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CANCER SUPPORT**

NO REGRETS

How talking more openly about
death could help people die well

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Foreword

For nearly 20 years my career has focused on improving end of life care. My passion developed during my time as a district nurse when I worked with dying people and their families. I've witnessed death first hand, and done my best to make a person's passing as peaceful and comfortable as possible. Working now at Macmillan Cancer Support, I know we make a huge difference to end of life care across the UK through our wide range of services and influencing work.

One of the biggest lessons I have learned, and one which really influences our work at Macmillan, is that there is a stark difference between a 'good' and a 'bad' death. At Macmillan, we want everyone, where possible, to have a death that's pain-free and in the place of their choosing. This is where the power of talking about death in advance is crucial.

As many of the medical professionals working in clinical roles will already know, having open and honest conversations about dying can be the first step towards having a 'good' death.

When my own mother died of oesophageal cancer a few years ago, we had often talked about her eventual death. Although it was hard making ourselves think about her final days, and about my life without her, I can't express enough how vital it was to know what she wanted. Far from 'giving up' on life, expressing her choice about where she wanted to die, and what her priorities were, was her way of taking control of what happened to her. For me and my dad it meant that, when she finally died, we had the peace of knowing it was what she would have wanted. This would never have happened without us talking about it.

Macmillan knows that not everyone who needs to is given the chance to have these vital conversations. We also know that, too often, people are not dying where they would like to, or in some cases do not even know they get a say on what happens around their final days. We've carried out research into possible reasons for this, exploring attitudes towards dying – among the general public, and people who have cancer – and our initial findings have been illuminating.

Macmillan wants people to be more prepared for dying, and less averse to talking about it. This report will outline some of our initial findings, and aims to start a national conversation, questioning existing attitudes about death.

The only certainty in life is that we will all die. What is less certain is where and what experience we will have when it happens. It's only by talking that we can agree what is really important to us, and put plans in place to make that happen.

Adrienne Betteley PG Dip Res,
BSC (Hons) Specialist Practitioner District
Nursing, RN (Adult)
**Head of Health and Social Care,
Macmillan Cancer Support**

Executive summary

There is a crisis of communication in the UK when it comes to death. Many of us face barriers that stop us talking about dying – and health and social care professionals, too, may be missing key opportunities to bring up the topic. **In fact, around two in three people (64%) think that we do not talk about death enough in this country.**

For those faced with a life-threatening illness like cancer, being able to share thoughts and fears is important. Around three in four of people with cancer have thought about the fact that they may die from their cancer, and around one in five said they think about it 'constantly' or 'often'. Yet just over a third (35%) of these people had not shared their feelings with anyone, and less than a tenth (8%) had spoken to their healthcare team.

Being able to talk about dying is essential when it comes to preparing ourselves for our own death. While it's becoming more and more accepted that everyone should write a will, it's much less common to think about your future care needs. But we need to. With the right support, 64% of people with cancer would like to die at home, but only 30% currently do. Only 1% would like to die in hospital, but 38% of people currently do.

By putting plans in place earlier, and thinking about what matters to you and your family, it may be possible to die 'well', and in the place of your choosing. Improving the way that we die is a huge topic, and not one that we can fully address in one report. But we have carried out initial research into our attitudes towards death and dying, and what some of the barriers to talking could be.

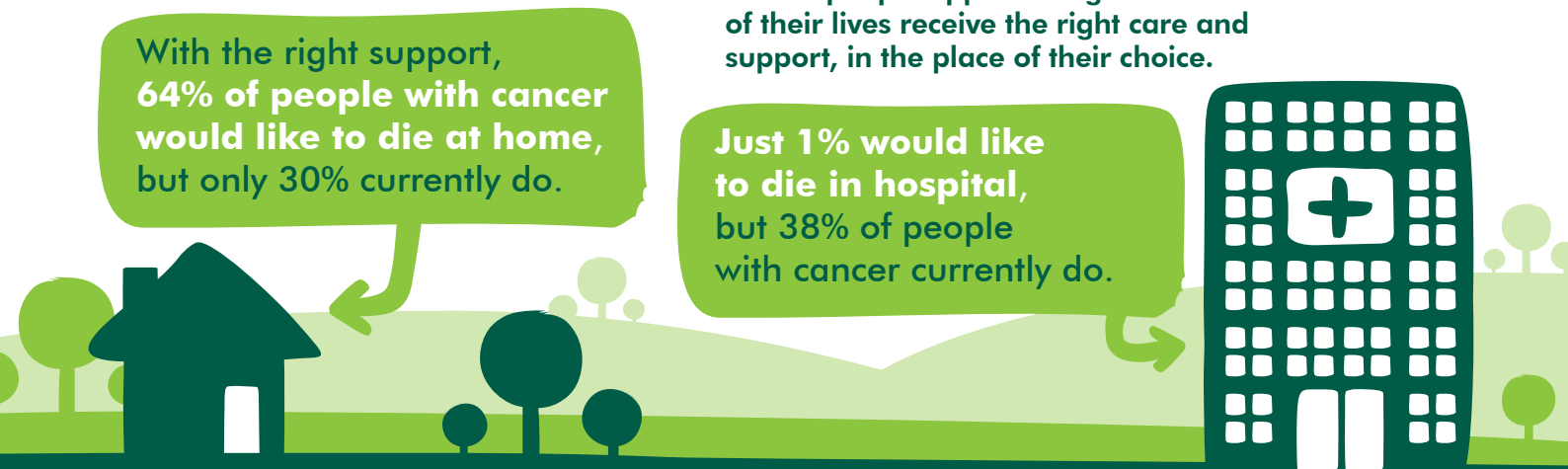
We will explore some of these issues in this report:

- Death as a 'taboo' subject
- The role of planning in improving care for dying people
- What needs to change – and what the UK governments can do.

At Macmillan, we're doing what we can to improve care for dying people, alongside other charities and organisations. But we can't do this alone. **It's vital that the next Government prioritises end of life care so that people approaching the end of their lives receive the right care and support, in the place of their choice.**

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

Just 1% would like to die in hospital, but 38% of people with cancer currently do.



About the research

This report outlines initial findings from three pieces of research:

- Macmillan Cancer Support commissioned ICM Unlimited to survey the general public. The total sample size was 2,096, and 1,786 answered the questions about death and dying. Fieldwork was undertaken between 22nd–24th March 2017. The survey was carried out online. The figures have been weighted to be representative of the population.
- Macmillan Cancer Support commissioned YouGov Plc. to survey people with cancer. The total sample size was 2,005 people with a previous cancer diagnosis, and 1,878 people answered questions relating to death and dying. Fieldwork was undertaken between 20–29 March 2017. The survey was carried out online. The figures have been weighted to be representative of the population of those living with cancer.
- Macmillan Cancer Support commissioned research agency Revealing Reality to carry out an in-depth qualitative study exploring the experiences of cancer patients at end of life and the wider health and social care system. This study included ethnographic methods as well as in-depth interviews with people living with a terminal cancer diagnosis and health and social care professionals.

'A patient I had known for many years convinced me of the importance of Advance Care Planning. Ron could so easily have died in hospital, enduring a futile and undignified attempt at resuscitation. After a hospital discharge, we documented his wishes together. Ron subsequently died at home with his wife present. After Ron's death, I visited his wife and we flicked through Ron's Preferred Priorities for Care (PPC) document. We realised he had achieved the death he had wished for those many months before. This was of great comfort to his wife. Without this planning process, her bereavement experience would have been very different.'

Dr Pete Nightingale GP Macmillan Cancer Support GP Advisor – End of Life Care

About Advance/Anticipatory Care Planning

Advance Care Planning – or Anticipatory Care Planning in Scotland – is the term used for planning ahead for a time when a person's health may change and they lose capacity to make decisions and/or communicate these with others.

The technical term, often abbreviated to ACP, gives the misleading impression that it is a complex process – but it's about thinking, talking, and recording plans.

Putting an Advance Care Plan in place for someone's death involves discussion between the individual and someone from their care team around their wishes. An Advance Care Plan can consider the individual's worries, values, personal goals, and preferences for their care.

Having a record of someone's preferences in advance of their death can significantly impact on their experience. For example, Macmillan has found that:

When staff have a record of where someone would like to die, that person is almost twice as likely to die in the place of their choosing.¹

The problem with talking

There are many reasons why people may not be having early and helpful conversations about death and dying. These are often linked to wider cultural barriers, which we will explore in this section.

Death and cancer as ‘taboo’ subjects

Our research has identified that there is still a considerable taboo around talking about death, and also talking about cancer.

For those who are faced with illness, death may be a sensitive topic, and something that they do not want to face just yet. For others, it may seem far off and irrelevant to them – or, so inevitable and out of their control that there is no point thinking about it, let alone having conversations about it.

When we surveyed the general public, one in seven people (15%) opted out of answering questions about death. This figure rises to 26% among young men. It seems that for some, it may be a topic that they simply don’t want to think about, or which they do not feel is relevant to them.² Fear may be a big part of this. Of the people we surveyed, the vast majority (84%) had fears about death.³

We found that 94% of people living with cancer answered our questions relating to death.⁵ This could be because they have been faced with the prospect of their own death.

Around three in four (76%) had thought about the fact that they might die from their cancer.⁶

23%

Around 1 in 5 people living with cancer said that they thought about their own death ‘constantly’ or ‘often’.⁶

Around two in three people (64%) think that we do not talk about death enough in this country.⁴



But despite this, there was reluctance to voice these concerns. **Just over a third (35%) of people who said they had thoughts and feelings about their death had not shared these feelings with anyone. Only 8% had spoken to their healthcare team.**⁷

When asked why they hadn't shared their worries with anyone, **a fifth (20%) said that they didn't feel comfortable talking about it and around one in five (22%) said that they didn't want to bother anyone.**⁸

More than one in four people with cancer (28%) find it hard to be honest about how they feel about cancer.⁹

'No one has ever discussed making plans with me. No one has even barely discussed the fact that I'm dying. From diagnosis, all the way up to now, there's a total avoidance of the idea that you might not actually make it – even though the consultant is there telling you it's terminal.'

Rhys

Rhys' story

Being able to talk about death, rather than avoiding the reality of it, can be vital, as Rhys' experience shows.

Rhys, 38, was living with his girlfriend Rhea and working as a bartender in Manchester, hoping to go to university to complete a PhD, when he was diagnosed with terminal lung adenocarcinoma in July 2015. In April 2016, Rhea and Rhys got married.

Rhys initially responded well to treatment and lived beyond his initial prognosis. However, his health deteriorated rapidly in October 2016 and in January 2017, Rhys died in hospital with Rhea at his side.

'All of the advice and guidance you get, you have to go and seek it out. It would be so great if a person just came to you and said, 'we should talk about this'. There are bereavement counsellors, and going back to work counsellors, but there's no 'hey, you're going to die' counsellor.' **Rhys**

'We had spoken about what he wanted between us, but we never really put anything formal in place. The whole experience has been really upsetting.'
Rhea, Rhys' wife



Planning a good death

So why is the taboo around death and dying important? It's because there is a vast difference between a 'good' and a 'bad' death – both to the individual and the people they have left behind.

We asked people with cancer where they would like to die, if they had the right care and support:

- **64% of people with cancer would like to die at home;**¹⁰ **only 30% currently do**¹¹
- **Only 1% stated a hospital as their preferred place;**¹² **38% of people currently die in hospital.**¹³

By making it more natural to talk about death, it will be less difficult to have those vital conversations about what someone's final wishes are. If concerns and preferences about care are raised early enough, a lot can be done to make sure they are dealt with. This is what happened with Peter, whose story is to the right.

'When you see someone die in the way you know they want; it can be empowering. If only people could see that a death could be a good one, they would be a lot more passionate about it.'

Macmillan clinical nurse specialist, Palliative Care



Peter's story

Peter, 81, was diagnosed with incurable lung mesothelioma – an asbestos-related cancer – in July 2016 after suffering from chest pains.

He was put in touch with the local hospice who began to work through an Advance Care Plan with him and his daughter, Vivien.

'I told him I wasn't scared of dying but I was apprehensive about dying in pain.' Peter

He died in November 2016 having fulfilled his wish not to die in pain.

'It was great because it didn't leave anything unsaid and brought us closer together. I knew exactly what he wanted and what he was scared of so when it came to the end I knew that he got what he wanted and it made things easier for me to cope with.'

Vivien, Peter's daughter

Peter's story is an example of the value of talking about death. Speaking with his healthcare team and with his daughter about his priorities meant that they could focus on fulfilling his wishes. For Vivien, it helped her cope emotionally with her father's death.

Supporting people to die well

For people to have the kind of death that they and their friends and family would want, it's essential to establish what is important to them.

In some situations, like Peter's, we have seen that pain relief is paramount. But it's only by creating environments where it is acceptable to discuss these issues that we will learn what matters to us, and put plans in place early enough for these to happen.

Make planning normal

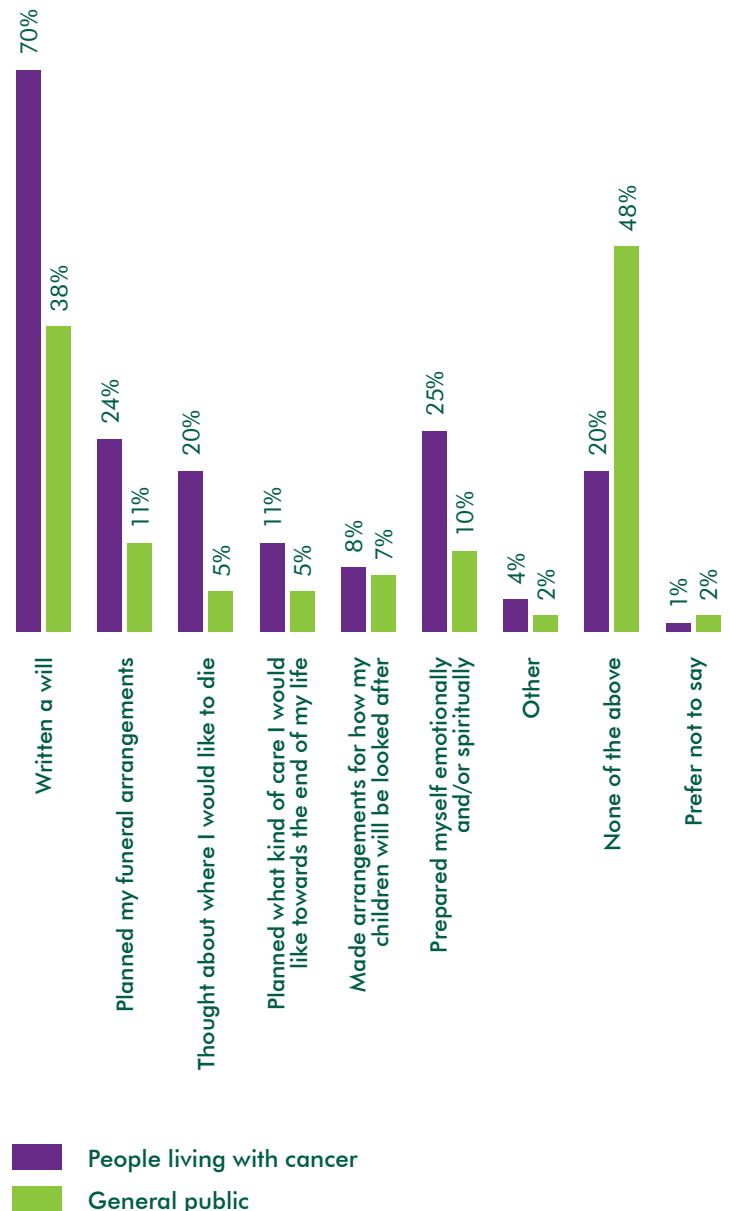
Across our research, many people were undertaking various levels of planning around their death. **Around two in five members of the public (38%) have written a will,¹⁴ and 70% of people with cancer have done so.¹⁵** Rhys, whose story is mentioned earlier, married Rhea in preparation for his death.

However, when it comes to thinking about future care, people are much less likely to have thought about their preferences.

Our survey of the general public found that just one in 20 people (5%) have thought about where they would like to die, and only 5% have planned their future care.¹⁶

Among people with cancer, these figures are higher, but still much lower than those who have made a will. One in five (20%) have thought about where they would like to die, and one in nine (11%) have planned their future care.¹⁷

Ways people have prepared for their death^{14, 15}



Macmillan believes that thinking about your future care should be as normal as writing your will.

Source ICM Unlimited (2017) and YouGov Plc. (2017)

Challenge perceptions

For beneficial conversations around planning to happen earlier and more regularly, we need to challenge existing perceptions that may be barriers:

Thinking or talking about death, and making plans for it, isn't giving up.

In fact, it is taking control of a situation that is otherwise out of your control.

Dying is too important to be left to the end. Dying is a part of life, and one which is – to some extent – in our control.

Take opportunities

For healthcare professionals working with people who have advanced cancer, it is important that they take opportunities where they can. This means having conversations around planning earlier, rather than waiting until the very end.

People also need to be made aware that:

- a 'good' death is possible
- they do have choices around their future care
- with early conversations, these can be managed.

However, recent research found that around two in three UK nurses (67%) feel that they don't have sufficient time to provide high quality care for patients who are dying.¹⁸

Healthcare professionals may be worried about promising certain levels of care which they feel may not be possible.

'Some people are on a rollercoaster and if you don't address something right away the opportunities become less frequent... and then they become too sick to have that conversation.'

**Ollie Minton,
Macmillan Consultant**

Take action

Macmillan believes that everyone at the end of life should receive high quality, personalised care and have their preferences met across all care settings. Across the UK, Macmillan views advance care planning (ACP) as a priority as we know that it can greatly improve people's experience of care; enabling more patients to die in their preferred place and reducing unnecessary hospital admissions.

England

Macmillan in England is calling for the next Government to fully implement the 'National Commitment' on end of life care, as set out in the 2015 Review of Choice in End of Life Care. If delivered, the commitments have the potential to improve the quality and personalisation of care for everyone at the end of life. This includes ensuring everyone is offered a way to express their care choices and preferences in advance, and ensuring staff responsible for the delivery of end of life care have training focused on the key elements of their roles which enable choice – such as advance care planning.

Scotland

In Scotland, Macmillan's current priority is to keep end of life care high on the Government agenda. We contributed to the development of the 2015 Strategic Framework for Action on Palliative and End of Life Care and now look to its implementation. The framework outlines the key actions to be taken that will allow everyone in Scotland to receive services that respond to their individual palliative and end of life care needs – which we believe is the right way forward.

Wales

Macmillan in Wales believes that for people who are no longer curative and are dying from cancer, their ongoing care and treatment needs to be planned holistically. With the support of primary care and through advance care planning (ACP), every effort should be made to ensure that people are able to be cared for and die in the place of their choice and that where possible, avoidable emergency admissions to hospital during this stage of illness are prevented.

Northern Ireland

Macmillan in Northern Ireland contributed to the development and implementation of the Living Matters, Dying Matters Strategy 2010–2015. We now want to see new policy developments for ongoing progress in end of life care and patient experience. We are calling for a comprehensive cancer strategy to include improvements in the quality and availability of personalised end of life care.

What Macmillan is doing

Specialist Care at Home

We have been working with six centres to deliver our Macmillan Specialist Care at Home service. This multidisciplinary team led by a Specialty Doctor and GP with Special Interest in Palliative Care provides community-based care to people with cancer and other life-limiting conditions towards end of their life. People are referred to the team early, allowing them enough time to build strong relationships, plan ahead and provide practical and emotional support when needed. With Macmillan Specialist Care at Home, we anticipate to avoid unplanned admissions, with people spending fewer days in hospital and being more likely to die in their preferred place of care. To date, in Hull, 95% of patients identified under the project's data achieved their preferred place of care.

Building on the best

We have formed partnerships with the National Council for Palliative Care in England, and the Scottish Partnership for Palliative Care in Scotland. We are supporting 10 sites in England and three in Scotland as they seek to improve the quality of their services. Colleagues from Wales and Northern Ireland will join the programme community of practice to learn from current initiatives taking place, and will take the lessons learned back to their local contexts. One of the key aims of this project is to have earlier conversations, involving patients and their families, about their care so they can be part of each decision and to take the opportunities offered by outpatient appointments to discuss advance and anticipatory care planning.

Get support

If any member of the public would like support or information, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit [macmillan.org.uk](https://www.macmillan.org.uk)

'Your life, your choices', Macmillan's booklet on Advance/Anticipatory Care Planning, can be downloaded at [be.macmillan.org.uk](https://www.be.macmillan.org.uk). There is a version for England and Wales, Scotland, and Northern Ireland.

This booklet explains how you can plan ahead for your future care. It discusses creating a Lasting Power of Attorney, writing down how you'd like to be cared for using a Preferred Priorities for Care document and writing Advance Decisions to Refuse Treatment. It also has information about making a will, organ and tissue donation, and funeral planning.

References

1. Macmillan analysis of Office for National Statistics, NHS England. (2015). National Survey of Bereaved People, 2014.
2. ICM Unlimited (2017). Macmillan commissioned ICM Unlimited to survey the general public. Total sample size was 2096, and 1786 answered our questions about death and dying. Fieldwork was undertaken between 22nd–24th March 2017. The survey was carried out online. The figures have been weighted and are representative of the population. Respondents were asked: “The next set of questions relate to issues about death and dying, including thoughts and feelings about your own death. If you would prefer not to answer these questions, please select the option below. Are you happy to continue to this section relating to issues about death and dying?” 15% of all respondents answered ‘No I would like to skip this section’, 25% of men aged 20–39 answered ‘no I would like to skip this section’.
3. ICM Unlimited (2017). Respondents were asked: “To what extent are you afraid of the following potential issues related to death?” 13% selected, ‘None of the above – I am not afraid of death’, meaning that 87% are afraid of death.
4. ICM Unlimited (2017). Respondents were asked: “To what extent would you agree or disagree with the following statement about death? We don’t talk about death and dying enough in this country”. 18% strongly agree, and 47% somewhat agree.
5. 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. Fieldwork was undertaken between 20th – 29th March 2017. The survey was carried out online. The figures have been weighted and are representative of the population of those living with cancer. Respondents were asked: “The next set of questions relate to people’s views related to death and dying, including some sensitive issues that some people with cancer may find upsetting. We are asking about this area because we know that many people find it difficult to talk about, and our client hopes to use the results to help people feel more comfortable talking about these issues. Are you happy to answer this section?”
6. YouGov Plc. (2017). Respondents were asked: “Have you thought about the possibility that you may die of your cancer?” Answers included constantly (6%), often (16%), sometimes (27%), occasionally (26%), never (24%) and prefer not to say (0%).
7. YouGov Plc. (2017). Respondents who had thought about the possibility they may die from their cancer were asked: “Since you were diagnosed, have you ever shared your thoughts or feelings about death or dying with any of the following people? Please tick all that apply.”

8. YouGov Plc. (2017). Respondents who hadn't shared their thoughts or feelings about death with anyone were asked: "You said that you have not ever shared your thoughts or feelings about death or dying with anyone. Could you tell us why this is? Please select all that apply."
9. YouGov Plc. (2017). Respondents were asked: "To what extent do you agree that these statements apply to your feelings about your experience of cancer? I sometimes find it hard to be honest about how I feel about cancer" Strongly agree 7%, and somewhat agree 21%.
10. YouGov Plc. (2017). 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?"
11. ONS, 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> In 2015 in England and Wales, 37% of people aged over 28 days who died from cancer died in an NHS hospital, 30% died at home or a private address, 17% died in a hospice, 14% died in a care home and 2% died elsewhere. ISD Scotland. Place of death for cancer. <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Place-of-Death/> (accessed April 2017). In 2015 in Scotland, 43% of people who died from cancer died in a hospital, 30% died at home, 19% died in a hospice and 8% died in a care home or elsewhere. Equivalent data not available for Northern Ireland. Combined using a weighted average, these figures show that in the UK, 38% of people who die from cancer die in hospital and 30% die at home.
12. Ibid 10
13. Ibid 11
14. ICM Unlimited. (2017) Respondents were asked "Have you prepared for your death in any of the following ways?"
15. YouGov Plc. (2017) Respondents were asked: "Now thinking about your eventual death in the future (in general – not necessarily related to cancer). Have you prepared for your eventual death in any of the following ways? Please select all that apply)".
16. Ibid 14
17. Ibid 15
18. Nursing Standard and Marie Curie, February 2017: <https://www.mariecurie.org.uk/media/press-releases/nurses-dont-have-enough-time-to-care/152288>

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** or visit **macmillan.org.uk**

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

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