



Marie
Curie

Care and support
through terminal illness

The hidden costs of caring

December 2015

Contents

Introduction	3
What do we mean by carers in this report?	5
What do we mean by terminal illness?	5
What do carers of people with a terminal illness do?	6
The economic contribution of carers	7
The costs of caring	8
The physical cost	8
The emotional cost	9
The financial cost	10
When caring ends	12
Loneliness and isolation	12
The financial costs carry on	14
Who will care in the future?	15
UK policy context	16
England	16
Wales	16
Scotland	17
Northern Ireland	17
Conclusions and recommendations	18
References	20

Introduction

In the UK, over 1 million people say they are supporting or caring for family members who have a terminal illness¹.

Each of their experiences of caring is unique. Some have provided care for a long time but are now dealing with the person they're caring for nearing the end of their life. Others have only recently taken up the role after a loved one has received a terminal diagnosis.

All have a different understanding of what it means to be a carer and to provide care to a loved one. Many don't even see themselves as a 'carer'; they think of what they do as simply part of being a husband, wife, daughter or son.

What all these people have in common is that the person they are caring for will die in the near future. That will be a profound transition for them. They will have to deal with grief, financial issues, funeral planning, and probably their own mental and physical health issues.

While this is the time when carers are at their most vulnerable, it is also when all the services that were arranged around the person they were caring for stop being provided. The sudden removal of these services can leave bereaved people feeling extremely isolated and alone.

In many cases, carers will continue to feel a negative impact on their health, mental wellbeing and financial circumstances long after the person they cared for has died.

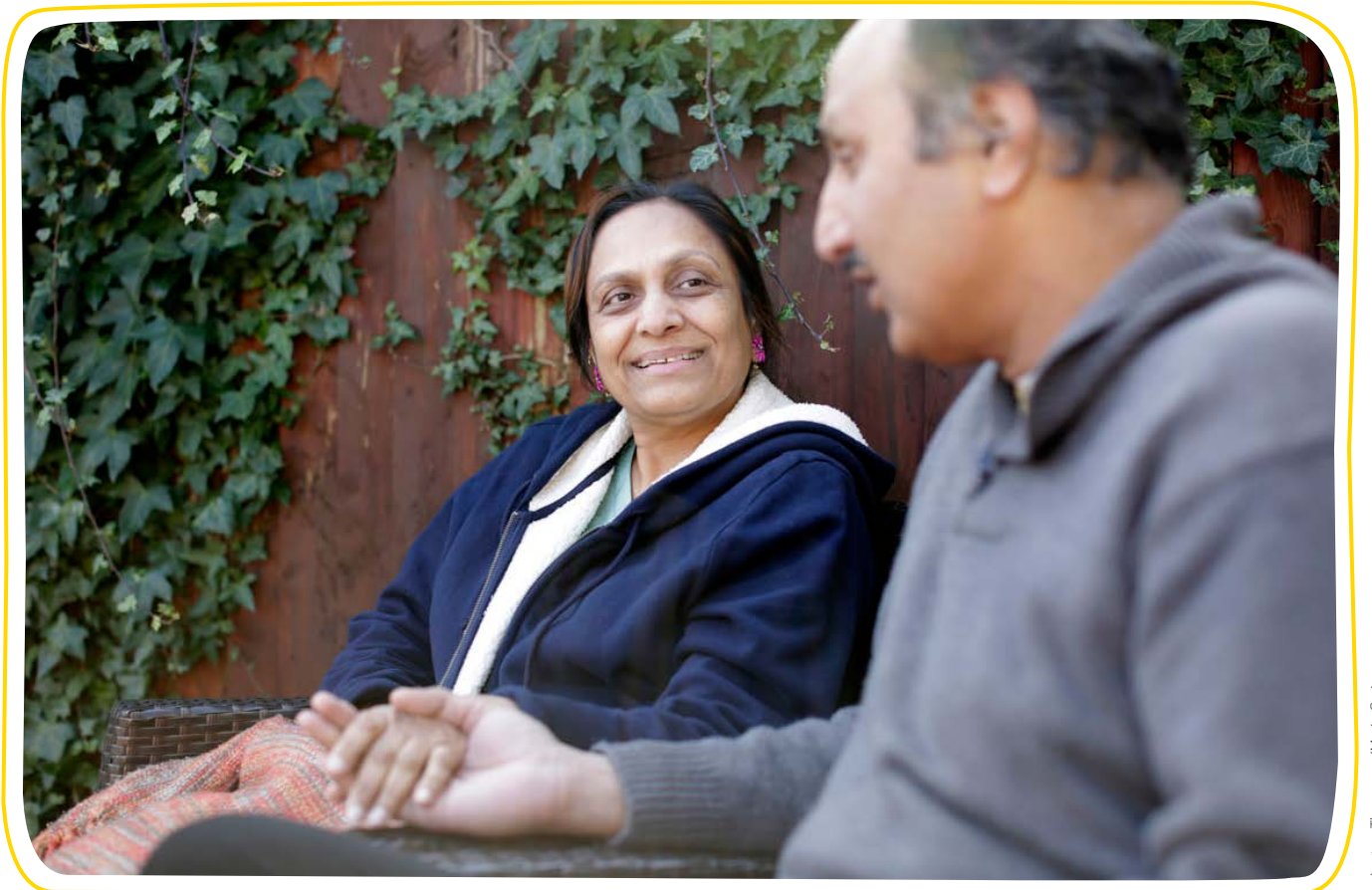
Carers are a huge asset to the UK, saving the state billions in health and social care spending each year². Family carers play a critical role in supporting people with a terminal illness so they can be cared for and die at home when this is their wish³. People with spouses or partners who can look after them are the most likely to die at home, and are more likely to experience better pain control⁴.

Much of the recent policy focus on end of life care has recognised the need to shift care out of hospitals and into the community, to people's homes and care homes, so it is more in line with where people want to be cared for and to die.

Evidence shows that the shift from acute to community care also makes economic sense; when good community support is available, dying at home rather than in hospital costs the system less⁵. However, while this approach does save the health service money, it also places even greater financial, physical, and emotional demands on carers.

Over the coming years, the need for care is only going to increase as more people live longer with complex, life-limiting conditions. By 2040, an extra 100,000 people will be dying each year, and most of these will have needed long-term care or support⁶ – so the demands for and on carers will be greater than ever.

It is therefore vital that further policy focus on end of life care includes a thorough assessment of the needs and costs carers face as they support a loved one in their final months and days, and after caring ends.



Layton Thompson/Marie Curie

What do we mean by carers in this report?

In this report we are discussing the issues affecting unpaid or informal carers. This is in contrast with formal carers, who include health and social care professionals.

A carer in this context is someone who provides unpaid care and support to a family member or friend who is ill, disabled or older and in need of care.

Often, carers will have no training for their role. Many family members and friends who provide significant amounts of care for loved ones do not see themselves as carers. Many of these people therefore remain hidden to support services, and get no help.

What do we mean by terminal illness?

We say someone is living with a terminal illness when they have reached a point where they, or their medical team, carers or loved ones, understand their illness is likely to lead to their death. Depending on their condition and treatment, they may live for days, weeks, months or even years after this point.

Terminal illness includes a wide range of different illnesses and individual needs. People may have a single disease or a number of conditions.

Some will experience a steady period of deterioration towards the end of their life, which is typical for people with many types of advanced cancer. Others, such as those with heart or respiratory disease, are likely to experience a more unpredictable cycle of crises and periods of remission. This can make it very difficult to predict how long that person is likely to live.

Caring for someone with a terminal illness will therefore be an individual experience depending on many factors, including what condition or conditions the person who needs care has.

What do carers of people with a terminal illness do?

Carers of people with a terminal illness provide vital unpaid support to a family member or friend through to the end of that person's life. They help with practical tasks (housework, shopping and cooking) or personal care (dressing, washing, going to the toilet), and provide emotional support. They also play a key role in coordinating and communicating with the many professionals who become involved in someone's care when they have a terminal illness.

Carers face complex and sometimes unpredictable issues as the person they support nears the end of their life. These may include meeting increasing care needs as their loved one's health deteriorates, as well as heightened emotional and spiritual needs⁷. Some carers say they have been made to feel upset and guilty by healthcare professionals, who fail to recognise that they have not had any training to perform this highly complex role⁸.

- **Janice cared for her father, Stephen, with her sister Tracey until his death in 2011 from bile duct cancer at the age of 55.**

“We felt a huge burden of responsibility; responsibility to care and nurse him and also responsibility to know when things weren't right. It was really frightening, particularly as he was in a lot of pain.”

The needs of carers of people with a terminal illness are hard to assess and are likely to change over time⁹. For example, this may happen when their loved one's condition worsens, if they are moved into residential care, or if they lose the ability to communicate¹⁰. It is also important to remember that the needs of carers are likely to change once again after bereavement.

Becoming a carer can be a gradual process. Relatives will often not see themselves in this way, but simply as a wife, husband, son or daughter, who are sharing the journey with their loved one¹¹. In some cases people feel that taking on this role leads to a loss of their sense of self or a change in the relationship with the person they are caring for¹².

- **Gail's mum Sheila was diagnosed with head and neck cancer in June 2008. Gail and her siblings cared for Sheila until her death in 2010, without the support of formal carers .**

“I regretted that afterwards, that I wasn't able to take a step back from the day-to-day care and be her daughter like she would have liked me to be.”

The economic contribution of carers

There are 6.5 million people providing care for a loved one who is older, disabled or seriously ill in the UK today, which is one in ten of the population¹³. By providing this care and support for free, carers save the economy around £132 billion, or more than £19,300 per carer, each year¹⁴. This is very close to the total amount spent on health in the UK (£134.1 billion), and almost double the value of care provided in 2001.

In the UK, over 1 million people say they are supporting or caring for family members who have a terminal illness¹⁵.

Recent research looking specifically at the costs of end of life care for people with lung, breast, colorectal and prostate cancer found that informal carers provided care worth £219 million, which is a third of the total end of life care costs¹⁶. The authors warn that service planners need to pay more attention

to this significant role that carers play, particularly as the number of people in need is predicted to grow without a comparable increase in the number of capable carers:

“If the pool of capable informal carers and volunteers shrinks relative to the population needing care, a greater need for state funding will arise. Commissioners and payers of formal care services should be aware of this, as it may lead to greater pressure on resources than are currently expected”¹⁷.

However, caring for someone with a terminal illness is not just about end of life care. Someone may live with a terminal diagnosis for many months or years, with family and friends providing different levels of care and support throughout this time. This can be incredibly demanding on carers, and carers’ inability to cope is a major reason why people are admitted to hospital towards the end of their life¹⁸.

1 million people in the UK say they provide care or support to family members who have a terminal illness



The costs of caring

Caring for someone who has a terminal illness can be emotionally, physically and financially demanding¹⁹, but most people undertake it willingly and many also highlight the positive impact that caring has on their lives. Despite this, carers still need high quality support both before and after the death of their loved one to help them cope with the physical, emotional and financial costs of their caring role.

“Mum and Dad had been together since they were 16 – they were childhood sweethearts. Having Marie Curie Nurses there meant that Dad could help give Mum the death she wanted and it brought comfort to him to know that he didn't have anything to reproach himself for – he had not let her down.”

- Deborah cared for her mum at home with her dad. Deborah's mum was diagnosed with renal cell carcinoma in 2003 and died on New Year's Eve the same year, aged 59.

The physical cost

Eight out of ten carers in the UK say that caring has a negative impact on their health (82%) and almost as many say they feel more anxious as a result of their caring role (78%)²⁰. Carers who provide more than 50 hours of care each week are three times more likely to report that their health is 'not good' when compared to non-carers²¹.

- Sam's dad Terry was diagnosed with prostate cancer in August 2009. Sam cared for dad, with help from her fiancé and family, until he died in December 2012. Sam coordinated all of Terry's care and believes that, without her input, he would have struggled as the system is disjointed and confusing.

“During my dad's last week, I knew he could die at any moment, and I really, really wanted to be with him when he went. During this week I didn't eat much, and hardly slept. I existed purely on cups of tea and the odd bite of toast. I lost an entire stone.”

Older carers are particularly at risk of poor health. Almost two-thirds of carers over the age of 60 have long-term health problems or a disability themselves²².

Worryingly, carers say that in many respects they experience more negative effects of caring now than they did a year ago²³. In England, carers say their quality of life and satisfaction with social services have dropped significantly since 2014²⁴.

The emotional cost

Coping with terminal illness can be very difficult for a family, and carers of people who are approaching the end of their life consistently report ‘intense, conflicting, negative and/or difficult emotions’²⁵. Over half (55%) of carers in the UK say their caring role has contributed to depression²⁶.

The carers we speak to often say that emotional support and help with preparing for the future are the things they need most. Research into the needs of people caring for a loved one with cancer shows that carers are even more likely to have unmet psychosocial needs than the people they care for, particularly when the carer is not a partner or spouse and already has other caring responsibilities, such as looking after children²⁷.

Depending on which condition or conditions a person has, caring for them can have particular challenges. For example, research shows that, for someone caring for a person with cognitive impairments (perhaps because of dementia, brain tumour or motor neurone disease), watching their loved one’s personality and behaviour change, or their ability to communicate deteriorate, can be one of the most difficult aspects of providing care²⁸.

Carers may particularly struggle when preparing a home for a loved one to die in. The physical transformations needed to turn a home into a site of care can take an emotional toll on carers²⁹.



Layton Thompson/Marie Curie

The person who is ill may find themselves emotionally and physically drained by dealing with various different health and social care providers, so carers may try to take on their stress by managing coordination and communication themselves³⁰.

“It was a big shock for me. I came home that day almost numb, and I told my husband but not my dad. I was trying to be quite factual. Dad was on the other side – he couldn’t face how ill she was, and didn’t want to accept that she was dying.

We got her home that night, for her last six weeks. She didn’t want anyone in the house apart from close family. She was a very private lady, and she had spent so long caring for my sister on her own, so she didn’t want any help. Mum needed me there because she relied on me to make the same decisions that she would.”

- **Ruth cared for her mother Selina in the last few weeks of her life following a diagnosis of vascular dementia.**

Some carers find it difficult to adjust to life after the death of their loved one, particularly in the first few months. Some will struggle with what they call the bureaucracy following a death at home at a time when they are grieving, such as not knowing what to do with the body, arranging the certification of death or post-mortem and returning borrowed hospital equipment³¹.

The financial cost

Because every family’s needs and situation are different, it is hard to put a number on the economic cost of living with a terminal illness or caring for someone who has one. For people who have been diagnosed with cancer, Macmillan Cancer Support estimates that the additional cost of living with the condition is £540 per month³².

The most common extra costs are associated with outpatient appointments, but more than half of people living with cancer face higher everyday living costs through extra heating or paid help around the home or garden. Even smaller costs like hospital parking fees can contribute to the financial strain on carers. For people with neurological conditions, the Extra Costs Commission estimates that someone will spend on average almost £200 a week on costs related to their disability³³.

Carers might also have to take a break from work, or give it up entirely, resulting in lost wages. Research from Carers UK and Employers for Carers found that 2.3 million adults have given up work to care for an elderly, disabled or seriously ill loved one³⁴.

State support in the form of Carer’s Allowance is available to people over the age of 16 who earn less than £110 each week and regularly provide at least 35 hours of care a week to someone with substantial care needs, who is

themselves in receipt of certain benefits. The benefit is worth £62.10 per week³⁵. However, making ends meet can still be a real struggle:

“A month before my dad died, I was in talks with my boss about going part time. I had planned to work part time and care for him part time, covering the gaps while I was at work with carers from the continuing care package. This didn't work out because he died over Christmas.

However the issue of carers not being given the financial support they need is crucial - the Carer's Allowance is just over £60 a week; that wouldn't pay my mortgage and bills, let alone food. I remember looking into it and not being eligible for it if I was working.”

- **Sam cared for her dad Terry, who had prostate cancer.**

Carer's Allowance is due to be devolved in Scotland under the Scotland Bill. This may lead to changes to this benefit in Scotland.

Applying for benefits and working out entitlements is often complicated, and carers can have difficulty navigating the complex system on top of providing care.

The 'overlapping benefits' rule means that people receiving the same amount as Carer's Allowance or more from another benefit, such as a state pension or bereavement benefits, will not be paid anything extra. However, if their pension is worth less than Carer's Allowance, they can receive a top-up. Some people may be entitled to a 'Carer Premium' or 'Carer Addition' as well as other means-tested benefits, such as Pension Credit.

Hundreds of thousands of people who are entitled to Carer's Allowance don't receive it, suggesting that they don't realise they are entitled. Carers UK estimates that 360,000 carers miss out on the benefit each year, meaning £1.1 billion of Carer's Allowance goes unclaimed³⁶.

“I knew I qualified for Carer's Allowance. The social worker told us but I should have got it a lot earlier, when it could have been helpful.”

- **Sara, 46, was a full-time carer to her grandmother Joan, who had vascular dementia. It was only after Joan was hospitalised that Sara was told by a social worker that she was entitled to money towards her care, which she had paid for herself.**

When caring ends

Many carers that we work with say that you never stop being a carer. The experience is life-changing and continues to have a profound impact on people after the death of their loved one. In many cases, carers continue to feel a negative impact on their health, mental wellbeing and financial circumstances long after the person they cared for has died. Some claim to feel like entirely different people, and it is quite common after bereavement for carers to give up social and leisure activities that they had enjoyed before caring³⁷.

Loneliness and isolation

Most carers will feel particularly vulnerable immediately after the death of their loved one, yet this is when they can be at their most isolated. Carers may have lost touch with family and friends while providing care, and services, such as community nurses, start to be withdrawn after the person has died³⁸.

Healthcare assistants and nurses will have become part of both the patient's and carer's social network. The quality of these interactions and the way in which they are withdrawn can have long-lasting effects.

Many GPs will continue to check in with the carer after the death of their loved one, but not all do so. In some areas, the support previously provided by a carer's centre might no longer be available, as some local authority contracts stipulate

that carers aren't eligible for support after bereavement³⁹.

As many as one in ten carers will have a very intense reaction to bereavement, known as prolonged grief disorder (PGD). This means they are likely to experience difficulty accepting the loss of their loved one, as well as numbness, identity disorientation and a feeling of being stuck in grief. This condition can have serious implications for their mental health. People who have cared for a spouse are particularly at risk⁴⁰.

Some carers may not have been able to look after their own needs properly for years, and may experience serious health problems once caring ends as a result.

Layton Thompson/Marie Curie



“After Chris’s death, I became very depressed and physically run down, culminating in my own admission to hospital with meningitis, encephalitis and septicaemia. The hospital wanted to know why my immunity was so poor and I do believe several years of poor sleep, diet, depression and fatigue took their toll. I was in a coma for nine days and had complicated head surgery to remove necrotised bone from around my right ear.”

- Helen cared for her husband Chris, who was diagnosed with a brain tumour in 2008, and died 18 months later.

Health and social care professionals are often uncertain of the best ways to support people through bereavement and identify those at risk of PGD⁴¹. Research suggests that people should be screened for PGD when palliative care is introduced, and also six months after bereavement⁴². Yet for many people the support has ended long before then.

For the one in four people in the UK who need palliative care but miss out⁴³, a full assessment of their carers’ needs and risks after bereavement is also unlikely to have happened.

The financial costs carry on

Carer's Allowance continues for up to eight weeks after someone has died. However, this period is often one of intense financial pressure on carers with many taking extended leave from employment or even leaving their jobs. On top of this, bereaved carers often have the added stress of putting their loved one's affairs in order.

“Our initial response was just to run away back to our own families. All the paperwork and selling the house, you get so bogged down in it and then it really hits you.”

- **Janice cared for her father, Stephen, until his death in 2011 from bile duct cancer.**

The stress and costs of planning a funeral, in particular, can place a significant burden on people who have just lost someone close to them. Funeral debt is on the rise in the UK as the costs of funerals spiral. Already, more than 100,000 people in the UK are living with funeral debt and 46% say a funeral cost more than they expected⁴⁴.

The average cost of a funeral in 2015 is £3,693 although there are significant regional variations: in London, people can expect to pay more than £5,000 for a funeral, a 5% increase on the 2014 average⁴⁵.

Not being able to pay for a funeral, or not being able to provide the funeral that their loved one would have liked as a result of financial constraints, can make an already difficult time overwhelming.

The government does provide some help for people with meeting funeral costs, through either the Social Fund or Funeral Payments. Both, however, are dependent on the carer already receiving benefits for the state. The benefits which grant eligibility do not include Carer's Allowance.

Who will care in the future?

The number of people living with a terminal illness is growing. The UK's population is ageing and more people are living longer with complex needs and conditions; the number of people dying each year will also soon start to increase⁴⁶. The Royal College of General Practitioners predicts that, by 2025, there will be 1 million more people living with life-threatening conditions⁴⁷.

This means there will be substantially more need for care from both formal services, such as the NHS and social care services, and unpaid carers.

As care moves out of hospitals and into people's homes, the need for support from family and friends will grow, and it is likely that this support will be needed for longer. Already, 40% of people who provide care to an immediate relative who is approaching the end of their life will have been providing care for at least a year⁴⁸.

More carers means even more people bearing the physical, emotional and financial costs identified above; assuming they are willing and able to take up that caring role, which is likely to increasingly be an issue.

Demand for unpaid care is expected to exceed supply by 2017, as the number of adult children able to provide care for their parents shrinks⁴⁹. Researchers at the London School of Economics have predicted that this could lead to 160,000

older people in England alone being made vulnerable and lacking the care they need over the next two decades⁵⁰. Research specifically looking at care for people with a terminal illness has identified a similar trend:

“As populations age, the impact of such effects increases; palliative care is shifting into patients' homes with longer survival time in the terminal phase. These effects are compounded by more potential caregivers working away from home and by increased social mobility, with the result that fewer family members are available to commit to regular caregiving than was the case a generation ago⁵¹.”

This crisis in care will be acutely felt by people living with a terminal illness and their carers, many of whom are older people themselves. Most of those providing care for someone approaching the end of their life are women aged 50–64, while in older groups slightly more men provide care⁵².

People over 65 account for more than four out of every five deaths in the UK each year⁵³, and there is evidence to suggest that older people are less likely to access formal, specialist support when they have a terminal illness⁵⁴.

UK policy context

Devolution makes the UK a varied environment for carers and those needing care. While there are comprehensive strategies in place in each of the nations to make sure carers get the support they need, there is also a relatively common picture of unmet need, with carers missing out on support and services they are entitled to.

However, devolution also allows different parts of the UK to lead the way by introducing new and innovative legislation to support carers, including the specific needs of carers of people living with a terminal illness.

England

The Department of Health's End of Life Care Strategy (2008)⁵⁵ and its refreshed Carers Strategy (2010)⁵⁶ set out national frameworks for improving the support available to carers, including for carers of people approaching the end of their life. The Care Act (2014)⁵⁷ further sets out the rights of carers, guaranteeing an assessment of their needs and placing a duty on local authorities to provide adequate support and information services.

However, in many areas there has been little improvement since the implementation of these national strategies, particularly in relation to the identification of carers and the availability of support. In February of this year, the Choice in End of Life Care Programme Board published

'What's Important to Me: A Review of Choice in End of Life Care'⁵⁸. The report highlighted several key issues: the need to identify and involve carers; the need for increased access to bereavement support and respite care; and the need to provide support for practical tasks such as planning a funeral. A new national Carers Strategy is now in development.

Wales

The current Carers Strategy for Wales was updated in 2013 and provides a framework for agencies across Wales to complete assessments and provide support to carers⁵⁹. However, many carers are missing out on both the initial assessment as well as the support they are entitled to receive. Over 121,000 people in Wales become carers for older, sick or disabled loved ones every year yet, despite these high numbers, around 21,000 carers in Wales continue to miss out on £66 million of unclaimed Carer's Allowance each year⁶⁰.

The rights of carers in Wales are due to be strengthened through the Social Services and Well-being Act which will become law in April 2016. The Act also aims to improve the availability of the information, advice and assistance on offer. A duty will be placed upon local authorities to undertake a carer's assessment and they will also be encouraged to proactively direct carers to help and advice.

Scotland

There are an estimated 759,000 carers in Scotland⁶¹. The Scottish Government has recognised that more needs to be done to support people in caring roles and is currently piloting a new Carers Bill through the Scottish Parliament. The Bill will change the definition of carers, so that more people can be defined as a carer. The Bill also promises an Adult Carer Support Plan, to all carers who request one, and a Young Carer Statement for those under 18 and in a caring role. The Scottish Government has stated its intention to include a fast-track system to create plans for people caring for someone with a terminal illness. The new law will create a duty to provide support to carers that meet local eligibility criteria. The Bill has so far received universal support from MSPs across all parties and it is widely expected to pass before the end of the current Scottish Parliament in March 2016.

The Scottish Government's new Strategic Framework for Action on Palliative and End of Life Care, due to be published in December 2015, will specifically reference carers and the support needed for carers of people living with a terminal illness.

A number of benefits that impact on people living with a terminal illness and those caring for them will also be devolved to Scotland as part of the Scotland Bill. The Scottish Parliament

will have the power to make carers benefit payments to anyone who provides regular and substantial care, no matter their circumstances. The Scottish Government is currently considering how they will be devolved and if there will be any changes to the current system. This could lead to a very different welfare system in Scotland, compared to other parts of the UK.

Northern Ireland

Northern Ireland's Carers' Strategy was set out in 2006 in 'Caring for Carers: Recognising, Valuing and Supporting the Caring Role'⁶². This instructed social care professionals to actively identify and recognise the needs of carers through a carer's assessment, as well as make support services readily available to them.

Despite the provision of a Carers' Strategy, not all carers have their needs assessed and many are unaware that this is an option. For example, the Commission for Older People revealed that 60% of older carers are not aware that they could be assessed for extra support⁶³. In light of this, the Strategic Implementation Plan for Transforming Your Care (2013) has set out recommendations to remedy this, including promoting Carer's Assessments, and offering flexible support services to carers⁶⁴.

Conclusions and recommendations

Caring for a loved one when they have a terminal illness can be immensely rewarding, but it may also entail substantial physical, emotional, social and financial costs.

Carers of people with a terminal illness face significant challenges to getting the high quality and timely support that should be available to them, both while they are caring and after bereavement. These challenges include:

- not having their needs recognised by support services
- not being supported to look after their own health, wellbeing and finances, and not knowing where to find support when they need it
- a lack of help with preparing for the future, both following their loved one's diagnosis and after bereavement

There will be a crisis in care for people with a terminal illness unless more is done to support carers and enable more people to take on this role when a friend or family member is approaching the end of their life.

We believe there are fundamental principles that should underpin the support available to carers of people with a terminal illness, no matter where they live:

- **People who provide care for someone who is approaching the end of their life have specific needs, which should be assessed as a matter of priority.** A suitable time for this might be when the person they care for is placed on a primary care palliative care register.
- **Information for carers should be available and accessible in a form that is most useful to them.** Strategies for providing information should take into account that carers often do not recognise this label for themselves, and that their information needs may be different to the person they care for.

- **Carers are not trained professionals, and they should not be expected to behave as such.**
The responsibility of taking on a caring role for someone who is seriously ill can be scary and daunting. Carers should be treated sensitively by professionals and, where appropriate, provided with training and support to help them look after their loved one and themselves.
- **No one providing care to a loved one with a terminal illness should suffer financial hardship as a result of their caring role.** Clear strategies should be in place to support carers who hope to balance caring with work, and more needs to be done to ensure people are aware of the benefits they may be entitled to. When carers of people with a terminal illness do apply for benefits, their applications should be dealt with as quickly as possible.
- **Health and social care professionals need to be ready and able to help carers identify themselves in this role and to plan for their future.** This must include a sensitive explanation of what supporting a death at home entails, and a recognition that carers' needs will often continue after bereavement.
- **Grief and bereavement are complex, and everyone experiences them differently.** Some people will begin the grieving process before their loved one dies, whereas others may not need support until months later. Services supporting carers must be flexible enough to meet their needs based on what suits the individual, not what suits the system.

Marie Curie will continue to work across each of the UK nations to improve the support available to people living with a terminal illness and the people who care for them. We look forward to working with governments, health and social care professionals, and carers themselves to make sure that, in the future, no one misses out on the support they need.

References

- 1 Ipsos MORI online survey of 6,136 UK adults aged 16–75, October 2014.
To the question Have you supported or cared for a family member, friend or neighbour who was, or is, terminally ill in the last 3 years? 3.33% selected either or both of
- Yes, I am currently supporting or caring for a member of my immediate family (for example a spouse, partner, parent or child) who is terminally ill
 - Yes, I am currently supporting or caring for a member of my extended family (for example a grandparent, aunt or cousin) who is terminally ill.
- This was an online survey. Ipsos MORI calculates the online UK population of 16–75 year olds at approximately 44,250,000 based on Eurostat 2014 population estimates.
Technical note: On behalf of Marie Curie, Ipsos MORI interviewed a sample of 6,136 online adults aged 16–75 within the UK. Interviews took place between across the UK using i:Omnibus, Ipsos MORI's online omnibus between 3rd and 29th October 2014. Data are weighted by age, gender, region, working status and social grade to match the profile of the target audience.
- 2 Carers UK (2015) [Valuing Carers 2015](#).
- 3 Grande G., Ewing G. (2008) [Deaths at home unlikely if informal carers prefer otherwise: implications for policy](#). *Palliative Medicine* 22: 971–71.
- 4 Dixon J. et al. (2015) [Equity in the provision of palliative care in the UK](#). LSE PPSRU, Marie Curie.
- 5 Nuffield Trust (2014) [Exploring the cost of care at the end of life](#).
- 6 Marie Curie (2015) [Changing the Conversation](#).
- 7 NCPC (2013) [Who cares? Support for carers of people approaching the end of life](#).
- 8 Holdsworth LM (2015) [Bereaved carers' accounts of the end of life and the role of care providers in a 'good death': A qualitative study](#). *Palliative Medicine* 29 (9): 834–41.
- 9 Candy et al (2011) [Interventions for supporting informal caregivers of patients in the terminal phase of a disease](#).
- 10 NCPC (2013) [Who cares? Support for carers of people approaching the end of life](#).
- 11 Cardiff E. et al (2014) [Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources](#). *BMC Family Practice* 15:48.
- 12 NCPC (2013) [Who cares? Support for carers of people approaching the end of life](#); Cardiff E. et al (2014) [Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources](#). *BMC Family Practice* 15:48.
- 13 Carers UK (2015) [Facts about carers 2015](#).
- 14 Carers UK (2015) [Valuing Carers 2015](#).
- 15 Ipsos MORI online survey of 6,136 UK adults aged 16–75, October 2014. *See note 1*
- 16 Round J (2015) [Estimating the cost of caring for people with cancer at the end of life](#). *Palliative Medicine* [online].
- 17 Ibid.
- 18 Gott M. (2013) [The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers](#). *Palliative Medicine* 27(8).
- 19 Candy B. et al (2011) [Interventions for supporting informal caregivers of patients in the terminal phase of a disease](#). *Cochrane Database of Systematic Reviews* 2011, Issue 6.
- 20 Carers UK (2015) [State of Caring 2015](#).
- 21 Carduff E et al (2014) [Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources](#). *BMC Family Practice* 15:48.
- 22 The Princess Royal Trust for Carers (2011) [Always on call, always on concerned: A survey of the experiences of older carers](#).
- 23 Carers UK (2015) [State of Caring 2015](#).
- 24 HSCIC (2015) [Measures from the Adult Social Care Outcomes Framework, England - 2014-15, Final release](#).
- 25 Funk L. et al (2010) Part 2: Home-based caregiving at the end of life – a comprehensive review of published qualitative research (1998–2008). *Palliative Medicine* 24 (6): 594–607.
- 26 Carers UK (2015) [State of Caring 2015](#).
- 27 The Institute for Health Research, Lancaster University (2001) [What are the psychosocial needs of cancer patients and their main carers?](#)
- 28 Sherwood P. et al (2004) Forgotten voices: lessons from bereaved caregivers of persons with a brain tumour. *International Journal of Palliative Nursing*. 10(2):67–75.
- 29 Marie Curie Cancer Care Research Programme – Final Report: Payne S 'Unpacking the home': family carers' reflections on dying at home.
- 30 Seamark D, Payne S.. (2014) [Dying at home: a qualitative study of family carers' views of support provided by GPs community staff](#). *British Journal of General Practice* 64: 629.

- 31 Holdsworth LM (2015) [Bereaved carers' accounts of the end of life and the role of care providers in a 'good death': A qualitative study](#). *Palliative Medicine* 29 (9): 834-41.
- 32 Macmillan Cancer Support. [Cancer's Hidden Price Tag](#).
- 33 Extra Costs Commission (2015) [Driving down the extra costs disabled people face](#).
- 34 Carers UK/ You Gov (2013) [Research reveals over 2 million quit work to care](#). [press release].
- 35 Gov.UK website. [Carers Allowance: Overview](#). [Correct at 12/11/15].
- 36 Carers UK (2013) [Carers missing out on unclaimed benefits](#). [news story].
- 37 Rosenwax L 'Change in carers' activities after the death of their partners.' *Support Care Cancer* (2014) 22: 619-26.
- 38 Holdsworth LM (2015) [Bereaved carers' accounts of the end of life and the role of care providers in a 'good death': A qualitative study](#). *Palliative Medicine* 29 (9): 834-41.
- 39 NCPC (2013) [Who cares? Support for carers of people approaching the end of life](#).
- 40 Thomas K. et al (2014) [Risk Factors for Developing Prolonged Grief During Bereavement in Family Carers of Cancer Patients in Palliative Care: A Longitudinal Study](#). *Journal of Pain and Symptom Management*, 47 (3): 531-541.
- 41 O'Brien M. et al (2015) ["Support is too fragmented": the bereavement needs of carers and the presence of Prolonged Grief Disorder](#). 14th World Congress of the European Association for Palliative Care, May, Copenhagen.
- 42 Thomas K. et al (2014) [Risk Factors for Developing Prolonged Grief During Bereavement in Family Carers of Cancer Patients in Palliative Care: A Longitudinal Study](#). *Journal of Pain and Symptom Management*, 47 (3): 531-541.
- 43 Based on ['Palliative Care Funding Review: Funding the Right Care and Support for Everyone'](#); the Final Report of the Palliative Care Funding Review (July 2011)'.
- 44 Royal London/ YouGov (2014) [Royal London National Funeral Cost Index](#).
- 45 Sun Life (2015) [Cost of Dying](#).
- 46 ONS (2013) [National population projections, 2012-based](#).
- 47 RCGP (2015) [1m more people living with life threatening conditions within a decade, forecasts RCGP](#). [press release]
- 48 Seamark D, Payne S. (2014) [Dying at home: a qualitative study of family carers' views of support provided by GPs community staff](#). *British Journal of General Practice* 64: 629.
- 49 Pickard L. (2015) [A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032](#). *Ageing and Society* (35): 96-123.
- 50 Ibid.
- 51 Candy B. et al (2011) [Interventions for supporting informal caregivers of patients in the terminal phase of a disease](#). *Cochrane Database of Systematic Reviews* 2011, Issue 6.
- 52 Payne S. (2010) EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 1. *European Journal of Palliative Care* (17):238-45.
- 53 Seamark D, Payne S. (2014) [Dying at home: a qualitative study of family carers' views of support provided by GPs community staff](#). *British Journal of General Practice* 64: 629.
- 54 Dixon J. et al. (2015) [Equity in the provision of palliative care in the UK](#). LSE PPSRU, Marie Curie.
- 55 Department of Health (2008) [End of Life Care Strategy](#).
- 56 HM Government (2010) [Refreshed, valued and supported: Next steps for the Carers Strategy](#).
- 57 [Care Act \(2014\)](#).
- 58 The Choice in End of Life Care Programme Board (2015) [What's Important to Me: A Review of Choice in End of Life Care](#).
- 59 Welsh Government (2013) [The carers strategy for Wales 2013](#).
- 60 Carers UK (2014) [Over 121,000 people in Wales become carers for older, sick or disabled loved ones every year](#). [news story].
- 61 Scottish Government (2015) [Scotland's Carers: Official Statistics](#).
- 62 Department of Health, Social Services and Public Safety (2006) [Caring for Carers](#).
- 63 Commissioner for Older People NI (2014) [Supporting Older Carers: Examining the reasons for the low level of uptake of Carers Assessments by Older Carers in Northern Ireland](#).
- 64 Health and Social Care Board (2013) [Transforming Your Care: Strategic Implementation Plan](#).

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.

mariecurie.org.uk

 MarieCurieUK

 @MarieCurieUK



Care and support
through terminal illness