



THE RICH PICTURE

OLDER PEOPLE WITH CANCER

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Joyce, 83, living with cancer

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



About this 'Rich Picture'

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

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

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

The information could be valuable in many ways:

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

This document is not intended to

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

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

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

This 'Rich Picture' is one of a suite of documents. To access these documents please visit

<http://www.macmillan.org.uk/Richpictures> or for further information please contact evidence@macmillan.org.uk

The legal bit

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

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

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

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



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Guidance on referencing this document

You are free to use any of the data contained in this document, however when quoting any factual data that do not belong to Macmillan, it is best practice to make reference to the original source – the original sources can be found in the References section at the back of this document on page 58.

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 booklet 'Cancer and Older People' (MAC11666) more helpful:



**Cancer and
Older People**
MAC11666

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

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

OTHER RELATED INFORMATION FOR MACMILLAN STAFF

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

Case Study Library

People affected by cancer

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

Professionals/Services

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



Comms Platform

Describes how to communicate with people affected by cancer.



Rich Pictures

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



Impact Briefs

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



Local Cancer Intelligence

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



Routes from Diagnosis

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



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

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SUMMARY OF OLDER PEOPLE WITH CANCER

Key stats

The **greatest risk factor for cancer is age**, and **60%** of new cancer diagnoses are amongst people **aged 65+**.^(1a, 1b, 1c, 1d)

Older people are much **more likely to have experienced cancer** than younger people. Around **13%** of people aged 65 or over are living with or beyond cancer, and there are almost **1.1 million older people (65+)** living with cancer in the UK.⁽⁹⁾

The total number of older people (65+) has increased over the last 30 years and this is set to continue. **By 2050 people aged 65+ could make up a quarter of the population.** Also, the fastest growing age group within this group will be those aged 85+. With cancer being strongly correlated with age, this has obvious implications for our health and social care systems.⁽¹⁶⁾

60% of everyone getting cancer are aged 65+.

Diagnosis

Some older people **may not be aware of their increased risk of cancer** due to age and may have **lower awareness of cancer symptoms** than the younger age groups – this can lead to late diagnosis for older people.⁽¹⁷⁾

Psychological distress amongst older people diagnosed with cancer can vary – elderly people alive today had grown up at a time when **cancer was unmentionable**, and for some older people a cancer diagnosis may bring **additional stress** that may not be felt by younger people.^(31, 48)

Breast, prostate, lung, colorectal, bladder, stomach, pancreatic and ovarian cancers are amongst the most commonly diagnosed cancer types for older people.⁽²⁹⁾

Older people can suffer additional psychological distress, especially at diagnosis.

Treatment

Evidence suggests that **older patients may be under-treated** and that their **outcomes may be poorer** as a result. Older people are less likely to receive radical surgery than younger people, and radiotherapy is used less often in elderly patients. Several studies suggest that differences in treatment partly explain poorer survival in older people with certain cancers.⁽¹⁸⁾

Fewer older people receive **information from hospital staff about financial help and benefits** than in other age groups.⁽²⁷⁾

Older cancer patients are less likely to receive certain treatments.

Survivorship

There is a **lack of information and knowledge** given to older patients and carers **regarding their follow-on care.**⁽⁹⁹⁾

The most frequently reported psychological problems in older cancer survivors are **anxiety, depression** and **loss.**⁽⁷³⁾

Older people with cancer can be **less likely than younger people to have a support system in place**, often because they have lost close family members or do not live close to them.⁽⁴⁸⁾

Older people with cancer may be less likely than younger people to have a support system in place

End of life

41% of the cancer deaths in older people took place **in hospital**, and only 29% of cancer deaths in older people take place **in the home.**⁽⁷⁸⁾

78% of all cancer deaths are amongst the 65+ age group.^(2a, 2b, 2c)

78% of all cancer deaths are amongst the 65+ age group.

Lifestyle & perceptions

Older people **tend to be stereotyped** as a homogenous group characterised by passivity, failing physical and mental health and dependency. However **it is difficult to categorise 'older people' as they are such a diverse group.**^(see page 48)

Frailty amongst older people varies – some older people are frail, while others are in good health, but all of them have different individual needs.^(see page 48)

Older people **watch more TV** than other adults, but **use mobile phones much less.** They listen to about the same amount of radio. Only **40% of those aged 65+ access the internet**, compared to 76% of those under 65 in the UK.^(92, 93)

INTRODUCTION TO OLDER PEOPLE WITH CANCER

Who are older people with cancer?

- We recognise that there is no standard definition of 'older people' and it varies according to country, organisation and context.
- For many, it means people of pensionable age, and this often translates to those aged 65+.
- For the purposes of creating this 'rich picture' we have taken the most easily available data, as data is sometimes only available for the 60+, 65+, 70+ or 75+ age groupings.
- Where possible we have given data on more than one age bracket (eg both 65+ and 70+) to give more consistent comparisons.
- There are some interesting differences for what might be termed 'very old' people – this is generally taken to be 85+.
- Where there are interesting variations between the 'old' and the 'very old' groupings, the insight has been included in this document.

Want to know more?

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

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

'I was diagnosed with cancer a couple of years ago. I'm 82 next year and not afraid to say it! I find it surprising that some people will still make judgements on a person because of their age. We're all different.

I don't drive so I've always walked everywhere. I soon got into my local walking group and now I'm very experienced. I plan and lead Rambler walks that some would find difficult but for me it's quite easy!'

Joyce, 83

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for older people with cancer

The estimated total number of people living with cancer in the UK in 2015 is almost 2.5 million. Assuming that all existing trends in incidence and survival continue cancer prevalence is projected to increase to **4 million** in 2030. Particularly large increases are anticipated in the oldest age groups and in the number of long term survivors. By 2040 77% of all cancer survivors will be at least 65 years old and 69% of cancer survivors will be at least 5 years from diagnosis.⁽⁹⁾

Macmillan's ambition is to reach all of these people and help improve the set of 9 Outcomes you can see opposite. Remember, certain groups will identify more or less strongly with the various Outcomes.

Around 1,093,279 older people were living with cancer in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.⁽⁷⁷⁾

How is this different for older people with cancer?

Macmillan is carrying out work internally to 'baseline' the 9 Outcomes, and we hope to be able to show how the 9 Outcomes vary for different groups. This document will be updated when this work is complete.

The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

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

Those around me are well supported

I am treated with dignity and respect

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

I can enjoy life

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

I want to die well

THE FACTS ON OLDER PEOPLE WITH CANCER

This section of the 'rich picture' presents some of the key stats and facts relating to older people with cancer. You may benefit from referring to the jargon buster on page 66 for details on some of the terms used in this section. Please note that incidence and mortality data on all cancers exclude non-melanoma skin cancer.

64%

of new cancer diagnoses are amongst older people (65+)^(1a, 1b, 1c, 1d)

1,093,279

older people were living with cancer in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.⁽⁷⁷⁾

14,000

cancer deaths in the UK in those aged 75+ could be avoided if UK cancer mortality rates in the elderly were the same as the USA⁽⁹⁵⁾

78%

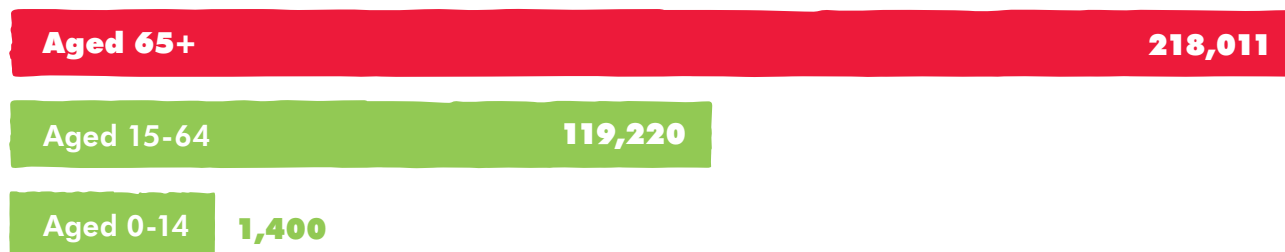
of all cancer deaths in the UK are amongst older people (65+)^(2a, 2b, 2c)

1/4

of the UK population will be aged 65+ in 2051⁽¹⁴⁾

How many older people get cancer per year? (incidence) ^(1a, 1b, 1c, 1d)

Cancer incidence, UK, 2012, by age grouping



64% of new cancer diagnoses are amongst older people aged 65+.

What are the most common cancer types amongst older people? ⁽²⁹⁾

The top 5 most commonly diagnosed cancers in men over 75 in the UK are prostate, lung, colorectal, bladder and stomach cancer.

The top 5 most commonly diagnosed cancers in women over 75 in the UK are breast, colorectal, lung, pancreatic and non-Hodgkin lymphoma.

How many older people die from cancer per year? (mortality)^(2a, 2b, 2c)

Cancer mortality, UK, 2012, by age grouping



78% of all cancer deaths are amongst the 65+ age group.

How many older people are currently living with cancer? (prevalence)⁽⁷⁷⁾

Older people living with cancer in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.

1,093,279

Older people are much more likely to have experienced cancer. 13% of the population aged 65 and over are living with or beyond cancer. This compares to less than 1% of the population aged under 45.

Total prevalence for the 4 most commonly diagnosed cancers for those aged 65+, UK, 2008⁽³⁾

People with cancer 65+ years		
	Number	% of population
Breast	316,000	6
Colorectal	186,000	2
Lung (& trachea)	50,000	<1
Prostate	219,000	5
All other cancers	488,000	5

Older people are more likely than their younger counterparts to have experienced cancers of the breast, colorectum, prostate and lung. However lung cancer has a relatively low prevalence, partly due to the poor prognosis for lung cancer.

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) 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 older people get cancer per year in England? (incidence)^(1a)

181,303

new cases of cancer diagnoses in those aged 65+ in England in 2012.

How many older people die cancer per year in England? (mortality)^(2a)

104,151

Cancer deaths in those aged 65+ in England in 2012.

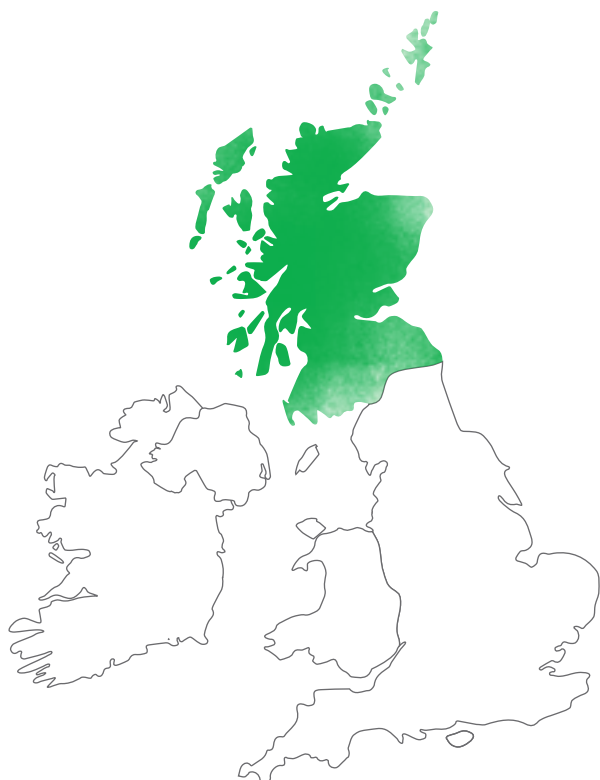
How many older people are living with cancer in England? (prevalence)⁽⁷⁷⁾

914,366

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

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



*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) 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 older people get cancer per year in Scotland? (incidence)^(1c)

19,264

new cases of cancer diagnoses in those aged 65+ in Scotland in 2012.

How many older people die cancer per year in Scotland? (mortality)^(2b)

12,234

Cancer deaths in those aged 65+ in Scotland in 2012.

How many older people are living with cancer in Scotland? (prevalence)⁽⁷⁷⁾

93,101

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

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



*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) 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 older people get cancer per year in Wales? (incidence)^(1b)

11,920

new cases of cancer diagnoses in those aged 65+ in Wales in 2012.

How many older people die cancer per year in Wales? (mortality)^(2d)

6,838

Cancer deaths in those aged 65+ in Wales in 2012.

How many older people are living with cancer in Wales? (prevalence)⁽⁷⁷⁾

59,728

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

What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



****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) 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 older people get cancer per year in Northern Ireland? (incidence)^(1d)

5,524

new cases of cancer diagnoses in those aged 65+ in Northern Ireland in 2012.

How many older people die cancer per year in Northern Ireland? (mortality)^(2b)

3,078

Cancer deaths in those aged 65+ in Northern Ireland in 2012.

How many older people are living with cancer in Northern Ireland? (prevalence)⁽⁷⁷⁾

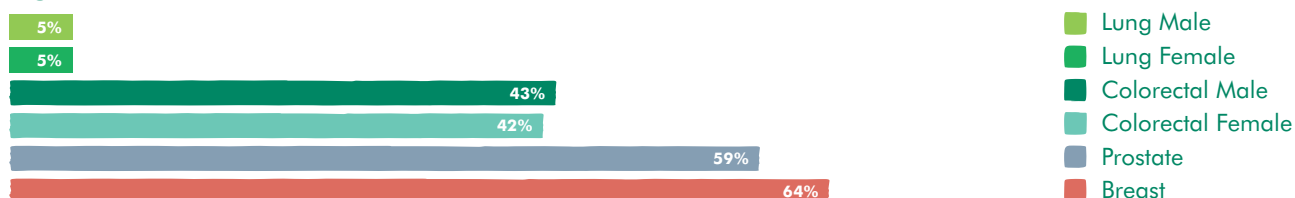
26,084

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

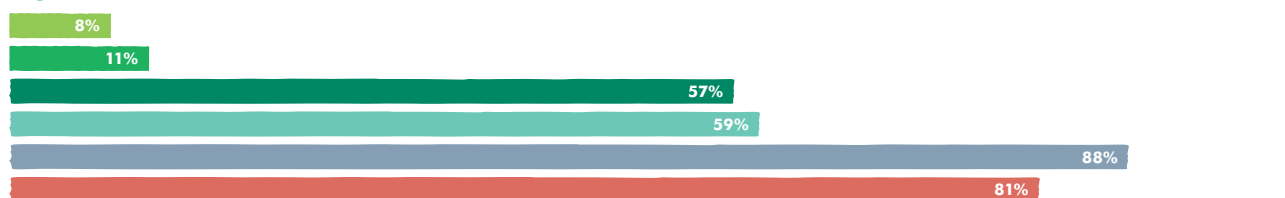
What proportion of older people survive cancer? (survival)⁽⁴⁾

Relative 5-year survival rates for the top 4 cancers, by age in England for patients diagnosed between 2007-2011, followed up to 2012

Aged 80–99



Aged 70–79



Aged 60–69



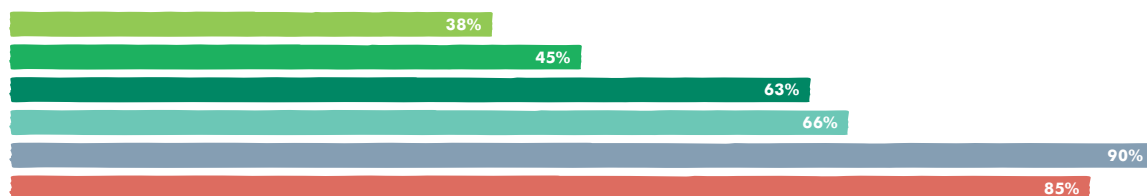
Aged 50–59



Aged 40–49



Aged 15–39



As a general rule, chances of survival decrease with age. Reasons for this could include less aggressive treatment offered to the elderly, a smaller proportion of older patients being entered into clinical trials, younger patients developing more easily treatable cancers (for some cancers) and older cancer patients being more likely to be diagnosed with later stage disease when survival rates are lower.

Exceptions to this general rule are breast and prostate cancer which tend to be more aggressive in younger people.

‘It is absolutely vital that we look at new assessment methods in order to improve survival rates and the experience of older people with cancer.’

Ciarán Devane,
Chief Executive 2007–14,
Macmillan Cancer Support

How do UK survival rates compare internationally?

Survival for older people in the UK with cancer is lower than in some other European countries. Relative 5-year survival rates for cancer patients aged 75+ diagnosed in 2000-2007 was 34% for the UK and Ireland, compared to 54% for Sweden, 49% for Germany and 46% for France. The UK is also performing worse than the average for Europe as a whole (42%).⁽⁶⁾

More than 14,000 cancer deaths in the UK in those aged over 75 would be avoided each year if UK mortality rates were the same as the USA.⁽⁷⁾

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

Gender

In terms of incidence, in the 25-49 age group, almost twice as many females than males are diagnosed with cancer; this trend reverses in those aged 50 and over with slightly more cancer cases in males than females. Therefore, with older people, men have a higher incidence rate of cancer than women.⁽²⁹⁾

As a general rule, one-year relative survival for women is better than for men, due to high survival rates for breast cancer as well as differences in the relative incidence of different cancers in men and women.⁽¹⁰⁾ However survival rates for men and women aged 70+ are usually approximately equal.⁽⁶⁾

Ethnic background

Both males and females from the Black ethnic group aged 65 and over are at a higher risk of cancers of the stomach, liver and myeloma as compared with White people. Asian and Black females aged 65 years and over are at higher risk of cervical cancer compared with White females.⁽¹¹⁾

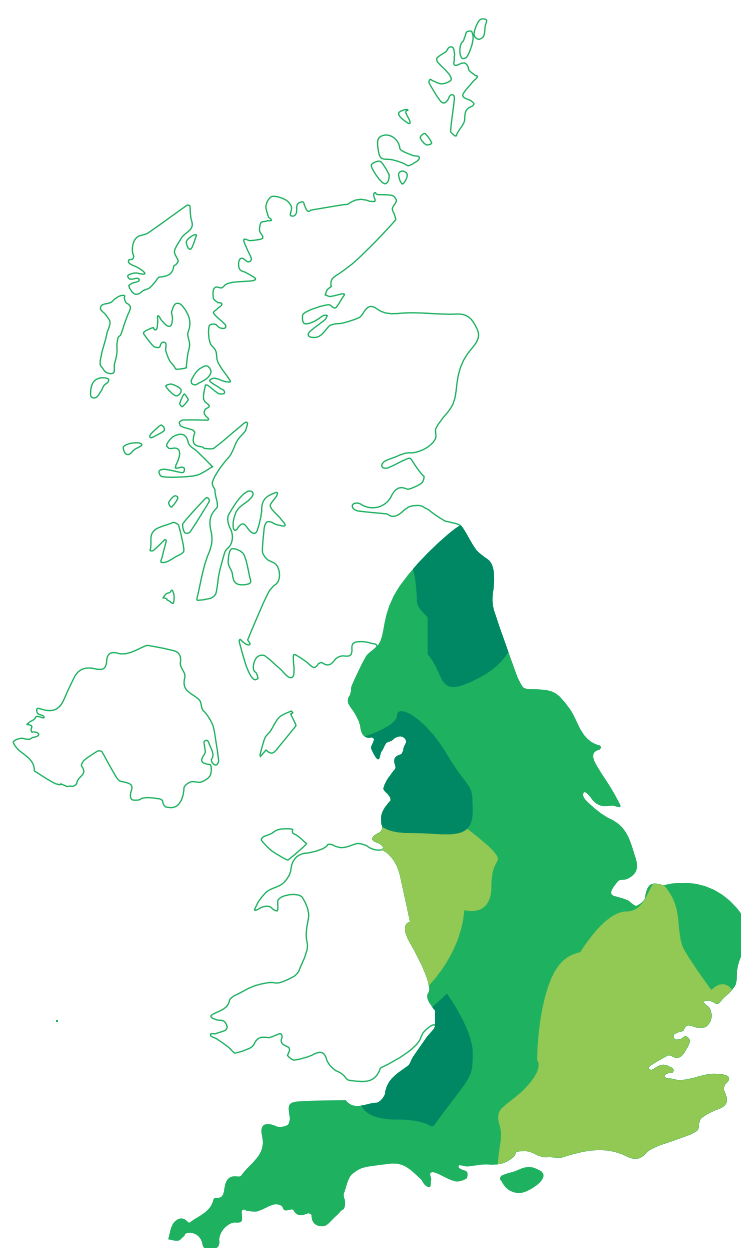
Age

Looking at differences between older people with cancer and very old people with cancer, we know that from 1995-97 to 2003-05 cancer mortality rates fell by 16-17% for those aged between 55 and 75, but cancer mortality rates increased by 2% in those aged over 85 years old over the same period.⁽⁷⁾

Social background

Although not specific to older people, we know that survival is worse in more deprived groups for each of the most common cancers (colorectal, breast, prostate and lung. Possible causes for these gaps include: differential stage at diagnosis related to uptake of screening and early diagnostic procedures, differential access to optimal treatments and co-morbidities that impact treatment.⁽¹²⁾

What are the geographical 'hotspots' for cancer incidence and mortality amongst older people?⁽⁸⁾



Incidence of cancer (75+) per 100,000 population, England, 2003–2005

Low

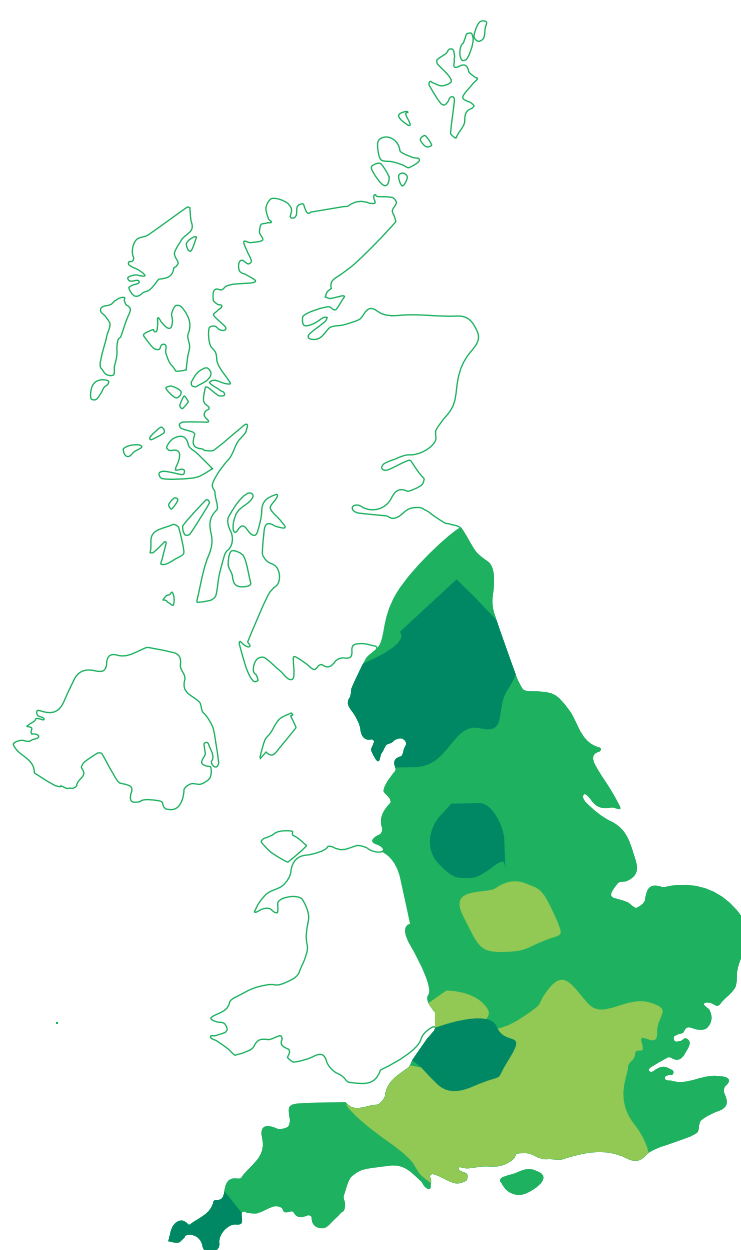
Medium

High

Important note

These maps show only the broad patterns of variation in incidence and mortality. Access to the very detailed and accurate data at the PCT/Health Board level is via the NCIN Cancer e-atlas website, www.ncin.org.uk/eatlas, or Macmillan staff members can contact Macmillan's Health Data team.

Incidence rates for older people are higher in the north and parts of the south-west than in other parts of England.



Mortality of cancer (75+) per 100,000 population, England, 2003–2005⁽⁸⁾

Low

Medium

High

Important note

These maps show only the broad patterns of variation in incidence and mortality. Access to the very detailed and accurate data at the PCT/Health Board level is via the NCIN Cancer e-atlas website, www.ncin.org.uk/eatlas, or Macmillan staff members can contact Macmillan's Health Data team.

Cancer mortality rates amongst older people tend to be lower in the south, with the exception of the far South West.

What are the major trends?

Population

Estimated and projected UK population of people aged 65 and over in 2014, 2020, and 2030, from 2012-based population projections.

2014	11,400,000
2020	12,762,000
2030	15,814,000

The average age of the UK population continues to increase gradually. In 2014, there are around 1,509,000 people in the UK aged 85 and over, accounting for 2% of the population. By 2030, the number of people aged 85 and over is projected to be two and a half times larger than in 2014, reaching approximately 2.7 million and accounting for 4% of the total population. With cancer incidence strongly correlated with age, the increasing age of the population has obvious implications for our health and social care systems.⁽¹⁴⁾

Mortality

The number of people dying from cancer in the under 75s dropped by around 17% between 1998 and 2007. However, improvements in mortality have been less pronounced in people aged 75-84 years with the mortality rate falling by only 4% from 1998 to 2007.⁽¹⁰⁾

Survival

For most cancers survival is generally improving for people of all ages. For those aged 75-99 in England the 1-year relative survival index for all cancers combined has improved from 47% in 1996 to 56% in 2011 and the 5-year has improved from 30% in 1996 to 35% in 2007.

‘10 million people in the UK are over 65 years old. The latest projections are for 5½ million more elderly people in 20 years time and the number will have nearly doubled to around 19 million by 2050.’

UK government forecasts

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 older people with cancer at these stages.

A typical 'cancer journey' showing four key stages:

1

Diagnosis

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

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

2

Treatment

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

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

3

Survivorship*

If I complete my treatment for cancer, what next?

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

4

Progressive illness and end of life

If my cancer is incurable, what might I experience?

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

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

NEEDS AND EXPERIENCES DIAGNOSIS

What are the general signs and symptoms of cancer?⁽⁵⁾

Reporting symptoms to a GP early can help ensure that if cancer is diagnosed, then it is **diagnosed as early as possible**. There are some **common signs** and **symptoms** for most cancers, though each cancer type has different signs and symptoms. Common ones (for many cancer types) are:

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

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

The priority given in the UK to cancer in the elderly has **increased considerably** in recent years.⁽¹⁶⁾

Some **older people** (over 70) may not be aware of their increased risk of cancer and may have **lower awareness** of cancer symptoms than the younger age groups.⁽¹⁷⁾

Older women have been found to **wait longer** before presenting with symptoms of breast cancer. Late presentation is linked with poorer survival.⁽¹⁸⁾

All registered patients over 75 are assigned a named GP, who is responsible for ensuring patients have access to a health check if requested.⁽²⁵⁾

Awareness of age-related cancer risk is particularly low in the UK: only 14% knew that 70-year olds are at a greater risk of cancer than younger people, compared to 38% in Sweden.⁽²⁰⁾

How well does screening work for older people with cancer?

Cervical screening in England is not offered to older women unless they have recently had an abnormal test result, because cervical cancer is not a significant problem in women aged 65 and over. Women in this age bracket who have had three normal test results in a row are very unlikely to develop cervical cancer.⁽¹⁰¹⁾

Breast screening is currently offered up to the age of 73 but women aged over 73 can self-refer for mammograms every 3 years. The uptake of breast screening is lower in older women. Those aged 71-74 had an uptake rate of 67% compared to 72% in those aged 50-70. In 2012-13 only 5% of those screened for breast cancer were aged over 70. This is despite the breast cancer detection rate being highest in those aged over 70 years.⁽²²⁾

32% of breast cancers in women of all ages and 56% of breast cancers in women between the ages of 50 and 69 years were screen-detected.⁽²³⁾

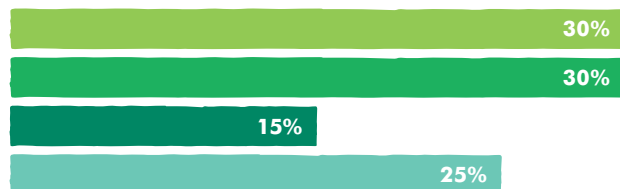
Bowel screening in England is offered to men and women from age 60 to 74 (recommended age groups vary in other UK countries).⁽²¹⁾ The uptake of bowel screening however, is 58%.⁽³⁶⁾

‘After diagnosis the consultant told me the only cure for my type of cancer was a bone marrow transplant and implied they would be finding a match for me. When I next saw my consultant he said to me: ‘When you get to your age you’re too old for a transplant’ – I couldn’t believe what he was telling me. I complained.’

Roy, South West

How is cancer diagnosed? (Routes to diagnosis)⁽³⁷⁾

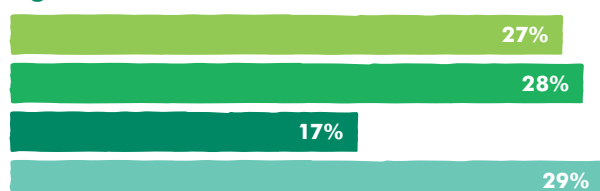
Aged under 50



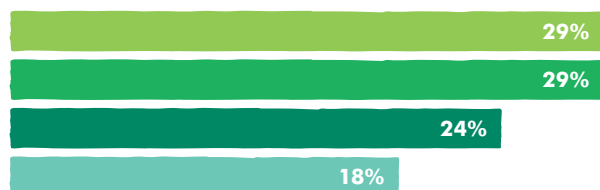
Aged 50-59



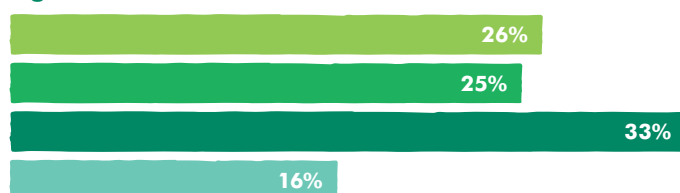
Aged 60-69



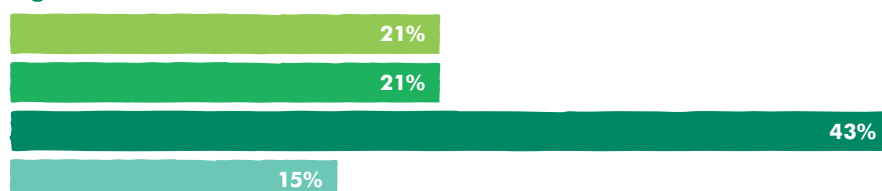
Aged 70-79



Aged 80-84



Aged 85+



The number of diagnoses through the emergency route is considerably higher in older patients with 43% of patients aged 85+ being diagnosed in this way compared to just 15% of those aged 59 and under. Emergency presentation was also the route through which patients aged 80+ were most commonly diagnosed.



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

How many older cancer patients had to see their GP more than twice before they were diagnosed?⁽³⁴⁾



Proportionally more older people (65+) have to see their GP more than twice before they are diagnosed with cancer.

How does stage at diagnosis relate to probable survival rates?

There is little UK-wide data on stage at diagnosis for older people of all cancer types and the links between stage at diagnosis and survival.

Most types of cancer have 4 stages, numbered from 1 to 4 ⁽²⁴⁾

Stage 1

Usually means a cancer is relatively small and contained within the organ it started in.

Stage 2

Usually means the cancer has not started to spread into surrounding tissue, but the tumour is larger than in stage 1. Sometimes stage 2 means that cancer cells have spread into lymph nodes close to the tumour. This depends on the particular type of cancer.

Stage 3

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 the area.

Stage 4

Means the cancer has spread from where it started to another body organ. This is also called secondary or metastatic cancer.

Being diagnosed at later stages usually correlates to poorer survival rates, although there is a general lack of data that is specific to older people.

‘I asked my [specialist nurse] about the decision on my treatment to have the injections and she brought my file in and showed me a letter that had been signed by four consultants. It said that ‘due to the patient being 85 we recommend hormone treatment.’



PHYSICAL AND MEDICAL NEEDS

Even when corrected for tumour characteristics and co-morbidities, studies indicate that **older people are less likely to receive intensive investigation and treatment and are more likely to be admitted as emergencies.**⁽¹⁸⁾

A 2011 survey of over 500 older people in Hampshire revealed that many patients cite **long delays in being diagnosed**, which they felt were due to GP misdiagnosis, late referrals, and patients themselves not recognising symptoms.⁽²⁶⁾

A study by Cambridge University found that women with breast cancer aged 70-74 were a **fifth more likely** to have been diagnosed with cancer that had reached the later stages compared with those aged 65-69.⁽⁵⁹⁾

While approximately 35% of young women report being worried about wasting a doctor's time this figure is closer to 70% for older women. **Older women are therefore more likely to be diagnosed at a later stage** as many of them will delay visiting the doctor when they suspect something is wrong.⁽⁴¹⁾

One third of the over 70s may have **problems with their existing medication regimens** at the time they are diagnosed with cancer.⁽⁶⁴⁾



FINANCIAL NEEDS

Not specific to older people living with cancer

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.⁽⁴⁷⁾

Over two-fifths (**42%**) of people with cancer **did not receive money or debt advice** following their diagnosis.⁽²⁷⁾



PRACTICAL AND INFORMATION NEEDS

Older people are almost as likely to **want information** about their cancer, it's treatment and their prognosis as any other age group.⁽⁴⁰⁾

Older people have been found to be **more likely to understand the explanation of what is wrong with them**. In the most recent Cancer Patient Experience Survey, over 75% of those aged 65 or over completely understood the explanation of what was wrong with them compared to under 50% of 16-25 year olds.⁽²⁷⁾

On the other hand, some older people have **more difficulties processing and remembering information** than younger people.⁽³⁰⁾

Older patients are **less likely to seek additional information to that provided by their healthcare professionals**, with many older patients with breast cancer saying that they would prefer to receive information face-to-face from healthcare professionals rather than from leaflets or websites.⁽⁴¹⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Elderly patients may have grown up at a time when **cancer was unmentionable**, and for these people a cancer diagnosis may bring **additional stress** that may not be felt by younger people.⁽³¹⁾

However some older people with cancer **have less psychological distress** in dealing with cancer compared with younger patients. This may be due to their **greater experience in dealing with the difficulties of life**, as well as the fact that their diagnosis is less likely to have an impact on work or family responsibilities.⁽³²⁾

Many older people **view their future differently to younger people** and many are better able to emotionally cope with illness.⁽³³⁾

NEEDS AND EXPERIENCES TREATMENT

Evidence suggests that older patients may be under-treated and that their outcomes may be poorer as a result⁽¹⁸⁾. Older people are less likely to receive radical surgery than younger people, and radiotherapy is used less often in elderly patients.^(38,40)

Several studies suggest that differences in treatment partly explain poorer survival in older people with certain cancers.⁽¹⁸⁾

What treatments do older cancer patients get?

Any active treatment

There is substantial evidence that **older patients are less likely to receive certain treatments**. Several studies suggest that differences in treatment partly explain poorer survival in older people with lung cancer and breast cancer. Even when corrected for tumour characteristics and co-morbidities, studies indicate that older people are less likely to receive intensive investigation and treatment and are more likely to be admitted as emergencies.⁽¹⁸⁾

A recent DH report also suggested that chronological age alone may be overly relied on as a proxy by clinicians for wider biological factors, resulting in some older patients being provided with less intense treatment that might be appropriate.⁽⁵⁵⁾

Chemotherapy

Patients should be assessed on their individual ability to tolerate certain cancer treatments, not merely based on their age. Chemotherapy can be a **difficult treatment to have**, and since older people are more likely to have other diseases as well as cancer, some of the side effects of chemotherapy for older people can be worse or more harmful in the long term. However advances in a number of areas have made the use of chemotherapy safer for older people.

Radiotherapy

Radiotherapy is **used less often** in elderly patients.⁽⁴⁰⁾

Surgery

A recent report from the National Cancer Intelligence Network showed that **the proportion of older people receiving radical surgery for cancer was substantially lower than younger people**. For cancers of the oesophagus, bladder, prostate, lung, pancreas and liver, less than 2% of patients aged 80 or over had a record of a major surgical resection in any of these cancer sites.⁽³⁸⁾

Large differences in the percentage of patients with a record of a major resection by age are seen for ovarian, kidney and cervical cancer. For patients aged 40-49 compared to patients aged 80+, the proportion decreased from 82% to 26% for ovarian, from 78% to 29% for kidney and from 58% to 10% for cervical cancer.⁽³⁸⁾

The highest percentage of patients aged 80 and over with a record of a major resection was seen in **uterine cancer** where a resection rate of 65% of NHS treated patients was seen.⁽³⁸⁾

For symptomatic breast cancers **surgical treatment decreased with age** at diagnosis. Only 74% of women aged 70-79 and 39% of women aged 80+ have surgery compared to 90% of women under 50.⁽²³⁾

Lung cancer patients at 75 are five times less likely to be given life-saving surgery than younger patients.⁽³⁸⁾

Biological therapy

Biological therapies are substances that occur naturally in the body to destroy cancer cells. Biological therapies are often given in combination with chemotherapy. There is little data on the use of biological therapies for older people.

How many cancer admissions are there amongst older people and how many older cancer patients stay in hospital (and for how long)?

Older people (65+) are less likely than younger age groups to spend some of their time in the year following diagnosis as an admitted hospital patient – 48% compared to around 40% for people under 65.⁽³⁵⁾

Older people (65+) are also less likely to spend some of the last year of their life as an admitted hospital patient.⁽³⁵⁾ This could be because they spend the time in a hospice, rather than a hospital.

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 dietitians.⁽⁴⁶⁾

How many older people with cancer were given the name of a CNS?

There is evidence that older people have less access to a Clinical Nurse Specialist (CNS) compared to younger age groups. Around 82% of people aged 75+ were given the name of a CNS compared to an average of around 90% across all age groups.⁽²⁷⁾

What does this mean for older cancer patients?

CNSs improve quality and experience of care for patients, reinforce patient safety, demonstrate leadership and increase productivity and efficiency.⁽⁴²⁾

CNSs also coordinate ward 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 as smoothly as possible** and diverts pressure away from other professionals such as doctors and the ward nursing team.⁽⁴³⁾

Without CNSs the cancer journey can be complex and disjointed, often leaving the patient with unmet needs, increasing the risk of emergency admissions and avoidable costs for the health service. Older patients could be having a harder time if they cannot access a named CNS.⁽⁴²⁾

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

Prevalence of co-morbidities (see Jargon Buster in Appendix A) increases with age, and one US study reported an **average of three co-morbidities in cancer survivors aged 70 years or above**.⁽⁴⁵⁾

Common co-morbidities amongst older cancer patients include conditions affecting the cardio-vascular system, the respiratory system and the gastrointestinal system, as well as conditions such as diabetes.⁽⁴⁶⁾

Co-morbidities in older patients **need to be approached in a systematic way** by clinicians, in order to integrate their consideration in treatment decisions.⁽⁴⁵⁾

Macmillan has produced an 'Impact Brief on Clinical Nurse Specialists'. This is an evidence review, which more fully sets out how our CNSs use their skills and expertise in cancer care to provide technical and emotional support, coordinate care services and inform and advise patients on clinical as well as practical issues, leading to positive patient outcomes. The paper, along with other Impact briefs, is available via the Macmillan website, at www.macmillan.org.uk/servicesimpact

‘A lot of how you get treated suggests that some people think that older people are past being useful and are taking resource from the government that could be spent elsewhere. Older people need to know what they are entitled to but very few people do know this. There should be information available at the hospital.’

Judy, North East



PHYSICAL AND MEDICAL NEEDS

Older cancer patients are more likely to agree that (in situations where their GP was involved) **their GP or Practice Nurse did everything they could to support them** while they were having treatment, with over 70% of those over 75 saying that they received enough support compared to under 60% of 26-35 year olds.⁽²⁷⁾

Older people are less likely to receive intensive investigation and treatment and are **more likely to be admitted as emergencies.**⁽²⁶⁾

In a 2012 survey of oncologists, clinical nurse specialists and GPs, **45% said they had dealt with a cancer patient who had been refused treatment on the grounds they were too old** and 67% had heard health professionals speak to older cancer patients in a condescending or dismissive way.⁽⁷¹⁾

Older people's experience of **hospital care varies significantly** – one survey of older cancer patients in Hampshire showed that some hospitals have been failing to ensure that patients get enough to eat and drink to aid their recovery.⁽⁵⁹⁾

Chemotherapy was found to be **less likely to be offered to older breast cancer patients** and, as age increased, frailty and co-morbidities were likely to be stated by Clinicians as the reasons why it was not offered, despite these factors not being recorded in a third of cases.⁽⁴¹⁾

People with cancer aged 65 or over are **significantly under-represented** in cancer clinical trials.⁽⁴⁸⁾ Only 5% of clinical trials nationally include patients aged 70 years plus.⁽⁶⁹⁾



FINANCIAL NEEDS

Fewer older people receive information from hospital staff about financial help and benefits than any other age group. Around 48% of those aged over 75 received this information compared to around 83% of those aged 16-25 and over 60% of those aged 26-65.⁽²⁷⁾

Not specific to older people living with cancer

The **cost of travel to and from appointments affects 69% of people with cancer** and costs them, on average, £170 a month. Parking for outpatient appointments affects 38% of people with cancer and costs them, on average, £37 a month. And over a quarter (28%) of people with cancer incur costs for inpatient appointments. On average, this amounts to £20 a month for those affected.⁽²⁷⁾



PRACTICAL AND INFORMATION NEEDS

Age can influence patients' information needs; younger patients tend to prioritise information on sexual attractiveness, while **older patients often prioritise information on self-care.**⁽⁴⁴⁾

Older patients who report using **exercise during and following treatment** also report less severe symptoms during and following treatment, including **less shortness of breath, weight loss and fatigue.**⁽⁷⁰⁾

Older people are likely to have **poorer literacy and numeracy**, especially those over 80, when compared to younger age groups.⁽⁵¹⁾

Older people **may not always have access to transportation, social support, or financial resources**, affecting their care and recovery from cancer.⁽⁴⁸⁾

Although more vulnerable, older patients may **not ask for help when necessary** and often need guidance in asking for and receiving help.⁽⁵³⁾

A recent survey found that oncology trainees are **not adequately informed about the particular needs of older people with cancer**; 66% of trainees reported never receiving training on the subject, whilst 19% reported receiving this training only once.⁽⁶⁷⁾

Not specific to older people living with cancer

40% of all cancer survivors (of all ages, not just limited to older people) are **unaware of the long term side effects** of cancer and its treatment.⁽⁵⁰⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Various studies suggest that **up to a third of elderly cancer patients may experience psychological distress**, and evidence suggests that generally speaking, the **psychological impact of cancer is less negative in the elderly compared to younger patients**. Possible reasons for this include older people having more developed coping skills for managing life events due to their lifetime experience. However, **many older patients are in distress**, the impact is real and cannot be ignored.⁽⁵⁴⁾

Major causes of distress in older cancer patients include poor physical function and loss of independence.⁽²⁸⁾

Older people are frequently reported to say that they are **concerned that decisions regarding their treatment lack fairness and transparency**. They frequently feel that they are made **excessively aware of the costs of treatment** and whether they **merit the expense of such treatments**, which could lead to psychological distress.⁽⁹⁹⁾



NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

Why are cancer survivors (all cancer survivors; not just elderly cancer survivors) not catered for properly by the current system?

The current system for cancer patients after the end of treatment concentrates on medical surveillance, and looking for recurrence. However we know that this does not address people's needs:

- **39%** who completed treatment in 2009/10 say that **no health or social care professional talked them through the needs** they might have.⁽⁵⁸⁾
- **94%** experience **physical health condition problems** in their first year after treatment.⁽⁵⁰⁾
- **78%** of people with cancer have experienced **at least one physical health condition** in the last 12 months which can occur as a result of cancer or its treatment.⁽⁵⁰⁾
- **62%** of people with cancer have experienced **at least one of the psychological conditions** that can occur as a result of cancer and its treatment.⁽⁵⁰⁾
- **40%** with **emotional difficulties** had not sought medical help or other support.⁽⁵⁷⁾
- **23%** lack support from **friends and family** during treatment and recovery.⁽⁵⁶⁾

- **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.⁽⁵⁶⁾

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.⁽⁹⁶⁾
- Currently only **22%** of cancer patients are receiving a needs assessment and a care plan – both of these are essential in providing personalised care for cancer patients and their carers.⁽⁵²⁾

Macmillan and NHS England are working to implement personalised support for all cancer survivors

The National Cancer Survivorship Initiative (NCSI) was a partnership between the Department of Health, Macmillan and NHS Improvement. NCSI reports were produced in 2013, including '**Living with and beyond cancer: Taking Action to Improve Outcomes**', which informs the direction of survivorship work in England, to support commissioners, health service providers and others to take the actions necessary to drive improved survivorship outcomes.

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

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

- Structured Holistic Needs Assessment and care planning,
- Treatment Summary to provide good communication to primary care including information about treatment, and the potential short-and long-term consequences.
- Education and support events, such as Health and Wellbeing Clinics, which give patients information about lifestyle choices, signs and symptoms of recurrence, getting back to work, benefits and financial support.
- The Cancer Care Review carried out by the GP six months following a diagnosis of cancer

Further key interventions include:

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





PHYSICAL AND MEDICAL NEEDS

Post-treatment care can be disjointed for some older patients – a survey of older people in Hampshire showed that older cancer patients feel that hospital discharge arrangements can lack continuity of care and that liaising with GPs and primary care teams can go wrong.⁽⁵⁷⁾

Around **1 in 8 people aged over 60 are carers for someone living with cancer**. 1 in 3 of these provide over 50 hours a week of care.⁽⁶⁰⁾

Many **older carers** have a **long-term condition or disability of their own**, meaning they need even more support, especially as the condition of the patient they care for worsens.⁽⁶¹⁾

Variations in functional status, cognition and co-morbidity accompany ageing within people with cancer. These changes can **influence tolerance to cancer therapy**.⁽⁶²⁾

It can be **difficult to define the effects of cancer and its treatment and separate these from normal ageing** and geriatric syndromes.⁽⁶³⁾

Not specific to older people living with cancer

94% of cancer survivors (of all ages) experience physical condition problems in their first year after treatment, but **even at 10 years after treatment 71% experience at least one physical condition** problem that can occur as a result of cancer and its treatment.⁽⁵⁹⁾



FINANCIAL NEEDS

Older people with 'low level' needs and carers may have **little access to state-supported care** until they reach crisis point.⁽¹⁹⁾

Older people are particularly likely to be **sensitive to the stigma associated with means-testing** of certain benefits.⁽¹⁹⁾



PRACTICAL AND INFORMATION NEEDS

As a general rule, **social vulnerability increases with age** and greater **social vulnerability is associated with mortality** in older adults.⁽⁶⁶⁾

For many older people with cancer, the biggest concerns are **being able to take care of themselves and feeling they are still in control of their health and decisions**. Cancer treatment may interfere with the ability to cook and eat independently, wash or bathe independently, walk, drive, or access transportation.⁽⁴⁸⁾

There is a **lack of information and knowledge** given to older patients and carers **regarding their follow-on care**. Some older people felt that **discussions between healthcare professionals did not allow for adequate time** to digest information and formulate necessary questions.⁽⁹⁹⁾

Many older people felt that **professionals did too little to ‘uncover’ information** from them which would have helped in planning follow-on care, **neglecting to ask important information** about the type of support network the patient had.⁽⁹⁹⁾

Not specific to older people living with cancer

In a 2007 report patients and carers (of all ages) in Yorkshire and the Humber Coast Cancer Network felt that information on living with cancer in the longer term (and advanced cancer) is very limited.⁽⁶⁵⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Older people with cancer can be **less likely to have a support system in place**, often because they have lost close family members or do not live near them.⁽⁴⁸⁾

One study on **cancer patients aged 70 and over found that 40% lived alone**. Furthermore, 40% had an impaired ability to plan and prepare meals, while 23% were completely unable to shop.⁽⁹⁴⁾

Evidence suggests that **up to a third of elderly patients suffer some form of psychological distress**.⁽⁵⁴⁾

Significant distress was reported by **41% of 245 elderly cancer patients aged 65+ with a solid tumour** or lymphoma.⁽⁷²⁾

The most frequently reported psychological problems in older cancer survivors were **anxiety, depression and loss**.⁽⁷³⁾

NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

How many older cancer patients are at End of Life?

147,000 people living with cancer were in their last year of life at the end of 2008 – 80% of them were aged 65+.⁽³⁵⁾

Older people living with cancer at the end of 2008 were **more likely to be in the last year of their life** – 2% of 0-44 year olds compared to 9% for those aged 65+ were in their last year of life.⁽³⁵⁾

Are older people getting the end of life care that they need?

Older people and their families may not be getting the dignified, pain-free end of life care that everyone deserves. Personal accounts examined by the Health Ombudsman present a picture of NHS provision that is (in places) failing to respond to the needs of older people with care and compassion.⁽⁷⁵⁾

What is the impact of giving cancer patients palliative care*?

Evidence suggests that compared to patients receiving standard care, those receiving regular palliative care input from the time of diagnosis had a better quality of life, received less aggressive treatments close to death, and survived longer.⁽⁸³⁾

*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.”

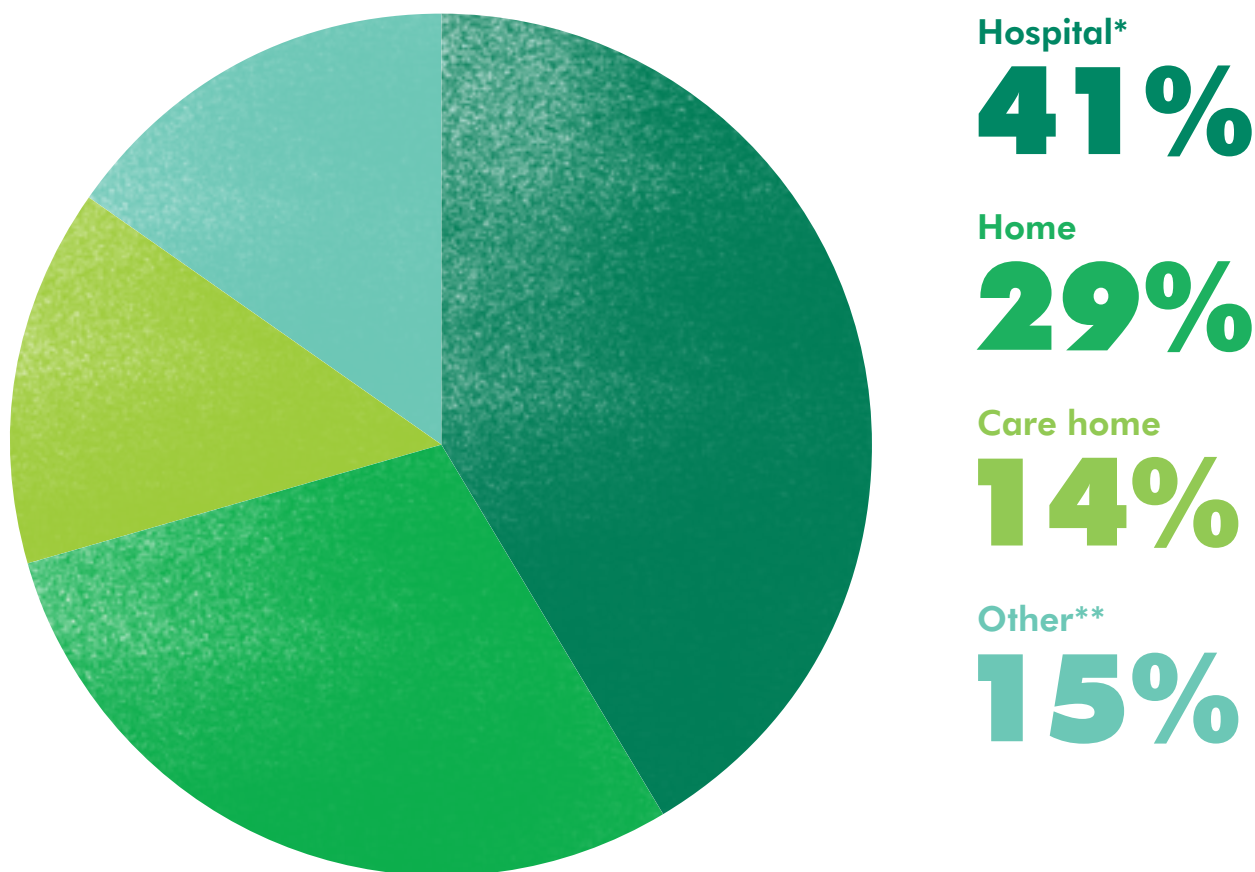
How many cancer deaths there are in each setting?

Data on place of death is not available broken down by cancer type and age. However for all cancers, we know that cancer deaths in England & Wales account for 90% of all deaths in hospices, 39% of all deaths at home, 23% of all deaths in hospital, 18% of all deaths occur in care homes, 19% of all deaths in communal establishments and 23% of all deaths elsewhere.^(2a)

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

Where do older people with cancer die?

Cancer deaths in those aged 65+, UK⁽⁷⁸⁾



*Deaths in hospital include NHS and non-NHS hospitals in England, Wales and Northern Ireland and NHS hospitals only in Scotland

** 'Other' includes deaths in hospices and other communal establishments

Numbers do not add up to 100% due to rounding

41% of the cancer deaths in older people aged 65+ in UK took place in hospital.

To what extent do older cancer patients die in the place of choice?

Not specific to older people living with cancer

A recent survey found that **73% of people who died from cancer would have liked to have spent the last weeks and days of their life at home.**⁽⁴⁹⁾ However, only 30% of those who die from cancer actually die at their home or own residence.⁽⁷⁸⁾

How many deaths in older people are due to cancer?

In 2012, 26% of deaths in England and Wales in those aged 65+ were due to cancer. This compares to 38% of deaths in those aged 64 and below.^(2a)

‘My doctor then said out of the blue: ‘there’s always euthanasia, you can go to a clinic in Switzerland’. I was so shocked.’

Anne, South East



PHYSICAL AND MEDICAL NEEDS

Cancer survival decreases with age. As well as this, we know that England has poorer survival rates than in comparable countries. This is **especially the case for older people.**^(26a)

More than **three quarters of cancer deaths occur in people aged 65 or over.**⁽⁷⁹⁾

Not specific to older people living with cancer

Appropriate **palliative care (for patients of all ages) introduced early after diagnosis can improve quality of life.** It can also lead to less aggressive care at the end of life and longer survival.⁽⁸¹⁾

Various **symptoms are very common in advanced cancer**, with patients having a median of 11 symptoms on admission to palliative care. Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common; occurring in some combination in virtually all patients.⁽⁸²⁾⁽⁸³⁾

Pain, as well as other symptoms such as fatigue and shortness of breath, may be caused by **co-morbid conditions and not the cancer.**⁽⁴⁰⁾

Various symptoms are very common in advanced cancer, with patients having an average of 6 uncontrolled symptoms on admission to palliative care.⁽⁸²⁾

Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common; they occur in some combination in virtually all patients.⁽⁸³⁾



FINANCIAL NEEDS

Not specific to older people living with cancer

In 2010 Macmillan reported that **36% of people with a terminal cancer diagnosis (of all ages, not just older people) did not claim the benefits they were automatically entitled to.** In 2010 this amounted to over £90m.⁽⁸⁴⁾

People with a terminal diagnosis who wish to travel may have their **travel insurance cover refused** by insurance companies, or be offered cover at prohibitively high premiums, stopping them from fulfilling their wishes.⁽⁶⁸⁾



PRACTICAL AND INFORMATION NEEDS

The proportion of people **dying at home decreases with age.**⁽⁸⁵⁾

Research has found that **older patients with cancer are often under-treated.** This under-treatment is present in palliative care. Older people with cancer are more likely to receive less social and practical support, which suggests that they are not getting the adequate care and services they need at end of life.⁽⁶⁹⁾

Not specific to older people living with cancer

Cancer patients and their families often want information about how long they may have to live after hearing that their cancer is terminal. However, **31% of doctors tend to over-estimate the survival times** of terminally ill cancer patients.⁽⁸⁰⁾

A study into advanced cancer found that patients identified the greatest areas of need in relation to psychological and medical communication/information domains. Patients' **specific needs were highest in dealing with a lack of energy and tiredness, coping with fears** about the cancer spreading, and coping with **frustration** at not being able to do the things they used to do.⁽⁷⁶⁾

A third of people who have had **cancer did not have all the information they needed**, including knowledge of how to self-manage conditions or guidance on when and how they should contact healthcare professionals in the future.⁽⁵⁷⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Access to community nursing at any time of the day or night is essential to support those who wish to die at home. Where these wishes are not met it can lead to traumatic experiences for patients and their families.⁽⁸⁹⁾

83% of people say they are scared of dying in pain, while 67% say they are scared of dying alone, and 52% are scared of being told they are dying.⁽⁹⁰⁾

LIFESTYLE AND PERCEPTIONS

Where do older people live?

Population density, 65+, UK, 2007⁽¹³⁾



What is the profile of the average older person living with cancer?

Older people tend to be stereotyped as a homogenous group characterised by passivity, failing physical and mental health and dependency. However it is **difficult to categorise 'older people' as they are such a diverse group**. Frailty amongst older people varies – some older people are frail, while others are in good health, but all of them have different individual needs. That said, we know that:

- Around **60% of new cancer** cases diagnoses in the UK **are in those aged 65+**.
- **Breast, prostate, lung, colorectal, bladder, stomach, pancreatic and ovarian** cancers are all common amongst elderly people.
- Almost all cancer patients over 65 have **at least one other disease**.
- People aged 75+ make **greater use of hospital, primary care and community health care services** than younger people.

Many older people move to coastal locations in the UK to enjoy their retirement

What is the demographic breakdown/market segmentation of the 1,093,279 older people with cancer (aged 65+)?⁽⁷⁷⁾

Older people fall into a wide range of demographic groups. They are well represented in the following **MOSAIC*** groups:

Group L: 'Elderly Needs'

Elderly people who are reliant on support either through specialised accommodation or the basic state pension.

Group E: 'Active Retirement'

Elders who have sufficient pensions and savings to choose pleasant locations in which to enjoy their retirement.

Group D: 'Small Town Diversity'

Residents of small and medium-sized towns who have strong roots in their local community.

Group B: 'Professional Rewards'

Experienced professionals in successful careers enjoying financial comfort in suburban or semi-rural homes.

Group C: 'Rural Solitude'

Residents of small and medium-sized towns who have strong roots in their local community.

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

Older people **watch more TV** than other adults, but **use mobile phones much less**. They listen to about the same amount of radio. **TV is the main news source**, and they are more distrustful of news websites online than the rest of the population.⁽⁹²⁾

In relation to cancer, they are **less likely to actively seek information** but when they do, it tends to be via friends, family and sometimes books.⁽⁹²⁾

Around **37%** of over 65s spend **most of their leisure time at home**.⁽⁹²⁾

In terms of internet access, only **40% of those aged 65 or over access the internet**, compared to 76% of those under 65 in the UK in 2010.⁽⁹³⁾

Older people **consult their GP more** than younger people.⁽⁵⁶⁾

What are older cancer patients saying in their own words about their lifestyle before, during and after cancer?⁽⁹⁹⁾

Before:

'The registrar just opened the file and said 'You have prostate cancer. It's aggressive. Any questions?' The nurse came in. I was really surprised and didn't really know what to say.'

Older person with cancer

During:

'For my mother it didn't seem like age was a barrier. But I have always been very particular about my mother's appearance because of the expectations associated with age. So I'm pretty sure that an elderly lady laid there with dishevelled hair would probably be overlooked or would have less value.'

Carer of older person with cancer

During:

'I'm sure if I was 65 I'd be on a different treatment. I've always been really active; I'm not necessarily a typical 85-year old.'

Older person with cancer

'In reality you don't get a lot of support. It wasn't until I started meeting a support group that I found out what things meant.'

Older person with cancer

After:

'Most of the people need some kind of care package at discharge because they are unable to manage their own cancer care. Invariably I am not contacted and then the person is discharged with no support and no care package.'

Carer in a residential home for older people

How the media* portrays older people with cancer...(98)



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

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

Macmillan hosts online discussions on its website. We have compared the frequency of words used in these discussions with the frequency of words used in media articles which talk about older people with cancer. The key conclusions of this analysis are given below:

- 'Time' features more prominently in the online community, as do 'months', 'week(s)', 'day(s)' and 'now', as opposed to 'year(s)' in the media: older people affected by cancer may be acutely aware of the passage of time and measure it in smaller, more manageable portions, focusing more on the immediate.
- The online community demonstrates a greater emphasis upon positive words: 'good', 'well', 'better', 'love' and 'lovely'. The media, on the other hand, shows similar emphasis upon 'risk', 'disease', 'patients', 'health' – the practical and general, rather than the positivity shared by individuals.
- Online, there are also more words to do with individual experiences of all kinds: 'pain', 'lonely', 'sorry', and 'hope', 'feel', 'hear'. The media shows much less experiential or emotional information.
- There may be a great deal of information in the UK media about older people and the increasing risks of cancer, but there may not be enough focus upon its emotional impact and the day-to-day experiences of those affected.

REFERENCES.

SOURCES, NOTES AND CAVEATS

Quotes

The quotes on pages 27, 31, 37, 47 and 52–55 are real quotes from older people with cancer or their carers, however we did not include their names to protect their identity. All quotes have been sourced from the reports cited in reference 100 and reference 99. The quote and photo on page 5 is from a Macmillan case study who has kindly agreed to be featured in this publication.

References

- 1a. Office of National Statistics. Cancer Incidence England. 2012. <http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--43--2012/rft-cancer-registration-statistics.xls> (accessed September 2014)
- 1b. Welsh Cancer Intelligence and Surveillance Unit. Official Statistics – Incidence Trends, 1985–2012. <http://www.wcis.u.wales.nhs.uk/offical-statistics-exel-files-of-trend> (accessed September 2014).
- 1c. ISD Scotland. Cancer Incidence in Scotland 2012. <http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp> (accessed September 2014)
- 1d. Personal communication with Queen’s University Belfast, Northern Ireland Cancer Registry.
- 2a. Office for National Statistics and London School of Hygiene and Tropical Medicine. Mortality statistics. Deaths registered in England and Wales 2012. <http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/dr-tables-2012.xls> (accessed September 2014)
- 2b. ISD Scotland. Cancer Mortality in Scotland 2012. <http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233> (accessed September 2014)
- 2c. Personal communication with Queen’s University Belfast, Northern Ireland Cancer Registry.
- 2d. Wales – Welsh Cancer Intelligence and Surveillance Unit. Official Statistics – Mortality Trends. <http://www.wcis.u.wales.nhs.uk/offical-statistics-exel-files-of-trend> (accessed September 2014)
3. Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547.
4. Office for National Statistics. Cancer survival rates, Cancer Survival in England: Patients Diagnosed 2007-2011 and Followed up to 2012. <http://www.ons.gov.uk/ons/publications/reference-tables.html?edition=tcM%3A77-320365> (accessed September 2014)
5. Macmillan Cancer Support. Signs and Symptoms of Cancer. <http://www.macmillan.org.uk/Cancerinformation/Aboutcancer/Signssymptoms.aspx> (accessed September 2014)

6. EUROCARE-5 Database. Eurocare 5 Survival Analysis 2000-2007. <https://w3.iss.it/site/EU5Results/forms/SA0007.aspx> (accessed September 2014)
7. Moller H, et al. High cancer mortality rates in the elderly in the UK. *Cancer epidemiology*. 2011. 35(5): 407-12.
8. NCIN. Cancer e atlas by local authority. http://www.apho.org.uk/addons/_49906/atlas.html (accessed September 2014)
9. Prevalence in 2015 estimated from Maddams et al. (2012). Prevalence in 2030 and 2040 taken directly from Maddams J, Utey M and Møller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*. 2012; 107: 1195-1202. (Scenario 1 presented here)
10. National Cancer Intelligence Network. Evidence to March 2010 on Cancer inequalities in England. 2010. <http://www.ncin.org.uk/view?rid=169> (accessed September 2014)
11. National Cancer Intelligence Network and Cancer Research UK. Ethnic differences in survival – Cancer Incidence and Survival by Major Ethnic Group, England, 2002 – 2006. 2009. <http://www.ncin.org.uk/view?rid=75> (accessed September 2014)
12. Cancer Research UK. Cancer Survival statistics by socio-economic variation. <http://www.cancerresearchuk.org/cancer-info/cancerstats/survival/socio-economic-variation/> (accessed September 2014)
13. Office for National Statistics. Animated map of ageing in the UK. <http://www.neighbourhood.statistics.gov.uk/HTMLDocs/dvc5/agemap.html> (Accessed Oct 2011)
14. Office for National Statistics. 2012-based projections - Principal projection for the UK - Population by five year age groups and sex. For mid-2012 to mid-2037 and selected years to 2112. 2013. <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2012-based-projections/rft-table-a2-1-principal-projection---uk-population-in-age-groups.xls> (accessed September 2014)
15. Office for National Statistics. Index of cancer survival for Clinical Commissioning Groups in England, patients diagnosed 1996–2011 and followed up to 2012. 2013. <http://www.ons.gov.uk/ons/rel/cancer-unit/a-cancer-survival-index-for-clinical-commissioning-groups/adults-diagnosed-1996-2011-and-followed-up-to-2012/rft---tables-2-4.xls> (accessed September 2014)
2010. <http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival-by-cancer-network/patients-diagnosed-in-1996-2009--followed-up-to-2010/index.html> (Accessed September 2013)
16. UK Parliament / Government Actuary's Department, London, UK. 2012. <http://www.parliament.uk/business/publications/research/key-issues-for-the-new-parliament/value-for-money-in-public-services/the-ageing-population/> (accessed September 2014)
17. National Cancer Intelligence Network. Evidence to March 2010 on Cancer inequalities in England. 2010. <http://www.ncin.org.uk/view?rid=169> (accessed September 2014)
18. Foot C, et al/The Kings Fund. How to improve cancer survival: explaining England's relatively poor rates. 2011. http://www.kingsfund.org.uk/publications/cancer_survival.html (accessed September 2014)
19. Roberts E, et al/The Kings Fund. Briefing note: Age discrimination in health and social care. 2000. <http://www.kingsfund.org.uk/publications/age.html> (accessed September 2014) (64)

20. L J L Forbes et al. Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival? *British Journal of Cancer*. 2013. 108(2): 292–300
21. Beating Bowel Cancer. Screening Programmes. <https://www.beatingbowelcancer.org/screening> (accessed September 2014)
22. NHS Information Centre. Breast Screening Programme, England 2012-14. <http://www.hscic.gov.uk/catalogue/PUB13567/bres-scre-prog-eng-2012-13-rep.pdf> (accessed September 2014)
23. West Midlands Cancer Intelligence Unit/NCIN. Screening data for women aged 50-69: All breast cancer report. 2009.
24. Cancer Research UK. How many stages of cancer are there? <http://cancerhelp.cancerresearchuk.org/about-cancer/cancer-questions/how-many-stages-of-cancer-are-there> (accessed September 2014)
25. British Medical Association. GP contract FAQ – named GP for patients aged 75 years and older. <http://bma.org.uk/working-for-change/negotiating-for-the-profession/bma-general-practitioners-committee/general-practice-contract/gp-contract-faqs/gp-contract-faqs-named-gp> (accessed September 2014)
26. Eastleigh Southern Parishes Older People’s Forum with support from Macmillan Cancer Support. Growth Negligence: Older people’s experience of cancer care. 2011. http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/OlderPeoplesProject/Growth_Negligence.pdf (Accessed Mar 2012)
27. NHS England. Cancer Patient Experience Survey 2013. The Impact of Age. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed September 2014)
28. Hurria et al. Distress in Older Patients with Cancer. *Journal of Clinical Oncology*. 2009. 27(26): 4346-4351.
29. Cancer Research UK. Cancer incidence by age – UK statistics. <http://info.cancerresearchuk.org/cancerstats/incidence/age/> (accessed August 2014)
30. Posma E, et al. Older cancer patients’ information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*. 2009. 8:1.
31. Roth A, Modi R. Psychiatric issues in older cancer patients. *Critical Reviews in Oncology/Hematology*. 2003. 48(2):185-97
32. Christian J. Nelson et al. The chronology of distress, anxiety, and depression in older prostate cancer patients. *Oncologist*. 2009. 14(9): 891–899.
33. Posma E, et al. Older cancer patients’ information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*. 2009. 8:1.
34. NHS England. Cancer Patient Experience Survey 2010. Q2. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_122516 (accessed March 2012)

35. Maddams, J et al. Levels of acute health service use among cancer survivors in the United Kingdom. <http://www.ncbi.nlm.nih.gov/pubmed/21592781#> (Accessed September 2013). All cancers excluding non-melanoma skin cancer (ICD-10 C00-C97 excluding C44).
36. Beating Bowel Cancer. "Unacceptable" variations in uptake of bowel cancer screening revealed. 2014. <https://www.beatingbowelcancer.org/news/apr2014/%E2%80%9Cunacceptable%E2%80%9D-variations-uptake-bowel-cancer-screening-revealed> (accessed September 2014) All cancers excluding non-melanoma skin cancer (ICD-10 C00-C97 excluding C44).
37. NCIN. Routes to Diagnosis, 2006-2010. <http://www.ncin.org.uk/view?rid=2645> (accessed September 2014)
38. NCIN. Major surgical resections, England 2004-06. www.ncin.org.uk/view.aspx?rid=540 (Accessed September 2013)
39. Macmillan Cancer Support. Older Lung Cancer Patients Five Times Less Likely To Have Surgery than Younger Patients. 2014. https://www.macmillan.org.uk/Aboutus/News/Latest_News/OlderLungCancerPatientsFiveTimesLessLikelyToHaveSurgerythanYoungerPatients.aspx (accessed September 2014)
40. Turner N, et al. Cancer in old age – is it inadequately investigated and treated? *British Medical Journal*. 1999. 319: 309-12.
41. Breakthrough Breast Cancer. APPG on Breast Cancer. Age is Just a Number. 2013. <http://www.breakthrough.org.uk/sites/default/files/media/Campaigns/Age%20is%20just%20a%20number%20-%20APPG%20report%20on%20older%20people%20and%20breast%20cancer.pdf> (accessed September 2014)
42. Macmillan Cancer Support. Cancer Clinical Nurse Specialists: An evidence review. 2010. <http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/ClinicalNurseSpecialistsAnEvidenceReview2012.pdf> (accessed September 2014)
43. Pollard C, et al. Justifying the expense of the cancer Clinical Nurse Specialist. *European Journal of Cancer Care*. 2010. 19: 72–79.
44. J. Tariman et al. Information Needs Priorities in Patients Diagnosed With Cancer: A Systematic Review. *Journal of the Advanced Practitioner in Oncology*. 2014. 5(2): 115–122.
45. Extermann M, et al. Co-morbidity and functional status are independent in older cancer patients. *Journal of Clinical Oncology*. 1998. 16: 1582-87.
46. Ashley Wilder Smith et al. Cancer, Comorbidities, and Health-Related Quality of Life of Older Adults. *Health Care Financing Review*. 2008. 29(4): 41-56.
47. Macmillan Cancer Support. Cancer's Hidden Price Tag: Revealing the Costs Behind the Illness. 2013. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf> (accessed September 2014)
48. Cancer.Net. Cancer in older adults. American Society of Clinical Oncology, USA. 2010. http://www.cancer.net/sites/cancer.net/files/cancer_in_older_adults.pdf (accessed September 2014)
49. Macmillan Cancer Support. February 2010 online survey of 1,019 UK adults living with cancer. Survey results have not been weighted.

50. Elliot J, et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer*. 2011. 105:511-520.
51. Jenkins A, et al. Literacy, numeracy and disadvantage among older adults in England. Nuffield Foundation, UK. 2011.
52. NHS England. Cancer Patient Experience Survey 2013. (Q68). <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file> (accessed September 2014)
53. Posma E, et al. Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*. 2009. 8:1.
54. Kua J. Psychological problems in elderly cancer patients. *Annals Academy of Medicine*. 2005. Vol. 34, No. 3.
55. Department of Health. The impact of patient age on clinical decision-making in oncology. 2012. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132796 (accessed September 2014)
56. Macmillan Cancer Support. Facing the Fight Alone. 2013. http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Isolated_cancer_patients_media_report.pdf (accessed September 2014)
57. Macmillan Cancer Support. It's No Life. 2009. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Campaigns/itsnolife.pdf> (accessed September 2014)
58. Macmillan Cancer Support/YouGov online survey of 1,740 UK adults living with cancer. Fieldwork conducted 26 July- 9 August 2010. Survey results are unweighted
59. Lyratzopoulos G, et al. Variation in advanced stage at diagnosis of lung and female breast cancer in an English region 2006–2009. *British Journal of Cancer*. 2012. 106: 1068–75.
60. Kennedy S, et al. Exploring key concerns and support needs of older people with advanced cancer. University of Nottingham for Macmillan Cancer Support. 2011
61. Thomas C, et al. Companions through cancer: the care given by informal carers in cancer contexts. *Social Science & Medicine*. 2002. 54(4): 529-44.
62. Pal, et al. Evaluating the older patient with cancer. *CA: a cancer journal for clinicians*. 2010. 60(2): 120.
63. Gosney M. General Care of the Older Cancer Patient. *Clinical Oncology*. 2008; 21(2): 86-91.
64. Lees J, Chan A (2011) Polypharmacy in elderly patients with cancer: clinical implications and management. *The Lancet Oncology*. 12(13): 1249-57
65. Spencer Grey, S.-A. Information for service users: educational implications. In: Foyle L and Hostad J (eds.), *Innovations in cancer and palliative care education*. Radcliffe Publishing, Abingdon, Oxon. 2007, pp.107-124.
66. Andrew M, et al. Social vulnerability, frailty and mortality in elderly people. *PLoS ONE Canada*. 2008. 3(5).
67. T. Kalsi et al. Are the UK oncology trainees adequately informed about the needs of older people with cancer? *British Journal of Cancer*. 2013. 108(10): 1936–1941.

68. Macmillan Cancer Support. Getting travel insurance when you have been affected by cancer. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Practicalissues/Travel/Gettingtravelinsurance.aspx> (accessed August 2014)
69. Macmillan Cancer Support. Age Old Excuse. 2012. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/AgeOldExcuse/AgeOldExcuseReport-MacmillanCancerSupport.pdf> (accessed July 2014)
70. Lisa K. Sprod et al. Exercise and Cancer Treatment Symptoms in 408 Newly Diagnosed Older Cancer Patients. *Journal of Geriatric Oncology*. 2012. 3(2): 90–97.
71. Macmillan/ICM online survey of 155 UK healthcare professionals involved in the treatment of cancer patients (55 GPs, 50 Oncologists, and 50 Cancer Clinical Nurse Specialists). Fieldwork undertaken September 2012. Survey results are not weighted.
72. Hurria A, et al. Distress in older patients with cancer. *Journal of Cancer Oncology*. 2009. 27: 4346.
73. Holland J, et al. *Psycho-oncology*. 2010. OUP, New York.
74. Maddams, J et al. Levels of acute health service use among cancer survivors in the United Kingdom. <http://www.ncbi.nlm.nih.gov/pubmed/21592781#> (Accessed September 2013). All cancers excluding non-melanoma skin cancer (ICD-10 C00-C97 excluding C44).
75. Parliamentary and Health Service Ombudsman. Care and compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people. 2011. <http://www.ombudsman.org.uk/care-and-compassion> (accessed September 2014)
76. Rainbird K, et al. The needs of patients with advanced, incurable cancer. *British Journal of Cancer*. 2009. 101:759-764
77. NCIN. 2013. Macmillan-NCIN work plan. Segmenting the cancer survivor population: By cancer type, 20-year prevalence at the end of 2010, UK. Available from: www.ncin.org.uk/view?rid=2493 (Accessed July 2014). Data sourced and presented in collaboration with the Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales, the Information Services Division Scotland and the Northern Ireland Cancer Registry. The analysis is based on patients diagnosed with cancer between 1991 and 2010 in England, Wales and Scotland, and between 1993 and 2010 in Northern Ireland. To ensure that patients, rather than tumours, were counted, only the first diagnosed tumour (excluding non-melanoma skin cancer) in each patient was included in the analysis. The numbers in this analysis may not agree with those published elsewhere due to slight differences in methodologies, periods of observation, datasets, and rounding.
78. Place of death from cancer by Local authority for the over 65s, 2011. England and Wales, Office for National Statistics personal communication; Scotland, Personal communication from Information services division Scotland. Death data from National Records of Scotland (NRS); data from ISD SMR01 (hospital inpatient and day case) records were used to obtain further details of place of death; Northern Ireland, Northern Ireland Statistics and Research Agency. (Accessed September 2013)
79. Cancer Research UK. Cancer mortality by Age. <http://www.cancerresearchuk.org/cancer-info/cancerstats/mortality/age/> (accessed September 2014)

80. Gwilliam B, et al. Prognosticating in patients with advanced cancer – observational study comparing the accuracy of clinicians’ and patients’ estimates of survival. *Ann Oncol*. 2013. 24(2): 482-488.
81. Temel J, et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine*. 2010. 363(8):733-42.
82. de Santiago A et al. A new palliative care consultation team at the oncology department of a university hospital: an assessment of initial efficiency and effectiveness. *Support Cancer Care*. 2012. 20(9):2199-203.
83. Higginson I, Constantini M. Dying with cancer, living well with advanced cancer. *European Journal of Cancer*. 2008. 44(10):1414-24.
84. Macmillan Cancer Support. Patients lose out on millions of unclaimed benefits. 2010. http://www.macmillan.org.uk/Aboutus/News/Latest_News/CancerPatientsLoseOutOnMillionsOfUnclaimedBenefits.aspx (accessed July 2014)
85. National Cancer Intelligence Network. Evidence to March 2010 on Cancer inequalities in England. 2010. <http://www.ncin.org.uk/view?rid=169> (accessed September 2014)
86. Macmillan Cancer Support. Feb 2010 online survey of 1,019 people living with cancer.
87. Macmillan Cancer Support. Always there: the impact of the End of Life Care Strategy on 24/7 community nursing in England. 2010. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/AlwaysThere.pdf> (Accessed September 2013)
88. Gao W, et al. Psychological distress in cancer from survival to end of life care: Prevalence, associated factors and clinical implications. 2010. *European Journal of Cancer*. 46(11):2036-44.
89. Macmillan Cancer Support. Always there? The impact of the end of life care strategy on 24/7 community nursing in England. 2010. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/AlwaysThere.pdf> (accessed September 2014)
90. NHS National End of Life Care Programme. What do we know now that we didn’t know a year ago? <http://www.endoflifecare-intelligence.org.uk/view?rid=464> (accessed September 2014)
91. Macmillan Cancer Support. Macmillan analysis of MOSAIC profile age distributions. <http://www.experian.co.uk/business-strategies/mosaic-uk-2009.html> (Accessed September 2013)
92. Ofcom. Media Literacy Audit: Report on media literacy amongst older people. 2006.
93. New Media Trend Watch. UK internet usage statistics. <http://www.newmediatrendwatch.com/markets-by-country/18-uk/148-usage-patterns-anddemographics> (Accessed September 2013)
94. Macmillan Cancer Support. Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project. http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/OlderPeoplesProject/CancerServicesComingofAge.pdf (accessed September 2014)
95. Moller H, Flatt G and Moran A. High Cancer Death Rates in the Elderly in the UK, *Cancer Epidemiology*. 2011. 35: 407-412. doi:10.1016/j.canep.2011.05.015 www.ncbi.nlm.nih.gov/pubmed/21852216 (accessed September 2014)
96. National Cancer Survivorship Initiative. Assessment and care planning. <http://www.ncsi.org.uk/what-we-aredoing/assessment-care-planning/> (Accessed September 2013)

97. Macmillan Cancer Support. Word cloud reflecting Macmillan's online community constructed from analysis on 15 September 2011, from the most recent posts of the 15 most active members of the online community aged 60+ (limited to those who make their age public), then using www.wordle.net to create the word cloud image.
98. Word cloud formed from analysis on 14 September 2011 using www.wordle.net of the 100 most recent UK national daily newspaper articles where the key words of "older people" and "cancer" both appeared at least once. Frequency of more frequent words are shown in larger fonts than less frequent words. Dates ranged from 10 October 2010 to 10 September 2011. UK national daily newspapers included: The Express, The Guardian, The Independent, The Daily Mail, The Metro, The Mirror, The Star, The Sun, The Telegraph and The Times.
99. BRAP/Macmillan Cancer Support. Walking into the unknown – Survivors and carers speak out on discrimination and inequality in cancer care services. 2011.
100. R Cracknell. The Ageing Population. 2010. http://www.parliament.uk/documents/commons/lib/research/key_issues/Key-Issues-The-ageing-population2007.pdf (accessed September 2014)
101. Jo's Cervical Cancer Trust. Frequently Asked Questions on Cervical Screening. <http://www.jostrust.org.uk/about-cervical-cancer/cervical-screening-smear-test-and-abnormal-cells/cervical-screening-smear-test/faq-cervical-screening> (accessed September 2014)

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 2012, and we know that over 300,000 people are newly diagnosed with cancer in the UK every year. Incidence can sometimes be given as a rate (per head of population).

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

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

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

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

(ii) Other terms

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

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

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

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

Full suite of the Rich Pictures

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

Overarching Rich Picture

The Rich Picture on people with cancer

(MAC15069)

The Rich Pictures on cancer types

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

The Rich Pictures on age groups

The Rich Picture on people of working age with cancer	(MAC13732_14)
The Rich Picture on children with cancer	(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	(MAC13841_14)
The Rich Picture on carers of people with cancer	(MAC13731_10_14)
The Rich Picture on people with cancer from BME groups	(MAC14662_14)
The Emerging Picture on LGBT people with cancer	(MAC14663_14)

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

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

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

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

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

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

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

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