



# The hidden challenges of palliative cancer care



Care and support  
through terminal illness

February 2016

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# Foreword

It is a sad truth that 167,000 people in the UK still die from cancer each year<sup>1</sup>. Yet, as this report shows, access to high-quality care and support, including palliative care, is not a universal experience for these people or their families. Wider research shows that one in four people don't get the care and support they need at the end of their life<sup>2</sup>. This is unacceptable.

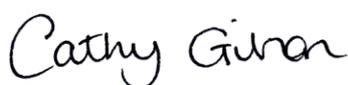
While much of the research around cancer is rightly directed at finding a cure, it is also important to focus on the needs of the people who are living and dying with cancer right now. As this report sets out, this area of research has been chronically underfunded, so even a small increase would be significant and meaningful.

We know that having a particular condition, such as blood cancer or a brain tumour, can result in additional barriers to getting great care and support, which then impacts further on quality of life. Seemingly simple things like good communication and being treated like an individual can make such a difference, but this doesn't always happen.

Our organisations are committed to making sure that people affected and their families are supported by the best possible care and research following diagnosis. We want to help in creating an environment where people can talk about their needs and wishes, while strengthening conversations about what needs to happen to ensure excellent care for every individual. We hope this report will provoke more of these vital conversations.



Dr Jane Collins  
Chief Executive, Marie Curie



Cathy Gilman  
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**Bloodwise**  
Beating blood cancer since 1960



Sarah Lindsell  
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The Brain Tumour Charity

**The BRAIN  
TUMOUR  
CHARITY**

# Introduction

*“At Marie Curie, we believe everyone has the right to palliative care when they need it, regardless of where they live or their personal circumstances. We are committed to working across the UK to ensure that everyone who has a terminal illness, and their families and carers, can access the care and support they need.”*

Dr Jane Collins, Chief Executive

The UK is judged to lead the world in end of life care<sup>3</sup>, and there is an idea that “cancer is the best death” because, as written by a former editor of the *British Medical Journal*, “you can say goodbye, reflect on your life ... and prepare”<sup>4</sup>. With the right level of high-quality care, as well as support for family and friends, people can be supported to live as well as possible until they die. However, we know that people with terminal cancer and their families still go without having their needs fully identified and met in a compassionate, dignified and timely way.

## What is palliative care?

Palliative care is the active, holistic care of people with advanced progressive illness, involving management of pain and other symptoms and the provision of psychological, social and spiritual support. It can be delivered alongside particular treatments, such as chemotherapy or radiotherapy. Palliative care aims to help people with advanced illnesses or at the end of their lives have the best possible quality of life. This also includes support for their families.

Specialist palliative care is typically delivered by a team with diverse expertise in caring for people with progressive and life-limiting illness.

## Identifying the challenges

In 2015, Marie Curie commissioned the London School of Economics and Political Science to review evidence on inequities of access to palliative care<sup>5</sup>. While the review found that people with cancer were typically more likely than those with a different terminal condition to receive specialist palliative care, it also found inequalities within cancer diagnoses. People who continue to receive aggressive treatment, such as chemotherapy, towards the end of their life and people with blood cancers were found to be especially likely to miss out on specialist palliative care.

People with brain tumours and their families also face additional, often distressing, challenges as they deal with the impact on their emotional and mental health and their ability to communicate. Work by Marie Curie and the James Lind Alliance has identified that this area requires significantly more research. Based on 1,403 responses from health and social care professionals, carers and people who have a terminal illness, the following unanswered question is one of the top 10 relating to palliative and end of life care research<sup>6</sup>:

What are the best ways to assess and treat pain and discomfort for those with communication and/or cognitive difficulties?

## Working together for change

This report looks at the evidence about palliative and end of life care for people with cancer based on a review of the literature, while highlighting personal experiences of how communication and care can break down.

We have chosen to concentrate on the experiences of people with blood cancer or a brain tumour because we know that these diagnoses are more likely to be associated with unmet care and support needs. However, we know that the type of cancer someone has is not the only thing affecting how likely they are to access the help they need, with factors such as age and deprivation also playing a part<sup>7</sup>. There is also wider evidence to suggest that people with cancer and other terminal conditions are not being referred to palliative care early enough<sup>8</sup>.

The recommendations at the end of this report set out what we want to see happen to reduce unmet need for everyone affected by terminal cancer, and many are applicable to people with other terminal conditions.

# Is palliative cancer care fit for the future?



Layton Thompson/Marie Curie

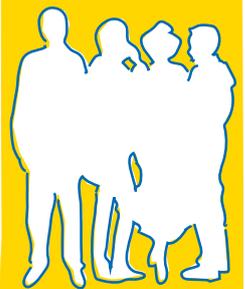
In the past 40 years, cancer survival has doubled in the UK<sup>9</sup>. Yet even with these improvements in survivorship, cancer still causes more than one in every four deaths<sup>10</sup>. Although the mortality rate for cancer is decreasing, the number of people dying from cancer is expected to increase from 157,000 deaths in 2010 to 193,000 deaths in 2030<sup>11</sup>. This is due to factors such as the UK's ageing population and variation in survivorship across different types.

**157,000  
deaths**



The number of people dying from cancer in 2010

**193,000  
deaths**



The number of people expected to die from cancer in 2030<sup>11</sup>

It is essential that the provision of quality palliative and end of life care stays high on the agenda for cancer care and that it adapts to the evolving nature of cancer mortality in the UK.

### Ageing population

As people live longer they are also more likely to develop numerous health conditions, which may include cancer, and multimorbidity is becoming the norm<sup>12</sup>. By 2040, older people will account for 77% of all people living with a cancer diagnosis, an increase from 66% in 2015<sup>13</sup>. This has significant implications for how services are organised, as models of care based on specialisation around a particular condition may not be appropriate to multiple needs and individual wishes.

### Different diagnoses

There has not been equal improvement in cancer survivorship across different types of cancer<sup>14</sup>. For example, there has been little if any improvement in survival for people with brain tumours<sup>15</sup>.

The number of people who die from rare or less common cancers has also increased, despite the number of diagnoses remaining in line with general trends. As of 2013, there were around 2,700 more deaths annually (compared to 2010) from cancers other than the most common types, i.e. not breast, colorectal, prostate or lung cancer. Rare and less common cancers make up more than half (54%) of all cancer deaths<sup>16</sup>. The National Cancer Patient Experience Survey identifies that people with rarer cancers sometimes report poorer quality care<sup>17</sup>.

## Palliative care: the sooner, the better

Palliative care is appropriate for people who have a complex illness such as cancer and who need their symptoms controlled, especially when their illness is advanced and progressive. This is why robust population-based estimates of need for palliative care include everyone who dies from cancer<sup>18</sup>.

### Missed and delayed referrals

Research has shown that not everyone with terminal cancer is formally identified as needing palliative care. For example, data from general practices across Scotland found that a quarter of people who died from cancer were not included on their practice's palliative care register<sup>19</sup>. Those that were included were identified on average seven weeks before their death, even though the time between their diagnosis and death was an average 27 weeks. Referrals to specialist palliative care were made five weeks before death on average.

These delayed referrals come despite research evidence across different types of cancer that earlier involvement of palliative care services can:

- improve quality and length of life<sup>20,21</sup>
- result in fewer hospital admissions and reduce the likelihood of dying in hospital<sup>22</sup>
- help family carers to have lower levels of anxiety and depression<sup>23</sup>

Access to community-based palliative care nursing, such as the Marie Curie Nursing Service, is also associated with cost savings<sup>24</sup>.

## Lack of funding

Research into palliative care and the best ways to provide care and support to people living with terminal illness is a chronically underfunded area.

- Analysis by the UK Clinical Research Collaboration's Health Research Classification System found that – of more than £2 billion of health-related research in the UK in 2014 – only 0.16% was spent on end of life care<sup>25</sup>.
- The National Cancer Research Institute Database shows that, since its launch in 2002, the funding for cancer-related palliative and end of life care research has been consistently below 0.7% of the total spent on cancer research in the UK<sup>26</sup>.

Everybody dies, and many of us will be affected by terminal illness. More research is needed into palliative care, so we can understand how and when to provide services that are of maximum benefit.

## The importance of good communication

People with cancer, and their families, often face difficult decisions about treatments, in addition to the associated stress, emotions and symptoms.

Doctors play a crucial role in communicating information to their patients in a sensitive and understandable way. However, this role is not always fulfilled, for example due to:

- not enough research into the best treatment options to properly inform these conversations

- limited understanding of when palliative care is appropriate
- lack of confidence in having these difficult conversations
- healthcare professionals not always following best practice

## Balancing hope and uncertainty

Our conversations with people who have been bereaved by cancer have shown that limited understanding about the likely risks or side effects, compared to the benefits, of certain treatments can leave families feeling unsure about their decisions.

“A lot of the drugs are to counteract the impact of the other drugs, rather than treating the main part of the disease. Had we known that the chemotherapy would have so little effect on the tumour, and would produce so many side effects, I'm not sure we would have wanted to go through with it. There was a lot of collateral damage, which you might accept if it's halting the progress of the tumour, but it didn't.”

Peter, whose wife Wendy died six months after she was diagnosed with an aggressive brain tumour.

Sometimes, family members will have conflicting information needs. For example, a caregiver may want to know in detail what to expect as the cancer progresses, while the person with cancer may prefer not to know. Family carers take on a significant amount of the caring role when someone has cancer<sup>27</sup>. It is therefore crucial that their information needs are met and they are supported in this role.

“As Tim didn’t want to know too much about what was going on and might happen in the future, the dilemma we faced as parents was: how much do we find out? How much should we know that he doesn’t want to know? How could we prepare ourselves to be the conduit for information that he may not want now, but might want in the future?”

John, whose son Tim died from blood cancer.

As every person is different, no clinician can give someone a fully accurate prognosis or a definite account of the outcome or side effects they will experience if they undergo certain treatments. They face a difficult job of “balancing hope and uncertainty”<sup>28</sup>

“Mr S was in his eighties when he was diagnosed with lung cancer. The Trust did not consider him suitable for treatment but he obtained a second opinion which said he could have radiotherapy. Mr S made a full recovery... Mr S suffered considerable shock and anguish at being given a prognosis of terminal illness.”

Case investigated by the Parliamentary and Health Service Ombudsman<sup>29</sup>

while advising their patient based not just on statistical likelihoods, but on an understanding of them as an individual and their personal wishes. Sometimes this is not done well, which can have damaging effects.

Ensuring doctors receive enough training and support to have these difficult conversations is essential to improving people’s experiences of care. However, recent work by the British Medical Association found that many doctors feel uncomfortable about having to give uncertain answers, especially in relation to life expectancy, and very few say they have had adequate training in discussing death and dying with patients<sup>30</sup>. This means many have to develop these important skills on the job.

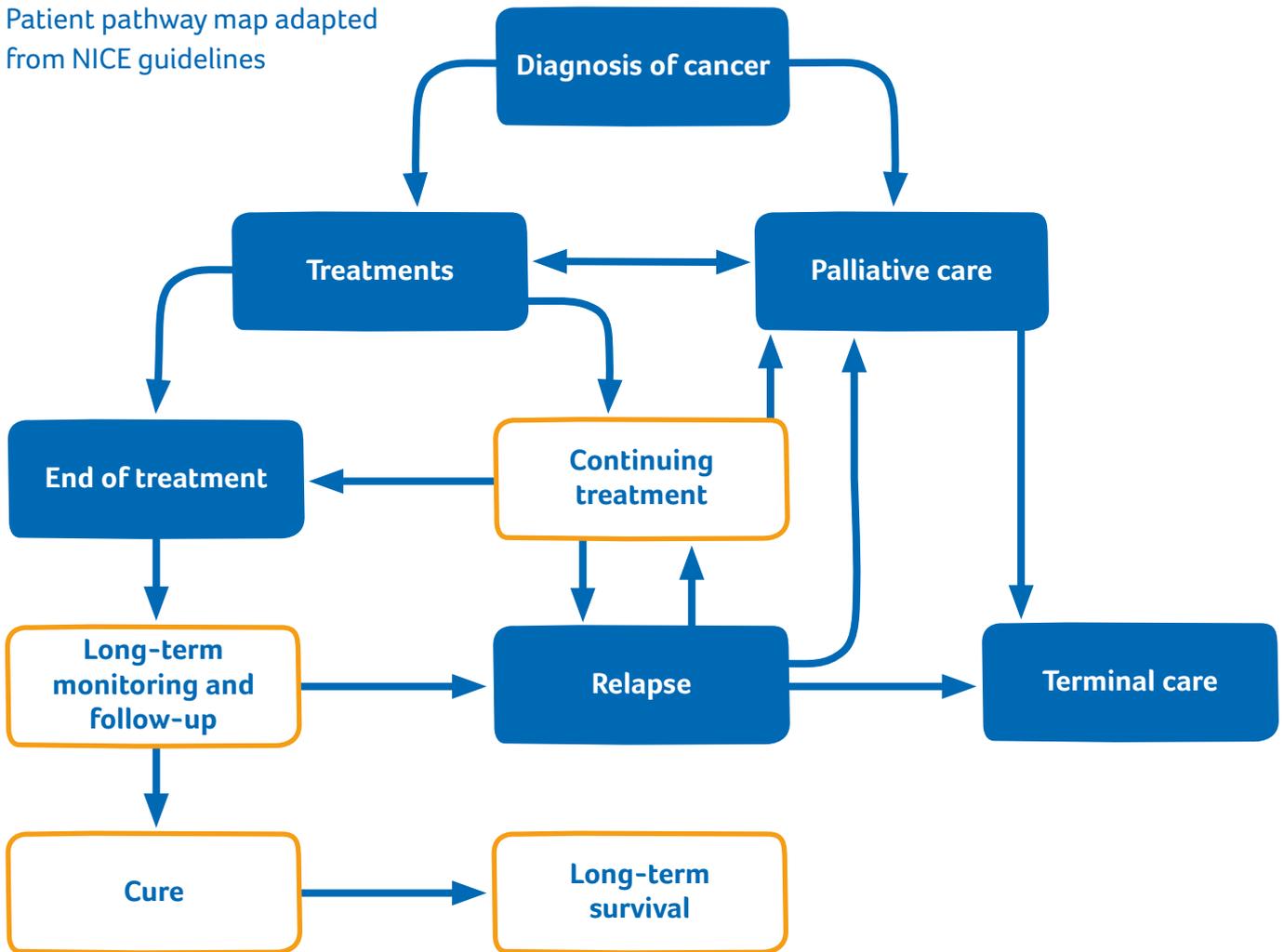
## Understanding of palliative care

Palliative care is appropriate for people with advanced, progressive conditions, but this does not mean it should only be considered when all other options have failed or when a person is considered to be at the end of their life.

The National Institute of Health and Care Excellence (NICE) guideline, Improving Supportive and Palliative Care for Adults with Cancer, clearly sets out that palliative care is a key point in the patient pathway following diagnosis

which may be offered at the same time as active treatments<sup>31</sup>. Marie Curie has previously called for earlier, ongoing and episodic involvement of palliative care for people in need<sup>32</sup>.

Patient pathway map adapted from NICE guidelines



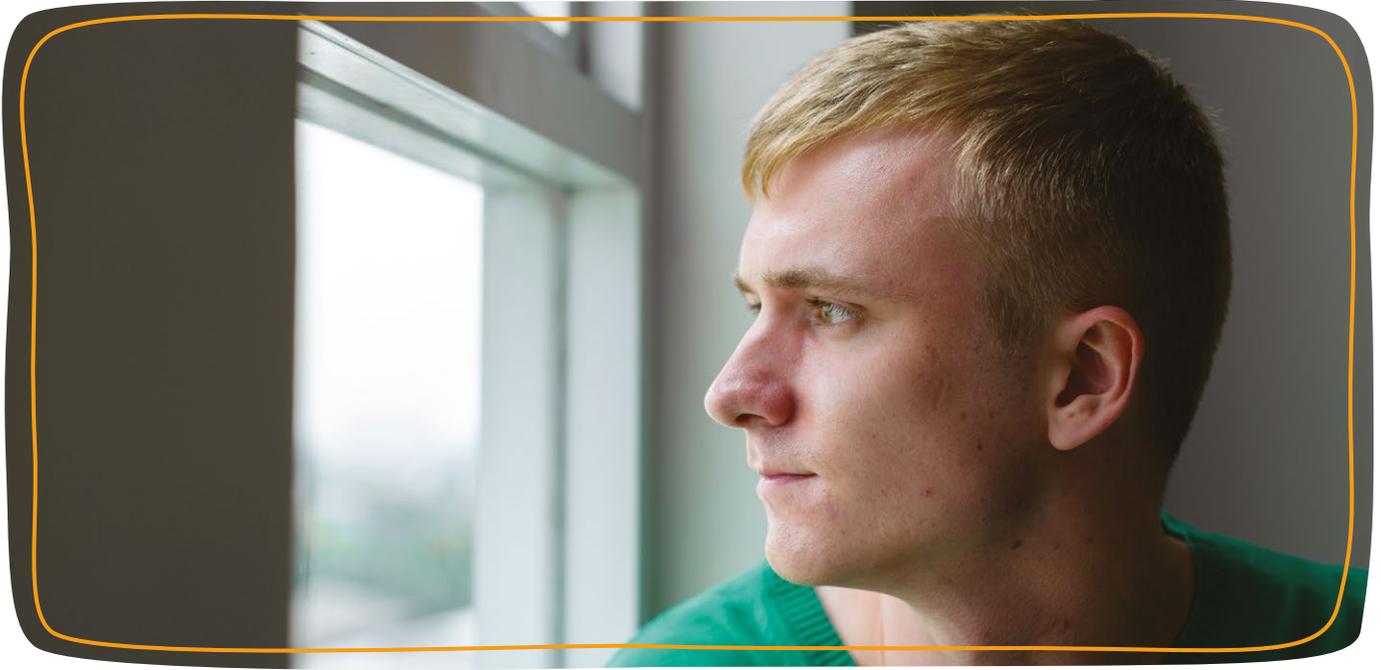
However, it has been found that public awareness “remains insufficient” around the concept and availability of palliative care<sup>33</sup>. This may mean that palliative care is feared because of its association with dying, and avoided until there are no other treatments<sup>34</sup>. With cancer care in particular, it can also mean that people undergo more aggressive forms of treatment – such as palliative chemotherapy – without understanding that it’s not intended

to cure their cancer, but should help to relieve symptoms and perhaps increase life expectancy.

The need for effective communication about the likely outcomes of treatments is critical here; yet studies have found that between one-third and four-fifths of patients with advanced cancer believe that palliative chemotherapy might cure their disease<sup>35</sup>.

# Living and dying with blood cancer

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The most common blood cancers (also referred to as haematological malignancies) include leukaemia, lymphoma and myeloma, but there are more than 100 types and related disorders. Every year in the UK, there are about 12,000 deaths from blood cancer<sup>36</sup>.

Research by the London School of Economics and Political Science has found that people with blood cancer are less likely to access specialist palliative care than people with other types of cancer<sup>37</sup>. This is despite NICE recommendations for effective integration between haematology teams and palliative care services throughout the course of a person's illness, not just when the terminal phase is acknowledged<sup>38</sup>.

Survey work by the charity Bloodwise has found that people with blood cancer, and their carers, report feeling that their cancer is different to others in respect of:

- levels of awareness in primary care settings
- the provision of care through haematology units rather than oncology
- the perceived availability of support services that are directed at their specific needs<sup>39</sup>

This may mean that people miss out on available support because they do not feel it is meant for them.

In this section, we highlight people's experiences of good and bad care, alongside research about the care that

people with blood cancer receive as they approach the end of their life. This evidence draws attention to barriers that might prevent people from accessing the high-quality care and support they need.

### Rapid progression

Some blood cancers behave like chronic conditions and a person may live with their diagnosis for many years, only needing occasional support to manage their symptoms. Others are very acute and there may only be a short time between diagnosis and the end of life. For example, research by Bloodwise has found that, in acute myeloid leukaemia and diffuse large B-cell lymphoma, half of deaths happen within three months of diagnosis<sup>40</sup>.

“She had a lump in her neck, which turned out to be leukaemia and lymphoma. She died just four weeks after she was diagnosed. The doctors said she had six to nine months to live but, in the end, it was much quicker. The whole situation was such a shock for all the family.”

When Wendy’s mum Florrie was diagnosed with cancer, her condition progressed much more quickly than expected.

Research has found that:

- a shorter length of time between diagnosis and death is associated with lower likelihood of palliative care referral<sup>41</sup>
- people with blood cancer who die within a month of diagnosis are twice as likely to miss out on discussing their preferred place of death<sup>42</sup>

### Hospital rather than home

Research has found that people with blood cancer are twice as likely to die in hospital compared to people with other cancers<sup>43</sup>. Yet we know that, in general, almost two-thirds of people say they would prefer to die at home<sup>44</sup>.

An analysis of 40,000 deaths from blood or bowel cancer in the UK found that nearly two-thirds (64%) of people with blood cancer died in hospital, compared to less than half (47%) of the people with bowel cancer<sup>45</sup>. The analysis found that time between diagnosis and death had a strong influence on place of death, and that 90% of those who died in hospital were admitted as an emergency, meaning it was unplanned.

Choice has become a focus of UK end of life care policy in recent years. Our research suggests that people with blood cancer and their families too often miss out on the choices.

“We hadn’t talked about it, but I am almost sure if he had a choice, Tim would have wanted to be at home.”

John’s son Tim wanted to focus on getting better, but John felt that more could have been done to prepare the family for what was coming.

## Advance care planning

Palliative care clinicians are more likely to engage patients in discussions about their end of life wishes than other healthcare professionals, and research shows a clear link between involving palliative care teams in terminal blood cancer cases and evidence of advance care planning<sup>46</sup>.

However, place of death should not by itself be taken as representative of whether an individual's preferences have been met. Some people with blood cancer may die in hospital but on a palliative care ward<sup>47</sup> while others may be more likely to choose to die in a hospital's haematology unit because they have developed a close relationship with the team providing their care<sup>48</sup>.

## Missed conversations

Blood cancers are relatively distinct from many cancers involving solid tumours because of their potential to respond to curative treatment, even when the disease is advanced<sup>49</sup>. Prognosis can be difficult because of the potential speed of change to a terminal diagnosis, and for many individuals the goal of treatment will be curability or long-term survival<sup>50</sup>.

The transition from cure-focused to end of life care can therefore occur very quickly for people with blood cancer which, as shown in this report, can mean people miss out on palliative care referral and a chance to fully discuss their end of life wishes.

## Lack of training and confidence

For many people with blood cancer, their care will primarily come through haematology teams rather than oncology.

A study published in 2014, based on in-depth interviews with a small group of haematologists in the West Midlands, revealed that a lack of palliative care training was a concern for all participants. It notes that "haematology specialist training was biased towards laboratory medicine, leaving trainees naïve to the fact that most haematology involved management of patients with terminal illness"<sup>51</sup>. While appreciating the benefits of earlier referral to palliative care, participants:

- felt uncomfortable referring patients with potentially curable disease, even when the chance of a cure was relatively low
- avoided referring at the point of diagnosis in case patients were overwhelmed or confused by conflicting information

More research is needed to ensure that the services, conversations and options available to people with blood cancer meet their needs and wishes.

# Living and dying with a brain tumour



Layton Thompson/Marie Curie

More than 5,000 people die from a brain tumour each year and brain tumours have a relatively low survival rate when compared to other cancers<sup>52</sup>. Brain tumours are the leading cause of cancer death for children and adults under 40<sup>53</sup>. However, there are significant variations depending upon factors such as tumour type.

In this section, we focus on the needs of people who have a brain tumour that is likely to lead to their death, and the needs of their family and carers.

Research suggests that some people with brain tumours face difficulties in accessing specialist palliative care in

a timely way, which can result in them missing out on the support they need, while variations exist based on where people live<sup>54</sup>.

When surveying people who had a brain tumour with a terminal diagnosis, The Brain Tumour Charity found that:

- more than half (55%) hadn't been given a choice of end of life care options<sup>55</sup>
- almost half (49%) had not been given appropriate information about end of life care<sup>56</sup>
- many also reported worrying about the strain they felt their condition placed on loved ones<sup>57</sup>

## Practical needs

Living with a brain tumour often means coping with life-changing symptoms, such as mental and emotional health issues, and communication and mobility problems. It may mean that additional help is needed with daily tasks, such as dressing, washing, and moving around, and reduced mobility can lead to extra problems, such as bedsores.

People with brain tumours may also develop additional medication needs if they have difficulty swallowing. Professionals need to be prepared to manage this common symptom properly and, wherever possible, medication should be available in an appropriate form to prevent unacceptable mistakes. But people tell us that this isn't always happening.

“There were very basic but potentially very damaging errors in getting the right medication, as he was unable to chew tablets and needed medicine in liquid form. Following a miscalculation by the GP, he was prescribed ten times the recommended dose of anti-depressant, which could have been fatal if he had taken it, and the mistake was not properly dealt with by the pharmacist.”

Beth cared for her dad Terry when he was diagnosed with glioblastoma multiforme.

## Cognitive and emotional needs

People with a primary malignant tumour may experience cognitive problems, such as short-term memory loss, personality changes and altered mood<sup>58</sup>, as well as distressing physical symptoms, such as seizures, which can take a significant toll on the individual and their family.

As transition from diagnosis to palliative care can be quick for those with the most aggressive types of tumour, coming to terms with a terminal diagnosis while learning to cope with difficult symptoms can be incredibly challenging<sup>59</sup>.

## Lack of support

Many people living with a brain tumour experience depression and emotional distress<sup>60</sup>. Despite this, families tell us that they feel they are not given enough support to cope with the illness and its symptoms. Some report that their loved one was never offered help with the depression they developed following their diagnosis.

“He began to suffer from anxiety and OCD as his confidence hit an all-time low. It was difficult watching him slowly being taken apart, piece by piece. People tell you that you are brave and strong, but inside you feel only pain and fear ... there are few opportunities to express any of this so the only option is to internalise it, where it causes more harm.”

Helen's husband Chris struggled with depression as a result of his brain tumour.

Medical professionals involved in the care of people with brain tumours have also echoed these concerns. One clinical nurse specialist published his views about the care and support available to people with high-grade glioma, and their families. He writes:

“The diagnosis of a brain tumour often provokes pity and fear. However, this is not good enough. To professionals, the diagnosis should give rise to the realisation of the catastrophic consequences for patients and their families. This should in turn encourage us to have a better understanding of the illness, so as to allow us to provide the best possible care and support.”<sup>61</sup>

The clinical nurse specialist’s article also references cases of senior professionals dismissing a patient’s distress over a symptom they consider ‘trivial’ in the context of the illness – such as loss of the sense of smell, or appearance changes resulting from steroid use or surgery<sup>62</sup>. These demonstrate the importance of trying to understand a patient’s needs on a personal, human level, and not just treating them as a collection of symptoms.

“Although we had friends and neighbours, increasingly Wendy didn’t want to see them. She couldn’t speak, she had no hair, she had a swollen face from the steroids. Ladies are always quite proud of their appearance. She didn’t want to be seen like it.”

Peter cared for his wife Wendy after she was diagnosed with an aggressive form of brain tumour.

## Communication needs

Speech problems are a common symptom of a brain tumour and, as the illness progresses, people may develop serious barriers to communication, while their intelligence is unaffected. This can be very upsetting for them and those close to them.

“It’s difficult to say in all of this that one aspect was worse than any other, but if there was one it was the fact that she couldn’t communicate. And she found that so frustrating.”

Peter’s wife Wendy lost the ability to speak as her illness progressed.

## Person-centred communication

Simple things, like calling someone by their preferred name or talking about a topic that interests them, is an important part of helping people maintain their identity and dignity. However, families tell us that healthcare professionals do not always relate to them as individuals.

“They didn’t understand his condition and treated him more like someone who had had a stroke, or had dementia. They didn’t make an effort to get to know him, and would talk to him about things he wasn’t interested in, like football. They also didn’t attempt to understand him when he tried to communicate with them, such as when he pointed to a picture of me and said ‘Japanese’ to tell them I could speak Japanese. They didn’t ask the family about it to try and make a connection.”

Beth felt that those who cared for her dad Terry didn’t try to understand him as a person.

### Difficult conversations

Healthcare professionals need to sensitively communicate what a diagnosis is likely to mean for the individual and their family. For some families, the consequence of a doctor avoiding this conversation is that they are given little opportunity to come to terms with the disease being terminal.

“The neuro-oncologist just kept giving us false hope. He would say ‘well, we’ve got patients who’ve survived four years or five years’ as if that was the norm, and was what we could expect. Wendy was dead within six months. At no point were we told it was incurable, terminal.”

Peter’s wife Wendy died six months after being diagnosed with a brain tumour.

### Families and carers

A recurring theme in the research is that more needs to be done to help carers and families cope with the particular, often demanding, needs associated with brain tumours<sup>63</sup>.

### Physical challenges

Brain tumours can impair people’s ability to move freely by themselves. Family members often take on a lot of responsibility for helping their loved one with routine tasks such as dressing and going to the toilet. This can mean a significant change in the dynamic of a relationship, which can be emotionally distressing.

“Initially Chris was able to get dressed and washed independently ... further through the illness he suffered from intense fatigue and depression which meant that he lost both interest and the ability to care for himself. He would struggle with making decisions and require a long time to think things through. I can’t imagine how difficult that must have been for someone who was usually so bright and active.”

Helen cared for her husband Chris.

## Emotional challenges

Brain tumours are also associated with mental and cognitive changes. Caring for someone with cognitive difficulties is linked to high levels of stress and anxiety<sup>64</sup>.

Research has found that carers of people with a brain tumour need support with adjusting to changes in the mental capacity of the person they care for, as well as coping with:

- difficult behaviour and personality changes<sup>65</sup>
- disorientation and confusion, which may also have a significant impact on social structures<sup>66</sup>
- financial difficulties<sup>67</sup>

## Lack of guidance

An English study based on in-depth interviews found that people caring for a family member with a brain tumour “lack guidance on how to access information at different stages of the caring journey”<sup>68</sup>. Inadequate support for carers can then impact on the care journey of the person they are caring for, with carer breakdown being associated with emergency hospital admissions<sup>69</sup>.

Family carers have also told us that inadequate provision of community care prevented their loved one from dying at home.

“I didn’t feel that we had been given a choice – I was at the end of my tether and they could probably see that, but I would have preferred to have had support looking after my husband at home. In the absence of that, the hospice was presented to us as the only option.”

Helen’s husband Chris died when his sons were seven months and five years old.

More needs to be done to ensure that people with brain tumours, and their families, receive care and support that meets their needs and wishes.

# Ensuring the best for everyone



Layton Thompson/Marie Curie

There are many examples of excellent practice in palliative and end of life care and support across the UK, particularly in relation to cancer care. However, the evidence and personal experiences contained in this report show that more needs to be done to ensure that:

- care and support is accessible when and where it's needed
- people living with a terminal illness and their families are always treated with dignity and respect

To make this a reality, it is essential that:

## **Palliative care is offered to people sooner, not just when they are close to the end of life**

Marie Curie believes everyone has the right to palliative care when they need it, regardless of where they live or their personal circumstances. Although a number of policy papers and guidelines

recognise the benefits of introducing palliative care earlier, this report shows that, in reality, people with cancer may be just weeks from death before they are referred.

## **Healthcare professionals are trained and supported to meet people's palliative care and communication needs**

In 2008, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviewed deaths that occurred within 30 days of receiving anti-cancer treatment. The review found evidence of inappropriate decisions to treat and, in many cases, little evidence of patient's wishes being documented if their condition suddenly deteriorated<sup>70</sup>.

Based on this evidence, the NCEPOD recommends that palliative care should be a core part of training for

all healthcare professionals and a requirement for continuing professional development. However, we know that doctors<sup>71</sup> and nurses<sup>72</sup> say this still isn't happening.

People have repeatedly told us they felt that professionals didn't communicate with them in a personal or sensitive way, or failed to meaningfully explain a treatment option. One way to improve this would be to mandate that all undergraduate courses include a compulsory clinical attachment to a specialist palliative care team. This would help trainees to understand early on how to navigate these situations and the need to focus on the person in front of them at a difficult time. Training and research should also focus on the particular needs of people who have communication difficulties.

### **Community care is resourced to meet need now and in the future**

Experiences shared in this report reveal inadequate care in the community, including a lack of support for family carers. The availability of high-quality care allows people to go home or into a care home from hospital, and support for family carers is a vital element of this.

Provision of social care plays an important part, but so does having access to clinical specialists and someone who can take on the role of care coordinator. For example, the 2014 National Cancer Patient Experience Survey showed that the single most important factor associated with high patient scores is the patient being given

the name of a clinical nurse specialist (CNS) in charge of their care, but one in 10 people with cancer don't have a CNS<sup>73</sup>. Ensuring that CNS coverage reaches 100%, and that they have enough time to help patients, would be a step towards ensuring that people with cancer have a better experience.

### **Information is made available to improve public understanding of palliative care**

This report has found that there is limited understanding of palliative care by the public, and that healthcare professionals may avoid referring a patient because they do not want to confuse or overwhelm them. Efforts to improve public understanding of palliative care, what it means and who it can benefit, could empower patients to make more informed decisions about treatments, and improve communication between patients and doctors.

### **Greater investment flows into quality of life, palliative and end of life care research**

Research into the best ways of providing care for people who have a terminal diagnosis is chronically underfunded. In 25 years, an extra 100,000 people will die each year<sup>74</sup>. Research investment is needed to ensure that services are configured and delivered in the most effective and efficient ways. The findings of the Palliative and End of Life Care Priority Setting Partnership provide an important foundation to inform future research<sup>75</sup>.

## Calls to action

Across the UK, Marie Curie is calling for specific actions to improve care:

### In England

Marie Curie calls for NHS England to ensure implementation of the 2015-2020 Cancer Taskforce strategy's recommendation to pilot "assessment of holistic needs for cancer patients at the point of diagnosis, evaluating the benefit of earlier palliative care"<sup>76</sup>.

We also continue to call on NHS England to improve the availability of out-of-hours palliative care support so it is in line with the NICE quality standard<sup>77</sup>.

### In Scotland

Marie Curie calls for the Scottish Government to ensure that its proposed Cancer Plan, due to be published in early 2016, includes:

- specific reference to palliative care and its benefits for those living with terminal cancer
- a commitment to ensuring that all cancer patients who need palliative care have access to it from the point of need
- reference to the new Strategic Framework for Action on Palliative and End of Life Care in Scotland, which was published in December 2015

### In Wales

Marie Curie calls on the Welsh Government to ensure that the refreshed Cancer Delivery Plan specifically identifies the need to ensure equity of access to palliative care, regardless of cancer diagnosis.

In addition, NHS Wales should conduct a bereavement survey, with respondents being able to describe their experiences based on the nature of cancer diagnosis.

### In Northern Ireland

Marie Curie recommends that the Department of Health publishes the review of Northern Ireland's Service Framework for Cancer Prevention, Treatment and Care, and incorporates its findings into the further implementation of the framework.

# Appendix: UK cancer and palliative care policy

## England

Two million people were estimated to be living with cancer in England in 2015. By 2030, this number is predicted to rise to 3.4 million<sup>78</sup>. Results of successive National Cancer Patient Experience Surveys show that, in many areas, people's experiences of cancer care are improving, and the 2014 survey found that 89% said their overall care was excellent or very good<sup>79</sup>. However, areas for improvement included communication around side effects and information for caregiving at home.

In January 2015, NHS England announced a new independent Cancer Taskforce. The group was tasked with developing a five-year action plan to improve survival rates, speed up diagnosis, and improve the care and after-care available to people diagnosed with cancer. Care at the end of life was identified as one of six challenges that need to be addressed<sup>80</sup>. The resulting strategy for 2015-2020 identifies several needs, including:

- earlier palliative care referrals and an assessment of needs and benefits
- improved access to community care
- increased support for people with cancer and their families in making decisions about their care as they approach the end of their life

This reflects a government commitment to support commissioners

in combining better health and social care services for people with a terminal illness, so that more are able to die in a place of their choice<sup>81</sup>.

## Scotland

Every year, around 31,000 people in Scotland are told they have cancer, excluding non-melanoma skin cancer. This is predicted to rise to over 40,000 cases by 2027<sup>82</sup>, largely as a result of the ageing population.

Cancer is a clinical priority for the Scottish Government and NHS Scotland. In 2008, the Scottish Government published Better Cancer Care, An Action Plan<sup>83</sup> which outlined priorities to improve cancer services and support. A progress report was published in 2010<sup>84</sup> in which further priorities for action were identified and the Scottish Cancer Taskforce<sup>85</sup> is responsible for taking them forward.

Other recent developments include:

- 2012: the Cabinet Secretary for Health and Wellbeing launched the Detect Cancer Early programme<sup>86</sup> to improve cancer survival through earlier diagnosis and treatment.
- 2013: the Transforming Care After Treatment programme<sup>87</sup> was launched to support a redesign of care following active treatment of cancer.

- December 2015: the Scottish Government published the Strategic Framework for Action on Palliative and End of Life Care. The framework outlines key actions to allow everyone in Scotland, including those with a terminal cancer diagnosis, to receive services that respond to their individual palliative and end of life care needs.

## Wales

In 2015, more than 19,000 people were diagnosed with cancer<sup>88</sup>. If current trends continue, 7% of the population in Wales will be living with or after cancer by 2030<sup>89</sup>. Despite rising survival rates, cancer is still the leading cause of death in Wales.

The Welsh Government has a target that 95% of patients diagnosed with cancer should start treatment within 62 days of being referred from their GP.

- For the quarter ending September 2015, 85.6% of patients started cancer treatment within 62 days, which is below the agreed standard, but 31% higher than five years ago<sup>90</sup>.
- Missing the 62-day target can be due to difficulties in diagnosing the cancer, or because the required treatment is complex. However, this is not always the case and more could be done by health boards to ensure patients are treated quicker.

The first annual report of the end of life care plan was published in 2014 and shows that Wales is the only UK country to provide 24/7 consultant-led specialist palliative care advice services to professionals<sup>91</sup>.

The Welsh Government want people who die in Wales to have access to high-quality care wherever they live, whatever their underlying disease or disability, and regardless of personal situation. However, statistics and case studies show that this isn't always the case.

## Northern Ireland

Each year from 2009 to 2013, an average 8,777 people were diagnosed with cancer, excluding non-melanoma skin cancer<sup>92</sup>. There are currently 63,000 people living with cancer in Northern Ireland and this is predicted to rise to 100,000 by 2030<sup>93</sup>.

Northern Ireland is the only region in the UK not to have a current cancer plan. However, a number of frameworks and strategies relating to the provision of cancer and palliative care in Northern Ireland have been published in recent years, including:

- the Service Framework for Cancer Prevention, Treatment and Care (2011)<sup>94</sup>
- Living Matters, Dying Matters (2010)<sup>95</sup> – Northern Ireland's palliative and end of life care strategy
- Transforming Your Palliative and End of Life Care Programme<sup>96</sup>

While the timeframe of Living Matters, Dying Matters and the Transforming Your Palliative and End of Life Care Programme came to an end in 2015, it has been agreed that they will be encompassed within a single palliative care policy agenda and structure for the future.

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**We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.**

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