



Johner/Image-Source

# Lost retirement

The impact on older people of caring for someone with a terminal illness



Care and support  
through terminal illness

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## Foreword

People in Northern Ireland are living longer and our older population is growing faster than any other segment of society. This is something to be celebrated, but it also poses major challenges for health and social care provision, as more and more people are living with one or more terminal illnesses and complex needs. Most of us look forward to taking things easy as we grow older, enjoying retirement and spending quality time with partners, family and friends, and having the good health to do so. At this time of life, few of us would imagine taking on a caring role – a role which is often physically and emotionally demanding, full time and has no remuneration. And yet, thousands of people in Northern Ireland aged 65 and over do just that, providing much-needed care for loved ones living with terminal illnesses.

Older carers play a pivotal role in providing vital unpaid support to a family member or friend, often through to the end of that person's life. This caring role is extensive, varied and, in many cases, round the clock. It includes help with the essential, everyday tasks we all take for granted, like housework or shopping; personal care like dressing or washing; and emotional support. Carers also play a key role in co-ordinating and communicating with the many professionals involved in someone's care when they have a terminal illness. This demanding role is often physically and emotionally exhausting, all at a time when the older carer's own health may be in decline.

Despite the critical role older carers play, and the huge contribution they make in supporting our health system, the support on offer to them falls far short of what is needed. This report highlights the experience of our older carers and the physical, emotional and financial impact that caring has on them. It also explores the unmet needs among our older carers, the lack of support available to them, and the poor awareness of their needs throughout Northern Ireland.

We need to better recognise the massive contribution that older carers make, because our struggling health system simply couldn't survive without it. With our ageing population and ongoing health transformation agenda, now is the time to deliver the commitment already made by policy makers to support carers better throughout Northern Ireland. That must include special consideration of older carers, who help provide the best quality of life possible to their loved ones throughout a terminal illness.



Care and support  
through terminal illness



## Key points from the report

- There are over 32,000 local carers aged 65 and over, and this is the fastest growing carer age group in Northern Ireland. These older carers provide thousands of hours of unpaid care every day – potentially saving the health service hundreds of millions of pounds a year.
- Local demographic trends mean that even if the proportion of people aged 65+ who are carers merely remained static, there could still be nearly 63,000 older people performing caring roles by 2041 – **almost double the current number.**
- Older carers often have to manage the physical demands of caring on their own health at the same time as the impact of ageing. Neglecting their own health needs and struggling to eat properly or get a good night's sleep because of the demands of caring can have a significant impact on their physical health.
- Caring for someone with a terminal illness can also impose an enormous mental and emotional strain; many older carers experience feelings of fear, anxiety, uncertainty, loneliness and depression.
- Older carers need regular breaks from their caring role. However, many don't know what support is available and struggle to find suitable replacement care to let them have some time off.
- Caring for someone with a terminal illness can have a significant financial impact for older people. They may have to leave work or reduce their hours to fulfil their caring role and, due to their age, many are excluded from the welfare support available to other carers – including Carer's Allowance. This can make them feel even more lonely and stressed, and in some extreme cases, push them into poverty and leave them unable to afford essentials like food and heating.
- For many older people, the effects of caring carry on after their loved one has died, with a continued impact on their health for months or even years afterwards.

## Introduction

### What do we mean by older carers?

In this report we are discussing the issues affecting unpaid or informal carers. This is in contrast to formal care providers, such as domiciliary care workers or social workers, who are employed to perform the role.

An older carer in this context is aged 65 or over and provides unpaid care and support for a family member, friend or loved one.

### What do we mean by terminal illness?

We say someone is living with a terminal illness when they have reached a point where 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.

The trajectories and needs associated with different terminal illnesses can vary widely. People with some types of cancer, for instance, may experience a steady period of deterioration towards the end of their life. Other conditions, such as chronic heart failure and dementia, are much more episodic – with people experiencing periods of decline and temporary recovery. This can make it very difficult to predict how long that person is likely to live, and their caring needs are likely to fluctuate as their condition progresses.

### What do older carers of people with terminal illnesses do?

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

Without this unpaid care, it would usually not be possible for someone with a terminal illness to be cared for in their own home.

### Methodology

Throughout this report there are testimonies from older people who describe their experience of caring for someone with a terminal illness in Northern Ireland. These views were gathered at focus groups with older carers, one-to-one meetings or Carers NI Carer Support Group meetings.

## Who are our older carers?

There are over 32,000 carers aged 65 and over in Northern Ireland – 15% of all carers. [1]

### Age and gender

Most older carers are aged 65-74 (65%), although a small but significant group of carers are aged 85 and over. (Figure 1).

More women aged 65 and over provide care than men (53% vs 47%) (Figure 2).

This changes in the oldest carer age group, however, with more men aged 85+ providing care (54% vs 46%) (Figure 3).

This may be explained by the gender dynamic of some conditions. For example, two-thirds of people with dementia are women, [2] and since the condition mainly affects people in older age groups, there may be a small but significant group of older male spouses caring for their wives, who are living with dementia.

Figure 1: Age of older carers in Northern Ireland

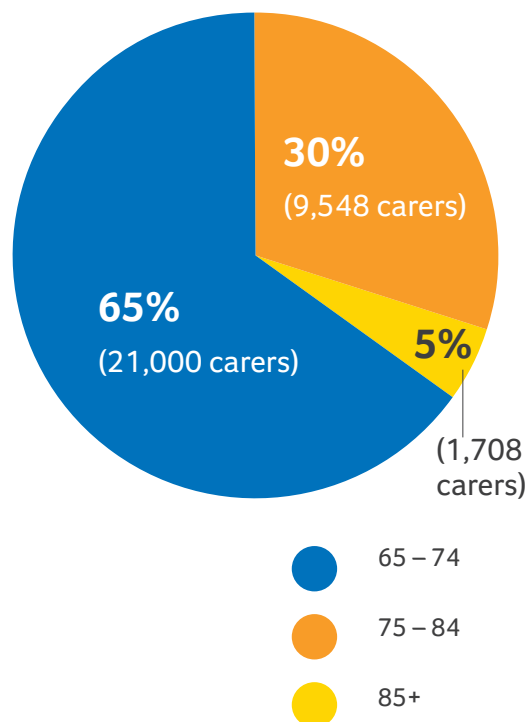


Figure 2: Gender of carers aged 65+ in Northern Ireland

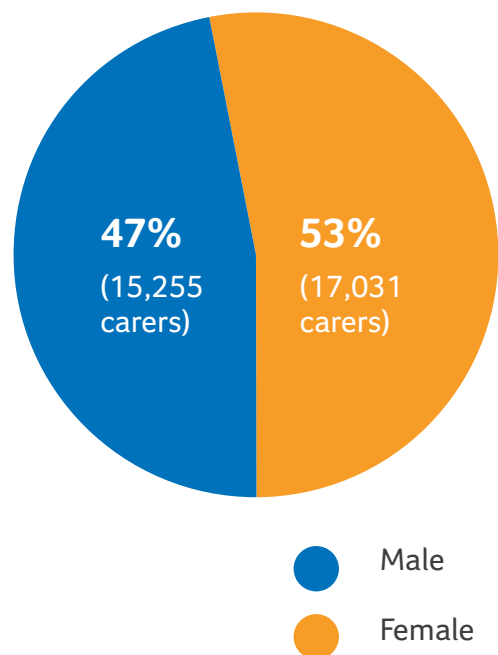
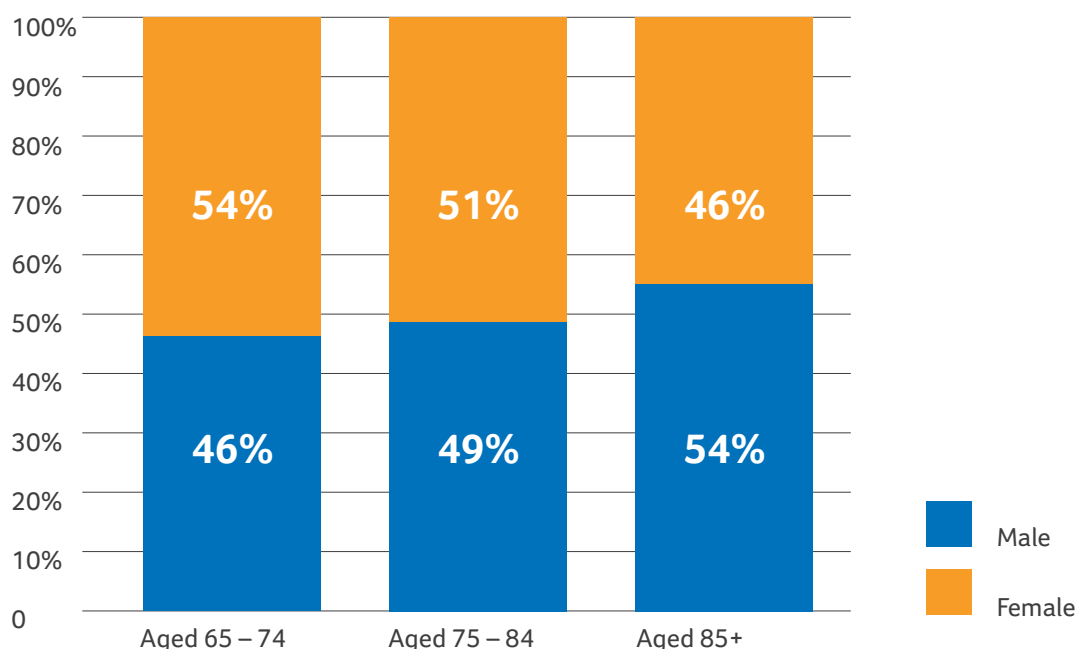


Figure 3: Gender of older carers in Northern Ireland



### Who do they care for?

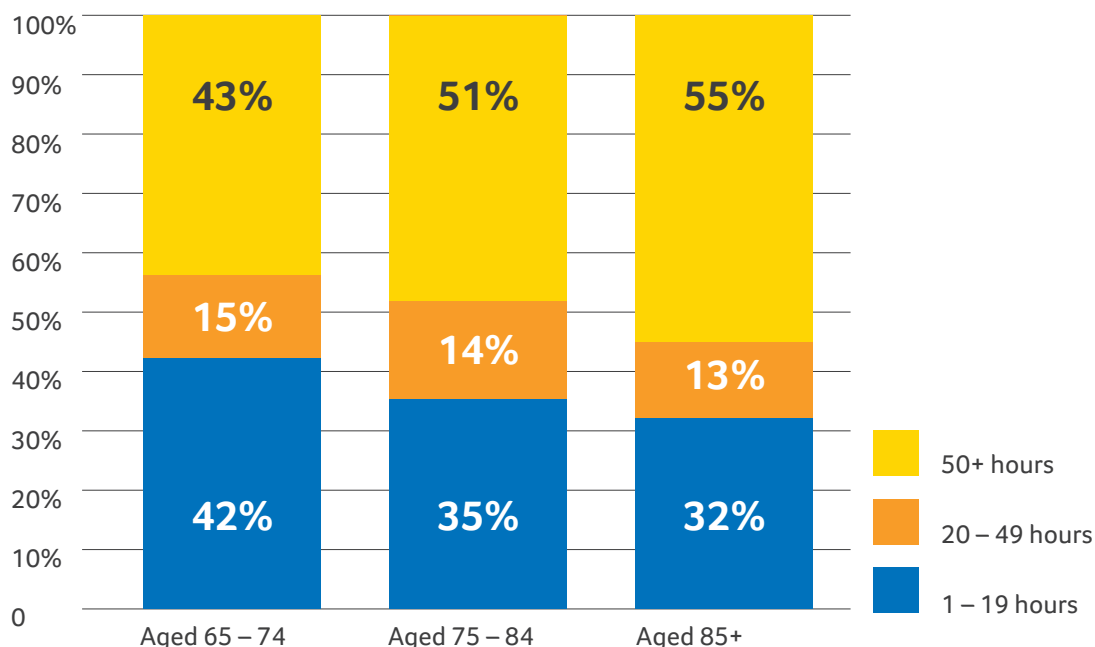
Older carers provide hundreds of thousands of hours of unpaid care to friends, family and loved ones every day in Northern Ireland. This equates to an enormous level of care from unpaid carers that would otherwise need to be met by health and social care services.

As carers get older, the number of hours of care they provide increases (Figure 4). This is likely to be, at least in part, because the person they are looking after is also getting older and their

health condition is getting progressively worse – meaning they require more support. [3] This is particularly true of people with terminal illnesses. They have complex personal and practical care needs which only heighten as their condition progresses, especially as they near the end of their life. Indeed, one study of carers of people with terminal cancer in England found that most spent an average of nearly 70 hours per week performing caring tasks during the last three months of life. [4]

Hours of care provided per week	Aged 65 and over in Northern Ireland
1-19	12,655
20-49	4,832
50+	14,769
<b>Total: 32,256</b>	

Figure 4: Hours of unpaid care by older carers in Northern Ireland



Data shows that the vast majority of unpaid care in Northern Ireland is provided to family members. In a 2015 survey of all carer age groups, 44% said they provided care for their parents or parents in law; 29% for a spouse or partner; 10% for a child; and 13% for other relatives. [5]

Given their age, many older carers in Northern Ireland will be caring for their spouse or partner.

This isn't always the case, however; a quarter of carers aged 65+ in the survey above said they were providing care for their parents/parents in law.

Fifty-seven per cent of people surveyed were providing care for someone with a physical disability, while 51% were caring for a loved one with a physical illness. This may include conditions like motor neurone disease, cancer, chronic heart failure or chronic obstructive pulmonary disease (COPD). Nearly a fifth of respondents (16%) were caring for someone with dementia.

Overall, more than one million people across the UK said they were caring for someone with a terminal illness in 2014, [6] and this number is likely to have grown since then.



Around 40% of people who provide care to a close relative approaching the end of life will do so for more than one year. [7] The exact length of time spent caring, and the level of the care provided, will depend on the condition(s) their loved one is living with.

For example, life expectancy for someone with dementia can vary between five and 12 years depending on the type of dementia. [8] In the early stages of the disease, the person may be fairly independent and able to do most things with only a little help, with their abilities and care needs becoming greater as the dementia progresses. [9] Their carer may therefore provide care for a long period of time, but the level of care required may vary as their loved one's condition deteriorates.

On the other hand, a condition like motor neurone disease has a much more rapid decline – killing a third of people within a year and more than half within two years of diagnosis. In this short space of time, people with MND may experience a range of complex symptoms, including muscle weakness, difficulty moving, breathing problems, communication problems and loss of speech. Their carers may therefore provide care for a relatively short time, but the level of care provided may be much more intense, with a lot of complex needs to deal with.

Many terminally ill people also live with more than one long-term condition, which makes their needs much more complex.

## Current and future trends

### Current patterns

Northern Ireland’s population is ageing rapidly. Between 2007 and 2017, the 65+ population grew by over a quarter (25.2%), while the number of those aged 85+ increased by over 30%. [10]

These trends, coupled with increasing pressure on health and social care services and the growing prevalence of progressive and terminal conditions, mean that the number of older people taking on caring roles has also grown significantly.

Between the Census in 2001 and 2011, the number of carers aged 65 and over in Northern Ireland increased by nearly 50% – from 21,534 in 2001 to 32,256

in 2011. [11] This is a much faster growth rate than any other age group (Figure 5). It is also a notably steeper rise than anywhere else in the UK during the same period (Figure 6).

It is very likely that the older carer population in Northern Ireland is bigger than that captured by the Census data, owing to the reluctance among many older people to reveal their caring status or identify themselves as a carer (see page 25). [12]

Calculating the monetary value of the care provided by older people is difficult. The Commissioner for Older People for Northern Ireland estimates that carers aged 60+ contributed £1.02 billion to the local economy through unpaid caring in 2012. [13] This is the equivalent of nearly a fifth of today’s health budget (over £5 billion).

Figure 5: Growth in carer age groups in Northern Ireland, 2001-2011

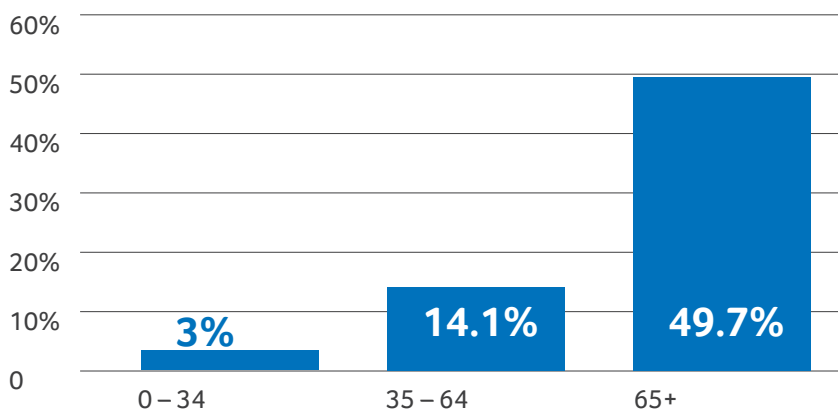
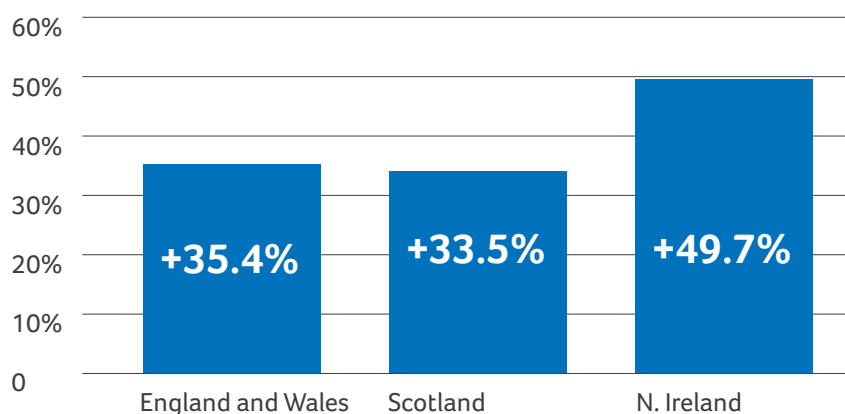


Figure 6: Increase in carers aged 65+, 2001-2011



Sources: Northern Ireland Statistics and Research Agency; Office for National Statistics; Scotland's Census.

### Future trends

Projections show that the older carer population in Northern Ireland is only likely to keep on growing.

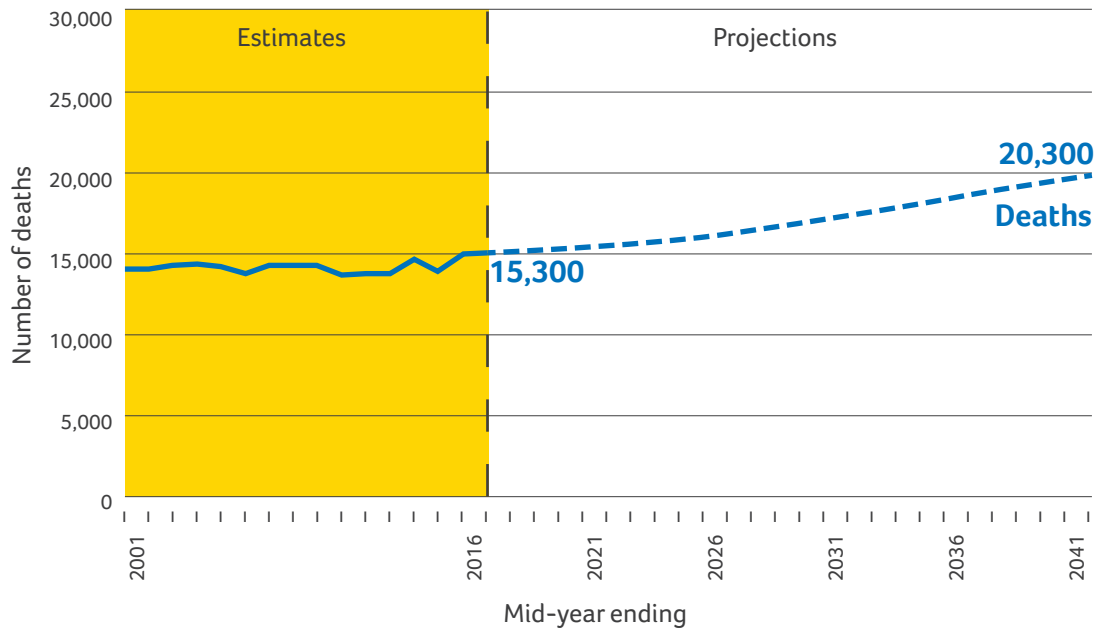
Firstly, the population is expected to keep on getting older. By mid-2028, those aged 65 and over are projected to outnumber children, reaching a staggering 491,700 people by mid-2041 – or almost one in every four people. The proportion of the population aged 85+ is also expected to double by mid-2041 (from 2% to 4.1%). This represents a growth rate of over 127% – over 20 percentage points higher than the projected rate for the rest of the UK.

Crucially, the size of the 'working age' population (those aged 16 to 64) is projected to fall by nearly 3% at the same time, while the number of children is also set to decrease by nearly 6%. [14]

Unsurprisingly, there will be a corresponding increase in the prevalence of terminal illnesses during this period, with the death rate rising sharply. For example, the number of people with dementia in Northern Ireland is projected to increase to around 60,000 by 2051 [15] – a roughly 200% increase on the number today – while the number of cancer cases diagnosed (excluding non-melanoma skin cancer) is expected to rise by 64% by 2035 (8,622 per year in 2009-13 vs 14,148 by 2035). [16] Overall, the number of people dying each year is expected to reach 20,300 by mid-2041 – a 32.6% increase on 2016 (Figure 7). [14]

**Figure 7: Estimated and projected deaths in Northern Ireland, year ending mid-2001 to year ending mid-2041**

Adapted from: Northern Ireland Statistics and Research Agency (2017). 2016-based population projections for Northern Ireland.



Taken together, these trends have important implications for the future caring environment in Northern Ireland. There will be a lot more people diagnosed and dying with one or more terminal illness in the coming years, meaning the demand for care will rise sharply. Formal health and social care services are unlikely to be able to meet this demand, and with fewer young and working age people around to provide informal care for the old and sick, more older people will pick up unpaid caring roles.

Indeed, even if the proportion of people aged 65 and over who are carers merely remained static, there could still be nearly 63,000 older people performing caring roles by mid-2041 – almost double the number in 2011. We have every reason to believe that this population will grow at a much faster rate.

## The impact of caring on older people's physical health and wellbeing

Caring for someone with a terminal illness can be a physically demanding and exhausting experience – especially in later life, when carers are more likely to be living with their own health problems.

Unlike those in younger age groups, older carers often have to contend with the long-term health problems associated with ageing while meeting the demands of caring. Over half (54%) of carers aged 65+ in Northern Ireland say they have a long-term health problem or disability that limits their day-to-day activities, compared to 9% of those aged 0-34 and 19% of those aged 35-64. [11]

Common health complaints among older carers include arthritis, joint problems, back pain, heart conditions, high blood pressure and diabetes. [17] These carers also encounter new problems as they get older, including loss of strength and mobility, tiring more easily and having difficulty sleeping. [18]

These issues are only exacerbated by the physical demands of caring. An average day for an older carer often

includes lifting or moving their loved one to help them with basic functions like washing and dressing. This can be an exhausting task which may cause injury or long-term physical problems. [17]

They are also likely to be responsible for all the household chores, which over time will cause fatigue and stress. [12]

Most of us take for granted the ability to get a proper night's sleep, but this is a challenge for many older carers. They may have to be awake during the night to help their loved one use the bathroom or to administer medication. Older carers of people with dementia may also be awake at night to help settle their loved one if they are wandering [19] or become distressed. Finally, the stress and anxiety associated with caring for someone with a terminal illness may keep carers up.

Not getting enough sleep was one of the biggest causes of stress identified by older carers in the 2018 Carers Week research report. [20] As well as being physically exhausting, disrupted sleep can have a serious impact on an older carer's health over time. Poor sleep is linked to lower immune function, elevated stress hormones, increased risk of cardiovascular disease and, in some cases, premature death. [21]

“I was struggling to get a proper night’s sleep and this had a negative impact on my physical health. I was exhausted all of the time. Then the Marie Curie Nurses came to stay overnight four or five times a week. This made a big difference. I couldn’t have continued the care my son needed without their help.”

**Victoria, who cared for her adult son when he had cancer**

Other everyday practices like exercise and maintaining a balanced diet can be incompatible with the demands of caring. In the 2018 Carers Week research, eating a balanced diet was one of the top three aspects of their health that older carers said they worried about.

Healthy eating and exercise are incredibly important for the health of older people. According to the British Nutrition Foundation:

“Good nutrition and regular physical activity play a protective role in a number of age-related conditions including cardiovascular disease and cognitive decline.” [22]

Even more worryingly, research suggests that many carers are also forced to miss or delay their own medical appointments, check-ups and even operations because of their caring role. [18][23] This would be problematic for any carer, but especially for older people who are living with the ill-health associated with ageing.

This trend can be explained in part by older carers not having the time, or being unable to find appropriate replacement care, to attend their GP surgery or visit the hospital. There is also evidence that carers of those with terminal illnesses develop a ‘blinkered’ inability to recognise and respond to their own needs, because they are so focused on the needs of their loved one, [24] and simply become ambivalent about their own health. [25]

“My health is second to my wife’s.”

**John, who cares for his wife now she has dementia**

Caring for someone with any terminal illness, especially if they are approaching the end of their life, is a huge task. A carer will often find themselves taking on the role of care co-ordinator – having to navigate and co-ordinate care from a complex web of different health and social care professionals and services, all on a 24/7 basis (Figure 8).

They may also be responsible for day-to-day tasks like administering medication, taking their loved one to and from appointments, collecting prescriptions and handling any benefits the person is receiving – all at the same time as tending to their personal and practical care needs, which may include help with dressing, washing, eating or going to the toilet. These needs become more complex as the illness

progresses. This is a frustrating, time-consuming and exhausting process, [26] especially for someone whose energy and mobility are already reduced due to their age.

Despite carers spending so much of their time every day interacting with health and social care professionals,

opportunities to talk about their own health are often missed or become an afterthought. Professionals are usually focussed on the patient's needs, and may not recognise or appreciate the individual health needs of carers.

Initiatives like the Carer Support Needs Assessment Tool (CSNAT) can help address this (see Box 1).

### Box 1: The CSNAT approach

Research has shown the value of the Carer Support Needs Assessment Tool (CSNAT) in facilitating holistic needs assessments for people caring for someone with a terminal illness.

The CSNAT is an evidence-based tool that facilitates support for family members, loved ones and carers of adults with life-limiting conditions. The tool comprises 14 domains, covering areas like practical help, physical health concerns and getting a break, and uses a simple question and answer format to ask carers which areas they need support with. [I]

An English study into use of the tool during the hospital discharge process showed significant benefits. During the discharge of their loved one from hospital, carers often prioritised the support needs of the cared-for person, but the CSNAT helped to legitimise their own need for support – giving them ‘permission’ to think about themselves as well.

Being able to see the CSNAT questions also prompted some carers to think about

different kinds of support which they may not have considered, or even known existed. Finally, the tool was also considered valuable in helping carers communicate their needs to healthcare professionals. [II]

In another trial of the CSNAT among carers of those receiving palliative home care services in the UK, carers who used the tool had significantly lower levels of early grief and better psychological and physical health than those who didn't; [III] while a pilot in Australia showed significant reduction in strain among carers of those with terminal illnesses who had access to the tool. [IV]

There is interest in using the CSNAT across a range of health and social care settings, but there are challenges with implementation.

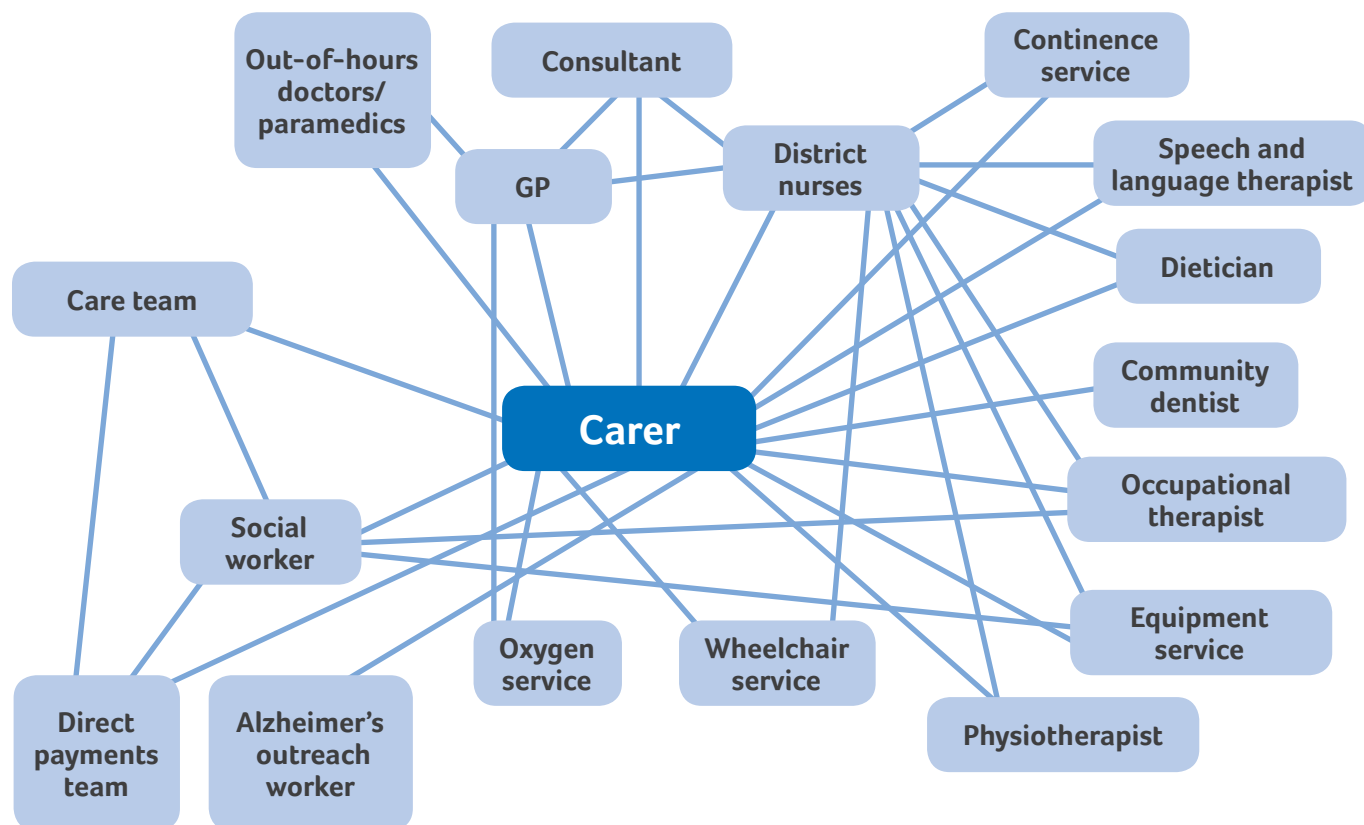
[I] <http://csnat.org/>

[II] Ewing, G et al (2018). Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using the Carer Support Needs Assessment Tool (CSNAT) approach. *Palliative Medicine*, 32 (5).

[III] Grande, G et al (2015). Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: A stepped wedge cluster trial. *BMJ Supportive and Palliative Care*, 7 (3).

[IV] Aoun, S M et al (2015). The impact of the Carers Support Needs Assessment Tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLoS One*, 10 (4).

Figure 8: Example of the services and organisations a carer of someone with dementia may deal with



Adapted from: The National Council for Palliative Care (2013). Who cares? Support for carers of people approaching the end of life.

The impact of caring on someone’s physical health can last for a long time, even after their loved one has died. For example, a survey of people affected by MND in the UK found that nearly 80% of carers were still feeling the impact of caring on their physical health a year after bereavement. The strenuous nature of caring for someone with MND, especially the need to lift and move the person regularly throughout the day and at night, is a contributing factor to this. [27]

Older carers in Northern Ireland face challenges every day. They must contend with their own health problems, the physical effects of caring and the heightened impact this has due to their age. It is concerning, but unsurprising, that over 60% of older carers across the UK in the 2018 Carers Week research said they expected their physical health to get worse in the future.





Layton Thompson/Marie Curie

## The impact of caring on older people's mental health and wellbeing

Looking after someone with a terminal illness can be a mental and emotional rollercoaster for older carers. Dealing with this enormous mental and emotional strain, at the same time as managing the impact that caring has on their physical health and providing care to their loved one, can feel like an overwhelming task, with a big impact on their health and wellbeing.

### An emotional rollercoaster

Older people caring for someone with a terminal illness have a range of complex emotions to deal with. Receiving news of a terminal illness diagnosis can be devastating, and carers can experience feelings of fear, anxiety and uncertainty about the future. How long does their loved one have left? How will their condition affect them as it progresses? Will they be up to the task of looking after them as their condition declines?

This last question is particularly important. Most carers are not professionally trained to look after someone with a terminal illness, so it can be very stressful when they suddenly find themselves responsible for providing personal and practical care for their loved one on a 24/7 basis. Many carers are left to learn through trial and error, and lack of confidence in performing caring tasks, especially things like administering medication,

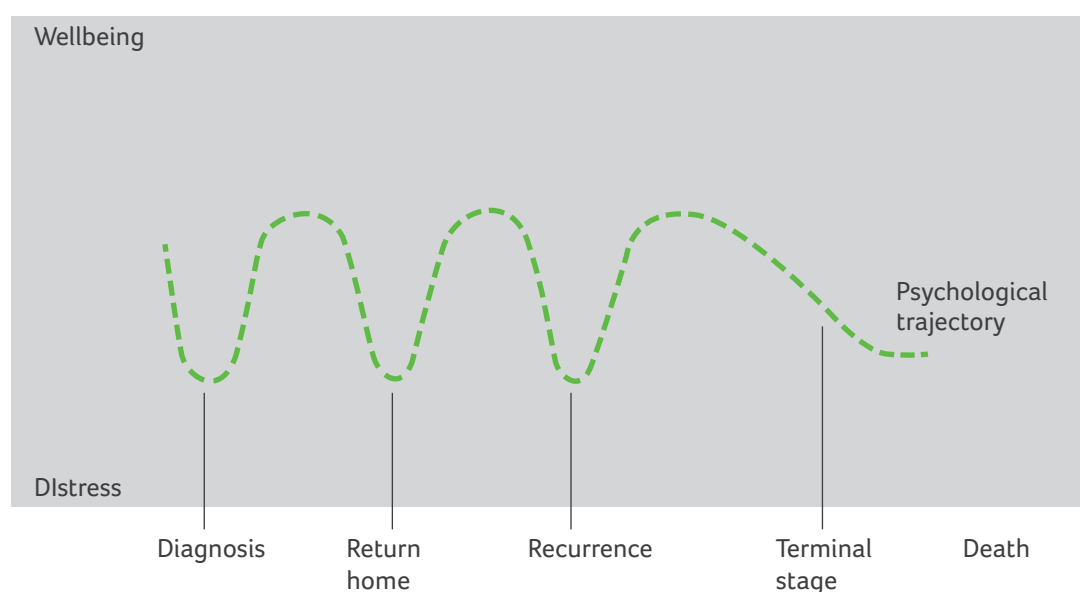
can cause stress and anxiety. [24] As the person's needs – physical, emotional, social and spiritual – become more complex, trying to cope with the situation can be overwhelming. [26]

As we have seen, carers will often take on the role of care co-ordinator – responsible for co-ordinating care between a complex web of health and social care providers around the clock. This can be stressful and exhausting. The care co-ordination role may also involve communicating information and breaking bad news to other family members and friends, which in itself is very stressful and demanding. [28]

Identifying and addressing these mental health impacts may not be straightforward, as they may occur episodically, in tandem with key events. For example, one study of carers of people with terminal lung cancer suggests that they may follow a pattern of mental and psychological wellbeing and distress that mirrors that of the patient. They experience peaks and troughs at key times of stress and uncertainty in the cancer trajectory – with acute anxiety at the time of diagnosis; feelings of being worn down, under pressure and distressed when the patient starts treatment; and significant anxiety once the patient has entered the terminal phase (Figure 9). [29] This last stage may be particularly traumatic for older carers, with another study showing that, during their loved one's last three months of life, prevalence

### Figure 9: Pattern of mental and psychological wellbeing and distress among carers of those with terminal lung cancer

Adapted from: Murray, S et al (2010). Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: Secondary analysis of serial qualitative interviews. *BMJ*, 304.



of significant psychological distress among cancer carers aged 65-74 may be up to seven times higher than the general population in this age group.<sup>[30]</sup>

It is likely that these patterns exist among carers of people with many other terminal illnesses as well, perhaps demonstrating that support for carers should be focused on these key events to ensure they get the help they need when they need it most.<sup>[29]</sup>

Many people may be placed in a nursing or care home at some stage of their illness. While this transition reduces day-to-day carer tasks, it may increase mental distress, as carers

develop feelings of guilt and failure because someone else is looking after their loved one. Some carers even feel a sense of loss akin to bereavement when their loved one transitions to a nursing home.<sup>[31][32]</sup> Evidence suggests that these issues may be particularly prevalent among spousal carers.<sup>[33]</sup>

#### Loneliness and isolation

The day-to-day pressures of caring – and the mental and emotional toll this takes on older carers – are often compounded by intense feelings of loneliness and isolation.

Due to their age, older people are already likely to have fewer social connections than in previous periods of their lives; some of their friends may have died, and mobility issues or ill-health may mean they are less socially active. [34] This is made all the worse by the demands of caring.

As we have seen, looking after someone with a terminal illness is often an all-consuming, 24/7 role, and many older carers simply don't have the time or energy to maintain relationships, see their friends or take part in social activities on top of their caring duties – even though these things may have been very important to them before they became a carer. This can leave them feeling lonely and isolated.

“My biggest challenge is finding time to do anything for myself. I just can't get time away from my caring role. I feel alone most of the time.”

**Adam, who cares for his wife following a stroke**

“My whole life revolves around caring... I can't remember the last time I left the house after 9pm.”

**John, who cares for his wife now she has dementia**

Even where a friendship network does exist, previous relationships can be complicated by the person's caring role. Friends may not want to visit because they are concerned about over-burdening the carer. Some friends may also feel uncomfortable with the condition of the person who is ill and stop coming to visit as a result. [35] This may be a particular problem when the person has a condition that impacts on their behaviour or personality, such as dementia, or causes cognitive impairments, like motor neurone disease or a brain tumour, where the person's communication and speech may be affected.

Some carers also find it hard to open up to their friends because they don't know what it's like being a carer. They can feel lonely even in a crowded room because no one else understands their situation or how difficult it is. [36][37]

“Caring is a very lonely place to be.”  
**Jane, who cares for her husband now he has dementia**

Research has shown that family members provide a fundamental source of support for carers of people with dementia, giving them the opportunity to release their feelings and share their emotions. [38] This support may not always be available, however, because older carers' children are likely to be grown up, living away from the family home with their own lives to lead.

The complex needs of people with terminal illnesses often result in an almost singular focus on them from health professionals, family members and friends. This can leave carers feeling like they've faded into the background. [36] Having their needs acknowledged by health and social care professionals would make a big difference to a lot of carers.

“You meet people and they'll ask: 'how is [person receiving care]?' It would be nice if sometimes they asked: 'how are you?'”

**Janine, who cares for her husband now he has dementia**

In practical terms, the financial pressures of caring (see page 29) may mean that an older carer can't afford to take part in social activities. The challenge of finding high-quality replacement care so that a carer can have a break is also an obstacle (see page 24). Even if suitable care can be found, the person who is ill may be unwilling to be cared for by someone else. These issues all make it harder for older carers to have a break, take part in social activities and see friends or family.

This can be an incredibly frustrating position for older carers. They may have worked all their lives and raised families, but are unable to fully enjoy retirement because of the demands of caring. Many describe feeling trapped – like they are in a period of waiting, during which time they only survive, without space for their interests, needs or social contacts. They may feel like their world is restricted and their future postponed indefinitely. [39]

“My whole life is on hold. I can't make any plans. I can't leave. I don't have anyone to talk to.”

**Janet, who cares for her husband now he has dementia**

“The most difficult part is when you can no longer leave them on their own. You're tied to them and to the house. You feel guilty for feeling robbed of the things you once enjoyed doing. I feel trapped.”

**Violet, who cares for her husband who has MS**

Beyond the direct impact on mental health and wellbeing, loneliness also puts people at 50% increased risk of an early death compared to those with good social connections. It is as damaging to health outcomes as obesity [40] or as smoking 15 cigarettes a day. [25]



**Box 2: Warwickshire Psychological Support Services help to tackle mental ill-health among older carers**

Run by Age UK, Warwickshire Psychological Support Services is a county-wide scheme offering a range of psychological support interventions for older people and/or those caring for an older person. Service users can access up to 25 counselling sessions with a trained counsellor – with sessions usually held in the person’s home.

The programme also offers sessions with volunteers to improve wellbeing and reduce isolation among older people diagnosed with depression, stress or anxiety. Evaluations of both services have shown notable improvements in service user mental wellbeing scores. [1]

[1] Local Government Association (2016). Combating loneliness: A guide for local authorities.

**Ongoing loss and grief**

Carers of people with terminal illnesses may feel like they are enduring a series of ongoing ‘losses’ as their loved one’s condition progresses. These feelings can start a long time before the person dies. The phenomenon is sometimes known as anticipatory grief – grief both in anticipation of the physical death, as well as other losses which are associated with the person’s terminal illness and the impact it has on their behaviour, abilities and personality. Dealing with these losses can be an upsetting and emotionally scarring process.

For example, carers of people with dementia often describe experiencing losses throughout their illness, including:

- **Loss of the previous relationship with their loved one** – the impact of dementia, especially the cognitive effects, means that ‘couplehood’ may no longer be possible. Someone with dementia may be unable to take part in joint activities, recall important memories or reflect on their shared history with their carer. This results in the loss of intimacy, emotional closeness and companionship. [21][33][41] The relationship changes fundamentally, with the carer feeling like someone who merely looks after the person with dementia, rather than someone who has known and loved them for many years; before they may have been a cherished husband, wife, partner or friend, now they feel like ‘just a carer’.

- **Loss of meaningful communication with their loved one** – many dementia carers describe a gradual and progressive diminution of adult interaction with their loved one, to the point where meaningful communication may become impossible or exclusively one way. [38] This is another aspect of the loss of the relationship and companionship a carer enjoyed with their loved one.
- **Loss of aspects of their loved one's personality and the person they once knew** – a carer may feel like they are losing the essence of the person they once knew, especially as their memories fade and they lose the ability to communicate properly. In some cases, the dementia will also cause challenging and unpredictable behaviour, with the person becoming easily frustrated, aggressive and even violent towards their carer. [19][42]

“I’m used to being married... now I’m completely on my own. This person I’m living with is not the person I married. There is no affection. It’s like having a stranger in the house. How do you cope with that?”

John, who cares for his wife now she has dementia

These experiences of loss can be very distressing and traumatising for a carer of someone with dementia. Anticipatory grief is not exclusive to carers of people with dementia, however, and may be felt by those looking after someone with other terminal illnesses as well.

For example, research describes the loss of intimacy between carers and patients with MND due to their cognitive and physical decline, and the strain this puts on carers. [43] The behavioural changes associated with amyotrophic lateral sclerosis – the most common form of MND – can also considerably add to the burden on carers, more so than that caused by the patient’s physical disability. [44] Brain tumours can impair a person’s ability to move freely by themselves, and many carers have to help with tasks like dressing and going to the toilet. This can mean a significant change in the relationship dynamic. [45]

Day to day, carers of people with terminal illnesses may have intense, negative and conflicting feelings of guilt, hopelessness, inadequacy, uncertainty and loneliness. [46] They may feel exhausted, depressed, vulnerable and burnt out.

## Access to respite

Caring for someone with a terminal illness, especially later in life, can be an incredibly demanding role, with a big impact on the person's health and wellbeing. Carers must be able to take a break from their caring role – giving them time to recharge their batteries, spend time with friends and family, and do the things they enjoy outside of caring.

Older carers in Northern Ireland recognise the importance of having regular breaks; in one local survey in 2014, 'respite and breaks' were among the most important things identified by older carers in relation to their caring role.<sup>[13]</sup> Despite this, evidence shows that older carers may face complex barriers to accessing the breaks they need.

### Box 3: Community Pharmacy Carers Support Service

The Community Pharmacy Carers Support Service was piloted in the South Eastern Local Commissioning Group area between October 2016 and March 2018. The project encouraged pharmacists to identify customers who have a caring role and refer them onto the South Eastern Trust's Carers Support Service. Carers identified through the scheme could access information about the support available to them, including short breaks, and would be referred for a Carer's Assessment. The pharmacist might also provide advice and information to help the carer look after their health.

Between October 2016 and November 2017, 61 referrals were made by pharmacists to the South Eastern Trust's Carer Support Team. Of the carers referred, 27 were aged 65+, and most (47) were caring for an older person.

Feedback on the service from carers was very positive, with over 75% of those who provided feedback saying that they wouldn't have known that support was available, nor how to access it, had they not been referred by their pharmacist.

An evaluation of the pilot recommended that it continue in the South Eastern Trust, and the scheme is also being rolled out across the Northern and Western Health Trusts.



## Practical barriers

### *Finding replacement care*

Many carers find it difficult to secure appropriate replacement care to allow them to have a break. Older carers may not have any family or friends close by to look after their loved one, and formal care services may not be available. Even when they are, carers may have concerns about the quality of the services, and may turn them down on this basis. For example, over a fifth of older carers in the 2018 State of Caring survey said they had refused health and social care support because of concerns over quality. [47]

### *Carer's Assessments*

One way to get respite is through a Carer's Assessment, but, for a variety of reasons, too few older carers are accessing them.

Firstly, many older people providing care for a loved one don't identify themselves as a carer. They think that what they do is simply part of being a partner, relative or friend. Research suggests this issue is more pronounced among older carers than those who are younger. [12] This makes it harder to identify carers, assess their needs and offer them support like respite.

There is also evidence that some older carers may be actively reluctant to undertake a Carer's Assessment. They may be suspicious that a Carer's Assessment will judge their ability to care; they may be fearful that an assessment will lead to them losing control, with someone else taking over the care of their loved one or removing them to another care setting; or they may simply value the sense of dignity that comes with remaining independent. [12]

Even when older carers want support, however, they may not be aware of what they are entitled to. Two surveys of older carers by the Commissioner for Older People for Northern Ireland found that:

- 66% of respondents didn't know they could have, or had the right to, a separate assessment of their needs
- 59% of respondents had not received any information on Carer's Assessments
- 70% of respondents had not been offered a Carer's Assessment. [13]



These findings suggest there is a lot of work to do to ensure carers know what they are entitled to and how they can access breaks from caring. GPs have an important role to play, but there is disappointing evidence that not enough GPs are providing carers with this information when they see them. For example, just 2% of older carers said their GP had given them information about how to get regular breaks from caring in the 2018 Carers Week research.

**“My health is suffering more the older I’m getting, and it’s hard to find a GP who understands my caring role.”**

**Violet, who cares for her husband who has MS**

There is evidence that the way Carer’s Assessments are offered and carried out also needs to be better calibrated to the needs and time demands facing carers. Between January 2017 and March 2018, over half (53%) of Carer’s Assessments offered in Northern Ireland were declined. Among those who gave a reason or for which a reason was recorded, around a fifth (21%) said they declined the offer of an assessment either because the time, place or environment offered was unsuitable, or because they felt the assessment would be too complicated or time consuming. [48] This suggests that, in their current form, Carer’s Assessments may not always be compatible with the busy lives carers lead.

Finally, there is the urgent problem that even if a carer is assessed and a need for respite is identified, there is no specific, binding requirement for Health Trusts in Northern Ireland to provide it.

### ***Patient unwillingness***

In some cases, even if the issues above can be overcome, a carer may still be unable to have a break because their loved one refuses or becomes distressed by the prospect of being looked after by anyone else. Research has identified this as a problem for carers of people with motor neurone disease. [49]

Older carers of dementia patients tell us that leaving the house even for short periods can be difficult because their loved one may become distressed, anxious or volatile over their absence.

**“You’re always thinking: ‘I just hope they’ll be in good form when I get back’”**

**Deborah, who cares for her husband now he has dementia**

### **Emotional barriers**

Older carers also face emotional barriers to accessing respite care. For example, research on carers of dementia patients found that carers can be conflicted about using respite services, due to guilt about ‘abandoning’ their loved one; feelings that they are failing to fulfil their marital or familial duty by leaving their loved one temporarily; apprehension that the person with dementia will become angry, resentful or distressed at their absence; [50] and concern that any disruption to the care of their loved one while they are away could lead to a deterioration in their condition. [18]

“I’m afraid to tell him that I need a break”

Olive, who cares for her husband now he has dementia

“Even when I was supposed to be having a break I was always thinking about what I needed to do when I got back.”

Victoria, who cared for her adult son when he had cancer

Research on carers of people with motor neurone disease also found that the sense of duty carers felt towards their loved one made them reluctant to take a break from caring; they wanted to spend as much time as possible with them before they died. [49] This highlights a wider trend – carers of those with terminal illnesses may be reluctant to have a break because they are afraid of their loved one dying while they are away. [28]

### **Stages to accessing respite**

Strang and Haughey identify three ‘stages’ to dementia carers accessing respite – two of which are emotional and one practical. [51] This model can be adapted and applied more broadly for carers of those with all terminal illnesses:

- 1) The carer recognises the need to get out of the ‘carer world’ and have a break.
- 2) The carer gives themselves permission to leave the carer world temporarily.
- 3) The carer can access appropriate support resources to facilitate a break from caring.

Completing these stages can be very challenging for older carers of people with terminal illnesses. Even when appropriate replacement care is available, carers may still be reluctant to take a break because of feelings of guilt, failure and concern about the impact on their loved one.



## Financial challenges and the impact on health

Caring has been shown to have a ‘scarring’ effect on many carers’ finances – reducing their income and financial resources at the same time as they face the extra costs associated with caring. [52] These financial pressures can have a serious impact on an older carer’s health and wellbeing.

### The cost of caring

Caring for someone with a terminal illness can cost a lot of money. Carers may incur large expenses for things like home adaptations and equipment, as well as regular additional costs for travel to medical appointments, care products, higher fuel/home heating bills, specialist food and higher phone bills. Carers may also find themselves contributing to, or solely responsible for, their loved one’s care home fees, which can be significant.

Putting an accurate number on these costs is difficult because every patient/carer’s needs are different. However, research from Demos estimates that people with MND and their families spend over £9,600 per year in regular costs (e.g. social care, transport, specialist diet) and enhanced costs (e.g. higher energy bills, insurance for vehicles and equipment, higher phone bills) as a direct result of the disease. In a survey of people living with MND and their families for the research, 72% of those aged 65+ said the disease had a

very or moderately negative financial impact. [27]

Research by the Extra Costs Commission also found that people living with a chronic condition, which could include COPD or coronary heart failure, face average extra costs of nearly £300 per week for things like energy, personal care and transport. [53]

### Work and caring

Many people in Northern Ireland are staying in employment beyond retirement age, both for financial reasons and the personal benefits derived from working. [52][54]

Employment among those aged 65+ in Northern Ireland has increased since the financial crash in 2008, [55] and looking ahead, nearly half (46%) of local people say they are planning to work into their late 60s and beyond. [54] The challenge of juggling work and caring can therefore be just as important to older carers as those of so-called ‘working age’.

As we have seen, caring for someone with a terminal illness can be an all-consuming, round-the-clock job, and many older carers struggle to meet the demands of their caring role while also fulfilling commitments at work. Analysis of Census data shows that a carer providing more than 20 hours of care a week is less likely to be in employment and more likely to be economically inactive than a non-carer in Northern Ireland. [56]

Finding good quality replacement care to fit around work schedules is a massive challenge. [23] Carers also need a certain level of flexibility from their employer, so that they can fit their working patterns around their caring responsibilities and take time off at short notice when necessary. [52]

Without these things, carers may be forced to reduce their working hours or

leave their job entirely. While evidence is lacking on the specific impact this has on older carers, the 2018 State of Caring survey showed that people providing care to those at the palliative or end of life stage are among the groups most likely to report having to reduce their working hours to care (two in 10). [47]

#### Box 4: Carers leave around the world

Japan is among the world leaders in the provision of employment rights for carers. Employees can take up to 93 days of long-term family care leave over the lifetime of each family member, which can be divided into three periods or less. This care leave is paid at 67% of earnings. [1]

In Belgium, carers can take paid leave for up to 12 months, while in Canada, employees

who have worked the equivalent of 12 hours a week during the previous year are entitled to eight weeks' leave to care for a family member approaching the end of life – paid at 55% of earnings for the first six weeks (up to a ceiling). [11]

[1] Blum, S et al (2017). 13th International Review of leave policies and related research 2017.

[11] OECD Social Policy Division (2016). Additional leave entitlements for working parents.

#### Box 5: Support for employees who are carers at the Scottish Courts and Tribunals Service

The Scottish Courts and Tribunals Service (SCTS) is a Carer Positive Employer, and has award-winning policies to support employees who care for a loved one. Employees who are carers are provided with additional benefits and support, including financial support for respite care, interest-free loans to help pay

for any specialist equipment their loved one may need, workshops on relevant topics like managing stress and depression, and up to six months' paid compassionate leave if they are looking after someone who is terminally ill. Flexible working options, including reduced hours and home-working, are also available for employees who are carers. [1]

[1] <https://www.workingfamilies.org.uk/wp-content/uploads/2015/03/33582-FFWS-Winners-Brochure-For-Web.pdf>

## Welfare support

The financial pressures facing some older carers are made worse by the fact that they are excluded from several welfare benefits that their younger peers may be entitled to.

The primary benefit available to carers in the UK is Carer's Allowance. However, overlapping benefit rules mean that if an older carer is in receipt of State Pension, and it is paid at a rate that is the same or more than Carer's Allowance, they will not receive Carer's Allowance. They may be able to get an increase in any means-tested benefits or become entitled to means-tested benefits for the first time, though.

Many older carers feel rightly aggrieved by this – they are providing care which would otherwise need to be paid for by the health service but receive no financial recognition for it. A lot of older carers are also in receipt of substantially lower pensions than they could have had, had they not had to give up work to provide care. [52]

Various benefits exist to support people bereaved by the loss of a loved one, but many older carers will find themselves ineligible for them as well.

Bereavement Support Payments provide financial help to deal with the immediate costs caused by the death of a spouse or civil partner. They are paid monthly and can have a total value of

thousands of pounds, but only those who are under State Pension age when their loved one died are eligible.

Similarly, Bereavement Allowance (formally called Widow's Pension) is only paid to those under State Pension age.

Older carers may be eligible for other benefits, but navigating the system and working out entitlements can be very complicated, especially for someone with little free time due to the demands of caring.

## Impact on health and wellbeing

These issues can leave older carers under serious financial pressure. The 2018 State of Caring survey showed that nearly 20% of older carers across the UK are struggling to make ends meet, and 7% are, or have been, living in debt as a result of caring. These pressures can have a big impact on an older carer's health and wellbeing.

For instance, financial pressures can increase feelings of loneliness, isolation and stress among older carers, who may be forced to sacrifice social activities and hobbies when money is tight.

Many older carers also describe a sense of identity, purpose and social connection that is associated with working, [52] which they may lose if they have to reduce their working hours or leave their job for caring.

Even if a carer can stay in work, many find themselves having to use annual leave and sick days to fulfil caring duties because their employer doesn't offer flexible working options. This depletes the time available for carers to have a break and look after themselves, with negative implications for their health.

[57]

In practical terms, financial pressures and poverty may leave some older carers unable to afford essentials like food and heating, which damages their physical health. [58]

Older carers may find the demands of caring incompatible with paid employment, depleting their financial resources at the same time as they are hit with the additional costs of looking after someone with a terminal illness. Welfare support may be inadequate, putting carers under financial pressure which damages their health and wellbeing.



## When caring ends

Caring for someone with a terminal illness is a life-changing experience. Many older carers will have known and loved the person they care for years – in some cases for most of their lives. Bereavement therefore has a significant and complicated impact on their physical and mental health.

### Long-lasting health effects of bereavement

Losing their loved one has been known to cause a health crash among some carers – resulting from the strain and intensity of caring, especially in the final days of life, and compounded by grief. The effects of this crash may be felt for months. [32]

Older people are also four times more likely to experience depression in bereavement, [34] and older women may be particularly at risk. [19] Some research has linked persistent depression to increased risk of cardiovascular disease among older carers. [21]

In some cases, an older carer may also develop Prolonged Grief Disorder (PGD) or complicated grief – an intense reaction to bereavement which disrupts daily functioning for an extended period. Spousal carers are the most likely group to develop PGD/ complicated grief after bereavement. [33] As well as the direct impact on a carer's mental health, PGD can increase

risk of hypertension by as much as tenfold, leading to heart attacks or stroke. [32]

These issues can have an impact on carers for a long time. A study of carers of people who died from cancer, COPD and dementia found increased use of prescription anti-depressants, anxiety medication and sleeping medication one year after bereavement. [59] In another survey of people affected by MND, over 80% of family members bereaved for more than a year reported a continued impact on their mental health. [27]

### Loneliness increases during bereavement

As we have seen, caring for someone with a terminal illness can be a very lonely and isolating experience, and these problems may get worse after the person being cared for dies.

Family and friends will often 'rally around' the carer and offer support immediately after bereavement, but, with their own lives to return to, this naturally lessens over time. [34] The way that caring may erode friendships and social networks [12] also means the carer may have a limited pool of support to call upon.

These trends are significant when we consider that it is the support from friends and loved ones that many carers value most when they are bereaved. For

example, one study of carers of people with advanced dementia found that carers valued support from their social network above formal services like counselling during bereavement. [31]

During the period of caring, much of the day-to-day contact a carer has is with a network of health and social care professionals. Someone with a terminal illness will receive care from a wide range of different services, and this often means a steady stream of people like district nurses, occupational therapists and social workers visiting the house throughout the day. These interactions can be important for the carer, so when their loved one dies and the services are withdrawn, it can feel like the loss of another social network. [60]

### **Loss of identity and purpose**

Older carers, especially those looking after someone with conditions with longer trajectories, like dementia, are likely to have been caring for years. Their entire daily lives will have revolved around their caring role. Whether intentionally or not, they may have come to define themselves as a carer.

When this role comes to an end after bereavement, carers report feeling at a loss, because their 'purpose in life' has gone. [60] This can be an incredibly emotional experience and filling the void may not be easy.

### **Disenfranchised grief among older LGBT+ carers**

Research from Marie Curie [61] has shown that LGBT+ people may experience unsupported or disenfranchised grief after their partner has died. For a variety of reasons, some LGBT+ people choose not to come out to those around them or tell them that they are in a relationship. It is easy to see why this may be the case among older LGBT+ people, who may have lived through times when identifying as lesbian, gay, bisexual or transgender could result in being arrested or diagnosed as mentally ill.

Due to the stigma and discrimination that many LGBT+ people still suffer, their relationships may also not be openly acknowledged or accepted by those around them.

Either scenario could result in grief not being recognised properly or in the usual way. This can make it harder for a bereaved LGBT+ carer to access the information and support they need to come to terms with their loss and deal with the impact of bereavement on their health and wellbeing.

## Conclusions and recommendations

Older carers of people with terminal illnesses face enormous challenges every day. Their physical health may already be poor due to their age, and this is only exacerbated by the hands-on, round-the-clock nature of caring. Their mental health may also suffer as they seek to deal with the stress, anxiety, loneliness and grief that comes with looking after a dying loved one.

Many older carers may remain in poor physical and mental health for months or even years after their loved one has died.

We believe this situation is unacceptable. Too many older carers in Northern Ireland aren't getting the support they need to look after their own health and take a break from their caring role. Together we are calling for urgent action to ensure that all older carers get the support they need, when they need it.

### Recommendations for the health and social care system

1. Modules on carers and carer issues should be a mandatory part of basic training and continuing professional development for all health and social care professionals.
2. All health and social care professionals should have a statutory duty to identify carers and, when appropriate, refer them for support.
3. GP and hospital appointments for older carers should be flexible and organised around the carer's schedule, including home visits when possible. They should also be offered twice-yearly health checks.
4. Older carers should be offered training and information to help them perform their caring role. This would include practical information, like how to lift and move their loved one safely, and information on topics like symptom management, administering medication, disease progression and prognosis. This information should be available in a format that is usable for older carers.
5. Older carers should have access to high quality, reliable replacement care to help them take a break, look after their own health and, if they choose, continue to work.
6. Everyone with a terminal illness in Northern Ireland should be assigned a key worker to help co-ordinate their care, rather than this burden falling solely onto carers.
7. Mental and psychological support interventions for carers of those with terminal illnesses should be responsive to key events in the disease trajectory, for example at diagnosis and when the patient enters the end of life phase, as this is when their need for support may be greatest. [29] Grief and bereavement support should also be flexible and available early in a disease trajectory.

### **Recommendations for policy makers**

8. A public campaign is needed to help older people identify themselves as carers. It should also raise awareness of where they can go for help, the welfare support they may be entitled to, and their right to a Carer's Assessment.
9. A Carer's Assessment can be very complex and may take up to three hours to complete. This is incompatible with the busy and frantic lives of many carers. The process should be streamlined where possible and assessment appointments offered at a time and location that suits the carer's schedule. Government should also facilitate a Northern Ireland-wide debate on how Health Trusts and third sector care providers can be supported to use the Carer Support Needs Assessment Tool, to help better identify the needs of older carers who are looking after someone with a terminal illness.
10. Legislation in England and Scotland places a duty on local authorities to provide support to carers with an identified need, whereas Health Trusts in Northern Ireland are under no such obligation. The law in Northern Ireland should be brought in line with the rest of the UK, giving carers a guaranteed legal right to support when they need it.
11. Funding should be made available for community-based initiatives, including social prescribing programmes and public health interventions, to help tackle loneliness and isolation among older carers. Local councils should be partners in this effort, with community planning powers used when appropriate.
12. All carers should have the statutory right to flexible working arrangements and 5-10 days of paid carer's leave per year.
13. Financial support for carers should be improved, with the level of Carer's Allowance increased to match the value of Jobseeker's Allowance, as is the case in Scotland with the introduction of the Carer's Allowance Supplement.
14. Consideration should be given to the development of a new bereavement benefit which older people above State Pension age are eligible to apply for.

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    - 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.
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