THE RICH PICTURE

WE ARE MACMILLAN. CANCER SUPPORT

PEOPLE AT END OF LIFE

Dorothy and Tony who supported their son Neil, who died of sarcoma aged 35

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. This Rich Picture does not focus solely on people with cancer at the end of life, but includes data on people at the end of life generally. However, within this there will at times be specific focus on people at end of life 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 October 2013, 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 52.

Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experiences of people at end of life. 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

Palliative care, end of life care and bereavement (for carers of people with learning disabilities) MAC13198

Your life and your choices: plan ahead MAC13616

Your life and your choices: plan ahead (Scotland) MAC14480

Your life and your choices: plan ahead (Northern Ireland) MAC14376

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

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

OTHER RELATED INFORMATION FOR MACMILLAN STAFF

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

Case Study Library

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

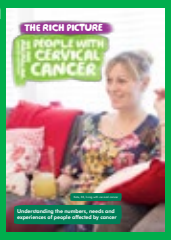
Professionals/Services
Contains specific examples of our services across the UK, and the impact they are having.

Comms Platform

Describes how to communicate with people affected by cancer.

Rich Pictures

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



Impact Briefs

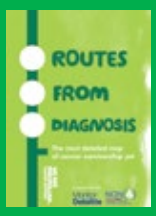
Generically describe what our services do, and the impact they have on people affected by cancer.

Local Cancer Intelligence

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

Routes from Diagnosis

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



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

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SUMMARY OF PEOPLE AT END OF LIFE

Key stats

Over **569,000 people die in the UK every year** and cancer is the **cause of 28%** of these deaths.[3,4,5]

Most people (77%) who died from cancer would have liked to have spent the **last weeks and days of their life at home**[8]. However, **only 30%** of them actually do.[8]

Proportionally more people die of cancer in the 60–69 age group compared with all other age groups (48% of deaths in the 60–69 age group are cancer deaths).[3]

Overall **mortality rates** (and overall cancer mortality rates) are **set to decrease in the future** as people live longer. However mortality rates for some specific cancers are predicted to increase in the future.[61]

28% of all deaths in the UK are cancer deaths.

Terminal Diagnosis

Receiving a **terminal diagnosis** is a very **emotionally difficult** thing to deal with.

More than **£90 million in disability benefits is going unclaimed by people diagnosed with terminal cancer** in the UK.[80]

Terminal cancer patients often want **information about how long they may have to live**. However doctors tend to over-estimate the survival times.[32]

Terminally ill people experience high levels of **psychological distress**.

Receiving a terminal diagnosis is a very emotionally difficult thing to deal with.

Palliative Treatment

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.[2]

The majority of older carers find the **main challenges to be due to miscommunication, disorganisation, lack of services, lack of information and over-reliance on informal carers**.[63]

86% of all hospital admissions in the last year of life are **emergency hospital admissions** with an average length of stay of 27 days, accounting for 2.8 million bed days.[7]

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.

Palliative care aims to achieve the best quality of life but not everyone has access to high-quality palliative care services.

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Death and Bereavement

Bereavement and grieving are normal responses to loss, and usually affect emotions, but can also affect physical health, behaviour and thinking.[58]

Practical issues, such as registering the death, arranging funerals and arranging financial matters are often experienced by the newly bereaved loved ones.[40]

Bereaved people tend to have **higher mortality rates**, and experience a range of different emotions and physical symptoms. Financial and information needs are also prevalent in the bereaved.[44]

Bereaved people experience a range of emotions and physical symptoms at a time when practical issues also need to be dealt with.

Perceptions

People at end of life and their families have a **wide range of experiences**.

People experiencing terminal cancer may be **acutely aware of how much time they have left**, often taking each day as it comes.[65]

Press articles relating to terminal cancer in the UK print media often **selectively highlight very extreme examples of end of life stories** which are not necessarily typical – this can distort people's views on end of life experiences.[66]

Specialist themes

People with learning difficulties at end of life often have specific social issues (such as home and family problems) and specific emotional issues (such as understanding, cooperation and capacity to consent).[14]

The **prison** population in England and Wales includes over 11,000 people aged 50 and over [96], and some of these will require **specialist palliative care**.[12]

7,638 children and young people were supported by **specialist children's hospices** in 2011/2012. Some children at end of life can have a poor experience, due to lack of awareness of services by families and professionals, and a lack of coordination of care.[68]

In 2012, **103,164** people died of all causes in a care home in England and Wales.[3]

INTRODUCTION TO PEOPLE AT END OF LIFE

Who are people at end of life?

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

The definition of 'end of life' should ideally be flexible, based around an individual assessment of the patient, for example whether or not they are likely to have a good quality of life, and how steep the trajectory towards death is likely to be. However, 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 end of life = people in the last 12 months of their life[1].

We use this definition whilst remembering that many people with terminal illnesses 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').

This Rich Picture does not focus solely on people with cancer at the end of life, but paints a picture of the numbers, needs and experiences of people at the end of life generally. However, within this there will at times be specific focus on people at end of life with cancer. There will also be people at end of life who have cancer but die of something else.

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

What is end of life care?[1]

'End of life care is care that helps all 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. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'

What is palliative care?[2]

Palliative care has been defined by 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].

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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[1]

What is specialist palliative care?[2]

Specialist palliative care is provided by specialist multidisciplinary palliative care teams, and typically includes doctors, nurses, a psychologist, a physiotherapist and an occupational therapist. 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 end of life. 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**

‘Our son, Neil, was diagnosed with a sarcoma in 2004 at the age of 30. That began a roller-coaster ride of alternately-raised and dashed hopes for Neil, Dorothy, my wife, and me. We are still filled with guilt and sorrow at missed opportunities for quality time together, three years after his death, but some of the ‘highs’ console us. After his first operation, we asked Neil what he wanted, and as a result, we had a wonderful holiday in New York. In the last month of his life, Neil and I became very close, because we would spend time chatting each evening, about whatever was on his mind. Sixteen hours before he died, when he was in hospital, a Macmillan Nurse asked him what he wanted, and as a result, made it possible for him to die in his own flat, fulfilling his dearest wish. These good memories are so important to us now.’

Tony, who cared for his son Neil

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for people at end of life

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.[104] 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.

Over 569,000[3,4,5] people died in the UK in 2012, including around 161,400[3,4,5] who died from cancer.

How are Macmillan's 9 Outcomes relevant to people at end of life?

One of the Macmillan outcomes for people with cancer is 'I want to die well' – meaning that we want to ensure that, for the 161,400[3,4,5] people who sadly die from cancer every year, they have the best experience that they possibly could have.

Macmillan believes that people who are nearing the end of their life should be able to die in the place of their choice, and for many this will be in their own home. Access to community nursing at any time of the day or night is essential to helping people to do this. We know that where end of life patients' needs are not met, it can lead to traumatic experiences for patients and their families.

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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

Contents

THE FACTS ON PEOPLE AT END OF LIFE

This section of the rich picture presents some of the key stats and facts relating to people at end of life. You may benefit from referring to the Jargon Buster on page 58 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.

1,559

people die in the UK every day.[3,4,5]

Over 569,000

people die in the UK every year[3,4,5]

28%

of all deaths in the UK are cancer deaths (around 161,400 cancer deaths in 2012)[3,4,5]

355,000

people a year need palliative care in England (a mid-point estimate)[34]

147,000

cancer survivors in the UK are in the last year of life[79]

How many people die per year? (mortality)[3,4,5]

Death by cause of death, UK, 2012

Cancer deaths
28%

Circulatory disease deaths
28%

Respiratory disease deaths
14%

Other disease deaths + other deaths
26%

External cause deaths
3%

*Does not add up to 100% due to rounding

28% of all deaths in the UK are cancer deaths; a further 28% of all deaths in the UK are circulatory (eg heart) disease deaths.

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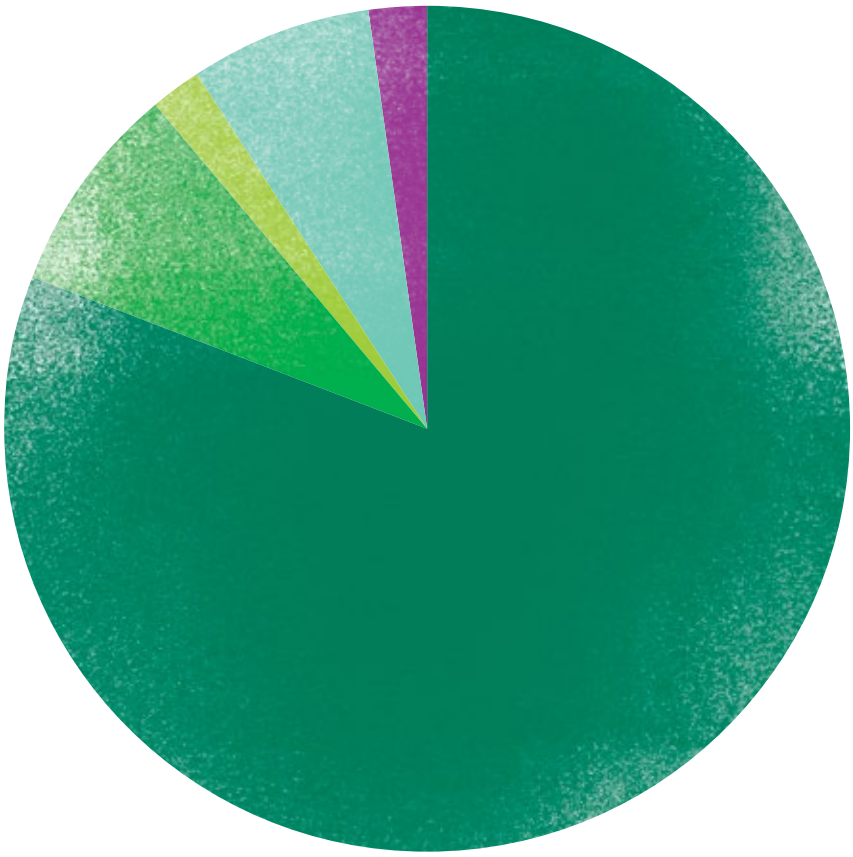
Where do people prefer to die?[6]

Preferred place of death, England, 2012



Own home
81%

Hospice
8%

Hospital
2%

Care home
7%

Elsewhere
2%

A recent survey found that 73% of people who died from cancer, and 81% of all people who died, would have liked to have spent the last weeks and days of their life at home. However, only 30% of those who die from cancer actually die at their home or own residence[8].

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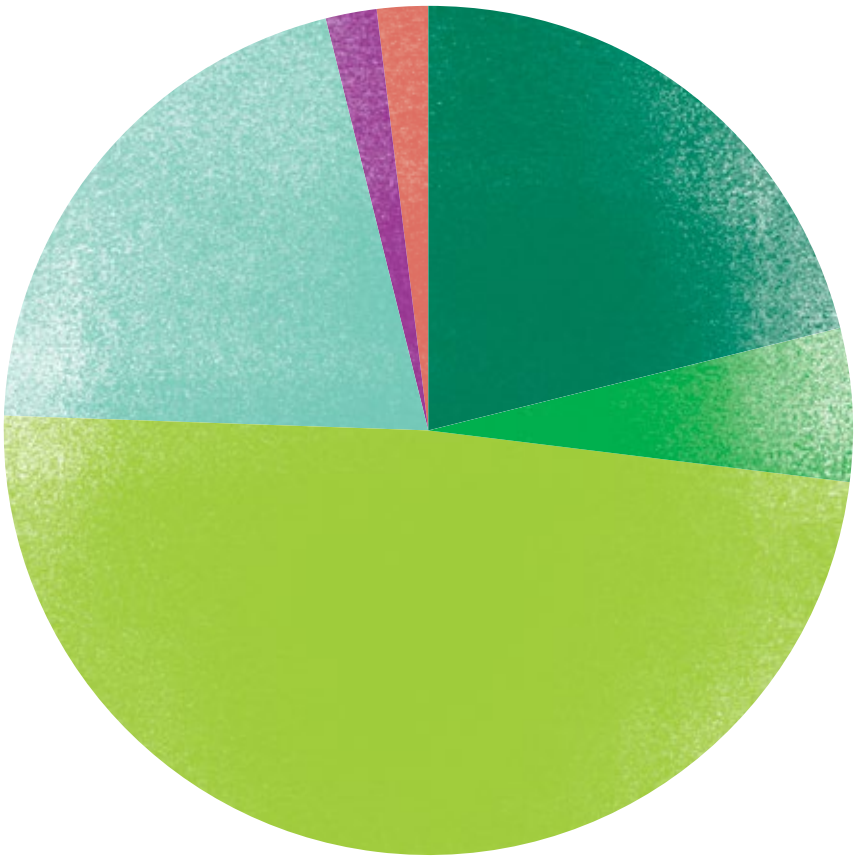
Where do people actually die?*[3]

Actual place of death, England and Wales, 2012



Own home
22%

Hospice
6%

Hospital
50%

Care home
21%

Elsewhere
2%

Other communal establishments
2%

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

Despite most people preferring to die at home if they could, only 22% of them actually do. Very few people say they would rather die in hospital, however most deaths (50%) actually occur there.[3]

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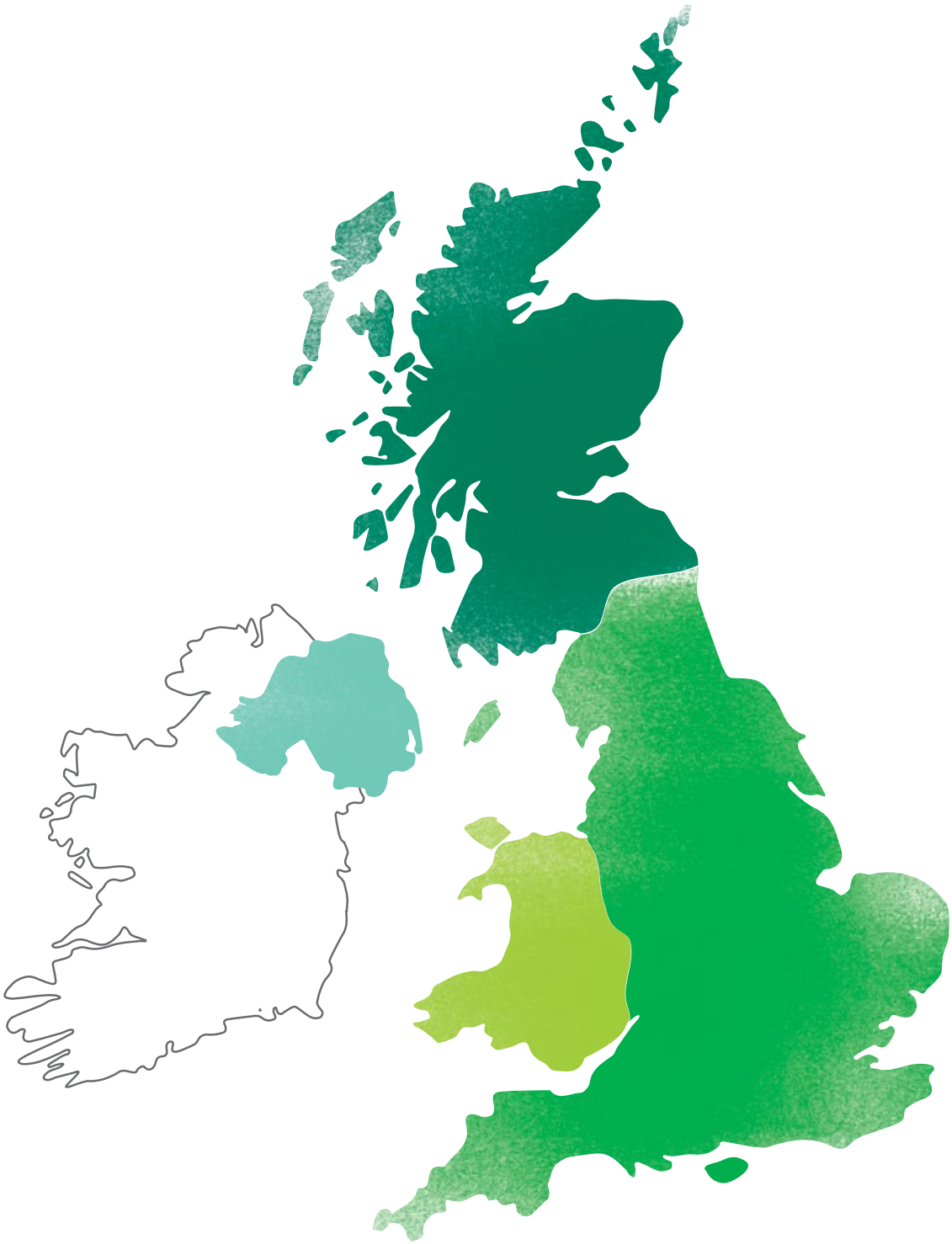
What are the key stats for the four UK nations?

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



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England

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

466,779

deaths in England in 2012.[95]

How many people die from cancer per year in England?

132,911

deaths from cancer in England in 2012.[3, 100]

Wales

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

31,502

deaths in Wales in 2012.[95]

How many people die from cancer per year in Wales?

8,654

deaths from cancer in Wales in 2012.[100]

Scotland

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

54,937

deaths in Scotland in 2012.[4]

How many people die from cancer per year in Scotland?

15,787

deaths from cancer in Scotland in 2012.[4]

Northern Ireland

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

14,756

deaths in Northern Ireland in 2012.[5]

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

4,027

deaths from cancer in Northern Ireland in 2012.[5]

Total deaths in the UK do not match deaths in the separate nations as England and Wales figures excludes those whose usual residence is outside England and Wales.

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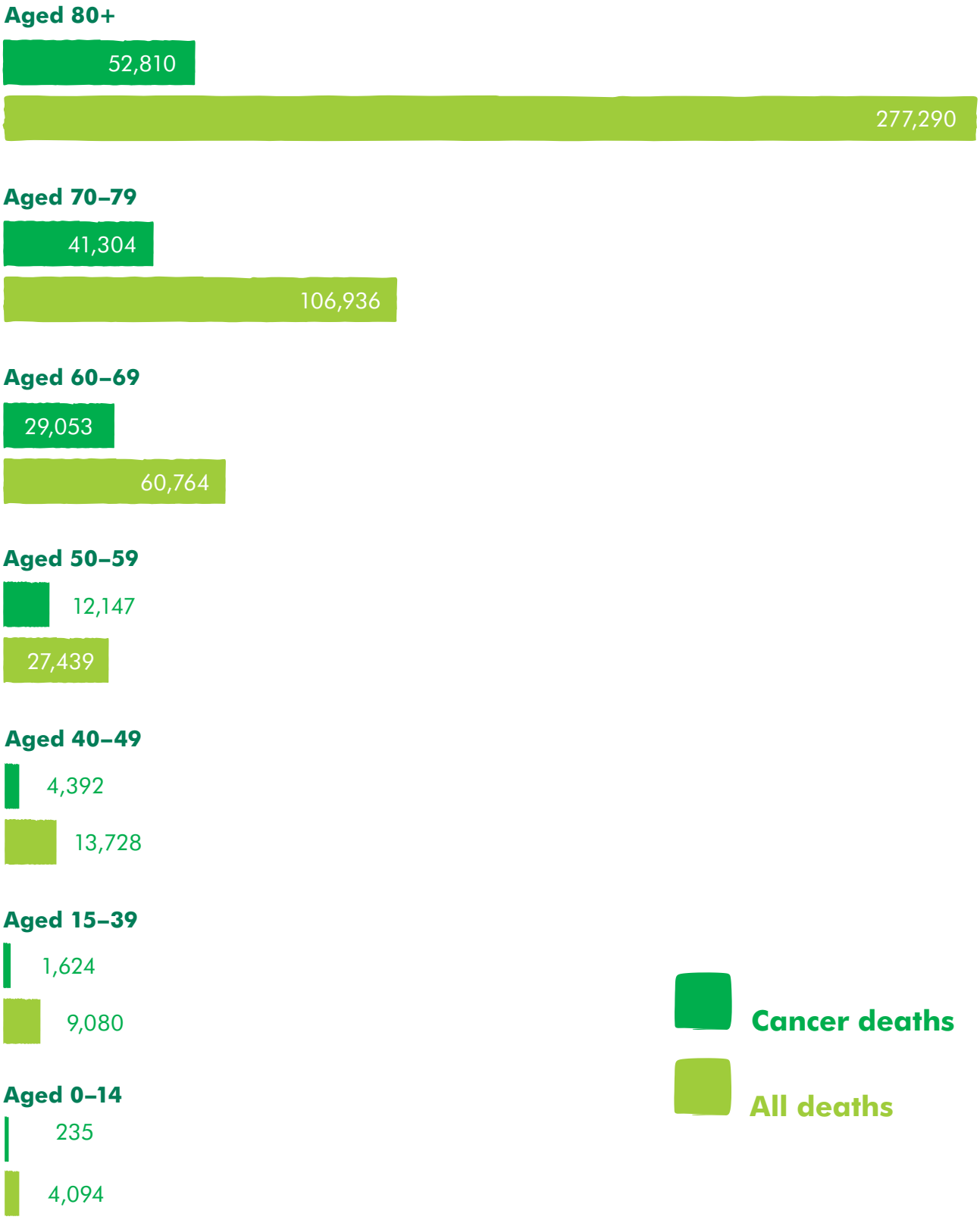
At what ages do people die?[3]

All deaths and cancer deaths, by age band, England and Wales, 2012



Proportionally more people die of cancer amongst the 60–69 age group compared with all other age groups.

48% of all deaths amongst 60–69 year-olds in England and Wales are cancer deaths, compared with 28% for all ages.

The numbers of deaths in people aged 85 and over are increasing and there is a decreasing trend in people aged 65 to 84. This is because the older age group has a greater likelihood of frailty and multi-morbidities[88].

'People at end of life should be offered the choice to die where they want, and those who wish to die at home should be enabled to do so. Sadly, too many people end up dying in hospital, against their wishes, simply because the support is not available for them to stay in their own home.'

Adrienne Betteley, End of Life Care Programme Lead, Macmillan Cancer Support

International and demographic comparisons

How do mortality rates in the UK compare internationally?

In 2011, the age standardised mortality rate for people with cancer (per 100,000 inhabitants) was 167 in England, 173 in Wales, 172 in Northern Ireland, and 195 in Scotland. (N.b. rates for individual UK nations are created around the age profile of the 1976 European standard population, the conventional standardisation used before 2013).[18]

The age standardised mortality rate in 2010 for people with cancer is higher in the UK (288 per 100,000 inhabitants) than the average for Europe as a whole (270 per 100,000 inhabitants). The country with the lowest mortality rate for people with cancer is Cyprus (197), with Hungary having the highest mortality rate (359). (N.b. rates for UK collectively, Europe and European nations created around the 2013 European standard population. The increase, compared to numbers in the previous paragraph, is due to the 2013 European standard population being weighted more heavily towards older ages where most deaths occur, rather than an increase in the actual number of deaths).[17]

How do overall mortality rates (all causes) in the UK compare internationally?

The age standardised overall (all causes) mortality rate was lower in the UK (1,016 per 100,000 inhabitants) than the average for Europe as a whole (1,056 per 100,000 inhabitants in 2010).(N.b. rates for UK and Europe for all mortality causes created around the 2013 European standard population).[17]

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

Gender

In 2012, there were slightly more deaths from all causes amongst females than males in the UK (295,677 compared to 273,347).[3]

In 2012, more males than females died in the UK as a result of cancer (76,604 females compared to 84,775 males).[3,4,5]

Ethnic background

People from Asian and Mixed ethnic groups are 30%-60% less likely to get cancer than people from the White population.[21] People born in Asian countries living in Europe, including the UK, generally have lower cancer mortality rates compared with native populations of European countries, although some specific types of cancer may be more common in Asian compared to European people.[86] The risk of getting cancer in Black men is comparable to men from the White population.[21]

People of Asian, Black and Mixed ethnicity, who are affected by cancer, are less likely to die in a hospice or own residence than people from all other ethnic groups.[93]

Although there is limited data on cancer survival by ethnic groups, initial results analyses from studies suggest that Black and Asian women with breast cancer have poorer survival rates, which may be explained by later presentation.[22]

Age

Deaths in England and Wales, from all causes, steadily increase with age, with over half of deaths in 2012 amongst those aged 80 or over.[3]

77% of all cancer deaths in the UK are amongst the 65+ age group.[94]

Social background

We know that the incidence and mortality of cancer is higher in deprived groups compared with more affluent groups[21]. A large part of this is likely to be attributable to lifestyle factors, and especially the higher smoking rates in deprived groups. For some cancers, patients from socio-economically deprived groups tend to present symptoms later than others and thus tend to have more advanced disease and a worse prognosis, while the excess mortality may also be linked to later presentation and later diagnosis in more deprived groups.[20]

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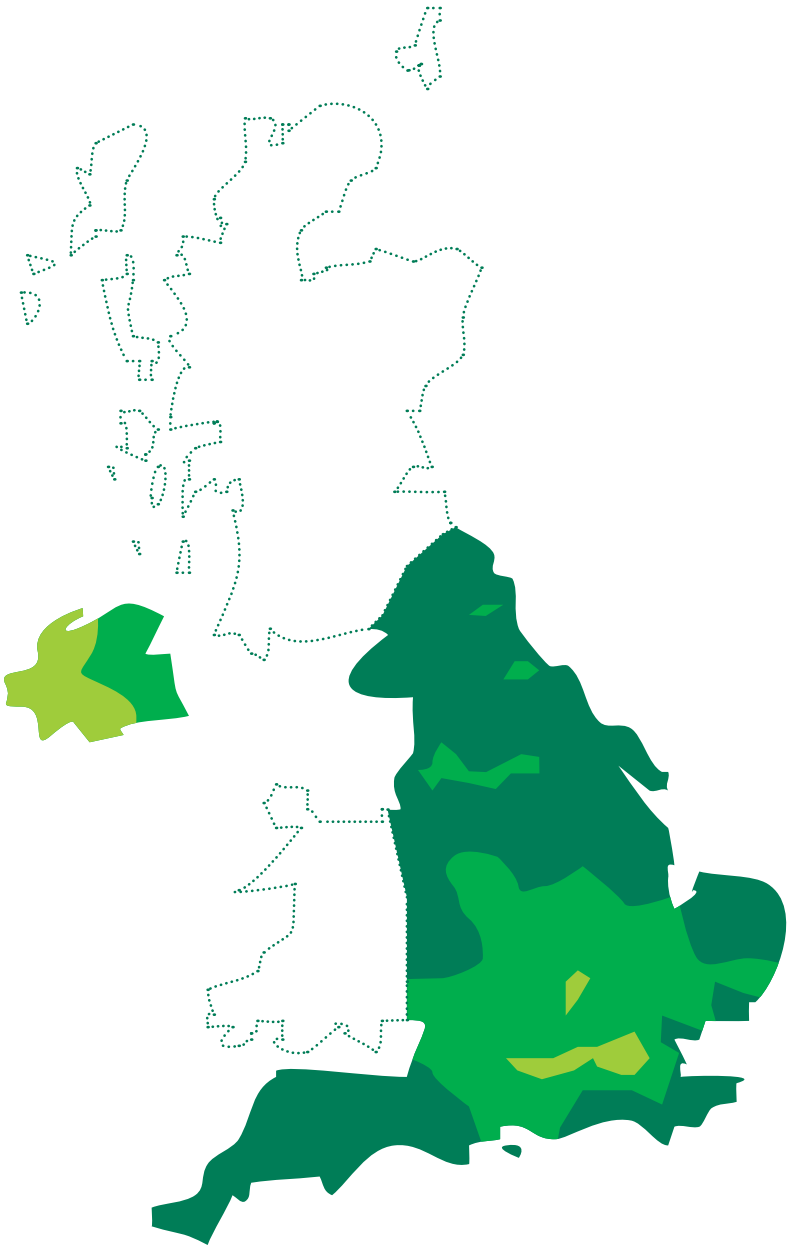
What are the geographical 'hotspots' for mortality for all causes of death and cancer mortality?[71–73]



Mortality of all causes of death (all ages per 100,000 population), England and Northern Ireland, 2008-2010

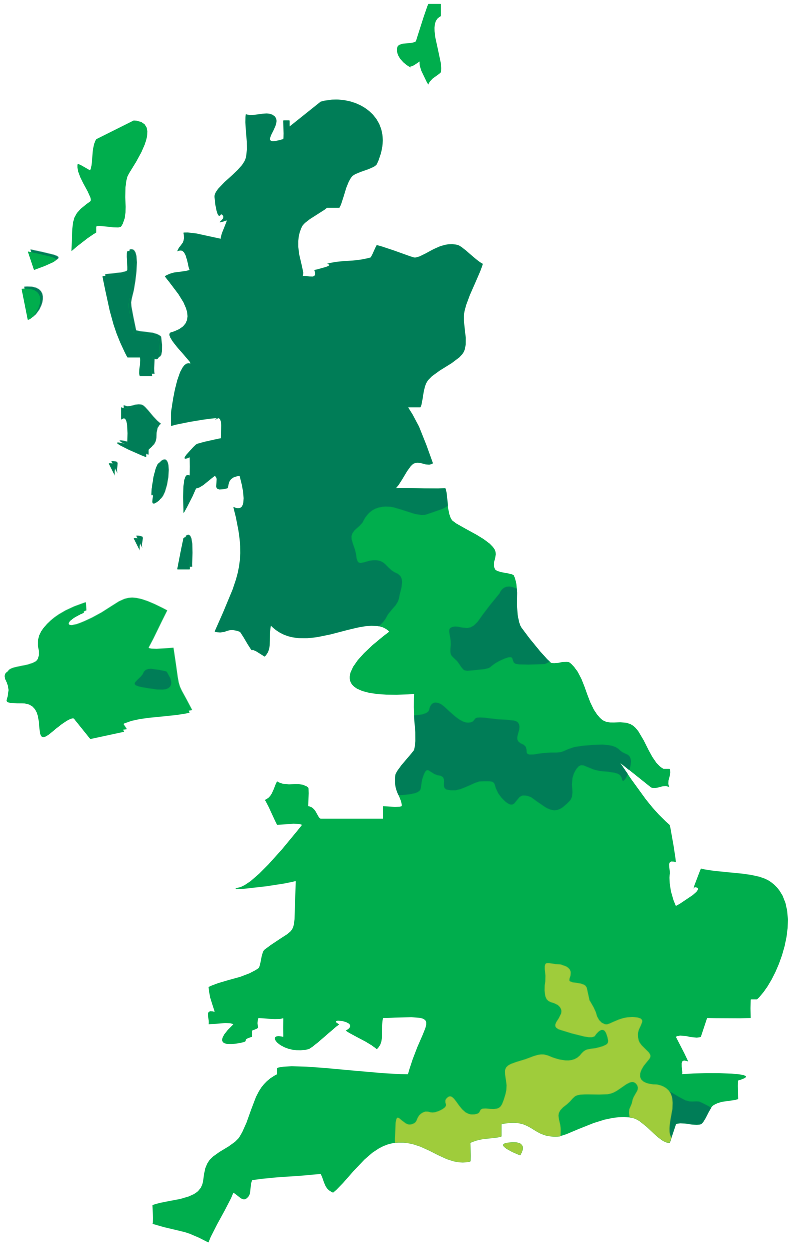
Low

Medium

High

Important note
These maps show only the broad patterns of variation in mortality. Crude mortality rates are presented and are likely to be a reflection of the age of the population in a local area. These two maps are not directly comparable.

Overall mortality (all causes of death) is higher in the North of England, the South-West, parts of the Midlands and parts of the South-East.



Cancer mortality (age standardised), UK, 2008-2010

Low

Medium

High

Important note
These maps show only the broad patterns of variation in mortality. Access to the very detailed and accurate data of the PCT/Health Board level is via the NCIN e-atlas website, **www.nicn.org.uk/eatlas**, or Macmillan staff members can contact Macmillan's Health Data team. These two maps are not directly comparable.

Cancer mortality rates are generally higher in Scotland, Wales, and parts of Northern Ireland.

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Trends in the data

What are the future trends in the mortality data?

In terms of **overall mortality** (deaths from all causes), the UK government predicts mortality rates to decrease over time, with life expectancies improving so much that the life expectancy for a child born in 2035 is projected to live between 10 and 11 years longer compared to one born in 2010 based on 2010 projections.[60]

In terms of **cancer mortality** (deaths where cancer is the underlying cause of death), overall cancer mortality rates are projected to fall in the future. Mortality rates from cancer as a whole have been falling in the UK since 1990, and are set to continue to fall. The 2008 projected reduction in age-standardised mortality rates for all cancers from 2003 to 2023 is 17% in men and 16% in women.[61]

However for some cancer types, there are some projected increases in cancer mortality rates by 2023:

- In men, there are projected increases in mortality rates from cancers of the liver, oral cavity, oesophagus and melanoma
- In women, there is a projected increase in the mortality rate for cancer of the uterus (womb).[61]

The proportion of deaths in the usual place of residence continues to increase (it reached 45% in 2013) and correspondingly the proportion of deaths in hospital is falling.[89]

Despite the decrease in hospital deaths in cancer between 1993 and 2010, hospitals have remained the most common place of death in England for people with cancer.[90-91]

In terms of **dying in the place of choice**, only around one in five people (or fewer in many local authorities) are supported to die in their own home. If these trends are to continue, over 500,000 people in England will die in a place other than their own home by 2015, suggesting that more needs to be done to ensure that people's wishes about where they want to die are met.[67]

‘Sometimes I feel so angry – not with anyone in particular, just with the situation we are in. I keep thinking, why me?’

Jessie, Midlands

THE END OF LIFE JOURNEY

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

1 Terminal Diagnosis

What happens when I am given a terminal diagnosis?

- A terminal diagnosis means that there is minimal chance of recovery.
- People with a terminal diagnosis will continue to require care, to allow them to live for as long as possible and die as well as possible.
- Receiving a terminal diagnosis is 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 donation, or making a will.

2 Palliative Care

What can I expect when I receive palliative care?

- Palliative care aims to achieve the best quality of life for patients and their families.
- Palliative care can enable people to die comfortably at home, rather than at hospital.
- 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.

3 Death and Bereavement

What issues will those left behind have to face?

- The death of a loved one often creates feelings of intense grief amongst those left behind.
- Practical issues also arise following the death of a loved one, which can make the situation more upsetting.

Contents

NEEDS AND EXPERIENCES TERMINAL DIAGNOSIS

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 receiving a terminal diagnosis?

A terminal diagnosis means that there is no chance of recovery. For those who receive a terminal diagnosis, 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 support in these circumstances.

What issues might need to be considered by someone with a terminal diagnosis?

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 (eg '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.[1]

Advance plans can be made for the more everyday decisions that have a major impact on our lives, which might have nothing to do with medical treatment. Such decisions might include the place in which we would want to be looked after if we were to become incapable of looking after ourselves. Or they may involve the patient appointing a person who can represent them. Under the Mental Capacity Act, this is known as 'lasting power of attorney'. Under the Mental Capacity Act it is also now possible to set on record 'advance decisions' to refuse specific treatments in particular circumstances.[24]

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 ACP, compared to 27 days for those without. 11% of people with ACP die in hospital, compared to 27% of those who have not engaged in ACP.[97]

Organ donation, or donation of body to medical science

In 2013/14, 7,026 patients were waiting for a transplant in the UK, which could save or dramatically improve their lives. However, only 4,654 organ transplants were carried out in the same year, of which 46% were donations by living donors. Most people in need of an organ transplant are waiting for a kidney, heart, lung, or liver transplant. Currently, 32% of people in the UK are registered organ donors.[25] 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. Organ donation is generally not possible when the cancer is has spread from where it originally started, or when the individual had blood cancer.[102] However, in those instances in which cancer patients cannot donate organs, cornea or certain tissue donations may still be possible. [103]

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[26]. 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 **35%** of respondents in the 2012 British Social Attitudes Survey said they have a will.[92]

Married people with cancer are **more likely** to achieve a home death than those who are single, divorced or widowed.[90]

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.'[62]

Removing life-prolonging treatment

It is acknowledged that sometimes giving adequate symptom control or withholding or withdrawing life-prolonging treatments may hasten a death that is already expected. This is not euthanasia.[24]

Macmillan has produced nation-specific 'Your life and Your Choices: Plan Ahead' booklets, which provide information on Lasting Power of Attorney, use of a Preferred Priorities for Care document and writing Advance Decisions to Refuse Treatment, as well as information about making a will, organ and tissue donation, and funeral planning. Three separate booklets are available, for people living in England & Wales, people living in Scotland and people living in Northern Ireland. These are available at our **be.macmillan.org.uk** website or by calling **0808 808 00 00**.

PHYSICAL AND MEDICAL 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 sometimes a build-up of waste chemicals.** These changes can make people lose weight, no matter how much they eat.[27]

As 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.[27]

Various symptoms are very common in advanced cancer, with patients experiencing an average of 13 symptoms on admission to hospital.[29]

Pain, breathlessness, fatigue, loss of appetite, constipation and insomnia are especially common and occur in some combination in a vast majority of cancer patients.[30]

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**.[28]

FINANCIAL NEEDS

More than **£90 million in disability benefits is going unclaimed by people diagnosed with terminal cancer** in the UK.[80]

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.

PRACTICAL AND 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, 31% of doctors tend to **over-estimate the survival times** of terminally ill cancer patients.[32]

EMOTIONAL AND PSYCHOLOGICAL 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.[97]

Cancer patients of all ages approaching end of life have **increased levels of psychological distress**.[33]

59% of bereaved cancer relatives felt that their loved one was told they were likely to die in a **sensitive way**. However, 12% felt that they were told not at all sensitively.[6]

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

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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.[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; and offer a support system to help families cope during the patient's illness and in their own bereavement.[1]

An estimated 355,000 people need good palliative care services every year in England but around 92,000 people are not being reached[34].

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 when a patient's symptoms become complex that they are referred for specialist palliative care.[1]

Although only 4% of deaths take place in hospices, specialist palliative care support is provided to many more people, which enables them to die at home[7].

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 ACP 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 less hospital treatment costs, compared to those without ACP. [101]

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‘Our Macmillan nurse was an absolute Godsend and she was our link to Macmillan’s West Sussex Unit for Palliative Care. The whole team were absolutely incredible.’

Amy, bereaved ex-carer

PHYSICAL AND MEDICAL NEEDS

An estimated **355,000 people need good palliative care services** every year in England, but around **92,000 people are not being reached**.[34]

14% of carers are currently supporting someone with progressive cancer, and **4% are caring for someone at the end of life.**[75]

17% of bereaved cancer relatives report that the overall care across all settings received in the last three months by the deceased was **outstanding**. 8% of respondents rated care as being **poor**.[6]

16% of bereaved cancer relatives reported that decisions were made about care which the patient would not have wanted.[6]

Amongst carers who have supported someone with cancer in the last 12 months, 27% are no longer providing this care because the person has since died – from this **we estimate there are around 2.1 million people in the UK who have cared for someone with cancer in the last 12 months who are now bereaved.**[75]

FINANCIAL NEEDS

The National Cancer Patient Experience Survey shows that, not limited to those at end of life, of those patients who said it was necessary **only 54% said they had been given information about how to get financial help or benefits by hospital staff.** Gaining such information can become a particularly pressing issue in end of life care.[19]

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PRACTICAL AND INFORMATION NEEDS

A recent review of literature concerning conversations about end of life care between people with heart failure and healthcare professionals found conversations focus largely on disease management and **end of life care is rarely discussed**. Clinicians are unsure how to discuss the uncertain prognosis and risk of sudden death, fearing causing premature alarm and destroying hope.[36]

EMOTIONAL AND PSYCHOLOGICAL NEEDS

People dying from cancer are more likely to have a record of their end of life care preferences than those with other conditions.[37]

Amongst older carers of people with advanced cancer satisfaction is reported particularly in being able to **provide love and care** to the person diagnosed with cancer and **enabling them to have a 'good' death**. However, the majority of older carers find the **main challenges to be due to miscommunication, disorganisation, lack of services, lack of information and over-reliance on informal carers**. These factors contribute to crisis admissions to hospital, poor pain control for the patient, carers feeling overwhelmed and residual feelings of anxiety and guilt in bereavement.[63]

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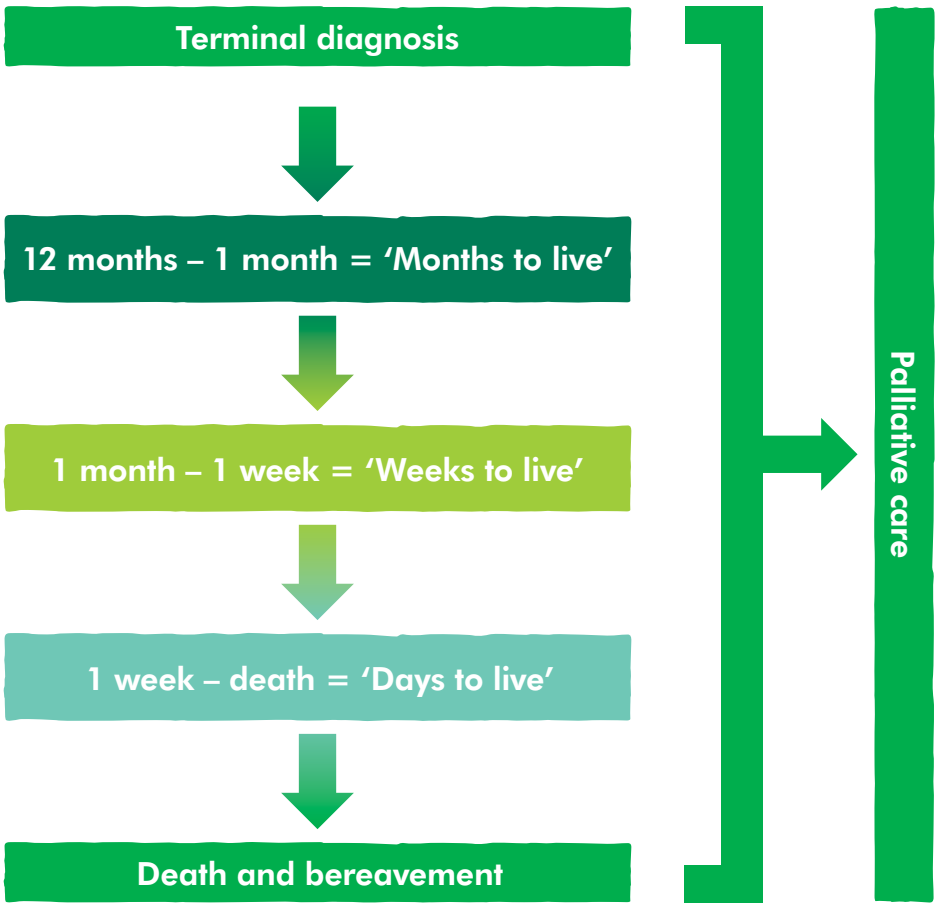
NEEDS AND EXPERIENCES APPROACHING DEATH

The final months of life for those with a terminal diagnosis 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 months ('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 with a terminal diagnosis might not be so marked, or might occur at different time periods. The time categories we have outlined give only a broad illustration of the typical changes in needs and experiences.



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

'Months to live' – 'Weeks to live'

Hospital admissions

Approximately 78% of people in England will be admitted to hospital at least once in their last year of life.[7]

346,000 people have an emergency admission in the last year of life in England.[7]

20% of those that die will have had three or more emergency admissions in the last year of life.[7]

Across England people average around 2.1 hospital admissions in the last 12 months of life, accounting for on average 30 bed days, and around 9.4 million bed days are occupied by people in the last year of life who have emergency admissions.[7]

Just over 200,000 emergency admissions end in death, per annum in England. This compares with 24,000 planned admissions which end in death. The 24,000 planned admissions ending in death account for around 500,000 bed days. The length of stay for most of these individuals is 8+ days.[7]

The price of an inpatient admission in England in the last year of life that ends in death is estimated to range from £2,352 – £3,779, with NICE estimating the cost to be £2,506.[7]

86% of all admissions in the last year of life (106,000) in England are emergency admissions with an average length of stay of 27 days (cancer 24 days, stroke 30 days) and account for 2.8 million bed days. Cancer accounts for around 25% of emergency admissions lasting 8+ days and ending in death (cardiovascular 17%, stroke 12%, respiratory 17%, other 28%). The vast majority of these deaths (over 90%) are thought to be in acute rather than community hospitals.[7]

Social care

Approximately 30% of people use some form of local authority funded social care in the last year of life. Though hospital use climbs steeply in the last few months of life, social care use shows only a steady increase in the last 12 months. The use of social care also differs according to the presence of certain long-term conditions. For example people with mental health problems, falls and injury, stroke, diabetes and asthma tended to use more; those with cancer appeared to use relatively less local authority-funded social care.[64]

A study of over 1,200 people who died in two Local Authorities indicated that around 15–20% of people used a care home in the last 12 months of life. Yet the figure for a third area was much lower, around 5%, indicating the scale of differences in social care provision across the country.[64]

'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.[40]

Communication with carers and loved ones

Communication between the patient, the carers and loved ones and health and social care professionals appears more challenging with people at the end of life. According to the latest data from the National Care of the Dying Audit Hospitals, 94% of relatives or carers are given a full explanation of the patient's care plan and healthcare professionals are able to discuss this with 56% of people at the end of life. The same audit also showed that 97% of relatives or carers are aware that the person is dying; healthcare professionals are able to discuss this with 58% of people at the end of life.[7]

Anticipatory prescribing

Where data was available, 91% of people at end of life had anticipatory prescribing of medications for five key symptoms that may occur in last hours or days of life (pain, agitation, respiratory tract secretions, nausea and vomiting and breathing difficulties).[7]

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.[59]

Confusion

During this time 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).[59]

Physical changes

The patient's physical condition may also change, with feet and hands feeling cold, or skin becoming very sensitive to any touch. 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.[59]

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 for a few days.[59]

Moment of death

It can be difficult to pinpoint the exact moment of death. Often the person's body will relax completely and their face will look very peaceful.[59]

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

‘She was frightened of dying, although she knew she was dying. None of the staff recognised her fears, they didn’t listen.’

Ivor, bereaved ex-carer

NEEDS AND EXPERIENCES DEATH AND BEREAVEMENT

What do we know about place of death?

As shown on page 13, **50% of people die in hospital**, 22% die at home, 6% die in a hospice, 21% die in a care home and a minority of people die in other communal establishments or elsewhere.[3]

89% of those who die in **hospital** do so following an emergency admission. 32% of these people die after a stay of 0–3 days, 18% after a stay of 4–7 days and 50% after a stay of 8 days or longer[7]. People who died in hospital were less likely to receive enough help with personal care than those who died at home, hospice or care home.

Many people live and die in the 21,000 **care homes** across the UK. 16% of people living in **care homes** who are in the last week of life die in hospital following an admission in their last week of life.[7]

The proportion of deaths in hospital following an admission in the last week of life from care homes is higher in London than in other regions.[7]

22% of people **living at home** with cancer and who are in the last two days of life die in hospital following an admission in their final two days of life.[7]

Out of all care settings, **hospices** were most likely (in 63% of cases) to relieve pain 'completely, all the time' in the last three months of life.[6]

What is bereavement and what do people experience?

Bereavement is the situation of having recently lost a significant person through death[38]. Grief and bereavement are normal responses 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.[58]

Bereavement may affect personal relationships and cause trauma for children, spouses and any other family members. Some people reassess issues of personal faith and beliefs following bereavement.[58]

Every year in the UK over 20,000 children under the age of 18 experience the death of a parent.[39]

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, GP or a community nurse, 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).[40]

Funeral directors provide a 24-hour service and 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 at home or at a chapel of rest.[40]

Some people want to be embalmed after death. In this process, the body is disinfected and treated with chemicals to help preserve it. Blood is drained out of the body and replaced with embalming fluid. This is carried out by the funeral directors.[40]

What are the issues around wills?

In 2013, 58% of the UK population did not have a will[42]. Over a quarter of those aged over 65 do not have a will.[74] 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.[40]

Cremation takes place in a designated crematorium, which is sometimes close to a church. In 2012, 425,784 people in the UK were cremated (74% of total deaths).[41]

Burial is usually in a churchyard or other designated burial place. With the right permissions, it is also possible for people to be buried in other places, such as a garden.[82]

PHYSICAL AND MEDICAL NEEDS

In the case of a sudden death physical effects can include; stomach churning, heart racing, shaking and being hypersensitive to noise. Nightmares or disturbed dreams can also be common, as can weight changes and tiredness, often associated with not looking after ourselves so well.[43]

People who have been bereaved are **more likely to have physical health problems**, particularly those who have been bereaved recently. Bereaved individuals also have higher rates of disability, medication use, and hospitalisation than non-bereaved counterparts.[44]

45% of bereaved relatives reported that the pain relief received by the family member they cared for in the last 2 days of their life was **excellent**. However, **6% reported the relief as being poor**.[6]

Bereavement is associated with an increased risk of mortality from many causes, including suicide.[44]

Individuals who have been bereaved for a short time are at greater risk of mortality than are those bereaved for longer.[44]

FINANCIAL NEEDS

Death of a partner has been shown to be a **trigger for claiming income support**.[49]

Bereaved people may experience **problems managing household finances** that had previously been undertaken by the deceased partner.[50]

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.[98]

A study on financial impact has revealed that, after a partner's death, the number of women feeling financially worse off doubled from 24% to 48%. The number of men who felt worse off also increased from 19% to 30% as a result of their partner's death.[99]

Feeling financially worse off can heighten the emotional impact of bereavement.[99]

PRACTICAL AND INFORMATION NEEDS

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.

People bereaved from cancer reported **unmet needs around advice on practicalities** following the death of a loved one. These unmet needs include; dealing with the deceased's clothing and handling any admin associated with the death.[55]

Married people with cancer are **more likely** to be able to die at home than those who are single, divorced, or widowed. [90]

EMOTIONAL AND PSYCHOLOGICAL NEEDS

34% of bereaved family caregivers experience clinically meaningful **depressive symptoms three months after the loss of their loved one.** [45]

41% of bereaved relatives (not cancer specific) reported that the emotional support received by the family member they cared for in the last 2 days of their life was **excellent**. However, **13% reported the care as being poor**.[6]

Increased health risks related to bereavement are attributable to factors such as **psychological distress, loneliness, changes in social ties, and living arrangements.**[44]

Emotions in bereavement are not always negative, **positive emotions can arise when individuals feel they have done as much as they possibly could** during the dying stage.[48]

PERCEPTIONS

People at end of life and their families have a wide range of experiences. This chapter of the Rich Picture attempts to indicate the sorts of experiences people with cancer (and their loved ones) experience at end of life, and compares this to the media's perceptions of end of life. The chapter begins with some quotes from real people, then goes on to compare Macmillan's online community discussions relating to terminal cancer with the UK national newspapers' reporting of terminal cancer.

What are ex-carers of loved ones who died of cancer saying about their end of life experiences?

'When they said 'she's got no chance' that was very harsh. It was very hard for my daughters too, they were so upset.'

Bereaved ex-carer, South East

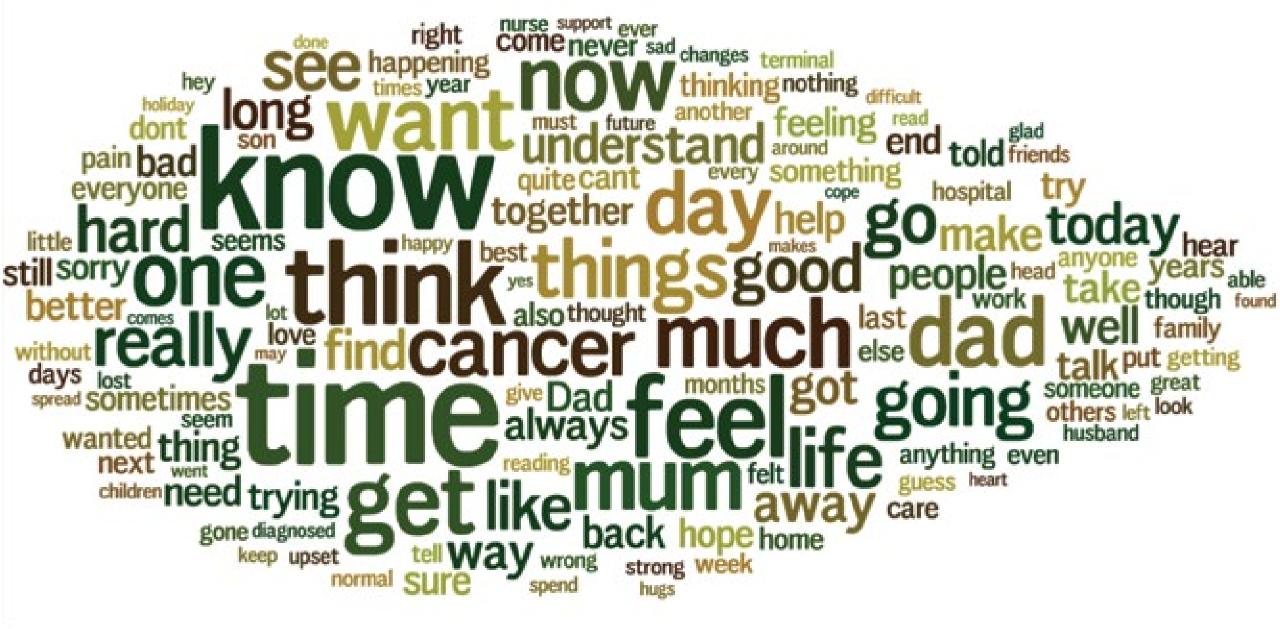
'I felt I was no part of what was happening. I was really shaken, I was gripping the side of the bed, my knuckles were white and tears were streaming down my face.'

Bereaved ex-carer, Wales

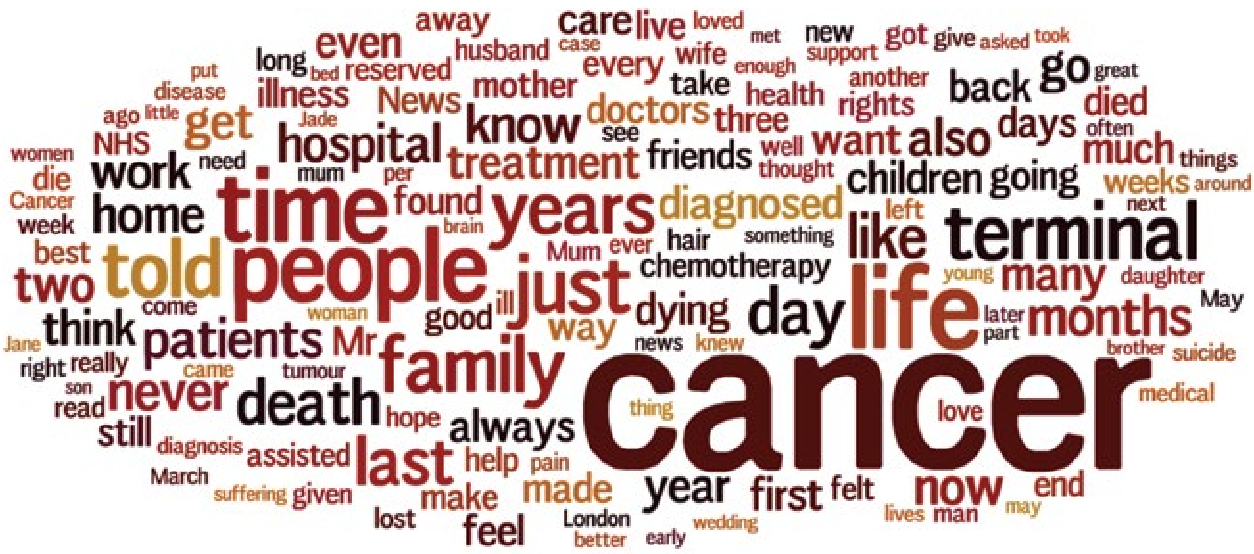
'I requested support for her to consider death and to face some of her concerns, but there was nobody for her to talk to.'

Bereaved ex-carer, North

What our Macmillan online Community members are saying about end of life and terminal cancer experiences…[65]



How the media* portrays terminal cancer end of life experiences…[66]



*UK national daily newspaper

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 terminal cancer. The key conclusions of this analysis are given below:

- 'Time' features prominently in the online community, as does 'now' and 'day', suggesting that people experiencing terminal cancer may be acutely aware of how much time they have left, perhaps taking each day as it comes. 'Time' also features prominently in the media articles relating to terminal cancer, but appears along with longer period time-related words such as 'year(s)' and 'months'.

- Words like 'think' and 'know' often feature in the online community discussions, suggesting people find it valuable to talk about their feelings, what they are thinking or feeling at end of life

- The word 'life' features very often in the media, and almost as often in the online community discussions. This is perhaps because many of the articles in the media talk about a particular person's life. However the media often selectively highlights very extreme examples life stories – these stories are not often typical and can distort people's views on end of life experiences.

- Perhaps due to the specific time period of media articles we analysed, the words 'assisted' and 'suicide' feature in the media with some frequency, due to sensationalised articles relating to euthanasia – whereas a very small number of people at end of life choose this controversial option (currently illegal in the UK).

SPOTLIGHT ON

People with learning disabilities at end of life

What issues affect care for people with learning disabilities at end of life?

Factors affecting palliative care provision for people with intellectual disabilities include social issues (home situation and family issues), emotional and cognitive issues (fear, patient understanding, communication, cooperation and capacity to consent), problems with assessment and the impact on staff and other patients. An underlying theme is the need to take more time and to build trust.[14]

In a study exploring the experiences and confidence of palliative care staff, 59% had cared for someone with intellectual disability, but felt that their level of experience was low. Staff lacked confidence in their ability to provide palliative care.[15]

Professional education is a critical component to improving end-of-life care and promoting better informed medical decisions for people with intellectual disabilities. Frequently, health care professionals (physicians, social workers, nurses, clergy and others), including hospice and palliative care staff, lack training on the special needs of people with intellectual disabilities and on methods to assess their decisional capacity.[16]

What are the needs of people with learning disabilities at end of life?

The support needs of people with learning disabilities who have a relative or friend with cancer are more important than their information needs.[7]

People with learning disabilities tend to 'keep quiet', and often do not ask questions or express true feelings to those who might be able to help.[7]

Macmillan works in partnership with leading organisations specialised in supporting people with learning disabilities to develop cancer information resources for people with learning disabilities and carers of people with learning disabilities. These are available at our **be.macmillan** website or by calling **0808 808 00 00**.

SPOTLIGHT ON

People at end of life in prison

What are the key stats for people at end of life in prison?

As of March 2010, 85,184 people were being held in prisons England and Wales with approximately 9,400 more held in Scottish and Northern Irish prisons.[9]

The number of deaths in prison is small. In 2012-13 there were 201 deaths in prison, of which 118 (59%) were from natural causes.[10] The most common natural causes of death in prison are usually heart attacks and cancer. In Scottish prisons, 4 inmates have died from cancer since August 2009.[11]

Although the prison and secure hospital population mirrors the general population, there is some evidence to suggest that ageing and associated pathology may be accelerated[12]. Within the prison population there are many premature deaths (in comparison with the community), with research indicating that the prison population dies younger[10]. There prison population in England and Wales includes over 11,000 people (men and women) aged 50 and over, including more than 3,700 aged 60 and over.[96] Older prisoners experience accelerated ageing, which means that they experience issues associated with older age from 50 onwards. Around five out of six (85%) of older prisoners have a longstanding illness or disability.[12]

What are the needs of people at end of life in prison?

Some health services within prisons have been able to meet the needs of prisoners and have enabled them to receive appropriate care, either in the prison, local hospital, hospice or in their own family home on a compassionate release order.[12]

Palliative care services in prisons vary. Most prisons now have access to specialist clinical services to provide advice and support to healthcare staff.[12]

A number of deaths are of prisoners who refuse to cooperate with the treatment plan to address their health needs. Sometimes the prisoner may be diagnosed with a terminal illness and refuse to accept any treatment to prolong their life.[12]

What are the experiences of people in prison at end of life?

A study in prisons in Cumbria and Lancaster revealed prison healthcare staff had limited experience of end of life care. Specialist palliative care staff had limited experience of working in prisons.[13]

Macmillan has hosted a UK-wide conference on palliative and end of life care in prisons. The conference report (recommended for health and social care professionals, prison governors, and commissioners) is available at our **be.macmillan** website or by calling **0808 808 00 00**.

SPOTLIGHT ON

Children at end of life

How many children have life-threatening conditions? How many children die in hospices?

It is estimated that there are about 40,000 children in England currently living with a life limiting condition.[70]

According to 2011/12 data collected from a sample of 33 children's hospice providers in the UK (including hospice at home services and community outreach teams), a total of 7,638 children and young people were supported by children's hospices across the UK. An additional 9,930 families were also supported.[68]

What are the specific issues facing children at end of life?

There can be poor awareness of services by families and professionals and a lack of co-ordination between those involved in delivering children's palliative care. Key working is seen by families as a necessity for helping navigate the complex health, education and social care systems – however there is a reported lack of a key worker contact to support children and families.[69]

There are concerns about the availability of support for young people with life-limiting conditions to make the transition to adulthood, especially as the number of children and young adults with life-limiting and life-threatening conditions who are surviving into adulthood is increasing year on year, particularly in the 16–19 age group.[70]

SPOTLIGHT ON

People at the end of life in care homes

How many care homes are there in the UK?

There are 20,012 registered Care Homes, Nursing Homes and Residential Homes in the UK. 86% of theses are located in England, 6% in Scotland, 6% in Wales and 2% in Northern Ireland[56]. The four nations have different end of life care strategies in place and governing bodies that regulate these.

At the end of 2012, there were a total of 464,329 care home places in England. A significant proportion of the residents of care homes are living with from dementia. Recent research indicates that over 200,000 people with dementia live in care homes.[12] Cancer specific information is not available.

How many people die in a care home?

In 2012, 103,164 people died of all causes in a care home in England and Wales, accounting for 21% of deaths.[3]

However, as some patients are admitted to hospital when they are very close to the end of their lives, the number of care-home residents who are dying is much greater[76].

What are the needs and experiences of people with cancer in care homes?

52% of relatives bereaved due to cancer felt that the quality of care received by their loved one by staff in a care home in the last three months of his or her life was excellent.[6]

68% of relatives bereaved due to cancer felt that their loved ones were always treated with dignity and respect by staff in a care home in the last three months of their lives.[6]

47% of relatives bereaved due to cancer felt that the pain their loved one experienced in the last three months of their lives was relieved all of the time in a care home.[6]

35% of care homes inspected by the Care Quality Commission in England indicated that getting medicines to residents on time was 'sometimes' a problem, while 4% indicated that this was 'often' a problem.[78]

16% of people living in care homes were admitted to hospital within their last week of life and died there.[7] Investment in training for care home staff was seen as a priority to enable individuals to remain within the home, reduce unnecessary hospital admission, and ensure rapid discharge back to their home (according to individual preference).[84]

In a 2012 CQC survey, all staff interviewed in three-quarters of care homes said that they definitely feel confident that they "understand the health care needs of people living in the care home and what they need to do to help meet these". However, in the remaining one quarter of homes some or all staff interviewed indicated that they only felt confident to some extent or did not feel confident at all.[78]

SPECIALIST THEMES

Specialist palliative care at home[81,83]

What is Specialist Palliative Care at Home?

As well as receiving specialist palliative care in a hospital setting, advances in technology and flexibility in team working means more specialist care can be offered at home. Macmillan are testing a new approach based on work that has been done in Midhurst with the Macmillan Specialist Palliative Care team since 2006.

What Happens in Midhurst?

People referred to the Specialist Palliative Care Service are able to have the majority of their care at home or in a community setting. This includes specialist clinical interventions such as blood/blood product transfusions, IV (intravenous) antibiotics and bisphosphonates, paracentesis (a body fluid sampling procedure), ultrasound and intrathecal analgesia (spinal anaesthesia). A clinical support team visit people at home as part of the service.

What makes Specialist Palliative Care at Home possible?

When people are referred to a palliative care service early, there is more time to discuss what is important, plan care and decide on preferences. This is because early assessment of a person's holistic needs makes it more likely the care team and family can fulfil these wishes.

Who is in the team?

The team is led by a consultant in Palliative Care and made up of a variety of professionals working collaboratively together to meet individual needs. These include Clinical Nurse Specialists (CNSs), nurses and support workers, doctors, an occupational therapist, a physiotherapist, a counsellor and trained volunteers.

It is important that patients and their carers are well supported at home at this difficult time, particularly when pain relief and emotional support is required. A rapid-response support service, available seven days a week, helps to ensure the best quality care for people at home, and helps prevent emergency hospital admissions.

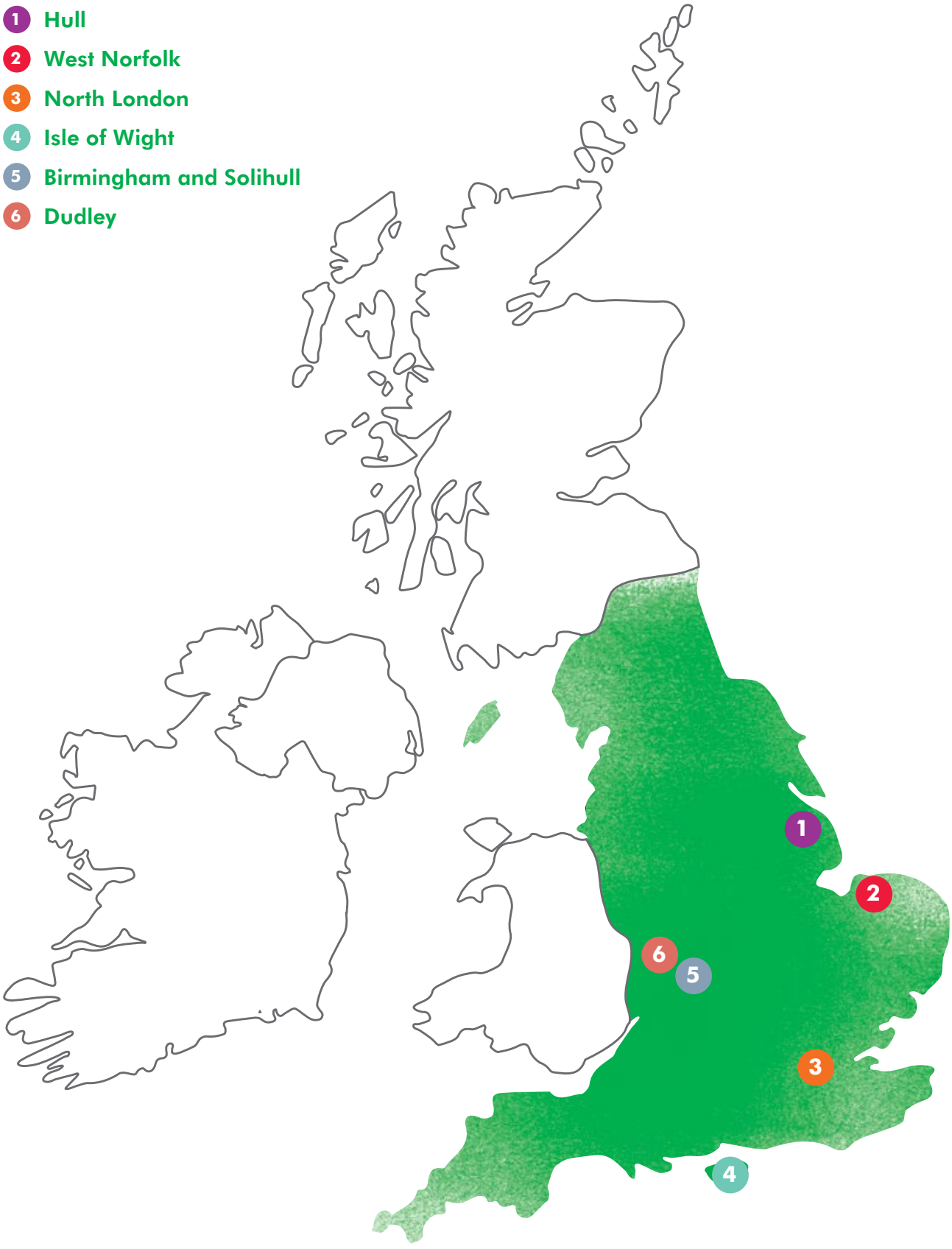
What is the evidence that this improves services?

The Midhurst service has been independently evaluated.[31] There is emerging evidence that supporting people with complex palliative needs to receive treatment at home can reduce their unplanned hospital admissions and the number of days they spend as an in-patient, and ultimately enable them to die in their preferred place of care. In Midhurst, 84% of patients referred to the specialist palliative care team died in their preferred place in 2012/13.

From 2014-16 Macmillan will be testing the coordinated services, like those in Midhurst, in six locations around the UK. More information on these pilot services can be found at **www.macmillan.org.uk/specialistcareathome.**

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



REFERENCES, SOURCES, NOTES AND CAVEATS

Quotes

The quotes on pages 23, 31, 37 and 43 are real quotes from carers of people with cancer, however we have changed their names to protect their identity. The quote and photo on page 6 is from a Macmillan case study who has kindly agreed to be featured in this publication.

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APPENDIX A JARGON BUSTER

Not sure of some of the cancer-related 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' we mean the number of people who die from cancer within a given time-frame, usually one calendar year. The latest data we have is for 2012, and we know that over 150,000 people die from cancer in the UK every year. Mortality can sometimes be given as a rate (per head of population).

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

Survival: When we talk about 'cancer survival' we mean the percentage of people who survive a certain type of cancer for a specified amount of time. Cancer statistics often use one-year or five-year survival rates. Relative survival (the standardised measure used) is a means of accounting for background mortality and can be interpreted as the survival from cancer in the absence of other causes of death. Survival rates do not specify whether cancer survivors are still undergoing treatment after the time period in question or whether they are cancer-free (in remission).

(ii) Other terms

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

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

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

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

Full suite of the Rich Pictures

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

Overarching Rich Picture

The Rich Picture on people with cancer	(MAC15069)

The Rich Pictures on cancer types

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

The Rich Pictures on age groups

The Rich Picture on people of working age with cancer	(MAC13732_14)
The Rich Picture on children with cancer	(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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