Bill, 73, husband to Betty, who died from pancreatic cancer

THE RICH PICTURE

PEOPLE AT THE END OF LIFE

WE ARE MACMILLAN. CANCER SUPPORT

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

2017 update

About this 'Rich Picture'

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

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

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

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

This document is not intended to:

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

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

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

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

The legal bit

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

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

Macmillan or any other organisation referenced in this document claim no responsibility for how third parties use the information contained in this document. We have endeavoured to include all the major data available to us as of July 2017, but a document of this nature (essentially a summary of a large body of evidence) inevitably goes out of date. Macmillan has sought external validation of this document from clinical experts and we aim to regularly update the content of this document.

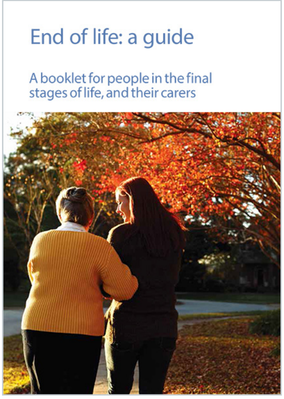
There may be data that have been released that does not appear in this document and Macmillan is under no obligation to include any particular data source. Any medical information referred to in this document is given for information purposes only and it is not intended to constitute professional advice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

Guidance on referencing this document

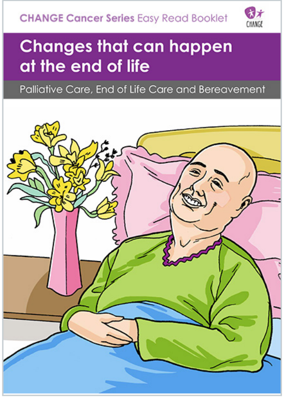
You are free to use any of the data contained in this document, however when quoting any factual data that do not belong to Macmillan, it is best practice to make reference to the original source – the original sources can be found in the References section at the back of this document on page 52.

Other related information for people affected by cancer

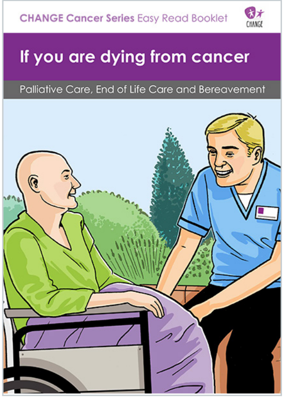
This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our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



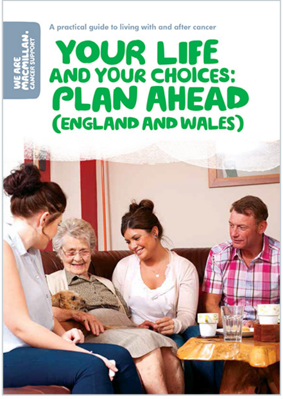
End of life: a guide
MAC14313



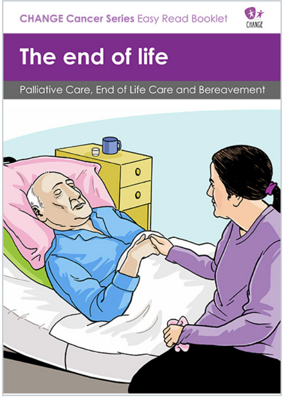
Changes that can happen at the end of life
MAC16303



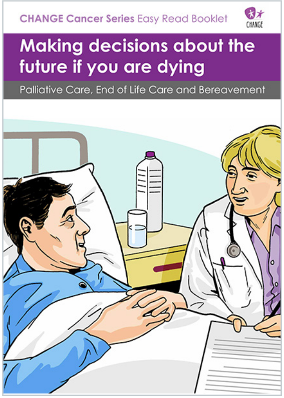
If you are dying from cancer
MAC16323



Your life and your choices: plan ahead England and Wales
MAC13616 (also available for Scotland and Northern Ireland



The end of life
MAC16343



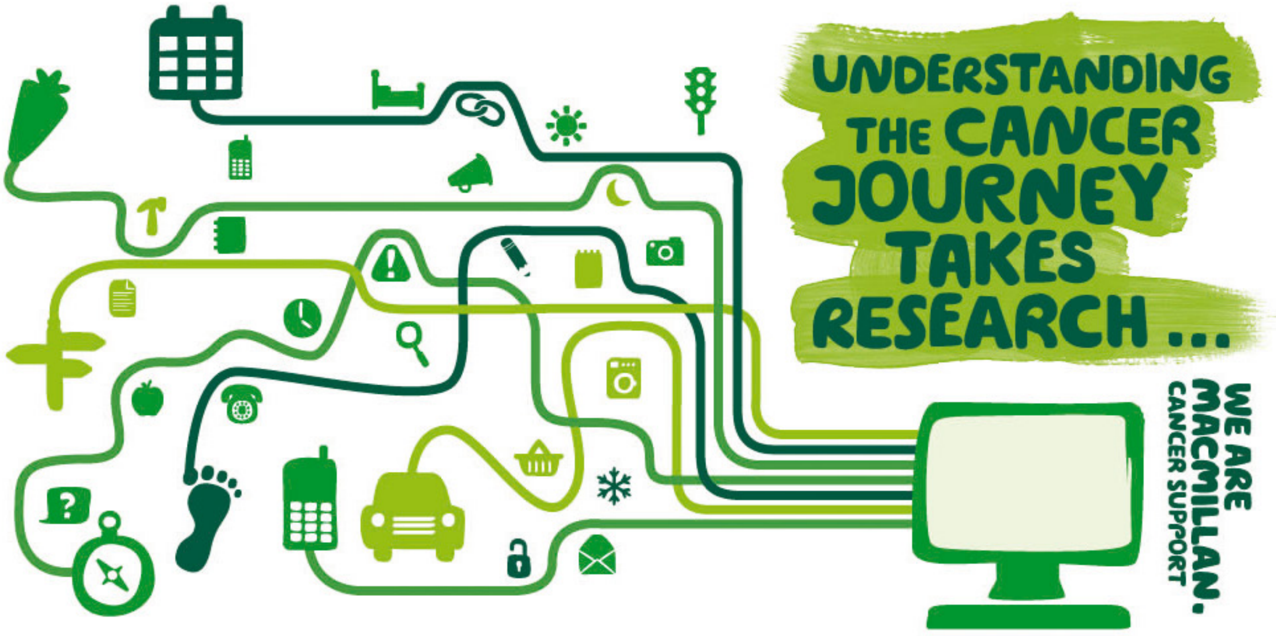
Making decisions about the future if you are dying
MAC16324

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

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

Find out more about cancer: what Macmillan can offer

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



Our research publications

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

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

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

Our cancer intelligence

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

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

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

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SUMMARY OF PEOPLE AT THE END OF LIFE

Key stats

Over **600,000 people died in the UK in 2015**.(1,2,3) Cancer was the **cause of 27%** of these deaths.(4,5,6,7)

With the right support, **64% of people with cancer would like to die at home**, but only 30% currently do.(14)

Just **1% would like to die in hospital**, but **37% of people with cancer currently do**.(14)

In England and Wales, proportionally more people die of cancer in the 65–74 age group compared with all other age groups (44% of deaths in the 65–74 age group are cancer deaths).(1,4,5)

The number of cancer incidence is expected to rise sharply over the next two decades (due to an expanding and ageing population). However, overall mortality rates (and overall mortality rates from cancer) are expected to decrease in the future. Therefore, **life expectancy and survival rates are expected to improve**.(8,9)

Cancer that cannot be cured

Being diagnosed with cancer that cannot be cured can trigger a wide and complicated range of emotions including **anger** or a **sense of injustice**. Some find it helps to talk to professionals from support organisations.(10)

An American study found that those who could recall being **given a prognosis** gave more realistic and accurate estimates of their own life expectancy, with **no negative effect on doctor-patient relationships**, or increased sadness or anxiety.(11)

Both patients and carers have described **receiving information at the right time** as important in helping them cope with advanced cancer.(12)

Terminally ill people experience high levels of **psychological distress**.(104)

Palliative care

Palliative care aims to achieve the **best quality of life** for patients and their families, but not everyone has access to high-quality palliative care services.(13)

More than **one in four** people with cancer (28%) find it **hard to be honest about how they feel** about cancer.(14)

The proportion of the UK population who are **cancer carers** has increased from 2.1% in 2011 to **2.7% in 2016**.(15,16)

Early involvement of palliative care can reduce the need for emergency admissions to hospital. Data from a pilot in Manchester shows that the service reduced admissions by a quarter.(105)

Approaching death

Among people with cancer in the UK, **only one in five (20%) have thought about where they would like to die**, and one in nine (11%) have planned their future care.(14)

83% of bereaved people in England agreed or strongly agreed that **the family member they cared for had their pain relieved** in the last two days of life.(20)

Clinical decisions concerning **starting or stopping artificial nutrition and hydration** are challenging, particularly for patients who lack decision-making capacity.(21)

The **last few days of life are very difficult for everyone**, with the patient often experiencing incapacity, confusion, difficulty breathing and complete loss of appetite.(48)

Specialist themes

People with learning disabilities can have conversations about death and dying, and their preferred end-of-life care, but require information that they can understand. They also need to have people around with whom they are familiar.(22)

Grieving is a normal response to loss. The bereaved are usually affected emotionally. However, physical health, behaviour and thinking can also be affected.(17)

In the first 15 months, **Macmillan Specialist Care at Home** helped to reduce unplanned hospital admission for patients at the end of life, as well as allowing more people living with cancer to die in their place of choice. Evidence shows that where a preference for place of death was known, 79% of people died in that preferred place.(94)

INTRODUCTION TO PEOPLE AT THE END OF LIFE

Who are people at the end of life?

We recognise that there is no standard definition of ‘people at the end of life’, and how these people can be grouped varies according to country, organisation and context.

In order to have some sense of what the ‘end of life’ phase of a person’s life journey typically looks like, for the purpose of this Rich Picture we are broadly using a widely-used definition of:

- People at the end of life = people in the last 12 months of their life(25).

We use this definition whilst remembering that many people who have been diagnosed with cancer that cannot be cured will live for more than 12 months, and many people may die much sooner after receiving a diagnosis of a life-limiting illness or condition (‘terminal diagnosis’).

Many of the needs and experiences of people at the end of life can be considered as palliative care needs. Although this Rich Picture is not primarily focused on palliative care, the topic features heavily, reflecting its importance to people at the end of life.

What is end of life care?(25)

End of life care helps those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of patients, their families and carers to be identified and met throughout the last phase of life and into bereavement.

What is palliative care?(13)

Palliative care has been defined by the National Institute for Health and Care Excellence (NICE) as the active holistic care of patients with advanced progressive illness, involving management of pain and other symptoms, and provision of psychological, social and spiritual support. The goal of palliative care is achievement of the best quality of life for patients, their families and carers. Many aspects of palliative care are also applicable earlier in the course of the illness (ie not necessarily associated with terminal illness), in conjunction with other treatments(2).

Palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help families cope during the patient’s illness and in their own bereavement(25)

‘Initially she was given six months. But Betty was a fighter without any shadow of a doubt. She was determined that she was going to make the most of the time that she had left, and that’s exactly what she did.

Betty had a very down-to-earth approach to things. She talked about a few things she was upset about – like not seeing the grandkids go to university. I used to wonder how she had the courage and strength to talk about things like that. She faced everything head on.’

Bill

What is specialist palliative care?(13)

Specialist palliative care can be provided by a range of disciplines such as doctors, nurses, psychologists, physiotherapists and occupational therapists. Where it is possible a multidisciplinary team consisting of all of these specialists will provide specialist palliative care. Specialist palliative care includes:

- Assessment, advice and care for patients and families in all care settings, including hospitals and care homes
- Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams
- Intensive coordinated home support for patients with complex needs who wish to stay at home

Want to know more?

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

At Macmillan, we know how cancer can affect everything. But you are still you. And we're here to help you live life no matter what. We'll give you the support you need to hold on to who you are and what's important to you.

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

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

> **‘I would say that the loneliness only really kicked in after Betty passed away. There was so much happening when Betty was in the house, so much going on and so much for me to think about, I didn’t really have time to think about what it would be like when Betty’s not here. It’s not until after she’s gone and the rest of the family goes home that it really hits you.’**
>
> Bill

KEY FACTS AND STATS ON PEOPLE AT THE END OF LIFE

This section presents some of the key stats and facts relating to people at the end of life. You may benefit from referring to the jargon buster on page 59 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.

1,651

people die in the UK every day(1,2,3)

Over 600,000

people died in the UK in 2015(1,2,3)

27%

of all deaths in the UK are cancer deaths(1–7)

More than 163,000

people died of cancer* in 2015(4,5,6,7)

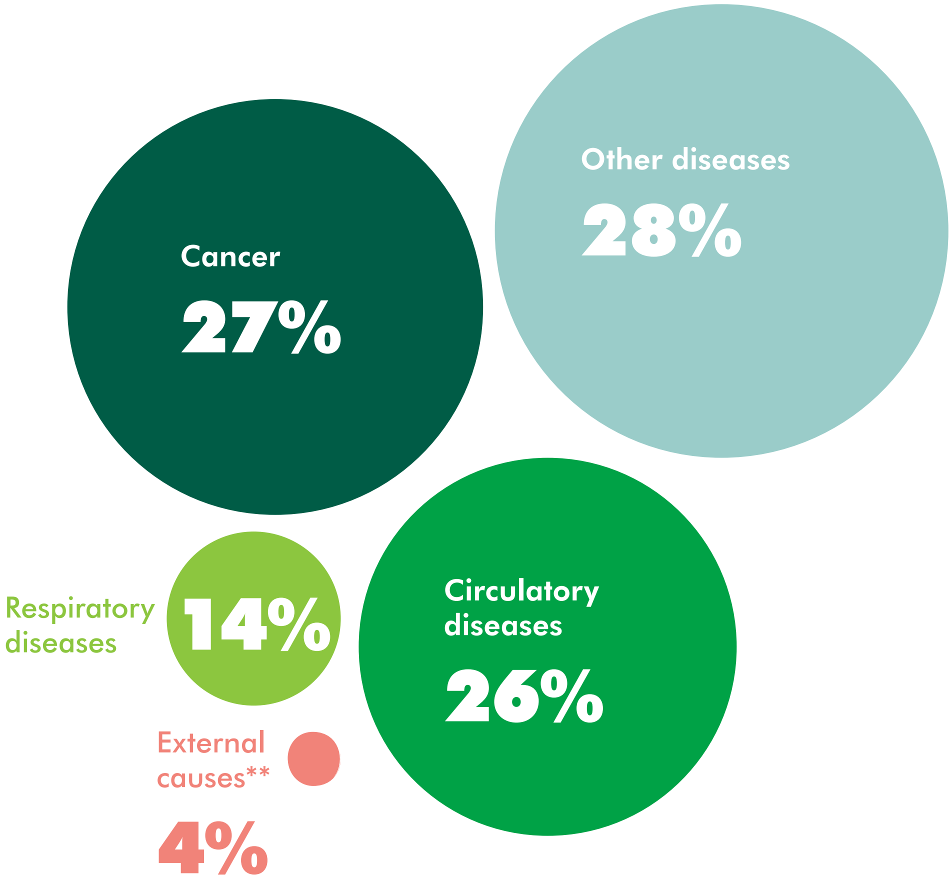
355,000

people a year need palliative care in England (a mid-point estimate)(26)

* C00-C97 excl. C44

How many people die per year? (mortality)(1–7)

Death by cause of death (broad disease group), UK, 2015*



* Does not add up to 100% due to rounding
**External causes of death include injuries, poisoning, falls, self harm and assault.

Cancer accounted for 27% of all deaths in the UK in 2015. It has now overtaken deaths by circulatory diseases (such as heart attack) as most common cause of death.

Key facts and stats

Where do cancer patients prefer to die?(14)

Preferred place of death in the UK, 2017*

Own home	Hospice	Hospital	Care Home	Elsewhere
64%	18%	1%	1%	2%

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

With the right support, 64% of people with cancer would like to die at home, but only 30% currently do, and just 1% would like to die in hospital.(14)

Where do cancer patients actually die?(1)

Actual place of death in England and Wales**, 2015

Own home	Hospice	Hospital	Care Home	Elsewhere
30%	17%	37%	14%	1%

**Does not add up to 100% due to rounding.

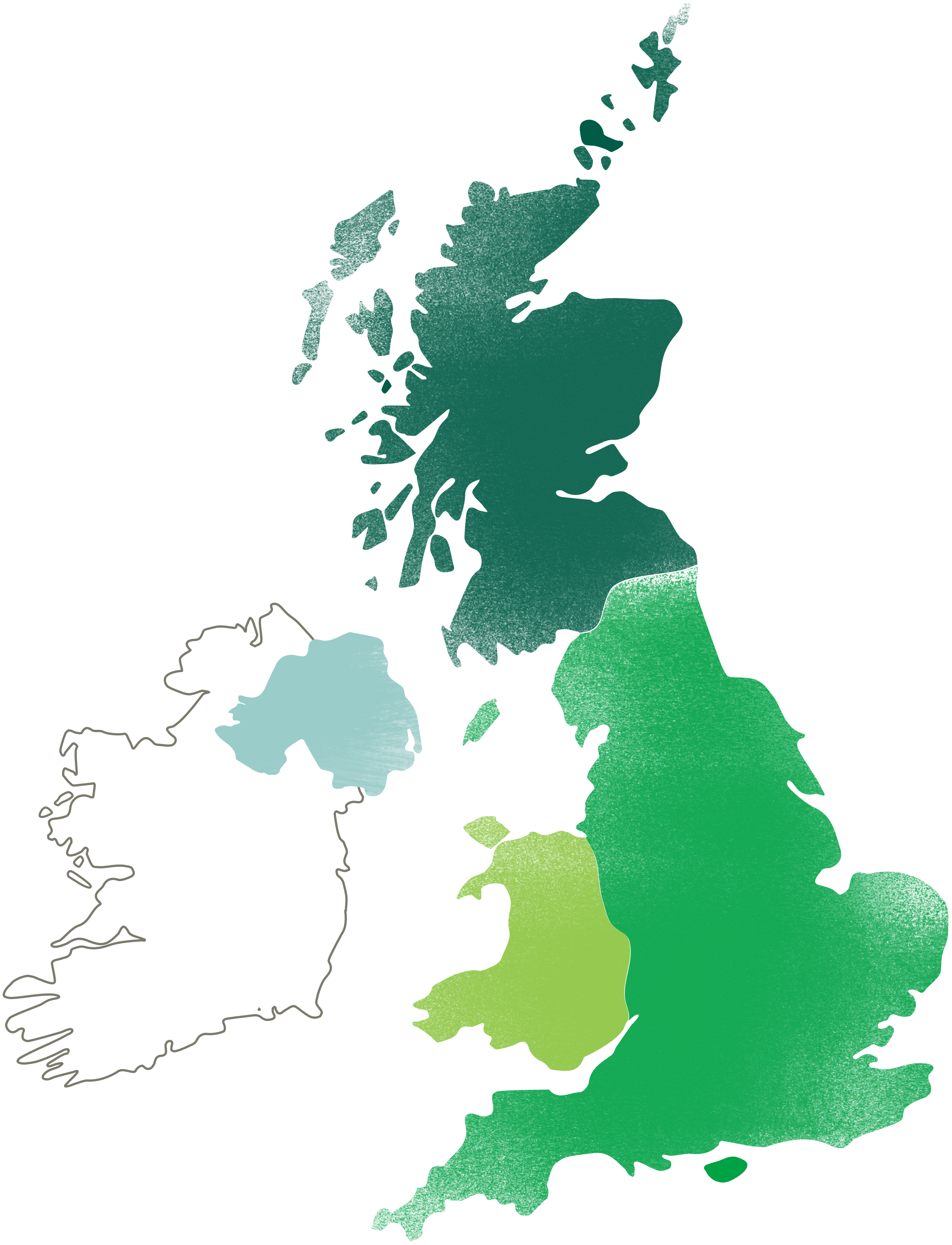
For people who died from cancer, these percentages have remained fairly consistent since 2012.(1,98)

> **‘When Betty was really ill, we weren’t sure how to handle things or what we should be saying to her. Tony [the Macmillan nurse who cared for Betty] pointed us in the right direction. Under his guidance we did the right things at the right time.’**

Bill

What are the key stats for the four UK nations?

There are variations between the four UK nations in terms of mortality from all causes of death and cancer mortality. The UK-wide data on mortality given on the previous pages is broken down into the four component nations here.



England

How many people die from all causes per year in England?(1)

495,309

deaths in England in 2015.

How many people die from cancer per year in England?(4)

134,679

deaths from cancer in England in 2015.

Wales

How many people die from all causes per year in Wales?(1)

33,198

deaths in Wales in 2015.

How many people die from cancer per year in Wales?(5)

8,700

deaths from cancer in Wales in 2015.

Scotland

How many people die from all causes per year in Scotland?(2)

57,573

deaths in Scotland in 2015.

How many people die from cancer per year in Scotland?(6)

16,011

deaths from cancer in Scotland in 2015.

Northern Ireland

How many people die from all causes per year in Northern Ireland?(3)

15,548

deaths in Northern Ireland in 2015.

How many people die from cancer per year in Northern Ireland?(7)

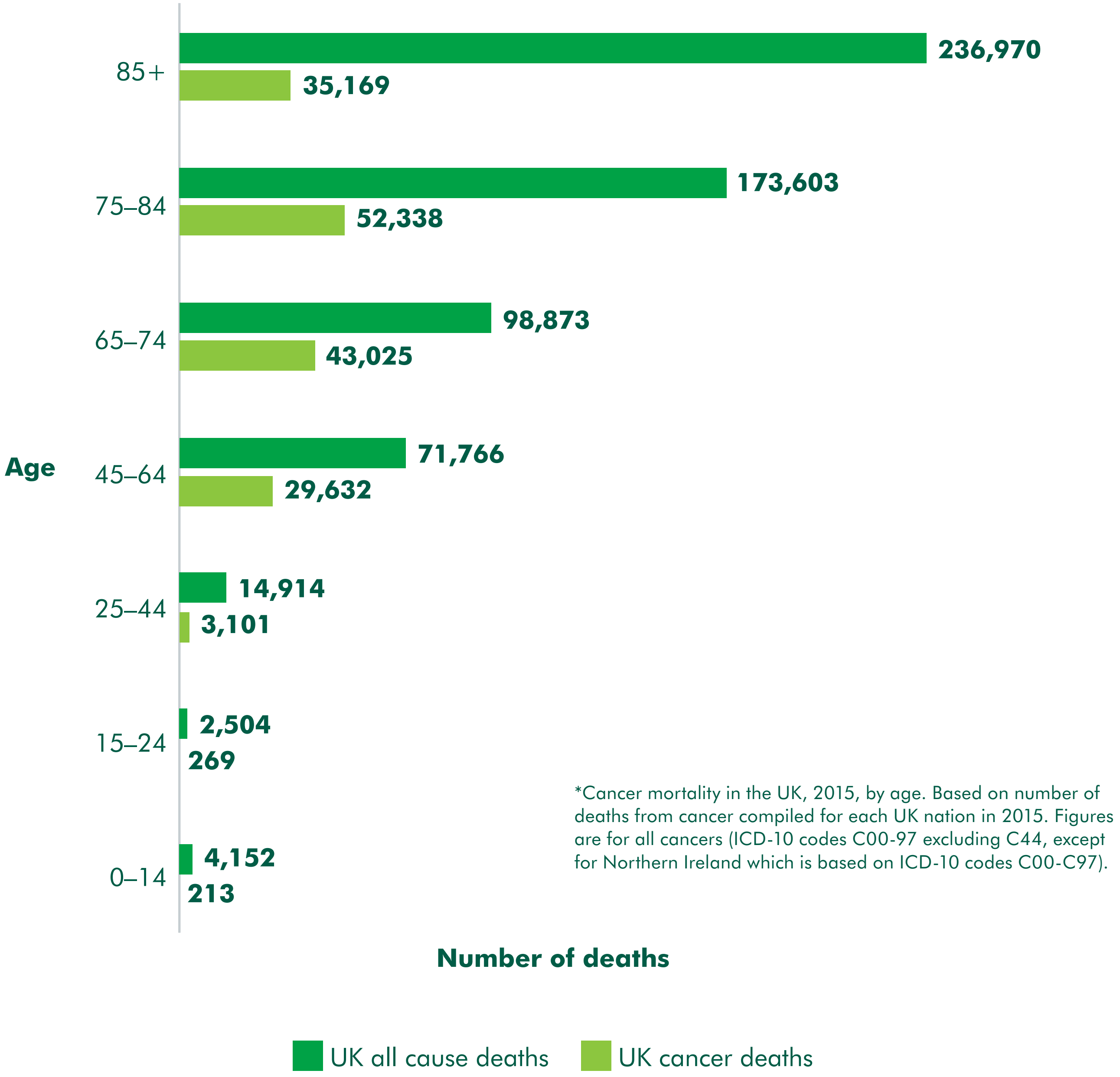
4,255

deaths from cancer in Northern Ireland in 2015.

The reported number of deaths in England and Wales relate to those who have died whose area of residence is in England and Wales and therefore may not match figures for total deaths in the UK.

At what ages do people die?(4–7,103)

All deaths and cancer deaths, by age band, UK, 2015*



*Cancer mortality in the UK, 2015, by age. Based on number of deaths from cancer compiled for each UK nation in 2015. Figures are for all cancers (ICD-10 codes C00-97 excluding C44, except for Northern Ireland which is based on ICD-10 codes C00-C97).

Whilst the 85+ age group has the highest number of deaths registered for all causes of death, the highest number of cancer deaths are in those aged 75–84.

International and demographic comparisons

How do mortality rates in the UK compare internationally?

In 2014, the age standardised mortality rate for people with cancer (per 100,000 inhabitants) was 273 in England, 289 in Wales, 287 in Northern Ireland, and 319 in Scotland.(27)

The age-standardised mortality rate for people with cancer in 2014 was 278 per 100,000 in the UK, compared with 262 per 100,000 on average across the European Union.(28)

What are the major demographic variations for people at end of life?

Ethnicity

Overall, the incidence of cancer in the Black and Minority Ethnic (BME) population is lower than in the White population, however this varies amongst different BME groups and cancer types. The statistics below give a broad impression of some trends related to ethnic groups and cancer incidence rates.(33)

In England, Asian ethnic groups have significantly lower risk of getting any of the four major cancers (breast, prostate, lung and colorectal) compared to White people.(33)

Both males and females in the Asian, Chinese and Mixed ethnic groups are between 20% and 60% less likely to get cancer than those from the White group.(33)

Black females are between 10% and 40% less likely to get cancer than White females. In contrast, there is no evidence that Black males have differing risks compared with White males, however, Black males are up to three times more likely to get prostate cancer than White males.(33)

On the whole, Black people are nearly twice as likely as White people to get stomach cancer and Asian people are up to three times more likely to get liver cancer than the White population.(33)

Age

Deaths from all causes in the UK steadily increase with age, with over two thirds (68%) of deaths in 2015 amongst those aged 75 or over.(103)

80% of cancer deaths in the UK are amongst the 65+ age group.(4–7)

Cancer incidence by deprivation

England

Deprivation can have a significant effect on the cancer incidence rate. In England, recorded cancer incidence rate increased with deprivation.(29)

In perspective, that means that if overall cancer incidence rates for the most deprived group were the same as the least deprived group, there would be 15,000 fewer cancers diagnosed each year in England.(29) The difference in cancer incidences related to deprivation in England have not improved over time in general.(29)

There is also significant variation in incidences of specific cancers in England. People from the most deprived group in England are more likely to be diagnosed with laryngeal, oesophageal, stomach, bladder, kidney, oral cavity and pancreatic cancers. Men from the least deprived group are more likely to be diagnosed with testicular cancer, and women with breast cancer.(29)

UK

Across the UK, incidence rates of lung cancer generally increase with levels of deprivation, for both men and women.(30) This is most likely linked to tobacco smoking.(31)

Incidence rates of stomach cancer also increased with deprivation for both men and women across the majority of the UK (this was not the case for women in Wales).(30)

For the least deprived groups, there were significantly higher incidence rates for prostate cancer and malignant melanoma (skin cancer) across the UK.(30)

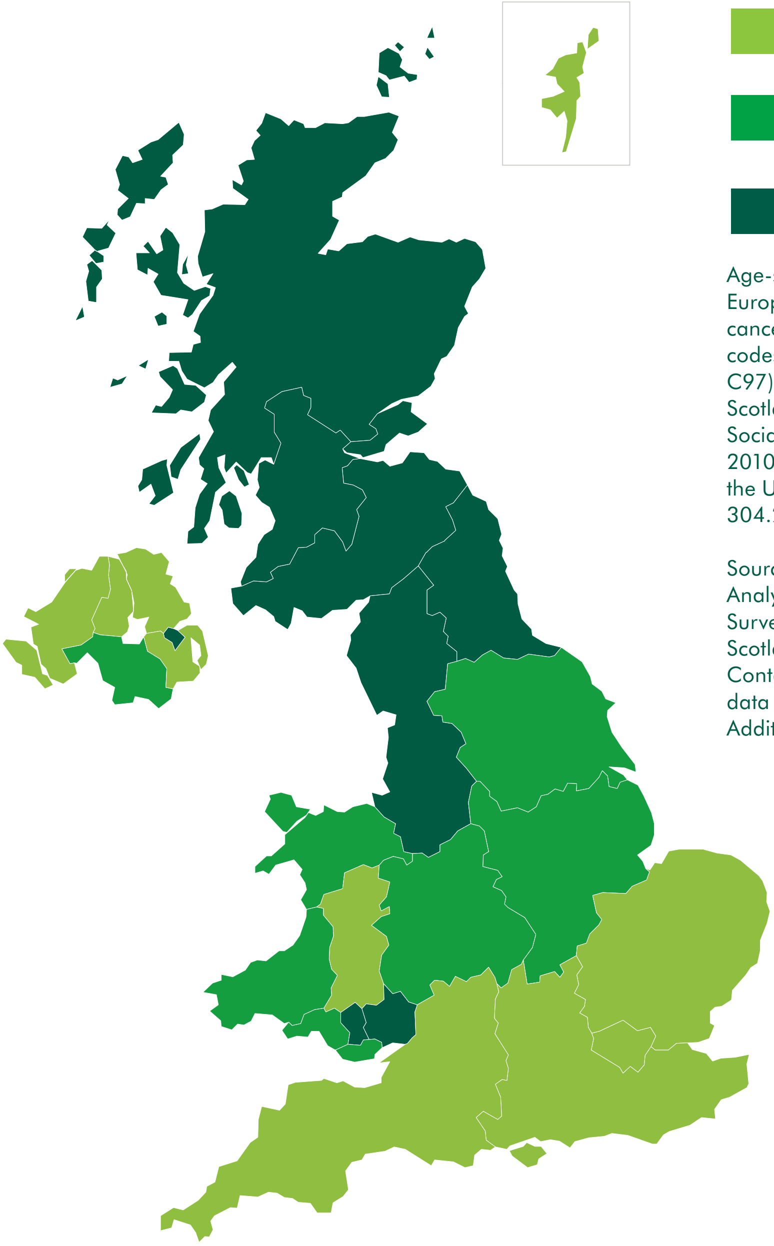
Cancer survival by deprivation

Scotland

In Scotland, survival rates were lower for the most deprived groups who had been diagnosed with a range of cancers. For men, there were significant differences at one and five years after diagnosis for lung, colorectal, and head and neck cancers. For women at one and five years from diagnosis, there was a significant difference in breast and thyroid cancer diagnoses.(32)

For men there was also a marked difference in cancer incidences for melanoma of the skin, oesophageal and liver cancers one year from diagnosis, and for prostate cancer at five years. For women, this was the case for colorectal cancer at one year.(32)

Thematic map – distribution of cancer mortality in the UK



Cancer mortality (age standardised), UK, 2010–2014

🟩 Low

🟩 Medium

🟩 High

Age-standardised mortality rates per 100,000 European Standard population, all ages, all cancers excluding non-melanoma skin (ICD-10 codes C00-C97 excl. C44. Scotland does not use C97). Rates are shown by region for England and Scotland, Health Board for Wales, and Health and Social Care Trust for Northern Ireland. Data is for 2010–2014 period. Data classified by tertiles for the UK combined [Low(<281.6), medium (281.7 to 304.2) and high (>304.2)].

Sources: National Cancer Registration and Analysis Service, Welsh Cancer Intelligence and Surveillance Unit, Information Services Division Scotland and Northern Ireland Cancer Registry. Contains National Statistics and Ordnance Survey data © Crown copyright and database right 2015. Additional mapping data provided by Experian.

Cancer mortality appears to be higher in Scotland and the North of England, compared to other areas of the UK.

Forecasts of cancer incidence and mortality

Overall mortality

In terms of overall mortality (deaths from all causes), the Office for National Statistics has reported that the assumed overall average annual rates of mortality improvement, will be 1.75% for males and 1.59% for females over the next 30 years in England and Wales.(34) This means that, overall, mortality will go down, with more people surviving longer.

In terms of life expectancy, based on mortality rates for a given year (period life expectancies) in the UK, the ONS reports that at birth, the period life expectancy in 2017 for men is 80.2 years, and for women is 83.6 years. By 2050 the ONS projects that period life expectancy at birth for men will be 85.5 years, and for women will be 88.2 years.(34)

Cancer incidence and mortality

A recent study has shown that future trends in incidences of cancer, and mortality caused by cancer, are complex and varied.(35)

Incidence

The study reported that between 2015 and 2035 in the UK, cancer incidence rates are projected to decrease by 0.03% in males and increase by 0.11% in females yearly. Four of the fastest growing cancers, would be thyroid, liver, oral and kidney cancer.(35)

In terms of the number of cancer cases projected for 2035, it is expected to be higher amongst men than women, with 270,261 male, and 243,690 female cancer cases projected.(35)

The types of cancer that are projected to be most common in 2035 amongst males and females are prostate and breast cancer respectively.(35)

Mortality

For most cancers, the mortality rate is decreasing over time. This is not the case for all cancers, however. Those cancers with notable increases in their mortality rates are liver, oral and anal cancer. It is projected that in 2035, there will be 95,961 female deaths and 116,585 male deaths from cancer.(35)

‘Betty’s never out of my mind. There’s a big canvas on the wall in my house and I find myself speaking to her sometimes, asking her questions. Some people will probably say I’m off my head – but I like doing it.’

Bill

THE END OF LIFE JOURNEY

We know that everyone dying from cancer will have unique experiences at different times of their 'end of life journey'. However, most people (and those caring for them) will go through some stages of the 'end of life journey'.

The following pages summarise what we currently know about the needs and experiences of people at these stages.

A typical 'cancer journey' at end of life comprises three key stages:

1 Being told your cancer cannot be cured

What happens when I am diagnosed with cancer that cannot be cured?

- Being diagnosed with cancer that cannot be cured means there is no chance of being completely cured from cancer, although people might be able to live with it.
- People with incurable cancer will continue to require care, to allow them to live for as long as possible and die as well as possible.
- Receiving an incurable cancer diagnosis can be very difficult and emotional, and people may begin to think of their wishes for care at the end of their life.
- There are practical issues around end of life that may also have to be considered, such as organ and tissue donation, or making a will.

2 Palliative care

What can I expect when I receive palliative care?

- Palliative care aims to manage a person's symptoms in order to achieve the best quality of life for patients and their families.
- Palliative care can enable people to die comfortably in their preferred place of care.

3 Approaching death

What issues will arise in the final few weeks and days of life?

- In the final few weeks and days of life for people living with cancer, there will be many things to consider, including practical and emotional concerns.
- The needs and experiences of people at end of life will change in time, from the final 12 months to the last few days, up to point of death.

NEEDS AND EXPERIENCES: CANCER THAT CANNOT BE CURED

For the purpose of this Rich Picture document, we are defining diagnosis of a life-limiting illness or condition – or 'terminal diagnosis' – as the final 12 months of life, after the time the patient is told their disease is incurable, as explained on page 4.

What are the typical experiences immediately after being diagnosed with cancer that cannot be cured?

Being diagnosed with cancer that cannot be cured means that there is no chance of recovery. For those who receive a diagnosis of cancer that cannot be cured, this can be a particularly emotional time – the initial shock and disbelief may be replaced after a few hours or days by powerful and often overwhelming emotions. These may make it difficult for people with a terminal illness to think clearly. They may need some time on their own or with a partner, a relative or close friend to deal with the news. Some people find it easier to talk to someone outside their family. For people affected by cancer, Macmillan's cancer support specialists are available to help.

What issues might need to be considered by someone who has been diagnosed with cancer that cannot be cured?

Advance Care Planning

Advance Care Planning (ACP) focuses on establishing a person's wishes around care at end of life and usually takes place as their condition is expected to deteriorate. Patients are supported to think about decisions they may not be able to make later, for example due to loss of mental capacity, around their needs and preferences surrounding the end of life, such as preferred type of care, limits on treatment (such as 'do not resuscitate') and place of care and death. The terminology and law around this type of planning and recording of wishes varies between the UK nations.(25)

Advance plans can also be made for the more everyday decisions that have a major impact on people's lives, which might have nothing to do with medical treatment. Such decisions might include the place in which they would want to be looked after if they were to become incapable of looking after themselves. Or they may involve appointing a person who can represent them. Under the Mental Capacity Act (England and Wales only), this is known as 'lasting power of attorney'. Under the Mental Capacity Act it is also possible to set on record 'advance decisions' to refuse specific treatments in particular circumstances.(42)

Hospice patients who have engaged in advance care planning (ACP) spend significantly less time in hospital. The average time spent in hospital in the last year of life is around 18 days for people with and Advance Care Plan, compared to 27 days for those without. 11% of people with an Advance Care Plan die in hospital, compared to 27% of those who have not engaged in ACP.(50)

There is evidence to suggest that ACP can aid people at the end of life in having a better experience at the end of life, including having a 'good death'. Some of the advantages of ACP are that it can:

- enable people to die at home(80)
- decrease hospital stays(81)
- enable patients to fulfil their wishes at end of life(82)
- enable children and adolescents to communicate with their families(83)
- reduce psychological problems for families(84)

However, only around one in nine (11%) have planned their future care(14). Some barriers which prevent people from engaging with advance care planning might be that:

- Families may not share their Advance Care Plan with medical professionals(85)
- Many elderly people do not have a chance to discuss end of life care as they do not know when to initiate a conversation(86)
- For those with dementia, it may be too late to have a conversation about ACP. This might be due to the lack of mental capacity derived from the illness.(87)
- Patients and carers may be ambivalent about discussing approaching death(88)
- The discourse around fighting cancer can prevent ACP conversations(97)
- Patients may wait until the end of active treatment to discuss ACP as this feels like the most 'obvious' time to start the conversation but by this time it may be too late(97)

Some factors which improve uptake of Advance Care Planning in patients are:

- People taking a positive view of ACP and involving their families and doctors in discussions(89)
- Having discussions about ACP gradually throughout the course of treatment(90)
- Nurses who are providing critical care being involved in the conversations (as they are highly trusted)(91)
- Having an actionable plan, signed by clinicians, containing patient's preference and course of treatment.(92)

Organ and tissue donation, or donation of body to medical science

Organ donation is generally not possible when the cancer has spread from where it originally started, or when the individual had blood cancer.(37) However, where cancer patients cannot donate organs, cornea or certain tissue donations may still be possible.(38)

In 2016/17, 6,388 patients were waiting for a transplant in the UK, which could save or dramatically improve their lives. However, only 4,753 organ transplants were carried out in the same year, of which 42% were donations by living donors. Most people in need of an organ transplant are waiting for a kidney, heart, lung, or liver transplant. Currently, 36% of people in the UK are registered organ donors.(36) People with cancer may be able to become an organ donor after their death, although not if they also have CJD (Creutzfeldt-Jakob Disease) or HIV.

Some people may want to donate their body for medical research. As part of the donation process, the patient and the next of kin are asked to sign a consent form, which is then kept with the will. Similarly to organ donation, not all those who wish to donate their body to medical research are able to do so.(108)

Making a will

Although there is no legal requirement to make a will, the possessions and property of those who die without one will be distributed according to the law, which may not be as they would wish.(39) Many people will want to ensure their wishes are met, and making or updating a will is something many people at end of life wish to do.

Only **38%** of respondents in the 2017 British Social Attitudes Survey said they have a will.(14)

Assisted dying

Assisted dying involves either euthanasia or assisted suicide. Both are illegal in the UK. A widely accepted definition of euthanasia is: ‘killing on request by a doctor via the administration of drugs at that person’s voluntary and competent request.’(41)

Removing life-prolonging treatment

It is acknowledged that withholding or withdrawing life-prolonging treatments may hasten a death that is already expected. This is not euthanasia.(42)

Needs when cancer cannot be cured

Physical needs

Most cancers affect the body's ability to use food to make energy, which can lead to exhaustion and weakness. Cancer cells can prevent the body from working normally, may cause a change in the chemical balance in the body, and can sometimes cause a build-up of waste chemicals. These changes can make people lose weight, no matter how much they eat.(48)

As many terminally ill cancer patients become weaker and less able to do things, just carrying out ordinary daily activities such as getting up can lead to exhaustion and the need to rest or sleep more during the day. During this time, it is common for people to lose interest in things that were previously important to them.(48)

Clinical needs

In England, only 64% of cancer patients (not limited to those with terminal diagnoses) said they were offered practical advice and support in dealing with the side effects of their treatment.(47)

15% of cancer patients (not limited to those with terminal diagnoses) say that they were not given additional information about future side effects of treatment.(47)

Practical needs

Advance Care Planning (ACP) is focused on establishing a patient's preferences surrounding end of life care, and can have practical benefits, especially when it is done early.(25)

ACP can help improve the quality of end of life care, and compliance with a patient's wishes.(45)

Engaging in ACP early on can result in reduced depression and stress in carers.(46)

Financial needs

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.(44)

Information needs

Cancer patients and their families often want information about how long they may have to live after hearing that their cancer is terminal. However, prediction of survival times for terminally ill cancer patients vary. A study found that 31% of doctors' predictions were overestimated (patients surviving fewer days than predicted) and 11% were underestimated (patients surviving longer than predicted).(49)

In a small qualitative study, both patients and carers described receiving information at the right time as important in helping them cope with advanced cancer.(12)

An American study found that those who could recall being given a prognosis gave more realistic and accurate estimates of their own life expectancy. This was not, however, associated with worse doctor-patient relationships, or increased sadness or anxiety.(11)

Emotional needs

Common concerns about death and dying include being in pain, leaving families behind, fear of the unknown, being alone, and the importance of quality of life over length of life.(50)

58% of those bereaved in the UK felt that their loved one was told they were likely to die in a sensitive way. However, 13% felt that they were told not at all sensitively.(20)

Emotional and psychological support needs for carers, family members and other loved ones can be very high at the point of death. These needs can continue for a long time after death.

Being diagnosed with cancer that cannot be cured can trigger a wide and complicated range of emotions. People receiving such a diagnosis may feel anger, depression, resentment, or a sense of injustice. Some find it helps to talk to professionals from support organisations.(10)

In a small qualitative study in England, both patients and carers rated trust in professionals as the most important factor in coping with advanced cancer.(12)

In the same study, patients and carers indicated a desire for individual, personal mentors, with lived experience of cancer, to help them through coping with advanced stage cancer(12)

NEEDS AND EXPERIENCES: PALLIATIVE CARE

What is palliative care?

Palliative care is the active holistic care of patients with advanced progressive illness, involving management of pain and other symptoms, and provision of psychological, social and spiritual support. 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.(13)

Palliative care aims to affirm life and regard dying as a normal process; provide relief from pain and other distressing symptoms; integrate the psychological and spiritual aspects of patient care; offer a support system to help patients live as actively as possible until death; and offer a support system to help families cope during the patient's illness and in their own bereavement.(25)

An estimated 355,000 people need good palliative care services every year in England but around 92,000 people are not being reached.(26)

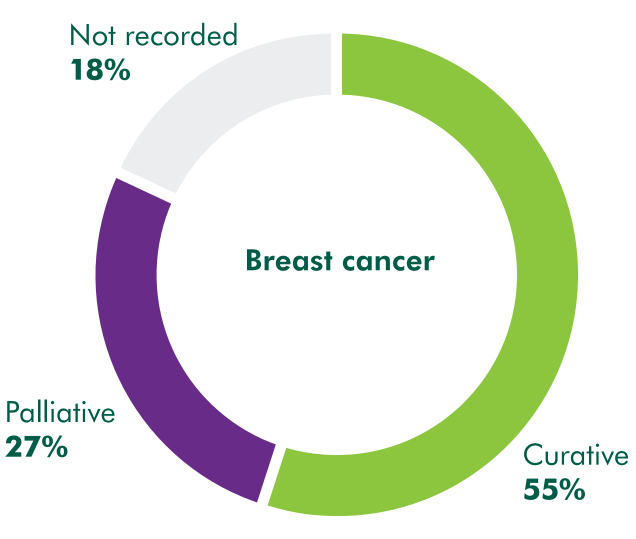
The majority of people requiring palliative care will not receive specialist palliative care: they are cared for by the generalist workforce such as district nurses, GPs, and generalist hospital staff. It is usually only if a patient's symptoms become complex that they are referred for specialist palliative care.(25)

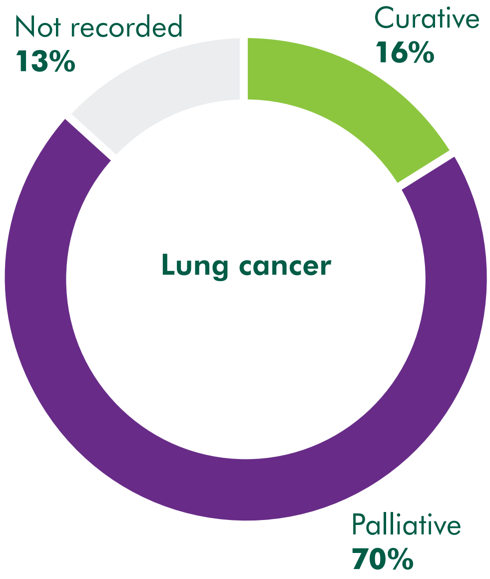
In England in 2014/15, around 126,000 people received specialist palliative care support in a community setting.(51)

An evaluation of Advance Care Planning (ACP), which focuses on establishing a person's wishes around care at the end of life including place of care, showed that cancer patients who completed an Advance Care Plan spend less time in hospital in their last year of life. ACP is associated with a reduction in the number of emergency admissions and hospital days, with decreased hospital treatment costs, compared to those without an Advance Care Plan.(52)

How many people receive palliative chemotherapy?(106)

Percentage of people receiving chemotherapy by reason for treatment, breast cancer and lung cancer, England

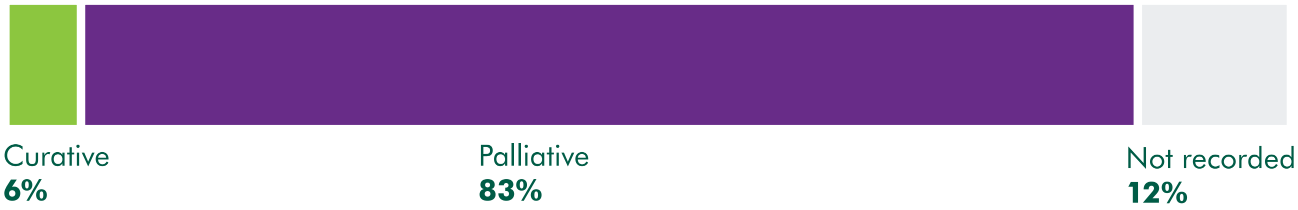




Over 28,000 people received chemotherapy for breast cancer in 2014 in England. 27% of breast cancer patients received chemotherapy for palliative care purposes, compared to 70% of lung cancer patients.

How many people die receiving palliative chemotherapy?(106)*

Percentage of people who die within 30 days of chemotherapy administration, breast and lung cancer combined, England



Despite the differences in rates of chemotherapy administered for palliative or curative intents, percentages of deaths within 30 days of chemotherapy administration are similar for breast and lung cancer. Combined, 83% of cancer patients who died within this period were receiving palliative chemotherapy.

*Breast and lung cancer combined.

Needs while receiving palliative care

Physical needs

An estimated 355,000 people need good palliative care services every year in England, but around 92,000 people are not being reached.(26)

In the UK, 18% of cancer carers are currently supporting someone with progressive cancer, and 8% are caring for someone at the end of life.(53)

In England in 2015, of those who had lost a loved one to cancer, 16% rated the care received in the last three months as outstanding, and 10% rated it as poor. In comparison, in 2012, 17% rated the care received as outstanding, and 8% rated it poor.(20,101)

In England in 2015, when asked to look back over the final three months of life, 19% of those who were bereaved by someone close dying with cancer said that decisions were made about care that the patient would not have wanted.(20)

About 1 in 3 cancer carers provide physical help to the person they look after, aiding them to wash, dress, eat and use the toilet. However, carers are getting older. In 2011, 37% of cancer carers were aged between 45 and 64. In 2016 that figure was 47%.(15)

Clinical needs

Those receiving palliative care reported lack of effective communication with healthcare professionals. Where these communications were lacking, participants in a survey reported adverse effects on both patients and carers.(54)

Only 33% of cancer patients in England in 2016 said they had received a care plan.(47)

In 2016 in England, 67% of cancer patients thought that waiting times when attending clinics and appointments for their cancer treatment were about right. However, 9% said they were much too long.(47)

A study of care provided to people with advanced progressive illness at three sites across England and Scotland found that care is often poorly co-ordinated in generalist settings for patients in the last year of life, although those with cancer tend to have better co-ordinated care than other patients.(55)

In 2014/15, the most common location for people to receive specialist palliative care was in their own homes, followed by hospital with the support of a specialist palliative care team (UK excluding Scotland).(51)

Early involvement of palliative care can reduce the need for emergency admissions to hospital. Data from a pilot in Manchester shows that the service reduced admissions by a quarter.(105)

A 2013 Cochrane review suggests that home palliative care increases the chance of dying at home and reduces symptom burden in particular for patients with cancer, without impacting on caregiver grief.(21)

A study carried out at a hospice in south west England found evidence to suggest that the use of ACP can increase the likelihood of the wishes of those at the end of life being met.(52)

Practical needs

Around two in three people (64%) think that we do not talk about death enough in this country.(102)

In England, in 2016 14% of cancer patients (not just those at the end of life) were not given clear written information about what they should or should not do after leaving hospital.(47)

In the same survey, 14% of patients reported that doctors and nurses did not give a relative or close acquaintance all of the information required to provide care at home for the person living with cancer.(47)

In a Danish study, hospitalised cancer patients receiving palliative care reported discrepancies between what their perceived needs were and the needs addressed by the interventions they were receiving. Lack of time for consultation was one of the main barriers to receiving appropriate support.(56)

Across the UK, 54% of those caring for people with cancer provide help with shopping and collecting prescriptions.(15)

On average, cancer carers in the UK are providing a greater range of support to people living with cancer in 2016 (5.4 types of support on average) than in 2011 (4.5 types of support on average). These include practical and emotional support, as well as other types of support such as advocacy.(15)

Financial needs

In England, the National Cancer Patient Experience Survey shows that (not limited to those at the end of life) of those patients who said it was necessary, only 56% said they had been given information about how to get financial help or benefits by hospital staff. Getting such information can become a particularly pressing issue during end of life care.(47)

In the same survey, 23% of cancer patients (not restricted to those at the end of life) would have liked information about how to get financial help or access any benefits they are entitled to, but did not receive any.(47)

Also in this study, 9% of cancer patients (not restricted to those at the end of life) say they were not told that they could get free prescriptions, but would have liked that information.(47)

Across the UK, more than 1 in 5 carers (28%) say they help manage the finances of the person they care for.(15)

Emotional needs

Participants in a small survey of patients and carers in Wales stated that the emotional experience of palliative care has fundamental importance.(57)

Across the UK, around three in four (76%) people with cancer have thought about the fact that they may die from their cancer, and around one in five (23%) said they think about it 'constantly' or 'often'. Just over a third (35%) of these people had not shared their feelings with anyone, and less than a tenth (8%) had spoken to their healthcare team.(14)

More than one in four people with cancer (28%) find it hard to be honest about how they feel about cancer.(14)

In a survey of patients in England, when asked about a recent hospital visit, 11% of people with cancer who were surveyed said that they could not find anyone to talk to about their worries and fears.(47)

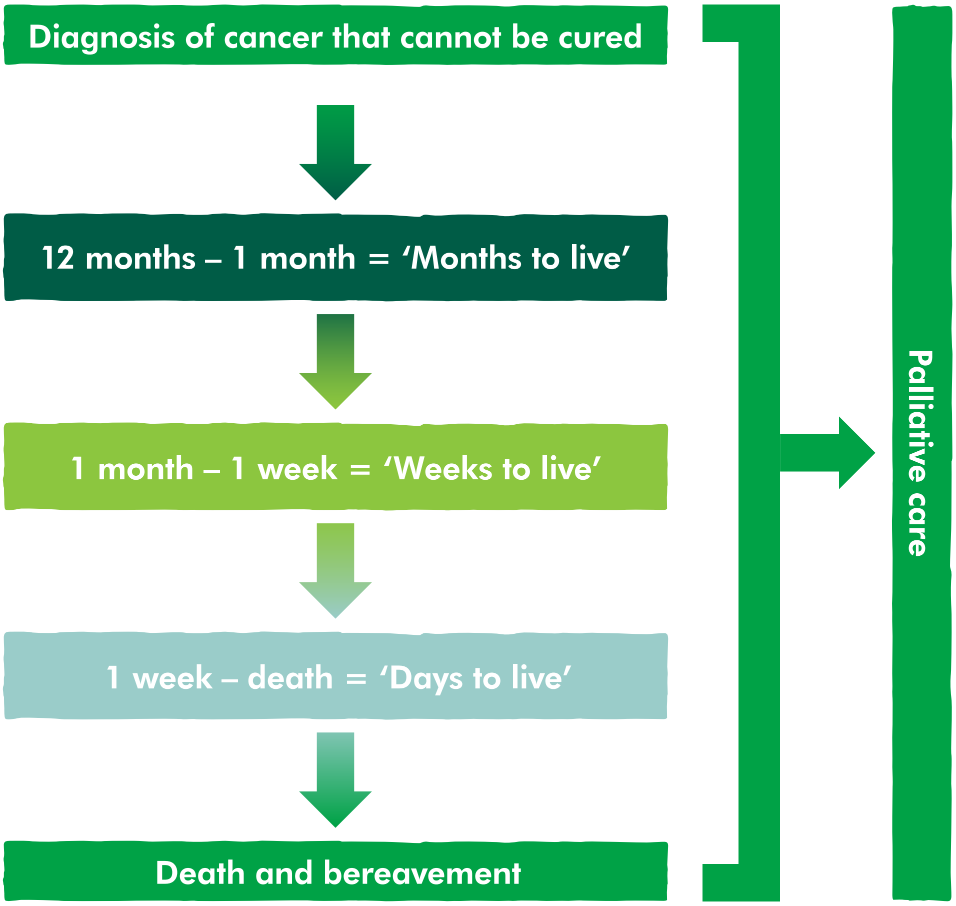
An American study, published in 2015, found that earlier interventions from palliative care can reduce depression and stress in carers for those at the end of life.(46)

‘Jokingly she used to say ‘I don’t know how you‘re going to book a holiday on your own because you’ve never booked one in your life. And I thought, that’s true. Because for the 40 odd years that we were married, she took care of everything.’

Bill

NEEDS AND EXPERIENCES:
APPROACHING DEATH

The final months of life for those who have been diagnosed with cancer that cannot be cured and their loved ones can involve changes in needs and experiences over time. These changes can broadly occur in the three time categories of 12 months – 1 month ('months to live'); 1 month – 1 week ('weeks to live'); 1 week – point of death ('days to live'). However, this is not necessarily always the case, and the changes for those approaching the end of life might not be so marked, or might occur at different time periods given the unpredictability of death. The time categories we have outlined give only a broad illustration of the typical changes in needs and experiences.



Diagnosis of cancer that cannot be cured

12 months – 1 month = 'Months to live'

1 month – 1 week = 'Weeks to live'

1 week – death = 'Days to live'

Death and bereavement

Palliative care

What are the needs and experiences during the stages as death approaches?

'Months to live' – 'Weeks to live'

Hospital Admissions
In England in 2014, nearly 30% of current acute hospital in-patients (not limited to those with cancer) will die within a year of being admitted.(21)

In a small study from 2014, the proportion of people living with cancer who had a hospital attendance or admission increased substantially from 35% a year before death to 60% in the penultimate month of life, with 30% having an emergency admission.(58)

On average, people living with cancer spent a total of roughly 25 days in hospital in the final year of life, with about 18 of those being emergency bed days, and 7 being elective.(58)

Hospice Care
In England and Wales in 2014, patients receiving hospice at home services were most likely to die at home (76% of patients audited died at home).(21)

A report from a hospice in the north-west of England stated that it is more than twice as likely that patients receiving hospice care will die at home, with 60% fewer hospital deaths compared to those not referred to the hospice.(21)

Social care
In a study across two sites in the UK, overall, 42% of those with cancer had a local authority social care assessment in the last 12 months of life, with the number of assessments rising sharply entering the final months of life.(58)

Overall 27% of those in the study used some form of social care in the final year of life, with the most prevalent usage by those over 85 in the final month of life.(58)

Over the course of the final year of life, the usage of nursing home care, meals and equipment all doubled or trebled, having started at low levels.(58)

The amount of home care service used increased sharply in the final three months of life.(58)

‘Days to live’

End of life care plan

Doctors and nurses may talk about an end of life care plan. This is the care that the doctors and nurses will plan to meet the specific needs of a person as they approach the end of their life. It will help to make sure that their needs for food, drink, symptom control, emotional, spiritual and social support, are met. The doctors and nurses will involve relatives and friends in decisions about treatment and the end of life care plan. They will also give support to relatives and friends.(59)

Communication with carers and loved ones

In a 2016 audit of patients dying in hospital in England (not limited to those with cancer), it was found that in the final few days of life, communications between doctors and carers and loved ones, tended to be much more frequent than those between doctors and patients.(60)

Where it had been recognized that a patient was likely to die, a nominated person close to the patient had been involved in a discussion about this in 95% cases. However, of those surveyed only 25% of those who were recognized as being likely to die had documented evidence of a discussion with a healthcare professional about their likely imminent death.(60)

Where there was an advance care plan, the team of healthcare professionals responsible took the contents into account in 91% of decisions, however only 4% of those surveyed were found to have an advance care plan in place(60)

Anticipatory prescribing

Anticipatory prescribing is the practice of making sure medications for common end-of-life symptoms are readily available to patients, so that they can be accessed without delay. Where people at the end of life (not limited to those with cancer) had a hospital stay of 24 hours or more, anticipatory prescribing was used to control the five key symptoms which present in the final days and hours of life.(60)

For pain, anticipatory medication was used to control symptoms in 75% of cases; for agitation the figure was 69%; for breathing difficulties, 66%; for nausea and vomiting, 66%; and for noisy breathing, 62%.(60)

Incapacity

In the last few days of life there usually comes a time when people are not able to get out of bed at all. After needing to sleep and rest a lot, most people move into a phase where they become more and more drowsy, drift in and out of consciousness and then become unconscious. Although a person in the final days or hours of life will not be able to respond to the people around them, it is likely that they will be aware that they are there and able to hear them if they talk. This phase may last only a few hours or can continue for a few days.(48)

Confusion

If this occurs, the patient may become confused, and not recognise family or friends, or hear or see things that are not there (hallucinations). This confusion can be due to chemical changes that are happening in the body and the build-up of waste chemicals (toxins).(48)

Physical changes

The patient’s physical condition may also change. Feet and hands may feel cold, or skin become very sensitive to any touch. For those who experience limited mobility, bed sores may occur, as well as issues with washing up. If a person is not moving around, the fluid normally produced by their lungs is not able to drain away and may collect in the air passages. This means that when they breathe they make a slight groaning (rattling) noise. Although noisy breathing can be upsetting for the people around, it does not seem to be uncomfortable for the dying person themselves.(48)

Food and drink

In the final stages, food and drink are not necessary as the body is no longer able to absorb or use them. Moistening the patient's lips or mouth are all that is needed. When a person who is near the end of their life stops drinking, they usually only live up to a few days.(48)

Moment of death

It can be difficult to pinpoint the exact moment of death. Once someone has died, often the person's body will relax completely and their face will look very peaceful.(59)

Needs in the last days of life

Physical needs

Of those surveyed in England in 2015, 80% of bereaved people agreed or strongly agreed that the person they cared for had support to drink or receive fluid in the last two days of life if it was wanted. However, 11% disagreed or strongly disagreed that this was the case. 77% believed support was provided to eat or receive nutrition if it was wanted, in the final two days of life (12% disagreed or strongly disagreed).(20)

The most common symptoms experienced by more than half of people during their last two weeks of life include shortness of breath, pain, and confusion.(43)

Clinical needs

83% of bereaved people agreed or strongly agreed that the person they cared for had their pain sufficiently relieved in the last two days of life. However, 10% disagreed or strongly disagreed with this statement.(20)

Clinical decisions concerning starting or stopping artificial nutrition and hydration are challenging, particularly for patients who lack decision-making capacity. A 2013 systematic literature review comprising data from 40 countries (but not limited to patients with cancer) found that increasing the patient's quality of life is the main decision-making factor, although the meaning of that term varied. Prolonging life was the second most cited factor; patient's wishes were influential but not determinative.(21)

Opioids are often prescribed to cancer patients at the end of life to keep pain under control. Yet prescriptions seem to be done on the basis of prescribing behaviours of clinicians rather than individual patient need.(100)

Medication may be prescribed to help deal with symptoms such as pain, sickness and vomiting. Techniques to help with problems such as difficulty sleeping, tiredness and lack of energy, breathlessness, difficulty eating or a sore mouth can be used. If the symptoms are too hard to manage at home, a person may be admitted to a hospice to have their symptoms controlled.(10)

Practical needs

Among people with cancer in the UK, only one in five (20%) have thought about where they would like to die, and one in nine (11%) have planned their future care.(14)

Emotional needs

Good planning at the end of life can help those left behind to cope emotionally.(14)

Some of the main barriers to choice at the end of life are: ineffective identification of end of life approaching, and conversations about it; a lack of planning or coordination; skills within the community workforce; a lack of access to 24/7 community services; a lack of access to social care; and a lack of support for carers.(99)

PERCEPTIONS

This section attempts to give an indication of the experiences people at the end of life with cancer go through, although we know that there is huge variation within the population. This section also provides insight into perceptions about cancer and the end of life.

Professionals perception

Two in three UK nurses (67%) feel that they don't have sufficient time to provide high quality care for patients who are dying.(68)

Medical students often view patients receiving palliative and/or end of life care as being in 'denial' about their condition, and approach denial as if it were a disease that they can, and should, diagnose and treat. Patients who do not behave in the way expected, such as those displaying what is labelled as denial, can ultimately block what student doctors consider to be good treatment, care and death. For some students such a dynamic can lead to feelings of personal failure. For patients this may affect their relationship with doctors and the timing and content of the communication that does – or does not – take place.(69)

Two in three UK nurses say they don't have time to provide high quality care at end of life.(71)

What do people diagnosed with cancer that cannot be cured say about their experience?

‘Within the space of five minutes I went from a stomach issue to an initial diagnosis of Lymphoma, the rest of the conversation was a blur other than a comment that this type of cancer has a better prognosis than most and that I needed to see another specialist. I went out into the carpark and cried my eyes out, I've never felt so alone or scared in my life.’

Mike

‘We’ve been given that chance by the medics. The chance to plan, to savor, to enjoy, to know what is really important to us. So yes, I’ve planned the usual stuff – will, finances, funeral. But I also do the important stuff – memories for my husband and son, a scrap book of me in case my son can't remember me.’

Karen

The Macmillan website hosts guest blog posts from Online Community members, which are a great source of information on the different experiences of people living with cancer.

Alan, 36, lives in Yorkshire with his wife and three young children. Alan is a lawyer and writer and blogs under the moniker 'Candid Daddy'. His mother was diagnosed with stage 4 lung cancer and passed away in 2010, aged 57.

What I learnt from my dying mother

I remember the day that I was told that my mother had cancer. I was sat on the train travelling home from work, speaking to a friend, when my brother called with the bad news. It came from nowhere. Despite not knowing any more than the fact that she had cancer, I was distraught. The word 'cancer' was terrifying and it transpired my fear wasn't misplaced. On that day, no-one knew how bad the cancer was, but after further tests were carried out, the verdict was stage 4 lung cancer.

Words cannot do justice on how it feels to learn that your mother is dying and that there is no cure. Here was a woman who was every reason why you were alive, and suddenly you knew her curtailed fate. In the not-too-distant future, she was no longer going to be there. No longer there to care for you, to give you that sage advice you were used to, to cook that special family meal that only mothers can cook, nor to love you in a way that no other person could.

Needless to say, this irreversibly changed the dynamic of the family. Everything became amplified and sensitive. The time you spend with your family, the time you spend away from your family, any illness my mother had irrespective of how serious it was, your faith, your hope and, ultimately, your love. I also started to realise my own limitations. Initially, I felt obliged to spend every minute with my mother and, regardless of how much of that I achieved, it never felt like enough. This didn't necessarily lead to guilt or regret, more of a sad reflection of my lack of ability to really dedicate myself to my own dying mother when there were so many competing priorities in life, even in the face of what seemed like the most important one. As someone who obsesses over trying to find solutions to problems, I researched cancer extensively, trying to understand its intricacies, in the bare hope that there might be a medical loophole in countering the severity of her diagnosis. However, some conundrums just cannot be undone.

Some days, in fact most days, my mother would look no different to any other person. The disease was within and did not show externally. What did show externally were the effects of treatment. Chemotherapy and radiotherapy each doing their bit to try and improve the prognosis, but in turn causing the symptoms commonly associated with such treatments. At times, we wondered whether it was worth having any treatment at all, and the constant battle to try and understand what the best course of action (or inaction) would be in the circumstances was one of the most difficult challenges we faced as a family. Selfishly, I wanted to have my mother around as long as possible, but this was not always in her best interests, and so I battled my inner demons to reconcile that internal conflict. There was no right answer.

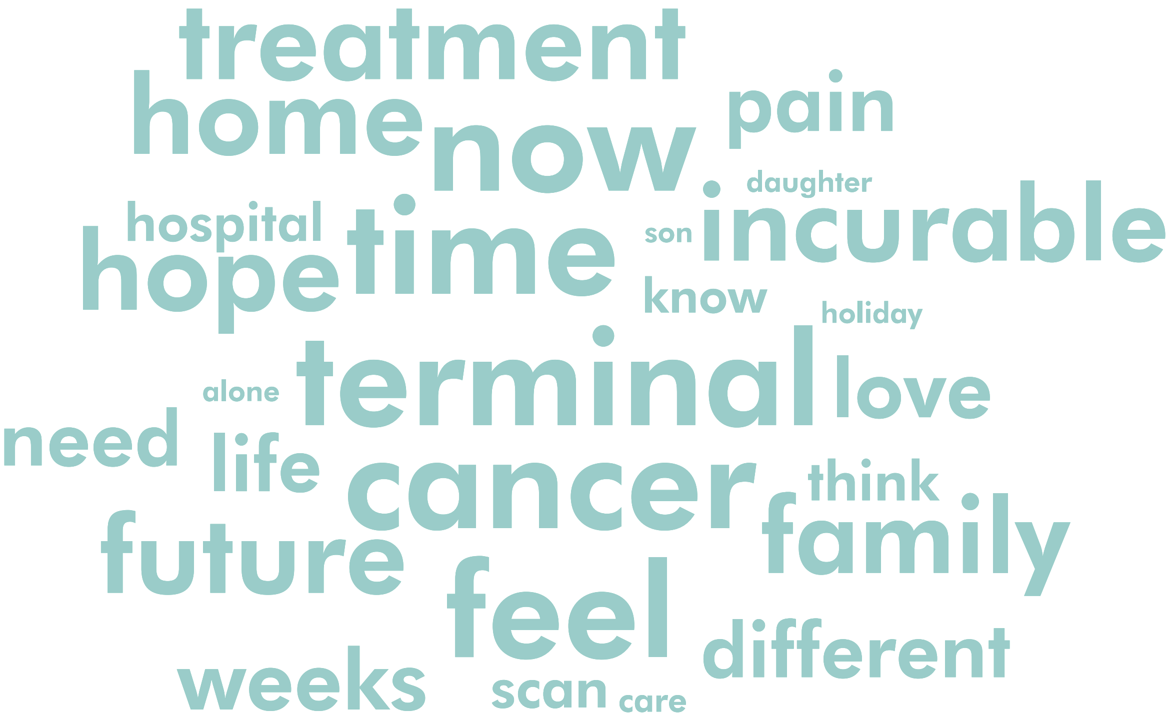
I would accompany my mother to the hospital appointments, to treatment sessions she had, and I would visit her at home when she was less mobile due to the intensive treatment. We would discuss the side effects of treatments and the impact of the cancer, like the time she had to buy a wig to mask her hair loss. I would speak to her about the way she felt physically as well as mentally, and how she viewed her remaining days. These were conversations that I sometimes wished I didn't need to have, but were also humbling and insightful and a way to know her on a deeper level.

In some ways, this was a positive by-product of cancer – that I spent more time with her and my family. It meant that we cherished what little time we had together, and that meant making more of an effort, whether it was in an organised way or a simple chat over a cup of tea. It also heightened my sense of gratitude, because when you realise life really is invaluable, everything becomes a blessing. Cancer taught me a lesson that I needed to take pleasure in the ordinary – the ordinary had transformed into something precious. Or, more accurately, I was reminded that the ordinary was always precious, it was just that I had overlooked it for a long time.

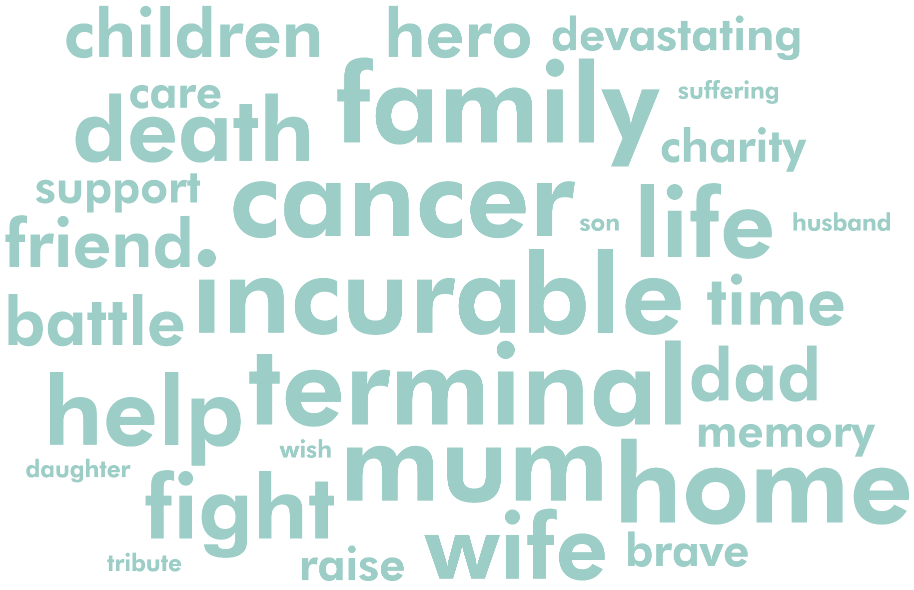
‘Betty used to confide in me. Lots of memories, lots of things she‘s probably never told anyone. Her fears. If she had any pain, she wouldn’t tell her family because she was trying to protect them.’

Tony (Macmillan nurse who cared for Betty)

What our Macmillan Online Community members are saying about living with cancer that cannot be cured…(65)



How the media* portrays end of life experiences…(66)



*UK national daily newspapers.

What does this tell us about people's perceptions of living with cancer that cannot be cured?

Macmillan hosts online discussions on its website; we have analysed the frequency of words used in the discussions relating to being diagnosed with cancer that cannot be cured compared to the frequency of words used in the UK media articles where incurable cancer is the subject. The results are summarised here:

References to diagnosis and treatment are predominant in the online community, as shown by the presence of words such as 'terminal', 'incurable', 'treatment' and 'hospital'. The emotional impact on the patients as well as those around them is also an important topic of conversation in the community, as words like 'feel', 'future', 'hope', 'family' and 'life' show.

The media tend to focus on depicting the perceived struggles people living with incurable cancer may face, as words such as 'hero', 'fight', 'battle' and 'brave' shows. Also, words like 'family', 'mum', 'home', 'children' and 'friend' are very prominent in the media. This shows how the attention is drawn to the impact the loss of a loved one has on family members.

SPECIALIST THEME: DEMOGRAPHICS

We know that everyone's experience at the end of life is different. This section looks at needs and experiences of some specific groups at the end of life.

People with learning disabilities

A study in Northern Ireland found that people with learning disabilities can have conversations about death and dying, and their preferred end-of-life care, but require information that they can understand and they also need to have people around with whom they are familiar.(70)

In a study in the Netherlands, end of life care for people with intellectual disabilities has been found to increase the bond between the 'two families' of relatives and care staff, with an interweaving of personal and professional involvement. Some of the key values behind this shift are a desire to 'be there' for the person with intellectual disabilities, and to be 'responsive' and 'attentive' to their needs.(71)

A survey of doctors in the Netherlands showed that medical professionals believed that considerations about quality of life were most important when considering whether to start or continue an intervention, or to withdraw treatment, when caring for people with intellectual disabilities at the end of life.(72)

The support needs for adults with intellectual disabilities will change over time, particularly at the end of life.(73)

Children, adolescents and young adults

For parents of a child who is approaching the end of life, their views of Advance Care Planning may change over time, and it is therefore important to allow them to keep with options open. Regular discussions over the course of the illness can help clinicians to understand the parents' motivations in their decision-making.(75)

Evidence from the USA suggests that adolescent and young adult patients with cancer are interested in having end-of-life discussions and that the patients, their families, and their health care professionals all benefit from such discussions.(24)

A study in the USA found that adolescent and young adult oncology patients followed by a palliative care team – when compared to those who received no palliative care – were less likely to die in the intensive care unit, less likely to have been on a ventilator, and received fewer invasive medical procedures during the last months of life.(76)

A study in Northern Ireland found that providing end-of-life care to children was associated with many challenging experiences, such as finding the right combination of medications to alleviate end-of-life care symptoms and reduce any distress for the child and family. However, staff viewed their role as rewarding in terms of the meaningful relationships developed with children and their families.(77)

Prisoners

The fastest growing section of the prison population is made up of older men, and at the end of March 2015 there were 11,720 people over the age of 50 held in prisons in England and Wales (14% of the total prison population). This number included 3,984 prisoners aged 60 and over, and 102 aged 80 and over.(78)

In England and Wales in 2014 there were 243 deaths in custody, the highest number on record; of these, 141 were due to natural causes.(78)

The Prisons and Probation Ombudsmen acknowledges that, given the increasingly ageing prison population, caring for those approaching the end of life is 'a growing responsibility for the Prison Service'.(78)

There are significant challenges in delivering palliative care, including constraints within the prison regime that make giving appropriate and timely medication for pain and other symptoms very difficult.(78, 79)

For security reasons, prison officers have to be present when nurses go into cells to assess or treat patients, but practical considerations surrounding this can prevent care reaching patients in a timely manner, even when the patient's need is acute (e.g. in the case of a heart attack or epileptic seizure).(79)

Prison officers and healthcare workers who care for those who are at the end of life in prisons are in need of extra support and training to cope with the emotional challenges which arise.(79)

Macmillan provides a wealth of 'Easy Read' information booklets, including on the end of life. These booklets use simple language and pictures, so that they can be more easily understood by anyone who finds it hard to read.

For more information visit **macmillan.org.uk**

SPECIALIST THEME:
SPECIALIST CARE AT HOME

Current estimates suggest that around 75% of all deaths per year (around 355,000 people) have palliative care needs, and that of those people, around 170,000 receive specialist palliative care services.(26)

The Macmillan Specialist Care at Home project is based on the successful Midhurst Macmillan Specialist Palliative Care Service which began in 2006. This service consists of a consultant-led, multidisciplinary team that provides integrated, community-based care to people with cancer and other life-limiting conditions towards the end of life. An independent evaluation of the Midhurst service found that people had fewer A&E attendances, spend fewer days in hospital, and are more likely to die in their preferred place of care.(107)

Following the Midhurst evaluation, Macmillan expanded the approach to six more innovation centres, launching in 2014 in Birmingham and Solihull, Dudley, Hull, the Isle of Wight, North London, and West Norfolk.(96)

By encouraging earlier referrals, Macmillan Specialist Care at Home services allow more time to get to know patients and families and plan how to meet a person's wishes for their care at the end of life. Multidisciplinary teams proactively manage people's care in the community – often through a central 'coordination hub' – allowing them to respond quickly in a crisis and avoid unnecessary hospital admissions.

The key features of the service are:

- Early referral – this allows time to build strong relationships, plan ahead and provide practical and emotional support.
- Clinical interventions at home – where possible, a broad range of interventions (such as blood transfusions, intravenous antibiotics administration, ultrasound and spinal anaesthesia) can be provided at home or in the community. This can be less stressful for patients and carers, saving their time and energy, as well as reducing the number of people admitted to hospital/clinics for these treatments.
- Close and proactive collaboration with primary care and other service providers – better coordination between services and service providers is key to a better experience of care.
- Flexible teamwork between specialists, generalists and trained volunteers – the flexibility of roles undertaken by team members is reported as key by patients, carers and staff. This fluid way of working allows for overlap between roles, working hours and geographical boundaries, making it more likely that patients will have their needs met by a healthcare professional who is familiar to them.(95,108)

The service provided in the centres is currently being evaluated. Some of the key findings are:

- Patients who were referred to these services had a wide range of symptoms, ranging from issues with mobility and with weakness, to nausea, vomiting and a lack of appetite.
- In the first 15 months, Macmillan Specialist Care at Home services carried out 450 interventions such as phlebotomy (323), delivering subcutaneous fluids (57), and performing ultrasounds (33). 80% of them occurred in the patients' usual place of residence.

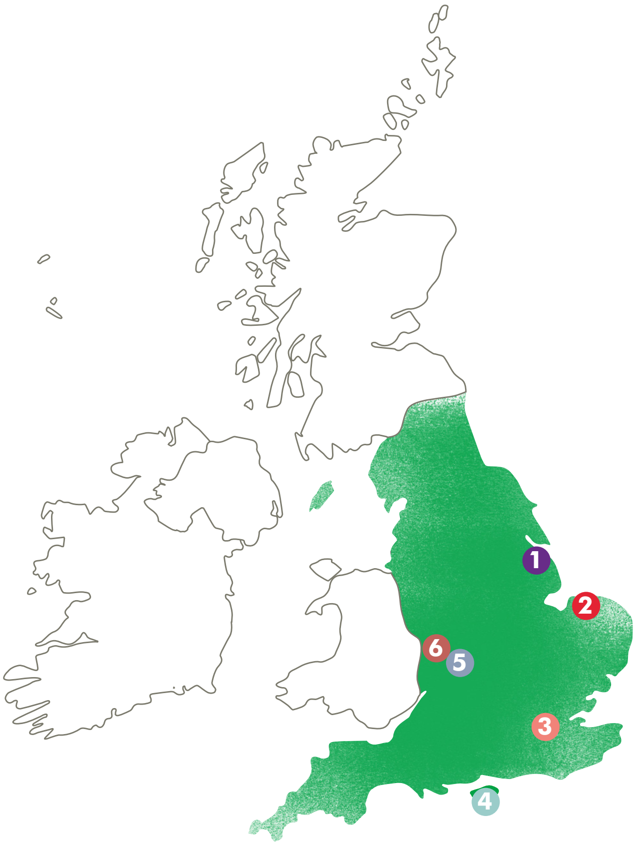
- Of the 2,217 people who died while receiving Macmillan Specialist Care at Home across all sites during the evaluation period, 1,085 (51%) deaths occurred at home. (It should be noted that comparing place of death across sites where services are based in different settings can be problematic. However, all of the sites increased their number of home deaths).

- Some barriers to achieving the preferred place of death were: complex symptoms that could not be controlled at home; a difference of professional opinions about whether the patient should remain at home; and the death happening sooner than anticipated.

- The diversely skilled Macmillan teams were able to provide more responsive support for patients, potentially reducing crises and unscheduled hospital admissions. The presence of consultants in the team allowed other members of the team to feel more supported and patients to feel reassured. Health Care Assistants enabled the needs of patients to be met quickly, as well as joining up the work of the rest of the team.(94)

- Across all six Macmillan Specialist Care at Home centres these combined principles have had a positive impact on the likelihood of a person being cared for, and dying in, their preferred place. Where a preference for place of death was known, 79% of people died in that preferred place. Nearly three quarters of bereaved carers (73%) felt that the person they had cared for had enough choice about where they died, and 77% of carers thought the person they had cared for had received the help and support they needed at the time of death. 88% of bereaved carers said their loved one died in the right place.

Macmillan Specialist Care at Home Innovation Centres



① **Hull**

② **West Norfolk**

③ **North London**

④ **Isle of Wight**

⑤ **Birmingham and Solihull**

⑥ **Dudley**

SPECIALIST THEME: DEATH AND BEREAVEMENT

What is bereavement and what do people experience?

Bereavement is the situation of having recently lost a significant person through death.(61) Grief is a natural response to loss, particularly to the loss of someone or something we care about. Usually, the response to this loss is emotional but it can also affect physical health, behaviour and thinking.(17)

Bereavement may affect personal relationships and cause trauma for children, spouses and any other family members.(62) Some people reassess issues of personal faith and beliefs following bereavement.(17)

Every year in the UK around 23,600 children under the age of 18 experience the death of a parent – roughly 111 children every day.(63)

For the bereaved, grief can cause many physical symptoms such as exhaustion, restlessness, anxiety attacks, difficulty breathing, lack of appetite or comfort eating, an inability to sleep or even a fear of sleep, and difficulty concentrating.(19)

34% of bereaved people strongly agreed that their emotional needs were supported during the last two days of life. However, 6% strongly disagreed.(20)

Bereavement for carers

Bereaved caregivers between 25–64 are around 50% more likely to be prescribed antidepressants than the general population. For bereaved non-caregivers of the same age, the figure is around 15%.(66)

Young carers are at greatly increased risk of mental health difficulties while providing care.(66)

Practical issues, wills and funerals

What are the practical issues that arise after the death of a loved one?

The death of a loved one is a time for grieving, but also raises numerous practical issues which can increase distress.

All deaths need to be certified by a doctor and the death will also need to be registered by a local council registrar in the area where it occurred, within five days (eight days in Scotland).(18)

Funeral directors can offer advice on what to do. They take care of the dead body. An undertaker can arrange for friends or family to see the person's body.(18) Some people want to be embalmed after death. In this process, the body is disinfected and treated with chemicals to help preserve it. This is carried out by the funeral directors.(18)

What are the issues around wills?

In 2017, 62% of the UK population did not have a will.(14) Around a quarter of those aged over 65 do not have a will.(64) The consequences of there not being a will could mean that the wishes of the person who has died may not be met.

What are the issues around funerals, memorials and cremations?

Funerals and memorials allow relatives and friends to pay their respects to the person who has died. While all arrangements for funerals and burials can be made independently, most people prefer to have the help of a funeral director, as they can answer most questions and provide guidance through the practicalities of arranging a funeral.(18)

Burials usually take place in a churchyard or other official burial place. According to people's preferences, it is also possible for people to be buried in other places, such as a garden.

Cremation takes place in a designated crematorium, which is sometimes close to a church. In 2015, 462,916 people in the UK were cremated (around 77% of total deaths).(1,2,3,65)

Financial issues

Anxiety about financial insecurity is common in the days and weeks after a partner has died, but uncertainties can extend into the first or second year after death. Feelings can worsen when faced with unexpected delays.(67)

The financial implications of having a funeral are also an important factor to consider. Funerals can be very expensive and the bereaved might need to arrange for payment, unless other plans were made prior to death. Whilst the Government provides some financial help to those in need, the financial costs of a funeral can have a high impact on the bereaved.(107)

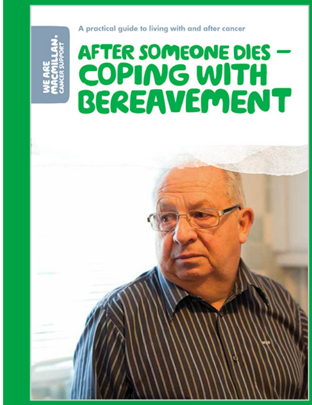
Evidence shows that the cost of funerals has risen significantly over time. In 2017, the estimated cost of an average funeral was just over £4,000. This is a 70% increase compared to 2007.(109)

Other issues and information

Married people with cancer are more likely to be able to die at home than those who are single, divorced, or widowed.(40)

Most bereaved people will have information needs at different times – for example information about what to do immediately after the death of their loved one, or information about how to deal with the financial issues.

For more information on coping with bereavement, people affected by cancer may find our information booklets below more helpful:



After someone dies: coping with bereavement
MAC15371

Preparing a child for loss
MAC15372

References, sources, notes and caveats

Photo and quotes

The photo on the front cover and quotes on pages 5, 7, 11, 19, 33 and 43 are from our cover star Bill, who has kindly agreed to be featured in this publication.

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Appendix A: Jargon Buster

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

(i) Health data terms

Incidence: When we talk about 'cancer incidence' we mean the number of people who are newly diagnosed with cancer within a given time-frame, usually one calendar year. The data can be 'cut' in a number of ways, for example by cancer type (breast, prostate, lung, colorectal, etc) or by gender, age, etc. The latest data we have is for 2015, and we know that over 350,000 people are newly diagnosed with cancer in the UK every year. Incidence can sometimes be given as a rate (per head of population).

Mortality: When we talk about 'cancer mortality', we mean the number of people who die from cancer within a given time-frame, usually one calendar year. The latest data we have is for 2015, and we know that over 160,000 people die from cancer in the UK every year. Mortality can sometimes be given as a rate (per head of population).

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

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

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

(ii) Other terms

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

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

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

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

Notes

Full suite of the Rich Pictures

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

Overarching Rich Picture

The Rich Picture on people with cancer	MAC15069_14

The Rich Pictures on cancer types

The Rich Picture on people living with cervical cancer	MAC13846_11_14
The Rich Picture on people living with breast cancer (2017 update)	MAC13838_17
The Rich Picture on people living with prostate cancer	MAC13839_11_14
The Rich Picture on people living with lung cancer	MAC13848_11_14
The Rich Picture on people living with cancer of the uterus	MAC13844_11_14
The Rich Picture on people living with non-Hodgkin lymphoma	MAC13843_11_14
The Rich Picture on people living with rarer cancers	MAC13847_11_14
The Rich Picture on people living with malignant melanoma	MAC13841_11_14
The Rich Picture on people living with head & neck cancer (2017 update)	MAC13845_17
The Rich Picture on people living with colorectal cancer	MAC13840_11_14
The Rich Picture on people living with bladder cancer	MAC13842_11_14

The Rich Pictures on age groups

The Rich Picture on people of working age with cancer (2017 update)	MAC13732_17
The Rich Picture on children with cancer	MAC14660_14
The Rich Picture on older people with cancer	MAC13668_11_14
The Rich Picture on teenagers and young adults with cancer	MAC14661_14

Other Rich Pictures

The Rich Picture on people at end of life (2017 update)	MAC13841_17
The Rich Picture on carers of people with cancer (2016 update)	MAC16275_10_16
The Rich Picture on people with cancer from BME groups	MAC14662_14
The Emerging Picture on LGBT people with cancer	MAC14663_14

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

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

Contents ← →

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

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

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

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

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

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

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