

# Treatable but not curable cancer

New research shows there are at least 130,000 people living with a 'chronic' form of cancer in the UK – and tens of thousands are not getting the support they need

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This brief report presents estimates of how many people in the UK are living with 'treatable but not curable' cancer – cancer that can very rarely be cured<sup>i</sup>, but can be treated to help manage symptoms or slow the progression of the disease and extend people's lives.

In this report we show who is living with these more 'chronic' forms of cancer, highlight what issues they face – and call for urgent action from the governments across the UK to help them get the support they need.

## How many people are living with treatable but not curable cancer?

New research from Macmillan Cancer Support and Public Health England's National Cancer Registration and Analysis Service (NCRAS)<sup>ii</sup> estimates there are **around 110,000 people in England who are currently living with treatable but not curable cancer**<sup>iii</sup>.

This includes an estimated:

- 48,000 people whose cancer was already advanced (stage 4) by the time they were diagnosed<sup>iv</sup>
- 27,000 living with an incurable blood cancer such as myeloma
- 1,000 living with mesothelioma (a type of cancer usually linked to asbestos exposure)
- 12,000 living with other types of cancer that were diagnosed at an early stage but have advanced to an incurable stage<sup>v</sup>

The new figures are based on analysis of routinely collected national health data combined with expert clinical opinion - see the 'About the Macmillan-NCRAS research' section on page 5 for more information.

The research has been carried out using data for England only. If the data showed a similar story across the rest of the UK, Macmillan estimates there could be around 12,000 people living with treatable but not curable cancer in Scotland, around 7,000 in Wales and around 3,500 in Northern Ireland<sup>vi</sup>. This adds up to around 130,000 people in the UK.

In addition, new Macmillan analysis of official figures suggests that **each year** in Scotland, Wales and Northern Ireland, there could be:

- At least 3,500 people newly diagnosed with stage 4 breast, prostate, bowel or lung cancer who will live for more than a year from diagnosis<sup>vii</sup>
- At least 800 people newly diagnosed with myeloma or mesothelioma who will live for more than a year from diagnosis<sup>viii</sup>

Some people will have treatable but not curable cancer from the moment they are diagnosed, while others will progress to having treatable but not curable cancer if their cancer continues to spread or comes back.

## What issues do people face with treatable but not curable cancer?

Further research by Macmillan shows that people with treatable but not curable cancer often need a great deal of emotional, physical and financial support. Most will face a prolonged and complicated treatment pathway involving repeated tests, procedures, medications and hospital appointments. Many face **uncertainty every day** and have specific needs that can change over time.

The uncertainty faced by people with treatable but not curable cancer can be all-consuming. Healthcare professionals often find it much harder to say how this kind of cancer might progress, and patients can find their physical and emotional health is very unpredictable. This can affect both small and big decisions, stop people being able to plan for the future, and make them feel that they don't have control. Some will have to continually monitor their health for symptoms as part of a 'watch and wait' approach, which can lead to anxiety and hypervigilance<sup>ix</sup>.

People with treatable but not curable cancer are also likely to need different or more detailed information to other people with cancer on many topics, such as their likely prognosis, what clinical trials are available, and how best to keep track of their health and their care and treatment. Many people with cancer face communication challenges such as new or confusing terminology and a reduced ability to concentrate and process information due to chemotherapy. For those with a more chronic form of cancer, these challenges are often made worse by the difficulty of talking about a life-limiting prognosis, having prolonged treatment involving multiple decision points, which can add to stress and anxiety, and having many different healthcare professionals involved in people's care<sup>x</sup>.

## Are people getting enough support with these issues?

The right support can help people with cancer to live life as fully as they can, including those with treatable but not curable cancer. However, in October 2019, Macmillan published new research that showed 68% of people recently diagnosed with or treated for cancer in the UK were **not getting all the support they need**

**with issues related to their cancer<sup>xi</sup>**. This figure rises to 77% among those with treatable but not curable cancer<sup>xii</sup>. According to our new estimates, this could represent around 100,000 people in the UK<sup>xiii</sup>.

The research also shows that compared to people recently diagnosed with or treated for cancer overall, those with treatable but not curable cancer are:

- More likely to have concerns about **worry, fear or anxiety** (58% of those with treatable but not curable cancer have these concerns compared with 52% of those with cancer overall)
- More likely to need more support with **pain** (45% compared with 36%)
- More likely to need more support with **sleep problems** (40% compared with 34%)
- More likely to need more support with **feeling exhausted or fatigued** (51% compared with 42%)

Other research from Macmillan suggests that there is a lack of support for emotional issues in particular<sup>xiv</sup>.

## Why aren't people getting the support they need?

The UK's health and social care services are not set up to meet the long-term needs of people with cancer in general, and this is a particular problem for those with treatable but not curable cancer. For example, palliative care can help relieve people's symptoms at any stage of their cancer, not just at the end of life, but there is a lack of clarity on when people with treatable but not curable cancer should be referred.



At Macmillan we believe one of the most urgent issues is that there are **simply not enough staff with the right skills and resources** to give people with treatable but not curable cancer the personalised care they need.

Macmillan's previous research showed that around one in five people recently diagnosed with or treated for cancer (19%) say the **healthcare professionals working on their care seemed to have an unmanageable workload**<sup>xv</sup>. This rises to more than one in five (22%) of those with treatable but not curable cancer – possibly because they are likely to spend more time in hospital and are therefore more aware of the current pressures on the NHS.

Having enough staff with the right skills and resources would mean they have enough time to have difficult conversations with people with treatable but not curable cancer, help explain their complex prognosis and also help identify and offer support for their non-clinical needs.

Thanks to the generous donations of the UK public, Macmillan is doing what it can to support people with treatable but not curable cancer. We provide physical, financial and emotional support to help them live their lives as fully as they can – see [www.macmillan.org.uk/tbnc](http://www.macmillan.org.uk/tbnc) for more information. We're also exploring how cancer care services can be improved to better meet people's needs. But we can't do it alone.

**Macmillan is calling for the governments across the UK to produce and deliver a funded plan to grow and sustain the NHS and care workforce to meet people's needs.**

## Appendix 1: How long people can live with treatable but not curable cancer

Advances in treatment and care mean **people may now live for several years with treatable but not curable cancer**. In some cases, having this kind of cancer can at times be similar to living with another long-term condition such as multiple sclerosis or type 1 diabetes.

People are now living for longer with many types of treatable but not curable cancer and official figures show there have been significant improvements in recent years. For example, half of people diagnosed with myeloma in England (50%) are as likely to live for a further five years as the general population, up from around a third (34%) ten years previously<sup>xvi</sup>. There have been similar improvements in relative five-year survival rates elsewhere in the UK, although the figures are not directly comparable as the time periods and methods involved vary: Scotland (47% compared with 33%<sup>xvii</sup>), Wales (45% compared with 34%<sup>xviii</sup>) and Northern Ireland (53% compared with 35%<sup>xix</sup>).

However survival rates for other types of treatable but not curable cancer remain dismally low. For example, fewer than one in 20 people with mesothelioma in England (5%<sup>xx</sup>) and fewer than one in 30 in Wales (3%<sup>xxi</sup>) are as likely to live for a further five years as the general population.

There is limited data on trends in how long people are living with stage 4 cancer. In England, the five-year net survival rate for women diagnosed with stage 4 breast cancer is 26%, and for men diagnosed with stage 4 prostate cancer it is 49%<sup>xxii</sup>. Previous research by Macmillan and NCRAS showed there are at least 17,000 people in England who have survived for



two years or more after being diagnosed with stage 4 cancer<sup>xxiii</sup>.

As well as seeing more people live longer with treatable but not curable cancer, Macmillan also wants to make sure people's needs are being met so that their **quality of life is as good as possible** during that extra time.

## Appendix 2: About the Macmillan-NCRAS research

Until now, little has been known about the numbers, needs and experiences of people living with treatable but not curable cancer. There is currently no direct measure of whether someone has treatable but not curable cancer in the UK's cancer registries, which makes it difficult to estimate the number of people affected. Macmillan and NCRAS therefore worked with over 20 oncologists, haematologists and specialist nurses to develop a set of rules and surrogate markers to estimate the size of this population in England. These rules first identified how many people in the England cancer registry have specific cancer types and stages at diagnosis that we have categorised as treatable but not curable from the point of diagnosis. We then identified additional people who showed signs of metastatic disease, or disease-modifying or palliative treatment, either at diagnosis or afterwards. For this we used additional information from a different set of routinely collected national health data (the chemotherapy, radiotherapy, hospital episode statistics and cancer waiting times data sets).

To get the best estimate of those living with treatable but not curable cancer specifically, rather than people approaching the end of life, we then excluded people who were in their last year of life. Our figures are based on people

living in 2015, who met our criteria for having treatable but not curable cancer between 2012 and 2015, and who were not in their last year of life.

Our work provides a **best estimate** for the treatable but not curable cancer population, and there are limitations to the analysis. This work is ongoing and the number will be refined further.

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<sup>i</sup> By 'very rarely be cured', we mean that there is general consensus that with current standard/approved treatment, eradicating disease is very unlikely. This means that if people with this type of cancer do not die from another cause beforehand, they will almost certainly have their lives shortened by their cancer.

<sup>ii</sup> Macmillan Cancer Support/National Cancer Registration and Analysis Service (Professor Jane Maher). Estimating the number of people living with treatable but not curable cancer in England using the cancer registry. Oral presentation at the 2019 National Cancer Research Institute conference. November 2019. Results shown have been further refined in March 2019. See [www.ncin.org.uk/about\\_ncin/releases](http://www.ncin.org.uk/about_ncin/releases) for further details.

<sup>iii</sup> People alive in 2015 who showed evidence of treatable but not curable cancer between 2012 and 2015. The treatable but not curable cancer population only includes those who were not in their last year of life on the 31<sup>st</sup> December 2015.

<sup>iv</sup> Based on people with a stage at diagnosis recorded in the registry. In 2012, 64% of all cancer had a recorded stage and in 2015, 80% had a recorded stage. NCRAS. [Stage breakdown by CCG 2017](#).

<sup>v</sup> Based on all cancers (except haematological cancers and mesothelioma), diagnosed at stage 1 to 3, who met the search criteria for treatable but not curable cancer a year or more after their cancer diagnosis.

<sup>vi</sup> 110,000 people represents around 14% of 5-year cancer prevalence in England (796,500). The crude estimates shown for Scotland, Wales and Northern Ireland are based on applying that percentage to 5-year prevalence for 2015 in those nations (86,900, 50,600 and 25,100 respectively). Source of prevalence figures: [NCRAS PHE](#), [ISD Scotland](#), Macmillan Cancer Support Local Cancer Intelligence (LCI) [Wales](#) (February 2019) and [Northern Ireland](#) (December 2018).

<sup>vii</sup> Crude estimate based on analysis of incidence and survival from [ISD Scotland](#), the [Welsh Cancer Intelligence and Surveillance Unit \(WCISU\)](#) and the [Northern Ireland](#)



[Cancer Registry](#). We have applied one-year net survival rates to incidence figures to estimate an upper limit for how many people will live for at least a year following diagnosis. Calculation does not take into account background survival however, survival data from Scotland includes both actual/observed and relative survival, and shows there are usually relatively small differences between the two for one-year survival (for example, for prostate, all stages, aged 15-99, it is 6 percentage points). Incidence is for 2015/16 for Scotland, 2015 for Wales, and 2013-2017 for Northern Ireland. Data is not publicly available for all nations for all featured cancer types, so some further estimates have been made; for example, survival rates by stage are not routinely published in Scotland so we have used England survival rates to produce our crude estimate. Survival for Scotland is based on survival rates for those diagnosed between 2013-2017 in England. Survival for Wales is based on survival rates for those diagnosed between 2012-2016 in Wales, and survival for NI is based on survival rates for those diagnosed between 2008-2012 in NI for all cancers except lung which is based on 2005-2012. All data accessed October 2019.

<sup>viii</sup> Method as per vii. Incidence is for 2015 for Scotland, 2015 for Wales, 2015 for Northern Ireland myeloma and 2016 for Northern Ireland mesothelioma. For myeloma survival for Scotland is based on 2007-11 diagnosis, Wales is based on diagnosis 2012-2016, and NI is based on 1993-2016. For mesothelioma survival for Scotland and Northern Ireland is based on 2013-18 diagnosis in England and Wales is based on diagnosis 2012-2016.

<sup>ix</sup> Internal insight based on in-depth interviews with people living with treatable but not curable cancer and healthcare professionals supporting those affected

<sup>x</sup> As per ix

<sup>xi</sup> Macmillan Cancer Support and Populus paper and online survey of 6,905 people recently treated for, or diagnosed in the last 5 years with, cancer across the UK. Fieldwork July-September 2019. Survey data has been weighted to be representative of recently treated cancer population in terms of age, gender and cancer type within England. The weighting of England, Scotland, Northern Ireland and Wales has been based on cancer prevalence data.

<sup>xii</sup> In this research, treatable but not curable disease was identified based on cancer diagnosis (e.g. myeloma) or those who indicated that their cancer had spread from where it started to another organ in their body. This can sometimes be called secondary, metastatic or stage 4 cancer (excluding specific cancers such as brain and Hodgkin lymphoma). This is comparable to the population included in the Macmillan-NCRAS estimates of the total

population size, but relies on patients knowing if their cancer has spread rather than using routinely collected national health data. The routinely collected national health data also has incomplete data and so may not include all cases where the cancer has spread. The treatable but not curable population in the survey excludes those who reported that someone involved with your care has told them there is a risk they might not live 12 months. By contrast the NCRAS-Macmillan work identified those in their last year of life based on a prospective analysis of deaths. Treatable but not curable figures are significantly different when compared to all respondents who did not fall into the treatable but not curable definition.

<sup>xiii</sup> If we apply the 77% to our estimate of 130,000 people, we get around 100,000 people

<sup>xiv</sup> As per ix

<sup>xv</sup> As per xi

<sup>xvi</sup> Office for National Statistics. Cancer survival in England - adults diagnosed [2001-2014 backseries due to methodology change](#). The five-year net survival rate for myeloma was 49.9% for those diagnosed between [2010-14](#) and 33.7% for those diagnosed between 2001-2005 (based on age-standardised rates). Data accessed October 2019.

<sup>xvii</sup> ISD Scotland. [Multiple myeloma and malignant plasma cell neoplasms: trends in survival by age group and period of diagnosis](#). The relative age-standardised five-year survival rate for myeloma was 47.2% for those diagnosed between 2007-11 and 33.2% for those diagnosed between 1997-2001. Data accessed October 2019.

<sup>xviii</sup> Welsh Cancer Intelligence and Surveillance Unit (WCISU). [Cancer survival in Wales, 1995-2016](#). The unstandardized net five-year survival rate for myeloma was 44.5% for those diagnosed between 2012-2016 and 33.5% for those diagnosed between 2002-06. Data accessed October 2019.

<sup>xix</sup> Northern Ireland Cancer Registry. [Multiple myeloma: Incidence, prevalence and survival statistics: 1993-2017](#). The net five-year survival rate for myeloma was 52.6% for those diagnosed between 2007-11 and 34.7% for those diagnosed between 1997-2001. Data accessed October 2019.

<sup>xx</sup> Office for National Statistics. [Cancer survival in England: adults diagnosed](#). Non-standardised net survival relates to those diagnosed between 2013 and 2017.

<sup>xxi</sup> Welsh Cancer Intelligence and Surveillance Unit (WCISU). [Cancer survival in Wales, 1995-2016](#). Unstandardised net survival relates to those diagnosed between 2012 and 2016.

<sup>xxii</sup> As per xx. Age-standardised net survival for those diagnosed 2013-17



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<sup>xxiii</sup> The number of patients alive in 2015 who were diagnosed with cancer at stage 4 and who were diagnosed between 2013 and 2012 (people who have survived 2 to 4 years). It includes the following cancer types bladder, female breast, colorectal, kidney, renal pelvis and ureter, lung, trachea and bronchus, melanoma of skin, non-Hodgkin lymphoma, ovary, prostate and uterine cancer. The 17,000 is an underestimate as there are a further 43,000 patients alive in 2015 who were diagnosed between 2 and 4 years ago but the stage at diagnosis was not recorded in the registry – many of these patients are also likely to have had stage 4 disease. White R, Maher J, Macmillan Cancer Support. Describing the Three Cancer Groups. Presented at; 2017 NCRl Cancer Conference, Liverpool UK and personal communication with Public Health England’s National Cancer Registration and Analysis Service

