

THE RICH PICTURE

WE ARE
MACMILLAN.
CANCER SUPPORT

CHILDREN WITH CANCER

Alex, 8, living with acute lymphoblastic leukaemia

Understanding the numbers, needs and experiences of people affected by cancer



About this 'Rich Picture'

This document is a collation of the key available evidence about the numbers, needs and experiences of people affected by cancer.

Our aim is that the insight within this document will summarise the numbers, needs and experiences of people affected by cancer for Macmillan staff, cancer care professionals, volunteers and other interested parties. It includes data specific to the particular group who are the focus of this Rich Picture, as well as more generic information about all people affected by cancer where specific data are not available or where the information applies to all groups of people with cancer.

The Rich Picture is intended to be accessible to both clinical and non-clinical cancer support staff. Therefore the language and facts included are intended to cater for information needs of both groups. We have included references to other documents to help with interpretation of some facts included, and a Jargon Buster of some technical terms is included in Appendix A.

The information could be valuable in many ways:

- Adding weight and evidence to negotiations with partners and commissioners
- Providing evidence to support campaigning
- Enabling more effective marketing
- Inspiring and engaging supporters to give and do more
- Providing some insight into the lives of people with cancer

This document is not intended to

- Be a comprehensive collation of all evidence on the group affected by cancer who are the focus of this Rich Picture
- Suggest or recommend that specific action should be taken

For simplicity, the year to which the data in this document relate and the sample size is not always shown in the main sections, however this is shown in the original data linked from the references section.

If you are short on time, a quick read of the summary on pages 2 and 3 will give you a brief outline of the rest of the content of this comprehensive document.

This 'Rich Picture' is one of a suite of documents. To access these documents please visit <http://www.macmillan.org.uk/Richpictures> or for further information please contact evidence@macmillan.org.uk

The legal bit

The information contained in this document is a summary of selected relevant research articles, papers, NHS data, statistics and Macmillan-funded research.

This document intends to summarise in a broad sense the numbers, needs and experiences of people with cancer, it is not an exhaustive systematic review that follows strict scientific community rules governing such types of review. However we have compiled the information using broad quality assessment criteria to ensure that the information presented in this document is largely representative and unbiased. It is worth noting that people with cancer have a very wide range of experiences; therefore the information presented here may not reflect the experiences or profile of everyone within the category presented.

Macmillan or any other organisation referenced in this document claim no responsibility for how third parties use the information contained in this document. We have endeavoured to include all the major data available to us as of August 2014, but a document of this nature (essentially a summary of a large body of evidence) inevitably goes out of date. Macmillan has sought external validation of this document from clinical experts and we aim to regularly update the content of this document.

There may be data that have been released that does not appear in this document and Macmillan is under no obligation to include any particular data source. Any medical information referred to in this document is given for information purposes only and it is not intended to constitute professional advice for medical diagnosis or treatment. Readers are strongly advised to consult with an appropriate professional for specific advice tailored to your situation.



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Guidance on referencing this document

You are free to use any of the data contained in this document, however when quoting any factual data that do not belong to Macmillan, it is best practice to make reference to the original source – the original sources can be found in the References section at the back of this document on page 56.

Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experiences of children with cancer. It is designed for a broad audience of health and social care professionals, commissioners, influencers and staff or volunteers working with (or for) cancer patients. Children affected by cancer and the parents/guardians of children affected by cancer may find our wide set of information booklets more helpful:



I'm still me
MAC6706



Katie's garden
MAC12968

All these titles are available in hard-copy by calling our Macmillan Support Line free on **0808 808 00 00** (Monday to Friday, 9am–8pm), or by ordering online at www.be.macmillan.org.uk.

A wealth of other resources are also available, all produced by Macmillan Cancer Support and available free of charge.

OTHER RELATED INFORMATION FOR MACMILLAN STAFF

Macmillan staff may also wish to use this Rich Picture document in combination with other connected documents, such as the Impact Briefs or the Macmillan Communications Platform. You may wish to select evidence from more than one source to build a case for support, add weight to your influencing, or to engage and inspire Macmillan’s supporters. A range of evidence that may be helpful to you is summarised here. Please note that any hyperlinks active below may not work for non-Macmillan staff.

Case Study Library

People affected by cancer

Contains stories and quotes from real-life examples of people affected by cancer who have been helped by Macmillan.

Professionals/Services

Contains specific examples of our services across the UK, and the impact they are having.



Comms Platform

Describes how to communicate with people affected by cancer.



Rich Pictures

Describe the numbers, needs and experiences of key groups within the 2.5 million people with cancer.



Impact Briefs

Generically describe what our services do, and the impact they have on people affected by cancer.



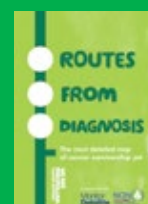
Local Cancer Intelligence

A local overview of the essential data on the changing burden of cancer in your area, including prevalence, survival, patient experience and comparisons across clinical commissioning groups.



Routes from Diagnosis

Results from the first phase of the Routes from Diagnosis study, including outcome pathways, survival rates, inpatient costs and morbidities associated with breast, lung, prostate and brain cancers.



For further information about any of the above, please contact a member of **Macmillan’s Evidence Department**, or contact evidence@macmillan.org.uk.

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SUMMARY OF CHILDREN WITH CANCER

Key stats

There were **9,936 children living with cancer** in the UK in 2010, based on patients diagnosed with cancer between 1991 and 2010.⁽¹⁾

Cancer in children is very rare as under 1% of those living with cancer are aged 0-14.⁽¹⁾

There is variation between 5-year survival in children compared to older age groups depending on the type of cancer, but **generally children tend to have a higher survival rate**. This could be due to the types of cancer children have compared to adults, and more aggressive treatment and higher resilience compared to some older groups.^(11, 12)

Almost half of parents (47%) said that their **child had grown apart from friends** because of their cancer diagnosis and treatment, leading to isolation.⁽³³⁾

9,936 children were living with cancer in the UK in 2010 based on children living up to 20 years post a cancer diagnosis.⁽¹⁾

Diagnosis

1,400 children were diagnosed with cancer in the UK in 2012.^(2,3,4,5)

The **most commonly diagnosed cancers in children** are **leukaemia, brain and central nervous system (CNS) tumours**, which account for almost a third of cancers in children, and **lymphomas**, which account for over a quarter of cancers in children, and **lymphomas**, which account for about 11% of cancers in children.⁽⁶⁾

The proportion of children who are **diagnosed via the emergency route (53%)** is significantly higher than the proportions presented via the same route who are teenagers and young adults aged 15-24 (25%).⁽²⁸⁾

The majority of children diagnosed with cancer are diagnosed via the emergency route

Treatment

In total there were **39,758 admissions to NHS hospitals in England** (emergency and non-emergency) **for cancer amongst children** aged 0-14 during 2012-13.⁽⁴⁶⁾

Children with Acute lymphoblastic leukaemia, one of the most common cancers in those aged 0-15, **continue treatment for 2 to 3 years and can miss some of their education** through being in hospital and having to attend appointments for treatment over a protracted period of time.⁽³²⁾

Treatment often occurs in specialist treatment centres many miles from home, sometimes leading to children being **separated from friends and extended family for long periods of time**.⁽³²⁾

Children can be separated from friends and family for long periods of time because of treatment in specialist centres

Survivorship

By 2021 there could be more than **40,000 people who have survived at least five years after developing cancer as a child.**⁽⁶⁸⁾

There are a number of **long term consequences of treatment**, such as cardiovascular abnormalities, thyroid dysfunction, or secondary cancers, which **can continue to manifest years after the completion of treatment.**⁽⁶⁴⁾

Childhood cancer survivors were found to be less likely to be in employment compared to those of the same age that had not had cancer as a child.⁽⁷³⁾

A number of side effects of treatment can continue to manifest years after completion of treatment

End of life

Cancer is the most common cause of death in children aged 1–14 years overall, accounting for around a fifth (21%) of all deaths in this age group in 2012.^(7, 10, 85)

Mortality from childhood cancer is slightly higher in girls than in boys (aged 1-14), with 24% of all deaths in girls and 19% of all deaths in boys due to cancer in 2012.^(7, 10, 85)

Of all cancer deaths in England amongst children, 47% occur in hospital, 39% occur at home, 11% occur in hospices of specialist palliative care units and 3% occur elsewhere.⁽⁷⁷⁾

There is often **poor awareness of palliative care services by families and professionals.**⁽⁸¹⁾

Cancer is the most common cause of death in children aged 1–14 years

Lifestyle & perceptions

The media tend to use a formal tone in reporting stories of children and cancer, focusing on medical terms and the delivery of facts and not giving much prominence to the emotional aspects of having a child living with cancer.⁽⁸⁴⁾

The **leisure activities of families that tend to have children with cancer** can include **sport and physical fitness**, while these families tend not to go out, but often **spend more time at home.**⁽⁸²⁾

INTRODUCTION TO CHILDREN WITH CANCER

Who are children with cancer?

We recognise that there is no standard definition of 'children', and it varies according to country, organisation and context.

For the purposes of this Rich Picture we are defining 'children' as 0- to 14-year olds.

This corresponds to the age range typically used for data collected by the National Cancer Intelligence Network (NCIN), who also collect data for the 15-24 age group. Evidence around 15- to 24-year olds can be found in another Rich Picture document, The Rich Picture on Teenagers and Young Adults With Cancer.

Want to know more

Macmillan produces a wealth of information about what cancer is, its causes, symptoms and treatment. If you're affected by cancer, call our Macmillan team on the number below, or visit our website.

Almost one in two of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way. Call the Macmillan team free on **0808 808 0000** (Monday to Friday, 9am-8pm) or visit **www.macmillan.org.uk**

'Alex was first diagnosed with acute lymphoblastic leukaemia in February 2009 at the age of 2. It's been a rollercoaster of emotions ever since.

It's so difficult to put into words just how hard life can be for a child with cancer and their family. To begin with, just giving Alex his chemotherapy drugs was a nightmare we faced each day. He was two and a half years old – how was he to know that the horrible smelling and tasting drugs his mummy and daddy were forcing him to take were saving his life? I'll never forget the feeling as he kicked and screamed and we choked back our tears.

I'm just so grateful that our Macmillan nurse was always there, to explain what was happening and tell us what to expect next and how to deal with it.'

Funda, mother of Alex, 8

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's Aims and Outcomes – and how they are different for children with cancer

The estimated total number of people living with cancer in the UK in 2015 is almost 2.5 million. Assuming that all existing trends in incidence and survival continue cancer prevalence is projected to increase to **4 million** in 2030. Particularly large increases are anticipated in the oldest age groups and in the number of long term survivors. By 2040 77% of all cancer survivors will be at least 65 years old and 69% of cancer survivors will be at least 5 years from diagnosis.⁽⁹²⁾ Macmillan's ambition is to reach all of these people and help improve the set of **9 Outcomes** you can see opposite. Remember, certain groups will identify more or less strongly with the various Outcomes.

9,936 children were living with cancer in the UK in 2010 based on children living up to 20 years post a cancer diagnosis.⁽¹⁾

The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

I get the treatment and care which are best for my cancer, and my life

Those around me are well supported

I am treated with dignity and respect

I know what I can do to help myself and who else can help me

I can enjoy life

I feel part of a community and I'm inspired to give something back

I want to die well

THE FACTS ON CHILDREN WITH CANCER

This section presents some of the key stats and facts relating to children with cancer. You may benefit from referring to the jargon buster on page 61 for details on some of the terms used in this section. Please note that incidence and mortality data on all cancers exclude non-melanoma skin cancer.

Less than 1%

of new cancer diagnoses are amongst children (aged 0-14) ^(2, 3, 4, 5)

4

children are diagnosed with cancer every day ^(2, 3, 4, 5)

9,936

children were living with cancer in the UK in 2010 based on children living up to 20 years post a cancer diagnosis.⁽¹⁾

Less than 1%

of deaths from cancer are amongst children (aged 0-14) ^(7, 8, 10)

89%

of children diagnosed with acute lymphoblastic leukaemia, one of the most common childhood cancers, live beyond 5 years of their diagnosis ⁽¹¹⁾

How many children are diagnosed with cancer each year?

Cancer incidence, UK, 2012, in children and young people^(2, 3, 4, 5)



Age has a direct effect on cancer incidence, with higher incidence as age increases. Less than 1% of new cases are diagnosed in children. This compares to 64% among those aged 65 and over.

What are the most common cancer types amongst children?⁽⁶⁾

The most commonly diagnosed cancers in children are:

Leukaemia

accounts for almost a third (30%) of cancers in children, of which 78% are acute lymphoblastic leukaemia

Brain and CNS tumours

account for over a quarter (26%) of cancers in children

Lymphomas

account for 11% of cancers in children, with more than half of cases (53%) being non-Hodgkin lymphoma

How many children die from cancer each year?

Cancer mortality, UK, 2012, in children and young people^(7, 8, 10)



Cancer among children is very rare, which is why only less than 1% of all deaths from cancer are among children. This compares to 78% of all cancer deaths from those aged 65+.

How many children are currently living with cancer?⁽¹⁾ (prevalence)

Children (0-14) living with cancer in the UK



9,936

children were living with cancer in the UK in 2010 based on children living up to 20 years post a cancer diagnosis.

What are the key stats for England?

See data on incidence, mortality and prevalence for England



How many children get cancer per year in England? (incidence)⁽²⁾

1,156

new cases of cancer diagnosed in those aged 0-14 in England in 2012

How many children die from cancer per year in England? (mortality)^(7, 9)

227

cancer deaths in those aged 0-14 in England in 2012

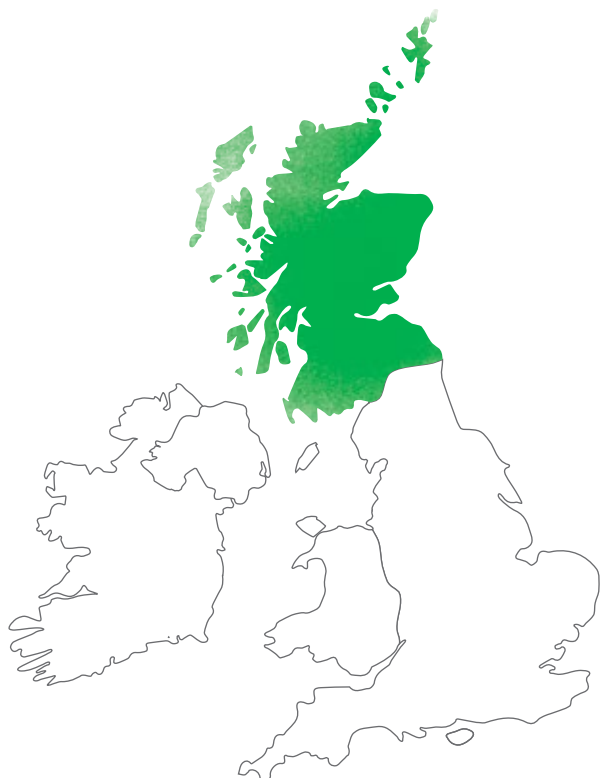
How many children are living with cancer in England? (prevalence)⁽¹⁾

8,345

children were living with cancer in England in 2010, based on children living up to 20 years post a cancer diagnosis (1991 and 2010).

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



How many children get cancer per year in Scotland? (incidence)⁽³⁾

112

new cases of cancer diagnosed in those aged 0-14 in Scotland in 2012

How many children die from cancer per year in Scotland? (mortality)⁽⁸⁾

16

cancer deaths in those aged 0-14 in Scotland in 2012

How many children are living with cancer in Scotland? (prevalence)⁽¹⁾

770

children were living with cancer in Scotland in 2010, based on children living up to 20 years post a cancer diagnosis (1991 and 2010).

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



How many children get cancer per year in Wales? (incidence)⁽⁴⁾

80

new cases of cancer diagnosed in those aged 0-14 in Wales in 2012

How many children die from cancer per year in Wales? (mortality)⁽⁹⁾

8

cancer deaths in those aged 0-14 in Wales in 2012

How many children are living with cancer in Wales? (prevalence)⁽¹⁾

505

children were living with cancer in Wales in 2010, based on children living up to 20 years post a cancer diagnosis (1991 and 2010).

What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



How many children get cancer per year in Northern Ireland? (incidence)⁽⁵⁾

52

new cases of cancer diagnosed in those aged 0-14 in Northern Ireland in 2012

How many children die from cancer per year in Northern Ireland? (mortality)⁽¹⁰⁾

10

cancer deaths in those aged 0-14 in Northern Ireland in 2012

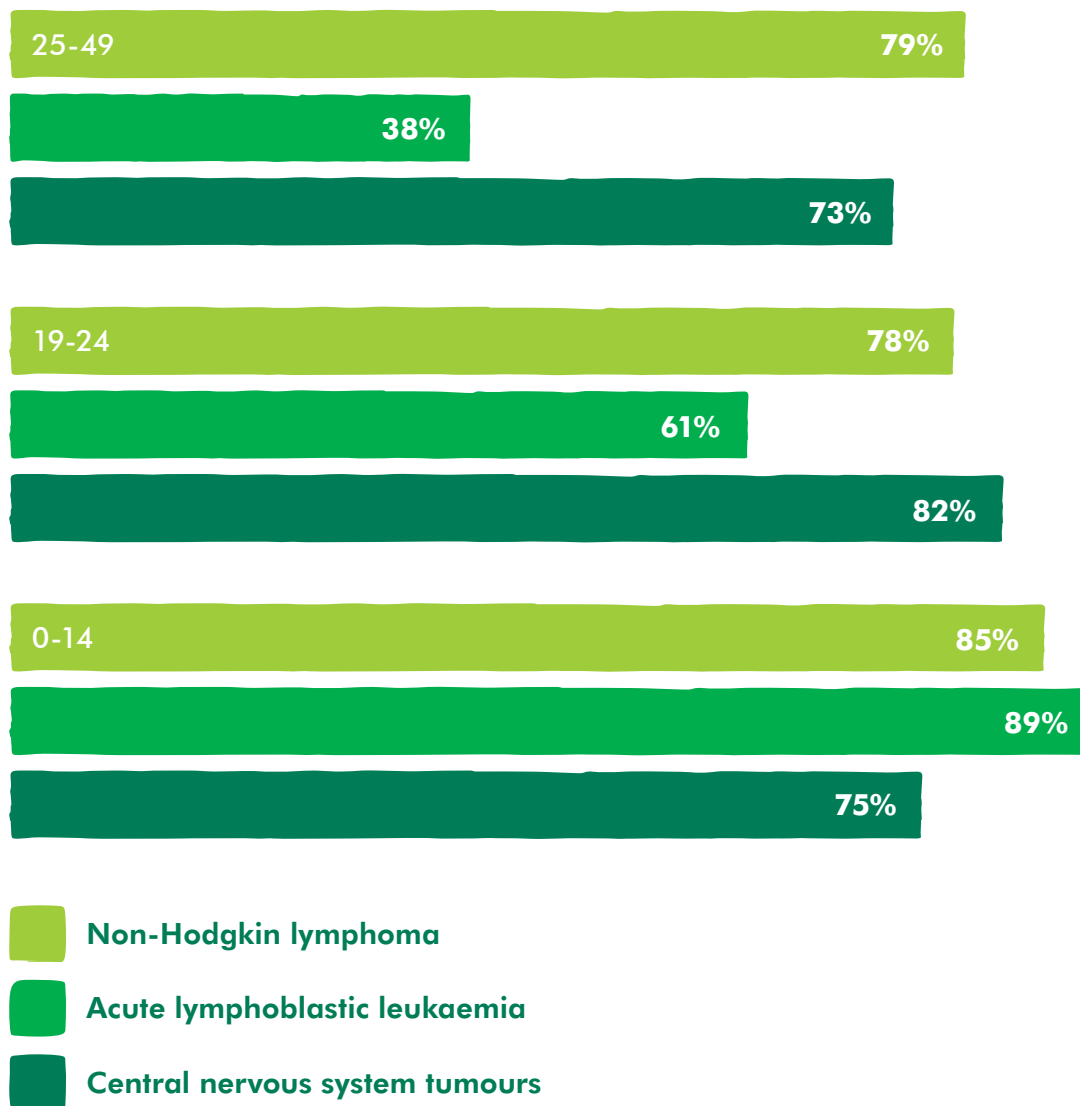
How many children are living with cancer in Northern Ireland? (prevalence)⁽¹⁾

316

children were living with cancer in Northern Ireland in 2010, based on children living up to 20 years post a cancer diagnosis (1991 and 2010).

What proportion of children survive cancer?

Relative 5-year survival for the top 3 cancers diagnosed in children in 2001-2005, compared to other age groups, UK ⁽¹¹⁾

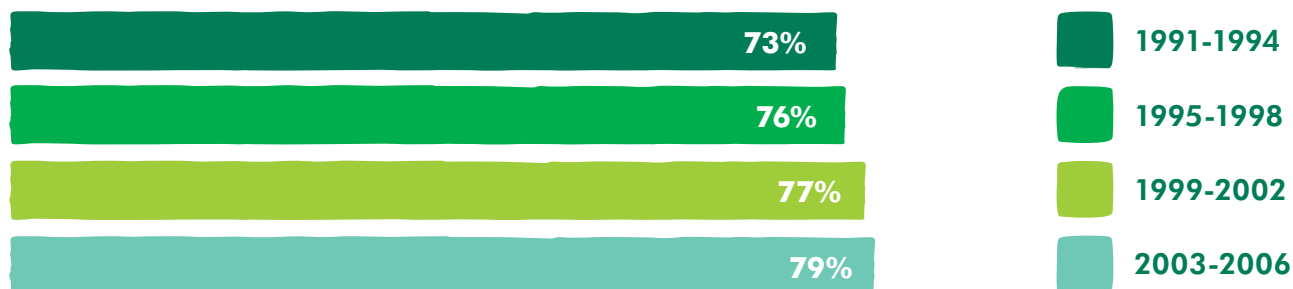


There is variation between survival in children compared to older age groups depending on the type of cancer, but generally children tend to have a higher survival rate. This could be due to more aggressive treatment and a higher resilience compared to some older groups.^(11, 12)

Survival for acute lymphoblastic leukaemia and non-Hodgkin lymphoma is highest in children, and survival reduces as age of diagnosis increases. Survival for central nervous system tumours however is an exception to the general rule; survival is highest in teenagers and young adults, with children and adults in the 25-49 age group having a similar, lower 5-year survival.

How many children live beyond five year of their cancer diagnosis?⁽¹³⁾

Five-year survival for children aged 0-14, England, 1991-2006



Five-year survival for children has gradually increased over time, which might be because of factors such as improved treatments and earlier diagnosis.

Similar trends are also evident for teenagers and young adults (aged 15-24) and those of all ages. However, the survival rates for children and teenagers and young adults are much higher than for those of all ages, which might be because younger people are less likely to have types of cancers with poorer outcome, such as lung cancer. They may also be able to tolerate more intensive treatments such as therapies and surgery better than older people. Young people are also less likely to have other medical problems, and their organs are usually healthy.

How do UK survival rates compare internationally?

One study comparing the survival rates of children from acute lymphoblastic leukaemia found that the UK had the lowest survival rates in Europe, and had consistently had the lowest percentage of cured cases since those diagnosed in 1991-1993, until 2000-2002.⁽¹⁴⁾

What are the major demographic variations in incidence, mortality, prevalence and survival for children with cancer?

Gender

The incidence of cancer in children is only slightly higher in boys than in girls. There were 152 new cancer cases for every million boys compared to 132 for every million girls in the UK in 2009 to 2011. Mortality from childhood cancer is slightly higher in girls than in boys (aged 1-14), with 24% of all deaths in girls and 19% of all deaths in boys due to cancer in 2012.^(7, 10, 85)

Ethnic background

There is limited data available on cancer incidence in children and ethnic group specifically. However, there is some evidence that South Asian children in England have either a similar or increased risk of developing cancer (particularly leukaemias and lymphomas) compared to their non-South Asian counterparts.⁽¹⁶⁾

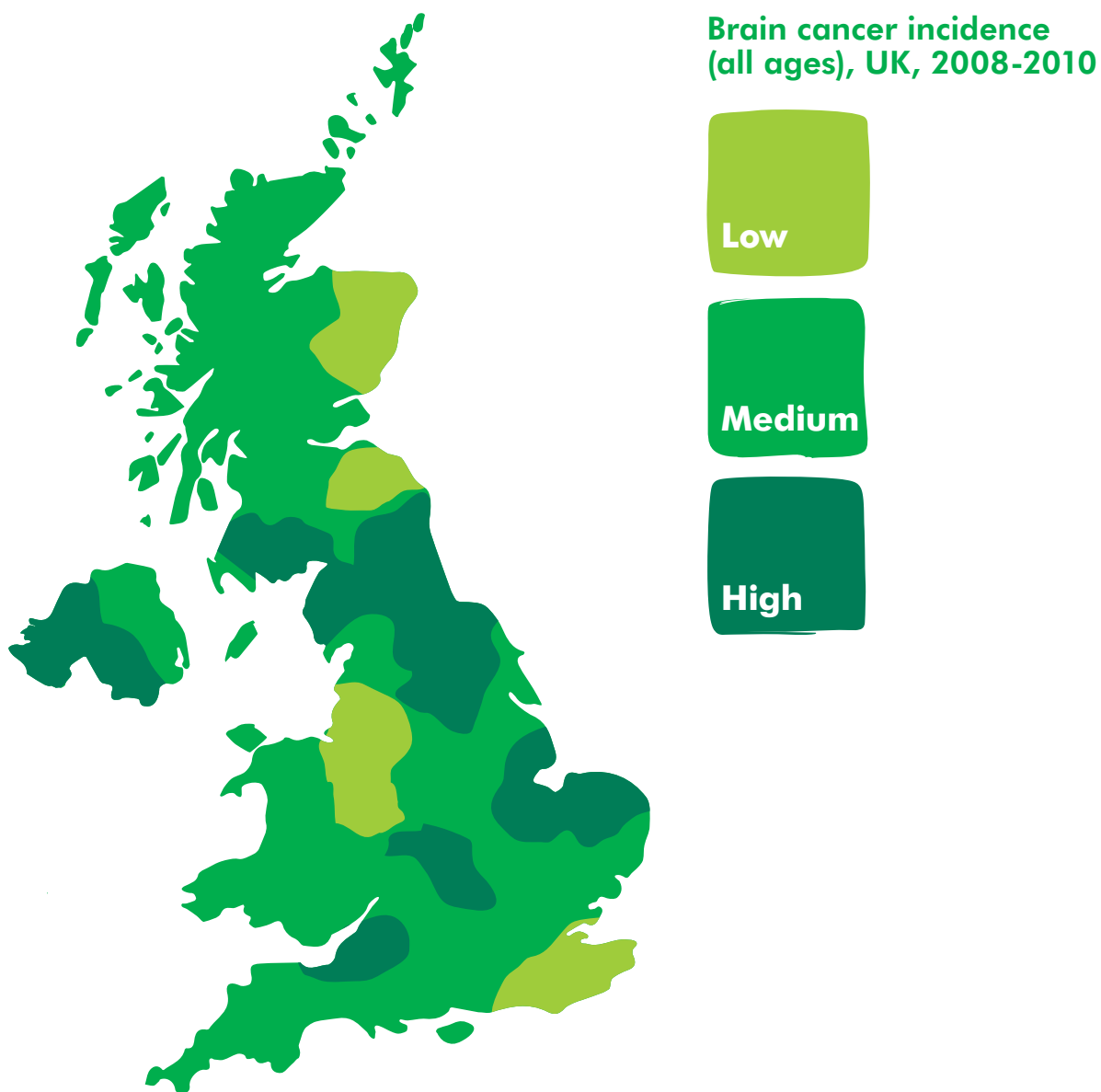
Social background

Childhood leukaemia incidence in England and Wales is higher in relatively affluent communities. Possible explanations include under-diagnosis of leukaemia in children from poorer communities, and/or an association of higher socioeconomic status and with hypothesised risk factors, such as population mixing and delayed exposure to infection.⁽²³⁾

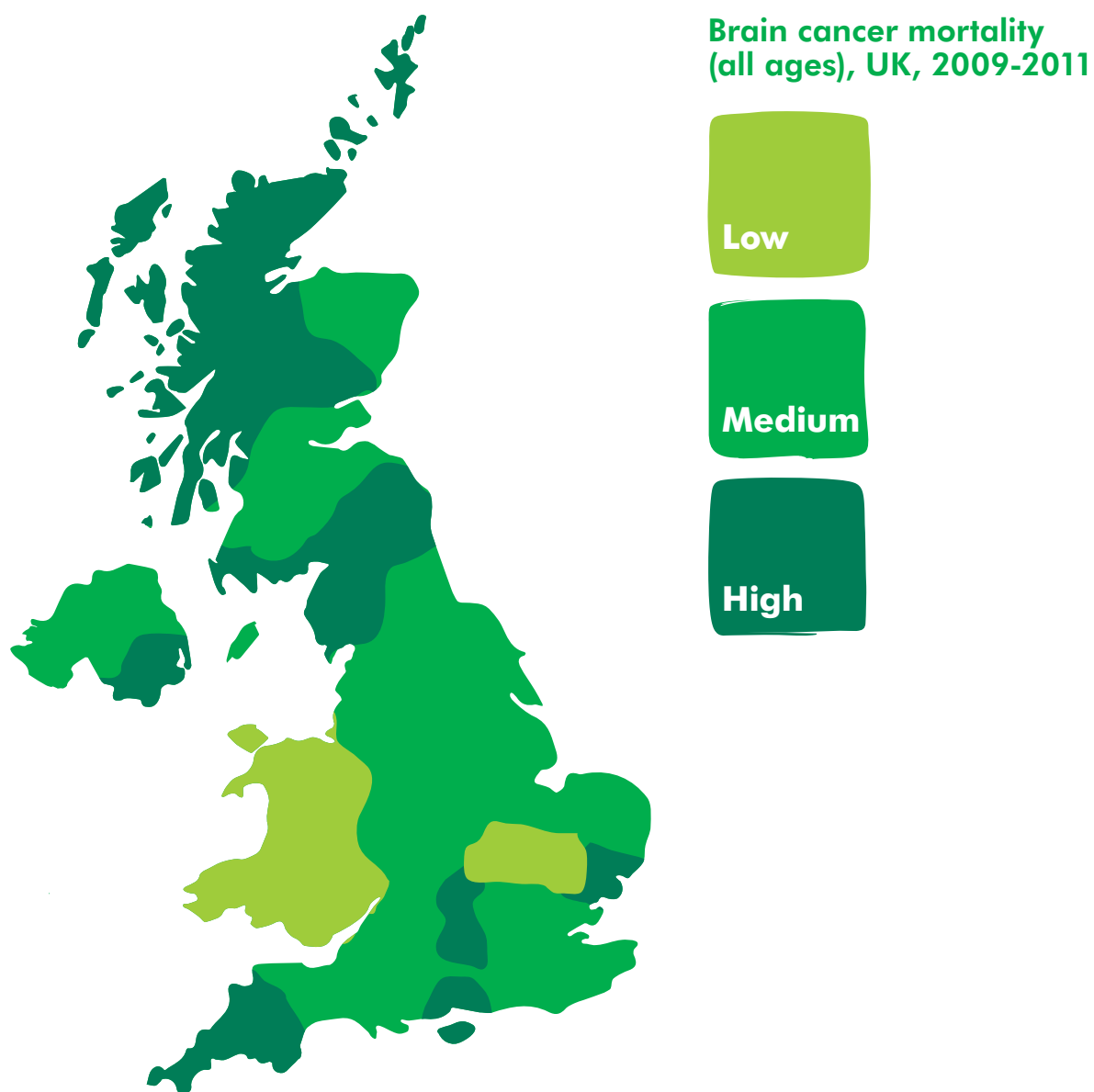
Although not specific to children, for leukaemia, the most common cancer in children, one-year relative survival is lower for those living in the most deprived areas. The difference in relative survival between the most and the least deprived group is also greater for men than for women.⁽¹⁷⁾

What are the geographical ‘hotspots’ for cancer incidence and mortality?

Leukaemia is the most common cancer in children but there is no data available on this type of cancer by geographical location. We have therefore included data for brain cancer which, along with other central nervous system tumours, is the second most common cancer in children. Brain and other central nervous system (CNS) tumours account for 26% of cancers in children.⁽⁶⁾ Maps grouped by age are not available, so the following maps represent the incidence and mortality of brain cancer (excluding other CNS tumours) for all ages.



Incidence of brain cancer is generally higher in Northern parts of England



Mortality from brain cancer is highest in Scotland and Northern Ireland

What are the major trends in mortality and survival?

There have been huge improvements in cancer treatment for children in the past 50 years. Over 8 in 10 (82%) children with cancer are now cured, compared with fewer than 3 in 10 (less than 30%) between 1962–1971.⁽¹⁹⁾

It is estimated that there were 57 deaths per million children due to cancer in 1975–1977. This has more than halved to 23 per million in 2009–2011. This decrease in mortality is true for all diagnostic groups.⁽¹⁵⁾

Dramatic improvements in the treatment of leukaemia in the 1970s and 1980s could account for some of these improvements. In the early 1970s, 33% of children survived for 5 years or more whereas today this survival has risen to more than 80%. These improvements in survival from leukaemia led to brain and CNS tumours overtaking leukaemia as the most common cause of cancer deaths in children in the early 1990s.^(20, 15)

'Toby was 21 months old when this all started happening. Toby never felt ill, I just picked him from nursery one day and he had a really small red mark underneath his eye. I didn't think anything of it, I just presumed he'd knocked it. But it was still there a few days later. I was given antibiotics from the doctors and they didn't make any difference. However, our GP said it might be a sty and so it might take six weeks to heal. He never said it felt sore, it was just red.

I thought it was a skin disease and just wanted to get it sorted, so I took him to the emergency room. They put him on an IV drip of antibiotics, thinking it was a blocked tear duct. But it didn't go down. They tried to lance it, but it was solid. Eventually, they decided to do a biopsy, and we were told it was cancer.

We navigated through an extremely political and complex process in order to get him proton therapy, on the NHS. The NCG (National Commissioning Group) funded the treatment, (living expenses still down to us) and it was provided abroad (Switzerland) due to the lack of provision in this country.

Living abroad while on treatment and trying to keep a family together brings its own challenges, let alone language and cultural differences.'

Claire, mother of Toby, 7, living with cancer

THE CANCER JOURNEY

We know that everyone with cancer has different experiences at different times of their cancer journey. However most people will go through one or more of the four stages of the 'cancer journey'.

The following pages summarise what we currently know about the needs and experiences of children living with cancer at these stages.

A typical 'cancer journey' showing four key stages:

1

Diagnosis

What happens to me when I'm diagnosed with cancer?

- People often **show signs and symptoms** that may be caused by cancer, and a GP can refer patients for tests to find out more.
- **Screening** aims to detect cancer at an early stage or find changes in cells which could become cancerous if not treated.
- However screening can only pick up some cancers, and we know that some people have their cancer **diagnosed at a late stage** – this can have a huge effect on their chances of survival.

2

Treatment

What can I expect when I'm being treated for cancer?

- Cancer can be **treated** in different ways depending on what type of cancer it is, where it is in the body and whether it has spread.
- Different cancer types can have **varying treatment regimes**, and treatment is personalised to each patient.

3

Survivorship*

If I complete my treatment for cancer, what next?

- An increasing number of people **survive** their initial (or subsequent) cancer treatments, and often have **rehabilitation** and **other needs** post-treatment.
- We also know they need support to be able to **self-manage**.
- Many people in this stage experience **long-term or late effects** of their cancer, and/or their cancer treatment.

4

Progressive illness and end of life

If my cancer is incurable, what might I experience?

- Progressive illness includes people with **incurable cancer**, but not those in the last year of life. Many of these people have significant treatment-related illnesses.
- End of life generally means those in the **last year of life**. Needs often get greater as the person moves closer to death.

*While Survivorship relates to the time both during and post-treatment, as illustrated by the Recovery Package (p41), this section largely highlights the post-treatment needs and experiences of people living with cancer.

NEEDS AND EXPERIENCES DIAGNOSIS

What are the general signs and symptoms of cancer?

Reporting symptoms to a GP early can help ensure that if cancer is diagnosed, then it is **diagnosed as early as possible**.

In children under 15, the most common type of cancer is leukaemia, which accounts for about a third of all cases in both boys and girls.⁽²¹⁾ There are 2 main types of acute leukaemia

- Acute myeloid leukaemia (AML)
- Acute lymphoblastic leukaemia (ALL)

Approximately three out of four of leukaemia cases are acute lymphoblastic leukaemia (ALL). ALL can affect children of any age, but is more common in children aged 1-4.⁽²²⁾

The symptoms of leukaemia in general vary according to the type, but common symptoms include:

- General weakness
- Feeling tired (fatigue)
- A high temperature (fever)
- Weight loss
- Frequent infections
- Bruising or bleeding easily
- Pain in the bones or joints
- Breathlessness
- A feeling of fullness or discomfort in the tummy (abdomen) from a swollen liver or spleen

When a child has symptoms that could be caused by cancer, they may be referred by their GP or local hospital to one of the following specialists:

- a paediatrician, who specialises in treating children
- a paediatric oncologist, who specialises in treating children with cancer
- a paediatric haematologist, who specialises in treating blood disorders⁽²⁴⁾

How good are we at early diagnosis? How aware are people of signs and symptoms?

Lots of young people are not aware of the common signs of cancer so they do not recognise themselves. It can also take a while for them to tell their parents or someone else close to them that they are worried about something and can feel embarrassed.⁽²⁶⁾

A 2012 survey of almost 500 11- to 17-year olds found that 26% could not spontaneously recall a sign or symptom of cancer.⁽²⁵⁾

The same study found that, when prompted, the most recognised symptom of cancer amongst 11- to 17-year olds was 'lump or swelling' (89%), followed by 'change in the appearance of a mole' (59%).⁽²⁵⁾

The same survey found that while 74% indicated that they would seek medical help within three days for a symptom they thought might be cancer.⁽²⁵⁾

The most common barriers to seeking help amongst respondents to the same survey were:⁽²⁵⁾

- 'Worry about what the doctor might find' – 72%
- 'Too embarrassed' – 56%
- 'Too scared' - 54%
- 'Not feeling confident to talk about symptoms' – 53%
- 'Difficulty talking to the doctor' – 34%
- 'Worry about wasting the doctor's time' – 33%
- 'Too busy' – 23%
- 'Difficulty arranging transport' – 15%

The figures above suggest that emotional barriers were far greater for 11- to 17-year olds than practical barriers.

How aware are GPs of signs and symptoms?

Given the rarity of childhood cancer it has been estimated that a GP will on average see one child under the age of 15 years with a cancer every 20 years. Added to the variety of possible cancer symptoms in children, teenagers and young adults, many of which may be non-specific and common, this poses a significant diagnostic challenge.⁽²⁷⁾

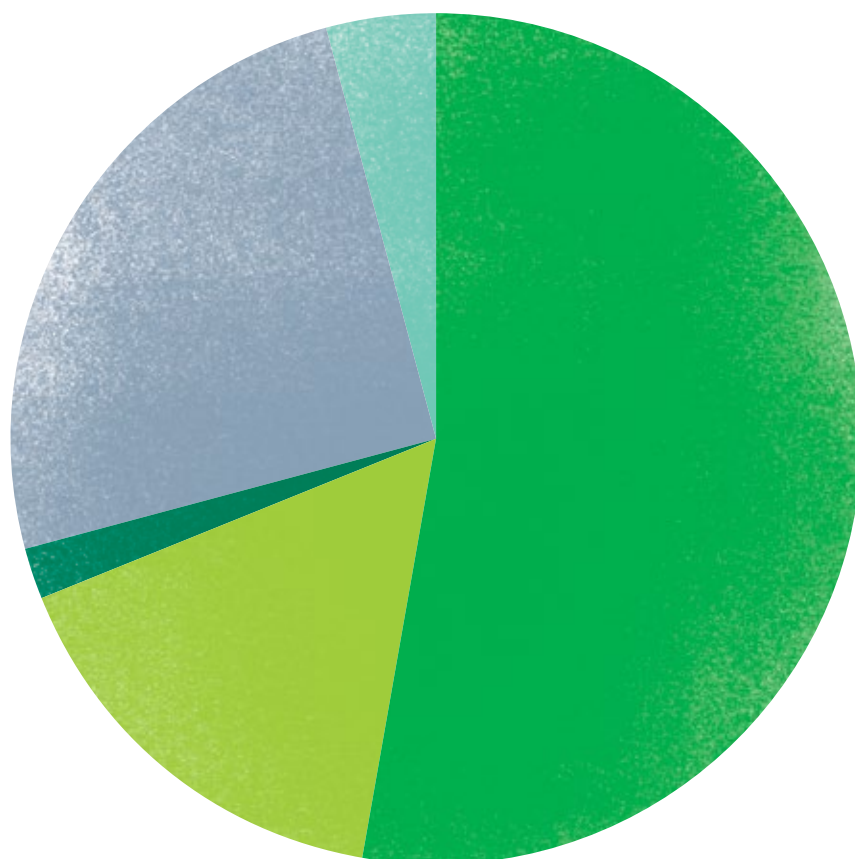
A 2011 poll of teenagers by the Teenage Cancer Trust suggests that 24% had to visit their GP at least four times before being referred to a specialist.⁽²⁶⁾

In the same poll, 21% of teenagers reported that their GP did not refer them to a specialist.⁽²⁶⁾

61% felt that their diagnosis could have been made quicker.⁽²⁶⁾

How is cancer diagnosed? (Routes to diagnosis)⁽²⁸⁾

Children aged 0-14, England, 2006-2010



Emergency presentation

53%

GP referrals

16%

Two week waits

2%

Other*

25%

Unknown**

4%

*'Other' includes 'An elective route starting with an outpatient appointment: either self-referral, consultant to consultant, and other referral or no earlier admissions can be found prior to admission from a waiting list, booked or planned'.

**'Unknown' is defined as 'No data available from Inpatient or Outpatient HES, CWT (Cancer Waiting Times) and Screening'

The majority of children are diagnosed with cancer via the emergency route. The proportion of children who are diagnosed via the emergency route (53%) is significantly higher than the proportions presented via the same route in teenagers and young adults, aged 15-24 (25%).

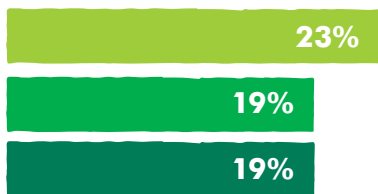
What are the routes to diagnosis for the most common cancers in children?⁽²⁸⁾

Children aged 0-14, England, 2006-2010

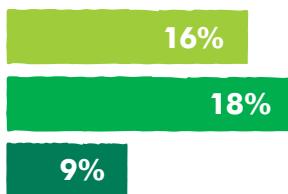
Emergency presentation



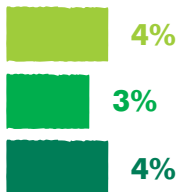
Other*



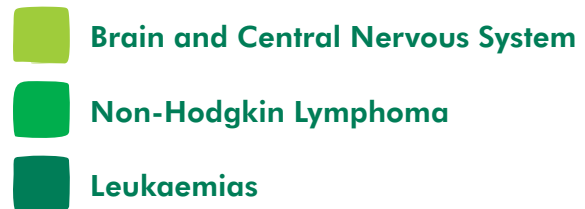
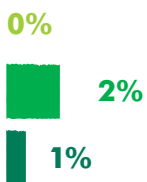
GP referrals



Unknown**



Two week wait



*'Other' includes 'An elective route starting with an outpatient appointment : either self-referral, consultant to consultant, and other referral or no earlier admissions can be found prior to admission from a waiting list, booked or planned'.

**'Unknown' is defined as 'No data available from Inpatient or Outpatient HES, CWT (Cancer Waiting Times) and Screening'

For each of the most commonly diagnosed cancers amongst children the most typical route to diagnosis is emergency presentation.

How does stage at diagnosis relate to probable survival rates?

There are currently very limited available UK-wide data on stage at diagnosis for children of all cancer types and on the links between stage at diagnosis and survival.

What are the cancer risk factors in children?

Very little is known about the causes of most childhood cancers, and many studies, particularly those involving few cases, have been inconclusive. The interpretation of these studies is often limited by the wide range of cancers in children, variation in the timing of exposure to risk factors, the small number of exposed subjects in many studies and the lack of information on specific substances.⁽²⁹⁾

Infections

Worldwide, the most important examples of childhood cancers caused by infections are Burkitt's lymphoma, Hodgkin lymphoma and nasopharyngeal carcinoma (all associated with Epstein-Barr virus), liver carcinoma (hepatitis B) and Kaposi sarcoma (HHV8) but together these account for a very small proportion of childhood cancer in Western countries.⁽²⁹⁾

Drugs and medication

There have been reports of the possible carcinogenic effects of many different drugs taken by mothers during pregnancy. The only carcinogen firmly established as being able to cross the physical and biological barriers of the placenta separating the mother and foetus is diethylstilboestrol (DES), a hormone which in some countries used to be given to pregnant women with threatened miscarriage, but its use was discontinued about 30 years ago, and there is no direct evidence for a transgenerational effect.⁽²⁹⁾

Parental Smoking

In 2009, the International Agency for Research on Cancer (IARC) classified parental smoking, during pregnancy or during the period prior to conception, as a cause of hepatoblastoma in offspring.⁽²⁹⁾

Birthweight

A meta-analysis showed a small increase in risk of childhood ALL in those with a high birth weight, with a 14% increase in risk for each additional kilogram.⁽²⁹⁾

Breastfeeding

There is a very small reduction in risk of ALL in children who have been breastfed, and a slightly larger reduction for children breastfed for six months or longer.⁽²⁹⁾

Genes and family history

In some cases, a child may be slightly more likely to get certain types of cancer if their siblings or other family members have also been affected. Retinoblastoma, a rare form of eye cancer is known to be inherited in 40% of cases. Siblings of someone with ALL are at slightly increased risk of developing it themselves. Certain genetic conditions can also increase a child's risk of cancer. For example, people with Down's syndrome have an increased risk of leukaemia.⁽³⁰⁾

Ionising radiation

The increased risk of childhood cancer associated with antenatal obstetric irradiation was discovered over 40 years ago. Since then, obstetric x-ray examination in pregnancy has been largely superseded by ultrasound examination. Evidence does not suggest that ultrasound causes childhood cancer.⁽²⁹⁾

Non-ionising radiation

There has been much public concern about the possible health effects of electromagnetic fields arising from electrical sources such as power lines and domestic wiring. Analyses of pooled data from case-control studies have shown no evidence of raised risk of childhood leukaemia with exposure to power frequency (50-60Hz) fields at the levels experienced by over 95% of children in western countries.⁽²⁹⁾

‘Toby was only a few months old when he was diagnosed with a rare form of kidney cancer. When he was 12 he caught a virus going around school. He was off school for 3 weeks, he was tired and had a dreadful cough. He was going straight to bed all the time. One time when he came home he said he was going straight to bed, but he had really big ankles. I pulled up the covers and his legs were absolutely enormous. I thought ‘There’s something serious going on here.’ I bundled him into the car and took him to hospital. They did initial assessments, then the radiologist said this is serious heart failure. I said ‘It can’t be possible. He’s just got a virus.’ The specialist said this is long term damage from the chemo drugs.’

Gilly, mother of Toby, 15, living with kidney cancer



PHYSICAL AND MEDICAL NEEDS

Symptoms for cancer in children are often **vague and non-specific** making it harder for GPs to know when to refer children on for further tests. This can result in delays in diagnosis and explain why the **majority of cancers in children are diagnosed through emergency presentation.**⁽³¹⁾



FINANCIAL AND EDUCATIONAL NEEDS

A study found that **two-thirds of parents of children with cancer lost earnings** and **three-fifths cut their working hours** following their child's diagnosis with cancer.⁽³³⁾

In many cases **one parent has to give up paid employment** to care for their child, compounding the financial impact of a cancer diagnosis.⁽³²⁾

Two in three (66%) parents built up debt to make ends meet as a result of their child's cancer, with two in five (41%) borrowing £1,000 or more and more than one in four (27%) borrowing over £2,000.⁽⁶⁵⁾

90% of children said that their cancer diagnosis and treatment has made a **difference to their school life.**⁽³³⁾

Just over half (56%) of parents said 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**, however only **23%** reported that they had been approached within the **first week.**⁽³³⁾

Almost two-thirds (62%) of parents of children with cancer, said their child had been **taught at home after receiving a diagnosis of cancer.** Statutory guidance notes that Local Authorities are responsible for children who are unable to attend school due to their medical needs. However, children who lived in one local authority but received their treatment in another, frequently leading to delays in receiving home education.⁽³³⁾



PRACTICAL AND INFORMATION NEEDS

A 2012 survey found that **almost two in three (64%) parents** of children with cancer **were consulted about how their child's diagnosis should be communicated** to other teachers and school children – although one in three (36%) were not consulted on the matter.⁽³³⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Almost half of parents (47%) said that their **child had grown apart from friends** because of their cancer diagnosis and treatment, leading to isolation.⁽³³⁾

One study reported that some children found that their **diagnosis also affected their siblings**. When the focus of the family routine revolved around the 'sick' child there could often be friction with their siblings.⁽³⁴⁾

Siblings may also experience **post-traumatic stress symptoms, increased negative emotions, and a poorer quality of life** in emotional, family, as well as social domains. These difficulties are **greatest around the time of diagnosis**.⁽⁸⁷⁾

NEEDS AND EXPERIENCES TREATMENT

What treatments do children with cancer get?

Before a child has any treatment, the doctor will ask the parent or child to sign a form to give permission (consent) for the hospital staff to give the treatment. Once a child reaches the age of 16, they can usually consent to their own treatment.⁽³⁵⁾

Surgery

If a child has been diagnosed with a solid tumour, it is likely that they will need surgery at some point during their treatment. Depending on the size of the tumour, surgery may be done in the first or second stage of treatment.⁽³⁶⁾ A biopsy of the tumour is often taken first to make the diagnosis. This involves taking a piece of tissue from the tumour so it can be looked at in the laboratory by the pathologist. They will then identify the type of cancer.⁽³⁷⁾

If the tumour is removed by surgery and is found to be benign (non-cancerous), then this operation may be the only treatment needed. However, if it is found to be a cancerous tumour, then they may also need chemotherapy or radiotherapy to kill any cancer cells that might be elsewhere in their body. If the tumour is large, or if removing it might damage any surrounding tissue, they may first be given chemotherapy or radiotherapy to shrink the tumour and increase the chances of successful surgery.⁽³⁶⁾

Chemotherapy

Chemotherapy (chemo) is the use of anti-cancer drugs to destroy cancer cells. These drugs can be given on their own, but often more than one drug is given. This is called combination chemotherapy. It can be given as tablets or liquid, but it's often given into a vein (intravenously). Some cancers, such as leukaemia, need chemotherapy because the cancer cells are in the blood and therefore all over the body. In other cases, when a solid tumour is removed with surgery, specialists may also prescribe chemotherapy to target any cancer cells that might remain in the body.⁽³⁸⁾

Children usually have a combination of different chemotherapy drugs. The number of drugs they have will depend on the type of cancer or leukaemia they have. The drugs are carried in the blood and can reach cancer cells all over the body.⁽³⁹⁾

Radiotherapy

Radiotherapy treatment is given in the hospital radiotherapy department as a series of short daily sessions over a few weeks. The treatments are usually given from Monday-Friday with a rest at the weekend. Each treatment takes about 10-15 minutes. The length of treatment will depend on the type of cancer the child has.⁽⁴⁰⁾

Radiotherapy involves using controlled doses of high-energy radiation to destroy the cancer cells while doing as little harm as possible to the normal cells.⁽⁴¹⁾ Radiotherapy can be used over a few weeks, to cure a cancer, often in addition to other treatments, such as surgery and chemotherapy. It can also be used to relieve symptoms such as pain, by helping to shrink the cancer, typically only needing one or two treatments.⁽⁴²⁾

Radiotherapy can be given in two different ways. External radiotherapy is given from outside the body using a machine that looks like a big x-ray machine. This is the most common type of radiotherapy. Internal radiotherapy is given from inside the body.⁽⁴²⁾

Radiotherapy is not painful, but the child has to lie completely still for a few minutes while the treatment is being given. Younger children or children who aren't able to keep still may be given a sedative. Occasionally, they may need to have a light anaesthetic so the treatment can be given.⁽⁴⁰⁾

Stem cell or bone marrow transplants

A stem cell transplant (sometimes called a bone marrow transplant) allows the child to have much higher doses of chemotherapy than usual. This can improve the chance of curing their cancer but has more side effects.⁽⁴³⁾

Before a stem cell transplant, stem cells are collected from either the bone marrow or the blood of the child or a donor. The child will then be given very high doses of chemotherapy, usually over a few days. Sometimes, radiotherapy to the whole body, known as total body irradiation (TBI), is also given.⁽⁴³⁾

As well as destroying any remaining cancer cells, the high doses of chemotherapy also destroy the stem cells in the bone marrow. After the chemotherapy, the child is given the stem cells that were collected before the treatment through a drip. They make their way into the bone marrow and start producing mature blood cells again.⁽⁴³⁾

Immunotherapy

Immunotherapy drugs target specific cancer cells. Because it targets specific cells, other parts of the body are not affected and the side effects are usually mild. Immunotherapy is only suitable for certain types of cancer. It's usually given with chemotherapy.⁽⁴⁴⁾

How many nurses are there for children with cancer?

Macmillan’s internal data suggest that we have (as of June 2013) 80 paediatric cancer Macmillan nurse posts across the whole of the UK.⁽⁴⁵⁾

How many cancer admissions are there amongst children, and how many children with cancer stay in hospital (and for how long)?

In total there were 39,758 admissions to NHS hospitals in England (emergency and non-emergency) for cancer amongst children with aged 0-14 during 2012–13.⁽⁴⁶⁾

Modelling work undertaken by Frontier Economics in 2010 indicated that a total of one-to-one support workers, such as Clinical Nurse Specialists, were needed for 0- to 15-year olds with cancer in order to meet demand in England. This equates to the need for 7 additional one-to-one support workers.⁽⁴⁷⁾

How many children with cancer have access to appropriate treatment and wards?

In August 2005 the National Institute for Health and Clinical Excellence (NICE) Guidance on Improving Outcomes (IOG) in Children’s and Young People with Cancer (CYPIOG) was published and made recommendations for the treatment and care of children, teenagers and young adults (TYA) with cancer, aged 0 to 24 years. NICE recognises that the emotional and physical needs of children and young people with cancer are different from those of older adults with cancer.

One of the key principles of the CYPIOG is that all children under 16 years should be referred to a Principal Treatment Centre.⁽⁴⁸⁾

The establishment of the UK Children’s Cancer Study Group (UKCCSG now called Children’s Cancer and Leukaemia Group, CCLG) in 1977 brought about a big shift towards treating childhood cancers in the specialist centres that are sometimes referred to as Principal Treatment Centres, and this has benefitted children with cancer enormously. There are currently 20 such Principal Treatment Centres forming a close-knit network across the UK and Ireland.⁽⁴⁹⁾

Children in Principal Treatment Centres are treated by multidisciplinary teams, including paediatric oncologists, haematologists, clinical oncologists, surgeons, junior ward doctors, clinical nurse specialists, nurses, pharmacists, physiotherapists and occupational therapists, pathologists, psychologists, radiographers, radiologists, dieticians, play specialists, social workers and teachers.⁽⁴⁹⁾

What does this mean for children with cancer?

Often, some of the treatment can be given at a local hospital under the guidance of the nearest specialist centre. This is called shared care and the local hospitals are known as Paediatric Oncology Shared Care Units. If the child has any shared care, the decisions about his or her treatment will still be made by the child’s consultant at the Principal Treatment Centre. Almost all children’s wards have facilities where parents can stay overnight. Brothers and sisters may be able to stay too.⁽⁴⁹⁾

What other health conditions do children with cancer have as a result of their treatment? How does this affect long-term outcomes and experiences?

Side effects of chemotherapy and radiotherapy in children can include sickness, diarrhoea or constipation, tiredness, mouth ulcers and taste changes, dental problems, changes in appetite, hair loss, skin problems (such as sensitivity to the sun and chemicals such as chlorine, rashes or colour changes), hearing loss, infertility, as well as blood changes such as reduced counts of red or white blood cells or platelets.^(50, 51)

Side effects of surgery cancer treatment in children with cancer can include pain and infection.⁽⁵²⁾

While there have been considerable improvements in survival after childhood cancer, some groups of survivors have long-term excess mortality and morbidity or are at an increased risk of physical, psychological and social health problems later in life (often referred to as late effects).^(53, 54, 55, 56)

Among a cohort of British survivors of childhood cancer, excess mortality from second primary cancers and circulatory diseases continued to occur beyond 25 years from diagnosis.⁽⁵⁶⁾

What are clinical trials?

In order to push the boundaries of cancer treatment forward, clinical trials need to be carried out. A clinical trial is a medical research study that compares an older treatment with a newer one. The aim is to find out whether the newer treatment works better. One group of people is given the established treatment and the other is given the newer one, with the results studied in terms of their benefits and drawbacks, such as side effects. Any clinical trial is strictly controlled, and all will have been tested fully in the laboratory, and often on other people too.⁽⁵⁸⁾

Clinical trials are reviewed every few months. If a patient agrees to take part in one, and it becomes clear before it is over that one treatment is definitely better than the other, it will be stopped and the more effective treatment will be given to everyone.⁽⁵⁸⁾

Around 50-70% of children with cancer in England/UK enter clinical trials, compared with less than 20% of patients aged 15-24, and around 8% in adults aged 35-39. A similar trend has been shown in other countries.^(57, 59, 60, 61, 62)

“In order to improve the quality of care services, NICE has recommended that eligible children and young people (aged 0-24) with cancer should be offered the opportunity to participate in clinical trials.”⁽⁶³⁾



PHYSICAL AND MEDICAL NEEDS

High dose radiotherapy for head and neck cancer in growing children affects the bone and soft tissue growth and **affects hormone production**, e.g. thyroid/pituitary hormones.⁽⁶⁷⁾

The most common symptoms experienced by **hospitalised children with cancer include nausea, pain, and fatigue**. The presence of these symptoms can impact on the total burden of symptoms experienced by children, increasing levels of global distress.⁽⁸⁹⁾

Diarrhoea or constipation, taste and appetite changes and hair loss are also common side effects of treatments such as chemotherapy and radiotherapy.^(50,51)



FINANCIAL NEEDS

Parents spend on average an extra £4,400 annually as a result of their child's cancer. The top three expenses are **travel and car parking, clothing, and extra food costs**. **Two in three parents of children with cancer had built up debt** as a direct result of trying to meet these additional financial demands.⁽⁶⁵⁾

Some families have to travel many miles for their children's cancer treatment, with an average round trip distance travelled by car being 60 miles. On average parents spend an additional **£86 a month on travel, with one in three parents (34%) spending over £100 extra a month**.⁽⁶⁵⁾

Cancer treatment can affect taste buds and the ability to eat, so food needs to be carefully planned. On average, parents of children with cancer spend an additional **£48 per month on food, with 22% spending over £100 extra a month**. This cost was highest for parents of children on active treatment.⁽⁶⁵⁾

The financial impact of cancer can be significant and immediate due to the additional costs associated with **travel to specialist treatment centres, food, childcare, phone bills** and other important items. These factors are compounded by the fact that families often experience a reduction in income at this time due to balancing care responsibilities and paid responsibilities.⁽³²⁾



PRACTICAL AND INFORMATION NEEDS

36% of 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.⁽³³⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Treatment often occurs in specialist treatment centres many miles from home, sometimes leading to children being **separated from friends and extended family for long periods of time.**⁽³²⁾ **Just over half (55%)** of parents of children with cancer say that their child **felt isolated from friends when they were in hospital** and 47% said their child felt isolated when they returned to school either during or after treatment.⁽³³⁾

It can be **difficult for children with cancer to continue with social activities** with their family and friends, particularly when time is spent away from home. This can lead to **poorly developed interpersonal skills, feeling isolated and can be a cause of low self-esteem.**⁽³²⁾

There are often many **visible side effects** to treatment such as **hair loss and weight gain** due to steroid treatment that can result in **low self-esteem.**⁽³⁴⁾

More than one in three (35%) parents of children with cancer report that their child had **experienced bullying or teasing from their peers** because of their cancer diagnosis and treatment.⁽³³⁾

NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

Why are childhood cancer survivors not catered for properly by the current system?

By 2021 there could be more than 40,000 people who have survived at least five years after developing cancer as a child.⁽⁶⁸⁾ The current system for cancer patients (of all ages) after the end of treatment concentrates on medical surveillance, and looking for recurrence. However we know that this does not address people's needs fully.

In a 2010 survey of 90 children with cancer aged 7-13

- 17% of children spoke of the impact tiredness and fatigue has on their quality of life.⁽³⁴⁾
- 18% highlighted 'How to tell peers about cancer and its treatment' as a matter of importance.⁽³⁴⁾

In a 2012 survey of 221 parents of children with cancer:

- 56% 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 and lack of clear responsibility from the school.⁽³³⁾
- 47% said that their child had grown apart from friends because of their cancer diagnosis and treatment.⁽³³⁾

- 56% of the parents of children who had 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.⁽³³⁾
- 26% of parents 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.⁽³³⁾
- 35% parents said their child had experienced bullying or teasing from their peers because of their cancer diagnosis and treatment.⁽³³⁾

Cancer survivors have greater health needs than the general population

Work to estimate the risk of specific adverse health outcomes for childhood cancer survivors showed that this group is at increased risk of adverse health outcomes, when compared to the general population. It also found that childhood cancer survivors should only be subject to regular contact if surveillance examinations or investigations are likely to lead to early detection of recurrence, second malignancies or non-cancer late effects.⁽⁶⁹⁾

Macmillan and the Department of Health are working to implement personalised support for all cancer survivors

The National Cancer Survivorship Initiative (NCSI) is a partnership between the Department of Health and Macmillan, and is supported by NHS Improvement. A new NCSI report, 'Living with and beyond cancer: Taking Action to Improve Outcomes', will inform the direction of survivorship work in England to 2015. It will support commissioners, health service providers and others to take the actions necessary to drive improved survivorship outcomes, including those for young adults. It includes⁽⁶⁹⁾:

- A set of working principles to underpin survivorship care for children and young people, incorporating the need for an established aftercare multi-disciplinary team (MDT), a Treatment Summary and care plan at the end of treatment and at all stages of transition, a care coordinator function to streamline their care and pre-planned and proactive transition arrangements at all stages of their aftercare;

- Four defined models of aftercare (clinician-led follow-up, professionally-led shared care, nurse-led follow-up and supported self-management);
- A competency framework for nursing roles in supporting children and young people after cancer;
- Interactive pathways for children, teenage and young adult patients, and teenage and young adult patients with complex needs.

For more information about the NCSI, and access to the 'Living with and beyond cancer' document, visit the NCSI website at www.ncsi.org.uk





PHYSICAL AND MEDICAL NEEDS

Many childhood cancer survivors experience frustration and concern at having poor memory and **difficulty organising their thoughts and understanding instructions** since finishing their treatment.⁽³⁴⁾

There are a number of **side effects** from cancer treatment, such as cardiovascular abnormalities, endocrine insufficiency, or secondary cancers, which **may not become apparent until several years after completion of treatment.**⁽⁸⁶⁾

Survivors treated with **ionizing radiation** are at **increased risk of nonmelanoma skin cancers leaving additional scarring and disfigurement.** A small scale study of dermatologic conditions and scarring found that 33% of 78 adult childhood cancer survivors reported treatment-related scarring compared to 1.5-4.5% in the general population.⁽⁷⁰⁾

Certain chemotherapy agents used to treat cancer in children can have a significantly **negative effect on fertility** in later life. One study which involved **male childhood cancer survivors** found that their levels of **reproductive hormones were significantly lower** compared to the levels found in the control group who had not had cancer as children.⁽⁷¹⁾

Female childhood cancer survivors are at increased risk of infertility, particularly after treatments such as radiotherapy to the pelvic organs.⁽⁹¹⁾ Female survivors may also suffer **decreased sexual functioning** unrelated to emotional factors, suggesting that some women may benefit from targeted interventions and increased awareness.⁽⁹⁰⁾



FINANCIAL AND EDUCATIONAL NEEDS

The **key challenges** identified by survivors of childhood cancer are around **education, employment** and issues such as **isolation.**⁽³²⁾

Children often have **difficulty keeping up with schoolwork** and teachers do not always understand the difficulties faced by children returning to school after treatment ends.⁽³²⁾

Survivors of childhood cancers have been found to have lower educational attainment than the general population. One study showed that the odds of childhood cancer survivors **gaining a degree is 77% of that expected from the general population.**⁽⁷²⁾

One study found that childhood **survivors of CNS tumours were less likely to obtain one A level/O level** compared to those who had **survived leukaemia, retinoblastoma, or other neoplasms.** The likelihood of obtaining this qualification increased as the age at cancer diagnosis increased.⁽⁷²⁾

Childhood cancer survivors were found to be less likely to be in employment compared to those of the same age that had not had cancer as a child. The likelihood of being employed was found to be the **lowest among survivors of brain and bone cancers.**⁽⁷³⁾

Childhood cancer survivors with poor physical health were found to be almost eight times more likely to be unemployed due to their health, compared to survivors with normal physical health.⁽⁶⁶⁾



PRACTICAL AND INFORMATION NEEDS

According to a recent report, the **two main sources of information for child cancer survivors are parents or doctors**; but parents did not always have the answers, and children were often too embarrassed to ask doctors certain questions.⁽³⁴⁾

In one study, several children said that they were **concerned about the possibility of getting hurt while playing**, resulting in them being hospitalised, and being concerned that the cancer might return if they were injured. This misconception that cancer can develop through an injury or trauma suggests that there **needs to be further information available to children in the survivorship stage to reassure them about these concerns.**⁽³⁴⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Almost one in five (18%) parents said their child lost **confidence or was anxious about returning to school** as a result of the cancer diagnosis and treatment. There were various reasons for this, including infection control, obtrusive intravenous lines used for administering medication, the child's changed appearance and nervousness about rough playtimes.⁽³³⁾

Visible side effects from treatment such as **scarring, disfigurement and persistent hair loss** in childhood cancer survivors can result in **long-term negative effects on psychosocial functioning and quality of life which remain into adulthood.**⁽⁶⁴⁾

NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

How many children with cancer are at End of Life?

For children aged 0 to 14 years who were diagnosed with cancer in England between 2003 and 2006, 79% survive at least five years.⁽¹³⁾

260 children died from cancer in the UK in 2012.^(7, 8, 9, 10)

Cancer is the most common cause of death in children aged 1–14 years overall, accounting for around a fifth (21%) of all deaths in 2012 in this age group.^(7, 10, 85)

Though tumours of the brain and central nervous system (CNS) rank second in incidence⁽⁶⁾, they are the most common cause of deaths from cancer in childhood, accounting for around a third (32%) of all cancer deaths in children. Leukaemia accounts for a slightly lower proportion of cancer deaths in children (30%) and tumours of the CNS account for around a tenth (11%).⁽¹⁵⁾

What is the impact of giving children with cancer palliative care*?

A 2012 report found that there are 40,000 children and young adults aged 0-19 in England who have long-term health conditions that, for most, will eventually end their lives and for which they may require palliative care. Of this total cancer represents around 14% of diagnoses, equating to around 6,000 people aged 0-19.⁽⁷⁵⁾

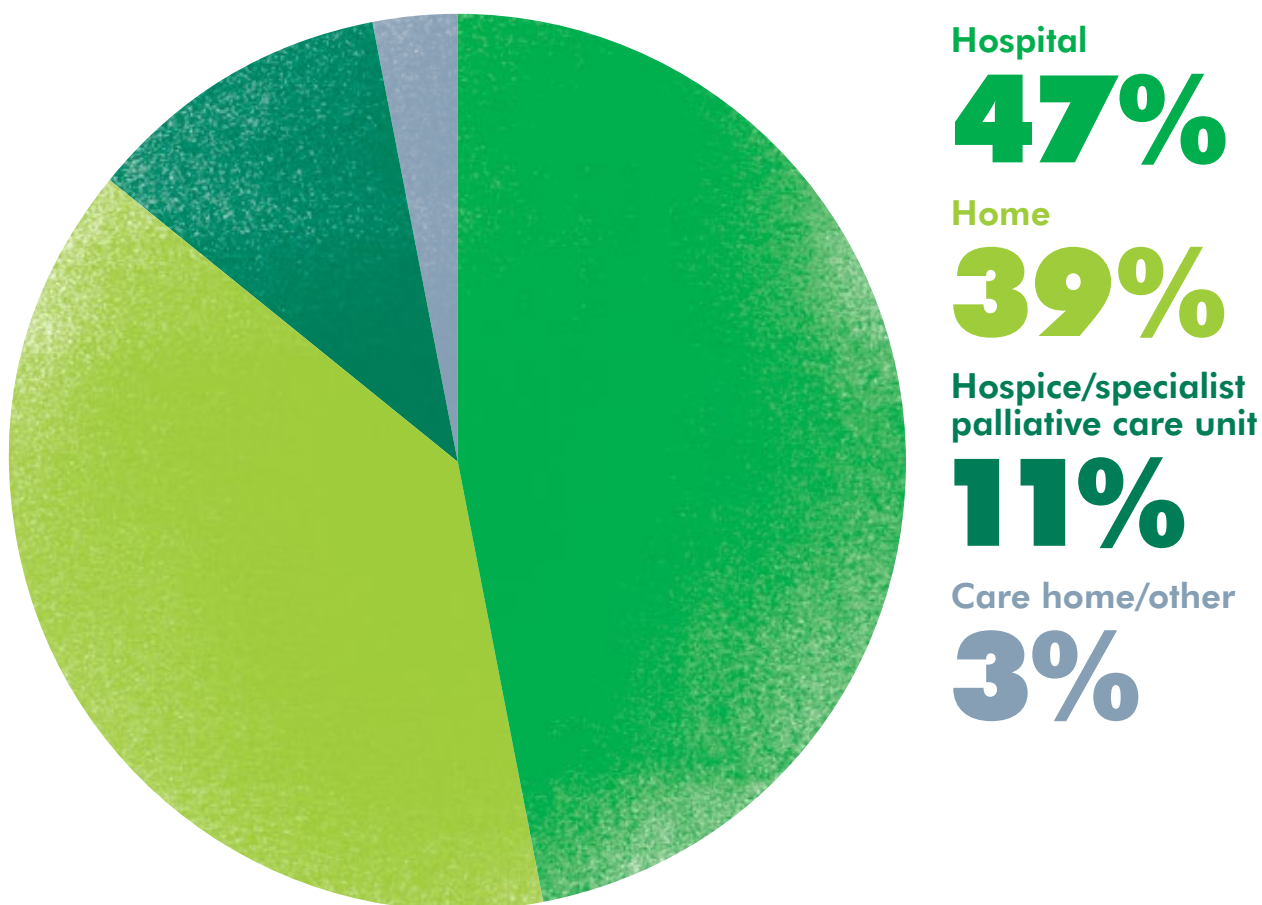
Evidence suggests that compared to patients receiving standard care, those receiving regular palliative care input from the time of diagnosis had a better quality of life, received less aggressive treatments close to death, and survived longer.⁽⁷⁶⁾

*The National Institute for Clinical Excellence (NICE) has defined supportive and palliative care for people with cancer. With some modification the definition can be used for people with any life-threatening condition: 'Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.'

For further information, visit the National Council for Palliative Care website, www.ncpc.org.uk

Where do children with cancer die?⁽⁷⁷⁾

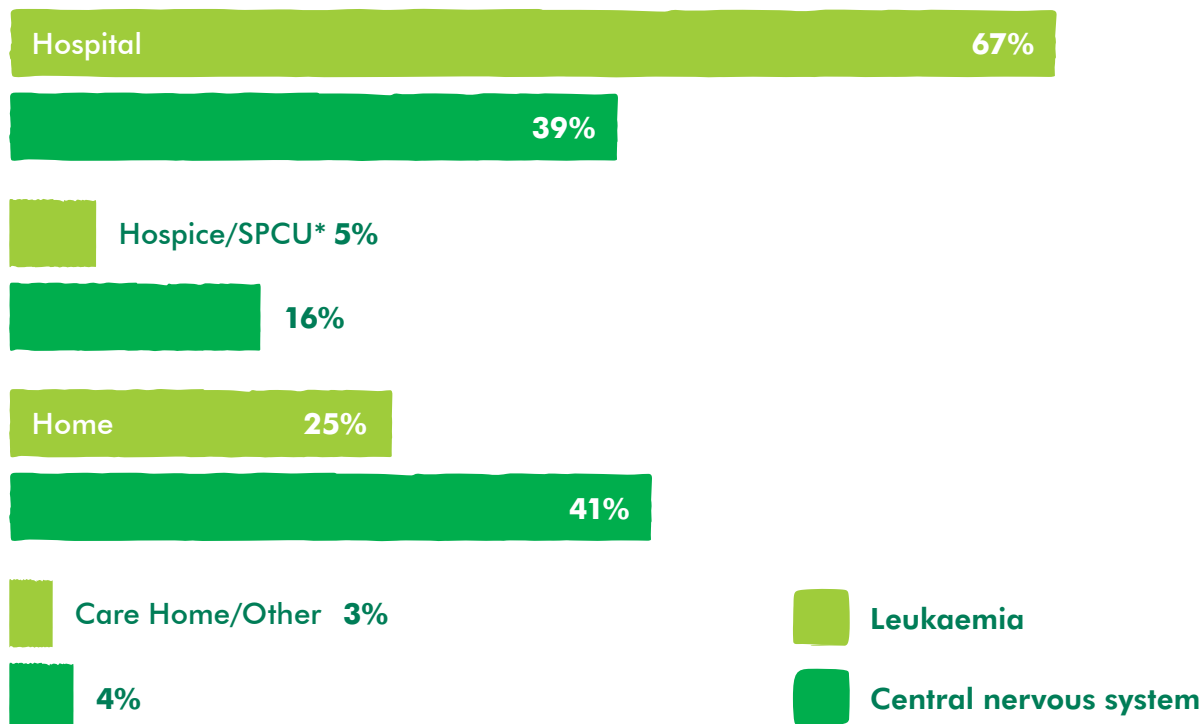
Place of death of children aged 0-14, England, 2000-2009



Of all cancer deaths in England amongst children, 47% occur in hospital, 39% occur at home, 11% occur in hospices or specialist palliative care units and 3% occur in a care home or elsewhere. By comparison, for people of all ages with cancer in England, 38% die in hospital, 30% at home, 18% in hospices and 13% in a care home.⁽⁷⁸⁾

Where do children with common types of cancer die?⁽⁷⁷⁾

Children’s place of death by most common cancer types, England, 2000-2009



*'SPCU' = specialist palliative care unit

Leukaemia and central nervous system (CNS) tumours, the cancers most commonly diagnosed in children, have significant variation in place of death.

Children with leukaemia are more likely to die in hospital than those with CNS tumours. Children with CNS tumours are more likely than those with leukaemia to die at home, and a similar trend is evident for those who die in a hospice or specialist palliative care unit.

‘Our Macmillan nurse has been great, everything from just listening, to a few bits of good advice and writing a letter to Butlins for us to secure a full refund on a fully paid holiday we can’t take. It’s not a massive sum, but it’s a big help.’

Phil, father of Ted, 5, diagnosed with acute myeloid leukaemia



PHYSICAL AND MEDICAL NEEDS

According to one study, bereaved parents reported that their **children suffered from at least one distressing symptom** during palliative care, most commonly **pain and fatigue**.⁽⁷⁹⁾

It is **common for children's conditions to fluctuate**, and as such, it is often much **more difficult to identify when a child is moving into their end of life phase**. This makes it difficult for health care professionals to know when they should be involving palliative care services in the child's care.⁽⁸⁰⁾



FINANCIAL AND EDUCATIONAL NEEDS

According to one study, **73% of bereaved parents said that they were given the option for their child to return to or continue at school after they had stopped receiving curative treatment**. Those that had taken up the offer felt that they had received sufficient support from the school and that by allowing their child to return to school they were able to **maintain as normal a life as possible** which was particularly important for many families.⁽³³⁾



PRACTICAL AND INFORMATION NEEDS

There is often **poor awareness of palliative care services for children by families and professionals**. It has also been reported that there is sometimes a **lack of co-ordination between those involved in delivering children's palliative care**. This can result in many children and families not receiving information about appropriate palliative care or having access to the right services.⁽⁸¹⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

A CLIC Sargent study found that **38% of bereaved parents** felt that their child's cancer had **negatively affected their child's friendships**.⁽³³⁾

81% of bereaved parents said that their child felt **isolated from friends when they were in hospital**. This was significantly higher than parents with a child at earlier stages of the cancer journey as 55% of these parents said that their child was isolated from friends.⁽³³⁾

Bereaved parents have an **increased risk of developing psychosocial problems**. A review of studies found **higher rates of anxiety, depression, prolonged grief, and poor quality of life** among bereaved parents. Parents also showed poorer adjustment if they had less time to prepare for their child's death.⁽⁸⁸⁾

LIFESTYLE AND PERCEPTIONS

This section attempts to give an indication of the typical profile of children living with cancer, however we know that there is huge variation within the population. This section also provides insight into perceptions about children with cancer.

What is the demographic breakdown/market segmentation of the 9,936 children living up to 20 years after initial diagnosis with cancer in the UK*?(1)

*Based on people diagnosed with cancer between 1991 and 2010

We have compared the UK-wide distribution of children (aged 0-14) with cancer across different Mosaic™ groups.

Amongst people with cancer, the following MOSAIC™ groups, of households that had high presence of children, show significantly greater than average representation:

Group G, Type 33 – ‘Military Dependents’

Military Dependants are people serving in the armed forces, along with their partners and children. They can be found scattered around the country wherever the military has barracks. Most adults are aged between 18 and 40. These service people and their partners are accompanied by children who are currently of pre-school and primary school age.

There is a tendency for Military Dependants to have large families of four or even more children, and the spouses are often part of strong support networks from other spouses on the base. Their homes are filled with communications and information technology. Many have several computers, Pay TV subscriptions, Wi-Fi networks and iPods.

Given that this type can move accommodation frequently and partners may be overseas with the forces, the Internet is a vital communication tool. Military Dependents are heavy users of both email and social networks, and their children also spend a lot of time online.

Group G, Type 32 – ‘Childcare Years’

Childcare Years are young professional couples at the start of their careers, and doing well.

Many of them are not married, but living together and have recently started families. Many hold down well paid jobs in large national organisations. They often have children of pre-school or primary school age. It is common for both partners to work – two incomes are often needed to cover the high costs of the monthly mortgage payments.

As well as the home and garden, newly arrived children also influence patterns of expenditure. Hatchbacks which served their needs when they were a couple are now replaced by small people carriers in which prams, pushchairs and all the other paraphernalia for young children can be easily transported.

This group tends to use the Internet for online shopping. In addition to the weekly grocery shop, toys and games are also likely to be purchased online and their children use the Internet for entertainment and education. However, as the children in these households tend to be younger – often of pre-school age – they may not yet be participating in social networks or online communities.

The children of ‘Childcare Years’ families typically spend much of the day at a nursery or childminder, and are often raised in a liberal fashion, encouraged to speak their mind and have much attention lavished upon them.

In addition to the above groups other populations that tend to have children with cancer include:

- Group F, Type 28: ‘Asian Attainment’
- Group N, Type 58: ‘Asian Identities’
- Group G, Type 30: ‘Soccer Dads and Mums’
- Group N, Type 60: ‘Global Fusion’

What are the typical leisure activities/where do they shop/what media they consume/what do they do?

Group G, Type 33 – ‘Military Dependents’

These households are particularly distinctive in their love of sport and physical fitness, and their high propensity to have pets, often many of them. The former is a natural consequence of involvement with the army, and the latter often stems from having many children in a stable environment. Keeping fit is important for both parents and children, and many will play several team sports as well as regularly visiting the gym. Sport seems to be a substitute for television.

Holiday time is restricted, but most have one big holiday a year, and maybe one other short break, too. These tend to be spent on a budget, and quite active holidays.

Group G, Type 32 – ‘Childcare Years’

Their leisure activities involve exercise, whether going to the gym during the week or taking short active breaks at weekends. They also take one or two longer holidays a year, often involving skiing, diving or some other physical activity. They are not that keen on going out, and do not spend much on restaurants or drinks while out and about, preferring to spend more time at home.

Their homes have expensive television and audio equipment, although they only watch one or two hours of television per day. They prefer to watch DVD boxsets and films, or programmes they have downloaded from the Internet.

What does this mean?

Macmillan hosts online discussions on its website; we have analysed the frequency of words used in the discussions relating to teenagers and young adults and cancer, compared to the frequency of words used in UK media articles where teenagers and young adults and cancer is the subject. The results are summarised here:

- The online community word cloud prominently contains numerous informal and conversational terms, such as 'really', 'get' and 'much'. There is also a greater experiential element to the online community terms, as 'think', 'hard', 'found' 'know' and 'time' are suggestive of people sharing their experiences of the cancer journey, and generate a personal tone. This contrasts with a more formal tone in the media word cloud, in which many of the prominent terms are nouns ('life', 'doctors', 'family', 'treatment'), suggesting a greater focus on the delivery of facts, rather than on the conversational sharing of experiences.
- The word 'euthanasia' is fairly prominent within the media word cloud, but not present at all within the online community word cloud. This contrast suggests that the approach within the media largely eschews the emotive, but identifies more pragmatic issues around cancer for children.
- Medical terms are more prominent in the media cloud, terms such as 'doctors', 'fertility', 'treatment', 'IVF', 'vitamin' and 'overweight', as well as 'euthanasia'. There are far fewer such terms in the online community cloud, and even when one is mentioned ('chemo') this is the informal, shortened form of 'chemotherapy', again reflecting the informality of the online community.
- The media cloud's most prominent three words are 'children', 'child' and 'cancer', reflecting that the media introduces such stories with the context and subject matter. By contrast, while 'cancer' is prominent in the online community word cloud, the words 'child' and 'children' are much less prominent. Instead, 'son' and 'daughter' are prominent, reflecting that the online community is heavily used by parents.

What are parents of children living with cancer saying about their children's lives both before and after a cancer diagnosis?

'When Rebecca was first diagnosed at the age of 5, she and the family had help from a Macmillan Children's Liaison Nurse. When Rebecca was diagnosed for the second time, another Macmillan Children's Liaison Nurse, helped the family. When the nurse heard that Rebecca's school friends were texting Rebecca with questions and worries she travelled 30 miles to speak to her classmates. She took them into a quiet room spoke with them and let them ask any questions they had.'

Janet, 66, whose granddaughter Rebecca, 15, is living with cancer

'Amy has coped really well – to her it's all just normal. At that age, kids just adapt and get on with it. She probably thinks every child in school has a Mr Wiggly – her name for the port under her arm. She doesn't think she's any different to any other child.'

Denise, mother of Amy, 9, living with acute lymphoblastic leukaemia

'I was 8 years old when diagnosed and the treatment began, it was not too bad when a child as you accept things so differently. I had around 4-5 years of treatment which ranged from ok to very bad and at times I was very ill. Unfortunately at 10 years old I had a stroke which the medical profession put down to the treatment as the drugs caused my blood to thicken. This was a very bad time as I my left side was affected lots of physio and care I gradually began to walk and talk again.'

Male, 40, diagnosed with childhood leukaemia when he was 8.

REFERENCES, SOURCES, NOTES AND CAVEATS

Quotes

The quotes on pages 23, 31, 47, 54 and 55 are real quotes from people with cancer or their carers, however we have changed their names to protect their identity. The quote and photo on page 5 is from a Macmillan children living with cancer case study who has kindly agreed to be featured in this publication.

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APPENDIX A JARGON BUSTER

Not sure of some of the terms used in this document? Our handy jargon buster should help you out.

(i) Health data terms

Incidence: When we talk about ‘cancer incidence’ we mean the number of people who are newly diagnosed with cancer within a given time-frame, usually one calendar year. The data can be ‘cut’ in a number of ways, for example by cancer type (breast, prostate, lung, head and neck, etc) or by gender, age, etc. The latest data we have is for 2012, and we know that over 300,000 people are newly diagnosed with cancer in the UK every year. Incidence can sometimes be given as a rate (per head of population).

Mortality: When we talk about ‘cancer mortality’ we mean the number of people who die from cancer within a given time-frame, usually one calendar year. The latest data we have is for 2012, and we know that over 150,000 people die from cancer in the UK every year. Mortality can sometimes be given as a rate (per head of population).

Prevalence: When we talk about ‘cancer prevalence’ we mean the number of people who are still alive and who have had, within a defined period, a cancer diagnosis. It equates to the number of people living with cancer. Any prevalence figure is for a snapshot (set point in time). The latest snapshot we have was made in 2015, and we estimate that there are 2.5 million people living with cancer in the UK. Some data are only available and presented for 20-year prevalence (i.e. anyone with a cancer diagnosis within a 20 year period). Prevalence can sometimes be given as a rate (per head of population).

Survival: When we talk about ‘cancer survival’ we mean the percentage of people who survive a certain type of cancer for a specified amount of time.

Cancer statistics often use one-year or five-year survival rates. Relative survival (the standardised measure used) is a means of accounting for background mortality and can be interpreted as the survival from cancer in the absence of other causes of death. Survival rates do not specify whether cancer survivors are still undergoing treatment after the time period in question or whether they are cancer-free (in remission).

(ii) Other terms

Co-morbidities: This means either the presence of one or more disorders (or diseases) in addition to a primary disease or disorder, or the effect of such additional disorders or diseases.

Curative treatment: When we talk about curative treatment for someone with cancer, we talk about treatments intended to cure the cancer; this usually mean the removal of a cancerous tumour. It works best on localised cancers that haven’t yet spread to other parts of the body, and is often followed by radiotherapy and/or chemotherapy to make sure all cancerous cells have been removed.

Palliative treatment: Palliative treatment is only used to ease pain, disability or other complications that usually come with advanced cancer. Palliative treatment may improve quality of life and medium-term survival, but it is not a cure or anti-cancer treatment. However palliative treatment can be given in addition to curative treatment in order to help people cope with the physical and emotional issues that accompany a diagnosis of cancer.

For further support, please contact
evidence@macmillan.org.uk

Full suite of the Rich Pictures

This document is one of the twenty in the full suite of Rich Pictures summarising the numbers, needs and experiences of people affected by cancer. See a full list below:

Overarching Rich Picture

The Rich Picture on people with cancer

(MAC15069)

The Rich Pictures on cancer types

The Rich Picture on people living with cervical cancer	(MAC13846_11_14)
The Rich Picture on people living with breast cancer	(MAC13838_11_14)
The Rich Picture on people living with prostate cancer	(MAC13839_11_14)
The Rich Picture on people living with lung cancer	(MAC13848_11_14)
The Rich Picture on people living with cancer of the uterus	(MAC13844_11_14)
The Rich Picture on people living with non-Hodgkin lymphoma	(MAC13843_11_14)
The Rich Picture on people living with rarer cancers	(MAC13847_11_14)
The Rich Picture on people living with malignant melanoma	(MAC13841_11_14)
The Rich Picture on people living with head & neck cancer	(MAC13845_11_14)
The Rich Picture on people living with colorectal cancer	(MAC13840_11_14)
The Rich Picture on people living with bladder cancer	(MAC13842_11_14)

The Rich Pictures on age groups

The Rich Picture on people of working age with cancer	(MAC13732_14)
The Rich Picture on children with cancer	()
The Rich Picture on older people with cancer	(MAC13668_11_14)
The Rich Picture on teenagers and young adults with cancer	(MAC14661_14)

Other Rich Pictures

The Rich Picture on people at end of life	(MAC13841_14)
The Rich Picture on carers of people with cancer	(MAC13731_10_14)
The Rich Picture on people with cancer from BME groups	(MAC14662_14)
The Emerging Picture on LGBT people with cancer	(MAC14663_14)

All these titles are available in hard-copy by calling our Macmillan Support Line free on **0808 808 00 00** (Monday to Friday, 9am–8pm), or by ordering online at www.be.macmillan.org.uk.

A wealth of other resources are also available, all produced by Macmillan Cancer Support and available free of charge.

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. How to talk to those close to you. What to do about work. How you'll cope with the extra costs.

At Macmillan, we know how a cancer diagnosis can affect everything. So when you need someone to turn to, we're here, because no one should face cancer alone. We can help you find answers to questions about your treatment and its effects. We can advise on work and benefits, and we're always here for emotional support when things get tough.

Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support to help you feel more in control of your life.

We are millions of supporters, professionals, volunteers, campaigners and people affected by cancer. Together we make sure there's always someone here for you, to give you the support, energy and inspiration you need to help you feel more like you. We are all Macmillan.

For support, information or if you just want to chat, call us free on 0808 808 00 00 (Monday to Friday, 9am–8pm) or visit [macmillan.org.uk](https://www.macmillan.org.uk)

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