

THE RICH PICTURE

CANCER CARERS

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Understanding the numbers, needs and experiences of cancer carers in the UK



**Sharon and Wendy –
Sharon is caring for her mother**

About this *Rich Picture*

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

Within this document, you'll find a summary of the numbers, needs and experiences of cancer carers. This is intended to support Macmillan staff, cancer care professionals, volunteers and other interested parties. It includes data specific to carers of people with cancer, as well as more generic information about carers.

Methodology The information contained in this document is a summary of selected relevant research articles, papers, NHS data, statistics and Macmillan-funded research. While the report includes a range of sources, recent research commissioned by Macmillan Cancer Support and undertaken by YouGov (2016) is the core source throughout the report.

The Macmillan and YouGov research consisted of two phases:

- **Phase 1:** Face-to-face interviews with 6,487 people from the UK general population via the TNS omnibus survey, between 26th February and 22nd March 2016 – this identified the overall proportion of cancer carers in the UK population.

People currently supporting someone with cancer were defined as carers for the purposes of the research if they were aged 16 or over and provided more than five hours of care a week ('care' was determined by asking them if they did any of a range of activities for someone because they had cancer) or provided 1–4 hours of care a week but said it had an impact on their lives in some way (eg financially or emotionally). It does not include those who provide care as their paid job or voluntary work. The definition does not depend on carers self-identifying as carers, as it is known that many people providing support to a relative or friend don't see themselves as a 'carer'. Self-identification would therefore have underestimated the number of carers.

This forms the definition of carers used within this document when referring to cancer carers.

Results have been weighted to be representative of the UK adult population according to age, gender, UK region and socio-economic group. Data weighting and all analysis carried out by YouGov. The unweighted UK breakdown of the sample was as follows: England: 5326 people; Scotland: 537; Wales: 333; Northern Ireland: 291.

- **Phase 2:** Separately to the face-to-face omnibus survey, a parallel survey with 892 UK cancer carers only, via YouGov's online panel, was conducted between 4th and 18th April 2016. This allowed us to explore the experiences of carers in more detail. This study also used a nationally representative sample and results were weighted by age, gender, social grade and region to reflect the overall population of carers identified in phase 1.

Throughout this Rich Picture, figures cited and charts included are clearly sourced to either Phase 1^{7a} or Phase 2^{7b} accordingly.

While some questions on the impacts of caring were explored in both phases, the detailed experiences of caring were only explored in phase two. As different methodologies and samples were used in each phase, this meant that for some questions asked in both phases different results were produced. To provide consistency and clarity on methodology and enable the use of a wider range of findings, when reporting on the impacts of caring and the detailed experiences of carers, findings from phase two have been presented. Where the same question was asked in both phases but produced different results, the findings from phase two have been referred to as an upper range of results (eg "up to x% experience y").

The *Rich Picture* is intended to be accessible to clinical and non-clinical cancer support staff. Therefore the language and facts included are intended to cater to the information needs of both groups. We have included references to other documents to help with interpreting some of the 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 carers 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.

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

macmillan.org.uk/richpictures or for further information please contact evidence@macmillan.org.uk

The legal bit

This document intends to summarise the numbers, needs and experiences of carers of people with cancer in a broad sense. It is not an exhaustive systematic review that follows the 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, claims 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 2016. But a document of this nature – essentially a summary of a large body of evidence – inevitably goes out of date.

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



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Guidance on referencing this document

You are free to use any of the data contained in this document. However, when quoting any factual data that does not belong to Macmillan it is best practice to refer to the original source. The original sources can be found in the References section at the back of this document.

Additional information for people affected by cancer

This document is designed to summarise the numbers, needs and experiences of carers of people with cancer. It is not designed specifically with people living with cancer in mind, although this group may find the information helpful.



Looking after someone with cancer

MAC5767

Our main resource for carers



A guide for young people looking after someone with cancer

MAC13009

Our resource for young carers aged 12 to 18 years



Working while caring for someone with cancer

MAC11688

Our main resource for cancer carers in employment



Questions for carers to ask about work and cancer

MAC13509

Containing essential questions to ask about work and cancer



Supporting a loved one through cancer?

We're here for you

MAC15927

Information about Macmillan's support and services for carers

Order a hard copy of these titles by calling our Macmillan Support Line free on **0808 808 00 00** (Monday to Friday, 9am to 9pm) or by visiting at **be.macmillan.org.uk**. A wealth of other resources is also available, all produced by Macmillan Cancer Support and free of charge.

The same information contained in our hard-copy booklets can also be found in the carers section of our main website at **macmillan.org.uk/carers**

ADDITIONAL 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

Stories and quotes from people affected by cancer who have been helped by Macmillan

Professionals/services

Specific examples of our services across the UK, and the impact they are having



Comms platform

How to communicate with people affected by cancer



Rich Pictures

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



Impact briefs

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 the **Evidence team**, or email evidence@macmillan.org.uk

CONTENTS

Impacts of providing support on cancer carers	27
Impacts of caring on physical health	28
Impacts of caring on emotional and psychological health	31
Impacts of caring on working life	35
Impacts of caring on finances	39
Impacts of caring on social life and leisure time	42
Unmet support needs	45
Experience of the health and social care system	46
Being identified as a carer	47
Carer's assessment	49

SUMMARY OF CARERS OF PEOPLE WITH CANCER

Key stats

There are an estimated almost **1.5 million people aged 16 and over** in the UK currently caring for someone with cancer, and **half of them are missing out** on the support available to them.^{17a, 17b}

Only around two-fifths of cancer carers **identify with the term 'carer'**.^{17b}

Cancer carers are **predominantly female (68%)**.^{17a}

Almost half (47%) of **carers are of late working age**, ie 45–64.^{17a}

Cancer carers are most likely to provide **emotional support**, as well as help with practical needs, such as transport and domestic chores, to the person they care for. They also provide a wide range of **other types of support** including advocacy and liaising with professionals, personal care and healthcare tasks.^{17a}

Cancer carers are most likely to be supporting **a parent, followed by a spouse or friend**.^{17b}

Recent research shows that **cancer carers give an average of 17.5 hours of support** to those they care for each week.^{17a}

Impact on working life

A total of **50% of cancer carers are employed**. Cancer carers are most typically in full-time employment (33%) while fewer (17%) are in part-time employment.^{17a}

Among those carers who are currently working, nearly 1 in 2 (43%) mention **one or more impacts on their working life**.^{17b}

Generally, **younger cancer carers**, who are more likely to be working in the first place, report more impacts on their working life.^{17b}

Many employed cancer carers report impacts of caring on their working lives.

Impact on finances

A total of 30% of cancer carers report an **impact on their income or household finance** as a result of caring.^{17b}

Carers of late working age (aged 45 to 64 years) are most likely to be negatively affected financially because of caring.^{17b}

According to Carers UK, up to 45% of all carers (not cancer specific) experience **higher utility, transport and food costs**.²⁸

Cancer carers of late working age are most likely to experience a financial impact due to caring.

Impact on social life and leisure time

About 1 in 3 (38%) of cancer carers state that **caring has had an impact on their social life or leisure time**. Some carers report spending less time with friends or family.^{17a} A total of 10% of cancer carers report a more difficult relationship with the person they care for as well as spending less time with their spouse or partner.^{17b}

A quarter (24%) of **carers who care for more than 10 hours a week report being invited out less**. This compares with just 6% of those providing up to nine hours of care.^{17b}

A total of 13% of carers reported that they had **developed a better relationship** with the person they care for.^{17b}

Carers who experience an impact on their social life or leisure time report spending less time with friends or family, as well as having more difficult relationships.

Impact on physical health

Up to 35% of cancer carers experience impacts on their physical health as a result of their caring responsibilities.^{17b} These impacts include **tiredness/exhaustion, sleep problems and weight gain/loss**.

Women were more likely to experience **tiredness/exhaustion as a result of caring** than men (33% versus 22% of men).^{17b}

People who care for more than 35 hours a week may experience more physical problems than those caring for under 35 hours a week (50% versus 24% of those caring for under 35 hours).^{17b}

More than half (51%) of all carers report that they have **let a health problem go untreated**.⁷

Carers who experience physical problems because of caring report tiredness/exhaustion, sleep problems and weight gain/loss.

Impacts on emotional and psychological health

74% of cancer carers say they provide emotional and psychological support to the person they care for.^{17a}

Half of cancer carers (51%) **experience stress**, close to half (45%) experience anxiety, and 26% experience depression related to caring.^{17b}

The most common source of support for **carers who experienced emotional impacts** was informal support from family and friends (32% of those experiencing impacts). A fifth (19%) had sought support from their GP.^{17b}

Most cancer carers provide emotional and psychological support.

INTRODUCTION TO CARERS OF PEOPLE WITH CANCER

Who are carers?

The government defines informal carers as:

- Informal carers – also called unpaid carers – are people who look after family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or care needs related to old age. This does not include any activities as part of paid employment.²

It is important to point out that many people who provide help and support to loved ones don't see themselves as carers. Macmillan is here to support anyone looking after someone with cancer, whether they see themselves as a carer or not.

Macmillan defines a carer as:

- Someone who provides unpaid support to a family member or friend with cancer who would not be able to manage without this help. Caring can mean many things including being a good listener, helping with personal care, providing transport or assisting with everyday chores.³⁷

How many people in the UK are carers and how many are cancer carers?

The 2011 census: population estimates for the United Kingdom estimated that 6.5 million people in the UK provide unpaid care to family members, friends, neighbours or others who are living with health problems, disability or issues

relating to old age.¹ The economic value of the contribution made by these 6.5 million carers in the UK is estimated at around £119 billion.⁵

An estimated almost 1.5 million people aged 16 and over are currently caring for someone with cancer in the UK. This is approximately 3% of the population aged 16 and over.^{17a, 17b}

What do cancer carers do?

Carers of people with cancer provide both practical and emotional support to the person they look after. This can include helping with shopping, providing transport, carrying out domestic chores, finding information and talking to professionals on behalf of the the person they look after. Cancer carers may also provide personal care including helping with washing, dressing and toileting, and they may even assist with healthcare tasks such as giving injections and changing dressings.⁶

Who do cancer carers care for?

Carers are most likely to support a parent (30%).^{17a} This is followed by 27% of carers supporting a spouse/partner and 17% caring for a friend/neighbour.^{17a}



**'My mother is dealing with the long-term side effects of her cancer. I live in Preston – Mum lives 20 minutes' drive away.'
Sharon – carer of her mother**

MACMILLAN'S AIMS AND OUTCOMES

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

The estimated total number of people living with cancer in the UK in 2015 was 2.5 million. Assuming that all existing trends in incidence and survival continue, cancer prevalence is projected to increase to four 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 five years from diagnosis.³⁶ Macmillan's ambition is to reach all of these people and help improve the set of 9 outcomes you can see on the next page. Remember – certain groups will identify more or less strongly with the various outcomes.

The outcome that is most relevant to carers is: 'Those around me are well supported'. There are an estimated almost 1.5 million people aged 16 and over currently caring for someone with cancer in the UK. It is likely that this number will increase together with increasing numbers of people living with cancer. We have an ongoing programme of support for carers, underpinned by our understanding of the experiences and unmet needs of this group.

The 9 outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

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

Those around me are well supported

I am treated with dignity and respect

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

I can enjoy life

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

I want to die well

THE FACTS ON CARERS OF PEOPLE WITH CANCER

This section of the *Rich Picture* presents some of the key stats and facts relating to people caring for someone with cancer.

**Almost
1.5 million**

people aged 16 and over are currently caring for someone with cancer in the UK.^{17a, 17b}

68%

of cancer carers are women.^{17a}

17.5 hours

is the average amount of care provided a week by those caring for someone with cancer.^{17a}

The majority (65%) of cancer carers surveyed had been caring for

1–2 years

A third (34%) have cared for three years or more. The majority (86%) care for one person, although one in eight (13%) look after two or more people with cancer.⁶

51%

of cancer carers say that they experience stress.^{17b} Close to half (45%) experience anxiety, and 26% experience depression.^{17b}

55%

of cancer carers do not think of themselves as a 'carer'.^{17b}

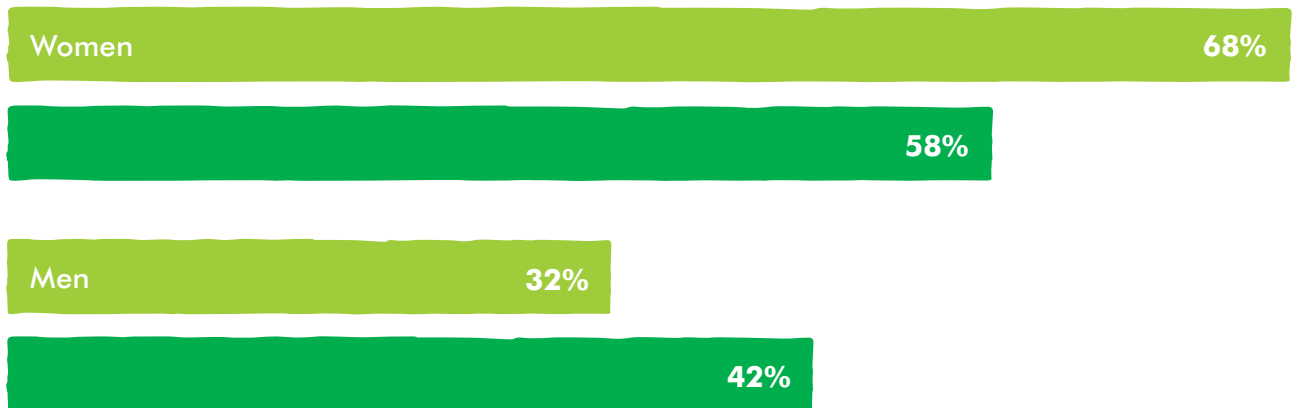
33%

of cancer carers are currently in full-time employment.^{17a} 17% work part-time and 30% are retired.^{17a}

Who are cancer carers in the UK?^{17a}

There are an estimated almost 1.5 million people aged 16 and over in the UK currently caring for someone with cancer. Cancer carers are predominantly women. Almost half (47%) of the cancer carer population is aged 45 to 64. This pattern is similar to the profile of the carers caring for those with other conditions.

Gender of UK cancer carers compared to UK population – 2016^{17a}



All UK adults¹
All cancer carers (n=177)

Number of cancer carers with children in their household, UK – 2016^{17a}



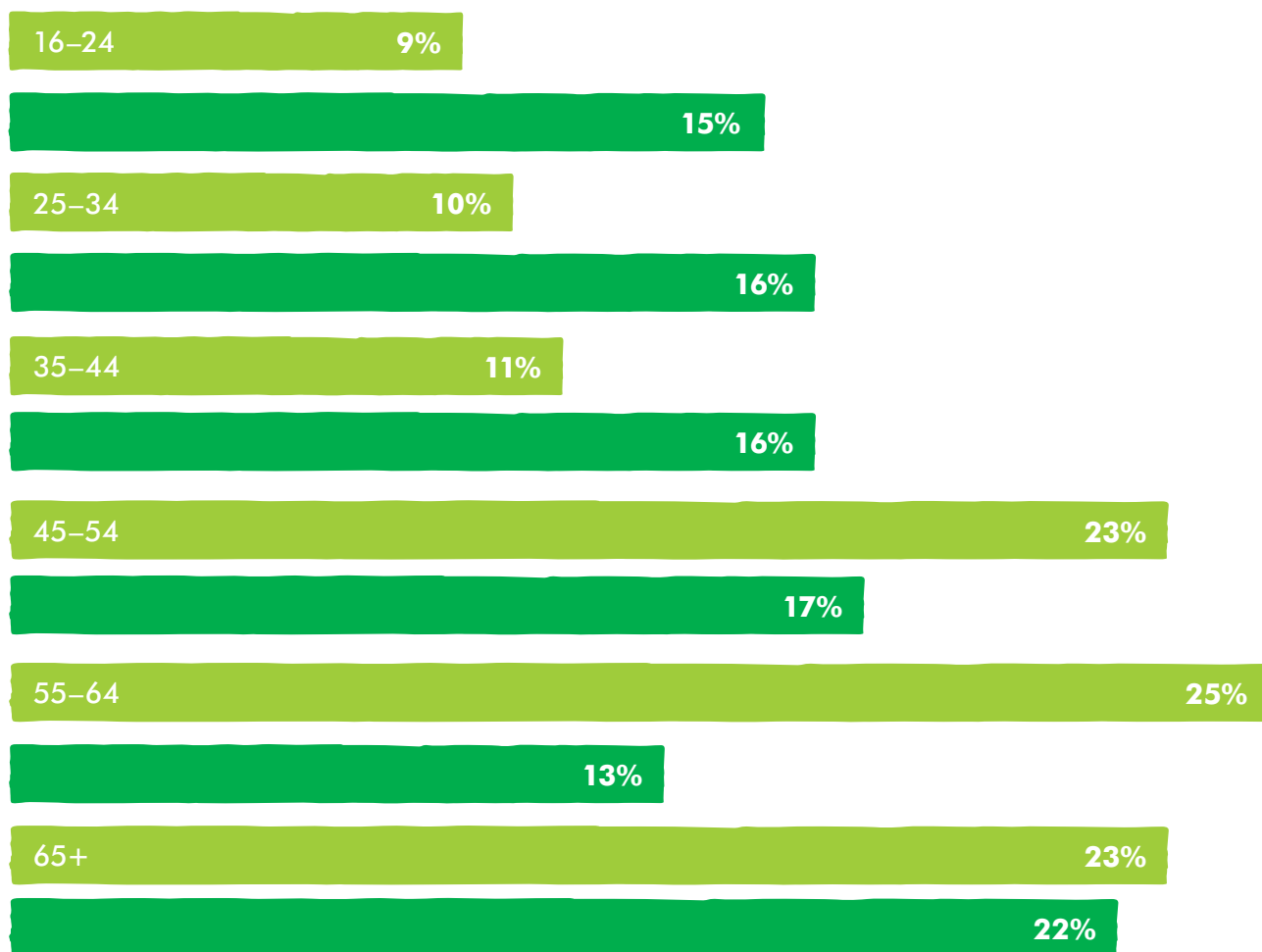
All UK adults¹
All cancer carers (n=177)

- UK carers of someone with cancer
- UK population (2011)

A fifth of all cancer carers have children at home, meaning they may also need to look after them while caring for someone with cancer.

Please see **page 12** for the numbers of carers in each of the four UK nations.

Age of UK cancer carers compared to UK population – 2016^{17a}



All UK adults¹
All cancer carers (n=177)

 UK carers of someone with cancer

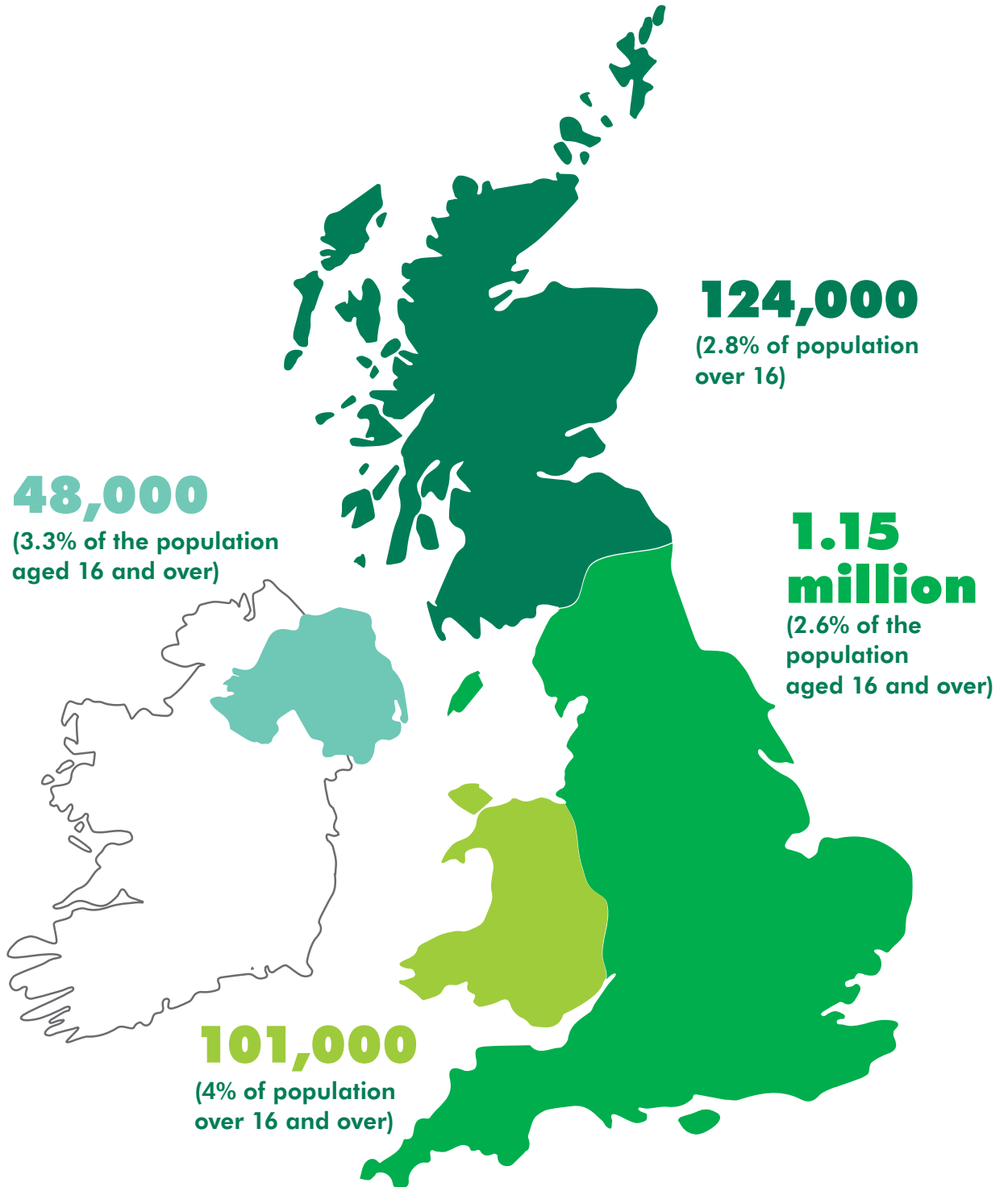
 UK population (2011)

'I help with loads of tasks for her including shopping, taking her to appointments, phoning people as she's lost all her confidence. And she has no saliva glands so she mustn't eat any sugars so I have to watch her diet. And her muscles in her head and neck are weak so she finds basic housework difficult such as vacuuming. She's changed a lot – she gets very tired. And it takes me a lot of planning and organising to support her. I just have to get on with it.'

Sharon, aged 35 to 44, caring for her mother

What are the key stats for the four UK nations?^{17a, 17b}

The almost 1.5 million people aged 16 and over currently caring for someone with cancer in the UK is broken down into the four component nations here.



These estimates are based on YouGov and Macmillan Cancer Support research *Estimating the population of cancer carers in the UK*^{17a, 17b}

England

There are an estimated

1.1 million people

aged 16 and over in England currently caring for someone with cancer.

This equates to 2.6% of the population aged 16 and over.

Wales

There are an estimated

101,000 people

aged 16 and over in Wales currently caring for someone with cancer.

This equates to 4.0% of the population aged 16 and over.

Scotland

There are an estimated

124,000 people

aged 16 and over in Scotland currently caring for someone with cancer.

This equates to 2.8% of the population aged 16 and over.

Northern Ireland

There are an estimated

48,000 people

aged 16 and over in Northern Ireland currently caring for someone with cancer.

This equates to 3.3% of the population aged 16 and over.

International comparisons

Developed countries outside the UK^{10, 11, 12, 13, 14}

The needs and experiences of cancer carers in other developed countries seem to be similar to those of carers in the UK. Research from Australia, Germany, Greece, Norway and Turkey reiterates unmet needs around emotional, financial and practical support. The research also confirms that home deaths are more likely to be achieved if there is support available from an informal carer.

Developing countries outside Europe

The situation may be slightly different in developing countries. For example, the needs and experiences of carers in Kenya and Scotland were compared. Physical pain and financial worries were highlighted as key concerns in Kenya whereas carers in Scotland had the biggest unmet needs in the area of emotional support. Carers in Kenya felt their emotional needs were met by a strong community network, family and spiritual beliefs.¹⁵

What are the geographical ‘hotspots’ for cancer incidence and mortality?³⁵

Broadly speaking, where people with cancer are found cancer carers are also found. Carers’ distribution is tightly linked with cancer distribution across the UK. This is because carers may often live close to or with those who they are caring for. The maps on these pages show broad variations across the UK in terms of cancer incidence and cancer mortality.

Cancer incidence, UK – 2008–2010



Important note

These maps show only the broad patterns of variation in cancer incidence and mortality. Access to the very detailed and accurate data at the primary care trust/health board level is available via the National Cancer Intelligence Network Cancer e-atlas website at www.ncin.org.uk/eatlas or Macmillan staff members can contact Macmillan’s Health Data team.

Age-standardised rate of tumour diagnosis per 100,000 European Standard population for all ages and all cancers excluding non-melanoma cancers. Rates are shown by region for England and Scotland, Health Board for Wales and by Health and Social Care Trust for Northern Ireland. Annual data for 2014 except for Northern Ireland which is for the 2010 to 2014 period. Data classified by tertiles for the UK combined [low (<595.7), medium (595.8 to 634.4) and high (= 634.5)].

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 Ltd, 2015.

Cancer incidence rates are generally higher in parts of Scotland, northern England and parts of Wales.

Cancer mortality, UK – 2009-2011



Important note

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

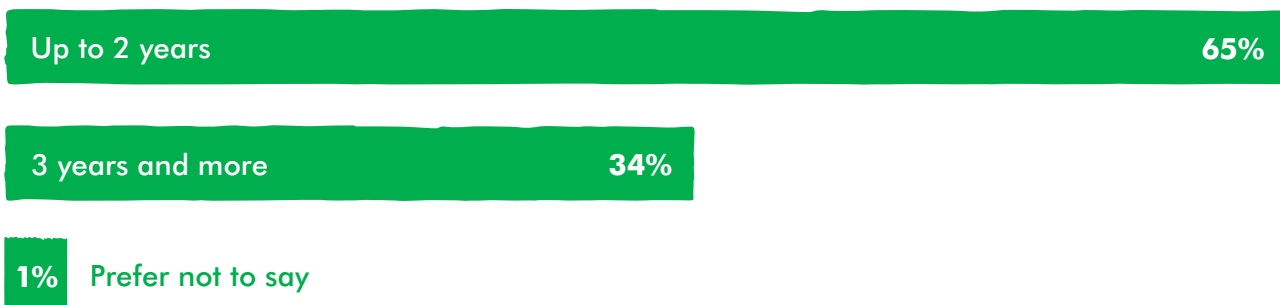
Age-standardised mortality rates per 100,000 European Standard population for all ages and all cancers excluding non-melanoma cancers. Rates are shown by region for England and Scotland, Health Board for Wales; and by Health and Social Care Trust for Northern Ireland. Annual data for 2014 except for Northern Ireland which is for the 2010 to 2014 period. Data classified by tertiles for the UK combined [low (<279), medium (279 to 298.5) and high (= 298.5)].

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 Ltd, 2015.

Cancer mortality rates are generally higher in Scotland, northern England and parts of Wales.

How long do cancer carers provide care for?^{17b}

Length of time as a carer, UK – 2016



YouGov and Macmillan Cancer Support research found that the majority of cancer carers have been providing support for up to two years. Around 1 in 3 have been providing support for three years or more. While 1 in 7 carers have been providing support for more than six years.

A total of 37% of carers who are ‘long-term carers’, ie have been caring for three or more years, are looking after a parent/parent-in-law. 36% of long-term carers are looking after a spouse/partner.^{17b}

A total of 22% of long-term carers provide more than 50 hours of care a week compared to 16% of all cancer carers.^{17b}

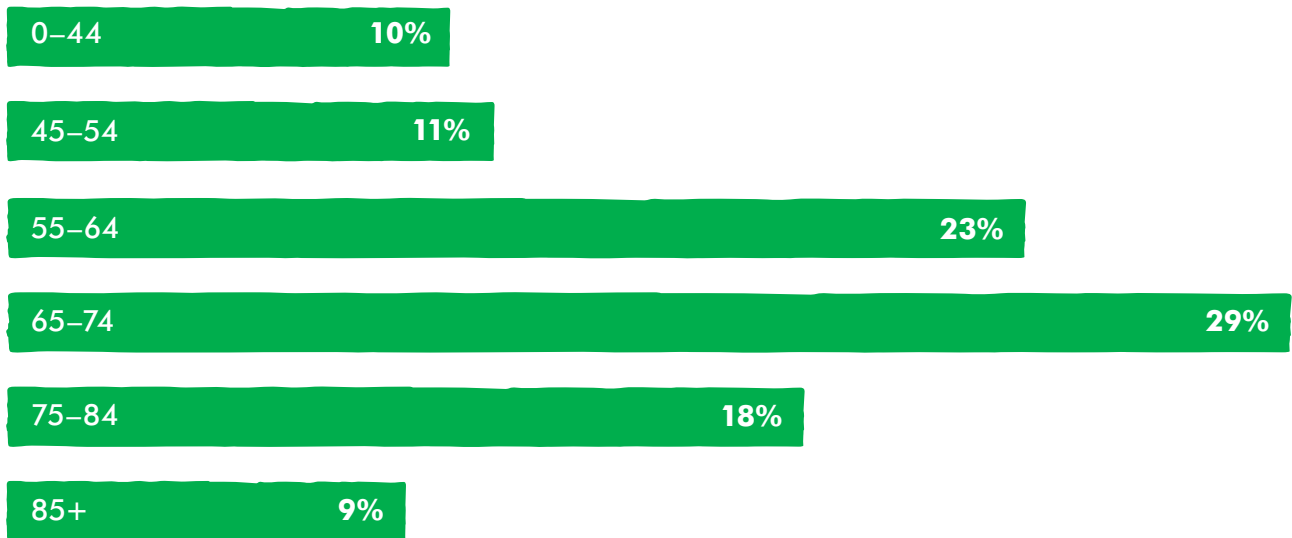
Who are cancer carers looking after?

Gender of person with cancer being cared for, UK – 2016^{17b}



All cancer carers – online survey (n=879)

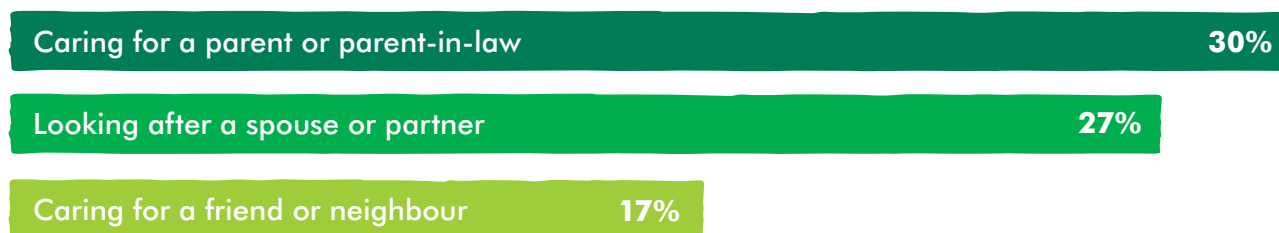
Age of person with cancer being cared for, UK – 2016^{17b}



All cancer carers – online survey (n=892)

Over half of people (56%) with cancer being cared for are aged over 65, whilst almost a quarter (23%) are of late working age, ie 55–64. This compares to around 23% of cancer carers themselves being over 65, as indicated on p10.

Carers are most likely to support a family member, UK – 2016^{17b}



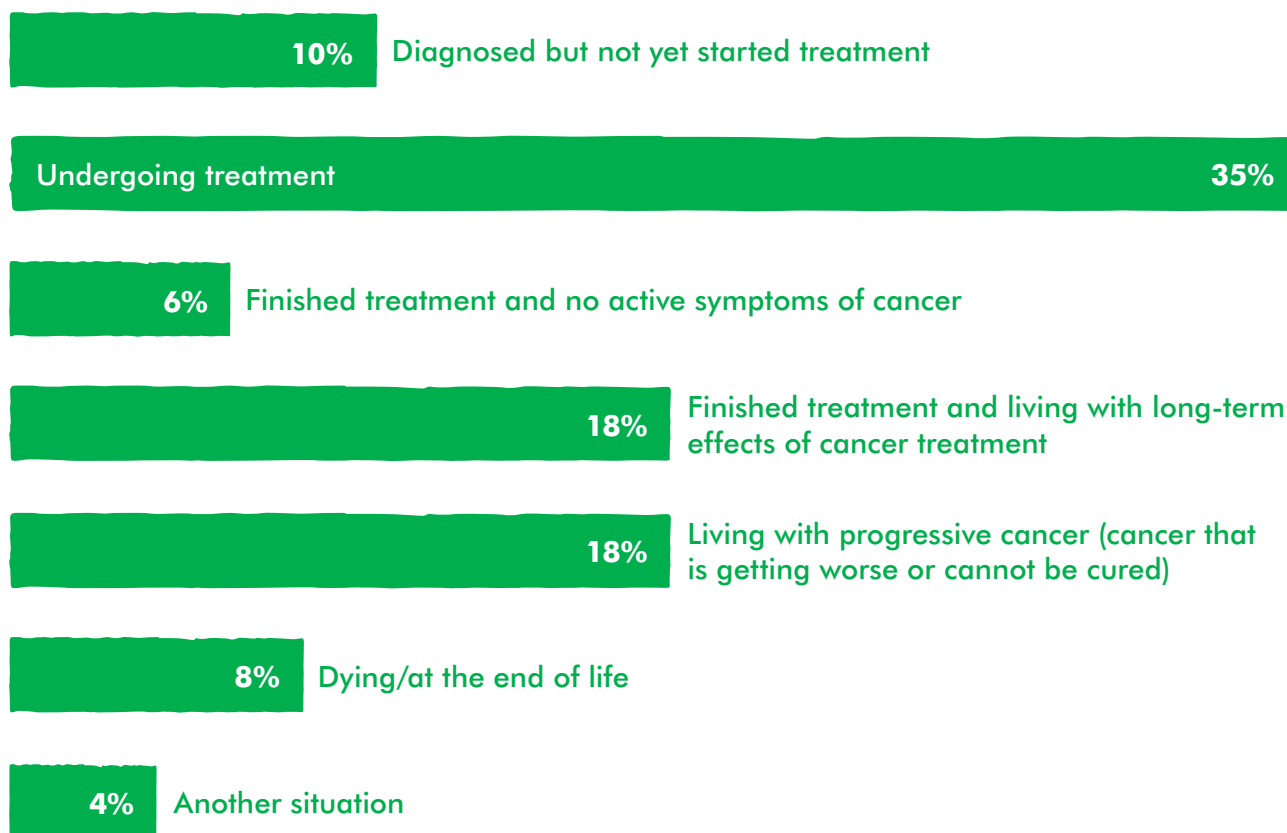
All cancer carers – online survey (n=892)

Around 1 in 3 (35%) are caring for a parent or parent-in-law. Just over a quarter (27%) of cancer carers are looking after a spouse or partner – the same proportion (17%) are caring for a friend or neighbour.

The majority (63%) of cancer carers don't live with the person they care for, while one third do.

Living separately may have the implications for the time and cost of travel, especially if people live far away.

Cancer stage of those being cared for, UK – 2016^{17b}



All cancer carers – online survey (n=892)

Carers are looking after people at all stages of the cancer experience. About a third (35%) of those being cared for are undergoing treatment. The proportion of people who have finished treatment and are living with long-term effects of cancer treatment is almost equal to the proportion of those who are living with progressive cancer.

The vast majority (78%) of carers reported that they began to care early in the person's experience of cancer – when they were diagnosed but had not yet started treatment.^{17b}

Should we use the term 'carer'?

The term 'carer' has been criticised as ineffective because it may imply burden and therefore devalue the individual who is cared for.

Many carers don't see themselves as carers but rather as a daughter, husband, sister, friend etc supporting someone close to them who has become ill. They see this as a natural part of their relationship and role in their loved one's life.

The term 'carer' is still used because it is a universally agreed term across different institutions and individuals. However, Macmillan uses it along with terms such as 'looking after' and 'supporting' to help people identify as carers and access much-needed support.

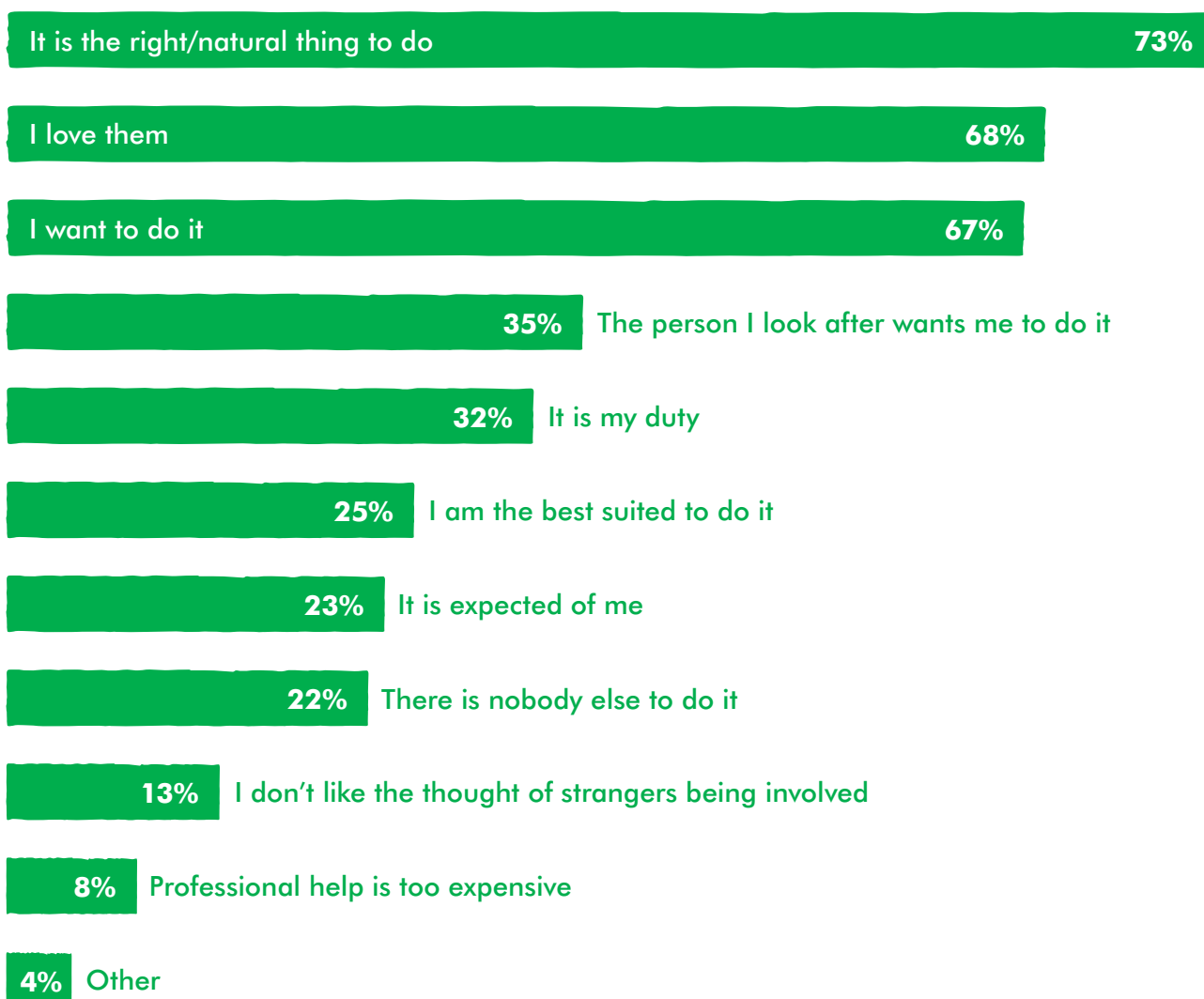
We have developed information that helps carers to understand the term and identify with it. Visit [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers) for more information.

Macmillan's research^{17b} shows that more than half of cancer carers (55%) don't identify with the term 'carer'. Those most likely to describe themselves as a carer include:^{17b}

- middle-aged and older carers (44% of those aged over 45 compared with 29% of those aged 16 to 44)
- those providing greater amounts of care (71% of those providing over 35 hours compared to 31% of those providing under 35 hours)
- those who had been caring for longer (50% of those caring for more than three years compared to 31% of those caring for up to a year and 40% of those caring for 1 to 2 years)
- those caring for a partner (57% compared to 37% of those caring for a parent and 20% of those caring for a friend/neighbour).

This has significant implications for how we communicate with and reach carers.

Reasons for providing cancer care, UK – 2016^{17b}



All cancer carers – online survey (n=892)

The above shows the reasons and motivations carers have for providing care and support. It seems to reflect strong personal motivations (eg 'I love them', 'I want to do it') and a sense that it is 'the right/natural thing to do'. When considering that those cared for are most likely to be a close family member perhaps this is not surprising.

**'I'm her husband not a carer –
she'd do the same for me.'**

Male, 49, caring for his wife

What types of care are cancer carers providing?¹⁷

Carers support the people with cancer they look after in all aspects of life – physical, emotional, practical and financial:

- As many as 74% of carers provide emotional support by listening and talking to those they care for, while 33% support someone who cannot be left alone.^{17a}
- Helping the person with cancer interact with health and social care professionals or access support is also a key form of care provided. A total of 45% talk to healthcare staff/social workers on behalf of those they care for and as many as 43% help them get advice and information. Furthermore, 44% support by making phone calls, writing letters or filling in forms.^{17a}
- Cancer carers provide support for a range of practical tasks both within and outside the home: doing the shopping and collecting prescriptions (54%), providing transport or accompanying the person on trips or to appointments (50%), help with cooking, cleaning, laundry, gardening and other household chores (52%).^{17a}
- More than one-third (38%) of carers provide assistance with giving medication and other healthcare tasks. About 1 in 3 (34%) help to wash, dress, use a toilet or feed the person they look after.^{17a}
- More than 1 in 5 carers (28%) say they help manage the finances of the person they care for.^{17a}

Most carers are looking after one person but a minority (13%) are caring for more than one person with cancer.⁶

Carers provide different amounts of support for people with cancer. Most cancer carers (53%) are providing support of between 1 to 9 hours a week. One in three carers (31%) give over 20 hours a week, and one in five (20%) give over 35 hours.^{17a} Many carers are balancing caring responsibilities with work and needing to look after children.

Just under two-thirds (63%) of carers do not live with the person they look after, and many have to travel to provide care. A total of 49% of carers travel less than one hour and 13% of cancer carers travel for more than an hour to visit the person they care for.^{17b}

Trends in the number of carers

Cancer carers

The number of people currently living with cancer stands at 2.5 million and this is increasing at an average of 3% a year. This is because cancer incidence is rising and people with cancer are surviving longer due to better treatment.⁸ The number of people living with cancer is expected to reach four million by 2030, and it is likely that the number of carers will therefore also increase.

Carers generally

According to the *2011 census: population estimates for the United Kingdom*, there were an estimated 6.5 million carers in the UK. Carers UK estimate that this number will increase to nine million in 2037.³

One of the emerging trends is that the number of carers who provide 50 or more hours a week is rising faster than the general carer population. In the last decade, the number of people caring 50 or more hours increased by 25% compared to an 11% increase in the total number of carers in general.³²

It is estimated that 3 in 5 adults will be carers at some point in their lives.³

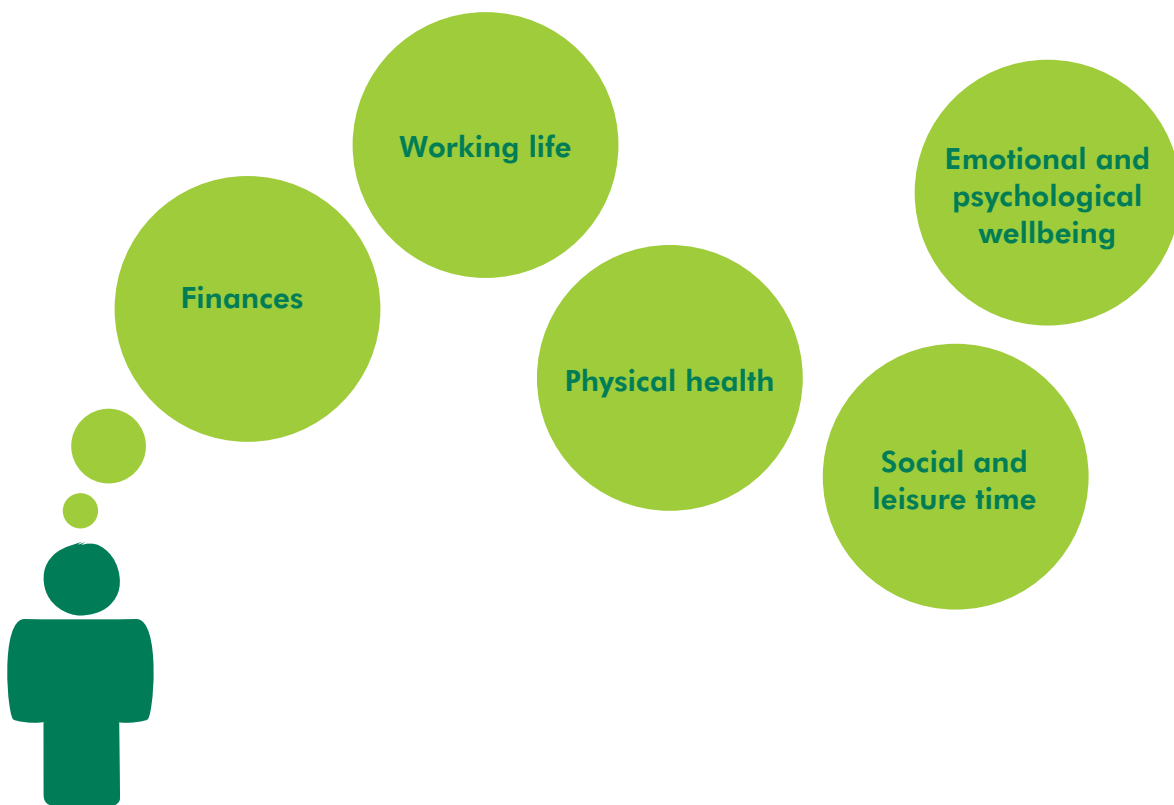
'As life expectancy rises and people live longer with disabilities and long-term conditions we must all come to terms with a growing care challenge.'

Heléna Herklots,
Chief Executive of Carers UK

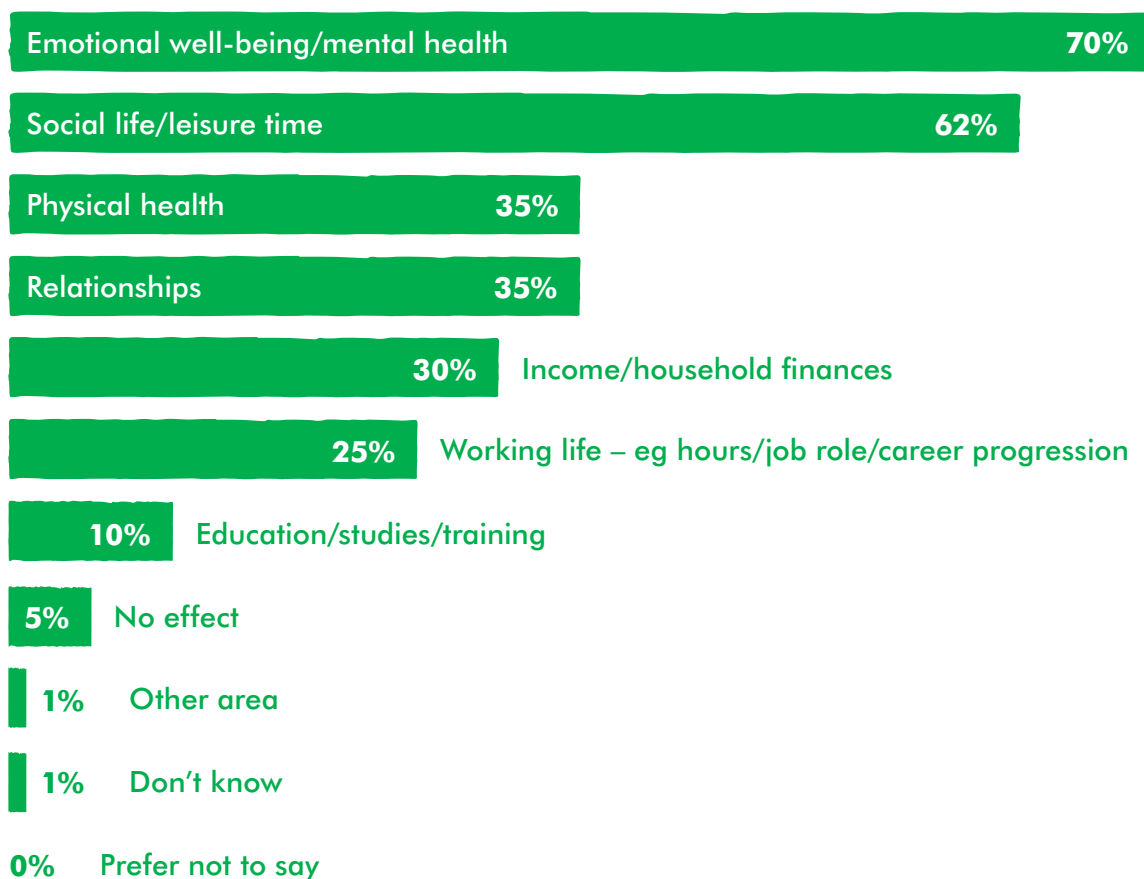
THE IMPACT OF CARING ON CANCER CARERS

The impact of caring on cancer carers

Looking after people with cancer requires commitment and a range of skills from carers. YouGov and Macmillan research shows that carers may struggle to maintain their quality of life due to caring responsibilities.^{17a, 17b} Amongst cancer carers, up to 94% report that having caring responsibilities affects their life in some way. The effects can be felt in a number of different areas, including:^{17b}



Impacts of providing support on cancer carers, UK – 2016^{17b}



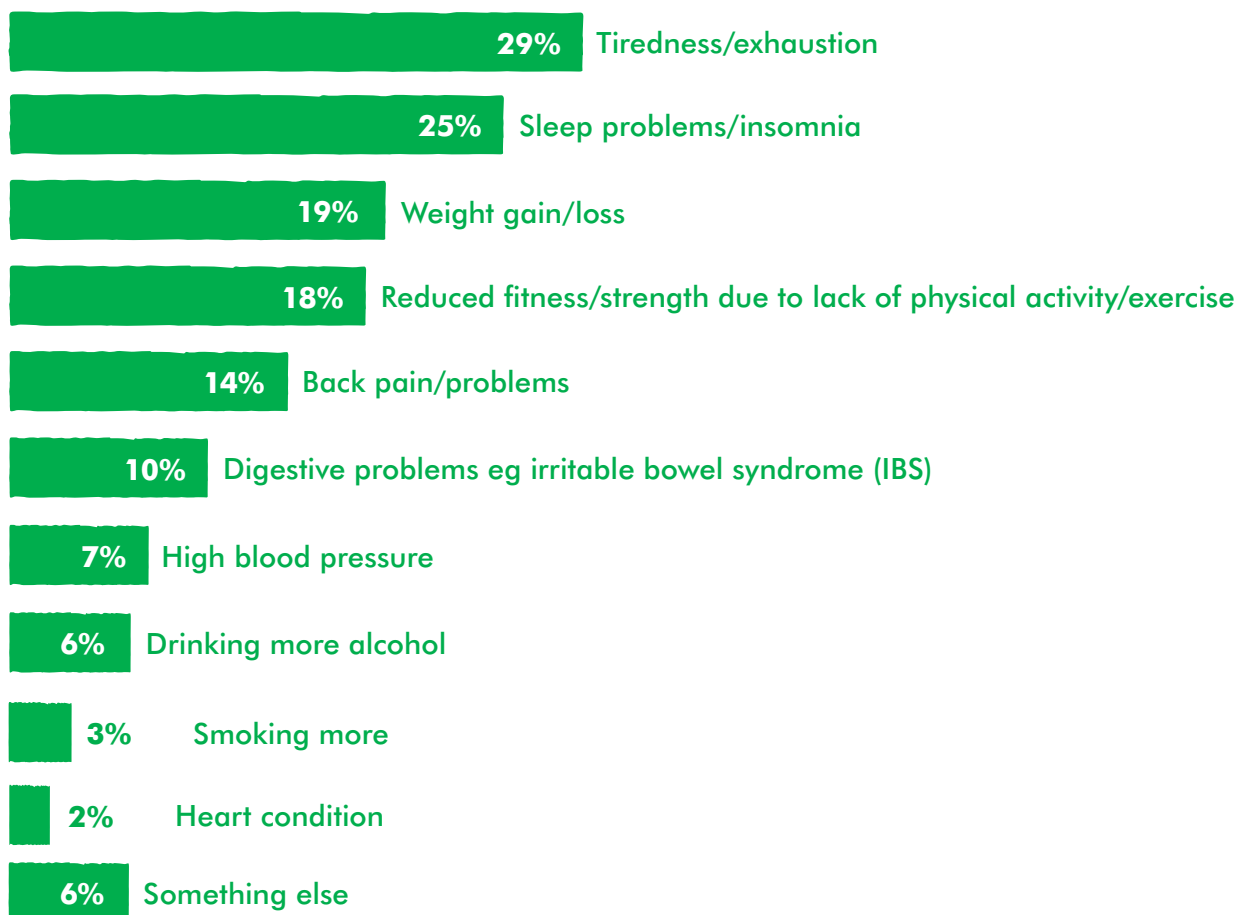
Note: figures add to more than 100% because the respondents could select more than one option.

All cancer carers – online survey and (n=892)

'Feeling overwhelmed with responsibility of being a carer, wife, mother and now being the breadwinner. Working part time in a demanding, pressured and stressful job on top of the stress which the cancer diagnosis has given rise to.'

Female carer, 55–64, caring for husband

Impacts of caring on physical health, UK – 2016^{17b}



Note: figures add to more than 100% because respondents could select more than one option.

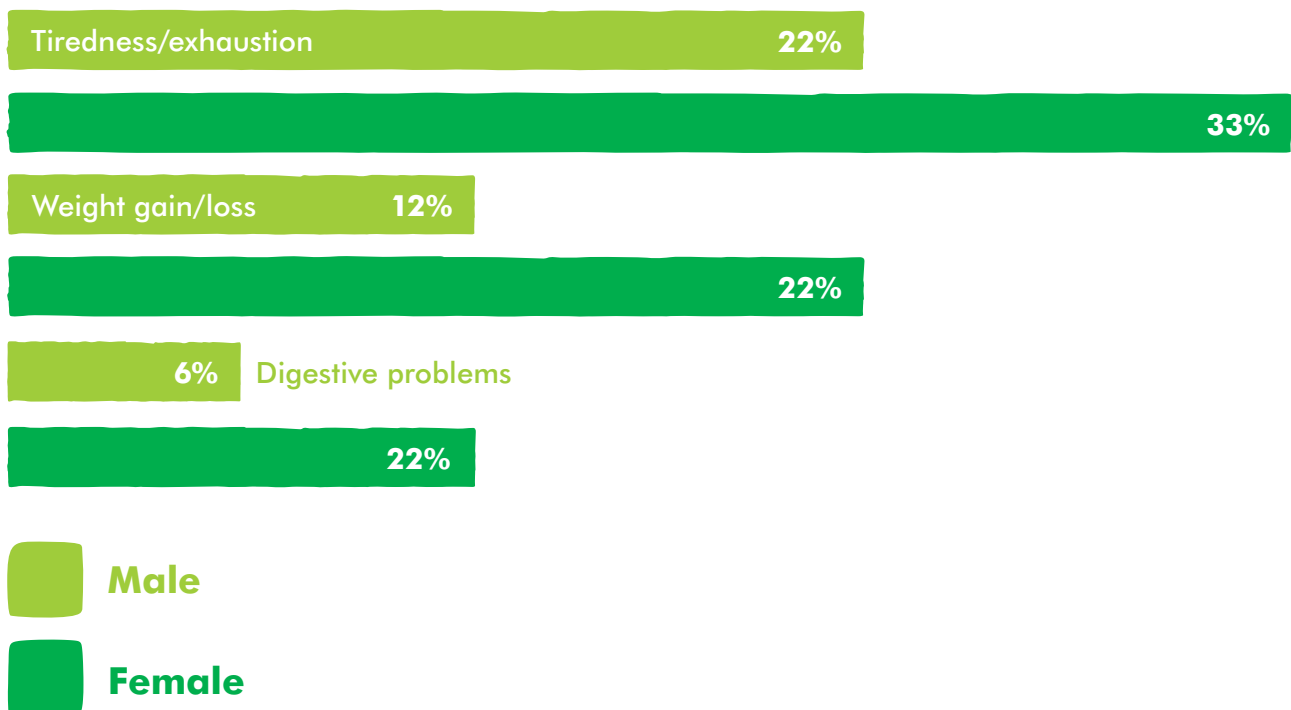
All cancer carers (n=177)

Up to 35% of cancer carers report that their physical health has been affected because of their caring responsibilities. A third of carers (35%) report that they experienced a physical injury due to caring.²⁴ The personal energy of carers appears affected by their caring responsibilities, with tiredness/exhaustion and sleep problems the two most common physical impacts.^{17b}

Providing care for long periods of time may increase the physical impact of caring:

- Cancer carers providing care for more than 35 hours a week are more likely to experience a physical impact. These impacts include tiredness (up to 50% versus up to 24% of those caring for under 35 hours), sleep problems (up to 45% versus up to 20%) and weight gain/loss (up to 35% versus up to 14%).^{17b}
- Cancer carers who have been providing care for over a year are more likely to experience physical problems than those caring for under a year.^{17b}
- Specifically, cancer carers who have been caring for over a year report tiredness/exhaustion (up to 36%), sleep problems (up to 30%) and weight gain/loss (up to 23%).^{17b}
- Carers UK research shows that more than half (51%) of all carers (not cancer specific) report that they have let a health problem go untreated.²⁸

Top three physical impacts of caring on cancer carers by gender, UK – 2016^{17b}



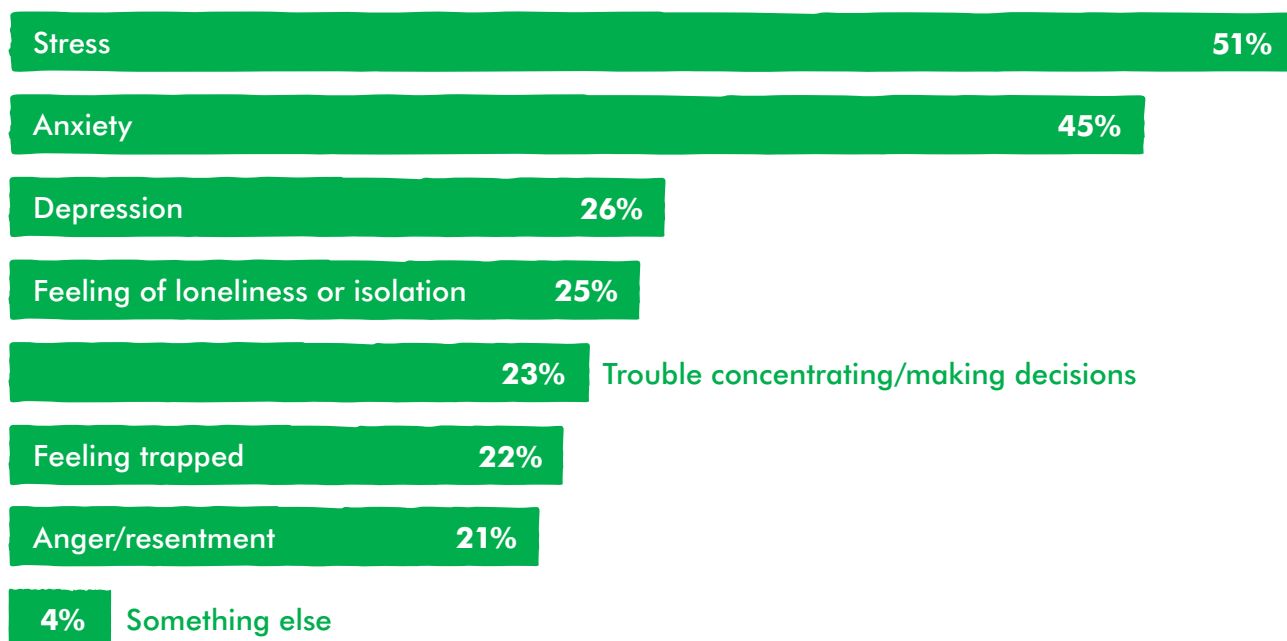
All cancer carers – online survey (n=892)

Women are more likely than men to experience negative physical impacts of providing cancer care.^{17b}

**'My own disabilities
have deteriorated.'**

Male carer, 55–64,
caring for wife

Impacts on emotional health of cancer carers, UK – 2016^{17b}



Note: figures add to more than 100% because respondents could select more than one option.

All cancer carers – online survey (n=892)

70% of cancer carers experience some form of emotional impact from caring.^{17b}

- The most common unmet need (up to 22% of cancer carers) is for more emotional support/ someone to talk to.^{17b}
- In addition to managing their own psychosocial wellbeing, cancer carers also need to manage the emotional health of the person they are caring for. A total of 74% of cancer carers state that the type of support they provide is talking and listening to those they care for.^{17a}

Caring for someone with cancer can have a wide range of negative impacts upon a carer's emotional and psychological health.

- Overall, three-fifths (up to 61%) of cancer carers had experienced either stress, anxiety or depression.^{17b}

The length of time spent caring can influence carers' experiences:

- For example, cancer carers who care for over 35 hours a week are more likely than those caring for under 35 hours to experience many emotional impacts. This includes depression (up to 34% versus up to 24% of those caring under 35 hours) and loneliness/isolation (up to 39% versus up to 21%).^{17b}
- Cancer carers who have been caring for more than a year are more likely to experience many emotional impacts than those caring for under a year. In particular, depression (33% versus 18% of those caring for under a year) and loneliness/isolation (27% versus 16%) and feeling trapped (27% versus 16%).^{17b}

Amount of travel may affect caring experience:

- Cancer carers who live more than an hour's travel from the person they care for are more likely to report feeling anxious than those living under an hour's travel away (up to 56% versus up to 39%).^{17b} Those living farther away are more likely to report feeling lonely (up to 27% versus up to 17%) and having trouble concentrating/making decisions (up to 34% versus up to 19%).^{17b}

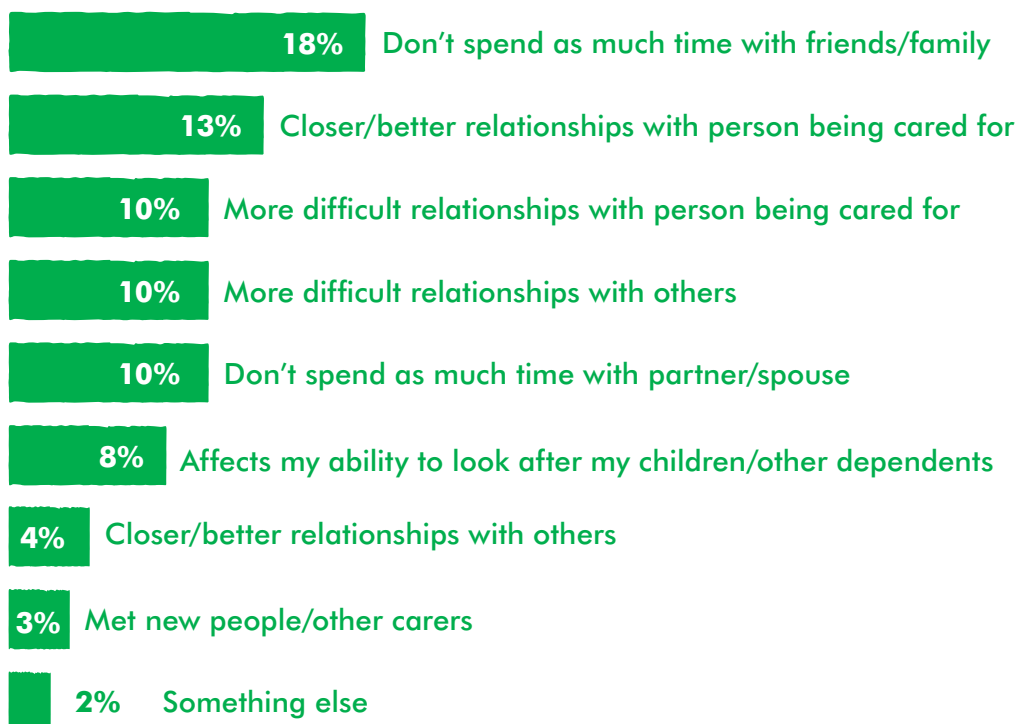
The emotional impacts of caring can vary by gender:

- Women are more likely than men to experience various emotional impacts, including stress (56% versus 40% of men), anxiety (50% versus 33%) and feeling trapped (25% versus 17%).^{17b}

Cancer carers experiencing negative emotional impacts seek support from various sources.

- The most common source of support for cancer carers (22% of those experiencing impacts) is from family and friends, followed by support from their GP (19%).^{17b}
- Fewer than 1 in 10 cancer carers seek counselling or other talking therapies (9% of those experiencing emotional impacts and 6% of all carers).^{17b} There is evidence that counselling has a positive impact on cancer carers by improving their emotional and mental wellbeing and their sleep.¹⁹
- Nearly half (44%) of all caregivers (not cancer specific) experience anxiety and/or depressive symptoms when the person they care for is dying.^{20, 21}
- Research suggests that some carers (not cancer specific) believe formal care, such as specialist palliative care, can ease the social, emotional and relational burdens of dying.²²

The impact of caring on relationships, UK – 2016^{17b}



All cancer carers – online survey (n=892)

Up to 35% of all cancer carers report that caring impacts on their personal relationships.^{17b}

- As the chart above shows, time is one of the key pressures experienced by cancer carers, which includes spending less time with friends/family and their partner/spouse.
- Women are more likely than men to report spending less time with their family and friends as a result of caring for someone with cancer (22% versus 12%) as well as with their spouse/partner (12% versus 5% for men).^{17b}
- 24% of those providing cancer care for three or more years reported spending less time with their family/friends compared with 14% of those caring for up to a year.^{17b}

For a small number of cancer carers (10%), caring can make their relationship with the person they care for more difficult.^{17b}

- Those caring for someone with cancer for over 35 hours a week are more likely to report more difficult relationships with the person they care for than those caring under 35 hours (18% versus 8%).^{17b}
- Those caring for a spouse or partner were particularly likely to say this had resulted in a more difficult relationship with the person being cared for (20% versus 8% of those caring for a parent and 2% of those caring for a friend).^{17b}

However, there is also a range of positive consequences of caring reported by carers.

- 13% of cancer carers report they have developed a closer relationship with the person they cared for.^{17b}
- As discussed (p.21), personal motivations appear to be key drivers for people providing care, with over two-thirds caring because they themselves 'want to do it'.
- International research by the National Opinion Research Centre in the United States has reported that the majority (83%) of all carers (not just cancer carers) view caring as a positive experience.²³ Fewer than 1 in 10 (9%) say that caring weakened their relationship with the recipient of care.²³

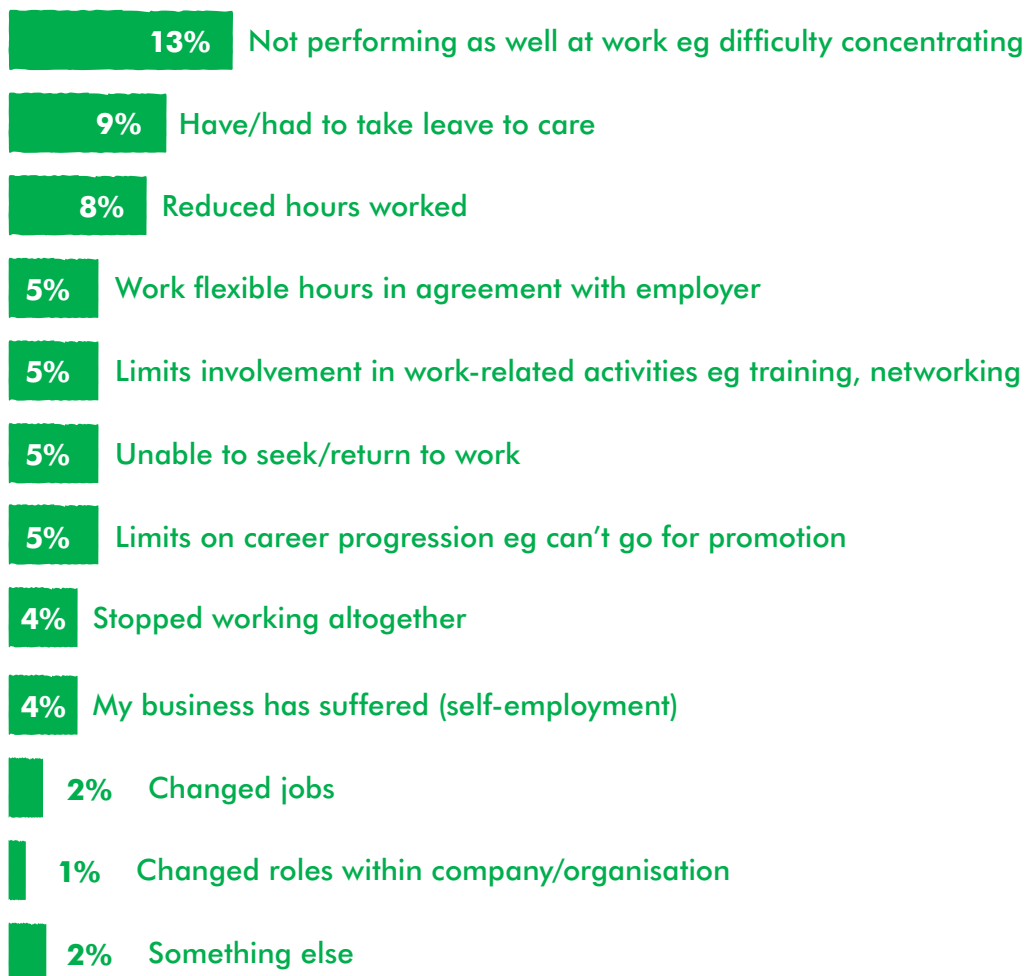
'Friends become bored with the unending inability to meet, and new people are weird when they find out, so new friendships don't happen as easily.'

Female carer,
45–54,
caring for husband

'It can be difficult as all of my family are focused on my spouse. This is quite right as he is the one who is ill, but I feel forgotten at times.'

Female, 63, caring
for her spouse

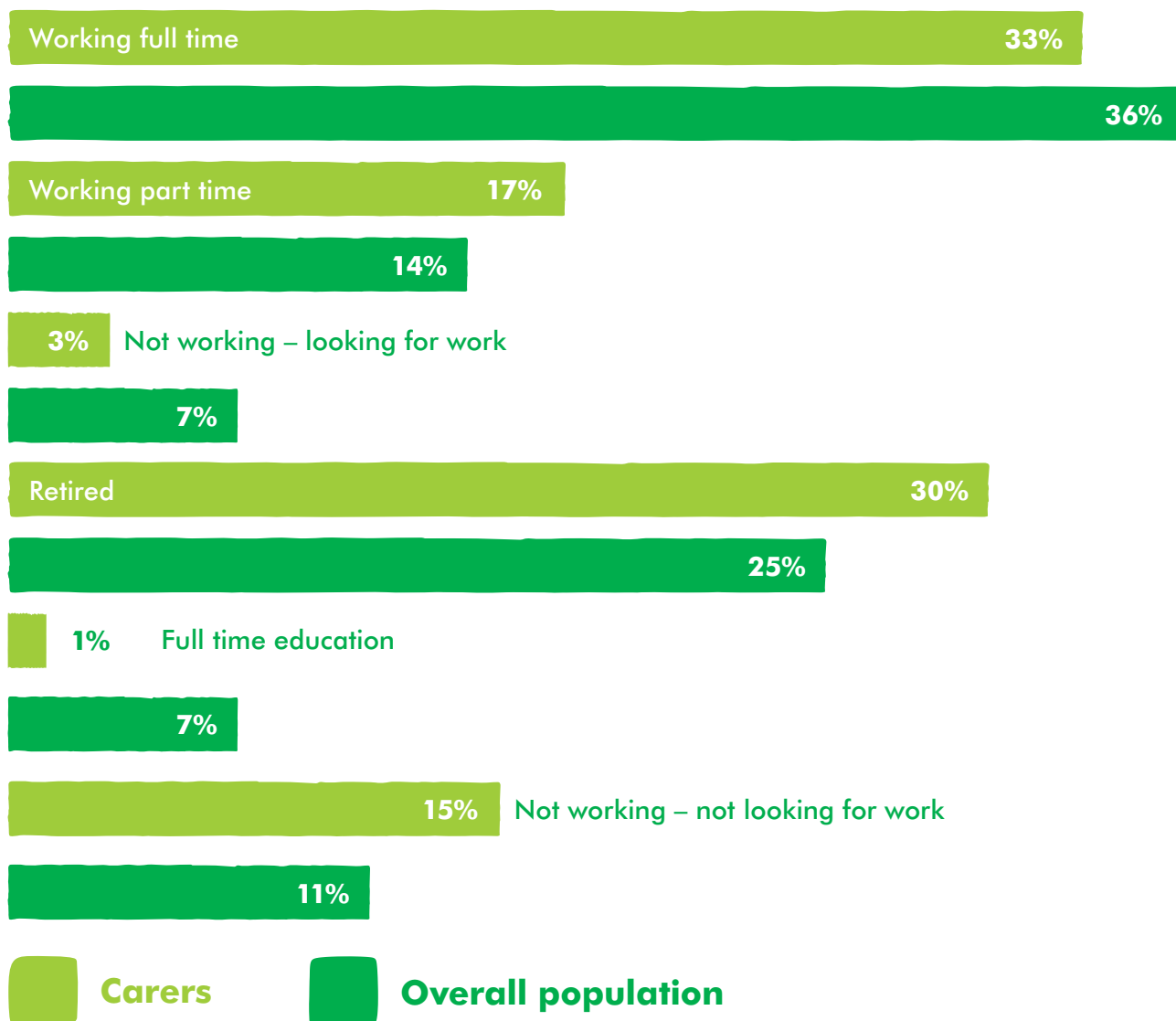
Impacts of caring on working life, UK – 2016^{17b}



All cancer carers – online survey (n=892)

The most common impact of providing care on a cancer carer's work life is a negative effect on their performance.^{17b} This may be linked to tiredness/exhaustion emerging as the most common physical impact on carers, as seen in the section Impacts of caring on physical health on page 28.

Profile of cancer carers' working status compared with the UK population, 2016^{17a}



All UK adults (n=6,487)
 All cancer carers (n=177)

Carers are more likely than the non-caring population to be retired, working part time or not working and not looking for work. This correlates with other evidence indicating that carers can often be older (see page 10).^{17b}

Caring can impact on carers' working hours and use of annual leave, as well as employment prospects.

- Carers UK research shows that employed carers (not just cancer carers) who spend more than 10 hours caring a week are at significant risk of leaving their job. More than half of all carers leave work or reduce their working hours if their employer does not have policies to address carers' needs.²⁴
- Carers (not just cancer carers) who stop working are often concerned about finding a job after finishing caring because they have been unemployed for a significant amount of time.²⁵
- It is thought that more carers will have to work while they are caring due to future increases in retirement age.²⁶

However, support that helps carers keep working can bring benefits to carers themselves.

- A study into end of life care support found that hospice at home provision may allow carers – not just cancer carers – in paid employment to concentrate on their work. This is due to the knowledge that their loved one is being cared for while also allowing them to maintain their income.²⁷

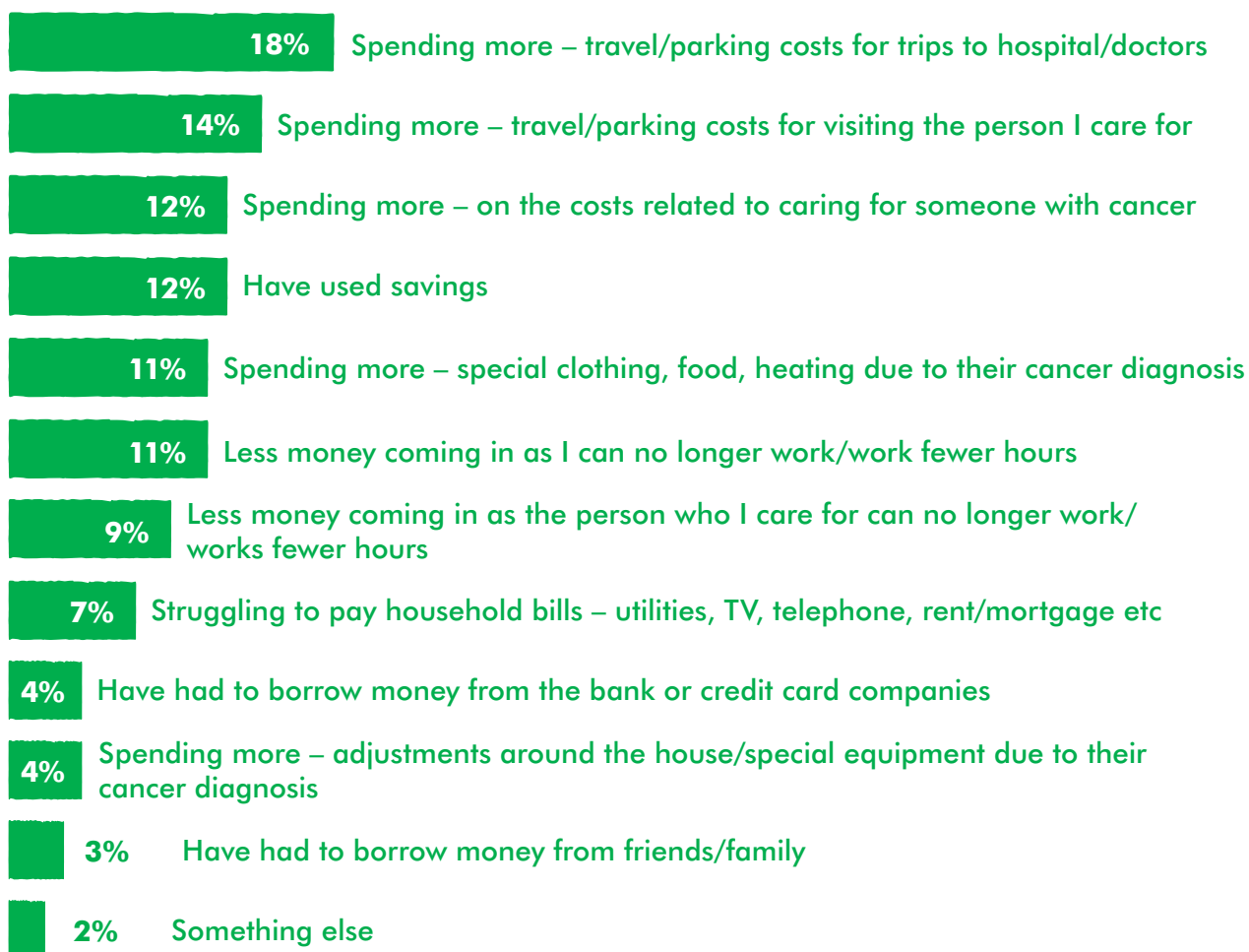
Amount of care provided

Non-working cancer carers (18%) provide an average of 21 hours of care a week compared with 14 hours for working cancer carers.^{17b} A total of 20% of all cancer carers provide 36 hours of care or more a week, which exceeds a normal working week.^{17b}

‘People knowing my husband has incurable cancer affects how they interact with me at work – not for the better.’

Female carer, 45–54,
caring for husband

Impacts on finances of cancer carers, UK – 2016^{17b}



Note: figures add to more than 100% because respondents could select more than one option.

All cancer carers – online survey (n=892)

Up to 30% of cancer carers report an impact on their income or household finances as a result of caring.^{17b} Similarly, Carers UK has found that nearly a half of all carers (not just cancer carers) report that they face financial problems.²⁴

Caring can cause increased costs and expenditure.

- The most common impacts relate to expenditure on travel – when visiting the hospital or GP (18%) or visiting the person being cared for (14%).^{17b}
- Additionally, according to Carers UK, many carers (overall, not cancer specific) experience increased utility, transport and food costs because they spend more on resources for the person who they are caring for.²⁸
- Our research found that a key financial impact of caring was that carers see their friends and family less (17%) followed by taking fewer holidays (16%).^{17b} This was particularly common among those aged 45 to 64 (23% compared to 7% aged 65+, and 12% of those aged 16 to 44).^{17b} Changes made to accommodate financial impacts associated with caring may therefore exacerbate other impacts on, for example, social life, relationships and emotional wellbeing.

The financial impact of caring affects various groups of cancer carers.

- Carers in the lower social grades (C2DE)* were more likely to report spending more on other caring-related costs aside from travel costs (16%) compared to those in higher social grades (9%). They also struggle to pay household bills (10% versus 4%).^{17b}
- Cancer carers in social grades C2DE were twice as likely to have gone without buying certain types of food or drink than those in the higher, ABC1 social grade (11% C2DE versus 6% ABC1).^{17b}

- Cancer carers living separately and more than one hour's travel from the person they care for were more likely to be affected by the cost of travel to visit the person with cancer (23% compared with 12% of those living less than an hour away).^{17b}
- Cancer carers caring for more than 35 hours a week were over twice as likely to report most types of financial impact, compared to those caring for under 35 hours (43% versus 21% caring under 35 hours).^{17b}
- Cancer carers of late working age (aged 45 to 64 years) are more likely to be affected financially by caring compared to carers in other age groups, for example by spending more on travel to hospital.^{17b}
- A total of 15% of cancer carers aged 45 to 64 stated that they had used their savings towards caring, compared with 8% of those aged 16 to 44 and 9% of those aged 65 and over.^{17b}

'Because you have no money, you cannot go out anywhere – not even for a short drive and a mooch around a park to clear your mind. So, I'm cooped up indoors in a small terrace with a through lounge diner – so one living room, with my husband 24/7 and our two young sons. I've cancelled the gym membership, so my health is suffering (I go to help with a medical problem), both physical and mental. It's really, really tough.'

Female, 50, caring for her spouse.

*The National Readership Survey social grades is a system of demographic classification used in the United Kingdom. C2DE is broadly taken to refer to people with a lower income, within the NRS (National Readership Survey), a system of demographic classification widely used in the UK.

Carer's Allowance

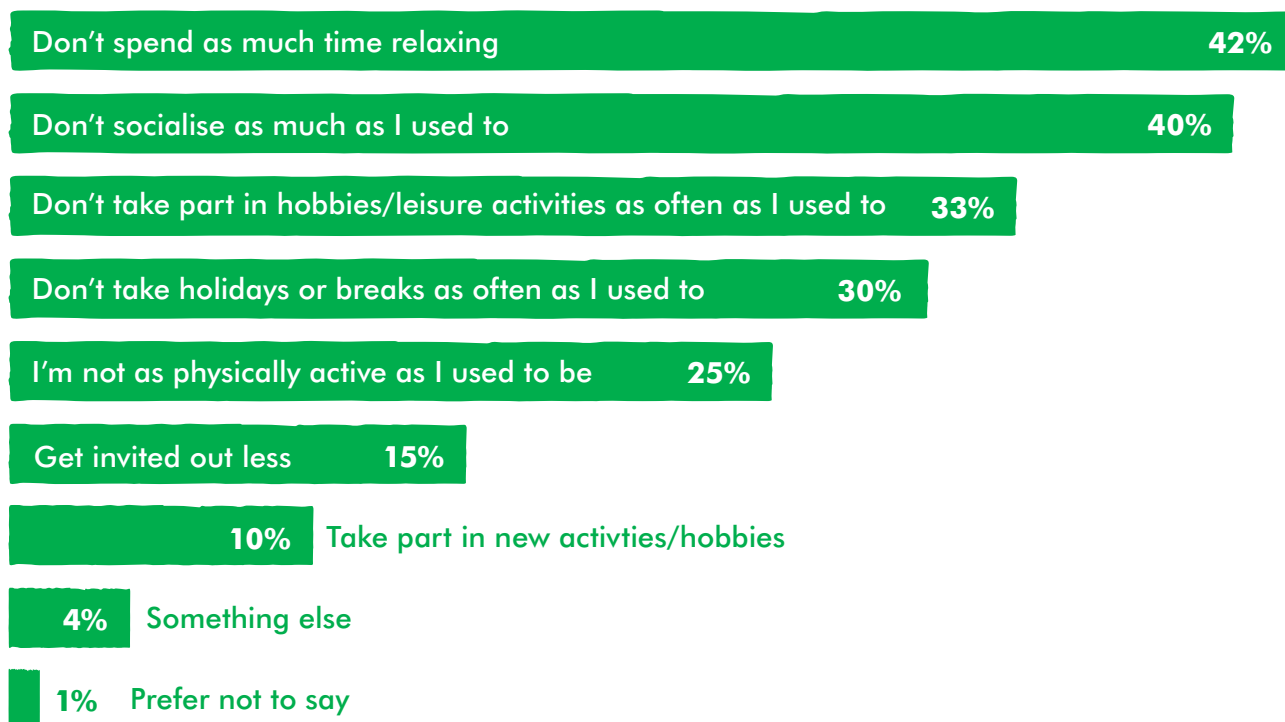
Carer's Allowance is a financial benefit for those who look after someone who is ill or disabled. Carer's Allowance provides a weekly payment if a carer looks after someone at least 35 hours a week and meets certain other criteria. People do not need to be related or live together to receive this support.³⁰

- Estimates from Carers UK show that around 360,000 carers (not cancer specific) may be missing out on a total of £1.1 billion in Carer's Allowance.²⁸
- The majority (67%) of cancer carers have heard of Carer's Allowance, but only 7% stated that they receive this benefit.^{17b}
- A quarter (24%) stated that they were not entitled to Carer's Allowance, and a third (33%) that they were aware of the benefit but had not claimed.^{17b}

Awareness of Carer's Allowance was higher among:^{17b}

- women (70% compared to 61% of men)
- those who self-identify as a carer (75% compared to 63% of those don't self-identify as a carer)
- those who are being identified as a carer by others (74% compared to 62% of those who are not being identified as a carer by others)
- those with experience of support from social workers (83% compared to 63% of those who don't have experience of support from social workers).

Impacts on social life and leisure time, UK – 2016^{17b}



Note: figures add to more than 100% because respondents could select more than one option.

All cancer carers – online survey (n=892)

Up to 62% of cancer carers state that caring affects their social life or leisure time.^{17b}

'I find it difficult to commit to something in the future because of not knowing what her needs may be that day.'

Female carer, 45–54,
caring for her mother

As may be expected, more time spent caring is associated with more impacts on a carer's social life.

Time

- Those caring for 10 hours or more were twice as likely to report taking fewer holidays or breaks (42% compared with 20% of those caring up to nine hours)^{17b} and almost twice as likely to report being less physically active (34% versus 18%).^{17b}
- Almost a quarter (24%) of carers who care for more than 10 hours a week reported being invited out less, compared with just 6% of those providing up to nine hours of care.^{17b}
- These impacts are particularly significant among those providing more than 35 hours of care. Half or more of these carers report spending less time socialising and relaxing, and taking fewer holidays or breaks.^{17b}

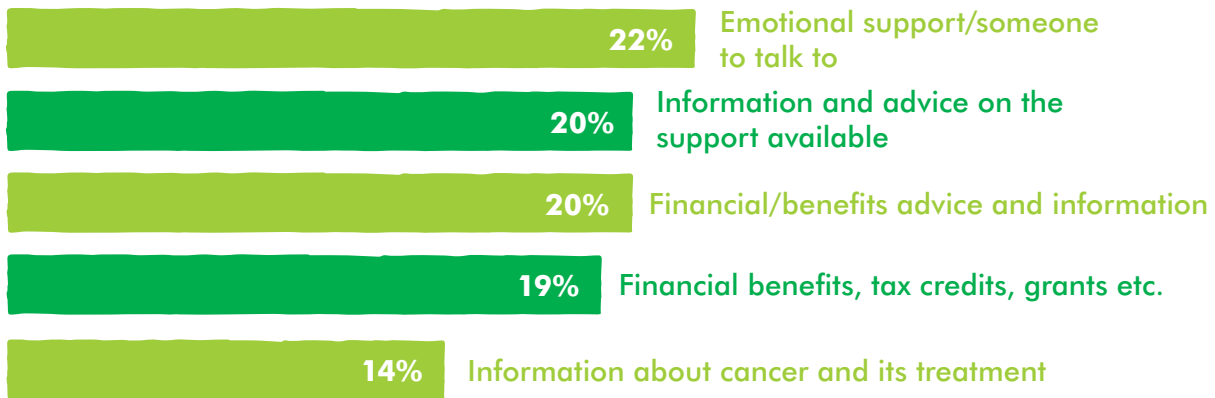
Relationships

- Those living in the same household as the person with cancer generally reported greater impacts on their social life/leisure time than those in different households. Those caring for a spouse/partner reported greater impacts than those caring for other relatives or friends.^{17b}

Unmet support needs

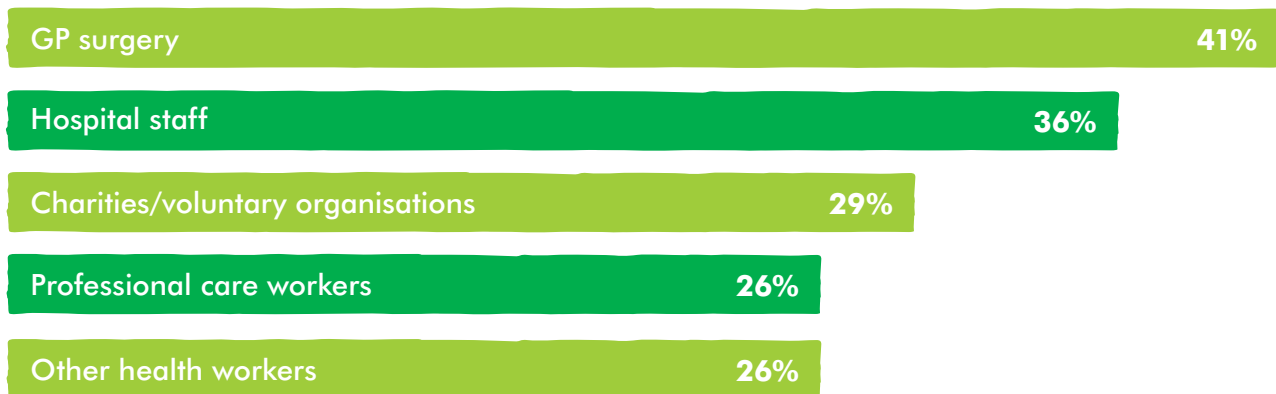
Cancer carers have support needs related to the impact of caring, but 55% don't receive any support to care. Close to two-thirds (65%) of cancer carers felt that some additional support would be helpful to them.^{17b} This includes those who are receiving some form of support but feel that another type or additional level of support would be helpful to them.^{17b}

Top five types of further support that would be helpful^{17b}



All cancer carers – online survey (n=892)

Top 5 preferred sources of support^{17b}



Those cancers carers who would like (further) support – 2016 (n=568)

Possibly linked to the key types of source desired, amongst carers who feel that further support would be useful, the most popular channel for receiving additional support is face to face (48%) followed by via a website (46%), and printed materials (40%).^{17b}

Experience of the health and social care system

While supporting a loved one through their caring journey, cancer carers are most likely to interact with the healthcare system.

- A total of 86% cancer carers interviewed had some experience of support from a healthcare professional.^{17b}
- A total of 39% of interviewed cancer carers have had some experience of support from a social care professional.^{17b}

Overall, cancer carers view the support they've received from different health professionals as good. For example, amongst cancer carers to whom it was applicable, 78% rate the support they receive from hospital doctors as 'very good' or 'quite good', 77% say the same about clinical nurse specialists, and 68% say the same about GP/practice staff.^{17b}

However, support provided by social workers compares less favourably to Clinical Nurse specialists/hospital doctors and GP/practice staff. Amongst those to whom it was applicable, 46% of cancer carers rated support received from social workers 'Not at all good' or 'Not very good', compared to 23% for Clinical Nurse Specialists and 23% for hospital doctors.^{17b} This illustrates that cancer carers typically rate support received from healthcare professionals higher than that from social care professionals.

'It is very strange really – if caring is shared, and you are living far away, you don't fit into any actual group to be supported.'

Female, 49, caring for her mother

While views of different professionals vary, some general patterns can be identified as to which carers have a worse experience of the health and social care system. These groups include^{17a, 17b}:

- female carers
- younger carers
- C2 (skilled manual workers) D (semi-skilled and unskilled manual workers) E (non-working) carers*
- those providing more hours of care each week
- those who have been caring for longer
- those caring for a parent.

'The actual clinical treatment in the NHS is excellent but waiting for treatment and navigating between GPs, consultants and other specialists can be a real obstacle course for older people, slowing access to treatment.'

Male, 47, caring for his mother

'It would be good if her appointments at the hospital were better organised, with each department talking to the others. When we actually see the right people, in the right order, they are excellent.'

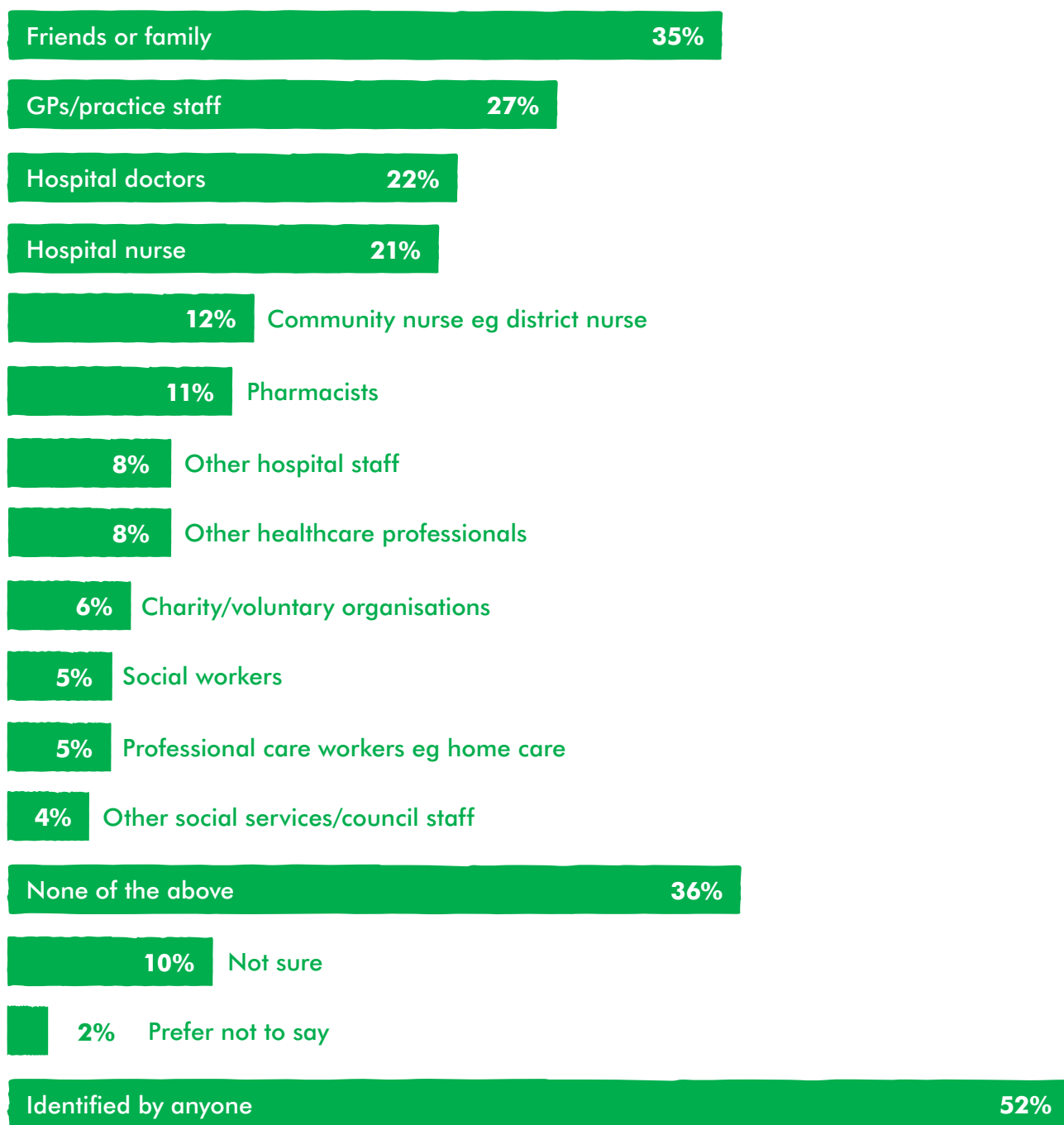
Female, 52, caring for her mother

*The National Readership Survey social grades are a system of demographic classification used in the United Kingdom. C2DE is broadly taken to refer to people with a lower income within the NRS (National Readership Survey), a system of demographic classification widely used in the UK.

Being identified as a carer

A total of 39% of cancer carers interviewed describe themselves as 'carers'. Around half (52%) of cancer carers had been identified as a carer by a friend/family member, professional or organisation. Being identified as a carer by others is one of the key factors in take up of Carer's Allowance.^{17b}

People/organisations that identify cancer carers as carers, UK – 2016^{17b}



All cancer carers – online survey (n=892)

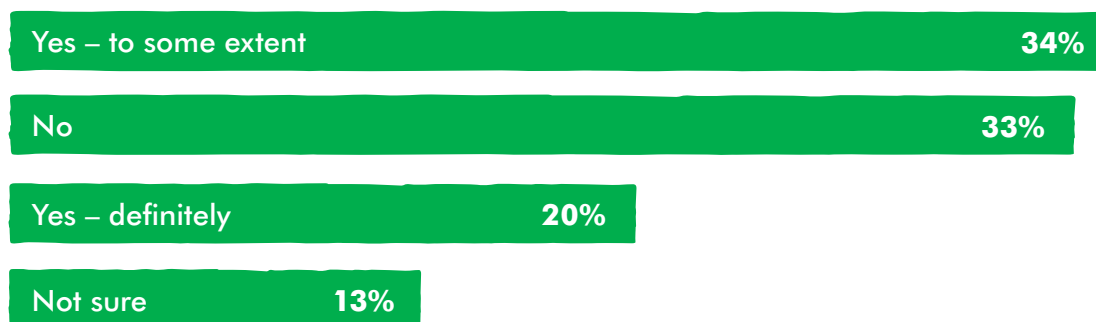
- Only 5% of cancer carers are identified by social care staff.^{17b} This may be due to cancer carers having less contact with the social care system.^{17b}
- A total of 36% of cancer carers said that they were not identified as a carer by any group/organisation. Not being identified as a carer is significantly higher among:
 - those who provide fewer hours of care a week
 - those who have been caring for under 35 hours a week (41%, compared to 18% of those caring for 36 hours or more)
 - female carers (40% compared to 29% of male carers)
 - younger carers (39% of carers under 65, compared to 29% of carers over 65).^{17b}

Positive consequences of being identified as a carer

- Of the options presented, the most commonly reported positive consequence of being identified as a carer by any group/organisation was to be directed to Macmillan Cancer Support (22% of cancer carers). This was followed by 14% of cancer carers being given further information and advice.^{17b}
- However, just under half of cancer carers (49%) who said that they were identified as a carer state that this doesn't lead to any outcome in terms of further advice or support (of the options of further support presented in the research).^{17b} This shows that more needs to be done to signpost identified carers to relevant support.

Health and social care professionals can use our guidance on identifying cancer carers and signposting them to support – visit [macmillan.org.uk/supportingcarers](https://www.macmillan.org.uk/supportingcarers) for more details.

Indication of how valued and included cancer carers feel by health and social care professionals^{17b}



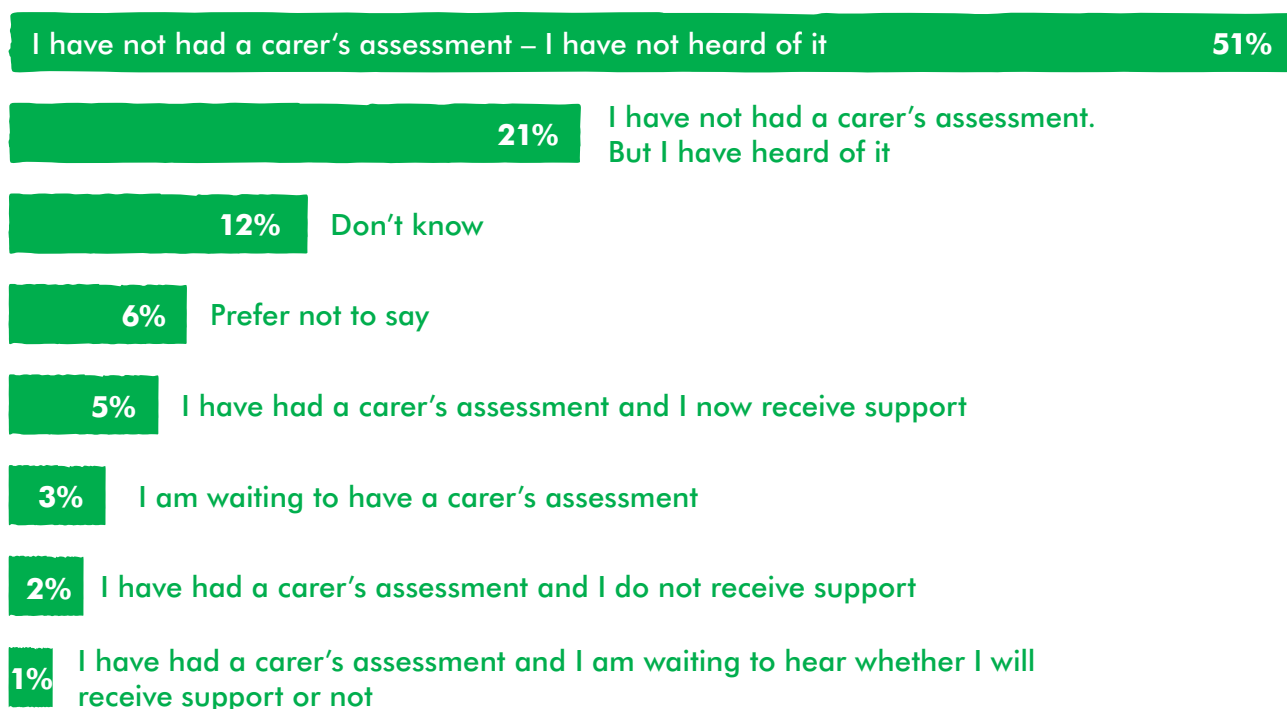
All cancer carers – online survey (n=892)

Over half (54%) of carers have felt valued and included by health and social care professionals.^{17b} In addition, carers feel that they have been involved in planning the care of the person living with cancer, with three-fifths (59%) of those to whom it was applicable feeling ‘very’ or ‘quite’ involved. Carers have not felt as involved with planning their loved one’s discharge from hospital, with just half (51%) of those to whom it was applicable stating they feel involved.^{17b}

Carer’s assessment

Carers’ assessments are the gateway to statutory support from the social care system, such as respite breaks. The assessment considers the impact of caring on the carer’s wellbeing and other aspects of their life such as work.

Only 31% of all carers have heard about the carer’s assessment^{17b}



All cancer carers – online survey (n=892)

LIFESTYLE AND PERCEPTIONS

What is the demographic breakdown of carers?

The following MOSAIC* profile breakdowns are based on responses from 176 cancer carers.^{17a} The five most common MOSAIC* groups among cancer carers are Small Town Diversity, New Homemakers, Active Retirement, Ex-Council Community and Claimant Cultures.

D – Small Town Diversity

Small Town Diversity mostly live in medium sized and smaller towns in neighbourhoods of older housing where there is relatively little turnover from year to year. These are people who tend to have strong roots in their local community, whose friends and family live nearby and who are likely to live the rest of their lives in the same community. For many, friends and family networks are a more important source of well being than the style of clothes that they wear or the make of car that they drive.

A key characteristic of these people is that they live in communities small enough for houses of different ages and styles to exist in close proximity and where council estates, if they do exist, are small in scale and their residents well integrated with the rest of the population. In general, people who prefer to live in neighbourhoods of similar people, tend not to live in Small Town Diversity.

For more detail and definitions, please see: <http://guides.business-strategies.co.uk/mosaicuk2009/data/mosaicuk/pdfs/portraits/group4.pdf>

E – Active Retirement

Active Retirement are mostly people aged over 65 whose children have grown up and who, on retirement, have decided to uproot themselves from their family home in favour of life in a retirement community among people of broadly similar ages and incomes. Most of these people, their mortgages paid off, have sold a detached or semi-detached property, from which they might have commuted to a well paid job, and used the proceeds to purchase a smaller property, perhaps in a place they got to know during holidays with the family.

In most instances people have made a deliberate attempt to distance themselves from the noise, diversity and disorder of large cities and to retreat into more homogenous communities. For many the move will have been an opportunity to downsize to a more manageable property and to reduce outgoings on council tax, utilities and other household costs. For some, the move to a rural or coastal location is an opportunity to make a new start, establish new friendships, engage in new leisure activities and explore new places.

For more detail and definitions, please see: <http://guides.business-strategies.co.uk/mosaicuk2009/data/mosaicuk/pdfs/portraits/group5.pdf>

H – New Homemakers

New Homemakers are people who, for one reason or another, live in homes which are likely to have been built only in the last five years. These homes can take a variety of forms, small but quite well appointed flats in

new brownfield inner city locations suitable for young, single people, many of whom rent from private landlords; very small starter homes on developments which are designed to be affordable by people on average incomes; mixes of flats and houses in larger new developments where local councils have required developers to include some affordable housing mixed in with more luxuriously appointed houses and flats.

Some residents are young single professionals who prefer living in a quiet, well equipped, purpose built flat to sharing a bedsit in a divided house or renting a studio apartment carved from a Victorian mansion; young people on middle incomes who rent a flat whilst sub-letting the second bedroom to a friend; people who have recently separated who are looking for well appointed accommodation which is convenient to maintain; older people downsizing into modern accommodation and some young couples just starting a family. Most residents have a ready income from a secure position working for a large public company or for central or local government.

For more detail and definitions, please see: <http://guides.business-strategies.co.uk/mosaicuk2009/data/mosaicuk/pdfs/portraits/group8.pdf>

I - Ex-Council Community

Ex-Council Community have relatively low levels of formal education but, through persistence and hard work, have created a comfortable lifestyle for themselves and their families. Many live on council estates which, because they were comparatively well built and pleasantly laid out, have had a large proportion of their properties purchased under right-to-buy legislation.

In general, these are people whose parents might have described themselves as belonging to the working class but who, as consumers,

aspire to a middle class lifestyle, at least in terms of the products and services they buy. This aspiration is a practical one as this group tends to live in the more economically successful regions of the country where wage rates are high and workers are least vulnerable to being laid off. In particular these are people who value concepts such as self reliance, responsibility and independency of the state.

For more detail and definitions, please see: <https://audiencefinder.org/wp-content/uploads/2014/09/Group-I-Ex-Council-Community.pdf>

J – Claimant Cultures

Claimant Cultures are some of the most disadvantaged people in the UK including significant numbers who have been brought up in families who for many generations have been dependent on the state for welfare benefits. Local councils have responded to their housing needs by providing them with accommodation in estates which people only want to live in as a last resort.

This group therefore contains people who are surrounded by others who find it a struggle to make ends meet and whose children, when they go to school, are highly unlikely to meet the children of parents who have been economically successful.

High levels of unemployment on these estates are exacerbated by low levels of car ownership and by residents' reliance on infrequent and expensive public transport services to reach places where they shop or might find work. There is a larger proportion of the cancer carer population who are from Claimant Cultures group compared to the overall population.

For more detail and definitions, please see: <https://audiencefinder.org/wp-content/uploads/2014/09/Group-J-Claimant-Cultures.pdf>

*Mosaic is a consumer segmentation model designed by Experian which is a global information services group. It is a cross-channel consumer classification system that segments the population into groups which help provide an understanding of an individual's likely customer behaviour. At postcode and household level, Mosaic UK classifies each postcode in to one of 15 groups and 67 types. Profiles in this report are based on MOSAIC UK 2010 Data Release.

What cancer carers are saying about their caring experience

'An emotionally challenging time but also very rewarding and we are in fact enjoying what time we have left together very, very much.'

Female, 58, caring for her partner

'It is an honour to help. I hope I brighten the days.'

Female, 75, caring for a friend

'I don't feel it as a burden, but something I can do to help someone I love.'

Female, 65, caring for sister

What does this mean?

Interestingly, support and help are consistent themes in both sources. While this may be due to support and provision of help being fundamental to caring, it may also reflect the needs of carers themselves.

For those in the online community, indications of emotions and potential impacts appear frequently, ie 'feel', 'time' and 'work', whereas the media is more concerned with the people around those who are ill, ie, 'family', 'children', 'friend' etc. This may indicate that the media focuses on carers' roles, while the online community expresses the experience of being a carer.

The online community refers to the medical aspects of treatment ie 'treatment' and 'site'. The media make greater mention of 'Macmillan', 'care' and 'patient'.

In summary the media seem to focus more on practical aspects of caring, while the online community has more focus on the emotional side.

Macmillan Online Community can be accessed <https://community.macmillan.org.uk>

SPECIALIST THEME

– OLDER CARERS

Who are older carers?

This section primarily describes the needs and experiences of older carers overall, as there is limited data on older cancer carers specifically.

Older carers are defined here as those over the age of 65 who provide regular and ongoing care and emotional support to a seriously ill or disabled relative or friend.³¹

How many older carers are there?

Around 1.2 million people in England and Wales over the age of 65 are carers (not just cancer carers), accounting for 23% of the overall carer population.³² Similarly, 23% (about 325,000) of cancer carers are over 65 years old.^{17a} The number of carers over the age of 65 is rising more rapidly than carers in younger age groups. While the total number of carers has risen by 11% since 2001, the number of carers aged 65 and over has risen by 35%.^{17b}

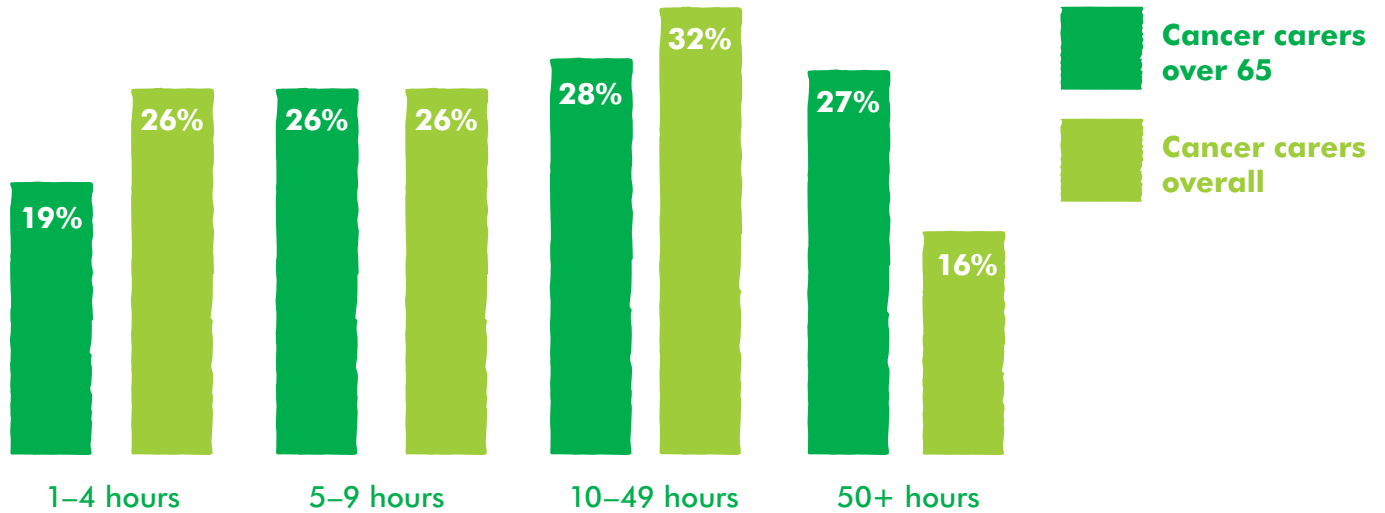
Older cancer carers are more likely than younger cancer carers to describe themselves as a 'carer'.^{17b}

Gender breakdown of older cancer carers, UK – 2016^{17b}



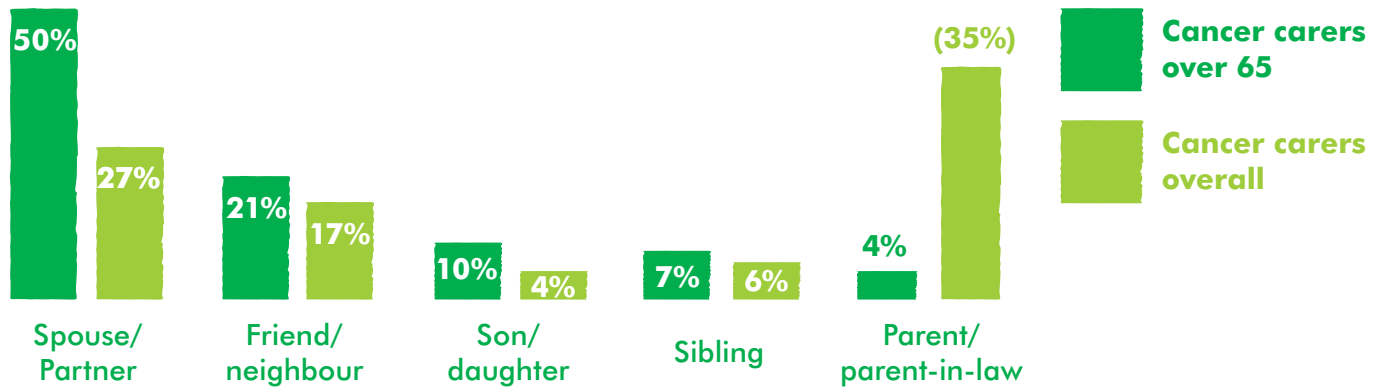
As shown in the gender breakdown, the majority of older cancer carers are women.

Comparison of time spent caring between older cancer carers and cancer carers overall, UK – 2016^{17b}



All cancer carers – online survey (n=892)

Comparison of the relationship to those being cared for between older cancer carers and cancer carers overall, UK – 2016^{17b}



All cancer carers – online survey (n=892)

Impact of caring

A total of 27% of older cancer carers report caring for 50 or more hours a week, compared to 16% of carers of people with other conditions.^{17b} 'Heavy end' cancer carers (those caring for more than 50 hours a week) of all ages are more likely to be negatively affected by caring than those providing fewer than 50 hours. They particularly feel these effects regarding their physical health. As older cancer carers are more likely to provide high levels of care, this suggests the physical impacts of looking after someone may be more prevalent among this group.^{17b}

Caring may have greater impacts on older carers because they themselves may be experiencing deteriorating health. As many as 65% of carers overall aged 60 to 94 (not just cancer carers) have long term-health problems or a disability. Research suggests that this can reduce their ability to care effectively for the patient and themselves.³³

Among older carers of people with cancer and other conditions, one-third of carers aged 60 or over say they've cancelled treatment or an operation for themselves because of their caring responsibilities.³⁴

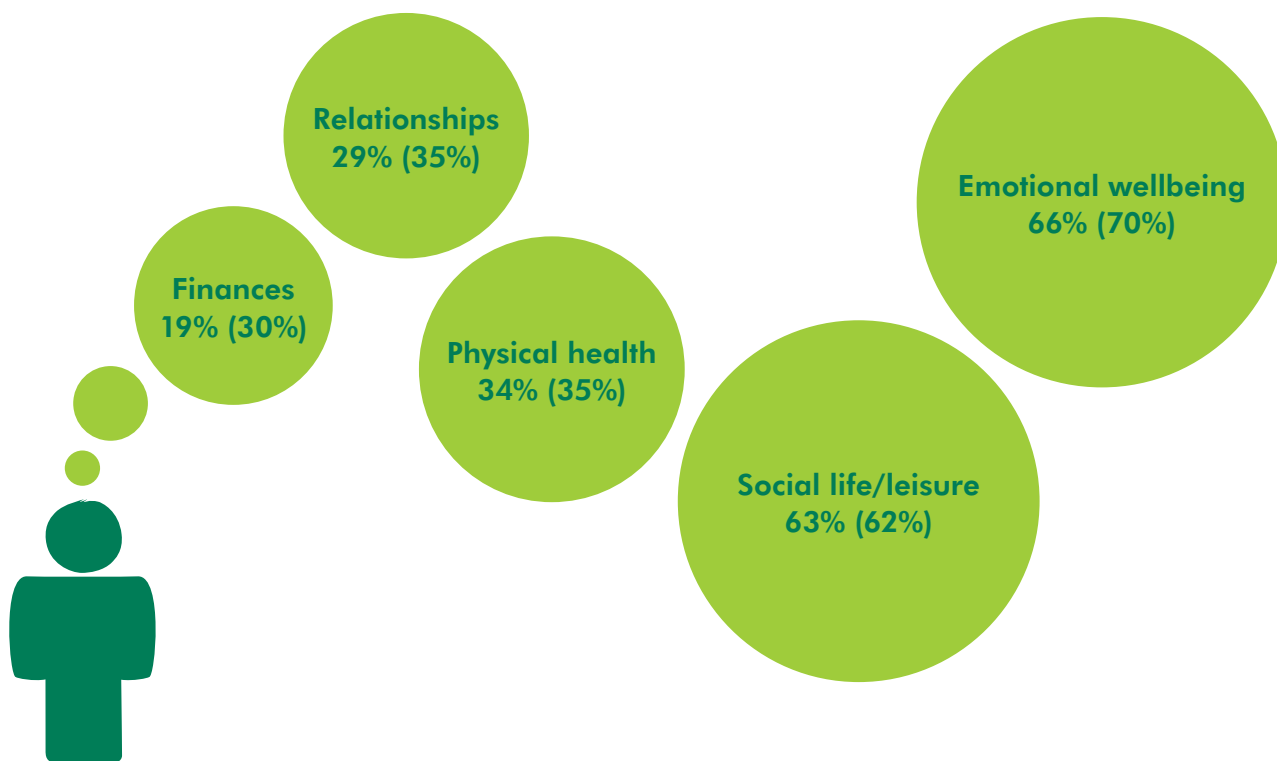
However, despite the time spent caring and the potential impacts, cancer carers over 65 do not report worse impacts themselves. Cancer carers over 65 are less likely to say they would rather not care if they could trust someone else to do so. By comparison, younger people provide less care on average but report worse impacts. One potential explanation is the presence of other competing demands in younger carers' lives, particularly work and dependent children, which may mean even a lower level of caring is more impactful.^{17b}

This may also reflect older carers' lower recognition of the impact of caring on themselves, particularly as the person they're caring for is more likely to be a spouse or partner (50%).^{17b}

In addition, cancer carers over 65 may have more experience of health issues and the healthcare system, which may help them in their cancer carer role.^{17b}

Key impacts on cancer carers

Figures in brackets represent percentage of all carers^{17b}



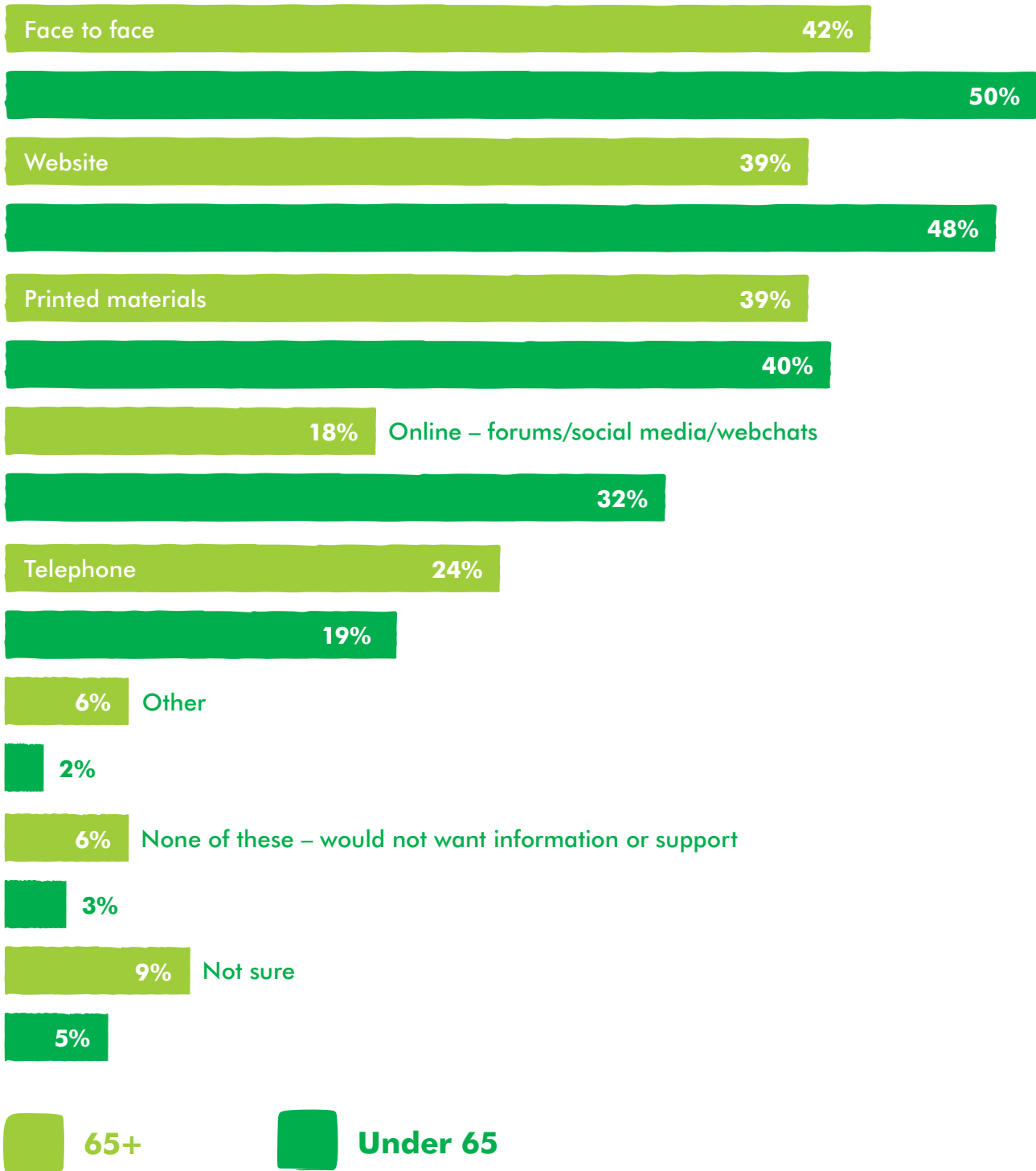
Unsurprisingly, as older cancer carers are in the age group that may experience deteriorating health, 66% state that being a carer has an adverse effect on their mental health.^{17b} Research by the Carers Trust shows that carers in their 70s are at particular risk of emotional distress.³⁴

Support for older cancer carers

More than a quarter (27%) of older carers overall (not just cancer carers) report that they've found it fairly or very difficult to access information and advice about support services or benefits.³¹

Preferred ways for older cancer carers to receive information and support, UK, 2016^{17b}

Among cancer carers of all ages who would like further support, support via the telephone is the least popular mode of support (behind face to face, website, printed materials and online support).^{17b} However, older carers are the age group most likely to want this kind of support.^{17b}



All cancer carers – online survey (n=568)

REFERENCES, SOURCES, NOTES AND CAVEATS

How do we define cancer carers?

To understand carers' experiences and needs, we need to define who they are. This document has taken a general definition of 'cancer carers' as someone who provides unpaid help or support to someone because they have a cancer diagnosis. A recent major piece of research into cancer carers (see references 17a and 17b) took a different approach. We used the term 'carer' to refer to people who currently provide support to someone with cancer, not as part of a paid job or voluntary work. Also, they must either care for that person for more than five hours' care a week or give one to four hours a week and say this affects their life in some way, for example financially or emotionally. We did not want to rely on carers self-identifying to participate in the research, as we know that many people providing support to a relative or friend do not see themselves as a 'carer'. Using a self-identification approach would therefore have underestimated the size of this key group. Identifying carers on the basis of the amount of time they spend providing support to someone with cancer, and/or whether the support they provided has an impact on them, enabled us to estimate the size of this group more accurately the size of this group. It also enabled us to explore their needs and experiences in a meaningful way. Macmillan is here to provide information and support to anyone looking after someone with cancer.

Quotes

The quotes in the report are real quotes from carers, however we have changed their names to protect their identity. The quote and photo on page 5 is from a Macmillan case study who has kindly agreed to be featured in this publication.

References

1. Office for National Statistics. *Unpaid care in England and Wales, 2011 and comparison with 2001*. www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15 (Accessed November 2016).
2. Department of Health. *How can we improve support for carers?* <https://consultations.dh.gov.uk/carers/how-can-we-improve-support-for-carers> (accessed November 2016).
3. Carers UK. *Facts about carers*. www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=4762 (accessed September 2014).
4. The Princess Royal Trust for Carers. *What is a carer?* www.carers.org/what-carer (accessed September 2014).
5. Carers UK, Circle and University of Leeds. *Valuing carers 2011: calculating the value of carers' support*. www.circle.leeds.ac.uk/files/2012/08/110512-circle-carers-uk-valuing-carers.pdf (accessed September 2014).
6. Macmillan Cancer Support/Ipsos MORI. *More than a million: understanding the UK's carers of people with cancer*. www.macmillan.org.uk/Documents/Cancerinfo/ifsomeoneelsehascancer/More_than_a_million.pdf (accessed September 2014).

7. Ipsos MORI. *One million give up work to care*. www.ipsos-mori.com/researchpublications/researcharchive/2526/One-million-give-up-work-to-care.aspx (Accessed September 2014).
8. Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *Br J Cancer*. 2009. 101: 541–547
9. Molyneux V, et al. Reconsidering the term ‘carer’: a critique of the universal adoption of the term ‘carer’. *Aging & Society*. 2011. 31: 422–437.
10. Beckmann K, et al. Patient and carer perceptions of cancer care in South Australia. *Aust Health Rev*. 2009. 4: 645–655.
11. Escobar Pinzon LC, et al. Preference for place of death in Germany. *J Palliat Med*. 2011. 14: 1097–1103.
12. Tsigaropoulos T, et al. Problems faced by relatives caring for cancer patients at home. *Int J Nurs Pract*. 2009. 15: 1–6.
13. Stenberg U, et al. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*. 2010. 19: 1013–1025.
14. Tuncay T, et al. Psychological symptoms, illness-related concerns and characteristics of relatives of Turkish patients with cancer. *Asian Pac J Cancer Prev*. 2010. 11: 1659–1667.
15. Murray S, et al. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *British Medical Journal*. 2003. 326: 358–371.
16. Thomas C, et al. Companions through cancer: the care given by informal carers in cancer contexts. *Soc Sci Med*. 2002. 54: 529–544
- 17a. YouGov and Macmillan Cancer Support. Estimating the population of cancer carers in the UK – Phase One. 2016. YouGov, London. See Methodology on Page B for more detail.
- 17b. YouGov and Macmillan Cancer Support. Estimating the population of cancer carers in the UK – Phase Two. 2016. YouGov, London. See Methodology on Page B for more detail.
18. Thomas C, et al. Companions through cancer: the care given by informal carers in cancer contexts. *Social Science & Medicine*. 2002. 54: 529–544.
19. Matthews M, et al. Impact of counselling on quality of life and sleep in cancer patients. *British Journal of Nursing*. 2014. 23: 11–16.
20. Thomas K, et al. Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in palliative care: a longitudinal study. *Journal of Pain and Symptom Management*. 2014. 47: 531–541.
21. Hudson P, et al. Psychological and social profile of family caregivers on commencement of palliative care. *Journal of Pain Symptom Management*. 2011. 41: 522–34.
22. MacArtney JJ, et al. Locating care at the end of life: burden, vulnerability, and the practical accomplishment of dying. *Sociology of Health & Illness*. 2016. 38: 479–492.
23. The National Opinion Research Centre. Long term care in America: expectations and realities. www.longtermcarepoll.org/PDFs/LTC%202014/AP-NORC-Long-Term%20Care%20in%20America_FINAL%20WEB.pdf (accessed October 2016).
24. Carers UK. *Building carer friendly communities. Research report for Carers Week 2016*. https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=5653 (accessed October 2016).
25. Cronin P, et al. Between worlds: the experiences and needs of former family carers. *Health and Social Care*. 2015. 23: 88–96.
26. Carers UK. Census data update – May 2013. www.carersuk.org/for-professionals/policy/policy-library/census-data-update (accessed October 2016).
27. Jack B, et al. Supporting family carers providing end-of-life home care: a qualitative study on the impact of a hospice at home service. *Journal of Clinical Nursing*. 2015. 24: 131–140.

28. Carers UK. Caring and family finances. https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=219 (accessed October 2016).
29. National Readership Survey. Social Grade. www.nrs.co.uk/nrs-print/lifestyle-and-classification-data/social-grade (accessed October 2016).
30. Gov.uk. *Carer's Allowance*. www.gov.uk/carers-allowance/overview (accessed October 2016).
31. Age UK & Carers UK. *Caring into later life. The growing pressure on older carers*. www.carersuk.org/component/cck/?task=download&collection=file_list&xi=0&file=document&id=5224 (accessed October 2016).
32. Carers UK. *Facts About Carers 2015*. www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2015 (accessed August 2015).
33. Carers Trust. *Key facts about carers and the people they care for* carers.org/key-facts-about-carers-and-people-they-care (accessed August 2015).
34. The Princess Royal Trust for Carers. *Always on call, always concerned: a survey of the experiences of older carers*. www.carers.org/sites/files/carerstrust/always_on_call_always_concerned.pdf (accessed August 2015).
35. NCIN. *Cancer e-atlas*. www.ncin.org.uk/cancer_information_tools/eatlas (accessed September 2014).
36. Prevalence in 2015 estimated from Maddams et al. (2012). Prevalence in 2030 and 2040 taken directly from Maddams J, Utey M and Moller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010-2040. *British Journal of cancer*. 2012; 107: 1195-1202. (Scenario 1 presented here).
37. Macmillan Cancer Support. *Looking after someone with cancer* (the title in Italics) www.macmillan.org.uk/cancerinformation/ifsomeoneelsehascancer/caringforsomeonewithcancer/lookingaftersomeonewithcancer.aspx (accessed November 2016).

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 timeframe, 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 timeframe, 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 is only available and presented for 20-year prevalence (ie 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.

Palliative treatment: Palliative care is only used to ease pain, disability or other complications that usually come with advanced cancer. Palliative care may improve quality of life and medium-term survival, but it is not a cure or anti-cancer treatment. However, palliative care can be given 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

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

The *Rich Pictures* on age groups

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

Other *Rich Pictures*

<i>The Rich Picture on people at end of life</i>	(MAC13841_14)
<i>The Rich Picture on carers of people with cancer</i>	(MAC13731_10_14)
<i>The Rich Picture on people with cancer from BME groups</i>	(MAC14662_14)
<i>The emerging picture on LGBT people with cancer</i>	(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 to 8pm) or by ordering online at **www.be.macmillan.org.uk**

A wealth of other resources is 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 to 8pm) or visit macmillan.org.uk

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