

# THE RICH PICTURE

WE ARE  
MACMILLAN.  
CANCER SUPPORT

## TEENAGERS AND YOUNG ADULTS WITH CANCER

Amy, 22, living with Non-Hodgkin's lymphoma

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](mailto: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 does 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 57.

## Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experiences of teenagers and young adults 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. Teenagers and young adults affected by cancer may find our wide set of information booklets more helpful:



**I'm still me –  
A guide for young  
people living  
with cancer**  
MAC6706



**Let's talk about  
you – Support  
for young people  
caring for someone  
with cancer**  
MAC13009



**Relationships,  
sex and fertility  
for young people  
affected by cancer**  
MAC11679

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](http://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.



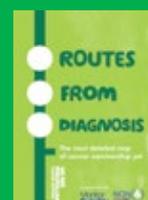
### Local Cancer Intelligence

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](mailto:evidence@macmillan.org.uk).

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# SUMMARY OF TEENAGERS AND YOUNG ADULTS WITH CANCER

## Key stats

**16,612 teenagers and young adults were living with cancer in the UK in 2010**, based on people living up to 20 years post a cancer diagnosis.<sup>(1)</sup>

**268 teenagers and young adults die from cancer in the UK each year.**<sup>(8, 9, 10, 11)</sup>

There is a slightly **higher incidence of cancer in males aged 15-24** compared to females.<sup>(7)</sup>

**16,612 teenagers and young adults in the UK are living up to 20 years after initial diagnosis with cancer**

## Diagnosis

**6 teenagers and young adults are diagnosed with cancer every day.**<sup>(7)</sup>

**42% of teenagers and young adults (16-25) have to see their GP more than twice before they are diagnosed with cancer**, proportionally more than any older age group.<sup>(28)</sup>

**50% of teenagers and young adults built up debt** to make ends meet as a result of their cancer diagnosis.<sup>(71)</sup>

Absences from school in teenagers and young adults with cancer occur most commonly in the year after diagnosis. These **prolonged absences can result in lower educational attainment which has been linked to lower likelihood of future employment.**<sup>(33)</sup>

**6 teenagers and young adults are diagnosed with cancer every day**

## Treatment

**Disability Living Allowance (DLA) is the main source of additional financial support for young people and their families** with one survey reporting that **88% of families with a child or young person (aged 16-24) with cancer had applied for DLA.**<sup>(71)</sup>

**Teenagers are often treated on adult or children's wards** and not with people their own age **so they do not have anyone they can relate to and share their experiences or concerns with.**<sup>(30)</sup>

**A cancer diagnosis as a teenager or young adult often disrupts educational or vocational goals** and can result in more of a reliance on family during a time when other teenagers and young adults are gaining more independence.<sup>(32)</sup>

**Teenagers are often treated on adult or children's wards and not with people their own age**

## Survivorship

**29%** of 16-18 year-olds who responded to a survey **had to leave education altogether as a result of cancer.**<sup>(75)</sup>

**Five out of six (83%) young people (aged 16-24)** that responded to a survey felt that their **quality of life had been affected by cancer.**<sup>(71)</sup>

**83%** of young people (aged 16-24) said that they **missed their friends at work/college/university** when they were unable to see them.<sup>(71)</sup>

**29% of 16-18 year-olds have to leave education altogether as a result of cancer**

## End of life

**Cancer is the most common cause of death from disease amongst teenagers and young adults,** accounting for 8% of all male deaths and 14% of all female deaths.<sup>(80)</sup>

**Brain, other central nervous system (CNS) and intracranial tumours** are the **most common cause of cancer deaths in teenagers and young adults,** accounting for around a fifth (20%) of the total cancer deaths in this age group.<sup>(80)</sup>

Of all cancer deaths in England amongst teenagers and young adults, **more than half (52%) occur in hospital,** and almost a third (32%) at home.<sup>(83)</sup>

**Cancer is the most common cause of death from disease amongst teenagers and young adults**

## Lifestyle & perceptions

**Lifestyle-related risk factors for cancer in adults are in general unlikely to apply in the same way to the teenage and young adult age-group,** as **periods of exposure will have been relatively short,** and due to the latency between exposure to risk factors and development of related cancer.<sup>(29)</sup>

The **leisure activities** of people with cancer aged 18-25 **often include watching television, and internet and mobile use.**<sup>(90)</sup>

When reporting on teenagers and young adults with cancer, **the media often uses terminology that is more factual** than emotive.<sup>(93)</sup>

# INTRODUCTION TO TEENAGERS AND YOUNG ADULTS WITH CANCER

## Who are teenagers and young adults with cancer?

We recognise that there is no standard definition of 'young adults', but that the definitions of the term can vary according to country, organisation and context. The literal definition of 'teenager' is 13-19.

Available data for 'young adults' (or 'young people' as they are often termed in relevant literature) are sometimes only available for specific age groupings, such as 15-18, 16-24, 16-25, 19-24 or others. Where such data is used we have indicated the age range used.

However, as many data are collected in the age groups of 0-14 and 15-24, **for the purposes of this Rich Picture we are defining 'teenagers and young adults' as 15-24 year-olds.** This also corresponds to the age range typically used for data collected by the National Cancer Intelligence Network (NCIN). Evidence around 0-14 year-olds can be found in another of our suite of Rich Picture documents, The Rich Picture on Children With Cancer (MAC14660\_14).

In some places in this Rich Picture the data is not available in the exact 15-24 age range so alternative similar age ranges are used. Where such data are used we have indicated the age range used.

## Want to know more?

Macmillan produces a wealth of information about what cancer is, its causes, symptoms and treatment. If you are 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](http://www.macmillan.org.uk)**

**'It was a few days prior to my 18th birthday that I was told that cancer may be a possibility. In the summer of 2009 I started experiencing extreme back pain. On two occasions the pain was so severe my Mum took me to A&E as she was so concerned. The first time I went to my doctor I was sent for routine blood tests and when the results came back normal they told me it was probably growing pains.**

**My physiotherapist was concerned that there was no improvement, so he referred me to a rheumatologist who put me on a waiting list to have an MRI. By this point it was 7 months since I had first started getting backache. Based on the MRI they told me I had a small collection of fluid in my back. I was admitted to hospital for the day in order to have the fluid drained. It was during the procedure that they realised it was a mass and they took several biopsies of it.**

**My results were sent to America before I was given my definite diagnosis, of non-Hodgkin's lymphoma.'**

**Amy, 22 living with non-hodgkins lymphoma**

# MACMILLAN'S AIMS AND OUTCOMES

## Macmillan's aims and outcomes – and how they are different for teenagers and young adults 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.<sup>(100)</sup>

**16,612 teenagers and young adults were living with cancer in the UK in 2010**, based on people living up to 20 years post a cancer diagnosis.<sup>(1)</sup>

## 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 TEENAGERS AND YOUNG ADULTS WITH CANCER

This section presents some of the key stats and facts relating to teenagers and young adults with cancer. You may benefit from referring to the jargon buster on page 66 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%**

Less than 1% of new cancer diagnoses are amongst teenagers and young adults<sup>(2)</sup>

**272**

teenagers and young adults die from cancer every year<sup>(1, 9, 10, 11)</sup>

**6**

teenagers and young adults are diagnosed with cancer every day<sup>(7)</sup>

**16,612**

teenagers and young adults were living with cancer in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.<sup>(1)</sup>

**95%**

of teenagers and young adults diagnosed with Hodgkin lymphoma, one of the most common cancers in this age group, live beyond 5 years after their diagnosis.<sup>(13)</sup>

## How many teenagers and young adults are diagnosed with cancer each year?

Cancer incidence UK, 2012, in young people and children <sup>(3, 4, 5, 6)</sup>



**Less than 1% of new cancer cases are diagnosed in teenagers and young adults, this compares to 60% of new diagnoses which are among those aged 65+. However there are more new cancer diagnoses amongst teenagers and young adults than amongst children.**

## What are the most common cancer types diagnosed amongst teenagers and young adults? <sup>(7)</sup>

### Lymphomas

account for over a fifth of cancers in teenagers and young adults. The majority of these are due to Hodgkin lymphoma, in contrast to lymphomas in childhood where the most common is non-Hodgkin lymphoma.

### Carcinomas

account for a fifth of cancers in teenagers and young adults. These can be of the thyroid, cervix, bowel or ovary.

### Germ cell tumours

account for 15% of cancers in teenagers and young adults, with around 90% of these occurring in males.

### Brain and central nervous system (CNS) tumours

account for 14% of cancers in teenagers and young adults.

There is a notable difference in the incidence of leukaemia among teenagers and young adults compared to that in children. Leukaemia accounts for almost a third of all cases of cancer in children, representing the most common cancer in children. However, in teenagers and young adults, leukaemia is only the sixth most common cancer accounting for less than 10% of cancers in this age group.

## How many teenagers and young adults die from cancer each year?

Cancer mortality, UK, 2011, in young people and children<sup>(8, 9, 10, 11)</sup>



**Less than 1% of deaths from cancer are among teenagers and young adults, this compares to 64% of cancer deaths from those aged 65+. However, more teenagers and young adults die from cancer each year than children.**

## How many teenagers and young adults are currently living with cancer? (prevalence)

**16,612**

Teenagers and young adults were living with cancer in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.

**Cancer in teenagers and young adults is relatively rare as the total incidence and mortality for teenagers and young adult's accounts for less than 1% of all cancer cases and deaths in the UK.**

## What are the key stats for England?

See data on incidence, mortality and prevalence for England



### How many teenagers and young adults get cancer per year in England? (incidence)<sup>(3)</sup>

**1,740**

new cases of cancer diagnosed in those aged 15-24 in England in 2012

### How many teenagers and young adults die from cancer per year in England? (mortality)<sup>(8)</sup>

**226**

cervical cancer deaths in England in 2012.

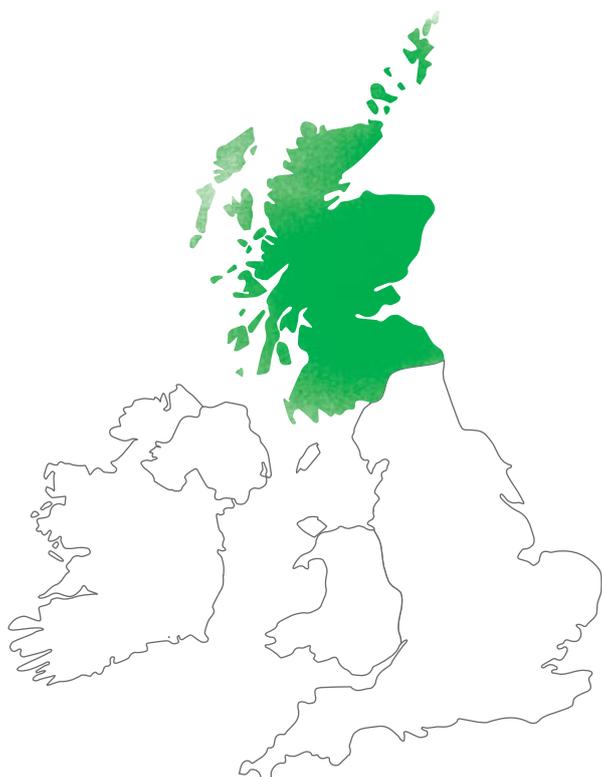
### How many teenagers and young adults are living with and beyond cancer in England? (prevalence)<sup>(1)</sup>

**13,886**

teenagers and young adults were living with cancer in England in 2010, based on people 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 teenagers and young adults get cancer per year in Scotland? (incidence)<sup>(4)</sup>

**161**

new cases of cancer diagnosed in those aged 15-24 in Scotland in 2012

### How many teenagers and young adults die from cancer per year in Scotland? (mortality)<sup>(9)</sup>

**18**

cancer deaths in those aged 15-24 in Scotland in 2012

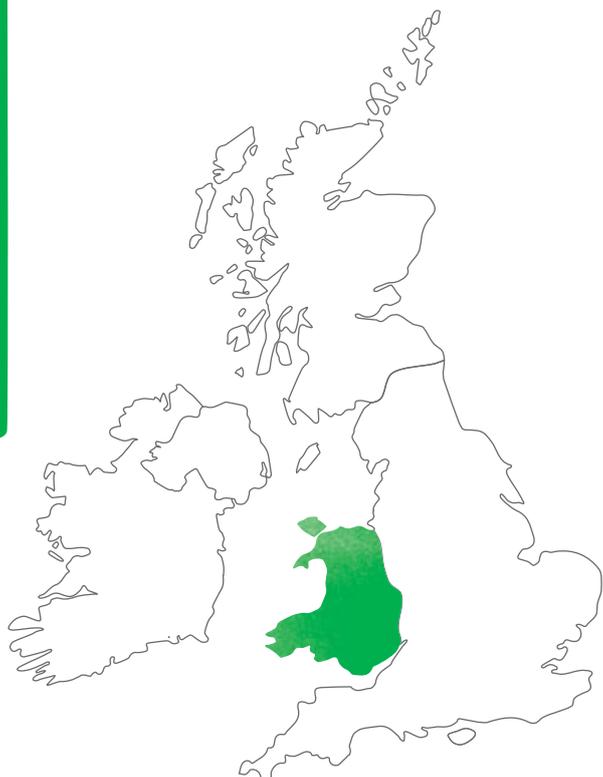
### How many teenagers and young adults are living with and beyond cancer in Scotland? (prevalence)

**1,399**

teenagers and young adults were living with cancer in Scotland in 2010, based on people 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 teenagers and young adults get cancer per year in Wales? (incidence)<sup>(5)</sup>

**126**

new cases of cancer diagnosed in those aged 15-24 in Wales in 2012

### How many teenagers and young adults die from cancer per year in Wales? (mortality)<sup>(10)</sup>

**18**

cancer deaths in those aged 15-24 in Scotland in 2012

### How many teenagers and young adults are living with and beyond cancer in Wales? (prevalence)

**825**

teenagers and young adults were living with cancer in Wales in 2010, based on people 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 teenagers and young adults get cancer per year in Northern Ireland? (incidence)<sup>(6)</sup>

**59**

new cases of cancer diagnosed in those aged 15-24 in Northern Ireland per year in 2007-2012

### How many teenagers and young adults die from cancer per year in Northern Ireland? (mortality)<sup>(11)</sup>

**10**

cancer deaths in those aged 15-24 in Northern Ireland in 2012

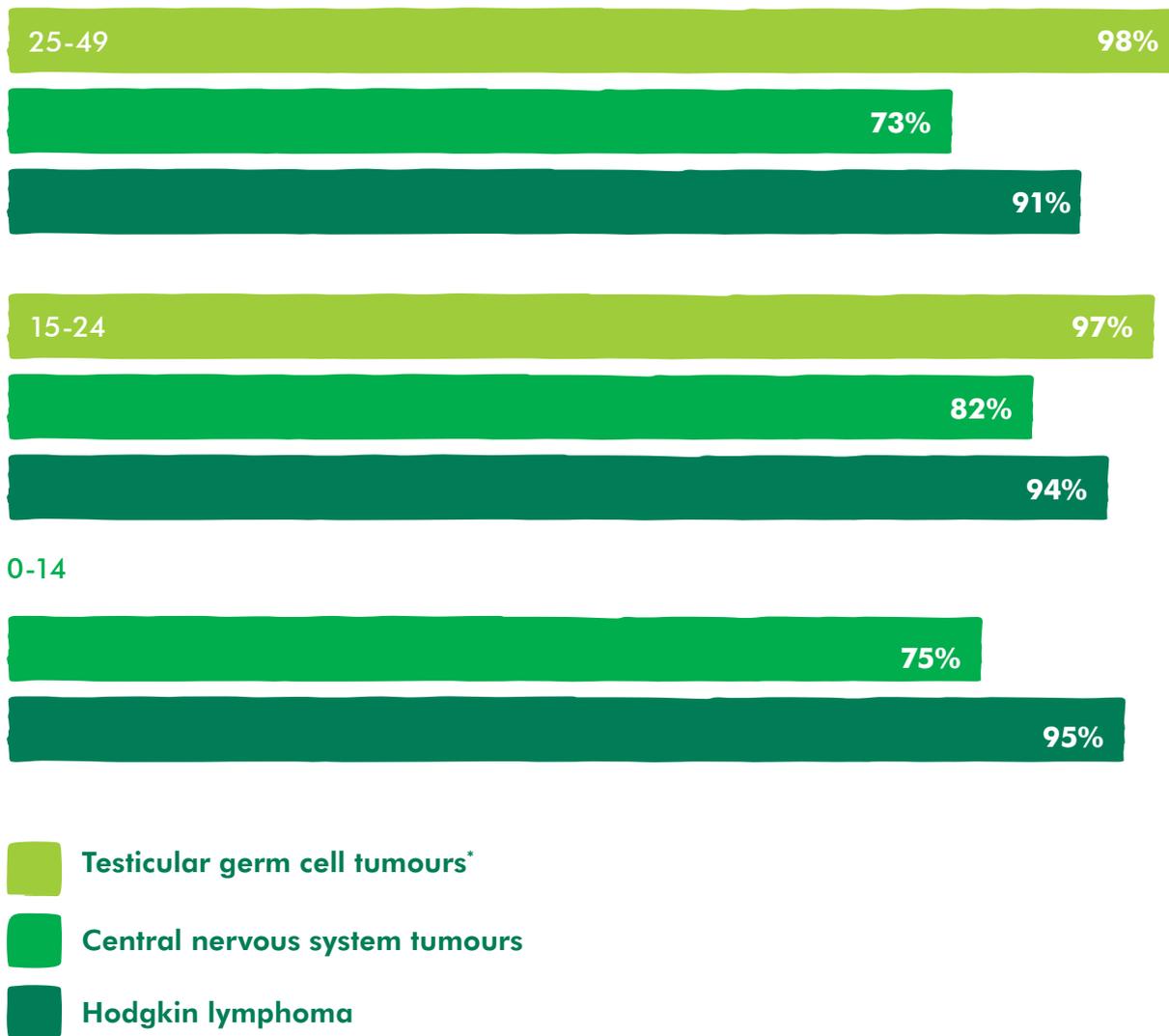
### How many teenagers and young adults are living with and beyond cancer in Northern Ireland? (prevalence)

**502**

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

## What proportion of teenagers and young adults survive cancer?

Relative 5-year survival for the top 3 cancers diagnosed in teenagers and young adults in 2001-2005, compared to other age groups, UK.<sup>(13)</sup>



\*There were no cases of testicular germ cell tumours in males aged 0-14 so no survival information for this age group is available to compare for this cancer.

**Amongst the most commonly diagnosed cancers in teenagers and young adults, their survival rates tend to be higher than those in the older 25-49 age group. In particular they have the highest survival rates for CNS tumours, comparing favourably to both children and those aged 25-49.**

**However, teenagers and young adults also have poor survival rates for some cancers. For example, in bone cancers the survival rates for teenagers and young adults are around 56%, compared to 65% in adults and 63% in children.<sup>(13)</sup> This reflects that a range of different survival rates exist within the teenage and young adult group, beyond those for the three most commonly diagnosed cancers**

**'I felt a lump in my neck in November but didn't go to the GP until I went home for the Christmas holidays. I hadn't taken the lump seriously; he did. He took blood samples and referred me to a consultant who organised a biopsy and CT scan.**

**The tests confirmed lymphoma and that I'd need six to eight cycles of chemotherapy over a six to eight month period which would put an end to my degree – at least for that uni year.**

**Thankfully, my specialist let me return in January to sit my exams. I got through. The university and my personal tutor, in particular, have been very supportive. It was agreed that I would have my treatment and return to pick up my studies the following year.'**

**Rob, 24**

## How do UK survival rates compare internationally?

In a European registry study, the five-year survival rate for teenagers and young adults with all cancers (excluding non-melanoma skin cancer) in 23 European countries in 1995-2002 was 87%. The five-year survival rate for teenagers and young adults in the UK, while not specified, was lower than this European average, although higher than for Northern Ireland. The survival rate in Europe was lower in males than females, and was generally highest in the Northern European countries studied and lowest in the Eastern European countries. Five-year survival ranged from 84% in Northern Ireland to 92% in Iceland, although neither rates were significantly different from the European average.<sup>(14)</sup>

## What are the major demographic variations in incidence, mortality, prevalence and survival for teenagers and young adults with cancer?

### Gender

There is a slightly higher incidence of cancer in males aged 15-24 compared to females. Germ cell tumours, which are the third most commonly diagnosed group of cancers in teenagers and young adults, specifically show a strong variation in gender incidence. Males account for approximately 90% of these cases in young people mainly as a result of testicular germ cell tumours.<sup>(7)</sup>

As with incidence, mortality from cancer in teenagers and young adults is slightly higher in males than it is in females.<sup>(80)</sup>

### Ethnic background

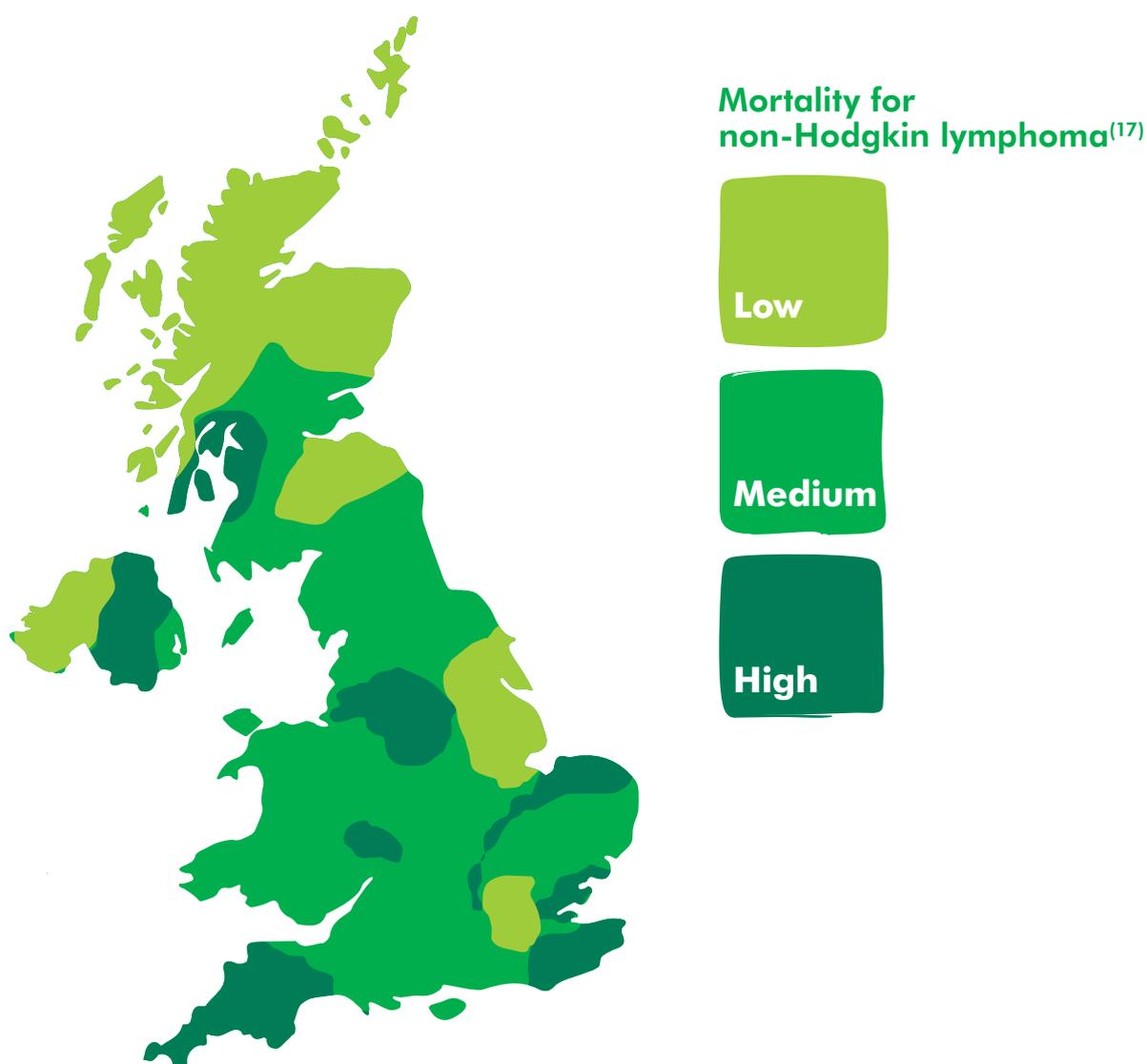
 There is little available data on cancer incidence in teenagers and young adults and ethnic group specifically.

For Hodgkin lymphoma, which is one of the cancers most commonly diagnosed in teenagers and young adults, there is some evidence that rates for males under 65 years are higher in the Asian ethnic group compared to those in the White ethnic group.<sup>(15)</sup>

### Social background

Although not specific to teenagers and young adults, survival is generally worse in more deprived groups for all cancers. However, for Hodgkin lymphoma, one of the most common cancers in teenagers and young adults, the one-year survival was higher in the more deprived groups in 2006.<sup>(16)</sup>





**Mortality for non-Hodgkin lymphoma shows more geographical variation than incidence does, but mortality does seem to be higher in the Midlands and Northern Ireland.**

## What are the major trends in mortality and survival?

Cancer mortality in teenagers and young adults has halved in Great Britain since the mid-1970s. Cancer mortality has fallen in males from 88 deaths per million in 1975-1977 to 44 deaths per million in 2008-2010, while in females it has fallen from 61 deaths per million in 1975-1977 to 31 deaths per million in 2008-2010.<sup>(80)</sup>

Survival is also improving for teenagers and young adults in the UK with cancer, as five-year survival in males has increased from 73% in 1986-1990 to 81% in 2001-2005, and in females it has increased from 77% in 1986-1990 to 84% in 2001-2005. Survival rates have increased for most diagnostic groups, with the exception of bone tumours and soft tissue sarcomas, where five-year survival rates have not changed significantly over this time period.<sup>(62)</sup>

**'When I was diagnosed with cancer, it seemed so unfair. I wanted to know why it had happened to me. Of course, there was nothing the doctors could say to this. I just had to accept it.'**

Young adult 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 teenagers and young adults 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**. There are some **common signs** and **symptoms** for most cancers, though each cancer type has different signs and symptoms. Common ones (for many cancer types) are:

- a lump
- a cough, breathlessness or hoarseness that doesn't go away
- changes in bowel habit
- abnormal bleeding
- changes in a mole
- unexplained weight loss
- headache
- tiredness

The signs and symptoms for most cancers tend to be the same, irrespective of the age of the person affected.

The most common cancer in young men aged 15-24 is testicular cancer, which accounts for more than a quarter of diagnosed cases. Other common types of cancer for young men include Hodgkin's lymphoma and leukaemia. The most common cancers in young women aged 15-24 are melanoma, Hodgkin's lymphoma and ovarian cancer.<sup>(18)</sup>

The most common symptoms of testicular cancer are:<sup>(19)</sup>

- a lump in the testicle
- pain or discomfort
- a heavy scrotum

The most common symptoms of melanoma are a mole that is:<sup>(20)</sup>

- getting bigger
- changing shape, particularly getting an irregular edge
- changing colour – getting darker, becoming patchy or multi-shaded
- itching or painful
- bleeding or becoming crusty
- looking inflamed

The most common symptoms of Hodgkin's lymphoma are:<sup>(21)</sup>

- painless swellings in the neck, armpit or groin
- heavy sweating – especially at night
- high temperatures that come and go with no obvious cause (often overnight)
- losing a lot of weight over a short period of time
- itching, which may be worse after drinking alcohol
- cough or breathlessness
- abdominal pain or vomiting after drinking alcohol

The most common symptoms of ovarian cancer include:<sup>(22)</sup>

- pain in the lower abdomen or side
- bloated, full feeling in the abdomen
- lower tummy (abdominal) pain
- back pain
- passing urine more often than usual
- constipation
- pain during sex
- a swollen abdomen
- feeling of fullness or loss of appetite
- irregular periods or vaginal bleeding after menopause

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

A survey of teenage cancer patients with cancer found that:<sup>(23)</sup>

- 59% presented at least two of the most common cancer symptoms: pain, lump/swelling, tiredness, headache or drastic weight loss.
- 50% said their main symptom was pain or a lump.
- 24% had to visit their GP four times or more before being referred to a specialist.
- 21% reported that their GP did not refer them to a specialist.
- 61% felt that their diagnosis could have been made quicker.

Cancer in teenagers and young adults is very rare and some GPs may never have a young person in their care diagnosed with the disease. When teenagers and young adults do seek medical advice they do not always explain themselves very well or they may feel intimidated by the GP.<sup>(24)</sup>

Another consequence of the rareness of cancer in teenagers and young adults is that when a GP sees a teen or young adult with certain signs or symptoms they may tend to think of the more common possible causes of these signs and symptoms first – for example when a girl with a swollen stomach presents to her GP, the GP may be more likely to start thinking ‘pregnancy?’ than ‘ovarian cancer?’. Some teenagers and young adults have said that their doctor was baffled by their symptoms, and dismissed them as ‘growing pains’, or put them down to things like ‘exam stress’.<sup>(25)</sup>

### **How well does screening work for teenagers and young adults with cancer?**

There are no screening programmes for cancer in younger people.<sup>(26)</sup>

## How is cancer diagnosed in teenagers and young adults? (Routes to diagnosis)<sup>(27)</sup>



Emergency presentation

**24%**

GP referrals

**26%**

Two week waits

**17%**

Other

**20%**

Unknown

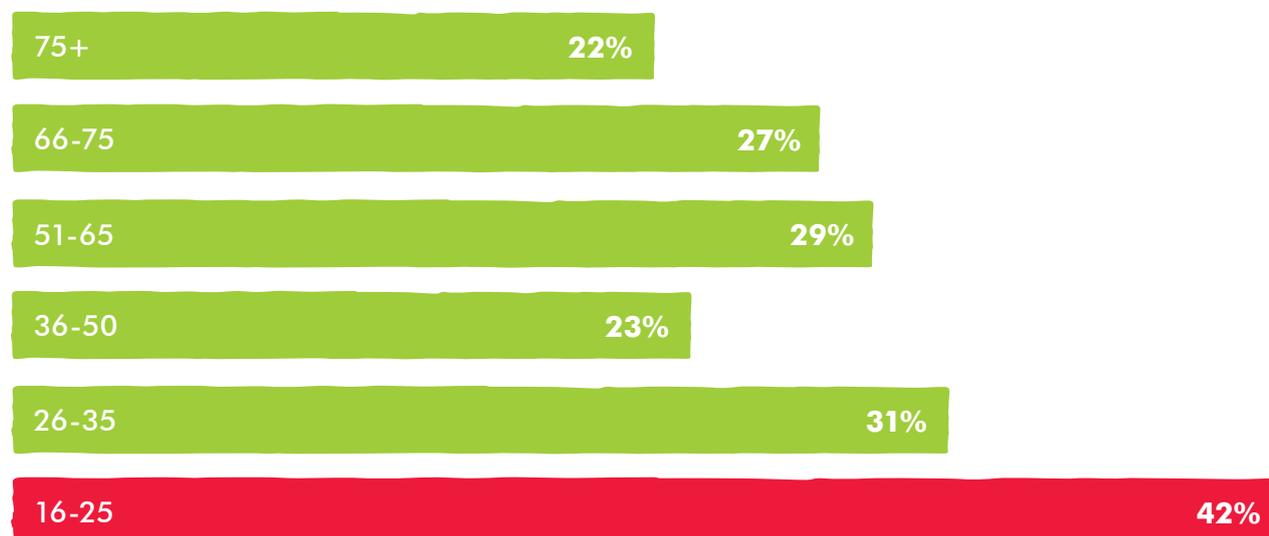
**13%**

'Other' is defined as 'An elective route starting with an outpatient appointment: either self-referral, consultant to consultant, other or unknown referral'. 'Unknown' is defined as 'No data available from Inpatient or Outpatient HES, CWT (Cancer Waiting Times) and Screening'.

**The most common route to diagnosis is via GP referrals (26%), which is slightly higher than the number of emergency presentations (24%). However, the number presenting via emergency presentation varies considerably by cancer type amongst teenagers and young adults, from 2% for malignant melanoma and thyroid carcinoma to 50% and over for brain and CNS tumours, leukaemias and bowel carcinoma.**

## How many teenage and young adult cancer patients had to see their GP more than twice before they were diagnosed?<sup>(28)</sup>

The available data record 'teenagers and young adults' as aged 16-25.



**Proportionally more teenagers and young adults (16-25) have to see their GP more than twice before they are diagnosed with cancer, compared to any older age group.**

## How does stage at diagnosis relate to probable survival rates?

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

## What are the cancer risk factors in teenagers and young adults?<sup>(29)</sup>

Lifestyle-related risk factors for cancer in adults are in general unlikely to apply in the same way to the teenage and young adult age-group, as periods of exposure will have been relatively short, and due to the latency between exposure to risk factors and development of related cancer.

However current evidence suggests that there a number of factors that increase the risk of cancer in teenagers and young adults.

### Previous cancer diagnosis

Treatment for cancer in childhood increases risk of being diagnosed with a second primary cancer in teenagers and young adults. There is a ten-fold risk increase for those aged between 5 and 19 who have been diagnosed with cancer at least five years previously. However the risk ratio falls with age.

### Infections

Infection with the Epstein-Barr virus (EBV) is estimated to be associated with 45% of cases of Hodgkin lymphoma in the UK. Hodgkin lymphoma is one of the most common cancers in teenagers and young adults.

### Genes and family history

Li Fraumeni syndrome (LFS) – associated with germ-line mutations on the TP53 gene – is a rare genetic condition that carries a high risk of multiple primary tumours in childhood and young adulthood.

Lynch syndrome (or hereditary nonpolyposis colorectal cancer, caused by mutations in one of the four MMR genes) is responsible for 2–4% of all bowel cancers, and is associated with bowel cancer in teenagers and young adults.

### Puberty and adolescent growth

Osteosarcomas occur much more frequently in the long bones of the arms and legs in teenagers and young adults, and it has been suggested that this is evidence of a link with the adolescent growth spurt, as these are the bones which have the greatest increase in length during that period.

### UV radiation

Exposure to ultraviolet radiation (UVR) is an established factor in development of melanoma in teenagers and young adults. White and black children have a similar incidence of melanoma in the first year of life, but by the age of 20-24, incidence is 40 times higher in whites.

Sunbed use, which increases risk of melanoma at all ages, has a particularly marked effect on risk of melanoma diagnosed before the age of 30. Use is higher among female than male adolescents, and is a likely factor in the higher incidence of melanoma in young women than young men.

### Smoking

Smoking doubles risk of developing cervical pre-cancerous lesions in young women, after controlling for HPV infection.

**'I had been suffering with back pain but put it down to pulling a muscle at work. When it persisted I went to an osteopath, who found a lump above my collar bone and told me to have it looked at by my GP, just to be on the safe side. The following week I went to my Doctor and he sent me straight up to the hospital for blood tests and x-ray. I felt fine with my general health it was only when the pain started to go down my arm I worried.**

**I got called to my Doctor's a couple of days later. He told me I had a lump the size of a grapefruit in my chest. Within two weeks of going to my Doctor I was diagnosed with Stage 2 Hodgkin's lymphoma.'**

Young adult living with cancer



## PHYSICAL AND MEDICAL NEEDS

Young people with symptoms of cancer and their families often report that they are **felt ignored by professionals when they raise their concerns** and this can have grave impacts on the relationship of trust between patients and professionals and better outcomes for young people.<sup>(30)</sup>

A 2011 survey found that **1 in 4 teenagers with cancer visited their GP four times or more** before they were diagnosed.<sup>(23)</sup>



## FINANCIAL AND EDUCATIONAL NEEDS

**Teenagers and young adults are more likely to be given information of any benefits they may be entitled to than any other age groups.** For example, 83% of teenagers and young adults (16-25) with cancer received information from hospital staff about financial help and benefits compared to only 48% of those aged over 75 and 55% of those aged 51-65.<sup>(31)</sup>

Teenagers and young adults spend on average £277 on extra expenses every month as a result of a cancer diagnosis and its treatment. This amounts to an additional annual spend of £3,325. The top three expenses are **travel and car parking, clothing, and extra food costs.**<sup>(71)</sup>

50% of teenagers and young adults **build up debt** to make ends meet as a result of their cancer diagnosis.<sup>(71)</sup>

**A cancer diagnosis as a teenager or young adult often disrupts educational or vocational goals** and can result in more of a reliance on family during a time when other teenagers and young adults are gaining more independence.<sup>(32)</sup>

Absences from school in teenagers and young adults with cancer occur most commonly in the year after diagnosis. These **prolonged absences can result in lower educational attainment which has been linked to lower likelihood of future employment.**<sup>(33)</sup>



## PRACTICAL AND INFORMATION NEEDS

**Teenage and young adult cancer patients (16-25) are less likely to understand the explanation of what is wrong with them.**

For example, a recent survey showed that only 48% of those aged 16-25 completely understood the explanation of what was wrong with them compared to 75% of those aged 65+.<sup>(31)</sup>

Teenagers and young adults may have less experience of being in hospital than older people, so are therefore in some ways **less likely to understand medical terminology and routines** and may consequently understand less of what is said to them than older patients.<sup>(31)</sup>

**Many young people are not aware of the common signs of cancer** so they do not recognise it in themselves. This can often lead to delays in young people visiting the doctor. More information on cancer symptoms for young people could help to reduce some of the delays in young people seeking help for unexplained symptoms.<sup>(34)</sup>

**Teenage and young adult patients often fall between paediatric and adult oncology practise**, which can often lead to being overlooked, with **support and information not being specifically targeted at them.**<sup>(35)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

**Teenage and young adult patients can find it emotionally hard to deal with their cancer diagnosis**, particularly as they view their whole life still ahead of them<sup>(36)</sup>. This is **in contrast to some older people who may view their future differently** and be better able to emotionally cope with illness.<sup>(37)</sup>

**Missing out on school** due to a cancer diagnosis has been found to have **adverse effects on well-being leading to social isolation and difficulties with peer interactions.**<sup>(33)</sup>

**At the point of diagnosis the primary concern for many teenagers was the possibility of absences from school.** Other concerns include not recovering, and having painful procedures or treatments.<sup>(33)</sup>

# NEEDS AND EXPERIENCES TREATMENT

**Teenage and young adult patients are generally more able to tolerate intensive therapies than older adults, as they are less likely to have other medical problems and their organs are usually healthy. Surgery may also be more feasible in teenagers and young adults than in older adults for the same reason.<sup>(38)</sup>**

**The mainstay treatments for most cancers in teenagers and young adults are various combinations of surgery, chemotherapy and radiotherapy.<sup>(39)</sup>**

## **What treatments do teenage and young adult cancer patients get?**

### **Surgery**

The surgery a teenager or young adult has will depend on the type of cancer they have and other factors like where it is and its size.<sup>(40)</sup> If they have 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. 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, and 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.<sup>(41)</sup>

### **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 medicine, but it is 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.<sup>(42)</sup>

The type of chemotherapy treatment given depends on different things, but mainly on the type of cancer, the risk of it coming back and whether the cancer has spread. It is often used with other treatments, such as surgery, radiotherapy, hormonal therapies and biological therapies.<sup>(43)</sup>

### **Radiotherapy**

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.<sup>(44)</sup> Radiotherapy can be used over a few weeks, to cure a cancer, often in addition to other treatments, such as surgery and chemotherapy, or it can be used to relieve symptoms such as pain, by helping to shrink the cancer, typically only needing one or two treatments.<sup>(45)</sup>

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. For example, it can be given as a drink called radioactive iodine, which is used to treat some thyroid cancers.<sup>(45)</sup>

### **Bone marrow transplants**

Bone marrow transplant is a way of giving very high dose chemotherapy, sometimes with whole body radiotherapy. Because you can have higher doses of chemotherapy with this treatment, there may be a better chance of curing the cancer than with standard treatment. High doses of chemotherapy drugs kill off bone marrow, meaning blood cells cannot be made. So doctors can take bone marrow from a donor or from the patient before chemotherapy. After the high dose chemotherapy healthy bone marrow is injected into the bloodstream through a drip.<sup>(46)</sup>

### **Donor stem cell transplant**

Stem cell transplants are used more commonly than bone marrow transplant these days. It involves very high doses of chemotherapy, sometimes with whole body radiotherapy. This has a good chance of killing the cancer cells but also kills the stem cells in the bone marrow. Stem cells are very early blood cells in the bone marrow that develop into red blood cells, white blood cells and platelets. So after the high dose treatment stem cells are injected into a vein through a drip to replace those that the cancer treatment has killed.<sup>(47)</sup>

### **Cancer Care through teams**

The National Institute for Health and Clinical Excellence (NICE) has recommended that all cancer patients aged 15-24 should be offered care in a young people's cancer facility and be referred to a specialist Teenagers' and Young Adults' Multidisciplinary Team (TYA MDT). The composition of the MDT at any one point in a patient's journey will vary and should reflect the patient's needs at that time, both disease- and age-related, as well as the expertise and skills of particular team members. The MDT includes professionals such as surgeons, oncologists, doctors who specialise in symptom control, radiologists, specialist cancer nurses, physiotherapists, occupational therapists, psychologists, social workers and dieticians.<sup>(51)</sup>

For cancers diagnosed in England in 2009 only 45% of teenagers and young adults were referred to a TYA MDT.<sup>(48)</sup>

## How many teenagers and young adults with cancer are given the name of a CNS?

A 2013 Department of Health Survey found that 90% of 16-25 year-olds with cancer were given the name of a CNS, down slightly from 92% in 2012, but higher than the average of 88% for patients of all ages.<sup>(49)</sup>

Modelling work by Frontier Economics has indicated that a total of 124 CNSs are needed for 16-24 year-olds with cancer, to fully meet the demand in England.<sup>(50)</sup>

## How many cancer admissions are there amongst teenagers and young adults, and how many teenagers and young adults stay in hospital (and for how long)? How many teenagers and young adults have access to appropriate treatment?

The National Institute for Health and Clinical Excellence (NICE) published Improving Outcomes Guidance in 2005, which recommended that all cancer patients aged 15-18 should be managed at a Principal Treatment Centre (PTC) for TYA cancers, and that those aged 19-24 should be given the choice of being managed at a PTC with unhindered access to age-appropriate facilities, or a hospital designated to provide care for young adults within its adult cancer services.<sup>(51)</sup> Implementation of the NICE recommendations has resulted in the establishment of 13 TYA PTCs in England for the management of care of all 16–24 year-olds.<sup>(52)</sup> A study using data on TYA patients diagnosed with cancer between 2009 and 2010 in England showed that 62% of 15–18 year-olds and 34% of 19-24 year-olds were notified by a PTC.<sup>(53)</sup>

More and more hospitals now have specially designed wards or units for teenagers with cancer. For example the Teenage Cancer Trust has created 28 units across the UK specifically for the care of teenagers with cancer.<sup>(54)</sup>

Each TYA PTC should have at least one clinician with expertise in the management of late effects of treatment for children and young people with cancer, and the risk of long-term health effects should be discussed with the patient and family at the time of diagnosis.<sup>(55)</sup>

The Scottish government, in its cancer plan for children and young people in Scotland 2012–15, has made a commitment to develop services appropriate to the needs of teenagers and young adults up to age 25, including working to open clinical trials across the age range, and development of a national TYA MDT.<sup>(56)</sup>

In Wales, a consultation document, published in 2012, sets out the plan for provision of cancer care for teenagers and young adults in Wales. The recommendations are based on NICE guidelines and include provision for the creation of two teenage and young adult cancer networks – North Wales and South Wales. Each network will comprise a TYA PTC with a single TYA MDT. The Cancer Services Co-ordinating Group has been tasked with taking this to completion.<sup>(57)</sup>

The needs of teenagers and young people with cancer are different from those of older adults with cancer. For example, during childhood and adolescence, physical changes occur that may affect the type of cancer present, how it needs to be treated, and how well the treatment works. Young people also undergo psychological changes that may influence their emotional response during and after treatment.<sup>(58)</sup>

## What other health conditions do teenagers and young adults with cancer have? How does this affect their treatment, survival, long-term effects or experiences?

36% of people between 16-44 who are living with cancer have at least one other chronic condition.<sup>(59)</sup>

Cancer treatment for teenagers and young adults is now often highly successful and a high proportion will live into middle and old age. The NHS will need to support a growing population of older people who have several long-term consequences after their cancer treatment as a young person, such as heart problems, second primary cancers, bone health problems, metabolic syndrome, and fertility or cognitive issues.<sup>(60)</sup>

Other health problems associated with treatment, that are experienced by people treated for cancer in childhood or young adulthood, can include impairment of endocrine function (including infertility and abnormal growth and development), cardiac and neurological impairment, cognitive decline and psychological effects, and increased risk of developing a second cancer.<sup>(39)</sup>

There is evidence that outcomes in teenage and young adult cancer patients, as measured by survival rates, are sometimes not as good as those for children.<sup>(61)</sup>

There is considerable variation in survival between diagnostic groups (and cancer sites where data are available) in teenagers and young adults, with five-year survival rates in males ranging from 55% for soft tissue sarcomas (STSs) to 98% for thyroid carcinoma, and in females from 56% for both acute myeloid leukaemia (AML) and bone tumours to almost 100% for thyroid carcinoma.<sup>(62)</sup>

Poorer survival for males than females has also been reported for certain types of cancer. Females aged 19-24 have statistically significantly better five-year survival than males for soft tissue sarcomas and melanoma.<sup>(61)</sup>

## 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 typically 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.<sup>(63)</sup>

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.<sup>(63)</sup>

There has been concern in the past with the number of teenagers and young adults that have been recruited into clinical trials. In 2005, the National Institute for Clinical Excellence (NICE) published the Improving Outcomes Guidance (IOG) for children and young people with cancer in England and Wales, and this was subsequently followed by the National Cancer Action Team Guidance for England in 2008. One of the findings from these reports was that the development of clinical trials that include teenagers and young adults should be encouraged.<sup>(51)</sup> As a result clinical trials have been incorporated into NICE's Quality Standards for Teenagers and Young People affected by cancer (2014),<sup>(95)</sup> identifying the need to give teenagers and young adults the opportunity to take part in clinical trials.



## PHYSICAL AND MEDICAL NEEDS

Teenage and young adult cancer patients are less likely than those in other age groups to agree that their GPs or Practice Nurses did everything they could to support them while they were having cancer treatment. 60% of 16-25 year olds agreed that they were fully supported compared to over 70% of those aged 75+.<sup>(31)</sup>

Some cancer treatments can result in **temporary or permanent infertility** in teenagers and young adults<sup>(96)</sup>. For more information see Specialist Theme on Teenagers and Young Adults With Cancer and Fertility, on p56.

It has been reported that **fewer teenagers and young adults are enrolled onto clinical trials** preventing the development of new treatments. **Less than a fifth of teenagers and young adults are treated as part of a clinical trial. This is compared to a reported 50%-70% of children.** This suggests the relative lack of participation of adolescent and young adult patients in clinical trials has lessened their chances for as good an outcome as patients in other age groups.<sup>(65)</sup>

**Some doctors are unsure how to proceed with treatment in the case of teenagers and young adults.** Where children are treated more aggressively than adults, teenagers fall in between these age groups so it is often unclear what the best treatment approach should be.<sup>(65)</sup>



## FINANCIAL AND EDUCATIONAL NEEDS

Many teenagers and young adults have to travel significant distances to receive treatment in specialist teenage and young adult centres. A 2010 survey found that 77% of children and young people with cancer do not live in a city with a principal treatment centre with the average round trip distance travelled by car 60 miles. The extra costs associated with this travel will have an adverse affect on finances particularly at a time when young people are unable to work or one or more of their parents need to give up work to care for them.<sup>(71)</sup>

**Disability Living Allowance (DLA) is the main source of additional financial support for young people and their families** with one survey reporting that **88% of families with a child or young person (aged 16-24) with cancer had applied for DLA.** Treatment for young people with cancer usually starts immediately after diagnosis but under proposed benefit reforms many will not receive any financial support until at least six months after diagnosis.<sup>(71)</sup>

A recent study found that **school absences due to a cancer diagnosis and its treatment are a concern for teenagers,** but do not necessarily lead to a reduction in educational and vocational attainment if health care, education professionals, parents and teenagers themselves are involved in school reintegration.<sup>(66)</sup>



## PRACTICAL AND INFORMATION NEEDS

**Three in four young people (aged 16-24) with cancer said that they would have liked improved information and access to financial support.<sup>(71)</sup>**

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## EMOTIONAL AND PSYCHOLOGICAL NEEDS

**Teenagers are often treated on adult or children's wards and not with people their own age so they do not have anyone they can relate to and share their experiences or concerns with.** Having age appropriate wards is an important part of maintaining some normality in life and making it easier to integrate back into life after treatment.<sup>(30)</sup> **Less than half of teenagers and young adults with cancer are getting access to age appropriate services.<sup>(68)</sup>**

Side effects of treatment can result in **infertility** which can have **devastating long term effects on the emotional wellbeing of teenagers and young adults.<sup>(67)</sup>**

Many teenage and young adult cancer patients have mixed feelings towards the end of their treatment. Many experience **relief that treatment is over but also anxiety about whether it has worked as there are no guarantees that the cancer will not return.<sup>(69)</sup>**

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# NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

## Why are teenage and young adult cancer survivors not catered for properly in the current system?

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.

- 35% of 25-34 year-olds diagnosed with cancer feel abandoned by the health system when they are not in hospital, compared to only 16% of over-65s.<sup>(70)</sup>
- 90% of young people (16-24) said their cancer had made them feel isolated at times.<sup>(71)</sup>
- 83% of young people (16-24) felt that their quality of life had been affected by cancer.<sup>(71)</sup>
- 83% of young people (16-24) said that they missed their friends at work/college/university when they were unable to see them.<sup>(71)</sup>

## Cancer survivors have greater health needs than the general population

90% of cancer survivors (of all ages, not just teenagers and young adults) have visited their GP and 45% have visited a specialist doctor in the last 12 months. This compares with 68% and 15% of the wider population.<sup>(72)</sup>

For young people diagnosed with cancer, the period of sustaining their recovery can last for many decades, during which time their needs and preferences will change. Unmet needs can affect a person's ability to lead a full and active life, with implications for work and education. The nature of the support provided to people diagnosed with cancer when a young person can have significant implications for the quality of survivorship, as well as for NHS costs.<sup>(72)</sup>

A 20% reduction in outpatient appointments amongst the 40,000 childhood cancer survivors could save 8,000 appointments per year.<sup>(72)</sup>

The document was followed by: **‘Innovation to implementation: Stratified pathways of care for people living with or beyond cancer: A “how to’ guide”**.

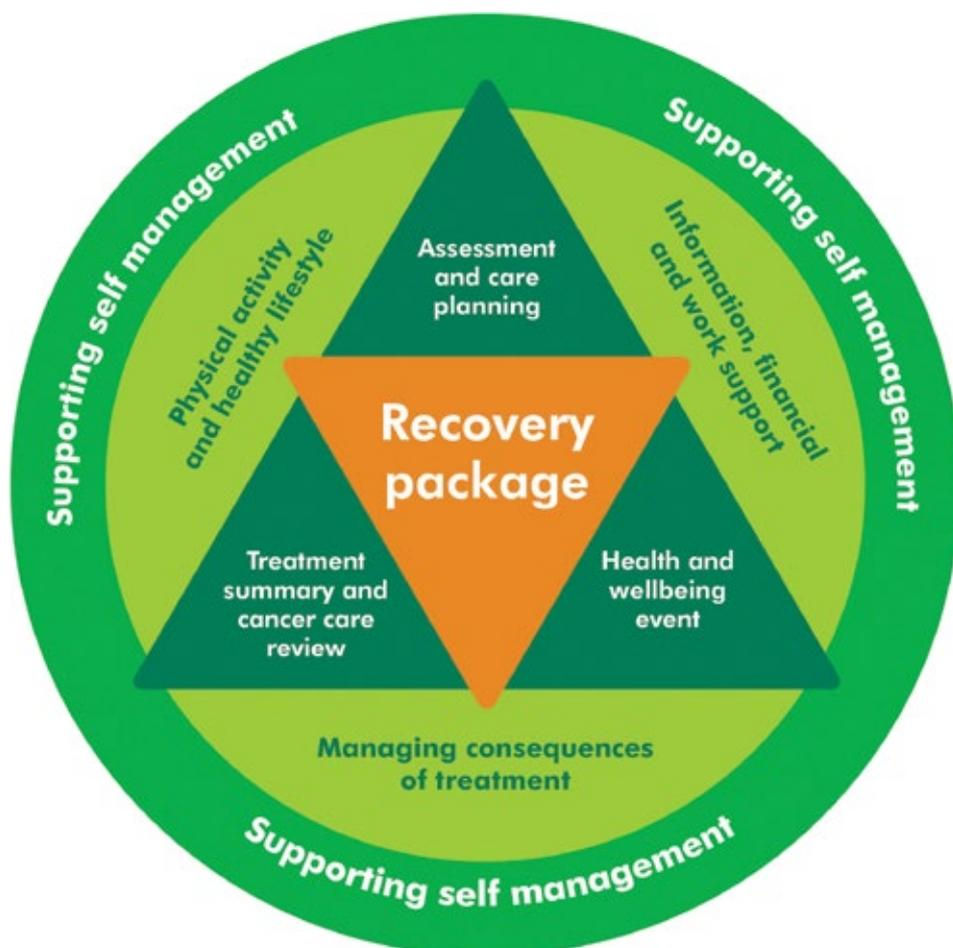
The documents set out what has been learned about survivorship, including interventions that have been tested and are ready to be spread across England, and could make an immediate difference to people affected by cancer. These include: A key intervention which is the ‘Recovery Package’ consisting of:

- Structured Holistic Needs Assessment and care planning,
- Treatment Summary to provide good communication to primary care including information about treatment, and the potential short- and long-term consequences.

- Education and support events, such as Health and Wellbeing Clinics, which give patients information about lifestyle choices, signs and symptoms of recurrence, getting back to work, benefits and financial support.
- The Cancer Care Review carried out by the GP six months following a diagnosis of cancer

Further key interventions include:

- Offering appropriate information including information about work support needs onwards referral to specialist vocational rehabilitation services and financial support
- Offering advice on physical activity, weight management and how to access appropriate programmes.





## PHYSICAL AND MEDICAL NEEDS

**One study of young adults (aged 17-34) cancer survivors found that 69% of participants had experienced at least one late effect with approximately a third that were moderate or severe.**<sup>(73)</sup> Late effects specifically for acute lymphoblastic leukaemia for example can include heart problems, lung problems and second cancers, many of which can appear months or even years after the end of treatment.<sup>(74)</sup>



## FINANCIAL AND EDUCATIONAL NEEDS

Cancer and its treatment can be very disabling. Sometimes alterations, like installing rails for support, are needed to make a home suitable for a teenager or young adult who has limited mobility. A 2011 study found that **the average cost of home alterations for a young person (aged 16-24) is £200.**<sup>(71)</sup>

**Learning can still be affected in teenagers and young people even after they have gone into remission.** They can experience symptoms such as chronic fatigue, attention and concentration difficulties and even psychological and emotional problems which make it difficult to continue with education.<sup>(71)</sup> 61% of 16-24 in one survey felt that cancer had presented barriers in their education.<sup>(94)</sup>

**29% of 16-18 year-olds who responded to a survey had to leave education altogether as a result of cancer.**<sup>(79)</sup>

The majority of young adult (aged 19-24) cancer survivors in one study reported that they felt that having cancer had significantly affected their education. **Five out of six young people said that they had not given up education,** showing the determination of many young people to continue to gain their qualifications. However, about **40% of young people felt that cancer had limited their future work prospects.**<sup>(99)</sup>



## PRACTICAL AND INFORMATION NEEDS

**Young adult (aged 20-39) cancer survivors have been found to be in need of further information about late effects after treatment.** Many are not currently told how to manage these effects if they occur, with one study highlighting the importance of continuing to reach survivors whose information needs will continue long after treatment has finished.<sup>(76)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

**Five out of six (83%) young people (aged 16-24) that responded to a survey felt that their quality of life had been affected by cancer.**<sup>(71)</sup>

**Many teenage and young adult cancer patients feel anxious or embarrassed about returning to school/college** during or shortly after treatment because their **confidence is low** and they are concerned about how their friends would react to their change in physical appearance and gaps in their work.<sup>(77)</sup>

**Many teenagers and young adults feel anxious and frightened going back to hospital for checkups because they fear the tests may reveal a return of cancer.** It can also be hard seeing other children and young people going through their treatment and especially hard if they find out that someone they know from the hospital has been ill again.<sup>(78)</sup>

# NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

## How many teenage and young adult cancer patients are at End of Life?

 Specific data for teenagers and young adults are not readily available, but for people of all ages with cancer around 7% of patients are in the last year of life.<sup>(79)</sup> 272 teenagers and young adults died from invasive cancer in the UK in 2012.<sup>(8, 9, 10, 11)</sup>

Brain, other CNS and intracranial tumours are the most common cause of cancer deaths in teenagers and young adults, accounting for around a fifth (20%) of the total cancer deaths in this age group; around nine out of ten (89%) of these are due to invasive tumours, and only around a tenth (11%) are due to benign/uncertain tumours.<sup>(80)</sup>

Teenagers and young adults is the only broad age group in which cancer is not the most common cause of death overall, with transport accidents accounting for the highest proportion of deaths in both males and females (accounting for 9% and 15% of the total deaths, respectively, in the UK between 2008 and 2010). Cancer is the most common cause of death from disease, however, accounting for 8% of all male deaths (excluding benign/uncertain brain, other CNS and intracranial tumours), and 14% of all female deaths.<sup>(80)</sup>

## What is the impact of giving patients palliative care\*? Where do people with cancer die?

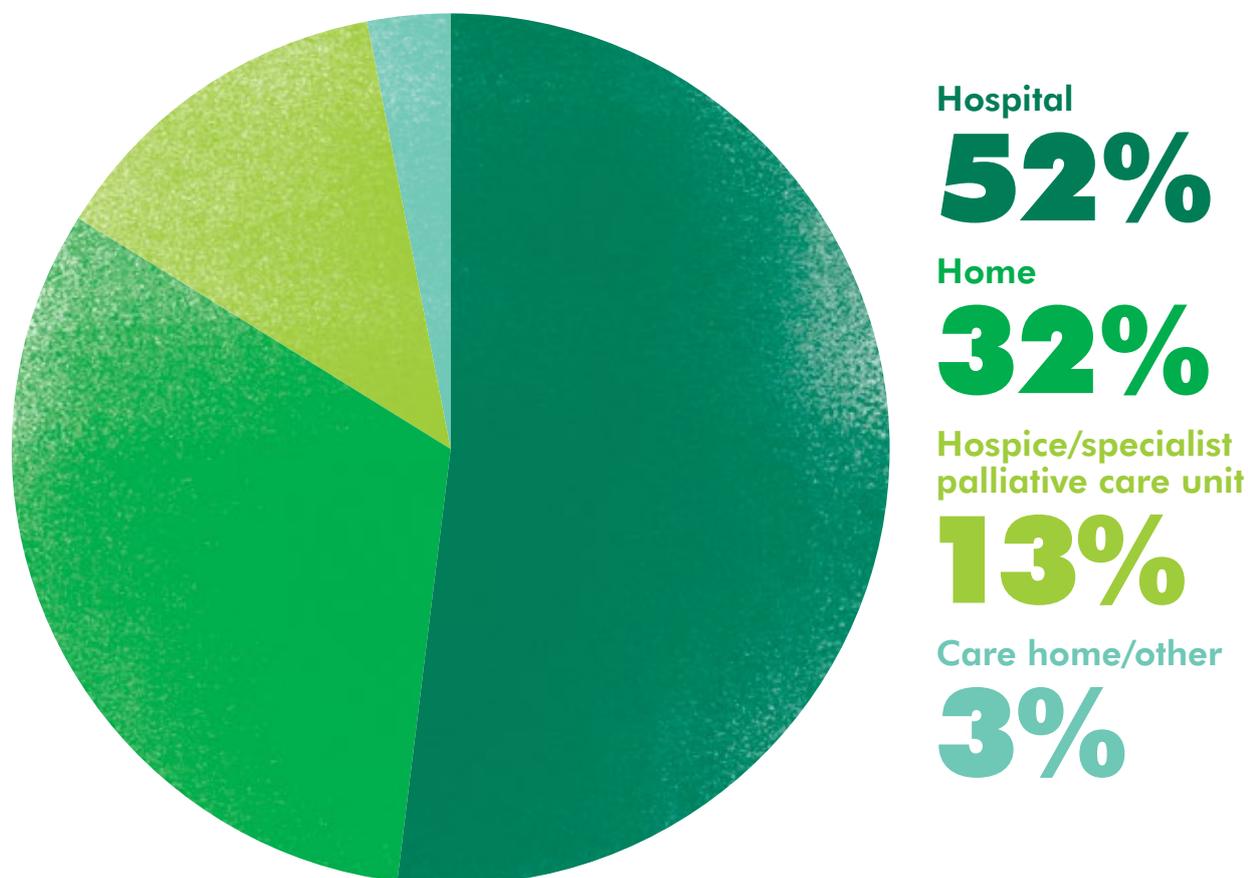
There are 40,000 children and young adults aged 0-19 in England who have long-term health conditions that, for most, will eventually end their lives and for which they may require palliative care. Of this total cancer represents around 14% of diagnoses, and of all long-term conditions, not just cancer, around 4,000 are amongst those aged 16-19.<sup>(81)</sup>

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.<sup>(82)</sup>

\*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](http://www.ncpc.org.uk)

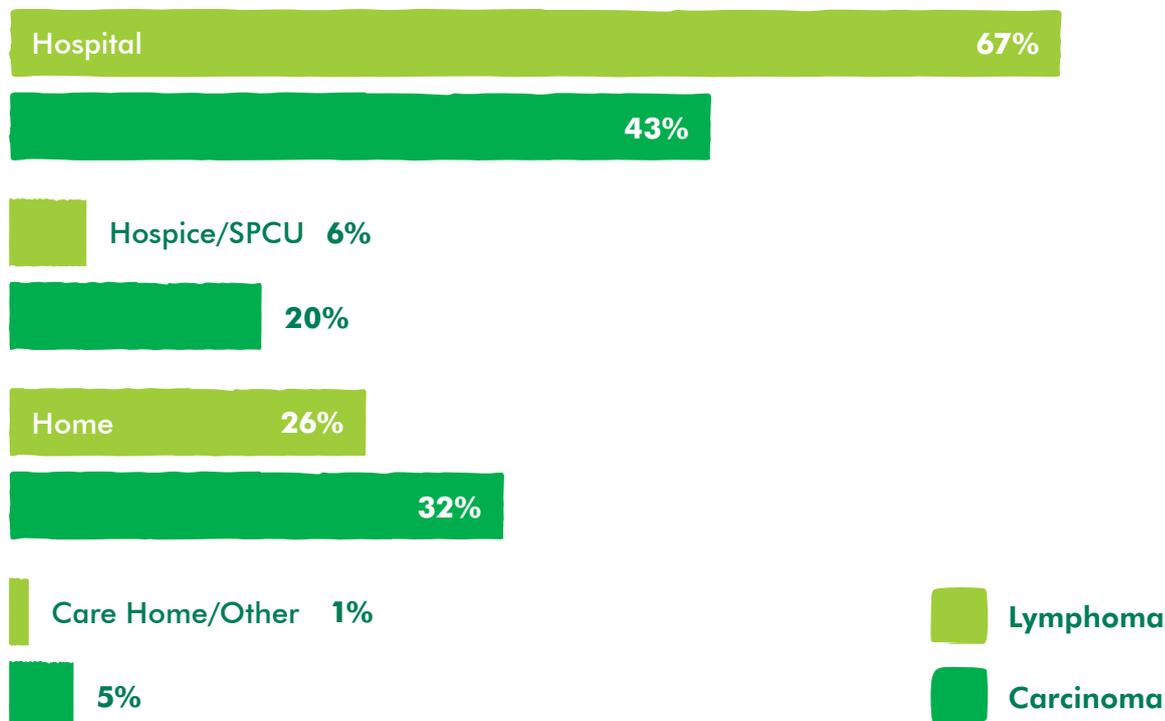
## Where do teenagers and young adults with cancer die?<sup>(83)</sup>



**Of all cancer deaths in England amongst teenagers and young adults, more than half (52%) occur in hospital, and almost a third (32%) at home.**

## Place of death by the most common cancer types<sup>(83)</sup>

Lymphoma and carcinoma cancers, the cancers most commonly diagnosed in teenagers and young adults, have significant variation in place of death.



\*'SPCU' = specialist palliative care unit

**Teenagers and young adults with lymphoma are more likely to die in hospital than those with carcinoma, as almost two thirds (67%) of young people with lymphoma will die in hospital compared to 43% of those with carcinoma.**

**Teenagers and young adults are only slightly more likely to die at home if they have carcinoma compared to lymphoma. However far more die from carcinoma than lymphoma in a hospice or specialist palliative care unit.**

**‘Hair loss was my biggest fear, at 19 it was my ‘look’ and femininity. I kept it for as long as I could, I’d had it cut short into a bob the day I was diagnosed but it came to a point after about 5 sessions of chemo when my boyfriend said it was time I shaved it off. He said I looked like Andy off little Britain! He shaved it for me and he was right, I felt better once it was gone.’**

Sam, aged 23 at diagnosis



## PHYSICAL AND MEDICAL NEEDS

Teenagers and young adults have specific palliative care needs that are not met in paediatric or adult hospice or palliative care services. It is therefore vital that there is a specific service where they can receive tailored care.<sup>(84)</sup> However, numbers are relatively small, as while one study found that 2,214 new diagnoses were made amongst people aged 15-24, in the UK in 2010, the same study found that 80% of those aged 13-24 will survive their illness for at least five years.<sup>(85)</sup> This means that the provision of dedicated resources for end of life care in every area might be difficult to achieve and may not be cost-effective.



## FINANCIAL AND EDUCATIONAL NEEDS

In 2010, Macmillan reported that **36% of terminally ill cancer patients** (of all ages) did not claim benefits they were entitled to. This amounts to £90 million. Reasons for low take up included people not knowing they were eligible, the perceived stigma and the confusing claiming process.<sup>(86)</sup>



## PRACTICAL AND INFORMATION NEEDS

**Some families tend to be dissatisfied with communication with health professionals at the end of life** and often feel that their wishes are disregarded.<sup>(87)</sup>

One study found that **many teenagers and young adults (aged 16-28) with life threatening conditions (including cancer) want to be involved in decisions about the kind of medical care they receive** and be able to choose what information is given to their family and friends as well as how they would like to be remembered. Young adult cancer patients should therefore be involved in these decisions as much as possible and be given information in order for them to make these choices.<sup>(88)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

There is an emphasis by some professionals that despite death being inevitable for teenagers in end of life care, **markers of achievement such as exams are also important as are any activities that foster socialisation and normality.**<sup>(89)</sup>

# LIFESTYLE AND PERCEPTIONS

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

## What is the profile of the average teenager or young adult living with cancer?

- There is a slightly higher incidence of cancer in males aged 15-24 compared to females.<sup>(7)</sup>
- The most common cancer types diagnosed amongst teenagers and young adults are lymphomas, carcinomas, germ cell tumours and brain and central nervous system (CNS) tumours.<sup>(7)</sup>
- 67% of teenagers and young adults live with their parents.<sup>(91)</sup>

## What is the demographic breakdown/market segmentation of the 16,612 teenagers and young adults 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 teenagers and young adults (aged 15-25) with cancer across different MOSAIC\*\* groups.

Amongst people with cancer, the following MOSAIC groups, that tend to be aged 18-25, show significantly greater than average representation:

### Group D, Type 16: 'Side Street Singles'

Side Street Singles are single people, both young and more mature, and childless couples living in the older cores of smaller towns and seaside resorts. They include young people on low incomes who want to move out of their parents' home, or singles who have a new job and need a temporary place to stay before finding something more permanent. Many of them live in low grade accommodation such as small flats above shops or small blocks of flats.

### **Group G, Type 31: 'Domestic Comfort'**

Domestic Comfort are large numbers of well paid workers, typically in middle management roles in successful companies, and living in modern style housing on the outskirts of large provincial cities. Domestic Comfort tend to follow the archetypal nuclear family model – married couple and two or three children of secondary school age, or perhaps in their early years at university. The parents are mostly university educated.

People in this type do not necessarily take an active interest in the arts but nevertheless typically recognise that they are important for their children's own personal development. At parent teacher evenings, these are the parents who are likely to probe teachers most carefully regarding the progress of their children and to be most thoughtful about long term strategies which will maximise the chances of their children being accepted by an old established university.

### **Group K, Type 47: 'Deprived View'**

Poor people who live in high rise blocks of socially owned housing. Most of them are young, single people without children. Many have disabilities or poor qualifications which make it difficult for them to hold down regular jobs. When they shop for groceries, Deprived View are among the least likely to travel by car to the local supermarket, typically being dependent on local neighbourhood stores which offer a poorer range of goods. These stores are often protected by iron grilles when closed and may take as much money from the sale of alcohol and tobacco as from food.

In addition to the above groups other populations that are more likely to include teenagers and young adults with cancer include:

- Group G, Type 30: 'Soccer Dads and Mums'
- Group N, Type 59: 'Low-Key Starters'
- Group J, Type 42: 'Worn-Out Workers'

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

### **Group D, Type 16: 'Side Street Singles'**

Side Street Singles do not spend much on food, as they only cook for one. Their media usage is fairly limited. They use the Internet fairly regularly, but mainly for relatively basic tasks. They buy online occasionally, and play online games quite often. Dating sites are not that popular, surprisingly.

### **Group G, Type 31: 'Domestic Comfort'**

These are families that tend to value highly their leisure time, and try to wring the most out of it. Domestic Comfort watch less TV than most, preferring to spend their time online or playing sports. They spend a couple of hours a day online, on average, which may include working from home and studying, as well as entertainment.

Sports are a major obsession for this type, whether simply going to the gym and running, or more organised activities such as golf and fishing. They also like watching sport, particularly football. The parents are as active as the children in this respect.

### **Group K, Type 47: 'Deprived View'**

Deprived View's lifestyles are defined by their budgets. Their main leisure activity is watching television, because it is cheap. They spend a lot on their mobile phones as they are their main link to the outside world. They like chat rooms and online dating sites particularly. They tend to have a few friends with whom they will socialise often, either at their houses or in a friendly space, such as a community centre or pub. At home, they always buy the cheapest possible food, and almost all their meals are home-made, to save money. They will occasionally fill up on cheap take-aways when out and about, however.

\*\*For more detail and definitions see [www.experian.co.uk/business-strategies/mosaic-uk-2009.html](http://www.experian.co.uk/business-strategies/mosaic-uk-2009.html)



## What does this mean? What do we want to change in terms of people's perceptions?

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. Those contributing to the online discussions are often, though not necessarily, themselves teenagers and young adults, but the subject of the discussions always is this group. The results are summarised here:

- The word 'treatment' is slightly more prominent than 'cancer' amongst the online community, seemingly reflecting the stage of the cancer journey at which many teenagers and young adults make use of the Macmillan online community. 'Chemo' appears just as prominently as 'cancer', again reflecting a key aspect of the cancer journey for many teenagers and young adults with cancer, as well as indicating the informal term used for this particular treatment type.
- 'Cancer' is by far the most prominent word amongst the media, and in general the terms used are more factual than the emotive terms of the online community, including 'diagnosed', 'hospital', 'scan', 'symptoms' and 'died'.
- The terminology within the online community tends to emphasise the positive and offer encouragement, reflected by the prominence of optimistic terms such as 'feel', 'hope', 'good' and 'well'. Words such as 'sure', 'see', 'started', and 'life' are also indicative of support offered by members of the community to one another. By contrast such support and positivity is absent within the media word-cloud, with 'died' the most prominent word after 'cancer'.

## What are teenagers and young adults affected by cancer saying about their lives both before and after a cancer diagnosis?

### Before:

'I wasn't a massive sunbather, but when I went abroad I would lie in the sun. When I went away with my parents I used to take care, but when I went with my friends, I was less careful, and was more likely to use oil than lotion! I remember one day I actually lay out in olive oil! Probably not so good (but the best tan i've had in my life!) If only I knew then what I know now!'

Phoebe, 24

'I think I was pretty ignorant about cancer before I was diagnosed with it. I remember seeing stuff on TV about it and thinking: "Oh God, that's depressing," and switching channels. After I was diagnosed, I felt a bit guilty for not having paid as much attention to issues relating to cancer previously. Nobody really talks about cancer. It's the "C" word that people are afraid to mention.'

Young adult living with cancer

## After:

'I have been diagnosed with a blood cancer; Essential Thrombocythemia. I was diagnosed within my first term of my first year at university, each alone come with several stresses. The particular cancer I have means that I must undergo treatment for the rest of my life through pills and injections which is incredibly hard fact to "get my head around".'

Kathryn, 21

'I wasn't feeling good and had taken a bit of time off. When I discovered I had cancer I didn't know if I'd get any money at all but my boss was great and paid me Statutory Sick Pay. After that finished I was referred to Macmillan who helped me claim benefits. I didn't know where to begin with the benefits system so having Macmillan's support was really helpful and took some of the stress off. I'm still going through chemotherapy and I'm waiting for surgery so I'm hoping I might get moved onto the higher rate of benefits but I don't know what will happen. Money is a real problem at the moment and I don't know if it's going to get any better until I can go back to work.'

Jahad, 26

# SPECIALIST THEME

## Teenagers and Young Adults With Cancer and Fertility

Cancer treatments can have a significant impact on teenagers and young people and their subsequent fertility. There is a lot of uncertainty with teenage subsequent fertility as it is difficult to predict fertility risk<sup>(97)</sup>.

### What are the issues surrounding fertility for young people?

Treatment for cancers, particularly chemotherapy and radiotherapy are recognised to possibly affect fertility. Although the impact of these treatments on fertility depends on a variety of factors it is an issue that has become increasingly important to teenagers.<sup>(96)</sup> It is not easy to predict or know the potential late effects of cancer treatment on fertility<sup>(97)</sup>. It has been found specifically with females that ovarian failure is more common among those diagnosed aged 13-20 compared to girls diagnosed aged under 12 years.<sup>(35)</sup>

### What are the needs?

Research suggests that between one-third and two-thirds of patients do not have a discussion with their oncologist regarding the impact of cancer treatment on their fertility. It has particularly been shown that women who do not have a discussion about fertility and have unmet information needs tend to have higher levels of anxiety.<sup>(67)</sup>

### What are the challenges in this area?

Part of the difficulty around fertility issues in female cancer patients is the fact that fertility options are much more limited as there is a risk with chemotherapy and radiotherapy of early menopause<sup>(97)</sup> Since current treatment options for female fertility involve undergoing ovarian stimulation and egg collection, not all patients will be able to undertake this.<sup>(98)</sup>

Although for male cancer patients, sperm banking has been around for many years there are still ethical, legal and practical issues surrounding this. Male, like female cancer patients, also have a limited window before treatment to undertake fertility preservation.<sup>(97)</sup>

For teenagers and young people, consequences of cancer treatments on fertility are a significant consideration. It is important for patient to have discussions at the beginning of treatment to discuss fertility and their possible options.<sup>(95,96,97)</sup>

# REFERENCES, SOURCES, NOTES AND CAVEATS

## Quotes

The quotes on pages 5, 18, 23, 31, 47, 54 and 55 are real quotes from people with head and neck 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 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](mailto: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

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

### The Rich Pictures on age groups

<b>The Rich Picture on people of working age with cancer</b>	(MAC13732_14)
<b>The Rich Picture on children with cancer</b>	(MAC14660_14)
<b>The Rich Picture on older people with cancer</b>	(MAC13668_11_14)
<b>The Rich Picture on teenagers and young adults with cancer</b>	(MAC14661_14)

### Other Rich Pictures

<b>The Rich Picture on people at end of life</b>	(MAC13841_14)
<b>The Rich Picture on carers of people with cancer</b>	(MAC13731_10_14)
<b>The Rich Picture on people with cancer from BME groups</b>	(MAC14662_14)
<b>The Emerging Picture on LGBT people with cancer</b>	(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](http://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)**

Code: MAC14661\_14

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