

**UNDER
PRESSURE**

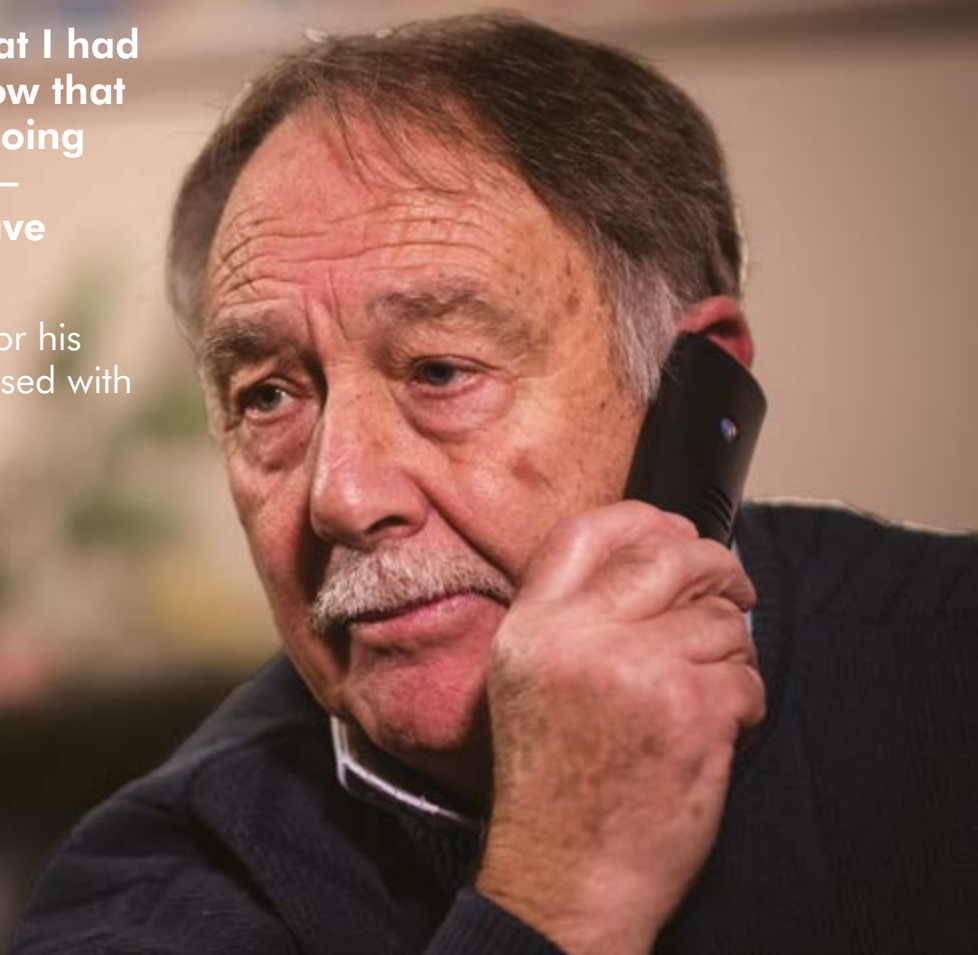
THE GROWING
STRAIN
ON CANCER
CARERS

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CANCER SUPPORT**

CONTENTS

'It never struck me at first that I had become a carer. You just know that your wife is ill, so you start doing things for her, for the house – without realising that you have become a full-time carer.'

Paul, aged 73, from Kent, cared for his wife Renate when she was diagnosed with lung cancer



FOREWORD

A cancer diagnosis doesn't only affect the person with the disease; it can reach deep into the lives of all those who know them, from their partner, children and parents, to their wider family, friends and colleagues.

As the number of people living with cancer continues to grow, so does the impact on those who care for them. In this report we show that cancer carers across the UK are under more pressure than ever before, and this is taking a toll on their health, finances and working lives.

For many people, cancer would be unbearable if they had to face it alone and most will rely on some kind of support from their family and friends. Support can range from seemingly straightforward tasks such as helping out with shopping and lifts to appointments, right through to deeply intimate care such as helping someone to wash or go to the toilet when they are very ill. No matter what kind of support someone provides, it can have a profound effect on their own life and health.

The number of cancer carers has soared over the past five years and they now provide more complex care and face an ever-growing strain. Caring for someone with cancer can be especially challenging as people often undergo gruelling treatments that can have an unpredictable effect on their health and ability to function. And with cancer being the leading cause of death in the UK, many carers are looking after someone who is terminally ill for weeks or months during a deeply upsetting time.

We must help to ease the growing impact on those who care for someone with cancer, particularly in light of current pressures on the health and social care systems across the UK. Carers who are left to cope with the strain of caring alone can quickly reach breaking point and become ill themselves. This can be traumatic for both the carer and the person they are caring for. It also puts more pressure on the NHS as it can lead to emergency hospital admissions.

At Macmillan Cancer Support, we help carers through the Macmillan Support Line and other services. But we can't do it all for everyone who needs us. The UK's governments and health and social care professionals must play their part. More than half of cancer carers still do not get any support for themselves. This must change.

No one should have to cope on their own when caring for someone with cancer.



Lynda Thomas
Chief Executive
Macmillan Cancer Support

'I did whatever I could to help mum and make things easier for her.'

Ben, aged 20, from West Yorkshire, cared for his mother Deanne when she was diagnosed with throat cancer



EXECUTIVE SUMMARY

The number of people in the UK who are caring for someone with cancer has soared from around 1.1 million in 2011 to almost 1.5 million in 2016.

Cancer carers are now spending an average of 17.5 hours a week looking after someone with cancer, 2.5 hours more than in 2011.

Compared with five years ago, cancer carers are also more likely to be:

- older
- caring for someone who is terminally ill
- caring for one of their own parents
- providing more complex and hands-on care
- experiencing an impact on their own physical health.

Carers also face many other persistent challenges, such as:

- detrimental impacts on their mental as well as physical health
- pressure on working lives and personal finances
- lack of recognition that they are a carer, either by themselves or by health and social care professionals, which can prevent them from getting the support they need.

Yet despite these issues, carers are no more likely to get help and support with caring than they were five years ago, and more than half do not get any support at all to care.

Almost two in three people caring for someone with cancer would benefit from more help and support.

Macmillan Cancer Support provides a range of services to those caring for someone with cancer, such as the Macmillan Support Line and information resources – but we can't do this alone.

We want to see better collaboration between government bodies, health and social care professionals, the voluntary sector and carers, to help carers get the support they need.

UNDER PRESSURE

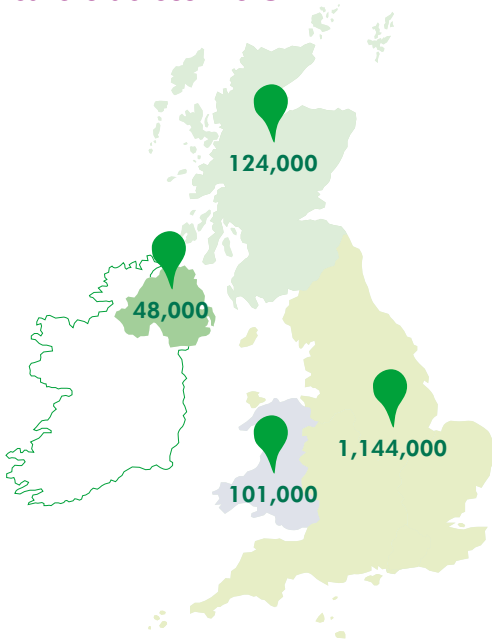
In 2011, Macmillan Cancer Support revealed for the first time that there were around 1.1 million people aged 16 or over providing unpaid care for someone with cancer in the UK¹. Since then, the UK population has continued to grow, life expectancy has increased, and the number of people living with cancer in the UK has risen from around 2 million in 2010 to around 2.5 million in 2015². We have therefore commissioned research agency YouGov to update our previous figures and explore certain issues in more depth³.

The growing strain

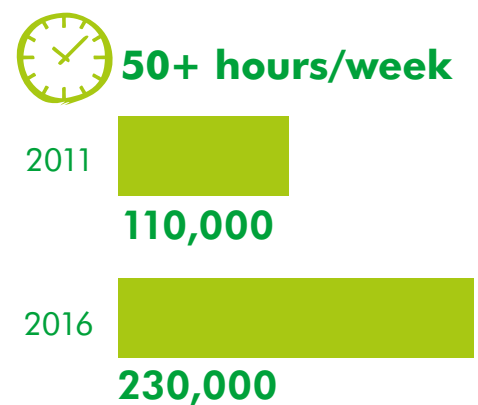
More people are caring¹ – The number of people in the UK who are caring for someone with cancer has soared to **almost 1.5 million in 2016⁴**. The proportion of people who are cancer carers has also grown, by more than a quarter from 2.1% in 2011 to 2.7% in 2016.

People are providing more hours of care – Family and friends are spending an average of 17.5 hours a week looking after someone with cancer, 2.5 hours more than in 2011. Shockingly, one in five carers (20%) provide this support for more than 35 hours a week – the equivalent of a full-time job – and one in six (16%) provide **more than 50 hours** of care a week.

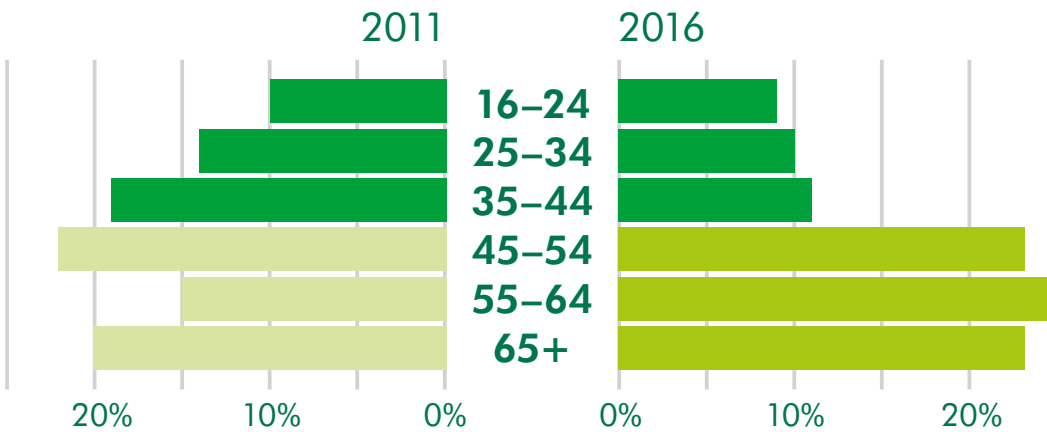
Estimated number of cancer carers across the UK



The estimated number of people in the UK who provide more than 50 hours of care a week has more than doubled in the past five years to almost a quarter of a million people:



Carers are getting older – More than two in three carers (70%) are aged 45 or over, compared with just over half (57%) in 2011. Almost one in four (23%) are now in the 65+ age group, who provide more hours of care on average than younger age groups⁵.



Caring is having a greater impact on the health of those who care – At least one in five carers (20%) say that caring is having an impact on their physical health, compared with around one in eight (13%) in 2011.

People are more likely to be caring for someone who is terminally ill – The proportion of people caring for someone at the end of life has doubled, from one in 25 (4%) to around one in 13 (8%). People who are terminally ill often need a much higher level of care than those going through treatment or recovery.

People are now most likely to be caring for one of their parents –

Three in 10 cancer carers (30%) are caring for a parent, up from 23% in 2011. People are now more likely to be caring for their own mother or father than any other person⁶.

- Around one in four people (27%) who are caring for a parent with cancer are 'sandwich generation' carers – they also still have children living at home. This represents more than 110,000 people in the UK. Almost all 'sandwich generation' carers (89%) are also working, which can present huge challenges when trying to juggle caring with work as well as childcare.

Carers are providing more complex and hands-on care –

The amount and types of care people provide has increased significantly, including:

- Help with healthcare tasks, such as **giving medication or changing dressings** – more than one in three carers (38%) now provide this type of support, up from 28% in 2011.
 - This rises to 59% of people caring for their partner and 43% of carers aged 65 or over⁷.
- Help with **intimate personal care**, namely washing, dressing, going to the toilet and eating – 34% in 2016, up from 23% in 2011.

One in 10 carers (11%) are helping a parent with cancer to wash, dress, go to the toilet or eat – representing more than 150,000 people in the UK



Other types of care that have also increased include providing help with finances, support with admin tasks such as making phone calls or filling in forms, and speaking to people such as healthcare professionals or social workers on behalf of the person with cancer⁸. This suggests the health and social care system is becoming more difficult for patients and their carers to navigate their way through.

The average cancer carer



- Age: 51
- Gender: Female
- Caring for: Own parent
- Hours of care: 17.5 each week



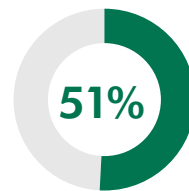
'I do everything – pay bills, cook, clean, put dad to bed, help him get around and give him morphine for the pain. Sometimes he cries in the night, saying he doesn't want to die. I comfort him and help him back to sleep.'

Amy, aged 20, from the West Midlands, cares for her father, who has prostate cancer

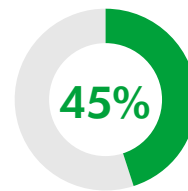
Persistent challenges remain

Caring has a major impact on people's physical health – Between one in five (20%) and one in three (35%) carers experience one or more issues with their physical health as a result of caring⁹. The top three are tiredness or exhaustion, sleep problems or insomnia, and weight gain or loss¹⁰.

Caring has a major impact on people's mental health – Up to 70% of carers experience one or more issues with their emotional wellbeing or mental health¹¹. The top three are stress, anxiety and depression. In addition, one in four (25%) feel isolated or lonely.



of cancer carers experience **stress**



of cancer carers experience **anxiety**



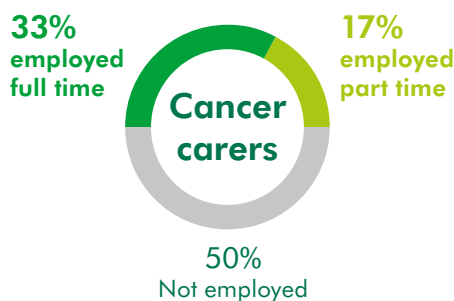
of cancer carers experience **depression**

'I cared for my mother-in-law [and I] have now cared for my own mother. During this time I have raised a family of four children. I feel as if I have lived my life for everyone else, and never had one of my own. I get depressed and cry sometimes... and then I feel really guilty for having these thoughts.'

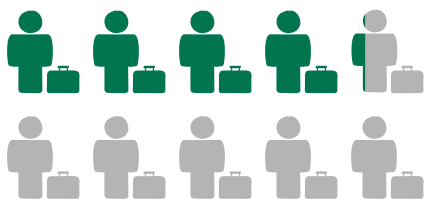
58-year-old woman, caring for her mother with cancer

Caring affects other areas of people's lives – Almost all carers (94%) say that caring has affected at least some part of their lives. As well as the impact on physical and mental health described overleaf, other significant impacts include:

- Half of carers (50%) are also working while they are caring for someone with cancer.



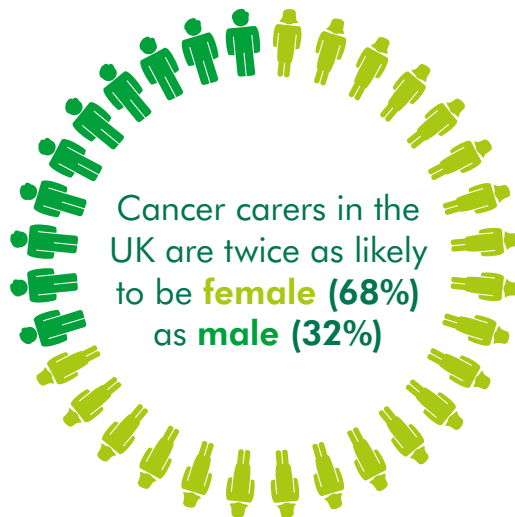
More than four in 10 (43%) of those currently in employment say that caring affects their working lives.



This includes **having to take leave in order to care**, and having to **reduce their hours**.

- Almost two in three carers (62%) say their social lives are affected by caring. Common issues include **taking fewer breaks or holidays** and **spending less time relaxing or socialising**, or taking part in leisure activities. Not being able to take a break from caring puts people's health at risk and can worsen the isolation and loneliness that many carers experience.
- Almost one in three carers (30%) say their income or household finances are affected by caring, rising to 42% of those in their 40s and 50s. Some of the most common costs include **spending more on travel**, either when taking someone with cancer to the hospital or GP (affecting 18% of carers) or when visiting them at home (14%).
 - More than one in eight carers (13%) live more than an hour's travel from the person they care for – this includes one in 20 (5%) of those who provide more than 35 hours of care a week.

Caring for those with cancer is not shared equally between women and men



- Among those who do provide care, women are more likely than men to say that caring affects their physical and mental health¹².
- **Many carers experience issues with the UK's health and social care systems** – More than four in 10 (42%) say that the professionals treating the person they are caring for either never or only sometimes work well together and a quarter (25%) say they were not involved when planning how and when the person with cancer would be discharged from hospital.
- **Many people do not consider themselves to be 'carers'** – More than half (55%) of people who care for someone with cancer according to Macmillan's definition do not consider themselves to be a 'carer'.
- **Many people are not recognised as carers by health and social care systems** – More than one in three (36%) people who care for someone with cancer have **not been recognised as a carer** by any health or social care professional (or any other group or organisation). This increases to 40% of female carers (compared with 29% of male carers).

If people are not identified as carers, they risk missing out on vital emotional, financial and practical support.

Support at a standstill

More and more people are caring for someone with cancer, the care they provide is ever-more hands on and complex, and carers themselves are getting older. Yet despite this, carers are **no more likely to get help and support with caring than they were five years ago**. More than half of carers (55%) do not get any kind of formal or informal support for themselves, a figure that hasn't improved from 2011¹³. This rises to two in three (67%) among carers who have not been identified as carers by others.

Around one in four (27%) of those who lack support say this is because they either don't know what support is available in their area, they couldn't afford it, or they don't have the time to look for or make use of support. This shows why it is so important for relevant information to be available to carers, at the times that they need it.

Social care services across the UK have statutory duties that require them to provide carers with a formal

assessment to help identify their support needs and how these could be met. Shockingly, only one in 10 people caring for someone with cancer (10%) say they have had a formal assessment¹⁴ and half (51%) have never even heard of them – up from 45% in 2011.

Among those who have had support from a health or social care professional, carers are most likely to say they had a good level of support from hospital staff and least likely to say they had good support from social services¹⁵.

One thing that has changed over the past five years is that when carers do get support, they are now twice as likely to say that they found out from Macmillan what support was available (19% of carers said this in 2016, compared with 8% in 2011). This could have been through our website, a Macmillan professional, the Macmillan Support Line (our telephone helpline, staffed by cancer specialists) or another of our services.

More than half of cancer carers do not get any support



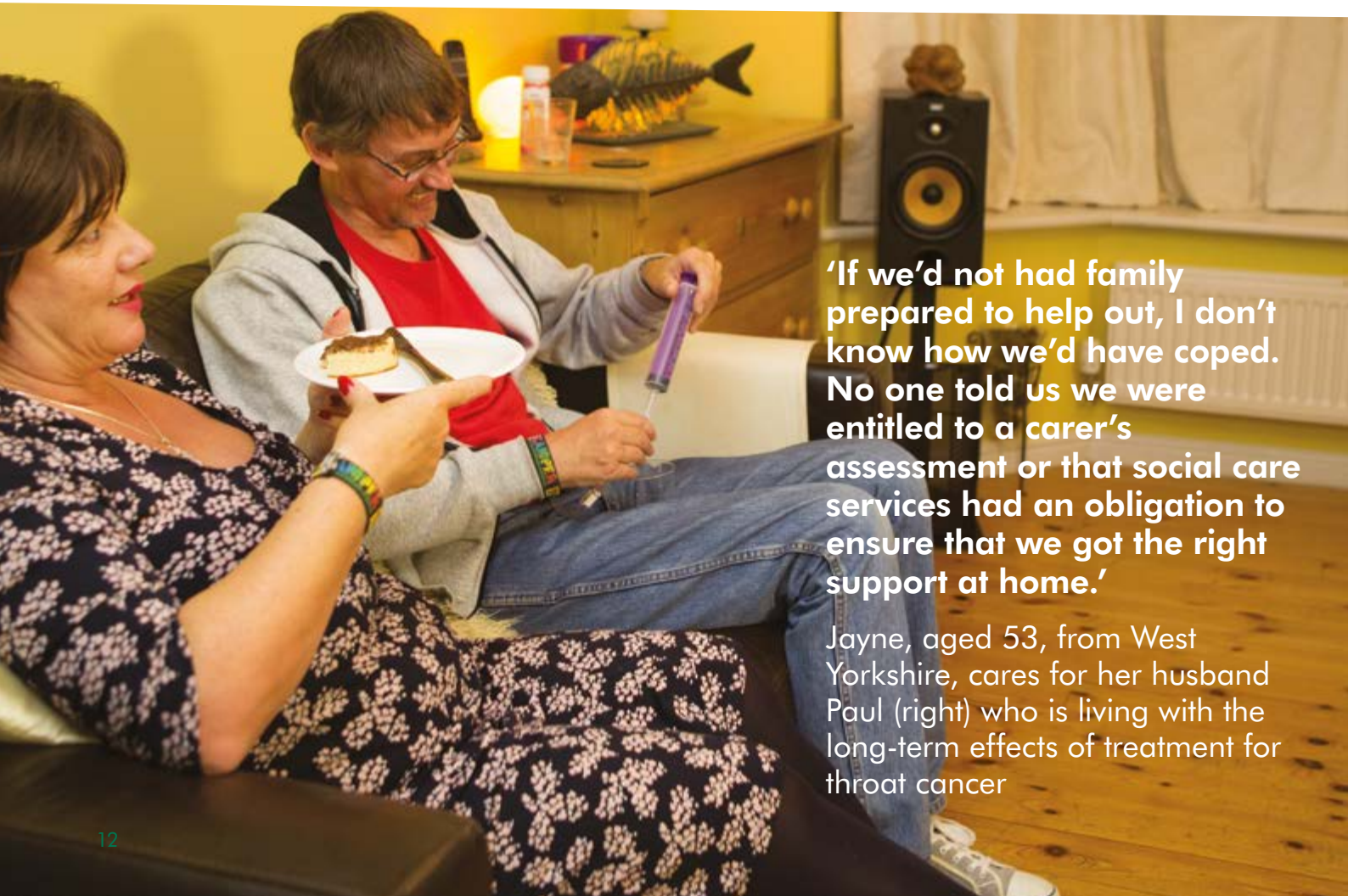
WHAT SUPPORT DO CARERS WANT?

Almost two in three people caring for someone with cancer (65%) say they would benefit from more support. The most common types of support that people would find helpful are:

- Someone to talk to/emotional support: 22% of carers would find this helpful
- Information and advice on the support available to those who care: 20% of carers would find this helpful
- Advice or information on financial issues or benefits: 20% of carers would find this helpful

Other types of support people would like include information about cancer and its treatment (14%) and advice and training on how to provide care (8%).

Carers are most likely to want health and social care professionals to provide this additional support, although more than one in four (29%) of those who want further support say they would like this from a charity or other voluntary organisation.



'If we'd not had family prepared to help out, I don't know how we'd have coped. No one told us we were entitled to a carer's assessment or that social care services had an obligation to ensure that we got the right support at home.'

Jayne, aged 53, from West Yorkshire, cares for her husband Paul (right) who is living with the long-term effects of treatment for throat cancer

HELPING CARERS GET MORE SUPPORT

In 2015 Macmillan supported around 600,000 carers through services such as the Macmillan Support Line, our information centres, our nurses and other health and social care professionals, and our website¹⁷.

We are also helping to raise awareness both locally and nationally of the

support that carers need. We are urging government bodies and health and social care professionals to work more closely with the voluntary sector and carers, to help carers get more support.

Everyone who comes into contact with carers must play their part.

How Macmillan supports carers

- The **Macmillan Support Line** (freephone 0808 808 00 00, Monday to Friday, 9am–8pm) is staffed by cancer specialists who offer practical, medical, emotional and financial support.
- The Macmillan website has a dedicated section for carers: www.macmillan.org.uk/carers
- Our guide for carers, *Looking after someone with cancer*, is available from be.macmillan.org.uk
- Our online community offers a dedicated online support group for carers: community.macmillan.org.uk/cancer_experiences/carers_only
- We also offer practical tips and guidance to help health and social care professionals to identify and support carers, available at: www.macmillan.org.uk/supportingcarers

REFERENCES

1. Our research identified people aged 16 or over who currently provide support to someone with cancer, not as part of a paid job or voluntary work, and who either provide more than five hours of care per week, or provide one to four hours a week and say this affects their life in some way eg financially or emotionally. We recognise that children under the age of 16 can also be carers.
2. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer* 2012; 107: 1195-1202. (Projections scenario 1).
3. The research consisted of two phases:
 - Phase one: 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 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. It does not include those who provide care as their paid job or voluntary work. 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 two: A survey with 892 UK cancer carers only, via YouGov's online panel, between 4th and 18th April 2016 – this allowed us to explore the experiences of carers in more detail. Results were weighted by age, gender, social grade and region to reflect the overall population of carers identified in phase 1.
 - Overall figures and comparison with 2011 are sourced from phase one unless specified. Figures on regional and demographic variations are sourced from phase two.
4. More precise estimates are as follows: 1,416,000 in 2016 and 1,080,000 in 2011.
5. Carers aged 65 and over provide 22 hours of care per week on average compared with 18 hours among those aged 45–64, and 13 hours among those aged 16–44.
6. 4% of carers are looking after their own child with cancer.
7. These figures are from phase two of the research.
8. Details are as follows:
 - Talking to others on their behalf e.g. healthcare staff, social worker – 45% in 2016 compared with 30% in 2011
 - Help with making phone calls, writing letters/emails, filling in forms – 44% in 2016 compared with 29% in 2011
 - Help with managing finances – 28% in 2016 compared with 19% in 2011
9. The research was done in two phases. The first phase reported a 20% impact on cancer carers' physical health. The second phase showed 35% of cancer carers reported an impact on their physical health. Both results are statistically valid.
10. Tiredness or exhaustion is experienced by 29% of carers, sleep problems or insomnia by 25%, and weight gain or loss by 19%.
11. See reference 9. In phase one, 51% of carers reported an impact on their emotional wellbeing or mental health. In phase two, 70% did. Both results are statistically valid.
12. Issues that affect female carers more include: tiredness/exhaustion (33% of women report this, compared with 22% of men), weight gain or loss (22% compared with 12%), digestive problems (12% compared with 6%) and impact on emotional wellbeing or mental health (75% compared with 58%).
13. The figure for 2011 is 49% – although this is lower than in 2016, the difference is not statistically significant.
14. Referred to as a 'Carer's Assessment' in the survey question.
15. 43% of carers who receive support from clinical nurse specialists or hospital doctors rate this as 'very good', compared with 21% of those who receive support from a social worker and 18% who receive support from other social services or local council staff.
16. The remaining 2% said 'don't know' or 'prefer not to answer'.
17. Macmillan Cancer Support. Annual report and accounts 2015.

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. At Macmillan, we know how a cancer diagnosis can affect everything and we're here to support you through. From help with money worries and advice about work, to someone who'll listen if you just want to talk, we'll be there. We'll help you make the choices you need to take back control, so you can start to feel like yourself again.

No one should face cancer alone. 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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