Marie Curie

Care and support
through terminal illness

“You’re the first person who’s sat on that sofa in 12 months”

Experiences of loneliness among people at the end of life and their carers in Northern Ireland

In partnership with QUEEN’S UNIVERSITY BELFAST

February 2022

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Cover photo: Phil Hardman/Marie Curie

Foreword

Loneliness is one of the major public health issues of our time. When it becomes chronic, it can affect people very deeply, causing them to lose confidence and withdraw from social life. It can even affect our mental and physical health. Research has actually shown loneliness and social isolation to be a risk factor comparable to obesity or physical inactivity.

Understanding how important our relationships are to us means it's vital we research who's most affected by loneliness and what can be practically done to reduce its toll. We're finding out more about loneliness all the time, but there's still a long way to go. As one of the first dedicated research projects in Northern Ireland on loneliness among people at the end of life and their carers, this report makes an important contribution to that growing evidence base.

The vast majority of Marie Curie frontline staff see loneliness among the people they work with. This can be due to some of the broader aspects of ageing, such as smaller friendship groups. Staff also said loneliness can have specific causes for people nearing the end of their lives, such as the effects of people's illness and a feeling that others will just not be able to relate to their situation.

Many thought the stigma of talking about loneliness made it harder for dying people to manage these feelings and get support, whether from friends and family or from formal services.

The report shows these feelings of loneliness have a deep impact. They cause people to withdraw further from social contact, experience worsening symptoms and sometimes even feel they have nothing left to live for.

These disturbing findings show the need for a comprehensive approach to tackling loneliness across society. In 2020, the Campaign to End Loneliness worked in partnership with the Action Group on Loneliness Policy to write *Loneliness in Northern Ireland: A call for action*.(i) With the support of the All Party Group on Preventing Loneliness and 73 civil society organisations, it set out a series of ways in which the Northern Ireland Executive can take action through a cross-government loneliness strategy.

A strategy can help show where the gaps are and create connections between different streams of work. It would help create the leadership that's necessary to drive action across society. It would also deliver targeted funding to improve the evidence base around what works in tackling loneliness and addressing groups who are particularly at risk. This would undoubtedly include those at the end of their lives and their carers.

As this report highlights, the pandemic has increased loneliness for many people, while all of us have learnt the value of our relationships. There's never been a better time to come together as a society and work out what can be done to end loneliness in Northern Ireland.

Robin Hewings
Programme Director
Campaign to End Loneliness

Introduction

Loneliness is commonly defined as a subjective, unwelcome feeling of lack or loss of companionship – which happens when there's a mismatch between the quantity and quality of the social relationships we have, and those we want.(ii)

There are a number of factors that put people at a heightened risk of experiencing loneliness, including older age, poor health, disability and low income. Individually they're bad enough, but what if you fall into most, or all, of those categories simultaneously? That's the reality for many people living with terminal health conditions like dementia, incurable cancer and motor neurone disease in Northern Ireland today. In many cases, their loneliness is more deeply entrenched and harder to resolve.

This report shows the scourge of loneliness is significantly affecting the health and wellbeing of people living with a terminal illness, and their carers, across Northern Ireland:

It's making their physical symptoms worse.

It's impacting their mental health.

It's robbing them of a good quality of life before they die.

And, in the most heart-breaking cases, it's causing them to simply give up on the time they have left.

To date, those affected by terminal illness haven't been given the attention they deserve in the public policy debate about loneliness here. This report shows that we can't allow that to continue any longer. Northern Ireland needs a robust, strategic and cross-sectoral response to tackling loneliness – and people affected by terminal illness need to be at the heart of it.

This report is based on two primary workstreams, delivered by Marie Curie in partnership with Queen's University Belfast in 2021:

- A survey on the prevalence, impact and potential solutions to loneliness among people living with a terminal illness, and their carers in Northern Ireland, from the perspective of Marie Curie Nurses, Allied Health Professionals (AHPs), social workers and other frontline staff.(1)
- A series of focus groups with these staff to further explore experiences of loneliness among people affected by terminal illness.(2)

The pages that follow provide an overview of our findings and a number of recommendations to help address loneliness among people at the end of their lives and their carers.

To the best of our knowledge at the time of writing, our work is among the first dedicated examinations of loneliness among this population that has ever been carried out in Northern Ireland – and perhaps even further afield. Given the enormous impact of loneliness on these groups, that's a troubling indictment of the existing research landscape.

Indeed, it's clear much more work is required before we'll find the solutions to eradicate loneliness among dying people and their loved ones for good. We hope, in a small way, this report will contribute to that crucial evidence base.

(1) The survey was conducted in April 2021 and was completed by 68 members of staff – representing a 30% response rate.

(2) Three focus groups were held during September and October 2021, involving 14 members of staff from Marie Curie's nursing, social work, Allied Health Professions and bereavement support teams.

Context: The loneliness landscape in Northern Ireland

In 2020/21, 20% of people in Northern Ireland reported feeling lonely at least some of the time, which equates to around 380,000 people. This represents a small (+3%) increase on the previous three years(iii), showing that, while the prevalence of loneliness here has likely increased as a result of covid-19, the problem was entrenched before the pandemic began.

Loneliness is not felt evenly across the population – those aged 75 and over, females and people living in the most deprived areas are more likely to feel lonely than the Northern Ireland average. A previous study also illustrated that people here with life-limiting, long-standing illnesses were nearly twice as likely to report deep feelings of loneliness than those without such conditions.(iv)

Feeling lonely can have a significant impact on someone's health and wellbeing over time. To name just a few, it's linked to declining physical health, mental ill health and a greater reliance on health and social care services. One estimate suggests the overall monetary impact of severe loneliness in the UK is at least £9,530 per person per year.(v)

These trends, and many more, are evidenced among people affected by terminal illness in Northern Ireland in the pages that follow.

The Campaign to End Loneliness argues that Northern Ireland needs "a step change in efforts to tackle loneliness" with similar levels of attention and resourcing as are dedicated to other public health challenges like smoking, obesity and air pollution.(i) Despite this, we're an outlier among our neighbours as the only jurisdiction in the UK without a dedicated loneliness strategy in place.

The lack of a strategic framework to co-ordinate anti-loneliness policy interventions across Northern Ireland Executive departments has resulted, inevitably, in piecemeal, ad hoc and ineffective efforts to date. The levels of funding required to really tackle loneliness haven't been secured.

Loneliness affects hundreds of thousands of people in Northern Ireland. While very few experiences are the same, greater action is needed from our policymakers to tackle the problem at its roots. The recommendations in this report focus on addressing loneliness among people living with a terminal illness, and their carers, but they would undoubtedly benefit some of the countless other local groups experiencing loneliness as well.

Prevalence and causes of loneliness at the end of life

This chapter will explore the prevalence and causes of loneliness among people living with a terminal illness, and their carers in Northern Ireland, through an examination of the Marie Curie frontline staff survey and focus groups. The next chapters of the report will look at the impact this loneliness has and how we can begin to combat it.

Prevalence of loneliness among people at the end of life and their carers

One Northern Ireland study, referenced earlier, found that people with life-limiting illnesses were more likely to be lonely than those without such a condition. Our findings firmly reinforce this trend, with **93%** of the frontline staff who responded to our survey saying that – before the covid-19 pandemic – they provided care or support for someone living with a terminal illness who they believed was experiencing loneliness.

93%
of Marie Curie frontline staff surveyed said they've supported dying patients who were lonely.

These levels of loneliness were both wide and deep, as the majority of frontline staff reported loneliness in at least 25% of their typical pre-pandemic caseload. Nearly a third of respondents said loneliness was present in over 50% of their patients pre-pandemic (see Chart 1).

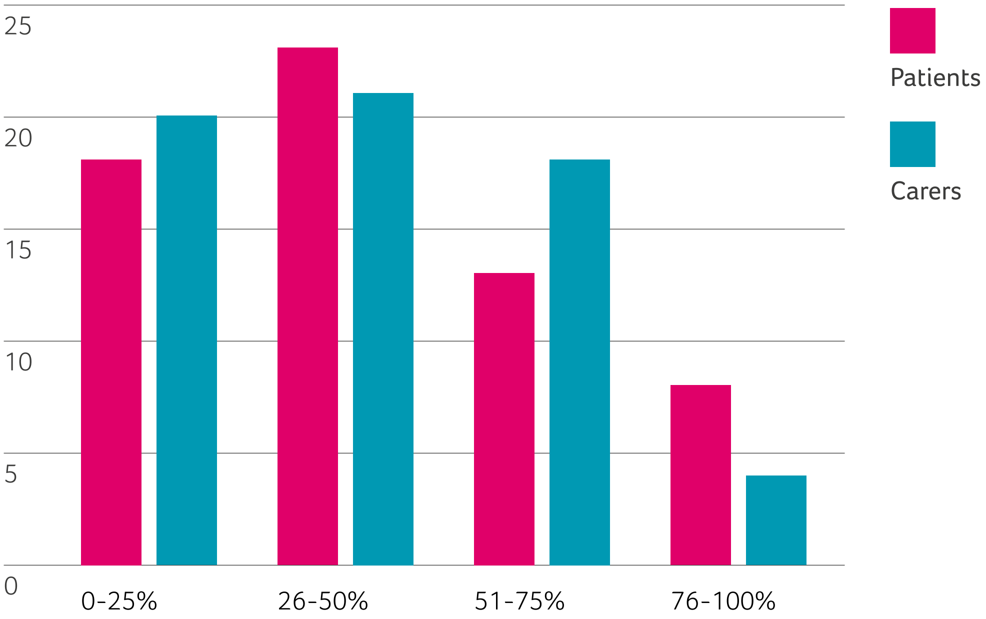
> *"[I remember] the occupational therapist going out and one very elderly lady saying to her: 'you're the first person who's sat on that sofa in twelve months'. That professional came back here in bits."*
> Marie Curie Nurse

87%
of Marie Curie frontline staff surveyed said they've supported end of life carers who were lonely.

Similarly high levels of loneliness were reported among carers of people at the end of life – with **87%** of survey respondents saying that, pre-pandemic, they had supported carers who they believed were lonely. The number of staff saying loneliness was present in over half of the carers they supported was higher than the equivalent question for people they cared for.

> *"I noticed that loneliness had a bigger impact on carers than on patients. Maybe this was because of the burden of caring and feeling of responsibility the carers experienced."*
> Marie Curie Nurse

Chart 1:
In your typical pre-pandemic caseload, what proportion of the palliative and end of life patients/informal carers that you supported do you believe may have been experiencing loneliness?



Unsurprisingly, there was a near universal consensus among Marie Curie staff that the covid-19 pandemic has resulted in increased experiences of loneliness among dying people and their carers in Northern Ireland (see Chart 2). Over **70%** of frontline staff said the pandemic had caused a substantial increase in the number of people living with a terminal illness experiencing loneliness – with a further **27%** noting either a moderate or slight increase.

Among carers of people at the end of life, **69%** of staff said the pandemic had substantially increased the number experiencing loneliness, with a further **30%** noting a moderate or slight increase.

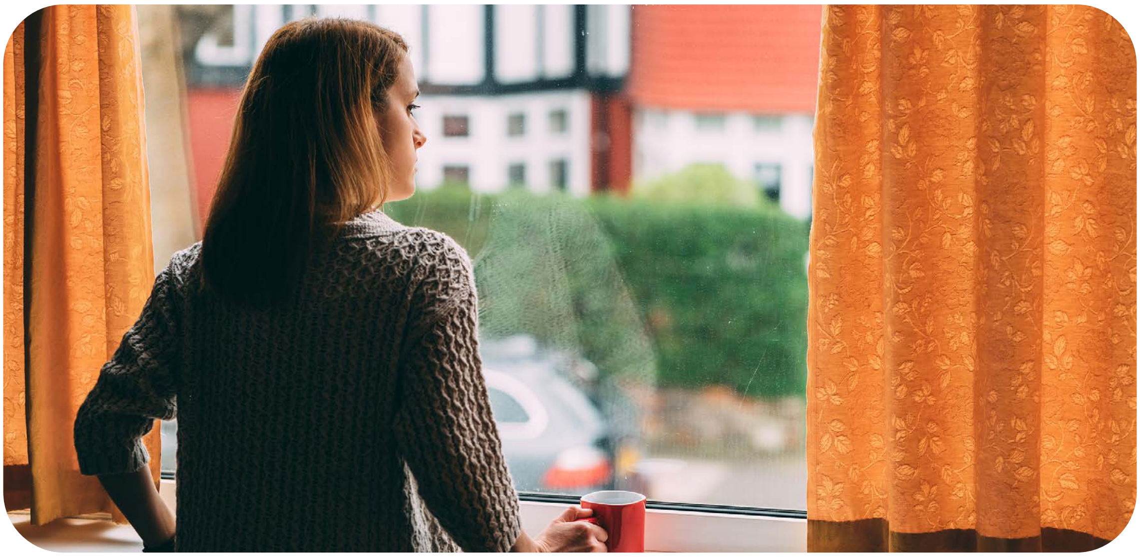


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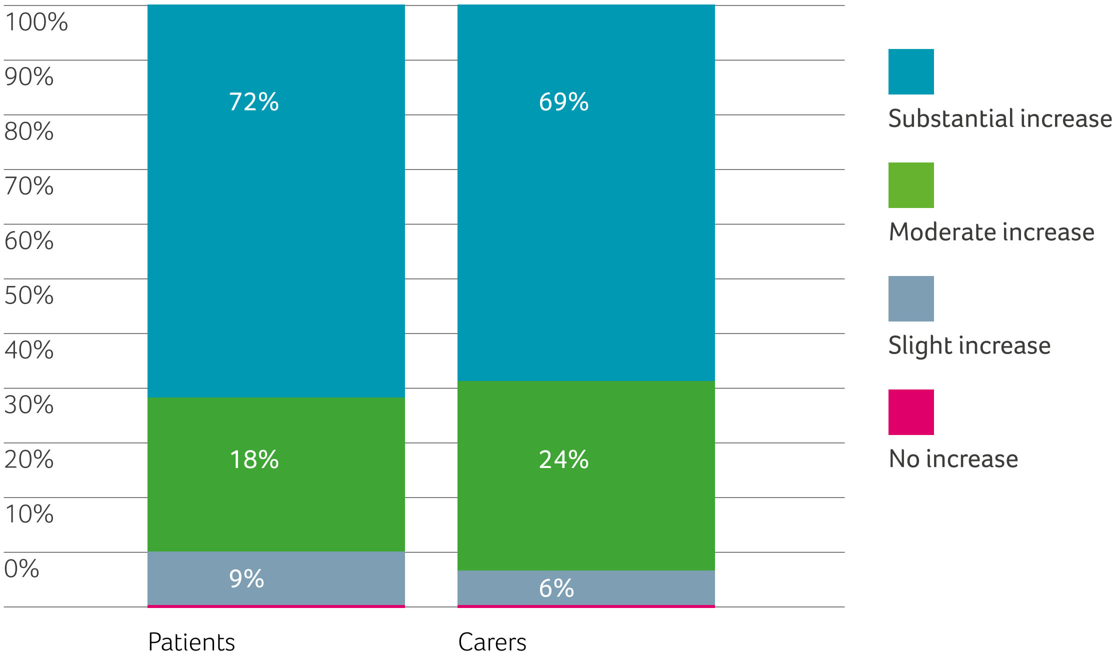
Chart 2:
In your opinion, to what extent has the covid-19 pandemic impacted on the prevalence of loneliness among the palliative and end of life care patients/ informal carers you care for/support?



> *"Particularly during the pandemic, there's been an increasingly worrying impact on people's wellbeing, including social isolation, feelings of being overwhelmed, loneliness and increasing anxiety around diagnosis and prognosis. All of these factors greatly impact on the overall condition of our palliative patients and their loved ones."*
>
> Marie Curie Nurse

Loneliness drivers: People living with a terminal illness

These high levels of loneliness are caused by a variety of factors. Many people living with terminal health conditions are in older age groups, and their social networks have dwindled over the years as friends have died and family members have grown up and have lives of their own to lead.

> *"A lot is to do with people living longer than their friends and having no one from their age group to relate to."*
>
> Marie Curie Nurse

This has been further compounded by the social restrictions associated with covid-19, which have made it even harder for people living with a terminal illness to spend time with others, particularly loved ones who don't live in the same household.

In many cases, a kind of surrogate social network will be formed by the health and social care professionals providing care, but these professionals are usually facing severe capacity pressures and often need to prioritise the person's symptoms and physical needs.

> *"One of the loneliest people I've ever met is a gentleman who's living with a terminal illness and he's in a nursing home. He doesn't have very many family visitors. And the care staff, he knows they care and they come in and they do their tasks. But he'd just like, at some point, one of them to take five minutes and sit down and say: 'how are you?' and just have a chat with him. They just don't have time. He understands that. But he's very, very lonely."*
>
> Marie Curie Patient and Family Support Team Member

The physical deterioration and other symptoms associated with terminal illness, particularly the cognitive decline caused by neurodegenerative conditions like dementia, can leave many people struggling to communicate or take part in things like social activities – creating feelings of loneliness and isolation.

> *"You'd have people with cognitive impairment, which is maybe meaning they're misunderstood and not able to communicate clearly. Or even patients with tracheas in place and they can't communicate verbally anymore. You can often identify how they've so many people around them, and genuinely a lot of the time people trying to reach out and trying to communicate and find a way, but yet, compared to how they'd normally communicate, they must feel completely trapped in their own mind. That must be a very lonely and very dark place."*
>
> Marie Curie Social Worker

> *"Reduced mobility and coming to terms with a palliative illness can cause a patient to feel isolated."*
>
> Marie Curie Nurse

Our staff also highlighted a mixture of reasons why people who are dying may not want to be around loved ones even if those networks do exist. On an emotional level, they may feel the people in their lives cannot truly understand what they're going through, leaving them without the meaningful connections they need.

> *"Who can they trust to talk to? Who will understand exactly how they feel?"*
>
> Marie Curie Nurse

They may be reluctant for loved ones to visit due to the impact their condition is having on them – including on their physical appearance and abilities.

> *"A patient's condition – especially fatigue [and the impact on] body image – leads to them not wanting visitors."*
>
> Marie Curie Nurse

And this may be matched with friends and loved ones feeling uncomfortable with confronting the fact that the person is dying – making them reluctant to spend time around them.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> *"[We see] friends and family feeling awkward at being around patients whose disease is progressing; not knowing what to say; avoiding contact with the person."*
>
> Marie Curie Nurse

> *"Friends are scared of patients' diagnosis. They maybe feel they can't cope and therefore don't visit."*
>
> Marie Curie Nurse

Finally, staff highlighted that healthcare services, such as day hospice sessions, often provided an opportunity for people living with a terminal illness to meet others who could relate to their situation, form friendships and receive peer support – but these services have been severely affected by the covid-19 pandemic.

> *"In [Marie Curie] day hospice, the thing that everybody reports they miss so much, is the company and the friendships they develop. They all say the same thing. It was the highlight of their week. It was what they looked forward to because they were with people who understood exactly what they're going through. And so many genuine friendships were developed. The social support they got was so valuable."*
>
> Marie Curie Allied Health Professional

Many of the Marie Curie frontline staff who provided evidence for this report highlighted that patients often hide the loneliness they're feeling so as not to add any extra burden or stress to those around them. Staff spoke of patients' need to 'protect' their loved ones when they were already experiencing so much distress and pressure as a result of the terminal illness in the household.

> *"One lady was cared for by her husband. She had a degenerative condition that had been ongoing for a while and now she was literally stuck in her chair and basically sleeping in her chair at night. And she actually said to me: 'this is the first time I've been able to talk to another woman about how I feel'. And it broke my heart, when you think of the amount of people coming in and out of the house. But it was just because I was there and I was there all night. And she was awake most of the night. And I think the impact for her was, she felt very sad. She felt she couldn't tell anybody how it was, how she felt. Not even her husband, because she was protecting him. She was lonely. Bottom line was, she was lonely."*
>
> Marie Curie Nurse

> *"Mostly what I would hear from the patient themselves is: 'it's been so difficult. I'm trying to protect them. I don't want them to feel any more pain than what they're already feeling'."*
>
> Marie Curie Nurse

The stigma attached to admitting loneliness is well evidenced,(vi) and our staff noted this embarrassment at admitting loneliness may mix with the protection instinct highlighted above.

> *"[There's] a sense of shame for people who feel lonely, because they feel either they don't have the family to support them, or they don't want to put that responsibility on their family. 'Or is it something about me? I don't have the support around me because people don't want to be around me.' Is there maybe a sense of guilt or shame that they don't have these people with them day-to-day, to reduce that loneliness?"*
>
> Marie Curie Allied Health Professional

While 93% of frontline staff who responded to our survey said they had cared for a patient they believed was experiencing loneliness, less than a third came to this conclusion because the patient directly told them – and 46% reported the loneliness based on their own observations of the patient.

This hints at the stigma of admitting loneliness and illustrates one of the many challenges of addressing it among vulnerable groups. So few are willing to admit to feeling lonely and ask for help.

In this context, there's more work to do on Health and Social Care (HSC) training and communication skills. As our staff noted, some healthcare professionals are not equipped to spot the signs of loneliness among their patients.

> *"Sometimes I've been in a situation where I've noticed that a person is definitely trying to tell another professional how they feel [about being lonely]. You're just kind of watching it and thinking: 'goodness, they're giving all the signals and they're not really picking up on it'. Time and the skills and communication, are the things we should all be armed with."*
>
> Marie Curie Nurse

Loneliness drivers: End of life carers

Among end of life carers, a similarly complex mix of loneliness drivers were reported by our frontline staff.

Over 70% of carers in Northern Ireland say they've felt lonely or isolated as a result of their caring role.(vii) A common issue identified in our findings is that end of life carers prioritise the care of their loved one above all else. This includes the need for a break and time away to see other people or to take part in recreational or social activities.

> *"There's that much going on in their lives, and they're busy, but they're also lonely. They're having to cope with so many other things. All the worry and all the stress of caring for someone who's [at the] end of life or needing palliative care. And their life becomes very focused on that. They haven't time to think for themselves. There are lots of people coming in and out of the house, but really there's nobody there for them to talk to. There's so many other stressors, so many other things going on, that they don't see that as a priority because they're just trying to cope with everything that's coming their way."*
>
> Marie Curie Nurse

> *"There's the unwritten rule that you don't complain, and it would appear selfish to put any of your own needs... well, not first, but even to care about your own needs, when you're caring for someone who's going to die. Some people wouldn't want to be seen to be thinking of themselves in a situation like that."*
>
> Marie Curie Patient and Family Support Team Member

Respite opportunities, which were so scarce for many carers of people at the end of their lives, have become even rarer during the covid-19 pandemic, as support services have closed or been scaled back. In one local study, nearly 80% of carers in Northern Ireland said they haven't been able to take a break during the pandemic.(viii) Our frontline staff recognised how important regular breaks are to combat loneliness among carers.

> *"If we're looking for a supportive package for someone going home, where there's maybe a carer who's very much lonely and on their own and quite isolated from other support, we're trying to advocate that the Trust recognises the impact on their mental wellbeing of the caring role, and the risk of breakdown, and the need for respite support. So they're maybe getting two afternoons a week where they can go and do a hair appointment if they need to. Attend to their own needs with the GP. Go for a walk with a friend. It's just trying to not only focus on the patient's needs, but identify the impact of emotional and mental wellbeing and loneliness and isolation in a caring role."*
>
> Marie Curie Social Worker

Even when carers do try to carve out time for themselves, many will feel guilty for doing so.

> *"Carers are afraid to leave the home and feel guilty abandoning them [the patient]."*
>
> Marie Curie Nurse

Previous research from Marie Curie highlighted that, due to demographic trends in Northern Ireland, many carers of people living with a terminal illness are themselves in older age groups – living with the health complaints and dwindling support networks that sometimes occur with ageing.(ix) Our staff highlighted that this can be an additional driver of loneliness among carers of people at the end of their lives.

> *"The carer is usually on their own due to family members living far away. Elderly carers may not be well themselves."*
>
> Marie Curie Nurse

Mirroring one of the causes of loneliness among people who are dying, it was also suggested that many end of life carers lack the kind of connections they need because it's so difficult for other people to relate to their situation. A carer may feel lonely even in a crowded room, because no one else truly understands what their life is like day-to-day.

> *"Quite often they're surrounded by family and friends. And they almost don't want to seem ungrateful for the support. But they're not really able to share their true emotions and feelings. And it's a sense of loneliness and isolation they're feeling."*
>
> Marie Curie Social Worker

Finally, our frontline staff noted that a long caring journey through terminal illness can lead some people to defining themselves solely as a carer. They retreat from social situations as a result, feeling they aren't worthy of spending time with because they've nothing to add to the lives of those around them beyond their caring role. They also don't want to burden others with what they're going through.

> *"[People] who have maybe spent so long caring for someone that there's an issue with their self-worth. And then they sort of disengage a little bit. They can become more lonely. And then it's actually quite hard to reach out and feel you want to get involved in activities, even if they're suggested. Because your whole feeling of self-worth, of that you can add anything of value, has sort of deteriorated in that time. You just don't think you're worthy of anybody."*
>
> Marie Curie Social Worker

As with people living with a terminal illness, our staff noted there are psychological barriers that prevent many end of life carers from admitting, acknowledging or even recognising the loneliness they're feeling.

The stigma of loneliness has an impact, with some carers unwilling to admit they're lonely because of fears around how that would reflect on them.

> *"There's almost a stigma around loneliness, almost like if you're lonely you don't have any friends. And there can be this perception that the rest of the world is having a great life and maybe that person thinks: 'Oh, what's wrong with me? Why am I lonely?'"*
>
> Marie Curie Patient and Family Support Team Member

Some of our staff suggested that gender dynamics may be at play when end of life carers are unwilling to admit to being lonely. While we can't make universal generalisations, it was highlighted that a fear of appearing 'weak' may be an additional barrier to some male carers acknowledging loneliness.

> *"Women are maybe a little bit more proactive at seeking out support and maybe it comes more naturally [for them] to talk. It's probably more likely that women would seek out support groups or try and seek support from friends or people who've been through the experience before. Whereas men maybe see that more as a weakness, don't want to admit those things and don't even know where to begin in terms of looking for support elsewhere, or admitting any of that."*
>
> Marie Curie Allied Health Professional

Our survey results reinforce that these stigmas may exist, as more of our frontline staff said they identified loneliness among the carers based on their own observations (43%) than because the carer directly told them about it (34%).

Finally, our frontline staff noted that some end of life carers may not recognise what they're feeling is loneliness – because even though they lack the emotional connections they want, they're still physically close to the person they're providing care for.

> *"When you say to people: 'do you feel lonely?' and if you were to ask them directly and they were a carer who is caring 24/7 for the person, I've had people say: 'how can I be lonely? I'm with them all the time.' So, it's almost they don't see the emotional loneliness because physically, they're not alone. You have to delve into that and say: 'you know, just because you're with them 24/7, it doesn't mean that you can't feel lonely'."*
>
> Marie Curie Social Worker

Our findings suggest that there's a high prevalence of loneliness among people at the end of their lives and their carers in Northern Ireland. These loneliness experiences are driven by a wide range of complex, sometimes inter-linking factors, which have only been exacerbated by the covid-19 pandemic. As we'll see in the coming pages, this loneliness can have a profound impact on the health and wellbeing of these groups.

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The impact of loneliness at the end of life

There's a wealth of research illustrating the significant impact loneliness can have on someone's health and wellbeing.(x) The World Health Organisation argues that, among older people in particular, loneliness "damage[s] their mental and physical health and quality of life".(xi) To the best of our knowledge at the time of writing, however, this report is among the first dedicated examinations of these themes among those affected by terminal illness in Northern Ireland.

This chapter is divided into two sections, looking at: (i) the impact of loneliness on the health, wellbeing and quality of life of dying people and their carers; and (ii) loneliness as a driver of increased use of health and social care services among dying people.

i) Loneliness, health and wellbeing at the end of life

As Chart 3 illustrates, our frontline staff reported significant impacts of loneliness across a range of health/wellbeing dimensions for people living with a terminal illness. The majority of staff told our survey that loneliness has a medium or high impact on dying people's physical, psychological, social and spiritual wellbeing – often times simultaneously, with devastating consequences for their health and quality of life.

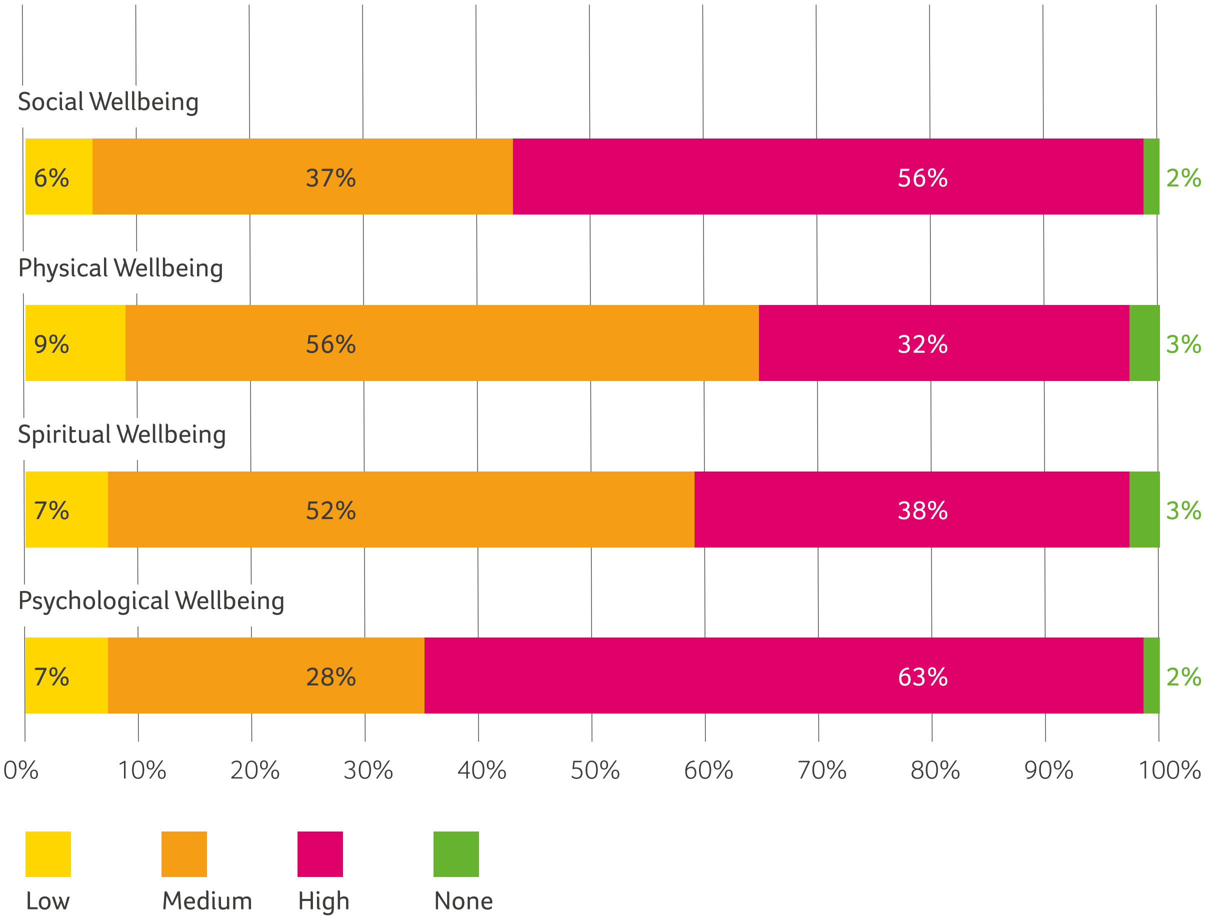
> *"Loneliness impacts on psychological, spiritual, physical and social wellbeing. As all are interrelated, this will impact on the overall palliative and end of life experiences of patients."*
>
> Marie Curie Nurse

One of the most common themes identified was loneliness as a trigger for mental ill health. People living with a terminal illness may already be at heighted risk of mental health challenges. One study suggests the incidence of major depression in some groups of people living with a terminal illness may be as high as 77%,(xii) while many also experience anxiety and a continuum of psychological suffering arising from things like uncertainty about the future and feelings of hopelessness.(xviii)

Chart 3:
How would you rate the impact of loneliness on the palliative and end of life care experiences of the patients you cared for or supported?

63%

of Marie Curie frontline staff surveyed said loneliness had a high impact on dying patients' psychological wellbeing.



Many of our frontline staff highlighted that experiences of loneliness can drive or exacerbate these issues among dying people.

> *"It can certainly be a trigger for depression and anxiety. And probably any other mental health problems. That feeling of isolation and being disconnected from society, maybe from their family. Maybe from life in general."*
>
> Marie Curie Patient and Family Support Team Member

> *"Loneliness can lead to significant low mood and depression. This has a real psychological impact on patients who are already living with a life-limiting illness."*
>
> Marie Curie Nurse

In some cases, these experiences of loneliness can make it harder for people to come to terms with their prognosis and what lies ahead.

> *"[It has a] huge impact on a person's ability to process their diagnosis, how they're feeling and how they're able to cope if they're also experiencing loneliness and isolation."*
>
> Marie Curie Nurse

In other, even worse cases, loneliness is driving dying people to the conclusion that they've nothing more to live for – causing them to give up on the time they have left.

> *"If they're feeling lonely they're more likely to give up and get depressed because there's nothing to live for, nothing to aim towards."*
>
> Marie Curie Allied Health Professional

> *"Loneliness, if not dealt with or discussed, usually leads to depression and giving up on life. [Like there's] nothing to care about or fight to live for."*
>
> Marie Curie Nurse

Linked to this, research on the psychology of loneliness suggests that feelings of loneliness can influence behaviour, causing us to lose confidence and withdraw from those around us. This causes a 'downward spiral of loneliness' – driving more negative thoughts and despair, which, in turn, lead to more intense feelings of loneliness (see Diagram 1).(vi)

This phenomenon was highlighted repeatedly by our frontline staff. They described the way loneliness can drive people living with a terminal illness to become more withdrawn and lose interest in self-care, with an enormous burden not just on their psychological wellbeing, but their physical health too.

> *"If people are feeling lonely, they'll start to go into themselves. And I find sometimes what happens is, when people start to feel lonely, they start to disengage from whatever company they do have around them. That might lead to depression and psychological pain. I think people could fall quickly into depression and then start feeling like even an everyday wash becomes a task for them. And illnesses increase. Symptoms increase."*
>
> Marie Curie Allied Health Professional

> *"If it [loneliness] has such a negative effect on their mental health, they can actually lose motivation and become more withdrawn and find it very hard to engage with people or reach goals."*
>
> Marie Curie Social Worker

> *"If you become a bit more withdrawn, it's that vicious cycle. That vicious cycle of feeling lonely, becoming demotivated and then maybe you don't make the same effort. Maybe you're wearing the same clothes all week long. You're not motivated to get up and get washed and get dressed, to make meals, to eat meals. By the time you've made them, if you're sitting eating on your own, you maybe can't be bothered. Your appetite can change."*
>
> Marie Curie Allied Health Professional

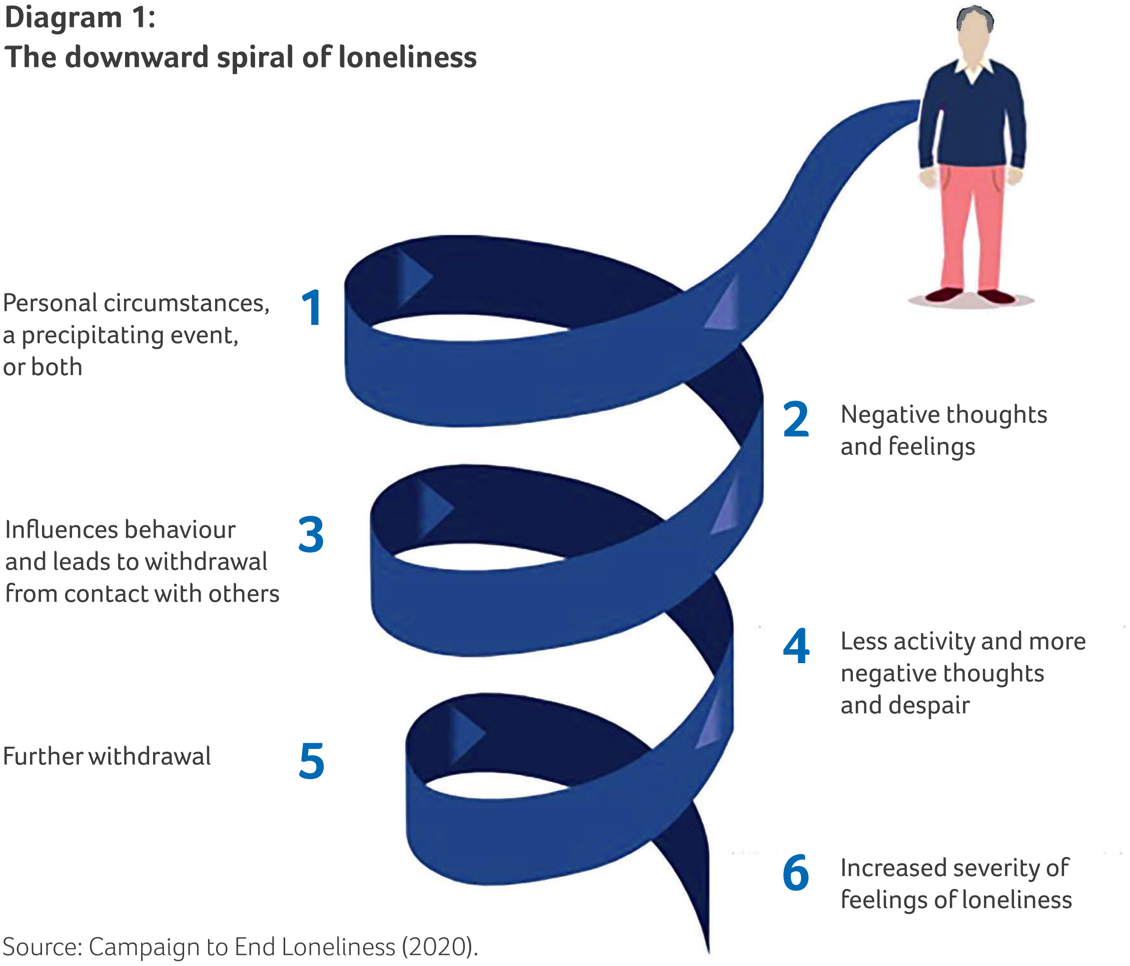
These findings suggest that, among people living with a terminal illness, extra layers may exist in addition to the original six-step downward spiral of loneliness concept – with effects on self-care and physical symptoms as well as psychological wellbeing.

We must also recognise that this downward spiral of loneliness will impose an even greater cost on people living with a terminal illness than many other groups, as they may not have time to reverse the descent during the limited time they may have left to live – spending their final days and weeks in a state of growing loneliness and associated mental ill health.

Another fascinating insight from our frontline staff concerned the connections between loneliness and experiences of physical symptoms. There's some evidence to suggest that positive emotional wellbeing is favourably related to the prognosis of physical illnesses.(xiv) Our staff highlighted the other side of that coin – where feelings of loneliness are increasing dying people's sensitivity to their symptoms and, in some cases, increasing symptom burden.

Pain was mentioned frequently in this context, which aligns with wider research illustrating that loneliness is a risk factor for the development of pain in groups such as cancer patients.(xv) Similarly, feeling lonely has been linked to increased breathlessness in people with chronic obstructive pulmonary disease (COPD).(xvi) Our staff highlighted how these issues can be driven by a lack of social connections.

Diagram 1:
The downward spiral of loneliness



Source: Campaign to End Loneliness (2020).
The psychology of loneliness: Why it matters and what we can do.

> *"Loneliness can increase anxiety and result in increased experience of symptoms, mainly pain and breathlessness. Often, we find these are more anxiety-related and can be improved with company, reassurance, support and distraction."*
>
> Marie Curie Nurse

> *"[Patients] just needed somebody beside them, sometimes even just to hold their hand. And it made a huge difference, particularly with anxiety, with breathlessness and with pain. I would think these are some of the big symptoms that are definitely affected by loneliness, and sometimes it's just about knowing that somebody's there and having somebody by your side."*
>
> Marie Curie Allied Health Professional

> *"If you're feeling lonely and you don't have that support around you, you don't have that listening ear, you don't have somebody to share those problems with, they're more heightened in your own mind. Because you don't have that opportunity to offload or to share or discuss, and things accumulate and escalate. There's also the distraction – when you're lonely, you have more time to dwell on things. You don't have the distraction of people around you. I do think there's an increase in symptoms, especially around pain and anxiety, because people don't have the support of their family coming in. They don't have that distraction. And symptoms are heightened and increased. There's a sense of panic. And what might before have been a little niggle of pain when they're surrounded by family distracting them and interacting with them and feeling supported, suddenly when they're on their own, it's seven out of ten pain, eight out of ten pain. It escalates things a lot more quickly."*
>
> Marie Curie Allied Health Professional

Among end of life carers, insights from our frontline staff focused predominantly on the impact of loneliness on their mental wellbeing.

End of life carers are particularly susceptible to mental ill health due to the demands of their role and the distress caused by their loved one's illness. For example, one study looking at carers of people with terminal cancer showed that, during their loved one's last three months of life, prevalence of significant psychological distress is between five to seven times higher than the general population.(xvii)

Our findings illustrate how loneliness can exacerbate mental ill health and even drive carers to a position where they no longer feel able to continue performing their caring role.

> *"From the point of view of the informal carers, if they feel loneliness, that could develop into a depression which gets to a point where they can't carry out their role as a carer effectively anymore. So, maybe the person who needs the care would have to go somewhere else, maybe go into a care home."*
>
> Marie Curie Allied Health Professional

> *"Increased loneliness often leads to increased carer fatigue and burnout."*
>
> Marie Curie Nurse

Some staff connected feelings of loneliness among end of life carers to the overwhelming nature of caring for a dying person with complex needs, often with little-to-no information or training.

> *"Often, informal carers don't know where to source help and support. Families are left in a very vulnerable caring role with no appropriate training, often with very complicated diagnoses. They can feel isolated, abandoned and overwhelmed – with feelings of anxiety and even despair."*
>
> Marie Curie Nurse

This not only impacts on their mental wellbeing, but can drive changes in the relationship between the carer and the person they're caring for.

> *"I suppose if they're feeling isolated in their role and maybe things become a bit overwhelming for them, it could even turn to resentment of their role: 'Why have I been left on my own to do this?'."*
>
> Marie Curie Allied Health Professional

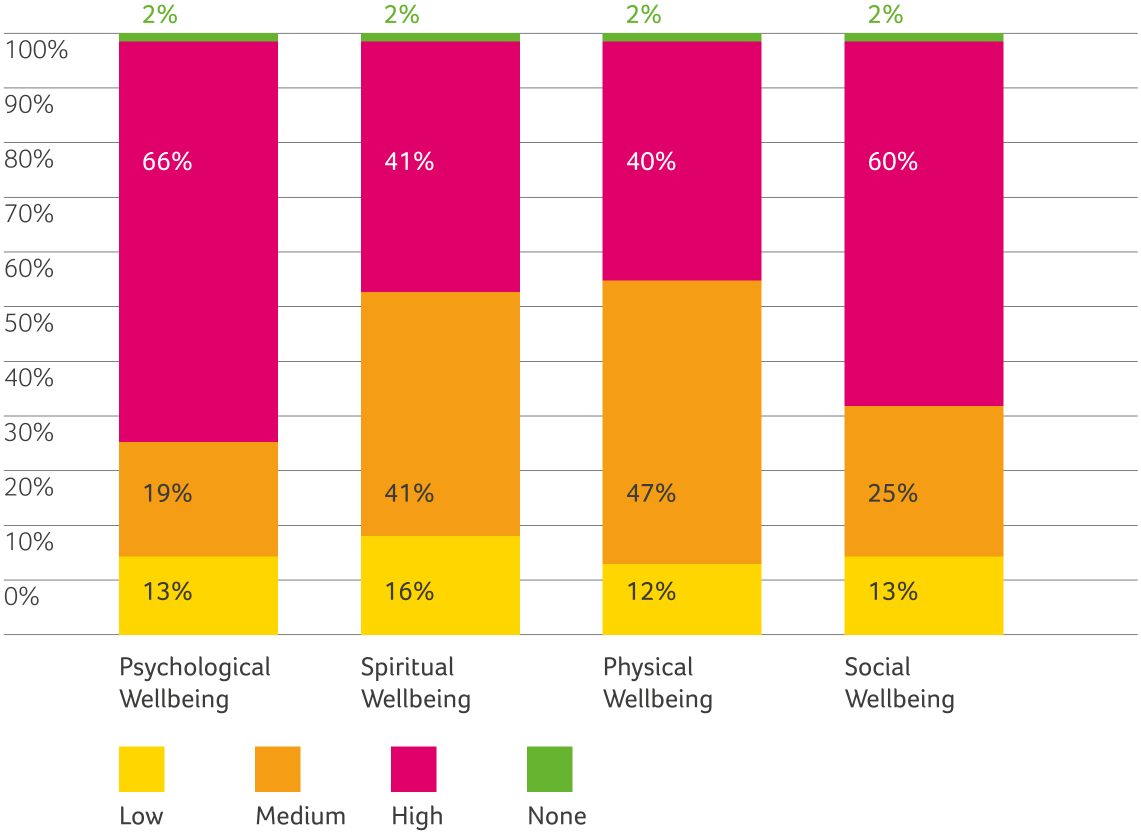
> *"For informal carers, it's a huge undertaking. And if there's loneliness on top of that, it's that feeling of: 'this is it. It's just me. There's nobody to share the load with'. If somebody feels that's all on them and they're lonely and don't have the support through that, it can nearly change that relationship with who you're caring for."*
>
> Marie Curie Allied Health Professional

Finally, staff noted that loneliness among end of life carers can make the process of grieving and re-building their life even harder once their loved one has died.

> *"[There's] a fear as well, in terms of what happens once that loved one passes on. If they have a real loneliness and they don't have the support, and bit by bit that's been lost, then it's 'who am I at the end of all of this? Who do I have? Where do I go from here?' Even in terms of how you fill your day. You're so used to having such a set routine. And that's a huge thing we experience with bereaved carers. They've spent sometimes months, sometimes years, being sole carers for their loved ones. But that changes very suddenly and it's mixed with grief, and if that social support network isn't what it was or what it should've been, it's how they fill that time, how they still have that sense of purpose, how they move forward."*
>
> Marie Curie Allied Health Professional

Our staff survey identified high levels of the impact of loneliness on carers' spiritual, psychological, physical and social wellbeing (see Chart 4). Some of these elements are addressed above, but greater research is also required to unpick the wider ways that loneliness affects these different health/wellbeing dimensions among end of life carers.

Chart 4:
How would you rate the impact of loneliness on the informal carers you supported?



ii) Greater use of health services among dying people who are lonely

There's strong evidence to suggest loneliness is a driver of greater use of health and social care services across different groups. Before the covid-19 pandemic, three quarters of GPs said they had seen between one and five people a day who'd come to the surgery mainly because they were lonely,(xviii) while older people are 50% more likely to use emergency department services if they're living alone.(xix)

Our findings reinforce these trends, illustrating that dying people in Northern Ireland may utilise health and social care services more as a result of feeling lonely.

Most commonly, staff noted that some people living with a terminal illness will engage frequently with care services on the pretext of a physical health complaint – but in reality, what they really need is someone to talk to.

> *"I see [it] in out of hours whenever we're triaging. You can see the regular patients coming on with a problem, and then requiring a home visit. And when you go out, it's actually not the problem. The problem is they need to talk. And they're lonely and have no connection, no family network there."*
>
> Marie Curie Nurse

> *"I'm dealing with a wee man at the moment and he's a very independent man. Has a catheter in. But I've been out to him the last two weeks, nearly every night I've been working. And the issue is not his catheter. The issue is he's lonely. The issue is he's no family here. He talked to me last night for the first time, for about half an hour, and he told me he's lonely. He says he's nobody to talk to. And he's ringing out of hours to get me out, or get one of us out, to come and talk to him. And that's really what it was. And he said last night: 'I want to go into a nursing home, because at least then somebody will talk to me'. And I found that very sad. This man is so independent. But he's isolated and lonely in his home. Three times I tried to leave last night. First it was his catheter. I was making my way towards the door, then he had a sore head. And then the third time: 'I've a sore stomach'. He just didn't want me to leave."*
>
> Marie Curie Nurse

As noted above, being in a state of loneliness can increase a person's sensitivity to their symptoms. Our staff highlighted that, in the worst cases, this situation can result in unnecessary use of emergency care or other services, which could be avoided simply by the person having company.

> *"When you're on your own and feel lonely, all of a sudden that little niggle is: 'I'm having a heart attack, ring 999'. Or: 'these symptoms are all accumulating and I must see my GP'. Things are under the magnifying glass. It's that sort of panic, that feeling of panic and feeling unsupported."*
>
> Marie Curie Allied Health Professional

At the other end of the spectrum, experiencing loneliness may cause patients to disengage from their condition and ignore new or deteriorating symptoms until it's too late – creating the need for unscheduled care.

> *"The patient we had who was lonely, not seeing enough people, didn't realise the deterioration in his skin. Now he needs a hospital admission. So, I suppose there's physical things that will cause people to hit a hospital or another service which could've been avoided if they weren't experiencing loneliness."*
>
> Marie Curie Nurse

These experiences demonstrate that loneliness may not only worsen a dying person's condition and symptoms, but can also be a driver for additional and, in many cases, avoidable pressure on health and social care services. This is a critical point to understand, because most of these services are already struggling with capacity – particularly during out of hours periods, which was noted specifically in two of the stories above.

Policymakers therefore need to address loneliness among dying people and their carers, not just for the good of those populations, but to help relieve avoidable pressure on health and social care services as well.

Recommendations to tackle loneliness at the end of life in Northern Ireland

This report has shown that loneliness is having a profound impact on people living with a terminal illness, and their carers, across Northern Ireland. These groups may be particularly vulnerable to experiencing loneliness, as they fall into several high-risk categories – including older age, declining health and low income – simultaneously.

We need to get to grips with this challenge urgently, not just for those dying people and their carers who are lonely today, but for the rapidly rising number of people who will be affected by terminal illness, and are therefore in danger of experiencing loneliness, in the months and years ahead.

Pre-covid estimates suggested that an average of over 18,500 people would be dying each year in Northern Ireland between now and 2040(xx) – an increase of nearly 20% on 2019. Demand for palliative care will grow by over 30% during this time,(xxi) and the number of people dying in their own homes – where loneliness is perhaps felt most acutely – could rise by a staggering 70%.(xxii)

With so many more people expected to be affected by terminal health conditions in the future, the scale of loneliness at the end of life here will grow dramatically without action. The rest of this report makes recommendations for policymakers and the Health and Social Care system to combat loneliness among dying people and their carers. These recommendations are based on the views of Marie Curie’s frontline staff and our wider work on loneliness policy in Northern Ireland.

While delivering these recommendations will inevitably require investment, we believe that pales in comparison to the physical, emotional and psychological costs inflicted on dying people and their loved ones by loneliness. We would also highlight research showing that every £1 invested in tackling loneliness can potentially save up to £3 in health costs.(xxiii) Tackling loneliness at the end of life in Northern Ireland makes moral, practical and financial sense.

Recommendations for policymakers

- The next NI Executive should commission and deliver a bespoke Northern Ireland loneliness strategy. This strategy should be: cross-departmental; developed using a co-design and co-production approach; utilise the experience and expertise of the charity sector, including palliative and end of life care providers; and identify existing best practice from Northern Ireland and beyond.
- Junior Ministers in the Executive Office should lead a public awareness campaign on loneliness, with input from every other Stormont department. This should be orientated around a number of interdependent goals: tackling the stigma attached to experiencing loneliness; ensuring people who experience loneliness know how and where to access support; and encouraging the wider public to play their part in combatting loneliness among vulnerable groups.
- The social care reform agenda must prioritise greater support for informal carers. This should include a much more robust system of respite provision, with measurable progress on this within the first year of the new NI Assembly mandate.

Recommendations for the Health and Social Care system

- As part of a wider compassionate communities model, Health and Social Care Trusts should deliver greater investment in befriending and companionship services for people living with a terminal illness and carers, which have been shown to improve outcomes of loneliness among those at the end of life.(xxiv) This should include the direct commissioning of such services where appropriate.
- Health and social care service providers should prioritise the safe re-opening and expansion of day hospice services for people living with a terminal illness throughout Northern Ireland.
- HSC training for relevant disciplines – particularly community-based roles – should equip staff to identify the signs of loneliness among people at the end of their lives and connect them with the support they need.

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