

CANCER MATTERS

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CANCER SUPPORT

Macmillan Cancer Support's manifesto
for the 2017 General Election



Claire, diagnosed with brain cancer,
and Shez, her Macmillan nurse

Foreword

The 2017 General Election is taking place in unique circumstances. It is happening at short notice, with only 50 days between its announcement and polling day, and is expected to largely focus on one issue: the UK leaving the European Union.

However, it is important to remember that the public will elect a new Parliament, which is expected to last until 2022. The MPs who enter the House of Commons in June 2017 will not only deal with Brexit but also make key decisions and have major influence over the future of health and social care policy, affecting millions of people for years to come.

There are 2.5 million people living with cancer in the UK today and, as more people live longer with their cancer, this number is set to grow to four million by 2030. The next UK Government must therefore ensure that care and treatment for people with cancer is a health priority.

We at Macmillan are making three key calls on the next UK Government. They are not the only issues we want ministers and their agencies to address, but they are three of our major priorities. They concern the following areas: the health and care workforce, financial support for people with cancer, and care for people at the end of their lives. Our calls are underpinned by research, the expertise of our health and social care professionals, and countless conversations with people with cancer and their carers.

Macmillan's priority over the next five years, as it has been since 1911, will be ensuring people with cancer get the very best care and treatment. My team and I will always play a full and active part in making this a reality, and we look forward to working with politicians of all political colours in doing so.

I hope you'll take the time to consider this Macmillan manifesto.



Lynda Thomas
Chief Executive



Introduction

Macmillan Cancer Support calls on political parties to commit to the following over the course of the next Parliament:

1. Ensure that there are enough health and care staff with the right skills so that people with cancer receive world-class treatment and support.
2. No cuts to welfare benefits for people with cancer or their carers.
3. Ensure that everyone approaching the end of their lives receive the best possible care and support and can die in the place of their choice.

Around one in every two people born after 1960 can expect to be diagnosed with cancer at some point in their lifetime.¹ However, improvements in diagnosing and treating the disease mean that more people are surviving, or living for longer with it.²

Yet, not all of these people are living well. One in four experience poor health or disability and many more face financial consequences of their illness and treatment, hence our recommendations to the next UK Government.

There is agreement that we have the right blueprint in the Independent Cancer Taskforce's *Cancer Strategy for England: Achieving World-Class Cancer Outcomes*, which includes the vital roll out of the Recovery Package for people with cancer.³

However, we must not be complacent as to how deliverable this is during a period of unprecedented operational pressure for the NHS in England. It is essential that the next UK Government implements the strategy in full to achieve world-class cancer outcomes and ensures new ambitions are in place for 2020 and beyond.

It is vital that everyone can access the best care when they need it. It is also crucial to ensure that the NHS is set up to meet the changing needs of people with cancer. Not only would this increase the quality and experience of survival, it would also ensure that resources are invested in the most efficient way. This is key for the NHS in England as the Five Year Forward View projections indicate that expenditure on cancer services will need to grow by about 9% a year, reaching £13 billion by 2020/21.⁴

¹ Macmillan estimate based on; Maddams J, Utley M, Møller H. *Projections of cancer prevalence in the United Kingdom, 2010–2040*. Br J Cancer 2012; 107: 1195–1202. (Scenario 1 presented here) Forman D, et al. *Cancer prevalence in the UK: results from the EUROPREVAL Study*. Annals of Oncology. 2003. 14: 648–654; Office for National Statistics; Information Services Division (ISD) Scotland; General Registrar Office Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry; Northern Ireland Statistics and Research Agency

² Macmillan Cancer Support (2013) *Cured – but at what cost? Long-term consequences of cancer and its treatment*

³ The Recovery Package includes a Holistic Needs Assessment and Care Planning, Treatment Summary, Cancer Care Review, and Health and Wellbeing Events. More information at macmillan.org.uk/recoverypackage

⁴ FYFV forecasts were based on a Technical Annex published in December 2013, which included assumptions indicating that budget lines related to cancer are likely to grow by around 9% per annum over the next five years, in the absence of any efficiency savings. Described further in the 2015 Cancer Strategy: Independent Cancer Taskforce (2015), *Achieving world-class cancer outcomes: A strategy for England, 2015–2020*, p. 6. Available at: http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf



Section one: Health and care staff

The next UK Government should ensure that there are enough health and care staff with the right skills so that people with cancer receive world-class treatment and support.

One of the biggest challenges facing the health and care sectors is maintaining a skilled workforce. With the number of people living with cancer set to grow from 2.5 million to four million by 2030, it is vital that workforce is a priority for the next UK Government.

Ahead of the General Election, Macmillan is calling on all parties to ensure that by the end of the next Parliament, the **health and care workforce is supported and equipped to meet the changing needs of people with cancer.**

In order to achieve this we want to see all parties commit to:

- **urgently setting out a clear and ambitious plan** for how the NHS will develop a workforce that is able to meet the changing and more complex needs of a growing cancer population
- **ensuring the UK's exit from the European Union will not negatively impact** the ability of the health and care workforce to deliver high quality cancer care.

There is consensus on the workforce challenges currently facing the NHS. A recent report from the House of Lords stated that 'workforce represents the biggest internal threat to the sustainability of the NHS'. Many think tanks and Royal Colleges have warned about the increasing pressure on the NHS due to an ageing population, financial pressure and the uncertainty surrounding Brexit. These challenges will be exacerbated by the fact that one in three nurses are due to retire in the next 10 years, and it is expected that by 2030 we will need an additional 7,000 Clinical Nurse Specialists to meet demand.⁵ Even where Clinical Nurse Specialists are in post, the rising demand means that they often unable to make best use of their specialist skills.

Doing nothing is not an option. We need to think differently about how we plan and organise the NHS workforce in future.

Planning

As well as the increase in the number of people living with cancer, the disease is also becoming increasingly complex. This is because more people are living with the consequences of treatment or with multiple long-term conditions. However, the workforce is built around the traditional perception of cancer being an acute disease only. We need to think differently if the NHS is going to be able to continue to provide high-quality care and support for everyone living with cancer.

Therefore, Macmillan is calling on the next UK Government to urgently set out a clear and ambitious plan for how the NHS will develop a workforce that is able to meet the changing needs of a growing cancer population.

Considering the impact of Brexit

The vision for how the workforce will meet the needs of cancer patients must take a long-term view and it must consider any impact that leaving the European Union may have.

It is estimated that around 5% of NHS staff are from EU countries, and therefore workforce is one of the key areas in the NHS which could be affected by Brexit. However, there remains a lack of clarity around what the impact would be on patients and how the NHS would address this. With a growing number of people living with cancer, and pressures on the health and care workforce already being felt, it is vital that there is no negative impact on cancer patients' care, in either the short or long term, as a result of exiting the EU.

Macmillan is calling on the next UK Government to ensure that the UK's exit from the European Union will not negatively impact the ability of the health and care workforce to deliver high-quality cancer care.

⁵ Internal Macmillan analysis based on Frontier Economics. *One to one support for cancer patients: A report prepared for Department of Health*. December 2010 (accessed January 2017)



Terry, diagnosed with Non-Hodgkin Lymphoma aged 56.

Section two: Financial support for people with cancer

The next UK Government should guarantee no cuts to welfare benefits for people with cancer or their carers.

Alongside the physical effects, cancer can come with a significant financial impact. Four out of five people with cancer are affected financially and are, on average, £570 a month worse off as a result of their diagnosis.⁶

Without the support to manage the financial impact of cancer, money worries can spiral out of control. This can leave people with cancer struggling to pay their bills, cutting back on food or not going to their medical appointments because they can't afford the cost of travel. A cancer diagnosis is typically sudden and unexpected, and almost half of people are taken by surprise by the extent of the financial impact.⁷

'Without a doubt without benefits I would have been repossessed and I would be in great debt. I can't describe how bad it would have been. The last thing you want to be worrying about when you're ill is money. The only fight you should have to take on is your fight to get better.'

Terry, who was diagnosed with Non-Hodgkin Lymphoma aged 56.

⁶ Macmillan Cancer Support (2013) *Cancer's Hidden Price Tag*

⁷ Macmillan Cancer Support / Truth online survey of 955 adults in England, Scotland and Wales who have had a cancer diagnosis. Fieldwork was undertaken between 3–21 September 2015. Data has been weighted.



Worryingly, our research shows this financial impact is having a significant knock-on effect on the physical and mental wellbeing of people with cancer. More than half (53%) reported feeling more anxious or stressed, whilst 43% said it had a detrimental effect on their overall health.⁸

At Macmillan, every year we help hundreds of thousands of people with cancer and their carers to cope financially. We do this through giving advice on benefits and energy costs, providing financial guidance and distributing grants.

However, we cannot tackle this problem alone. As the number of people with cancer grows, more people will need help to cope with the financial impact. It is vital that all parties commit to ensuring people get the support they need.

The importance of welfare support to people with cancer

It is essential that people living with cancer and their carers are provided with the support they need. In March 2016, the then UK Government committed to not making any further welfare savings over the course of the Parliament. Therefore, ahead of the General Election, we want to see all parties committing to – as a minimum – **not making any cuts to key welfare benefits for people with cancer and their carers over the course of the next Parliament. This means ensuring there are no cuts to sickness and disability benefits, including reductions to benefit rates or restrictions on eligibility.**

⁸ Macmillan Cancer Support / Truth online survey of 955 adults in England, Scotland and Wales who have had a cancer diagnosis. Fieldwork was undertaken between 3–21 September 2015. Data has been weighted.

Macmillan welcomes commitments to ensuring people with cancer have the support they need to remain in and return to work if they are ready and able. However, the need to support those who can work to do so must be balanced with the UK Government's duty to ensure people who are unable to maintain an income through work – be it temporarily or permanently – are provided with adequate support.

For example, many people living with cancer awaiting, undergoing or recovering from most types of chemotherapy and radiotherapy currently benefit from a vital protection. This means they are placed into the Support Group of Employment and Support Allowance (ESA) without having to go through a face-to-face assessment. This provision recognises the significant impact of cancer and its treatments, reduces the number of unnecessary work capability assessments, and leads to greater efficiencies and a better experience for people with cancer. It is essential that it is maintained.

We also know that family members and friends who care for people with cancer are financially affected by their diagnosis. Almost one in three carers say their income or household finances are affected by caring, as a result of them spending more on travel and other caring-related costs. A fifth of all cancer carers say they are missing out on financial information or advice, including information and advice on benefits.⁹

In addition to this commitment, we hope all parties will continue to explore ways to improve the welfare system to ensure it provides people with cancer with the support they need.

Ensuring everyone plays their part in tackling the financial impact of cancer

The next UK Government needs to ensure people with cancer get the right support from the welfare system, but it's crucial that others play their part too.

Banking providers are in a unique position to help people affected by the financial impact of cancer. For many people, a mortgage is the single biggest financial commitment they have, so mortgage lenders are well placed to help customers who are living with cancer to manage this. However, our research shows that often people are not getting the support they need from their banks, with less than 5% of people saying they used financial services firms as a source of information and support.¹⁰

Some banks have made improvements to the services they offer. However, Macmillan believes that the sector could – and should – do more to ensure people with cancer have consistently positive experiences, whoever they bank with.

We are therefore looking forward to continuing to work with the financial sector and with all parties in the next Parliament to ensure that vulnerable customers, such as those with cancer, get the support they need from their banking providers.

'When I was diagnosed, I was worried about money. I wasn't able to work at all for three months, so my freelance business had to go on hold. There were huge financial implications for our family.'

Ashley, who was diagnosed with cancer for the second time in 2011

⁹ Macmillan Cancer Support (2016) *Under pressure: the growing strain on cancer carers*

¹⁰ YouGov / Macmillan Cancer Support online survey of 3,007 UK adults who have or have had cancer. Fieldwork was undertaken between 5 and 27 December 2013. Survey data has been weighted to be representative of the wider cancer population.



Nikki, whose mum was 89 when she was diagnosed with an eye tumour that spread and became terminal.

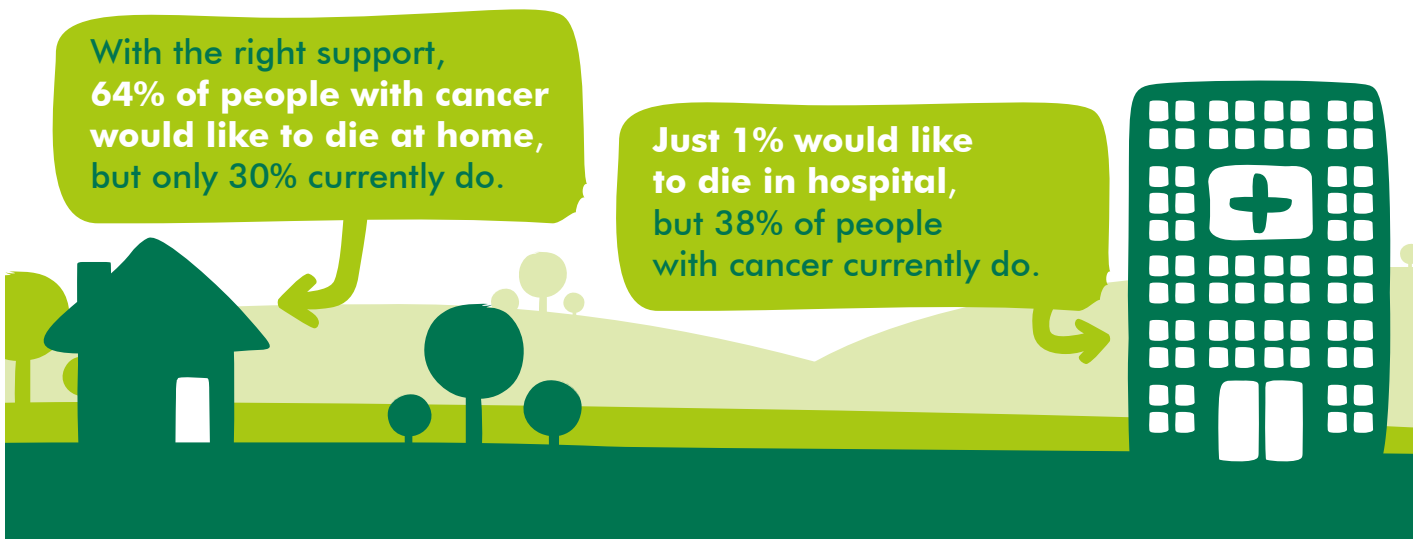
Section three: Care at the end of life

The next UK Government should ensure that everyone approaching the end of their lives receive the best possible care and support and can die in the place of their choice.

Most people will need access to end of life services at some point, either when they are dying themselves or when they are supporting someone they love. Everyone deserves to live well, but they also deserve to die well. To make this happen, it is vital that health and social care services work together to ensure people approaching the end of life receive high quality and personalised care.

'It was mum's dearest wish to be able to die at home. We did everything we could to ensure that she would be surrounded by the people that she knew and she loved. It was clear that she had not very long to go and we felt that we could offer the best care. But getting people to take the situation seriously was the most difficult thing. It was a challenge to ensure the services were actually available, and then to coordinate them.'

Nikki, whose mum was 89 when she was diagnosed with an eye tumour that spread and became terminal.



Macmillan believes that people at the end of their lives should receive the care they need, be comfortable and have their pain controlled no matter where they are being looked after. We want to make sure everyone is able die with dignity in the place and manner of their choosing. To achieve this, Macmillan is looking to the political parties to commit to implementing and funding the recommendations set out in the 2015 independently-led *Review of Choice in End of Life Care* (the Choice Review).¹¹

Recent reports and studies have also indicated that many people are not having a good experience of care at the end of life. Both the Health Select Committee and the Parliamentary and Health Service Ombudsmen have found variations in the experiences of people approaching the end of life and, in too many cases, it is unacceptably poor.¹⁴ We know that only one in five (22%) of those with cancer have complete pain relief all the time when they are at home in their last three months of life.¹⁵

Improvements are needed to increase the personalisation and quality of the care most people receive. We know that currently too many people's preferences at the end of life are not being met: **64% of people with cancer would prefer to die at home with the right support,¹² yet less than a third (30%) do.¹³** Macmillan estimates that every year 62,000 cancer patients die in hospital when they would have preferred to die at home.

11 Choice in End of Life Care Programme Board (2015), *Review of Choice in End of Life Care*

12 YouGov Plc. (2017). Macmillan commissioned YouGov Plc. to survey people with cancer. Total sample size was 2005 people with a previous cancer diagnosis, and 1878 people answered our questions relating to death and dying. Respondents were asked "If the right care and support was available in any of these locations, where would you prefer to spend your final days?"

13 Office for National Statistics, *Deaths Registered in England and Wales in 2015* (Released November 2016, accessed April 2017) <https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables/2015/drtables15.xls>

14 Health Committee, *End of Life Care: Fifth report of session 2014–15, March 2015*. Available at <http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf>; Parliamentary and Health Service Ombudsman, *Dying without dignity*, May 2015. Available at <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity>

15 Office for National Statistics, 2016. *National Survey of Bereaved People (VOICES): England, 2015* (Accessed April 2017)

Furthermore, the combination of a growing and ageing population means there will be increased strain on already overstretched end of life and palliative care services in the future. Developing sustainable and adequately-resourced end of life care services that keep people out of costly acute care for as long as possible is therefore becoming ever more critical. This is particularly important as the number of people dying each year is expected to rise by 20% over the next twenty years.¹⁶

Macmillan is calling on all parties to ensure that more is done to make sure people's preferences at the end of life are recorded, shared and acted upon. This will enable more people to die in their preferred place and reduce unnecessary hospital admissions.

Giving people choice at the end of life

In February 2015, an independently-led review published recommendations to the coalition UK Government for enabling both greater choice and high-quality care for people at the end of their lives in England. The Choice Review focused on establishing a 'national choice offer' of what should be offered to everyone who needs end of life care. This offer would be backed up by dedicated funding, better training for healthcare professionals and better research and data collection around the care provided.

In July 2016, the Conservative UK Government published its response to the Choice Review. It set out a new National Commitment, based on everyone at the end of life receiving high-quality care tailored to their needs and wishes. If delivered, Macmillan believes the commitments in the Choice Review have the potential to:

- deliver a significant increase in out-of-hospital care to ensure every dying person has access to **round-the-clock care** in the place of their choice, seven days a week
- provide **greater coordination and integration** between services to improve the quality of end of life care and to support carers and families
- deliver a **reduction in hospital admissions** for people at the very end of their lives
- **empower patients and carers** to be able to exercise greater choice in the place of death, through person-centred, coordinated care
- provide **practical and emotional support for families and carers** during care-giving and bereavement, ensuring they are involved in discussions about care preferences where the dying person has said they should be
- support the use of the **latest technologies** to support end of life care.

For more information, please contact:

Chris Walden
Head of Public Affairs
cwalden@macmillan.org.uk

¹⁶ There were 468,875 deaths in England in 2014 according to ONS death registrations data published in 2016. According to the latest (2014) ONS population projection for England, this is projected to rise to 561,000 deaths by 2035/36, an increase of 19.6%.

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

We can be there for you during treatment, help with work and money worries and we'll always listen if you need to talk. We've helped millions of people through cancer and we can do the same for you. Life with cancer is still your life and we will help you live it.

From the moment you're diagnosed, for as long as you need us, you can lean on Macmillan.

Call us free on **0808 808 00 00**

(Monday to Friday, 9am–8pm)

or visit **macmillan.org.uk**

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