse told us. "This was done in collaboration with his parents, and it helped ensure his individual needs were addressed during school hours. I also applied for continuing health care funding¹⁶ so he could get one-to-one support in school. This entails regular meetings at the school to monitor the child's progress, and requires a further request to the local health board for continued funding."

16 National Health Service (NHS) continuing healthcare is a package of care provided outside hospital, arranged and funded solely by the NHS for people with ongoing healthcare needs



Lola's story

Lola is six years old and was diagnosed with acute lymphoblastic leukaemia in January 2010. Their CLIC Sargent Nurse, Jane, helped Lola and her family when she returned to school.

Lola's mum, Lucy, told us: "Jane, our CLIC Sargent Nurse, came to our house every week and also visited Lola's school. When Lola was teased at school about her hair falling out, Jane suggested that we arrange for her to visit Lola's school with the play specialist from the hospital. Jane and the play specialist spoke to each class up to Year 6 and explained Lola's condition and how it was affecting her health and life in general. Jane really did her best to give the children an insight into cancer and educate them on what it is and how it is treated.

Jane then also conducted Lola's finger prick test in front of her peers as she knew it would earn her respect from them. Lola became a little hero at school after that. The teasing literally stopped overnight. Jane really cared about Lola and did her best to make things better for her and for us. Jane also recognised

the importance of looking out for Lola's twin sister Maya during this time and she made sure she included her. For example, she dressed Maya up as a nurse when she took Lola's blood in front of the other kids.

"Jane and the play specialist spoke to each class up to Year 6 and explained Lola's condition and how it was affecting her health and life in general."

Jane was amazing. She encouraged and supported me and provided constant reassurance. She had a very clear insight into what was ahead of us and was, to a degree, able to prepare us for this. Her help, knowledge and experience was fantastic."



Good practice

A hospital school teacher from John Radcliffe Hospital in Oxford told us about how she and her colleagues are involved in a child's reintegration to their primary school: "We often visit a school early on after diagnosis to meet with the class teacher so that we can discuss both the medical aspect, because the nurse specialist is there, and the education aspect, because I'm there too. I think it works very well, because often the class teachers are anxious – so we do find that the joint visit is very productive. Thankfully, many of them have never come across a child with cancer in their class before."

Information for schools

One in five (20%) parents and two in five (40%) CLIC Sargent health and social care professionals thought there should be more information on childhood cancer available for teachers, with realistic information about the expectations of children with cancer in

education and the psychological impact of cancer on children. Many recognised that returning to school isn't just about educational needs – it's about emotional needs too.

One tool that has been effective in improving schools' understanding of children with cancer is a 'Teachers' Day'.

Teachers' Days

In partnership with CLIC Sargent, a Teachers' Day is held annually by a number of hospital schools, including the Royal Victoria Infirmary in Newcastle, Addenbrooke's Hospital in Cambridge and St James's University Hospital in Leeds. The Teachers' Days we learnt about follow a similar model.

In Newcastle, teachers of pupils who have been diagnosed or relapsed in the last year, and those who teach their siblings, are invited to an event where they get an overview of childhood cancers and a chance to speak to all members of staff in the hospital's MDT, including consultants, paediatric outreach nurses, play specialists, radiotherapists, pharmacists, physiotherapists, CLIC Sargent health and social care professionals and hospital school staff.

Past hospital school pupils also give a talk about their experiences of hospital and home education, and teachers who have previously had pupils with cancer in their class talk about how the school managed their illness. Often a bereaved parent and their child's school will discuss their experiences too. The day concludes with a chance for teachers to gather together in groups, defined by the type of cancer their pupil has been diagnosed with. Members of the MDT join the groups to facilitate discussion and answer any questions.

School visits are another good way of educating school staff and pupils about childhood cancer. CLIC Sargent health and social care professionals told us that they provide schools with printed literature, including information leaflets and CLIC Sargent's award-winning storybooks designed to explain childhood cancer and treatment.

"My CLIC Sargent Nurse came in and explained to the class what had happened. It made me feel relieved as it stopped so many people asking me questions."

School girl, now aged 13



Liaison between hospital schools and primary schools

One hospital school told us that on occasions they make a visit to the child's primary school. But they often lack the funds or the capacity to do this on a routine basis.

Another told us that they used to make routine school visits alongside a paediatric outreach nurse to talk about a child's reintegration, but because of funding restrictions they have been told by their local authority that they are no longer able to do this. The same hospital school told us they believed it was never possible, or even necessary, to visit every child's primary school. However, school visits can be beneficial where specific issues arise, particularly with brain tumour patients who are more likely to have ongoing learning issues following their treatment.

In all, four hospital schools told us they occasionally visit the child's primary school to advise them on the child's needs and what to expect. One head teacher from a hospital school told us they would like to be more involved in home visits and planning reintegration if resources allowed: "I might need someone else on my team who is focusing on supporting the school when the child goes home, but at the moment I can't do that, because I haven't really got the funding."

Working in partnership

The East Midlands Cancer Network is working with the region's Children and Young Person's Integrated Cancer Service to redesign community health services. One of the areas identified by parents and young people was the need to improve educational provision and support in primary schools. Specialist nurses are currently improving the information given to schools to prepare for a child's return and developing more robust ongoing communication to enable the children to access appropriate educational provision and support in school while they are on treatment for cancer.





Josh's story

Josh, 13, from Northwich in Cheshire, was diagnosed with acute lymphoblastic leukaemia in September 2004.

His mum, Lynda, told us: "Josh was diagnosed a week into Year 1 at primary school, and missed half of his first year, which meant he had gaps in his learning of basic reading and writing. In the second year he was there 70% or 80% of the time, so he was still missing out.

I noticed that he was gradually finding things more difficult and he was falling behind on things. Josh received extra support in primary school and they developed an Individual Education Plan for him, but this wasn't enough for him to catch up sufficiently. I felt like I was always asking for work from the school. There just wasn't the extra specific support there for him.

Josh did receive 'in house' individual support from the school, but it just wasn't targeted enough for his individual needs. So we pushed for individual pupil funding (IPF) because he was so behind. It took over a year to secure this funding. I just can't understand why the IPF wasn't given to us at an earlier stage. Josh had physical and psychological impacts from his cancer diagnosis and he obviously needed individual help tailored for him.

I think it's so important for children who have experienced cancer to be able to access appropriate funding and also get an individual tutor that recognises

their unique needs. We did actually test this out because we paid for an individual tutor to come in when Josh was in Year 6, after he had received 10 sessions from the school. Josh's learning came on so well, his confidence increased and you could really notice a difference, but what about families who aren't able to pay themselves?"



"I noticed that he was gradually finding things more difficult and he was falling behind on things."



Additional support with catching up

One in three (35%) CLIC Sargent Nurses told us they do not think that there is sufficient educational support for primary school aged children with cancer when returning to school. This was echoed by a CLIC Sargent Social Worker, who told us: "In most cases the school put in extra support to assist a child back into school, but we have examples of where there have been serious shortcomings."

56% of parents said their child found it difficult to readjust to school work and activities after returning to their primary school. Reasons included:

- Lack of concentration
- Lack of appropriate support
- Loss of memory and processing
- Lack of clear responsibility from the school.

However, two-thirds (66%) of parents said their child's school made sure they were able to get back into school life and catch up with their school work. One parent told us: "There was no suggestion that my son would be able to achieve what his peers were achieving, as

the effects of his cancer and treatment have been so devastating. But I think the school has enabled him to achieve his new potential." This leaves one-third (34%) of parents who are dissatisfied with the support their child received on returning to primary school. One in five parents said they felt their child had been unnecessarily excluded from activities or trips because of their treatment. If health and social care professionals who understand cancer were given more opportunities to work with teachers and school staff, this could give schools a better understanding of the adjustments that can help children with cancer to take part in activities.

"Once she stopped attending school on a regular basis she wasn't invited to any of the school discos, trips or other activities."

Parent of a child with cancer

However, other parents told us that the school worked well to include their child: "The school was very flexible and allowed her to take things at her own pace. She did half days between her treatments, as mornings were not good for her. She also managed to take part in an outward bound-type of trip."

Good practice

A number of schools in London have adopted a card system. Children show the card to a member of staff or a friend to let them know when they may be in need of additional support. A CLIC Sargent Nurse told us: "We made a little card to go in their pocket so if they have injured themselves in the playground or weren't feeling well, they gave it to their friend and their friend would go to the teacher – and then they would know to go and see that child."

Just under half of the parents we spoke to (46%) thought their child had received the help they needed to keep up with school since their cancer diagnosis and treatment. A little over a third (36%) did not think their child received sufficient help, and 18% were not

sure. The same proportion of parents (46%) were happy that their child's needs had been properly assessed by a teaching professional since their diagnosis, although 34% did not think that their child's needs had been adequately assessed and 20% were not sure.

"Some children (very often those who have been or are being treated for brain tumours) need much more support when they return to school after cancer treatment, including one-to-one provision, and I am often involved. It can depend on which local authority the child lives in as to how difficult it is to set up and fund special needs requirements."

CLIC Sargent Social Worker

Nearly one in five (18%) parents thought their child would benefit from more individual support. One told us: "They need a lot more one-to-one help if they are trying to catch up and build their confidence. Sometimes they may require extra homework to try to keep up, but they need support from all areas."

Assessment of needs

In our survey, a small number of parents said they thought their child required a more rigorous assessment of their educational needs when they returned to school. "They need a proper assessment of their educational needs, rather than a 'one size fits all' approach," one parent told us, while another said: "It should be straightforward to apply for a statement if you need one. This is a stressful time for parents."

One hospital school told us they have a system in place where all children who have been learning in hospital for six weeks are identified as being in need of a written Individual Education Plan. If it is considered that the child does not require an Individual Education Plan because they have no adverse side effects as a result of their treatment, their needs will still be monitored in case they change or they need emotional support.

Special educational needs (SEN)

Children learn in different ways, and can have different levels or kinds of SEN. In the UK there are different categories of SEN. The basic level of extra help could involve a different way of teaching certain things or some extra help from an adult. School staff may decide to write an Individual Education Plan which could include what special or additional help is being given and a child's targets and progress. If these measures are put in place and a child is still at a disadvantage, it might be advised that they get extra help from outside the school. It is possible that a child's school still cannot give a child all the help they need, in which case a 'statutory assessment' can be requested. This is a detailed assessment to find out what a child's special educational needs are and what additional help they might need.

This question of how effectively children's needs are assessed on their return to primary schools, and particularly whether they should be put on the SEN register, can be critical to the success of reintegration. 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.¹⁷

¹⁷ 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

"Children with brain tumours who have radiotherapy as part of their treatment have very different learning needs, and discussing this with their teacher is beneficial. However, the information is not always handed on as they move up the school."

CLIC Sargent Social Worker

Transitional support

Many primary schools have a new class teacher for each year. Teachers' relationship with, and understanding of, a child with cancer can be critical. Some children with cancer may find that by the time they've built up one teacher's understanding, it's time to move on to a new one. CLIC Sargent Nurses tell us that transitional support is essential. This might vary from a teaching assistant helping the child manage the transition to a new class to support from a CLIC Sargent Nurse who might go into the school and advise the new teacher on the child's needs.

A number of hospital schools told us that it is often the primary school which takes the lead on assessing the needs of children when they return to primary school. However, as primary schools don't always know the specific, changing needs of the child, hospital schools may be asked to feed into this part of the assessment process.

Hospital schools told us that while they might be involved in informing an assessment of a child's educational needs, it is an integrated process which is often led by the primary school, outreach nurse, psychologist or consultant. This might be coordinated through a multi-disciplinary meeting, for example, such as the 'Getting it right for every child' meetings in Scotland.

A total of 16% of parents told us that their child had a statutory statement of SEN as a direct consequence of their diagnosis and treatment. In addition, 25% of parents reported that their child has an Individual Education Plan and 31% reported that their child receives additional support from a SEN coordinator or a learning support assistant.

31% of CLIC Sargent health and social care professionals surveyed said the process of securing a statement or additional support for children with cancer is too long and complex. Many CLIC Sargent Nurses get involved in the statementing process: "We're often the team that provides all the information for schools applying for a statement for SEN on medical grounds."

Making adjustments

Just over half (55%) of parents of children who had returned to their primary school reported that the school made adjustments because of the extra support needs their child had acquired as a result of their cancer and its treatment.

"The teacher moved my son down a level in case he couldn't keep up due to the amount of time off he required, but when he showed he was able to keep up he was moved back up. The teacher adjusted to his needs."

Parent of a child with cancer

A CLIC Sargent Nurse told us that if there's a need to think about occupational therapy to help children make the adjustments necessary to return to education, they will refer the school to occupational therapy services to help make those assessments. Occupational therapists can also assess whether anything is needed to help promote the child's learning within school, particularly in the case of children with brain tumours who may have visual or hearing impairment. CLIC Sargent's 2010 report, *The impact of cancer on a child's world*, found that children recognise that their absence

from school has an impact on their level of academic achievement and their potential future career prospects, putting them at a disadvantage compared to their peers.

One CLIC Sargent Social Worker told us: "I have arranged 'Team around the child' meetings with other professionals, including occupational therapists and SEN coordinators, to look at issues children face when returning to school. The paediatric oncology outreach nurses will usually contact the schools to discuss their medical needs."

Good practice

Steroids can have a dramatic impact on the way a child behaves and deals with returning to school. A CLIC Sargent Nurse from the South West told us that a school in her local area has allowed a child to wear a badge to inform teachers and other pupils when he is on steroids, as this may result in mood swings. The badge helps teachers deal with the child in an appropriate way by helping them realise that the child is not misbehaving. Another nurse told us that wearing a badge can also alert other children and school staff to be more aware of the child at break times so that they do not get caught up in any rough play.

Of those children whose schools made adjustments, more than one in three (36%) were allowed flexible start or finish times, or were allowed to go back to school on a part-time basis. "My daughter is allowed time out when she feels she cannot cope," one parent told us. "When she was recovering from surgery, her school was very flexible about when she could attend school. For a while this was only for one hour a day."

Almost one in four (23%) children were given extra time to complete homework and assessments, and almost one in 10 (9%) received special equipment as a result of their cancer diagnosis and treatment. "The school gave him extra support lessons instead of subjects like PE, which he was unable to do. They gave him longer to do homework and gave him extra work to catch up on since he missed a year of school," said one parent.

Just over half (56%) of the parents of children who have returned to school felt that their child had received sufficient support to enable them to resume as normal an education as possible. However, 25% did not think they received sufficient support, and 19% were not sure. One parent of a child with cancer, whose cancer resulted in an amputation, told us their family had to fight the education system to get any physical reasonable adjustments for their daughter because she wasn't falling behind academically.

It can be difficult for children if they are diagnosed towards the end of their primary school education and then move on to secondary school, where they will have to build new relationships with classmates, cope with a more physically demanding environment and get to know a great many new teachers.

"It's difficult to get proactive support, particularly for children with brain tumours. Often the problems don't show themselves until they are well-established back at school, and then accessing support can take ages," a CLIC Sargent Social Worker told us.

However, a number of parents told us they had regular updates from their child's school, and that their child was able to vary their timetable to enable them to catch up with their previous learning level and with their peers.

One parent said that despite the school's encouragement, her daughter felt that she was struggling to keep up with school work as a result of her cancer diagnosis and treatment. "My daughter's school is working with us to help keep her at school, as she finds it very stressful. The school says that she is a bright girl and will catch up eventually, so there is no need to worry. However, my daughter does not agree."

Children receiving palliative care

73% of the bereaved parents we spoke to said they were given the option for their child to return to or continue at school after they had stopped receiving curative treatment. Nine bereaved parents told us they had taken up the opportunity and that they felt that they had received sufficient support from the school.

Three in four (75%) bereaved parents reported that they felt supported by their child's primary school and/or their hospital school when their child stopped receiving curative treatment. However, 25% did not feel supported.

Some parents told us that education became less important when their child was receiving palliative care. "We knew that my son's life was limited, and we wanted to spend as much quality time with him as possible. We did briefly visit the school a couple of times." Others told us that their child's return to school was important as it enabled them to maintain as normal a life as possible.

We also asked CLIC Sargent's health and social care professionals about how they support children with cancer receiving palliative care.

Over half told us they had supported a child who was receiving palliative care so they could continue to access education.

"I have supported a child to attend school while receiving palliative care. The school was very accommodating and allowed the child to attend as much or as little as possible. They were also very supportive of their sibling, and I provided bereavement support at the child's school."

CLIC Sargent Social Worker

Two-thirds (66%) of CLIC Sargent health and social care professionals surveyed told us they thought there is sufficient educational support for primary school age children with cancer who are receiving palliative care. "We do provide bereavement support as well," one CLIC Sargent Nurse told us. "Obviously, if a child's known to be dying, we would support the teachers and the school to support those pupils."

43% of CLIC Sargent health and social care professionals surveyed told us that emotional support is a key issue when supporting a child who is receiving palliative care to access education – and that includes emotional support for both the family and the staff at the child's school. They also highlighted the emotional impact: "You need good communication for the staff involved, with lots of support to enable them to cope with the situation," said a CLIC Sargent Nurse. "You need to help the school staff to give support to the pupils. And you need to support the family to allow the child to go to school if that is what the child would like to do. If education is given in the home or the hospital, then support and good communication there is also vital."

The CLIC Sargent health and social care professionals we spoke to stressed the need for appropriate information for schools to support children receiving palliative care. In total, 31% highlighted the need for schools to take a flexible, individualised approach when supporting a child receiving palliative care: "Children receiving treatment when a cure is no longer available should be able to access education at a level that suits and meets their needs," a CLIC Sargent Social Worker told us.

Social impact and support

Our study showed that the social impact of cancer on primary school children is profound. This is consistent with our 2010 research¹⁸ which found that children were concerned about their prolonged absence from school and/or the number of classes they missed while on treatment.

We have found some excellent examples of schools keeping in touch with absent pupils in inventive ways. However, we also found that children with cancer who are absent from school can get a great deal of attention from their school friends at the beginning of their treatment, but that this decreases with time and prolonged absence. They can be ostracised for being 'different', see their siblings bullied for having a brother or sister with cancer, and even be teased for receiving too much attention because of their condition.

Maintaining communication

Our findings demonstrate that the consistency of communication between primary schools and children in hospital and their families varies considerably. Some parents told us that good communication with the school was critical in helping their child to still feel part of school life. "My child has not been to school for eight months," said one parent, "but he frequently has visits from class friends, and when we are at home the head teacher

and his class teacher have visited. He's also been invited to join in school activities."

However, others told us that communication could have been better. As one parent explained: "My daughter missed her friends most of all. The school was very good at keeping her involved and up-to-date as much as she was able (ie half days at school, homework, weekly visits at home from the head teacher) but with no internet or phone access in the ward she really missed being in contact with her friends during treatment. We would take her out to a local internet cafe when she was able and set up Skype to use when we were staying in CLIC Sargent's Home from Home¹⁹. But it would have been great to have a little internet area in the ward. In this day and age internet is vital, even some of her school work could have been done via the internet."

Almost half (47%) of parents surveyed said their child's school did not help to maintain contact with peers and friends during their absence from school. "My child's teachers weren't keen to involve other children in case it scared them," said one parent.

Communication between education professionals and families can aid the transition from nursery to primary school. One parent told us that their six-year-old daughter, who was diagnosed when she was one, now finds it difficult to engage with children her own age as she has missed out on so much of her first two years of primary school.

18 CLIC Sargent (2010) *The impact of cancer on a child's world*

19 CLIC Sargent has eight Homes from Home, located near seven principal treatment centres, where families can stay for free during their child's cancer treatment

"My daughter was able to have a video link up between the hospital school and her primary school to chat with her teacher and friends from time to time. This was great because the children could see her in hospital and understand what was happening, and the teacher was then able to discuss her treatment with them."

Parent of a child with cancer

Of those parents who said that their child's school did help to maintain contact with peers and friends, more than half (53%) said that communication was kept up through cards, letters and emails. One in four (26%) parents told us that their child's primary school teacher visited their child while they were absent from school. 9% said that their child was able to attend some school events, such as assemblies. This was a major factor found to help children with cancer feel in touch with their primary schools. However, the survey shows that only a small number of children were invited to do this.

"What worked well for us was the school being flexible and keeping in regular contact with us, particularly enabling my daughter to maintain communication with her friends. Our school allowed my daughter to write updates on her treatment which were put on a notice board in the school. She took photos and wrote about what she had been doing. This meant that when she came into school there were fewer questions to answer, which she liked."

Parent of a child with cancer

A number of parents said their child's school did maintain communication at the start of their child's absence from school, but this faded with time. "We felt completely forgotten about," a parent told us. "We received one get well card at the beginning of the treatment but then nothing for the rest of the year." A number of hospital school staff we interviewed also reported this.

Parents told us that the support from the primary school needs to be continuous, and it needs to be consistent throughout a child's cancer journey. "It would be better if the school would encourage peers to keep in regular contact," one parent told us. "Our daughter got a big card when she was first diagnosed and then when she relapsed, but maybe a weekly letter from one of her peers would be a better way to make her feel she is still part of it."

Four of the hospital schools we spoke to told us that one of the reasons a child's primary school might keep its distance is fear that they would be interfering or bothering the family if they maintain communication.

"We really try to tell the schools to keep the letters coming, and they shouldn't expect to have responses from the child or the family, it's just to keep them in the loop. We encourage them to invite them to the school fête – they might not come, but it's still important to send the circular letters home. I feel these families are pretty swiftly dropped by their school. Not out of any malicious thinking or anything, but it is this attitude that 'they're going through hell at the moment and we'll leave them alone and not bother them with education'. And what we're trying to say to them is 'Bother them, but only a little bit. Make them feel a sense of normality – don't burden them too much, but keep them included.'"

Hospital school teacher

Five of the hospital schools we spoke to talked about the role that technology can play in maintaining communication – for example through Skype, emails, instant messaging and social networks. One hospital school told us that they encourage schools to set up Skype sessions with the child in hospital.

In Aberdeen the hospital school explained that children in hospital in Scotland use an online education community called 'Glow', which can be used to engage in virtual learning and communicate through audio and written messages. However, not all primary schools are keen to engage this way.

Good practice

Great Ormond Street Hospital in London uses video conferencing software to include bed-bound patients in Christmas festivities. "When we had our carol service a patient did a reading from her bed through iChat," a member of the hospital school's staff told us. "We held the laptop up so everyone could see her. That way the world was taken to her." Such activities can help a child feel a lot less isolated during their stay in hospital.

Friendships and peer relationships

While some children have a warm reception when they return to school after a period of absence, others can feel left out because their peers have developed other friendships. As one eight-year-old girl with cancer explained: "I was feeling down because I had lost some friends, and I felt lonely and sad."

Our research demonstrates that perhaps the most significant effect of cancer on school life is the impact on peer relationships, as supported by CLIC Sargent's previous research²⁰. Many children said they had become estranged from friends during their treatment. Almost half (47%) of parents said that their child had grown apart from friends because of their cancer diagnosis and treatment, and 38% of bereaved parents felt that their child's cancer had negatively affected their child's friendships.

20 CLIC Sargent (2010) *The impact of cancer on a child's world*





James' story

James was diagnosed with acute lymphoblastic leukaemia in 2005, aged six. He missed out on hospital schooling as this wasn't available at the shared care hospital where he received most of his non-treatment care. When he returned to primary school he had no formal assessment of his needs, and little tailored support to help him catch up. This lack of educational support was made worse by a feeling of isolation as he found friends had grown apart from him and he was subjected to bullying and teasing at school.

His mum, Jo, told us about their experience: "James used to have friends at school, but the ones closest to him started to be really cruel and nasty to him when he returned after his main cancer treatment. There were occasions when older kids would laugh at him and tell him he was going to die. Many of his friends were really jealous of the perceived level of attention he received from staff and other parents, and the gifts he'd receive and the holidays. When he went to Lapland and Euro Disney as a treat, other kids would ask, 'Why's he going on holiday and not me?'. The other kids would resent it when he was off school – they assumed he was spending time watching telly and playing video games, but he was probably sleeping as a result of his treatment or coping with pain and limited movement.

It got to the stage where James was asking if he could leave school as he could no longer see it getting any better – he was giving up hope. James' confidence is still affected by the bullying and although he's learnt

"It got to the stage where James was asking if he could leave school..."

to deal with the jealousy from his friends, he changed from being a really adventurous boy to being shy and introverted, unwilling to start conversations and feeling like he had to ask permission to join in with their activities and groups. He's a frustrated lad who is learning slowly to trust people again after his friends betrayed him."

After his isolation continued in the first two years at secondary school, James' parents decided to move him to a completely new school in September 2012, where he has been able to make a new start and has settled in well with lots of new friends.



"My daughter's friends all worked incredibly hard to stay in touch with her when she was in and out of hospital. Her class bought her an iPad so she could FaceTime them and every week we would arrange large play dates when her main group of friends would just come over and hang out with her."

Parent of a child with cancer

Just over half (55%) of parents said their child felt isolated from friends when they were in hospital – this was significantly higher when we just consider bereaved parents (81%). Almost half (49%) of parents reported that their child felt isolated from friends when learning from home, and 47% said their child felt isolated when they returned to school, either during or after treatment. "My child felt isolated, overly-protected and not listened to," one parent told us. "Her mood became very low and she was angry at the school for treating her differently."

"My daughter has been suffering from separation anxiety since being diagnosed, and she has found getting back to school (without me) very hard. I feel if the school had been funded to have someone to work one-to-one with her at school, the situation could have been eased."

Parent of a child with cancer

Around a quarter (26%) of parents we surveyed said their child had told them that some of their friends and peers no longer wanted to play or talk to them at school during or after their cancer treatment. "It's quite hard, because younger kids always look at you like you're some kind of monster," said a school girl, aged eight. Some parents told us that peers were jealous of their child's extra attention.

"One of the schools I work with set up a buddy system, so the child with cancer has a friend. They leave the classroom together five minutes early to avoid the rush, and the buddy carries the books and things like that. It works really well."

CLIC Sargent Nurse

Bullying and name calling

61% of the CLIC Sargent health and social care professionals we surveyed said emotional issues are a key consideration for primary school age children who are diagnosed with cancer. Common causes of anxiety or distress include bullying, missing friends and changes in their physical appearance, such as hair loss. "Going back with an altered body image can be very daunting for a child," a CLIC Sargent Nurse told us.

More than one in three (35%) parents said their child had experienced bullying or teasing from their peers because of their cancer diagnosis and treatment. "Schools should educate primary school pupils about childhood cancer to reduce the stigma associated with it," one CLIC Sargent Social Worker said. One parent told us that some of their son's fellow pupils would try to steal his hat and would laugh at his eating habits, while another said their daughter was picked on because she'd gained weight (due to steroid treatment) and lost her hair.



"A couple of children said a few hurtful remarks to my son during his hair loss, but I think it was because the children involved didn't understand about his treatment. I think the school could have done with supporting and explaining to other children in all of the other year groups about his treatment. I think if children understand they are less likely to pass judgement."

Parent of a child with cancer

Some parents told us that although their child did experience some name calling or teasing because of their cancer diagnosis, the school reacted quickly and put a stop to it. However, 15% of parents told us that their child felt different from their peers at school and another 13% reported that their child felt isolated and excluded from social groups and friends.

"Because of my son's cancer treatment, he could not do every activity and felt frustrated and left out. The school is trying hard to get him back into a normal routine. However, I feel they are frightened and tend to shy away from things. They are trying their best though."

Parent of a child with cancer

Brothers and sisters can also experience bullying and isolation because of their sibling's cancer diagnosis and treatment: 13% of parents surveyed said their children had suffered in this way. Our study found that 36% of siblings had been offered emotional support at school because of their brother or sister's cancer, although 41% said that they were not offered any emotional support.

"My eldest daughter was teased because her brother had cancer and was different, and she was also pushed out of her peer group as she became very emotionally vulnerable while we were experiencing treatment and its aftermath."

Parent of a child with cancer



Conclusion

Our research has demonstrated that cancer can significantly disrupt a child's education – nine in 10 (90%) children told us that their cancer diagnosis and treatment made a difference to their school life.

Improving communication between education professionals, a pupil with cancer and their family can considerably lessen the impact of cancer on a child's primary school education. Good communication, for example, can enable a child with cancer to keep in touch with classmates when they are absent from school, allow for a smoother transition when they return to school and help parents feel empowered and informed.

Raising awareness and building knowledge and understanding of the impact of cancer on a child can help teachers and other pupils to better understand and support a classmate with cancer during and after cancer treatment.

It is essential that information about hospital education and home tutoring services are made freely available to parents and professionals in order that they can more easily access these services.

CLIC Sargent wants to see a primary education system that enables children diagnosed with cancer to receive the support they need quickly, and for as long as they need it, so that cancer does not unnecessarily impact on their education or their social and personal development. In order for this to become a reality, systems for funding hospital schools and

home tuition must be fair and transparent to enable children with cancer to receive sufficient education that is flexible enough to meet their needs.



Ways forward

Policy and influencing

- Proposed changes to SEN and disability provision across the UK, in particular the Children and Families Bill in England, must take into account the needs of children with cancer. CLIC Sargent will seek to raise awareness of their needs and influence policy makers to ensure that children with cancer receive the support they need in education to achieve their full potential
- Government funding reforms must ensure that hospital school and home tuition funding arrangements allow children with cancer to access appropriate, quality provision. We will continue to work together with hospital schools to ensure that government funding reforms are informed by the needs of children with cancer

Information

- Good information for children, parents and professionals on how they can support continued education during cancer treatment and beyond is vital. Parents must be empowered with information about how the education system works, their child's rights and how to access the support that they need. CLIC Sargent will signpost families and professionals to existing information and work in partnership with others to develop resources where there are gaps
- Our research illustrates a number of good practice examples of how to support children learning in hospital, at home and when they return to primary school. We will share these ways of working with policy makers and education professionals to help them gain new insights and inspiration

Communication and engagement

- Primary schools, hospital schools and families play a vital role in helping children with cancer stay in touch with classmates when they are absent from school. CLIC Sargent will seek to raise awareness of good practice, such as encouraging phone calls and letters and by maximising the use of technology
- Our research shows that by primary schools adopting an individualised and flexible approach to supporting a child, the experience of children returning to school during and after cancer treatment can be greatly improved. CLIC Sargent will share examples of good practice and provide information to schools encouraging them to deliver the reasonable adjustments that a child with cancer might need on their return to school
- Our research highlights the importance and benefits of improving communication between education and other professionals involved in a child's cancer journey, and CLIC Sargent will share the findings and best practice to support a more integrated response. In particular, we will promote the use of Teachers' Days as a particularly effective tool in improving primary school teachers' understanding of childhood cancer.



Glossary

Barriered learning

When a child is learning in an isolated room to prevent infection from others.

Chemotherapy

One of the three main ways to treat cancer. Chemotherapy is the use of anti-cancer drugs to destroy cancer cells.

Hickman/central line or portacath

A tube which is placed into a vein in the child's chest to give an intravenous injection. A portacath is slightly different in that it's located under the skin and accessed with a needle when it is needed.

Home tuition

Education taught by a home tutor on a one-to-one basis in the child's home.

Hospital school

Schools maintained by local education authorities, within the premises of a hospital.

Individual pupil funding (IPF)

The money given to schools to provide additional support for children with SEN.

Palliative care

Palliative care usually begins when curative treatment is no longer an option.

Primary school

A school for children between the ages of four and 11. In this report we refer to primary schools as being the school the child regularly attends within their local authority area.

Principal treatment centre (PTC)

All children with cancer are diagnosed at one of 18 principal treatment centres in the UK. The PTC makes the definitive diagnosis and initiates treatment.

Radiotherapy

Treats cancer by using high energy rays which destroy the abnormal cancer cells, while doing as little harm as possible to normal cells.

Shared care centre

A local hospital working in partnership with a PTC to provide some aspects of the care a child with cancer needs.

Special educational needs (SEN)

A legal definition referring to children who have learning difficulties, or disabilities, that make it harder for them to learn or access education than most children of the same age.



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 - ▶ Royal Hospital for Sick Children, Edinburgh
 - ▶ Great Ormond Street and University College Hospital London
 - ▶ St James's University Hospital, Leeds
 - ▶ Leicester Royal Infirmary (shared care centre)
 - ▶ Alder Hey Children's Hospital, Liverpool
 - ▶ Royal Manchester Children's Hospital
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How we help

Being diagnosed with cancer is a traumatic and often bewildering experience and children, young people and their families need support in many forms.

Every child or young person with cancer is different and consequently will have a different experience. At CLIC Sargent we know that people's reactions to a cancer diagnosis can vary considerably, so we take time to listen and understand. Our aim is to help ensure that the whole family receives the support which works best for them.

We provide:

- Clinical, practical and emotional support to children and young people with cancer, and their families
- Financial support, including grants and benefits information, to help families deal with the financial impact of cancer
- Free accommodation at our eight Homes from Home – close to specialist hospitals so that families can be near to their children during treatment
- Free holidays and specialist short breaks so that families can spend time together, with the support of our care professionals, away from the everyday challenges of childhood cancer
- A wide range of valuable information on childhood cancer and its impact for children, young people and their families.

We also campaign and influence others to raise awareness of the needs of children and young people with cancer and to improve the support they and their families receive.





CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical 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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