

Vivek, 35, diagnosed with brain tumour

THE RICH PICTURE

PEOPLE OF
WORKING AGE
WITH CANCER

WE ARE
MACMILLAN.
CANCER SUPPORT

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

2017 update

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 the 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 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 July 2017, 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 68.

Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our information booklets more helpful:



Work and cancer
MAC11675



Your rights at work when you are affected by cancer
MAC12981



Managing cancer in the workplace
MAC12891



Questions for carers to ask about work and cancer
MAC13509

Visit our work and cancer page for further information at www.macmillan.org.uk/work.

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.

Find out more about cancer: what Macmillan can offer

Macmillan's own evidence has revealed the story of cancer is changing. We produce a variety of evidence that helps us, and others, understand the needs, numbers and experiences of people affected by cancer.

Our research publications

Our reports and posters

Published Macmillan research and evaluation reports, as well as summaries of commissioned research and research posters, produced either by Macmillan or our partners.

Rich Pictures

Our suite of Rich Pictures describe the needs, numbers and experiences of key groups within the 2.5 million people living with cancer.

Impact Briefs

Our suite of Impact Briefs describe what some of our services do and the impact they have on people affected by cancer.

Our cancer intelligence

Local Cancer Intelligence tool (LCI)

Combining local cancer population data with insight from Macmillan and other sources, LCI is an online tool designed to help you use data as evidence to plan services and influence decisions.

Routes from Diagnosis

Results from first phase of the Routes from Diagnosis study, including outcome pathways, survival rates, inpatient costs and comorbidities associated with some cancers.

Cancer Patient Experience Survey

Macmillan's partnership work to gain insight on how patients feel about their care, what's working and what could be done better.

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SUMMARY OF PEOPLE OF WORKING AGE WITH CANCER

Key stats

In 2015, there were an estimated **890,000 people of working age living with cancer** in the UK. This is set to increase to 1,150,000 by 2030.⁽¹⁾

85% of people with cancer who were employed when diagnosed say it was important for them to **continue work after diagnosis**.⁽²³⁾

Cancer survivors (who were in work at the point of their cancer diagnosis) are **1.4 times more likely to be unemployed** than the general population.⁽⁹⁴⁾

An estimated 1 in 3 people living with cancer are of working age.⁽¹⁾

Diagnosis

There is variation in the number of cancer patients of working age who said they **saw their GP or doctor within three months of thinking something might be wrong**. The lowest rate is recorded in those aged 25–34.⁽²⁶⁾

A study focusing on the barriers to presenting cancer symptoms to a physician showed that individuals aged between 15–54 were more likely to report that they were **too busy and had difficulty making an appointment** than older people.⁽³⁶⁾

Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, **around half of all people with cancer experience levels of anxiety and depression severe enough to adversely affect their quality of life**.⁽⁴⁰⁾

Treatment

People aged 16–64 are more likely to have access to a Clinical Nurse Specialist (CNS) than those aged over 65, with 90% of those of working age confirming that they had received the name of a CNS, compared to 83% amongst those aged 65 and over.⁽²⁶⁾

Cancer related fatigue is one of the most common symptoms of cancer treatment. **Fatigue can affect a cancer patients productivity levels** and ability to do tasks at work, as well as causing many people to **give up work or change jobs**. With proper support from employers people can manage fatigue and do not need to leave work unnecessarily.^(50,53)

A study looking at the needs of working age women with breast cancer showed that **women in the UK had more prevalent practical needs** compared with their counterparts in France and Germany.⁽⁵⁶⁾

Life after treatment

Of survey participants of working age who returned to work before they felt they were ready, **58% said they would have liked to return to work once they were emotionally able to do so.**⁽²³⁾

On average, **27%** of people aged 35–64 said that they **did not receive information on getting financial help** or benefits they may be entitled to.⁽²⁶⁾

In a 2016 Macmillan survey, around **55%** of people stated that they **did not know where to go for more information and support** regarding making decisions on staying in work or returning to work after cancer.⁽²³⁾

End of life

With the right support, **64% of people with cancer** (of all ages) **would prefer to die at home but only 30% actually do.** 27% of people aged 15–64 die in a hospice.^(8,69)

At end of life, **patients and their families may have concerns about managing finances**, particularly as a patient may have a reduced income and other additional costs.⁽⁷³⁾

Being diagnosed with cancer that cannot be cured can trigger a wide and complicated range of emotions. People receiving such a diagnosis may feel **anger, depression, resentment, or a sense of injustice.** Some find it helps to talk to professionals from support organisations.⁽⁸⁵⁾

Lifestyle & perceptions

A 2016 Macmillan survey found that, of those who said it was important for them to keep working after diagnosis, **60% said it was to give a sense of normality.** 57% said it was to stay positive, keep up morale or self-esteem.⁽²³⁾

44% of people living with cancer say that **their career is important to their personal sense of identity** before diagnosis.⁽¹⁸⁾

87% of line managers said they have not been given any training on how to support people with long term conditions including cancer.⁽²³⁾

INTRODUCTION TO PEOPLE OF WORKING AGE WITH CANCER

Who are people of working age with cancer?

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

People of working age can be as young as 16 (which is generally when compulsory education ends), while working age typically ends when the person retires, for those who are economically active. Retirement ages are usually between 60 and 65, although State Pension age will gradually rise up to 68 for both men and women after 2020.

For the purpose of this Rich Picture on People of Working Age, the definition of 'working age' usually means patients aged 16–64.

This definition accords with that provided by the Office for National Statistics, which also uses the 16–64 age range in their regular UK Labour Force survey.

However for the purposes of this Rich Picture we have in places taken the most easily available data, as data is sometimes only available for broader groupings such as 15–64, 15+, up to 69, 15–99 and 15–65. Where such data is used we have indicated the age range used.

Are people living with cancer protected from discrimination in the workplace?

Equality and discrimination legislation⁽²⁾

In England, Scotland and Wales, employees with cancer are protected from discrimination in the workplace by the Equality Act 2010. The Disability Discrimination Act 1995 and its extension, the Disability Discrimination Order of 2006, protect workers in Northern Ireland.

Discrimination happens when an employee is treated less favourably than another person because of their disability. Discrimination can affect different aspects of employment:

- the recruitment process
- terms, conditions and benefits
- opportunities for promotion and training.

Under these acts employers are requested to make reasonable adjustments to make it easier for an employee with a disability to work.

Discriminatory actions fall under three categories:

- direct discrimination
- discrimination arising from disability (DAD)
- indirect disability discrimination.

Legislation also protects employees from:

- harassment – when an employee experiences unwanted behaviour due to their disability.
- victimisation – when an employee is treated unfairly after making a complaint.

Under the acts, carers are also protected from direct discrimination and harassment.

In England, Scotland and Wales, employers can only ask questions about a candidate's health in an interview under very limited circumstances. They should ensure they are not discriminating against a candidate because of their health. Information about an employee's health is confidential and protected under the Data Protection Act 1998.

'It was a good few years before they actually diagnosed me with the brain tumour. I went to the GP quite a few times with different issues, but they never quite put two and two together. In the end it was 2006 and I went to the opticians because I had a big blind spot in my left eye, and they then sent me to hospital for a scan, which then showed there was a brain tumour.'

[...]

'I was still working at the stockbrokers at the time – in fact I'd only been there for a year. So I was off sick for nearly two years when I was recovering.'

Vivek

KEY FACTS AND STATS ON PEOPLE OF WORKING AGE WITH CANCER

This section presents some of the key stats and facts relating to people of working age with cancer. You may benefit from referring to the jargon buster on page 76 for details on some of the terms used in this section.

339

cases of cancer were diagnosed on average everyday among people of working age in the UK in 2015^(4,5,6,7)

890,000

people of working age (aged 16 to 65) were estimated to be living with cancer in the UK in 2015⁽¹⁾

90

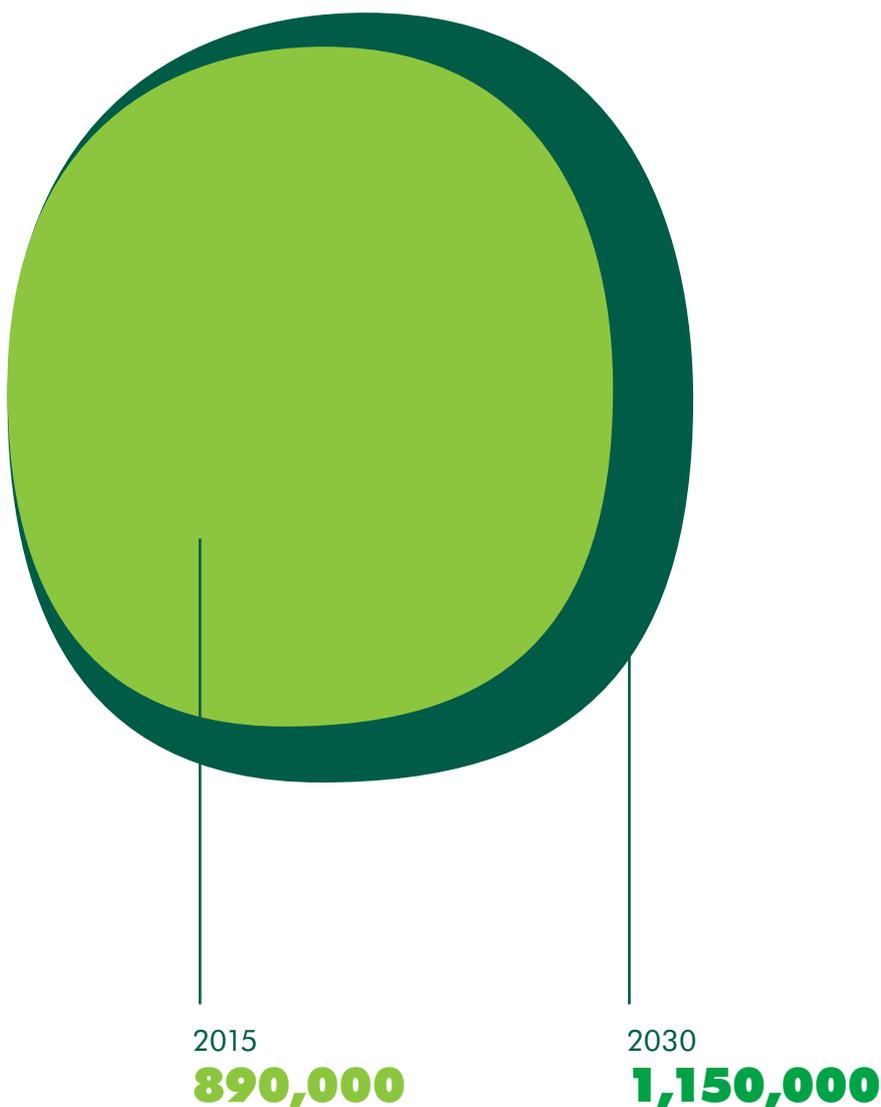
people of working age died of cancer on average every day in the UK in 2015^(8,9,10)

85%

of people with cancer who were employed when diagnosed say it was important for them to continue work after diagnosis⁽²³⁾

How many people of working age are living with cancer? (prevalence)

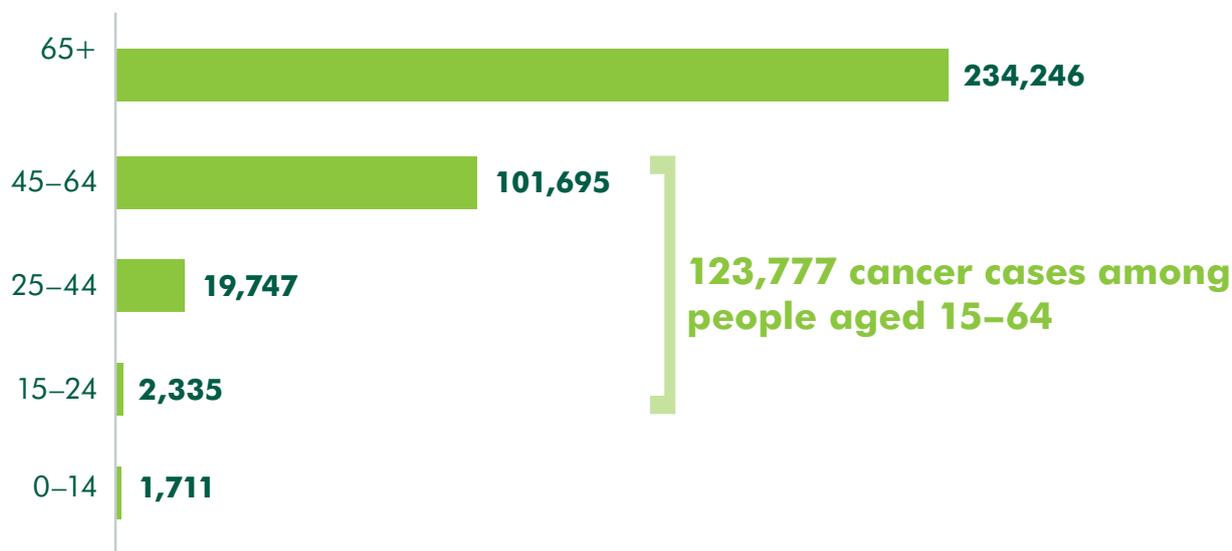
Estimated number of people of working age (16–65) living with a cancer diagnosis in the UK, 2015 and 2030⁽¹⁾



In 2015, there were an estimated 890,000 people of working age living with cancer in the UK. This is set to increase to 1,150,000 by 2030.

How many people of working age get cancer every year? (incidence)^(4,5,6,7)

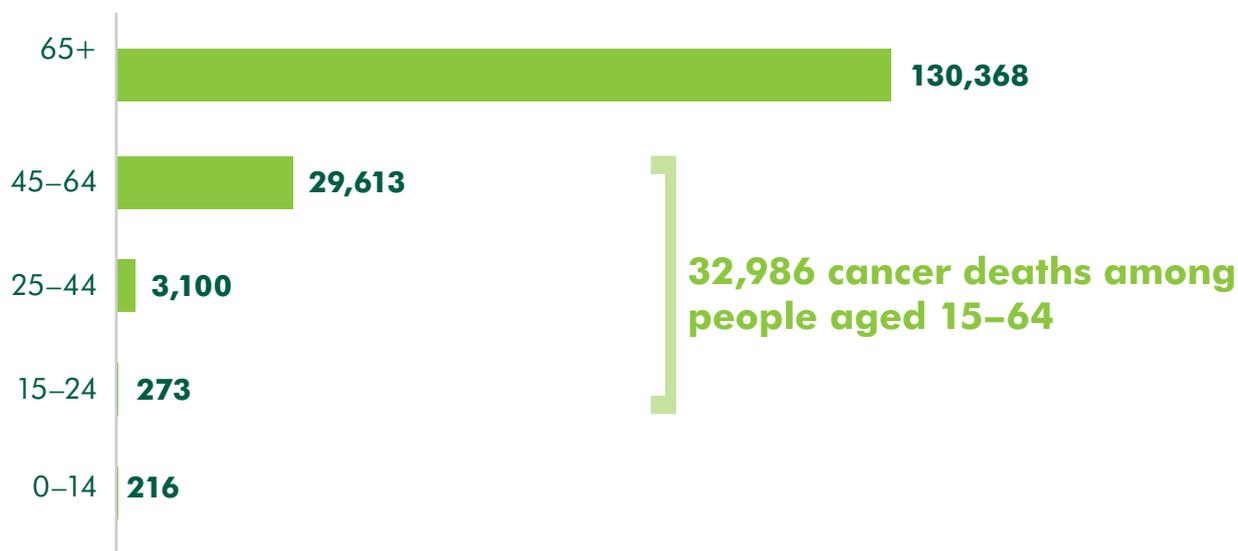
Cancer incidence, UK, 2015, by age grouping, all cancers combined



In total, 123,777 cases of cancer were diagnosed among people of working age (15-64). This accounts for 34% of all new cancer diagnoses in the UK in 2015.

How many people of working age die from cancer per year? (mortality)^(8,9,10)

Cancer mortality, UK, 2015, by age grouping, all cancers combined



In total, there were 32,986 deaths from cancer among people of working age (15-64) in the UK in 2015. This accounts for 20% of all cancer deaths.

What are the key stats for England?

See data on incidence, mortality and prevalence for England



*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population 2013) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

How many people of working age get cancer per year in England?⁽⁴⁾

103,057

new diagnoses in England amongst people of working age in 2015

How many people of working age die from cancer per year in England?⁽⁸⁾

26,911

cancer deaths amongst people of working age in England in 2015

How many people of working age were living with cancer in England in 2015?⁽¹⁾

730,000

people of working age (16–65) were estimated to be living with cancer in England in 2015

How many people of working age are projected to be living with cancer in England in 2030?⁽¹⁾

950,000

people of working age (16–65) estimated will be living with cancer in England in 2030

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population 2013) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

How many people of working age get cancer per year in Scotland?⁽⁵⁾

11,109

new diagnoses in Scotland amongst people of working age in 2015

How many people of working age die from cancer per year in Scotland?⁽⁹⁾

3,384

cancer deaths amongst people of working age in Scotland in 2015

How many people of working age were living with cancer in Scotland in 2015?⁽¹⁾

80,000

people of working age (16–65) were estimated to be living with cancer in Scotland in 2015

How many people of working age are projected to be living with cancer in Scotland in 2030?⁽¹⁾

100,000

people of working age (16–65) estimated will be living with cancer in Scotland in 2030

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population 2013) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

How many people of working age get cancer per year in Wales?⁽⁶⁾

6,196

new diagnoses in Wales amongst people of working age in 2015

How many people of working age die from cancer per year in Wales?⁽⁸⁾

1,722

cancer deaths amongst people of working age in Wales in 2015

How many people of working age were living with cancer in Wales in 2015?⁽¹⁾

50,000

people of working age (16–65) were estimated to be living with cancer in Wales in 2015

How many people of working age are projected to be living with cancer in Wales in 2030?⁽¹⁾

70,000

people of working age (16–65) estimated will be living with cancer in Wales in 2030

What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population 2013) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

How many people of working age get cancer per year in Northern Ireland?⁽⁷⁾

3,387

new diagnoses in Northern Ireland amongst people of working age in 2015

How many people of working age die from cancer per year in Northern Ireland?⁽¹⁰⁾

972

cancer deaths amongst people of working age in Northern Ireland in 2015

How many people of working age were living with cancer in Northern Ireland in 2015?⁽¹⁾

30,000

people of working age (16–65) were estimated to be living with cancer in Northern Ireland in 2015

How many people of working age are projected to be living with cancer in Northern Ireland in 2030?⁽¹⁾

40,000

people of working age (16–65) estimated will be living with cancer in Northern Ireland in 2030

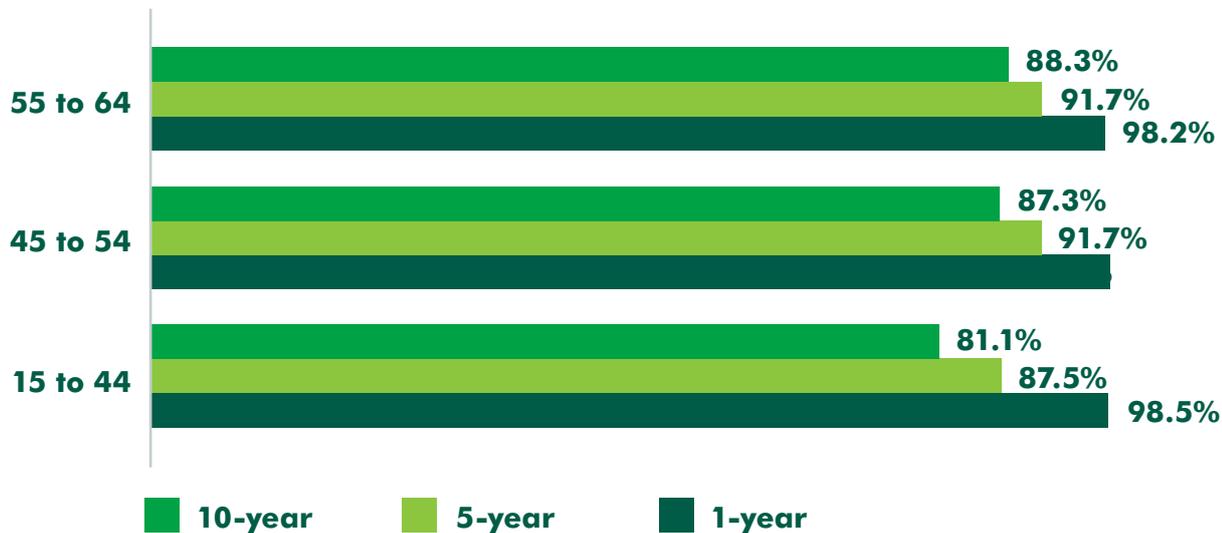
What proportion of people with cancer of working age survive cancer?⁽³⁾

Survival for female breast cancer and prostate cancer for people of working age are shown in this section, as these are the most common cancers in women and men respectively.

Age-standardised 1-year, 5-year and 10-year predicted net survival (%), by age groups for people of working age (15–64), for those who would be diagnosed in 2016, prostate cancer



Age-standardised 1-year, 5-year and 10-year predicted net survival (%), by age groups for people of working age (15–64), for those who would be diagnosed in 2016, female breast cancer



As a general rule, chances of survival are higher amongst those of working age than among older people. However, breast and prostate cancer are exceptions to the general rule, as they tend to be more aggressive in younger people.

International stats

There is limited data on the incidence and mortality of cancer globally just for people of working age, so here there is a focus on cancer incidence for all ages.

What are the global statistics on incidence and mortality of cancer (all ages)?⁽⁹⁷⁾

In 2012, it was estimated that there were 14.1 million new cases of cancer worldwide. Lung, breast colorectal and stomach cancers accounted for more than 40% of all new cases. Breast cancer was the most commonly diagnosed cancer in women globally (and in the UK alone), accounting for 25.2% of all new cases. The most commonly diagnosed cancer in men was lung cancer, accounting for 16.7% of all new cases. This is different to the UK, where prostate cancer is the most common in men.

If global cancer incidence trends continue, the incidence of cancer globally is projected to increase to 23.6 million new cases of cancer each year by 2030.

Cancer caused 8.2 million deaths internationally in 2012. Lung, stomach, liver, colorectal and breast cancer make up more than half of all cancer deaths.

Demographic comparisons

As with international statistics, there is limited data on the demographics of people with cancer, so there is a focus on people with cancer of all ages.

How do incidence, mortality and vary by gender (all ages)?

More men are diagnosed with cancer every year. In 2015, 176,985 women and 182,749 men were diagnosed with cancer in the

UK than women.^(4,5,6,7) Breast cancer is the most commonly diagnosed cancer in women, accounting for 36% of new cancer diagnoses in women in 2015. For men, prostate cancer is the most commonly diagnosed, making up 30% of total new cases in men in 2015.

In the same year, 76,652 women and 86,993 men died from cancer in the UK.^(8,9,10)

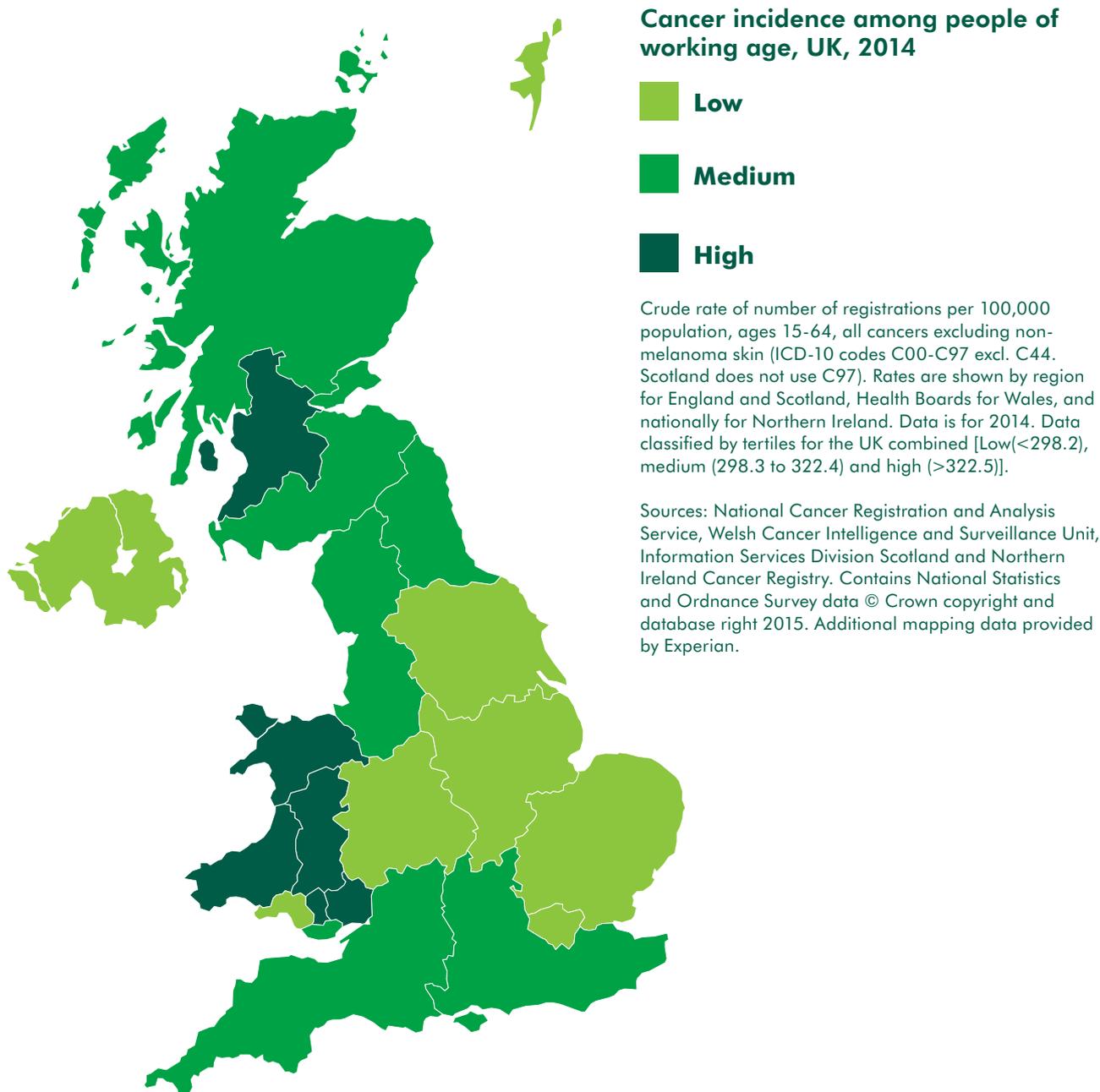
How does incidence vary by ethnic background (all ages)?^{*(98)}

Overall the incidence of cancer in the black and minority ethnic (BME) population is lower than that in the white population. However, this varies for different BME groups and cancer types:

- Asian, Black, Chinese and Mixed ethnic groups have significantly lower risk of getting any of the four major cancers (breast, prostate, lung and colorectal) compared to White people.
- Men and women in the Asian, Chinese and Mixed ethnic groups are between 20% and 60% less likely to get cancer than those from the White group.
- Black women are between 10% and 40% less likely to get cancer than white women; in contrast, there is no evidence that black males have differing risks compared with white men.
- Black men are up to three times more likely to get prostate cancer than white men.
- Black people are nearly twice as likely as white people to get stomach cancer.
- Asian people are up to three times more likely to get liver cancer than the white population.
- Black and Asian women aged 65 years and over, are at higher risk of cervical cancer compared with White women.

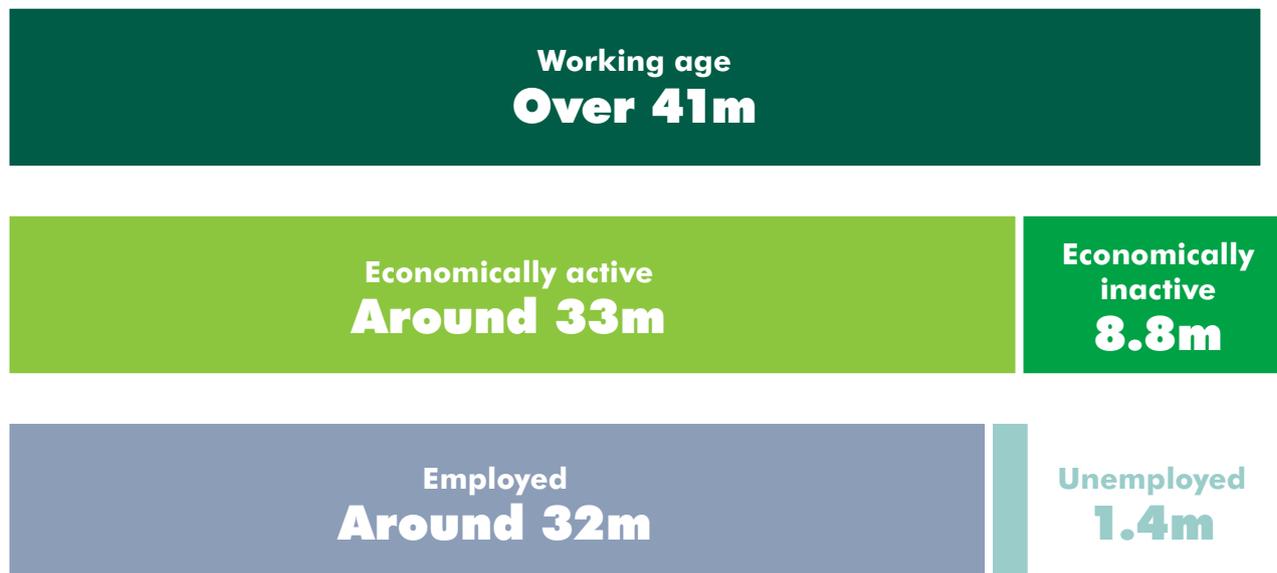
*Note: Data are for England only. There are several limitations to the analysis presented here. Ethnicity information for almost a quarter of the cancer patients included in the analysis is missing. The methodology in the source report makes use of a number of relatively crude procedures to assign these patients to specific ethnic groups for incidence data. However, despite these limitations, this report has been able to provide a first look at the overall pattern of cancer incidence by ethnicity in England.

Thematic map – distribution of cancer incidence in people of working age in the UK



Cancer incidence for people of working age appears to be higher in Wales and parts of Scotland, with lower rates found in some areas of England.

How many people of working age are 'economically active'?



There are over 41 million people of working age in the UK, of which around 32 million are employed, 1.4 million are unemployed and 8.8 million are 'economically inactive' – this means they are either in education, in retirement or looking after home or family.

What are employment and unemployment rates in the UK?⁽¹²⁾

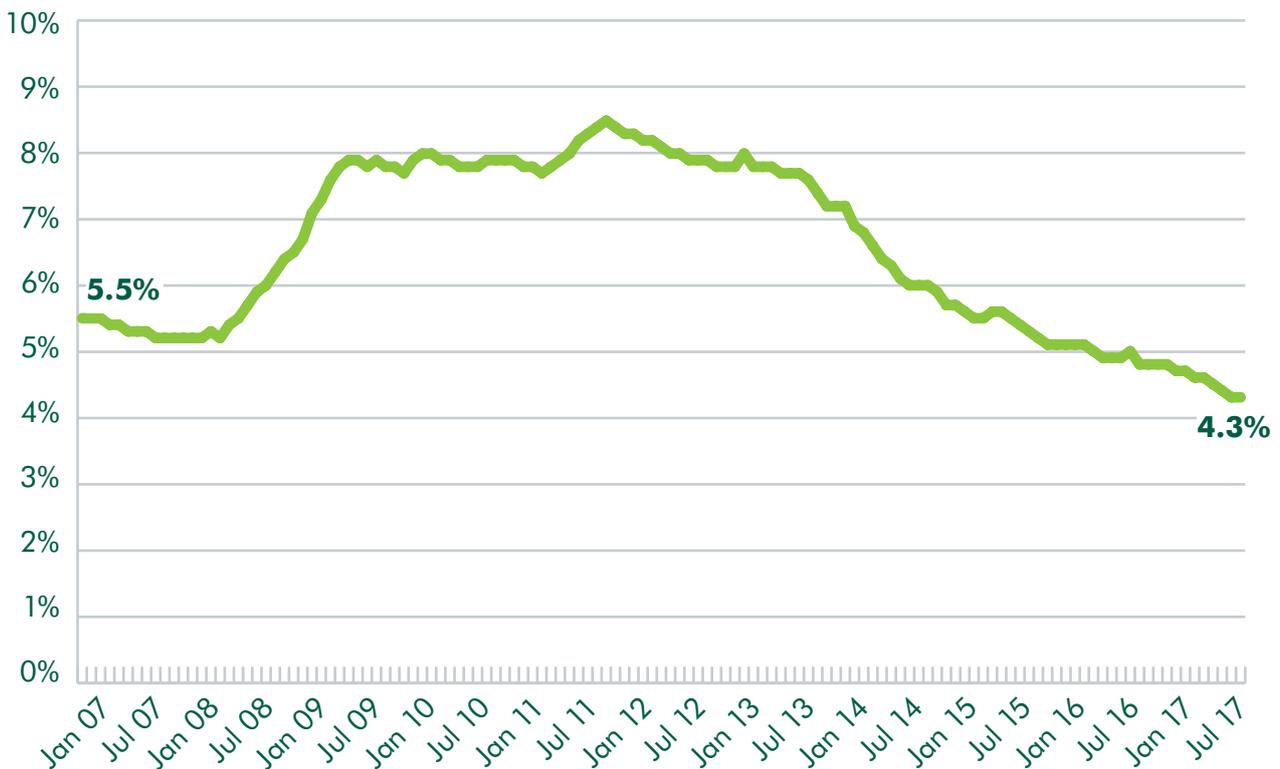
70.7%

Female employment rate
(aged 16–64, UK, August 2017)

79.5%

Male employment rate
(aged 16–64, UK, August 2017)

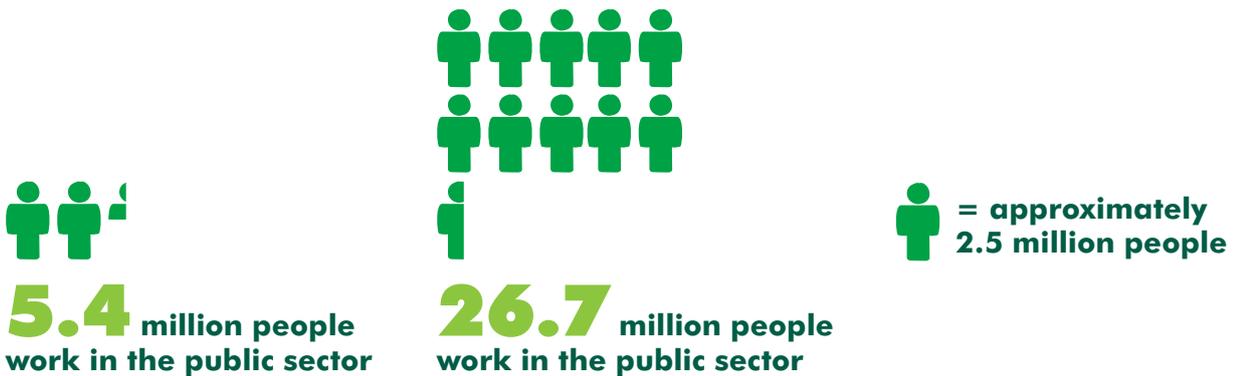
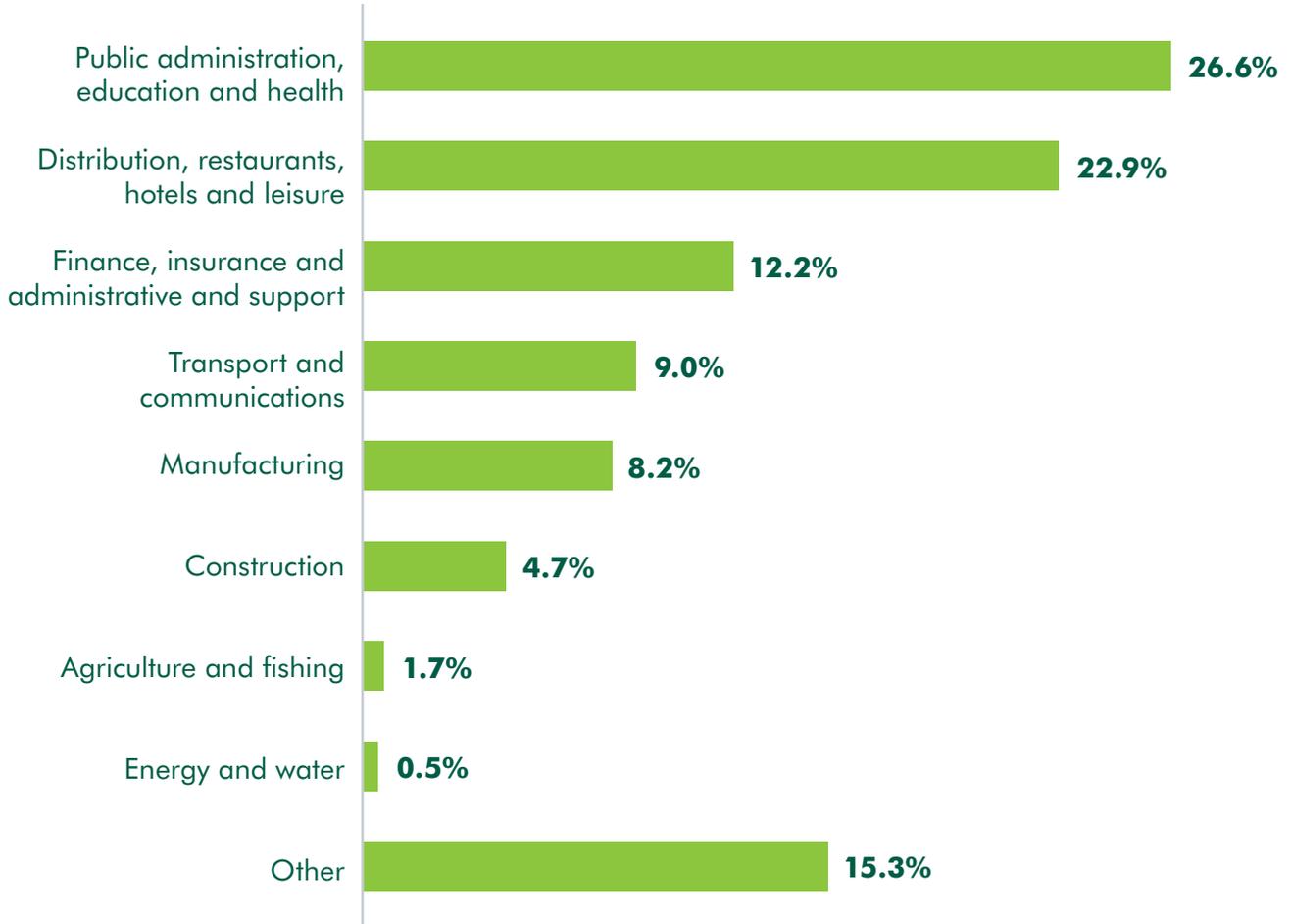
Unemployment rate, aged 16 and over, January 2007–July 2017, UK⁽¹³⁾



As of July 2017, unemployment rates in the UK are at 4.3%, 0.7 percentage points down from 5% in July 2016. Cancer survivors (who were in work at the point of their cancer diagnosis) are 1.4 times more likely to be unemployed than the general population.⁽⁹⁴⁾

In what industry sectors do people in the UK work?⁽¹¹⁾

Employee jobs by industry, June 2017



The largest sector for people of working age in the UK is public administration, education and health with a just over one in four currently working in this sector.

What are the links between cancer and employment?

There is no evidence to confirm any sort of causal link between areas of cancer prevalence and employment or unemployment rates, and the geographical information provided on pages 14 and 16 do not allow for anything more than general observations about unemployment and cancer prevalence levels in the UK.

In terms of socio-economically deprived groups we know that the incidence and mortality of cancer is considerably higher in deprived groups compared with less deprived groups.⁽⁹⁹⁾ Evidence suggests that socio-economic status and demographics are also key factors to consider when looking at unemployment before and after a cancer diagnosis.⁽¹⁵⁾

Many people who have had cancer want to go back to work when they feel ready and able. However, there is some evidence to suggest that they can struggle to do so. A US study looking at the experience of women diagnosed with breast cancer found that, despite many desiring to go back to work, nearly a third of those employed before diagnosis were no longer working four years later. Also, those who had received chemotherapy were less likely to go back to work, compared to those who did not receive chemotherapy.⁽¹⁴⁾

Whilst leaving work (or full-time employment) is common during cancer treatment and recovery, evidence suggests that many cancer survivors would like to go back to work when they feel ready and able to do so.⁽²³⁾

Returning to work is not an easy process for cancer survivors. Evidence shows that several factors need to be taken into account and monitored, including whether a person is physically ready to go back to work and also the ongoing process needed to manage any arising symptoms.⁽¹⁹⁾

Many people struggle with little or no support to remain in work. Research shows that 85% of people with cancer say that work is important to them.⁽²³⁾

Occupational risk of cancer

There is a link between occupational exposure to particular substances such as asbestos, benzene and mineral oils and the occurrence of cancer. There are over 100 substances used in some occupational industries such as construction and manufacturing, which are known to cause cancer. Mesothelioma, a cancer of the thin membrane that lines the chest and abdomen, is a particular cancer that has a strong link to occupational exposure. 94% of cases of mesothelioma in the UK are linked with exposure to asbestos.⁽¹⁶⁾ Similarly, 13% of lung cancer cases are linked to occupational exposure, with lung cancer mortality being 77% higher in those exposed to asbestos than the general population.⁽¹⁷⁾ Therefore, a number of people of working age in these particular industries who are exposed to one of the known carcinogenic substances will have a higher risk of developing cancer.

The Diffuse Mesothelioma Payment Scheme (DMPS)⁽¹¹¹⁾

The DMPS provides payments to people diagnosed with diffuse mesothelioma as a result of negligent exposure to asbestos at work. Applicants need to be unable to claim compensation through their employer.

The scheme receives an average of 29 applications per month, with an average 65% success rate (April 2016 to January 2017). Overall, the scheme awarded almost £98 million in compensation between April 2014 and March 2017, with an average payment per successful claim of £141,000 (between March 2016 and March 2017).

What is the uptake of benefits for people living with cancer in the UK?⁽⁸⁶⁾

The data on this page only relates to England, Scotland and Wales. There is no comparable data for Northern Ireland.

People living with cancer may be eligible for a variety of benefits. Some benefits help people with cancer deal with the increasing costs derived from their illness, while others specifically target those with a reduced income or unable to work. However many people do not claim all of their benefits, in 2015/16 the DWP estimated that up to £12.3 billion of means tested benefits went unclaimed. The following are benefits where the data is available by condition.⁽¹¹⁴⁾

Employment and Support Allowance (ESA)

Employment and Support Allowance (ESA) is a benefit for working age people who are unable to work or returning to work as a result of a health condition or disability.

As of May 2017, there were over 56,000 ESA claims for people with neoplasms (cancer and non-cancer) in Great Britain.

Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is a benefit for disabled people who need help with mobility or care costs. From 2013, DLA for people of working age is gradually being replaced by Personal Independence Payment (PIP).

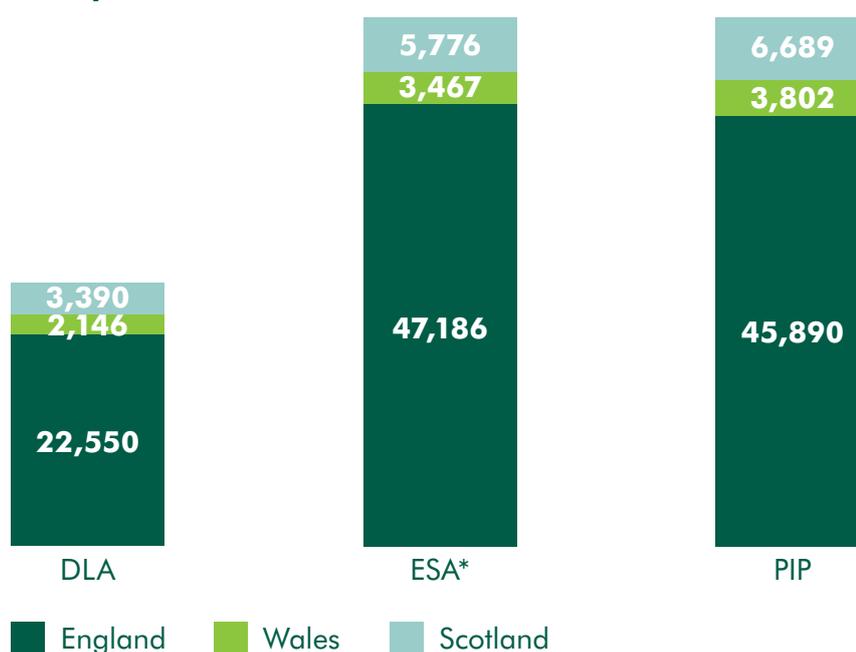
As of May 2017, there were over 28,000 DLA claims from people with cancer in Great Britain.

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) is a welfare benefit which aims to help people living with a long-term health condition or a disability cope with the extra costs associated. It is available to people in and out of work. PIP is replacing DLA, but is not meant to be a substitute for other benefits (such as ESA).

People living with cancer may be eligible for PIP. As of May 2017, there were over 56,000 PIP claims from people with cancer in Great Britain.

Number of DLA, PIP and ESA claims for people with malignant disease in Great Britain, May 2017⁽²¹⁾



*Data on ESA claims is for all neoplasms (cancer and non-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 people of working age 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?

This stage of the cancer journey can include different elements, such as:

- Being concerned about health and going for tests
- Receiving a cancer diagnosis
- Cancer coming back – when people are diagnosed with a new cancer after surviving a previous cancer

2 Treatment

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

This stage of the cancer journey can include different elements, such as:

- Starting and going through treatment
- Finishing treatment and recovering from cancer

3 Life after treatment*

If I complete my treatment for cancer, what next?

This stage of the cancer journey can include different elements, such as:

- Living with consequences of cancer and/or its treatment
- Living well after cancer

4 Progressive illness and end of life

If my cancer is incurable, what might I experience?

This stage of the cancer journey can include different elements, such as:

- Cancer that is treatable but not curable
- End of life

*This is often referred to as 'survivorship' or 'Living with and beyond cancer'. 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:

- a lump (in breast or colorectal cancer)
- a cough, breathlessness or hoarseness that doesn't go away (in lung cancer)
- changes in bowel habit (in colorectal cancer)
- abnormal bleeding (in colorectal or cervical cancer)
- changes in a mole (in skin cancer)
- unexplained weight loss
- pain

How good are we at early diagnosis?

Patients with cancer in the UK tend to present with more advanced disease and have poorer survival rates than many of their European counterparts. The most likely explanations are either late presentation by patients due to high level of barriers to symptomatic presentation and low awareness of age related risk.⁽²⁰⁾

Over 123,000 people of working age are diagnosed with cancer each year.^(4,5,6,7) Cancer is relatively rare in teenagers and young adults, with less than one per cent (0.6%) of the total cancers being diagnosed in the 15–24 age group. One in ten cancers are diagnosed in people aged 25–49 years. Older adults carry the greatest burden of cancer, with over half (53%) of all cancers being diagnosed in 50–74 year olds.⁽²¹⁾

In England, low cancer awareness is observed in socioeconomically deprived parts of London. Although survival rates vary for different cancers, low cancer symptom awareness is associated with poorer survival rates for all cancers. In the case of breast cancer, high barriers for seeking medical help is also associated with poor survival.⁽²²⁾

The most commonly endorsed barriers to seeking medical help with potential cancer symptoms are; difficulty making an appointment, worry about wasting the doctor's time and worry about what would be found. Emotional barriers are more prominent in lower socio-economic groups and practical barriers (such as 'too busy') are more prominent in higher socio-economic groups.^(27,100)

In an international study comparing various European and western populations, more people in the UK than in other countries said that there were specific reasons they wouldn't go to their GP, even with a symptom that worried them. People in the UK mentioned that embarrassment and not wanting to waste the doctor's time would put them off seeing their doctor.⁽¹⁰⁵⁾

GPs typically consider cancer a priority, partly because of its profile in the public mind and partly because of its importance in the QOF (Quality and Outcomes Framework) process. Most, however, feel that they have little time to improve their understanding of cancer in general and about treatments in particular.⁽²¹⁾

Around 43% of all cancer patients in England saw their GP once about a health problem caused by cancer before going to the hospital.⁽²⁶⁾

How well does screening work for cancer in people of working age?

There are national screening programmes for breast, cervical and bowel cancer that monitor people regularly. Bowel cancer screening is the only national cancer screening programme which applies both to men and women. Uptake rates vary according to screening centre.⁽²⁷⁾

Breast screening

Women between the ages of 45 and 74 are invited for breast screening every three years under a national programme. This is intended to detect breast cancer at an early stage. In England, a total of 2.85 million women were screened for breast cancer in 2015–16, with a total of 18,320 cancer cases detected in women aged over 45. Amongst women aged 50–70, detection rate is lower than for all women aged 45 or over (8.2 and 8.5 cases per 1,000 women screened respectively).⁽²⁸⁾

Best estimates are that the NHS breast screening programme prevents 1,300 deaths a year.⁽²⁸⁾

Cervical screening

There is variation in the recommended age groups for cervical cancer screening in the different nations of the UK:⁽⁸⁸⁾

- In England, Wales and Northern Ireland, women aged between 25 and 49 years are invited to a screening every three years, while women aged between 50 and 64 are invited every five years.
- In Scotland, women aged between 20 and 60 years are invited to a screening every three years.

In 2016, the percentage of eligible women (aged 25–64) who were recorded as screened for cervical cancer at least once in the previous 5 years (coverage) was 77%.⁽²⁹⁾

Bowel screening

The NHS Bowel Cancer Screening Programme offers screening every two years to all men and women aged 60 to 74. People in the invitation age range are automatically sent an invitation, followed by a screening kit, so that they can do the test at home.⁽³⁰⁾

How is cancer diagnosed?⁽³¹⁾

Routes to diagnosis, England, 2006–2014, all cancers combined, all ages

Emergency

22%



GP referral

26%



2-week wait

30%



Screening

6%



Other

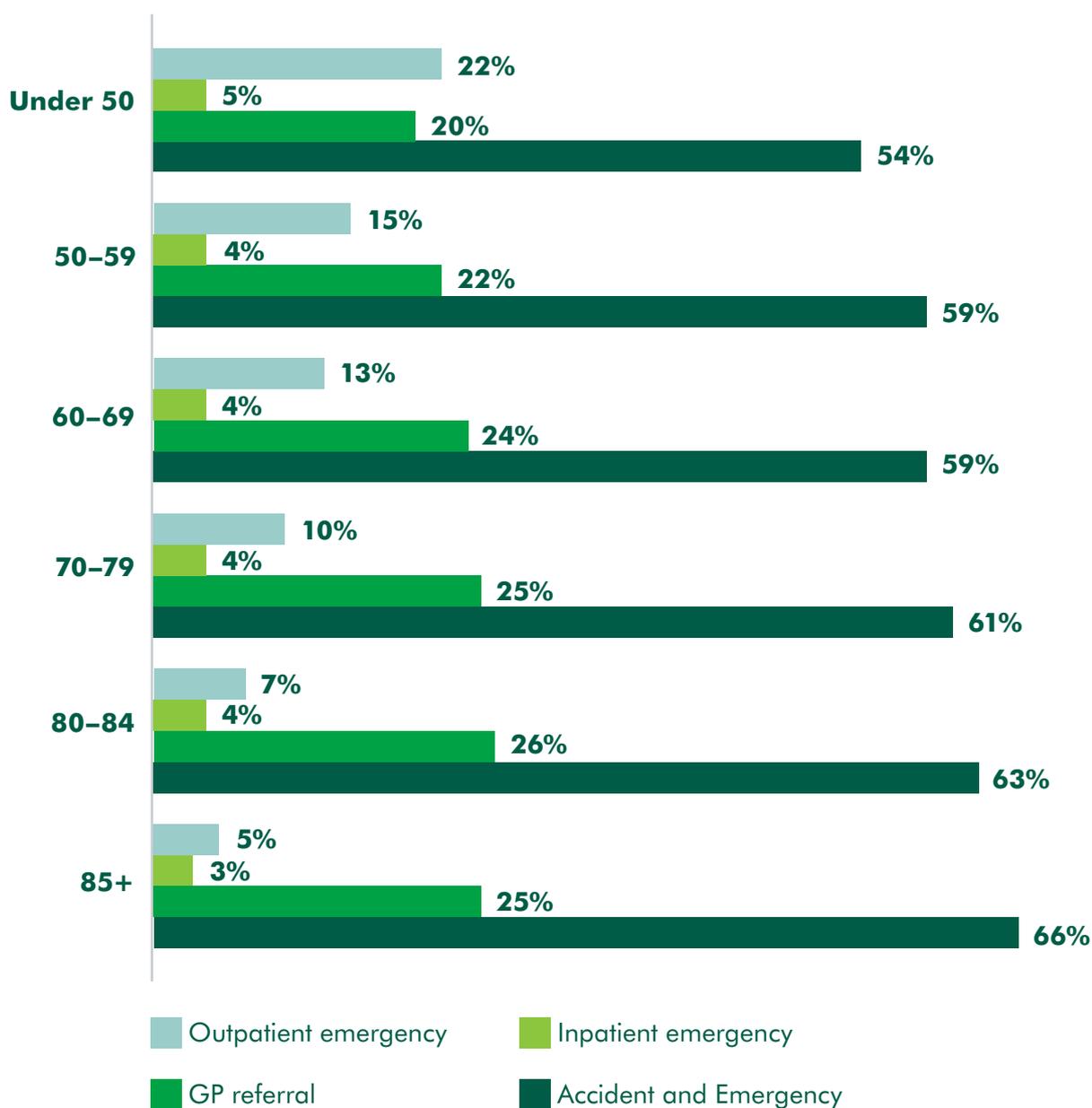
16%

'Other' includes in-patient and out-patient routes, 'death certificate only' diagnoses, and 'unknown' routes.

22% of cancer diagnoses are through emergency presentation. People diagnosed via emergency presentation tend to have poorer outcomes. Diagnoses following screening happens only in 6% of cases, however screening is only available for some cancer types (such as breast).

How do diagnoses at emergency presentation vary by age?⁽³¹⁾

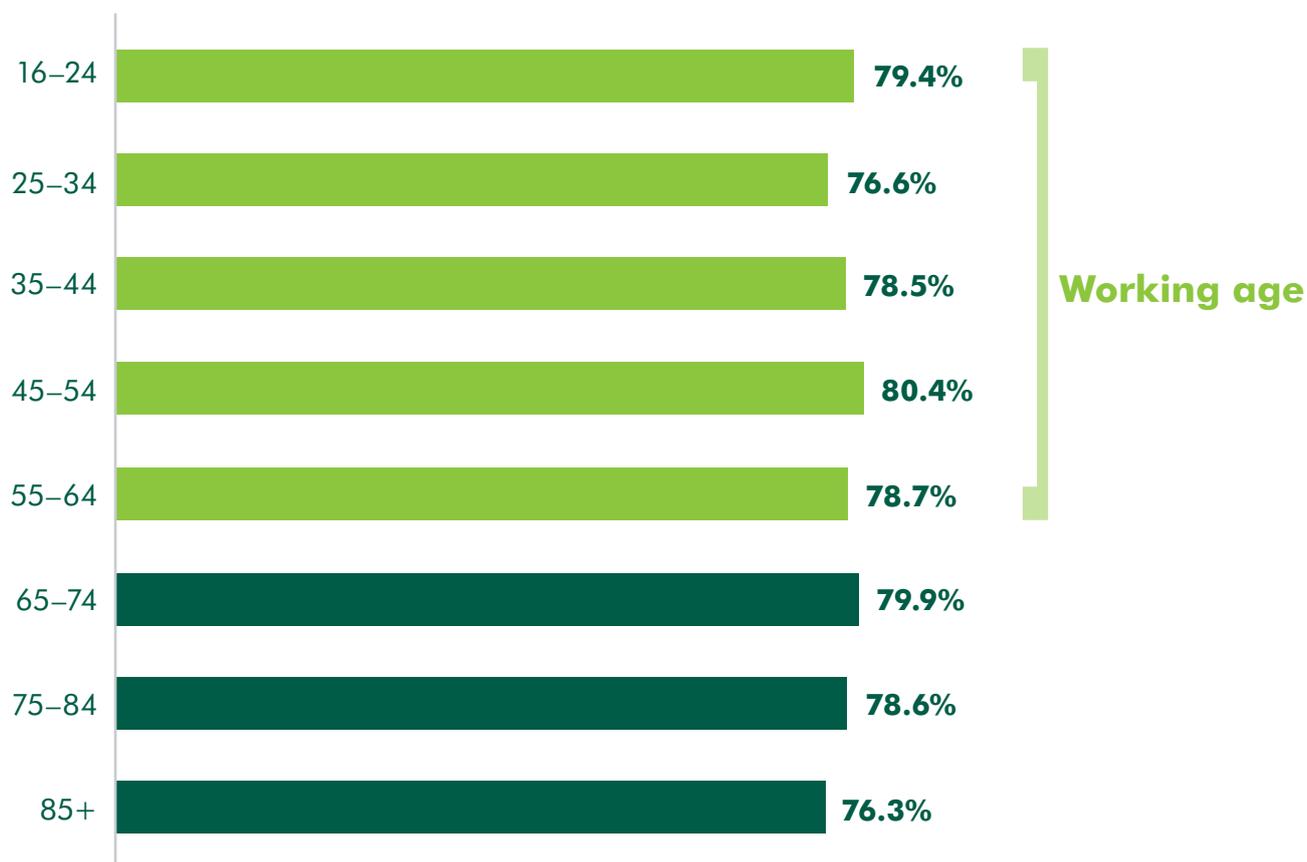
Routes to emergency diagnosis, England, 2006–2014, by age groupings, all cancers



Among all diagnoses made via emergency route, people of working age tend to be diagnosed less via presentation to A&E and emergency GP referral, compared to older patients. Conversely, outpatient emergency diagnoses (for patients not hospitalised overnight) are much higher in people of working age.

How long do patients of working age wait before seeing their doctor, after they think something was wrong?⁽²⁶⁾

Number of cancer patients who saw their doctor or GP within 3 months of thinking something might be wrong, England 2016



There is variation in the number of cancer patients of working age who said they saw their GP or doctor within three months of thinking something might be wrong. The lowest rate is recorded in those aged 25-34.

How does stage at diagnosis relate to probable survival rates?

There is little UK-wide data on stage at diagnosis for people of working age with cancer and the links between stage at diagnosis and survival.

Most types of cancer have 4 stages, numbered from 1–4.

The later the stage at diagnosis, the poorer the chances of survival – in other words early diagnosis and treatment saves lives.

Stage 1	Stage 2	Stage 3	Stage 4
Usually means a cancer is relatively small and contained within the organ it started in.	Usually means the cancer has not started to spread into surrounding tissue, but the tumour is larger than Stage 1. Sometimes Stage 2 means that cancer cells have spread into lymph nodes close to the tumour. This depends on the type of cancer.	Usually means the cancer is larger. It may have started to spread into surrounding tissues and there are cancer cells in the lymph nodes in one area.	Means the cancer has spread from where it started to another body organ. This is also called secondary or metastatic cancer.

TNM staging system

Many cancers, including the top 4 most commonly diagnosed, are staged using the TNM system. In this case, doctors will assess and rate the size of the tumor (T), whether the cancer has spread to the lymph nodes (N) and whether the cancer has spread to another part of the body (M).⁽²⁰⁾

Needs at diagnosis



Physical needs

A study looking at physical needs of breast cancer patients after diagnosis revealed that fatigue was the most common physical concern which had an impact on return to work for certain individuals, as well as the inability to return to leisure activities and to remain physically active. Concerns over body image, particularly skincare, was a significant concern in breast cancer patients within 1 year of diagnosis. In this particular study, only 32% of the questionnaire participants reported that they were offered support with dealing with their concerns.⁽³²⁾

A study found that some cancer patients felt, in hindsight, they did not receive enough preparation in the period between diagnosis and treatment for possible changes in body appearance as a result of cancer treatment.⁽³³⁾



Clinical needs

A study showed that women aged 15–44 were more likely to be diagnosed for breast cancer at a more advanced stage than women aged over 64. Similar results were found for colorectal cancer, with people aged 15–44 more likely to be diagnosed with colorectal cancer at a more advanced stage than over 64s.⁽³⁵⁾

A study focusing on the barriers to presenting cancer symptoms to a physician showed that individuals aged between 15–54 were more likely to report that they were too busy and had difficulty making an appointment compared to older age groups.⁽³⁶⁾

Practical needs

Employees with cancer in England, Wales and Scotland are protected from discrimination in the workplace from the point of diagnosis under the Equality Act 2010. The Disability Discrimination Act 1995 and the Disability Discrimination Order of 2006 protect workers in Northern Ireland.⁽³⁸⁾

37% of cancer patients aged 35–64 in England were not told the impact their illness would have on their work or education.⁽²⁶⁾

Only 58% of people surveyed in a Macmillan YouGov survey who were employed when diagnosed knew that the Equality Act covered cancer patients, despite 73% knowing about the Equality Act itself.⁽²³⁾

Out of the people who had given up their work as a result of their diagnosis, 32% had stated that they were physically unable to return to the same role.⁽²³⁾

Financial needs

It is estimated that 30% of people with cancer experience a loss of income as a result of their cancer, with those affected losing on average £860 a month. Additional costs and loss of income arise at different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families.⁽³⁷⁾

In a survey carried out by Macmillan, 54% people said that they chose to carry on working after diagnosis because they needed the money. As a result of their cancer diagnosis, 10% of people surveyed gave up work and 4% were made redundant. 10% returned part time or were able to agree changes to their job with their employer such as flexible hours or changes in targets.⁽²³⁾

About 54% of cancer patients experience increased day-to-day living costs. These costs include heating bills and help with household chores, adding up to £63 a month for those affected.⁽³⁷⁾

The most common and impactful indirect cost of a cancer diagnosis was loss of income which normally occurred when sick pay ran out.⁽⁷⁷⁾

Information needs

Patients of a working age have been found to be considerably less likely to feel they understand the explanation of what is wrong with them. Among cancer patients in England in 2016, only 63% of 35–44 year olds and 67% of 45–54 year olds completely understood the explanation of what was wrong with them compared to 77% of 75–84 year olds.⁽²⁶⁾

Generational differences affect informational needs and preferences. Older patients seem to have a more passive role and don't express a need for information as much as younger patients. For instance, younger women are more likely to seek information on how their treatment would affect their sexual lives.⁽³⁹⁾

Cancer patients have different preferences around their information, both relating to the quantity of information and how they receive it. Some people report that they were "front loaded" with information at the beginning of their cancer diagnosis and were not given as much information later on in their cancer journey. Others stated that they preferred to be given information at the time when it was relevant to them.⁽³³⁾

Emotional needs

Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, around half of all people with cancer experience levels of anxiety and depression severe enough to adversely affect their quality of life.⁽⁴⁰⁾

A study showed that rates of anxiety and depression are highest at diagnosis for women with breast or gynaecological cancer, with improvement over time.⁽⁴¹⁾

Receiving psychosocial support emerges as very important for those patients experiencing multiple sources of stress associated with their cancer diagnosis.⁽⁴²⁾

Of the people with cancer who gave up work as a result of their diagnosis, 16% said that it was because they did not feel emotionally strong enough.⁽²³⁾

Some people may prematurely access their pension pots following a cancer diagnosis which can lead to people feeling anxious about their future and standard of living later on in life.⁽⁷⁷⁾

Some people felt isolated as a direct result of their cancer diagnosis. Around 18% of people who lack support say that they lost touch with family and friends because of their diagnosis.⁽⁴³⁾

'Physically it's completely draining. Emotionally, I'm not someone to let something like this pull me down – I just take things in my stride. I just accept things as they are and, if I get told that something's happened, then I move on to the next stage. Like, okay, what do we do next?'

Vivek

NEEDS AND EXPERIENCES: TREATMENT

What treatments do cancer patients of working age get?

Surgery

Surgery is a common treatment for many cancers. For the majority of cancer sites, there is a decrease in use of resection for people aged 85+ compared to people aged 15–54. In England, kidney cancer in males shows the biggest fall in resections depending on age, with 72% of males in the 15–24 age group undergoing a resection compared to 13% for the oldest group. For breast cancer patients, there is a fall in females resections in the 85+ age group where only 25% underwent a resection, compared to 82% in 15–54 year olds.⁽⁴⁶⁾

Chemotherapy

Chemotherapy involves the circulation of anticancer (cytotoxic) drugs in the blood stream to kill cancer cells. This can be administered through various methods including intravenous drip, oral chemotherapy and intramuscular chemotherapy. There are many drugs used for chemotherapy and typically a patient will be given a combination of 2 or 3 drugs. The type of drugs given will depend on how aggressive the cancer is and other health conditions the patient may have. In some cases, chemotherapy is the main type of treatment for cancer. For those who also receive surgery, chemotherapy can be administered after surgery to reduce the risk of the cancer coming back or before surgery to reduce the tumour.^(65,66) Chemotherapy can cause side effects, which can vary in their severity. Most side effects are short term, so start to stop once treatment has finished, and can be reduced through medication. A doctor or a chemotherapy nurse may be able to advise patients about the likely effects of chemotherapy being undertaken. Most people would need time off work for intravenous chemotherapy (chemotherapy through a drip).⁽⁴⁴⁾

Radiotherapy

Radiotherapy kills cancer cells by using high energy x-rays and may also be used as part of the treatment regime if there is a likelihood of the cancer coming back after surgery or if the surgeon removed cancerous lymph nodes. Careful planning and newer ways of giving radiotherapy have reduced the risk of damage to healthy tissue and nearby organs. Cancer cells cannot repair themselves after radiotherapy, but normal cells usually can.⁽⁶⁷⁾ About 4 in 10 people with cancer (40%) have radiotherapy as part of their cancer treatment.⁽⁴⁵⁾

Radiotherapy affects people in different ways, with varying severity in the side effects experienced, and it is often difficult to predict exactly how a given patient will react. For many people the side effects will wear off within a few weeks of treatment ending. But for some people radiotherapy can cause long term side effects, which can impact upon their ability to work.⁽⁴⁵⁾

Biological Therapy

Biological therapies use substances that occur naturally in the body to destroy cancer cells. Immunotherapy is one of the most common types of biological therapies, but there are many other treatments of this kind. They all work differently and the administration of biological therapies depends on the type of cancer, the stage at diagnosis and which other cancer treatments the patient had. Whilst biological therapies are increasingly used for some cancers, they are still a new and experimental type of cancer treatment, so they are not used for all cancers.^(87,88)

Hormonal therapies

Hormones are substances produced naturally in the body. They act as chemical messengers and influence the growth and activity of cells. Hormonal therapies – typically given either

through tablets or injections – work by altering the production or activity of particular hormones in the body. The type of therapy given depends on the type of cancer, but this type of treatment is most commonly used for some cancers, such as breast prostate.⁽⁸⁹⁾

What healthcare professionals do people of working age receive support from?

Cancer care through teams

NHS guidelines state that anyone diagnosed with cancer should be under the care of a multi-disciplinary team, which includes professionals such as surgeons, oncologists, doctors who specialise in symptom control, radiologists, specialist cancer nurses, physiotherapists, occupational therapists, psychologists, social workers and dieticians.⁽⁴⁸⁾

How many people of working age with cancer have access to a CNS?

People aged 16–64 are more likely to have access to a Clinical Nurse Specialist (CNS) than those aged over 65, with 90% of those of working age confirming that they had received the name of a CNS, compared to 83% amongst those aged 65 and over.⁽²⁶⁾

What does this mean for patients?

CNSs help improve cancer care for patients by using their technical knowledge of specific cancers and its treatment. This enables them to coordinate services by liaising with other professionals and acting as the key accessible professional in the multidisciplinary team, whilst meeting the needs of patients. Their knowledge and insight from patient experience is used to assess and improve services including alleviating the psychological effects of cancer and its treatment and reducing the risk of disease to patients.⁽⁴⁹⁾

CNSs reduce costs in primary care by coordinating admissions for unwell patients, expedite outpatient clinic appointments, reorganise reviews to minimise cancelled procedures or operations and give advice on managing medication throughout the cancer

journey. This enables patients to move through the system more smoothly and diverts pressure away from other professionals such as doctors and the ward nursing team.⁽⁴⁶⁾

What other health conditions do people with cancer have? How does this affect their treatment, survival, long term effects or experiences?

Around 70% of people living with cancer (all ages) have at least one other chronic health condition, with the top three conditions being high blood pressure, obesity and mental health problems.⁽⁷⁶⁾

Understanding other health conditions cancer patients may have can help to predict or explain decisions to treat outcomes, longer term complications, as well as ensure care and support are tailored to the individual.

Needs during treatment



Physical needs

Cancer related fatigue is one of the most common symptoms of cancer treatment, with reports stating that up to a third of cancer patients' experience fatigue and can persist for years after treatment. Fatigue can affect a cancer patients productivity levels and ability to do tasks at work during and after the treatment phase.⁽⁵⁰⁾ Fatigue can also cause many people to give up work or change jobs.⁽⁵³⁾

With proper support from employers people can manage fatigue and do not need to leave work unnecessarily.

Cancer treatments such as chemotherapy and radiotherapy have been shown to cause memory deficits in patients as the treatment interferes with the normal neurogenesis in the brain.⁽⁵¹⁾ A study on breast cancer patients showed that those who had undergone chemotherapy and radiotherapy had higher problems in retaining memory and scored lower than average on neuropsychological tests.⁽⁵²⁾ These neurological setbacks could have an impact on a patient's job performance.

Of people surveyed, 15% of those who returned to work said that they returned before they felt ready to do so, of which 63% said they would have liked to go back, when they felt they were physically able to do so.⁽²³⁾



Clinical needs

Cancer treatments can cause nausea which can be treated by anti-sickness medication in the form of tablets, skin patches and injections. These treatments may cause other side effects themselves including constipation, headaches and tiredness.⁽⁹⁰⁾

Lymphoedema is swelling that develops because of a build-up of fluid in the body's tissues. Primary lymphoedema is rare and is thought to affect around 1 in every 6,000 people. Secondary lymphoedema is much more common, and affects around 2 in 10 women with breast cancer.⁽⁶⁸⁾



Practical needs

87% of line managers stated that they had not received training on how to support people with cancer and 36% of employers stated that their workplace did not have a HR or Occupational health workplace policy which included guidance on how to support people with cancer.⁽²³⁾

Generally, occupational health services and private healthcare providers only provide vocational rehabilitation services to large organisations. Government-back-to work programmes focus more on supporting people on long term benefits and may not support the specific needs of people living with cancer.⁽⁵³⁾

Three quarters of people living with cancer do access support services such as an occupational health professionals or Jobcentre Plus.⁽⁵³⁾

A study for Macmillan found that only 2% of people with cancer access specialist return to work services.⁽¹¹²⁾ Other studies have shown that specialist Vocational Rehabilitation services can be an effective way to help people with cancer remain in or return to work.⁽¹¹³⁾

A study looking at the needs of working age women with breast cancer showed that women in the UK needed help with regards to household chores, shopping for groceries, cooking, gardening and laundry during chemotherapy. These needs were more prevalent compared with their counterparts in France and Germany.⁽⁵⁶⁾



Financial needs

Taking time off work during treatment can affect economic independence. Thirty per cent of people with cancer experience a loss of income and those that are affected lose an average £860 a month.⁽³⁷⁾

On average, 27% of people with cancer in England aged between 35–64 said that they did not get information on how to receive financial help or any benefits that they'd be entitled to.⁽²⁶⁾

The most common cost that people face during the cancer treatment period is the cost of getting to and from hospital appointments. For some patients, public transport may not be the best option for travel due to reduced immunity so will have to rely on traveling by car or using taxis which can be more expensive. The cost of travel to and from outpatient appointments add up to on average £170 a month.⁽³⁷⁾

Information needs

A study showed that patients who received information on the impact cancer would have on their work and life were 1.72 times more likely to have a positive treatment outcome. Similarly, patients who receive written information about their type of cancer are almost twice as likely to have a positive treatment outcome. This may be due to patients being able to prepare themselves and plan their work life during the treatment period. This, added to the psychological benefits having a job during treatment, may also be a contributing factor.⁽⁵⁴⁾

One of the main barriers preventing people living with cancer from remaining in the workforce is a lack of information and advice from health professionals about how cancer affects their working life as well as ways to manage this. Macmillan recommends a three-tier cancer support work model which comprise of open access to information and support, active support for self management and specialist vocational rehabilitation.⁽⁵³⁾

In a 2016 Macmillan survey by YouGov, 14% of line managers said that they were uncomfortable talking to their employees about their employees' cancer in the workplace.⁽²³⁾

Only 48% of patients discuss employment issues with their oncology treatment team.⁽⁵⁵⁾

Emotional needs

A US study identified that emotional distress was one of the barriers affecting people living with cancer experience during work in the treatment period.⁽⁵⁷⁾

Of the people of working age who were surveyed who did return to work before they felt they were ready, 58% said they would have liked to return to work once they were emotionally able to do so.⁽²³⁾

A study found that patients may feel a level of embarrassment and awkwardness around their work colleagues about their illness and felt less confident in being able to deal with high work-related stress. Others have reported that they felt unsupported by their colleagues due to the amount of sick-leave they had to take.⁽⁵⁸⁾

More than four in ten people with cancer have experienced emotional issues in the past week. This includes anxiety, loneliness and depression. Overall, around 45% of people living with cancer encounter a lack of support for their emotional needs.⁽⁴³⁾

Four in five people felt that due to the financial cost of cancer, they could not see their friends and family as much, which leads to them feeling isolated.⁽⁴³⁾

'For the surgery, they went through my nose to remove the tumour. They were hoping to get all of it but I think they only managed about half. It's very weird because I look relatively normal now, whereas other people on the ward had surgery through the side of the skull or the back and you could see massive scars. Within a month I started the radiotherapy and that continued for a couple of months. I had to have it down my spine as well because the tumour was moving.'

Vivek

NEEDS AND EXPERIENCES: LIFE AFTER TREATMENT

What needs of cancer survivors (of all ages) are not catered for properly by the current system?

An estimated 500,000 people living with cancer had at least one physical or psychosocial need.⁽⁵⁹⁾

- At least 350,000 people are living with chronic fatigue.
- At least 350,000 people are living with sexual difficulties.
- At least 240,000 people experience mental health problems such as anxiety, depression and symptoms related to PTSD.
- 200,000 people are living with moderate to severe pain.

Other problems may include urinary and gastrointestinal problems and lymphoedema.⁽⁶⁰⁾

- Fear of cancer recurrence is a common psychosocial problem. Cancer treatments can also increase the risk of other health conditions such as osteoporosis and heart disease.⁽⁵⁹⁾
- 40% of people with cancer with emotional difficulties had not sought medical help or support.⁽⁵⁹⁾
- 23% lack support from friends and family during treatment and recovery.⁽¹⁰⁶⁾
- One in six people (17%) who were diagnosed with cancer more than 10 years ago have not been visited at home by a friend or family member for at least six months.⁽¹⁰⁶⁾

Cancer survivors have greater health needs than the general population

- 90% of cancer survivors have visited their GP and 45% visited a specialist doctor in the last 12 months. This compares with 68% and 15% of the wider population.⁽⁶⁸⁾
- GPs play a very important part in the experience of cancer survivors, as they are a key point of contact for them. Evidence suggests that cancer survivors seek different types of support from their GPs, such as psychological support, discussing the impact of their disease, medical help (also for non-cancer related problems), and getting general information about their disease.

Macmillan and NHS England are working to implement improved aftercare for people with cancer.

The National Cancer Survivorship Initiative (NCSI) was a partnership between the Department of Health, Macmillan and NHS Improvement. In 2013, NCSI published documents to support commissioners and the health system to deliver services to improve the long-term quality of life of cancer patients. This included tested interventions which can address the needs of people after cancer treatment, including the Recovery Package.

In 2015, an Independent Cancer Taskforce published 'Achieving world-class cancer outcomes: a strategy for England 2015–2020'. The strategy recommended that everyone with cancer has access to personalised care and support after their treatment ends. To help

achieve this, it recommends that NHS England commission services ‘for patients living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the Recovery Package by 2020’.

The strategy also recognises supporting people with cancer to return to work as a key focus. Recommendations include ensuring that return to work is fully integrated into assessment and care planning commissioning of vocational rehabilitation services.

The Government and NHS England have since committed to delivering on these recommendations. The provision of the Recovery Package for cancer patients was included in the ‘NHS Five Year Forward View’, and reiterated in the ‘Next Steps on the Five Year Forward View’, published in 2017. To help deliver these commitments, the NHS Operational Planning and Contract Guidance for 2017–2019 included commissioning all elements of the Recovery Package within its ‘must-dos’ for cancer.



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The Recovery Package consists of:

Holistic Needs Assessment (HNA) and Care Plan – HNA identifies the holistic needs and concerns people with cancer have at a particular time, considering the patient as a whole person rather than just focusing on their cancer. The HNA can be administered at any time during the cancer journey. The responses to the HNA inform the ‘Care Plan’, which captures a record of what needs are most important to the person – including asking about work needs – and how they are going to be addressed, as well as providing the foundation for future re-assessment as needs change along the pathway.

Treatment Summary – sent to the patient and the GP after at the end of each stage of active treatment, it serves as a record of the treatment the patient received that can be looked back on and used to inform conversations around recovery, side effects of treatment, and possible future courses of treatment.

Cancer Care Review (CCR) – triggered by the completion of the treatment summary and carried out by the GP, the CCR encourages conversations between patients and professionals about any issues related to cancer or its treatment – whether clinical or non-clinical – and the impact they have on patients’ quality of life or wellbeing.

Health and Wellbeing events – semi-structured education events that offer relevant support and information to people living with cancer in order to help them become more able to self-manage. Health and wellbeing events can be big or small, based on working with groups or individuals, and are highly flexible depending on the needs or means of the community setting in which they are held.

Needs after treatment



Physical needs

The long term consequences following treatment can involve physical effects with about 500,000 people in the UK suffering from poor health after treatment of cancer. Chronic fatigue, sexual difficulties, pain, urinary and gastrointestinal problems and lymphedema were some of the most frequent physical problems people faced after cancer treatment.⁽⁶⁰⁾

Fatigue and cognitive problems were common barriers identified by cancer survivors to job productivity. These problems lead to having trouble concentrating, reduced ability to multitask and mistakes being made. Fatigue and cognitive problems were not necessarily noticed by managers, leading to them overestimating cancer survivors' capacity to work.⁽⁶¹⁾

A Macmillan survey showed that of the people who returned to work but did not feel ready to 63% said that they would like to return to work when they were physically able to do so.⁽²³⁾



Clinical needs

Around 1 in 3 people report experiencing pain years after their cancer treatment. Pain can be controlled to an extent, with doctors prescribing pain medication or patients trying out alternative therapies such as acupuncture.⁽⁶⁰⁾

On average, 3.9% of working age people with cancer in England stated that they did not receive sufficient help from hospital staff to reduce the pain. This contrasts with only 1.3% of people over the age of 64 experiencing the same dilemma.⁽²⁶⁾

Macmillan research found that around 1.8 million people that had been diagnosed with cancer in the UK in 2015 were living with one or more serious long term health conditions with the top 5 being hypertension, obesity, mental health problems, chronic heart disease and chronic kidney disease. These long term conditions lead to increased needs within the cancer survivorship population.⁽⁷⁶⁾

With more people surviving cancer and an aging population, it is important that primary care plans to support the growing number of people living beyond cancer. GPs are well placed to support these patients, whilst identifying unmet needs and supporting them in the context of other illnesses.⁽⁶²⁾



Practical needs

One of the main practical needs for people who had just finished cancer treatment were issues around going back to work. This involved negotiating working hours and getting a GP letter to secure time off work.⁽⁷⁸⁾

Of those line managers who have made reasonable adjustments to support their employees returning to work, 69% said it was easy or very easy to make these adjustments. This compares with only 35% of those who had not been in this situation, who thought making reasonable adjustments would be easy or very easy.⁽²³⁾

Practical needs after treatment can involve finding out about what benefits people are entitled to and applying for them, dealing with the job centre, and courts during disputes and queries.⁽⁷⁸⁾

Other unmet practical needs involve needs around transport when people have to attend follow-up appointments and other voluntary services which can be difficult to schedule around work and family commitments.⁽⁷⁸⁾

Around 21% of people of working age with cancer in England felt that they were not given enough care and support from health and social services after their treatment. This contrasts with 16.3% of people over 65 who felt the same way.⁽²⁶⁾

Going back to work after cancer treatment can present many challenges to people living with cancer. A Macmillan survey found that only 2% of people with cancer have access specialist return to work services.⁽¹¹²⁾



Financial needs

Costs can occur years after remission due to side effects, and other health conditions. The length of time to recover financially also varies with some people taking two years and other people taking 3–6 years for a recovery. Certain people were considered to be at a greater risk of encountering financial difficulty and would therefore find it harder or take longer to recover from it. These include people who work part time and those who have dependents.⁽⁷⁷⁾

On average, 27% of people with cancer aged 35–64 said that they did not receive information on getting financial help or benefits they may be entitled to.⁽²⁶⁾

A study in Ireland found that cancer-related financial stress was significantly higher in people with dependents, a mortgage or personal loans and who incurred higher household bills after treatment.⁽⁶³⁾

For people unable to return to work, reliance on benefits becomes a necessity although it can cause stigma to the individual.⁽⁶⁴⁾

Information needs

A study found that working age breast cancer patients in the UK felt there was a need for more information on the consequences of treatment. Around 74% of people stated that they wanted to know more about the short term effects of chemotherapy and around 96% wanted to know more about the long term effects.⁽⁵⁶⁾

The same study found that the need for more information on future tests and scans was reported by 79% of working age breast cancer patients. Many people after cancer treatment have a fear of it coming back.⁽⁵⁶⁾

In a 2016 Macmillan survey by YouGov, around 55% of people stated that they did not know where to go for more information and support regarding making decisions on staying in work or returning to work after cancer. Approximately 88% of people were not made aware of return-to-work services in their area which would help manage any health and work issues.⁽²³⁾

Emotional needs

In the life after treatment phase, the emotional needs of patients were a common unmet need as people try to deal with the emotional impact of finishing treatment. Losing the safety net of going through cancer treatment lead to people suffering from anxiety, depression and post traumatic stress. During this time, patients had reduced access to health professionals and family, friends and employers assume that people didn't need as much support at this point of their cancer journey. This can lead to a gap in emotional support at this stage.⁽⁷⁸⁾

In a Macmillan survey, of those people who returned to work before they felt ready to do so, 58% felt that they would have liked to return to work when they felt emotionally ready to do so.⁽²³⁾

Cancer survivors that do return to employment may have trouble coping with work demands if adjustments are not made (as they are entitled to under equalities legislation), and may not physically be able to be as productive as they were before diagnosis. This may lead to feelings of guilt for these individuals.⁽⁵⁸⁾

'I actually enjoyed going back to work. After a long time out sitting on the sofa watching rubbish TV all day long, I was really glad to be able to do it'.

Vivek

NEEDS AND EXPERIENCES: PROGRESSIVE ILLNESS AND END OF LIFE

What do we know about people of working age reaching the end of life?

There were 136,645 cancer deaths in 2015, of which around 32,986 were amongst people of working age.^(8,9,10)

With the right support, 64% of people with cancer (of all ages) would prefer to die at home but only 30% actually do. 27% of people aged 15–64 die in a hospice.^(8,69)

A number of cancer patients at end of life indicate that they still want to work, as it provides a sense of competence and normality, as well as a welcome distraction. However, patients have often said that both they and their employers have found such conversations upsetting and difficult.⁽⁵⁷⁾

What is the impact of giving people with cancer palliative care

Evidence suggests that increased use of palliative care is associated with improved patient functioning which leads to a better quality of life and possibly less aggressive treatments close to death.⁽⁷⁰⁾

To what extent do people of working age die in the place of choice?

Looking at all cancer patients, the proportion of people dying in their own homes decreases with age and there is a corresponding rise in the number of deaths in old people's homes. The proportion of people dying in hospices decreases with age – almost a third of people who die in a hospice are under the age of 65, while only 9% of people age 85 or over died in a hospice.⁽⁸⁵⁾

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

*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.'⁽⁷¹⁾

Where do cancer patients prefer to die?⁽⁸⁰⁾

Preferred place of death in the UK, 2017

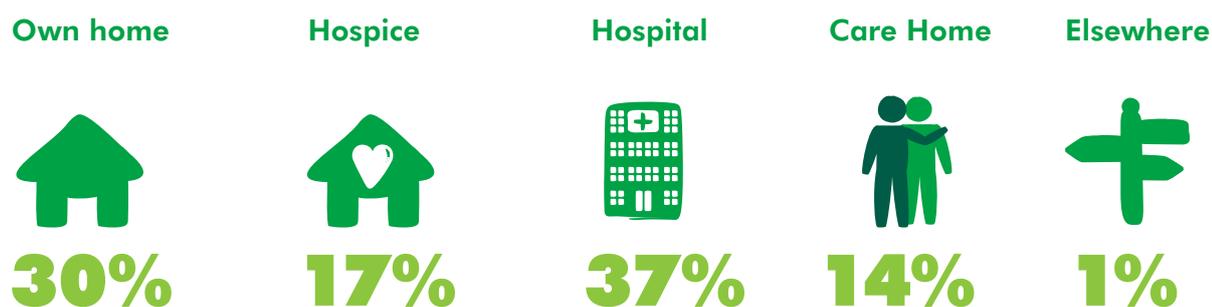


Does not add up to 100% due to an excluded 14% of respondents saying 'don't know'.

With the right support, 64% of people with cancer would like to die at home, and just 1% would like to die in hospital.⁽¹⁴⁾

Where do cancer patients actually die?⁽⁸⁾

Actual place of death in England and Wales*, 2015



Does not add up to 100% due to rounding.

For people who died from cancer, these percentages have remained fairly consistent since 2012.^(8,91)

*Using figures for all neoplasms (C00D48).

Needs at end of life

Physical needs

Various symptoms are very common in advanced cancer. Pain, breathlessness, fatigue, loss of appetite, constipation and insomnia are especially common, occurring in some combination for most patients.⁽⁷²⁾

78% of bereaved families said that the family member they cared for had support to drink or receive fluid. 75% said support was provided to eat or receive nutrition.⁽⁸⁰⁾

Clinical needs

The most frequently reported unmet need for those receiving palliative care is effective communication with healthcare professionals. Where these communications were lacking, participants in a survey reported adverse effects on both patients and carers.⁽⁸²⁾

People who receive specialist nursing care at home in the last three months of their life are more than twice as likely to die at the place of their choice than those who receive no specialist nursing care.⁽⁷⁹⁾

Clinical decisions concerning starting or stopping artificial nutrition and hydration are challenging, particularly for patients who lack decision-making capacity. A systematic literature review found that increasing the patient's quality of life is the main decision-making factor, although the meaning of that term varied. Prolonging life was the second most cited factor; patient's wishes were influential but not determinative.⁽⁸¹⁾



Practical needs

Social care at the end of life includes services offers such as helping people with personal care, helping them get in and out of bed, grocery shopping, meal preparation, prescription collection and other tasks around the house. Getting help with these tasks alleviates some of the pressure from the patient as well as their family members.⁽⁷⁴⁾

Difficulty accessing social care at the end of life is one of the reasons why people are unable to die at home. Social care can provide respite and support for carers who may be struggling as well as avoiding crisis moments which could lead to people being readmitted to hospital.⁽⁷⁵⁾



Financial needs

Patients and their families may have concerns about managing finances at the end of life, particularly when it comes after the patient has experienced a reduced income and other additional costs. Most people who need care at the end of life qualify for disability benefits. People aged under 65 can qualify for Personal Independence Payment (PIP) or Disability Living Allowance (DLA).⁽⁷³⁾

Bank accounts are frozen at the time of death and cannot be used after that point. Patients nearing the end of life may have to consider putting bank accounts under joint names.⁽⁷³⁾

Some pension schemes won't pay out any benefits to partners if the owner of the pension scheme wasn't married, meaning that the pension fund would be lost. A financial advisor may have to be consulted for the best advice on dealing with the situation.⁽⁷³⁾

Information needs

Cancer patients state that they would like to have more information regarding their prognosis when they enter the palliative care. Other key points include information on how to access support services which would facilitate patients at the end of life, and can help with practical needs a patient may face. Involving carers with this information is important as sometimes they get left out of these conversations.⁽⁷⁸⁾

Following hospitalisation in end of life care, patients reported feeling that there was a discrepancy between their priority problems and the palliative intervention determined by professional problem assessment and routines. For example, a lack of time for conversation about their own assessment of issues created barriers.⁽⁸³⁾

In a small qualitative study, both patients and carers described receiving information at the right time as important in helping them cope with advanced cancer.⁽⁸⁴⁾

Emotional needs

Generally emotional needs are less well met at the end of life, as when a patient receives palliative care, physical and practical needs tend to have a greater focus. Carers themselves felt that they were putting the needs of their patient over their own. Generally there is a need for people to talk about their concerns and for additional comfort and company.⁽⁷⁸⁾

Being diagnosed with cancer that cannot be cured can trigger a wide and complicated range of emotions. People receiving such a diagnosis may feel anger, depression, resentment, or a sense of injustice. Some find it helps to talk to professionals from support organisations.⁽⁸⁵⁾

Good planning for end of life circumstances can help those left behind in being able cope emotionally.⁽⁶⁹⁾

Some of the main barriers to choice at the end of life are: ineffective identification of end of life approaching, and conversations about it; a lack of planning or coordination; skills within the community workforce; a lack of access to 24/7 community services; a lack of access to social care; and a lack of support for carers.⁽⁹²⁾

'I've been told that there is a small amount of scar tissue left, which may develop into another tumour at some point in life. But you can't stop and worry about that. If it happens, it happens, and then we deal with it. And I'm fairly happy. I'm very easy going so I'm just getting on with doing things I like. Which is now my teaching and coaching'.

Vivek

LIFESTYLE AND PERCEPTIONS

This section attempts to give an indication of the typical profile of people of working age with cancer, however we know that there is huge variation within the population.

Work and wellbeing

There are not only financial and social benefits of being in work, but also strong evidence to suggest that work and a positive workplace are key drivers for wellbeing.⁽¹⁰¹⁾ For people who experience ill health or disability, remaining in or returning to work can actually help promote recovery and rehabilitation, and lead to better health outcomes.⁽¹⁰²⁾ A Macmillan survey found that, of those who said it was important for them to keep working after diagnosis, 60% said it was to give a sense of normality. 57% said it was to keep positive, keep up morale or self-esteem.⁽²³⁾

Work also promotes independence and full participation in society, and improves quality of life and wellbeing. This was shown in a 2012 survey by the Department of Health in England, where participants in full-time employment after a cancer diagnosis were revealed to be more positive on a range of issues compared to those who were unemployed.⁽¹⁰³⁾

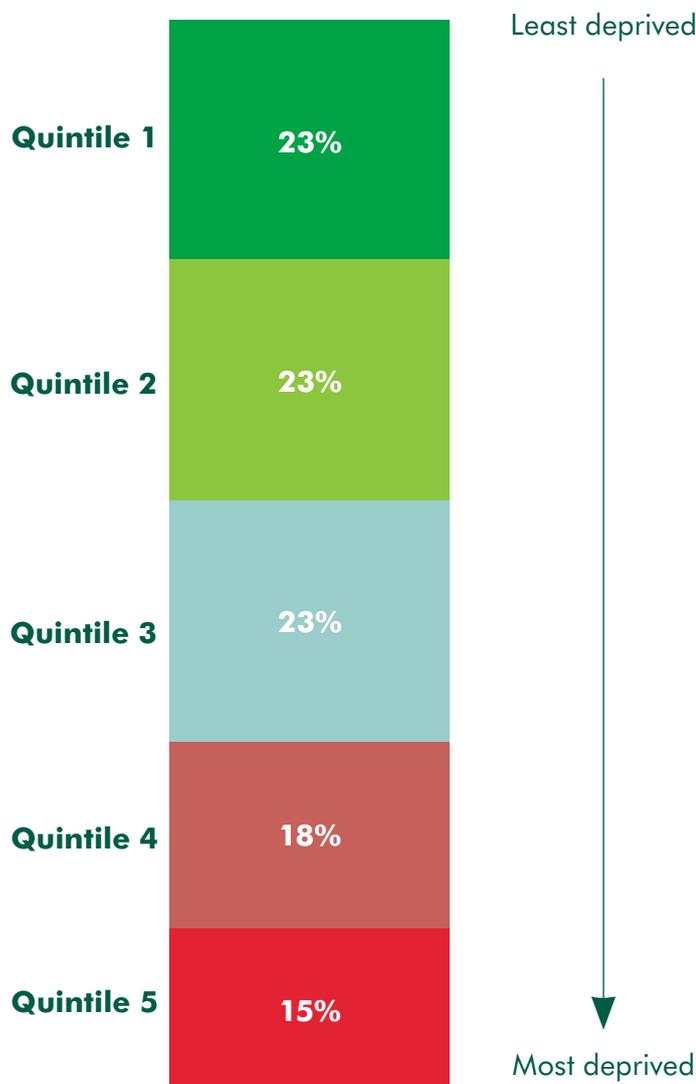
Work and cancer

Work is important for people with cancer. A 2016 YouGov survey for Macmillan found that 85% of people working when diagnosed said that it was important for them to continue working after diagnosis.⁽²³⁾

Cancer and its treatment affect people differently and so the ability to return to work varies greatly between people with cancer. In many cases, however, it is not the effects of the illness or its treatment that stops people with cancer from returning to work, but an absence of the right support. A consequence of this is that many people with cancer fall out of work unnecessarily.⁽¹⁰⁴⁾ In fact, cancer survivors (who are in work at the point of their cancer diagnosis) are 1.4 times more likely to be unemployed than the general population.⁽⁹⁴⁾

How does prevalence vary according to deprivation?

20-year cancer prevalence in 2010 (based on diagnosis in 1991–2010)
by deprivation quintile, England^{(93)*}

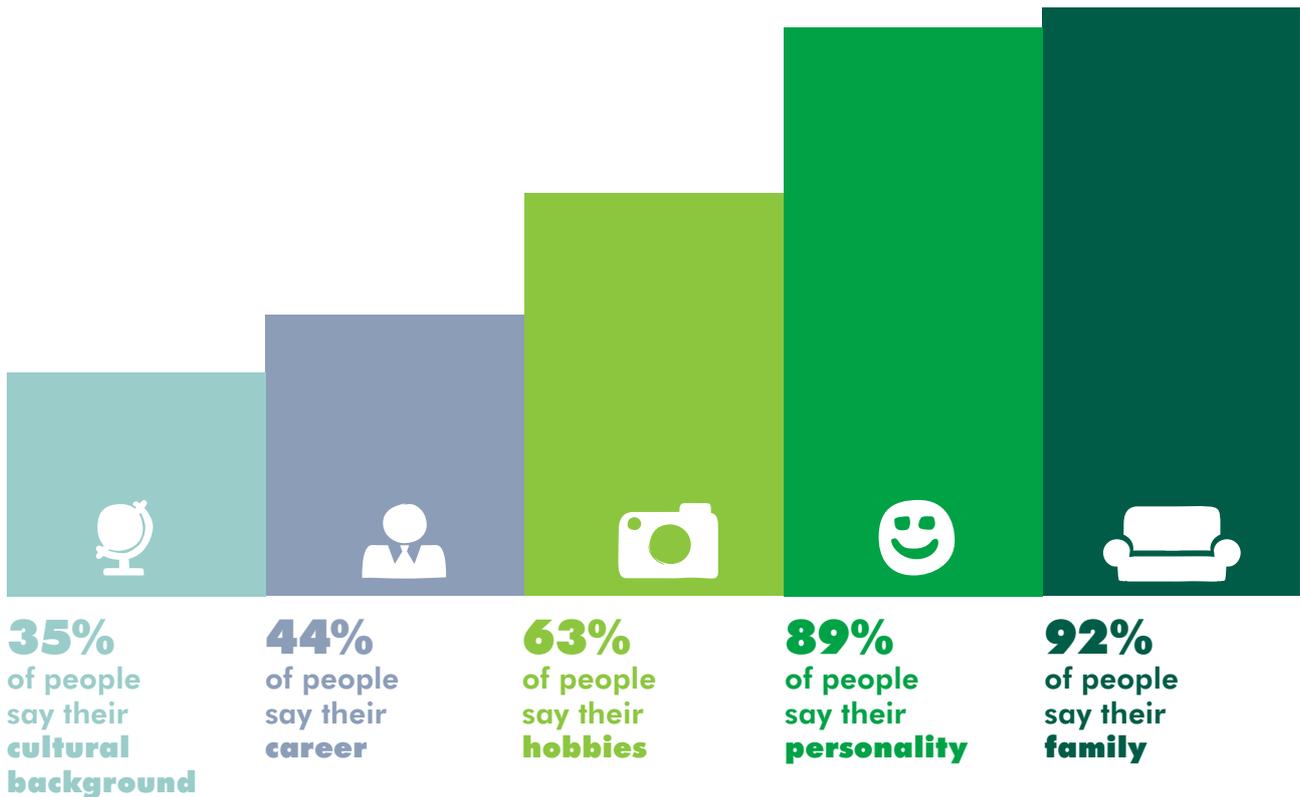


*Based on the Income Domain of the Index of Multiple Deprivation at time of diagnosis.

The levels of deprivation are usually split into quintiles, going from least deprived (quintile 1) to most deprived (quintile 5).

The two least deprived quintiles have the highest cancer prevalence (23% each). This means that there are more people living with cancer in the least deprived quintile, compared to the most deprived quintile (15%).

What is important to people with cancer to their personal sense of identity before diagnosis?⁽¹⁸⁾

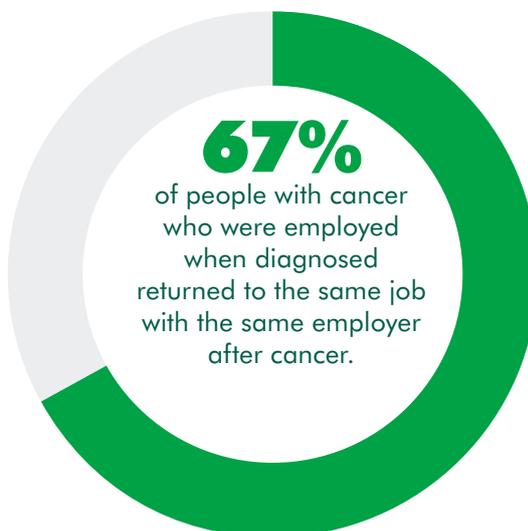
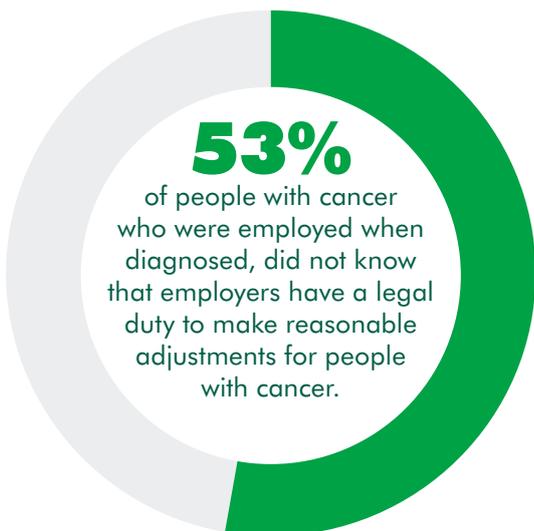
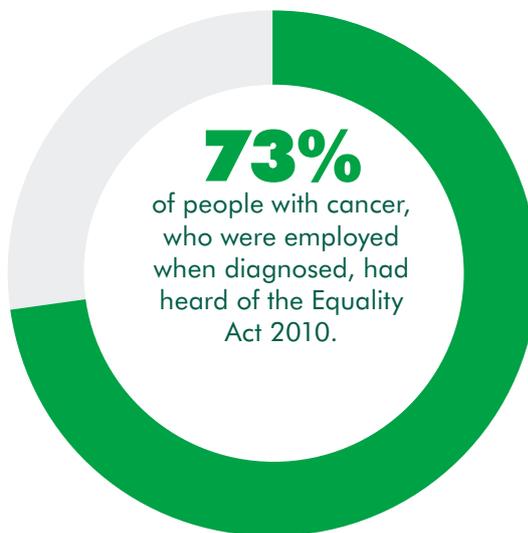
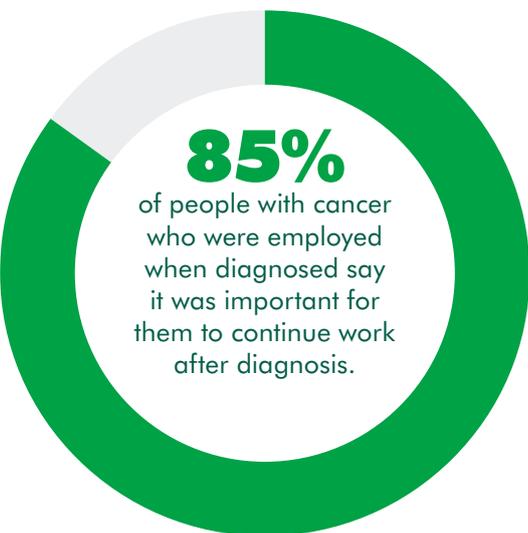


44% of people living with cancer say that their career is important to their personal sense of identity before diagnosis.

'Work were actually very good with it. Being a big financial company, they do have the money to be able to support people when they're off sick. So there was absolutely no issue with that. They let me take my time, and when I did start going back I just started off doing a few hours here and there. But I do realise that I was quite lucky. I've heard some horror stories of people who weren't so lucky with their employers'.

Vivek

What is employees' experience of work and cancer?⁽²³⁾



What is line managers' experience of work and cancer?⁽²³⁾



What do people of working age living with cancer say about work and cancer?

People living with cancer can have different experiences about dealing with cancer in the workplace. The posts in the next two pages show two very different experiences people living with cancer had of managing cancer in the workplace.

The post below is from Terry, who was diagnosed with non-Hodgkin lymphoma in 2010. After taking some time off work due to his illness, he returned and shortly after was told that he would lose his job, to avoid 'hindering his recovery'.

Six years ago, I was diagnosed with non-Hodgkin Lymphoma. Following my diagnosis I had a meeting with my line manager and informed him of my wish to continue working through the treatment.

Initially my line manager was supportive, he said they'd continue to pay me and to take any time off I needed. But I'd only been back at work for a couple of weeks after treatment when he informed me they'd have to let me go. He made it clear he was sacking me because I had cancer, saying they didn't want to hinder my recovery and that by sacking me it would reduce the stress on me.

I went into a state of shock. When I told my wife she burst into tears, it was awful, we had a new born baby and it was the most horrible time for both of us. We really struggled financially during this period and the stress and worry of it all impacted on my recovery.

That month's edition of a Macmillan newsletter had an article on the changes in employment law and people with cancer's rights at work, and it made it clear in the Macmillan booklet that it could be unfair dismissal. After further consideration, we decided that we would sue the company for unfair dismissal and disability discrimination. I was awarded a sum because

of the unfair procedure that was used to sack me.

What had happened made me even more determined to prove that I was in the right and I still look back on my tribunal success with a sense of pride. Pride that my old employer will never be able to do that to someone else and that I stood up for what was right.

Following the case, when applying for jobs you have to declare your reason for leaving. I had to say I'd been dismissed and they'd ask why. I was very good at what I did, but I was now stigmatised because I'd taken a company to court and because I'd had cancer. I was going for jobs where I'd be the most experienced person there, but when I asked for feedback afterwards I was told the reason I hadn't got the job was 'lack of experience'. That hurt.

I decided to turn everything on its head. I am now a mature student studying photography in Preston which has been really good for me. I am in my element. I lost a lot of my confidence after cancer and this has helped me climb back. I suppose photography has been my therapy and it's cancer I have to thank for where I am now. It has given me a fresh start. I wouldn't have gone to university at this age if I hadn't had cancer.

The post below is from Julia, who was diagnosed with ovarian and womb cancer in 2011, and a year later the cancer returned in her lymph nodes, which required both radiotherapy and chemotherapy. After speaking to her consultant about side effects and her employer about the support available, Julia realised that working during treatment was possible and right for her.

I needed two operations three weeks apart and the longest time that I took off work completely was six weeks. I didn't initially know how long I would need to be off work, but was reassured when I found out about my sick pay entitlement.

When the cancer returned in my lymph nodes I needed chemotherapy and radiotherapy. I asked my consultant whether I should or shouldn't return to work during treatment. I knew if I could I wanted to be working as it is something I love doing and it would help me feel that life was carrying on as normal. They told me that it could be possible, but that I shouldn't feel pressured to do anything, and also let me know about side effects that I might face, like tiredness. I also found out about what time off I would need for treatment, which for chemotherapy was every three weeks for six sessions.

When I spoke to my head of department, Judy, I found out that changes could be put in place to support me. This reassured me that I could return to work during treatment and not compromise my health. It was helpful that I had already been given information from the consultant about side effects. I knew chemotherapy would make me tired and I needed to be careful not to be surrounded by

germs so we were able to agree changes to my responsibilities. Instead of teaching whole classes I mainly did administrative tasks that didn't involve me having to stand up for an hour and weren't stressful or urgent. I did some one-to-one work with children too, but if they were ill they wouldn't come to see me.

During my radiotherapy I had appointments every day for five weeks. Knowing that my employer could be flexible with my timetable helped me feel confident that remaining in work during treatment was the right decision. It also helped that I spoke to my manager about reviewing how things were going on an ongoing basis, so I knew I could approach her if there was a problem or if I was struggling.

I teach at the same boarding school today and this experience made me realise how much my employer supports and values its staff. My advice to anyone who wants to continue working with cancer would be to find out information you need about your situation, including the side effects you may face, and relay this information to your employer so adjustments you need can be put in place. I think it's also important to be prepared and to find out about legislation that protects you at work in case you need it.

What are people of working age living with cancer saying about their experience?

My employer has been supportive in the sense that there hasn't been any pressure to return early, but I do feel I've made more effort to keep in touch with them than they have with me. The last time I went in to take my sick note I felt very much like a spare part.

Anonymous

I have a stressful job which is physically demanding and unsympathetic managers. I'm only entitled to eight weeks sick pay and I need to save them for the hysterectomy so don't know how I'll cope to continue working.

Julie

I found the hardest thing through it all was how much my life had changed, always having worked. I felt really isolated as everyone around me continued as normal.

Jane

What do employers think about providing support to staff members with cancer?

Research with employers for Macmillan has shown that many employers do not understand cancer or how best to support employees with cancer in the workplace. Macmillan has developed a programme – Macmillan at Work – offering information, training and resources to line managers and HR Professionals. More information can be found at www.macmillan.org.uk/atwork

The example below is from a manager at Norwich City Council, who talks about the challenges of managing a staff member with cancer.

I supported a team member through their cancer and it was a strong desire of my team member to continue working as long as possible. We supported this until they took the decision to stop working themselves. Consideration needed to be made around the health and safety for the individual and adjustments were made to the role to ensure this.

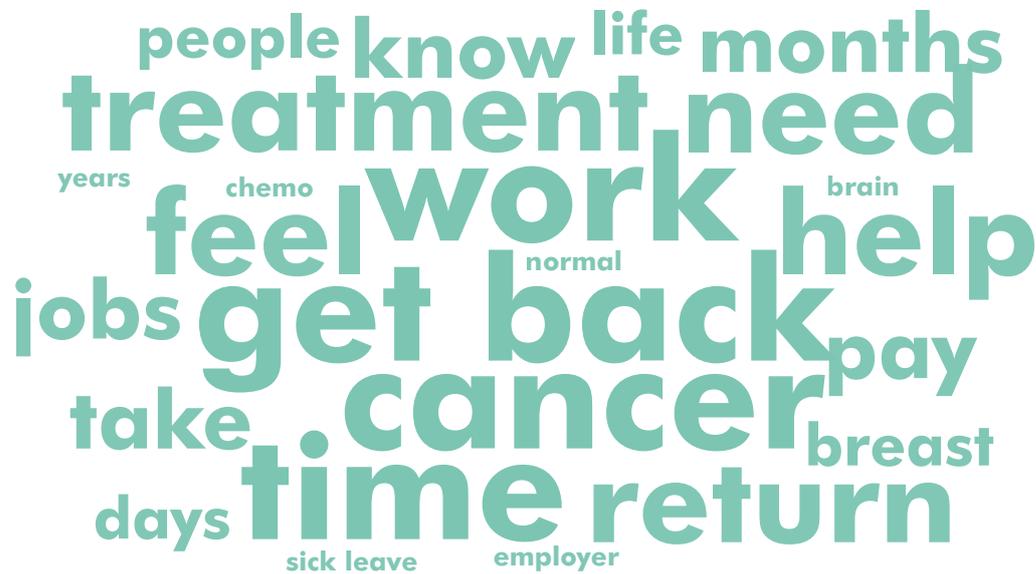
I agreed with the individual that they could take short notice days off when they became tired. When their health deteriorated and they were unable to manage their full workload or undertake site visits, I brought in a consultant to work alongside them. It was important to balance allowing them to work as long as possible and ensuring they did not feel sidelined with ensuring the service to the public didn't suffer. The proximity of their desk to the toilet and to fire exits was a consideration.

As an employer, we also needed to consider how to maintain the service. This can be especially hard when the person with cancer is the only one who does a job within the organisation.

I was given a great deal of support by the HR team. They helped me to understand the council's policies, the legal obligations on the council, access the occupational health service and provided advice about the best way to deal with the difficult situations that arose through managing my team members' decline. I am also very grateful for the emotional support they gave to me, as it was especially difficult because there was such a sad outcome. I could not have done this without support from HR colleagues, useful information from Macmillan and a brilliant team who loved the individual and wanted the best for them.

As to advice to employers dealing with cancer in the workplace, I would say that the employer needs to be sensitive to the needs of the person with cancer. The starting point for this is to ask them what support they need. People have different preferences, for example, whether to remain at work, have their workload eased and the knowledge of their condition shared. The way they would like to be treated will vary over time according to the progression of their condition and their own mental attitude towards it, so it is important to regularly check how they feel. It is important to monitor and respond to the emotional needs of other members of staff who are likely to be affected by their concern for their colleague.

What our online Macmillan Community members are saying about work and cancer



How the media* portrays work and cancer...



*UK national daily newspapers.

Note: these 'word clouds' give greater prominence to words that appear more frequently in the source text.

What does this tell us about people's perception of work and cancer?

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

References to going back to work after cancer are predominant in the online community, as shown by the prominence of words such as 'return' and 'get back', as well as references to time (such as 'years', 'months', 'days'). The presence of terms like 'sick leave' and 'pay' shows how financial issues in particular are an important topic of conversation for members of the community.

The media seem to focus more on the implications of work and cancer from the point of view of the employers. Terms such as 'employees', 'workers' and 'staff' highlight an interest in the relationship between people living with cancer and their employers. The system regulating work and cancer also emerges as an area of focus for the media, as shown by the presence of words such as 'regulatory', 'association' and 'company'.

SPECIALIST THEME: WORKING THROUGH CANCER

People respond to cancer and its treatment in different ways. Whilst not everyone will be able to work after a cancer diagnosis, Macmillan research shows that 85% of people who were working when diagnosed felt that it was important to them to be able to return to work.⁽²³⁾

44% of people with cancer say that their career was important to their personal sense of identity before they were diagnosed.⁽¹⁸⁾

However, long term side effects of cancer or its treatment, such as fatigue, pain, nerve damage, incontinence, or mental health problems can affect people's ability to work. These don't necessarily have to mean giving up work, but adjustments may be needed at any time after a person returns to work.

A recent survey for Macmillan found that 1 in 5 people with cancer were discriminated against at work because of their cancer.⁽²³⁾

Cancer survivors are 1.4 times more likely to be unemployed than the general population. Many struggle with little or no coordinated support to remain in work following treatment.⁽⁹⁴⁾

The longer people remain off work, the more likely they are to fall out of work completely.⁽¹⁰⁵⁾ It is well recognised that more needs to be done to prevent people from falling out of work and to support them to remain in work.

What does this support look like?

Everyone with a cancer diagnosis who is employed or who has the potential to be employed should receive support to remain in or return to employment. This 'work support' comprises of any activity concerned with meeting the needs of people with cancer with regard to work.

Vocational rehabilitation is a service or approach which aims to help people with a health problem to stay in or return to work. Vocational rehabilitation is not a matter for healthcare alone. It commonly requires a combination of healthcare and workplace interventions, to address the health problem and work issues.

Macmillan's Working through Cancer programme works to ensure that people with cancer are supported to return to or remain in work if they are able to. The Programme has identified three main barriers which people face in returning to work after cancer:

1. A lack of information and advice about the impact of cancer on work
2. A lack of support or understanding from employers
3. A lack of specialist vocational rehabilitation programmes

1. Improving access to information about the impact of cancer on work

Most people with cancer will need some information or support to understand how to self-manage their condition – for example, advice on how best to manage the side-effects or consequences of their treatment in relation to work. They may also need:

- employment advice, such as information on their rights at work under the Equality Act 2010 or how to talk to an employer
- advice to understand what is meant by “reasonable adjustments” and what adjustments could be made to aid return to work. A recent survey for Macmillan found that 53% of people with cancer who were employed when diagnosed did not know that employers have a legal duty to make reasonable adjustments for people with cancer.⁽²³⁾
- information from healthcare professionals on the impact of their condition or treatment on their work-life

What is Macmillan doing?

Macmillan has been active in providing information and support to people affected by cancer through several different channels:

- Online and offline information resources and content for both people with cancer and their carers. For more information, see www.macmillan.org.uk/work
- Online awareness raising campaigns to help people living with cancer understand their rights at work under the Equality Act 2010 and the Disability Discrimination Act in Northern Ireland, including the right to reasonable adjustments and the support that is available through our website and elsewhere. (To find out more visit: www.macmillan.org.uk/rightsatwork)
- A telephone based Work Support service, established in 2014 in partnership with the legal charity LawWorks. The aim of the service is to help people self-manage their work-related issues. And, where legal advice is needed, the service can help people access this from LawWorks’ volunteer solicitors.

Macmillan has also developed resources for Healthcare professionals to help them support patients with work issues. For more information, please see www.macmillan.org.uk/workandprofessionals and be.macmillan.org.uk/work.

Top five work issues raised by people affected by cancer on Macmillan’s helpline:



41%
reasonable
adjustments

34% 
capacity/
coping at work



26%
discrimination



21%
unhelpful/
unsympathetic
employer



18%
sickness
absence

2. Building supportive workplaces

With the numbers of people of working age with long term conditions, including cancer, expected to rise, employers need to consider and improve their response to supporting these employees at work.

Communication with employees is key – line managers need to be upskilled and equipped to have conversations with staff in order to be able to discuss their needs and properly support them.

There is also a need for more proactive and supportive approaches to be developed across organisations, such as developing clear company policies and applying these consistently across organisations. At the same time line managers also need to be able to interpret the policies flexibly to make the right decisions for each employees case.

There is also a need to build understanding amongst employees and employers of rights at work under the Equality Act 2010, including

the right to reasonable adjustments. For example, more could be done to improve understanding of how a variety of reasonable adjustments, depending on need, can be implemented to support an individual to stay in or return to work.

It is important that line managers understand the fluctuating nature of cancer – and the long term impacts – which result in a need for reasonable adjustments to be regularly reviewed and changed if required.

A survey for Macmillan found that 69% of line managers who had made reasonable adjustments said it was easy or very easy to make the adjustments, compared with only 35% of line managers who had not been in this situation, who thought making reasonable adjustments would be easy or very easy.⁽²³⁾

Understanding an individual's needs and what reasonable adjustments could be made can be a key factor in job retention.

Macmillan at Work – Macmillan's offer to employers

Initial research carried out by Macmillan with large employers (>250 employees) found nearly **a fifth of line managers felt either quite or very uncomfortable talking about cancer.**⁽¹⁰⁶⁾ Further findings indicated a relatively weak understanding of cancer as an illness and its effects in the workplace, with 90% of line managers saying they would benefit from additional resources or support, both online and offline, as well as access to more bespoke face-to-face support.⁽¹⁰⁶⁾

Key areas where they felt more support was needed included:

- Awareness raising of work and cancer issues generally e.g. how it impacts on sickness absences
- Dedicated support for line managers with a focus on dealing with the 'emotional side', 'having difficult conversations' and 'awareness of the types of treatment and support'
- Increased awareness of signposting to support employees living with and beyond cancer.

In response to these findings and subsequent market research, in July 2014 Macmillan set up a programme of information, training and resources for employers called Macmillan at Work. Macmillan at Work has been specifically designed for line managers and HR professionals to help them support employees affected by cancer. Once signed up online to Macmillan at Work, employers get access to a range of free resources including the Macmillan Essential Work and Cancer Toolkit, quarterly newsletters and e-learning modules. In addition, employers can also book a free specialist workplace training sessions or more in-depth paid for training to upskill line managers and HR professionals.

For more information contact the Macmillan at Work team at workandcancer@macmillan.org.uk or visit www.macmillan.org.uk/atwork

3. Access to work-focused health support

As well as supportive workplaces, many people will need help to overcome the health barriers of their condition. People with cancer need information from healthcare professionals (HCPs) about how their illness or treatment might impact their work. Healthcare professionals need to be encouraged to raise work routinely with patients.

Macmillan has carried out research into attitudes of HCPs which found that uncertainty about how to talk about employment issues was one of the main reasons HCPs did not raise work with patients.⁽¹⁰⁸⁾

Any service to support people to remain in work will need to consider the health needs of individuals and provide access to appropriate health interventions to manage or resolve the health impacts of the condition.

This should begin with referral to an occupational health service or vocational rehabilitation service for an assessment of individual needs, but more complex cases or those requiring rehabilitative treatment will require access to occupational therapy or specialised vocational rehabilitation services.

Any service to manage the health impacts of a condition should include case management and advocacy on the patient's behalf to the employer, when necessary. Regular reviews are also needed with individuals to make sure they are still managing with their employment, especially with a long-term, fluctuating conditions such as cancer.

Currently most employees, particularly the self-employed, do not have access to Occupational Health services via their employer, and only 2% of people with cancer access specialist return to work services.⁽¹⁰⁷⁾

What is Macmillan doing in this area?

Vocational rehabilitation pilots

As part of the National Cancer Survivorship Initiative (NCSI), Macmillan piloted new models of Vocational Rehabilitation (VR) services for people with cancer at seven pilot sites across England from April 2010 to July 2011. The service configuration and methods varied at each site. The final evaluation of the pilots demonstrated:

- A significant improvement in employment status between referral and discharge for many of those who received an intervention. 38% went from "not working to working" or from "sick leave to full work or modified work". Whilst 7.8% remained in work or remained in a modified role.⁽¹⁰⁹⁾
- The average cost per patient was approximately £850, with a range of £380 to £1,500. Costs altered depending on the number of referrals, with more referrals bringing the cost down.⁽¹⁰⁹⁾
- That the VR interventions required for people with cancer are transferable to a range of other long term conditions.⁽¹⁰⁹⁾ This was further confirmed in a roundtable held in 2012 by Macmillan and The Work Foundation and representatives from a range of long term condition organisations.⁽¹¹⁰⁾

References, sources, notes and caveats

Photo and quotes

The photo on the front cover and on page 5 and quotes on pages 5, 33, 39, 45, 51 and 55 are from our cover star Vivek, 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, colorectal, etc) or by gender, age, etc. The latest data we have is for 2015, and we know that over 350,000 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’ 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 2015, and we know that over 160,000 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, five-year or ten-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_14
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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 (2017 update)	MAC13838_17
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 (2017 update)	MAC13845_17
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 (2017 update)	MAC13732_17
The Rich Picture on children with cancer	MAC14660_14
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 (2017 update)	MAC13841_17
The Rich Picture on carers of people with cancer (2016 update)	MAC16275_10_16
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 [be.macmillan.org.uk](https://www.be.macmillan.org.uk)

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

At Macmillan, we know how cancer can affect everything. But you are still you with a life to lead, friends to see, family who need you and people to love.

Macmillan is here to help you get on with your life no matter how cancer affects you. We can give you the practical, emotional and genuinely personal support you need to hold on to who you are and what's important to you.

We can be there for you during treatment, help with work and money worries and give you the time you need to talk about your feelings or whatever's troubling you. Whether it's everyday things like the cost to park at hospital during treatment or big stuff like explaining cancer to your children, we'll do all we can to support you.

We'll be honest: cancer can be tough. But we've helped millions of people through it and we can do the same for you. To us you're always a person, never just a patient. Life with cancer is still your life and we will help you live it.

From diagnosis, for as long as you need us, you can lean on Macmillan. Call us free on **0808 808 00 00** or visit **macmillan.org.uk**

Life with cancer is still life – we'll help you live it.

**WE ARE
MACMILLAN.
CANCER SUPPORT**