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Every minute matters

The impact of delayed discharges from hospital on terminally ill people in Northern Ireland

Marie Curie

Care and support through terminal illness

Introduction

The Health and Social Care (HSC) system in Northern Ireland is facing a period of unprecedented pressure. Significant growth in the older population, along with increasing levels of chronic illness and multi-morbidities, is putting enormous demand on services. This strain is felt particularly in the timely discharge of patients when they are ready to leave hospital.

Marie Curie provides care and support to people living with all terminal illnesses in Northern Ireland. Our recent research has uncovered high levels of emergency hospital admissions experienced by terminally ill people in their last year of life.[1] We are also concerned about how effectively terminally ill patients are being discharged home or into the community when they are ready to leave hospital. This report focuses on the extent – and underlying causes – of delayed discharges across local hospitals, the impact these delays are having on terminally ill people and what can be done to address the issue.

This report's findings show that patients in Northern Ireland are experiencing discharge delays amounting to thousands of days a month spent unnecessarily in hospital, with a detrimental impact on their health and quality of life. This comes at a cost that the health service can ill afford.

More worryingly, we have found that some patients are even dying in hospital while waiting to be discharged – preventing them from spending their final days and hours at home or in the community.

The scale of Northern Ireland's delayed discharge problem isn't surprising. More people are being admitted to hospital with multiple chronic illnesses; assessing their community care needs and putting in place the complex packages required can be difficult. More broadly, the lack of an Assembly and Executive has meant that HSC transformation has been stymied, while the tactical budgetary problems facing public services have also largely been unaddressed.

Over the next 20 years, the population is predicted to keep getting older and, unfortunately, sicker, so solutions are required urgently in order to prevent the number of delayed discharges growing further.

We do not want to see terminally ill people spending time in hospital unless it is absolutely necessary. In many cases, with the right mix of community care and specialist palliative services, terminally ill patients can be cared for outside of the acute setting. However, this isn't always the reality for patients today, so we need to ensure that those who do end up in hospital are able to be discharged safely and quickly when they are ready.

Executive summary

Data show that in 2017-18 there were:

204

PATIENTS IN NORTHERN IRELAND WHO **DIED IN HOSPITAL** WHILE WAITING TO BE DISCHARGED

46,000

DELAYED BED DAYS ACROSS THE NORTHERN IRELAND HEALTH SERVICE

12,900

DELAYED DAYS CAUSED BY **A LACK OF DOMICILIARY CARE PACKAGES**

10,100

DELAYED DAYS CAUSED BY **HOSPITAL CARE PLANNING ISSUES OR DELAYS**

7,775

DELAYED DAYS CAUSED BY **A SHORTAGE OF CARE HOME BEDS**

Delayed hospital discharge has a significant impact on terminally ill people, causing distress and frustration, affecting their quality of life and preventing them from spending as much time as possible in their own home or the community during their final days and weeks. Trust data shows they may even end up dying in hospital while waiting to be discharged.

The population is ageing and more people are living with multiple chronic and terminal illnesses, so urgent solutions are required to help tackle the issue.

The Department of Health and the Department of Finance should work with other stakeholders to scope out potential funding measures for adult social care and take action to introduce a longer-term, more strategic budget setting process for local HSC Trusts.

Measures are needed to ensure social care workers are fairly rewarded and have genuine and attractive career opportunities. More also needs to be done to ensure the workforce has the necessary expertise and training to meet Northern Ireland's growing social care demand and provide high-quality, compassionate care to people with terminal illnesses.

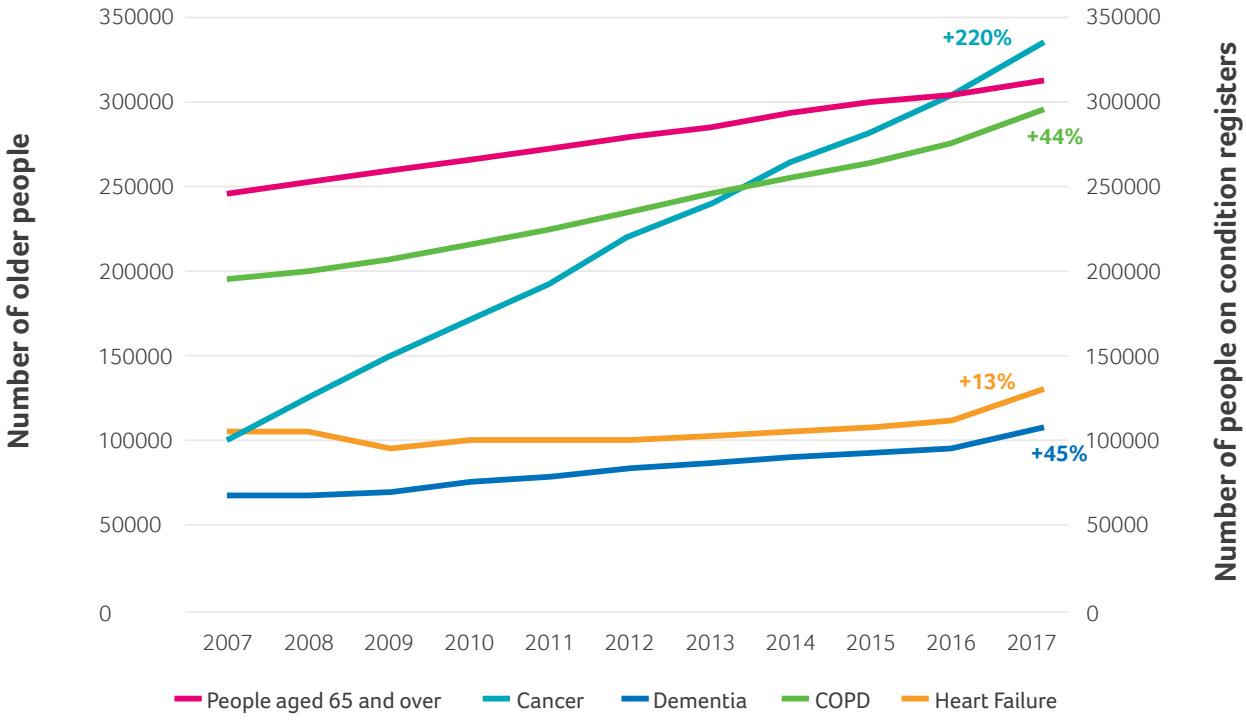
HSC stakeholders and palliative care providers should work together to design and deliver new hospital-based specialist teams to assist the timely and smooth discharge of terminally ill patients.

Growing demand for health and social care services in Northern Ireland

Demand for health and social care services in Northern Ireland is rising exponentially, partly because of large growth in the number of older people, many of whom are living with one or more terminal illnesses and increasingly complex needs.

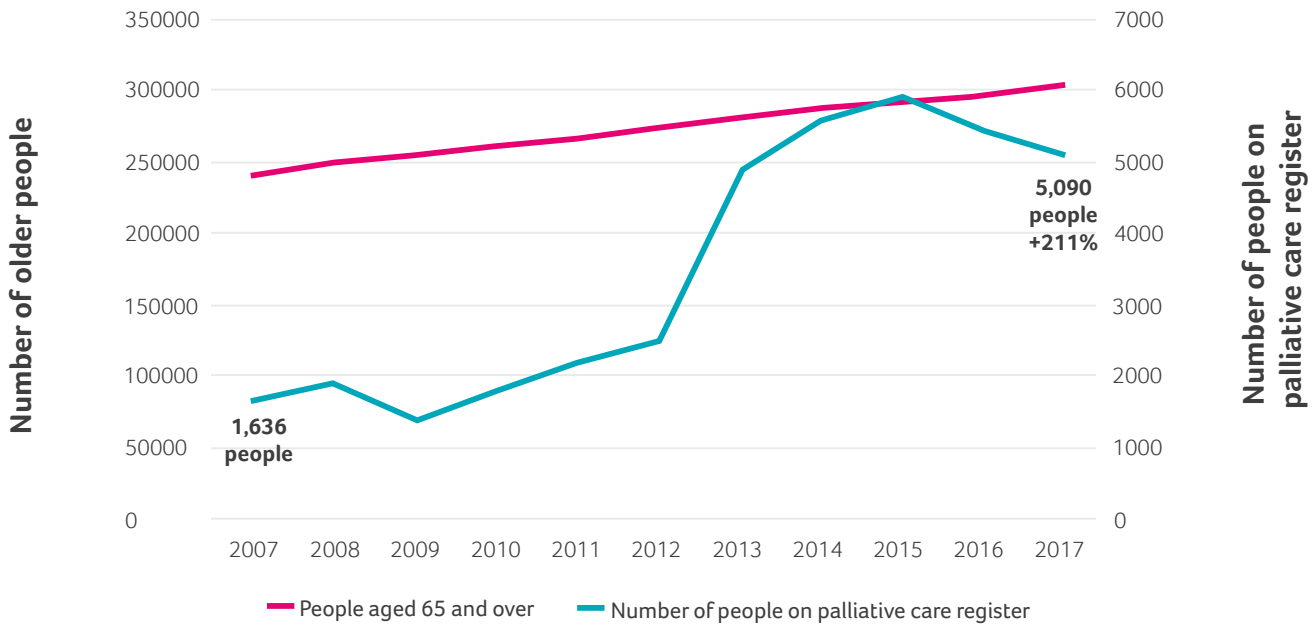
Between 2007 and 2017, the number of local people aged 65 years and over grew by more than 25%, while the population aged 85 years and over grew by more than 30%.[2] The prevalence of chronic and terminal illnesses has been growing at a similar rate (or an even faster rate for some conditions, such as cancer and COPD; Chart 1). Perhaps the most stark figure is the number of people on Northern Ireland's palliative care register, which increased by more than 200% during the period.[3]

Chart 1: **Population and chronic/terminal illness trends in Northern Ireland, 2007–17**



Source: Northern Ireland Statistics and Research Agency. Disease prevalence (Quality Outcomes Framework).

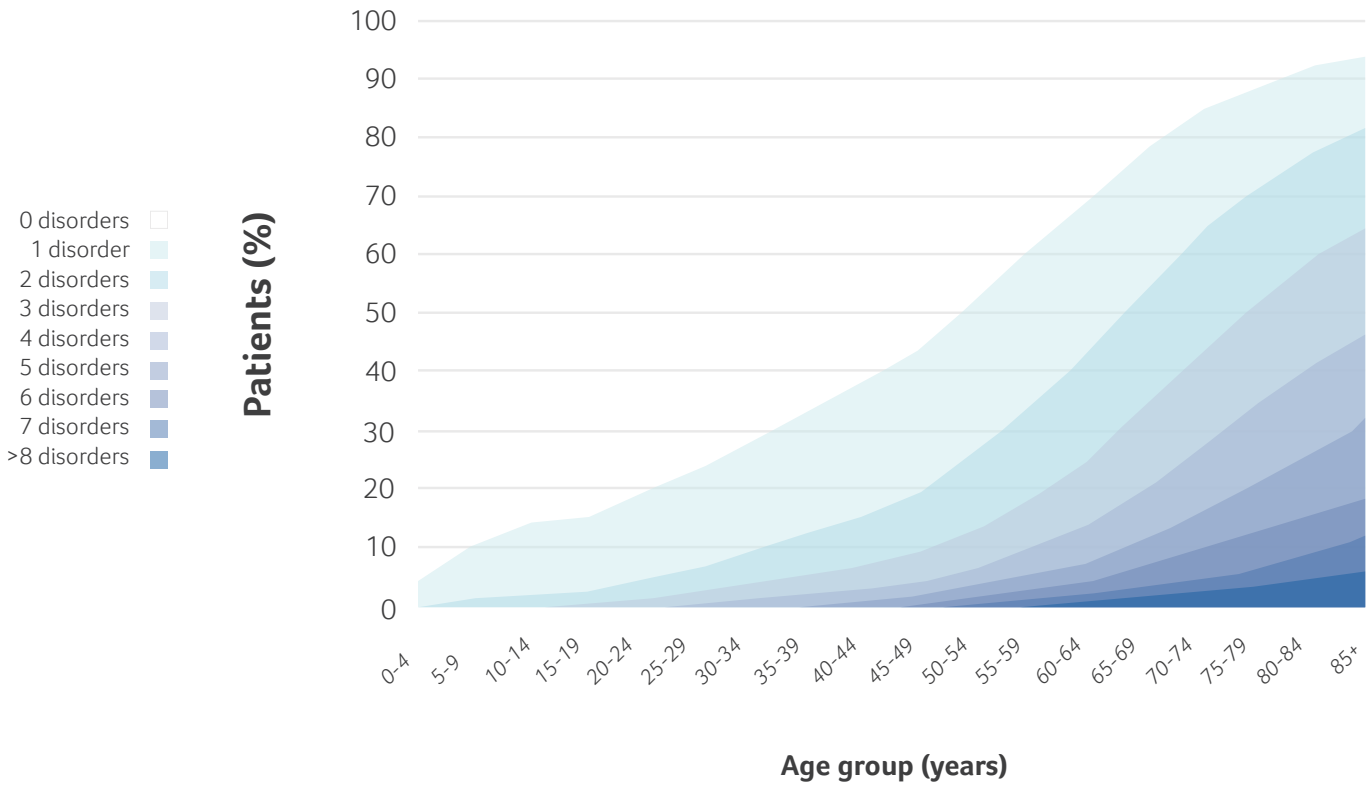
Chart 2: **Northern Ireland palliative care register, 2007-17**



Source: Department of Health. 2017/18 Raw disease prevalence data for Northern Ireland.

Many patients with terminal illnesses will have multi-morbidities; in other words, they are living with secondary conditions alongside their terminal illness diagnosis. For instance, research on people with dementia in care homes found that it was common for these patients to have a secondary diagnosis of conditions such as high blood pressure, heart disease, stroke and diabetes.[4] More broadly, it is estimated that one in four people in the UK have multi-morbidity, increasing to at least two-thirds of those aged over 65 years.[5]

Chart 3: **Multi-morbidity trends by age group**



Source: Barnett, K et al (2012). Epidemiology of multimorbidity and implications for health care, research and medical education: A cross-sectional study. *The Lancet*, 380.

The steep rise in the number of older people living with multiple chronic conditions has led to a significant increase in the number of patients being admitted to hospital, often via A&E, who require complex community care packages to enable their safe discharge. We estimate that there were approximately 200,600 emergency bed days for terminally ill people in their last year of life in Northern Ireland in 2015.[6] Discharging these patients safely and promptly puts enormous pressure on care planning in hospital and community care provision.

The health service is already struggling under this pressure, and, based on future demographic projections, the situation looks set to get even worse.

The Northern Ireland Statistics and Research Agency projects that by 2028, people aged 65 years and over will outnumber children, representing almost one in every four people by 2041. The 'oldest old' – those aged 85 years or over – are also expected to double in number during this time.[7] Unsurprisingly, there will be a corresponding increase in terminal illness rates and multi-morbidity, with palliative care need expected to rise by 31% by 2040.[8] This will put even greater pressure on a system that is already approaching breaking point.

Katie Hyams/Marie Curie

The extent of delayed hospital discharge in Northern Ireland

Marie Curie secured data from five HSC Trusts in Northern Ireland relating to delayed discharge patterns in local hospitals during 2017–18. Consistent data from all five Trusts relating specifically to patients in the last year of life were unavailable. The data discussed in this report therefore refers to all patients whose discharge from hospital was delayed and recorded by each Trust. The pages that follow provide an overview of these data, with specific analysis on the impact of delayed hospital discharges on people who have terminal illnesses (who will be a proportion of the overall number affected).

The data show that there were over **46,000** delayed bed days across the five HSC Trusts in 2017–18, averaging more than **3,800** delayed days per month or nearly **900** delayed days per week. (Table 1).

Delayed discharge has a significant and detrimental impact on patients. Being kept in hospital longer than necessary can be distressing and frustrating for patients. The consequences are especially acute for those with terminal illnesses, who may have little time left and whose quality of life may be severely affected (page 24). A patient may even die while waiting for their discharge to take place, and data shows that this happened to 204 people across the Northern Ireland health service in 2017-18 (Table 2).

Many people living with chronic and terminal illnesses want to be cared for at home or in the community, surrounded by their loved ones – especially as they are approaching the end of their lives. While this may not always be possible for every patient, it is unacceptable that so many people in Northern Ireland are dying in hospital after being declared fit to leave.

The picture looks even more concerning when we compare these statistics to those elsewhere. For instance, there were over 40,000 more deaths recorded in Scotland than in Northern Ireland in 2017, but recorded data shows that 300 people died in Scottish hospitals while waiting to be discharged last year,[9] compared to 204 in Northern Ireland.

From the point of view of the health service, delayed discharge also incurs a cost to the acute sector at a time when budgets are already under significant pressure. Important savings could be made if these delays were addressed by investing in community care, which is notably cheaper. Addressing discharge delays would also help to alleviate pressures felt elsewhere in the health service, especially in A&E and elective waiting times.

Table 1: **Total delayed bed days resulting from delayed discharge in Northern Ireland, 2017–18**

Health and Social Care Trust	Number of delayed bed days*
Belfast	17,887
Northern	8,591
Southern	3,896
South Eastern	5,547
Western	10,227
	Total: 46,148

*this excludes days that were coded as 'No significant delay' by the Trusts, which refers to delays of <48 hours.

Table 2: **Patients who died while waiting to be discharged from hospital in Northern Ireland, 2017-18**

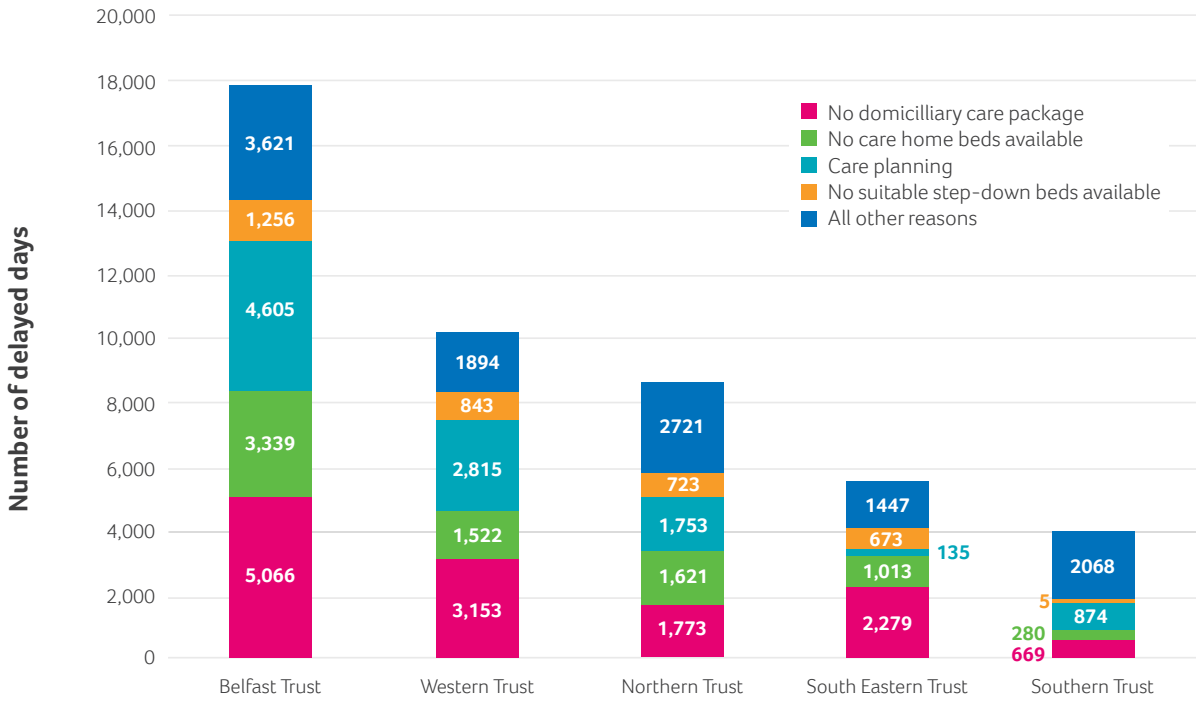
Health and Social Care Trust	Number of patient deaths while waiting for hospital discharge
Belfast	52
Northern	56
Southern	48
South Eastern	34
Western	14
	Total: 204

The data show that discharge delays can be caused by a number of factors. Unsurprisingly, the single biggest contributor is capacity in community care – in particular, lack of domiciliary care packages and care home places – but issues with care planning in hospital and shortage of step-down beds are also factors. These challenges, along with other issues causing discharge delays, are covered in more detail in the pages that follow.

What causes delayed discharges in Northern Ireland's hospitals?

A multitude of factors are contributing to delayed hospital bed days in Northern Ireland (Chart 4). The single biggest cause across all Trusts is the lack of domiciliary care packages, followed by delays related to care planning. Shortage of care home beds and step-down beds are the other biggest factors accounting for delayed bed days, with issues such as unavailability of equipment or home adaptations causing fewer, but still significant, numbers of delayed days. A full list of the issues accounting for delayed bed days, broken down by HSC Trust, is in Appendix 1.

Chart 4: **Causes of delayed bed days in the Northern Ireland health service, 2017-18**



Lack of domiciliary care packages

One of the single biggest factors causing discharge delays in Northern Ireland's hospitals is pressure on domiciliary care provision. Domiciliary care is vital to ensuring terminally ill patients can receive high-quality care in their own home. Their needs may include physical care, such as help with washing, dressing and getting out of bed, and/or practical support, including shopping, cooking or tasks around the home.

In most cases, the healthcare services that terminally ill patients need to be cared for at home – both palliative care services such as the Marie Curie Nursing Service and more generalist services such as District Nursing – cannot be provided without this support already being in place. Delays in assessing patients' social care needs and putting an appropriate domiciliary care package in place prevent patients being discharged from hospital when they are ready to leave.

The impact that domiciliary care pressures are having on both hospitals and patients in Northern Ireland is stark. During 2017–18, lack of domiciliary care packages caused nearly **13,000** delayed bed days across the health service, (Table 3).

Table 3: **Delayed bed days resulting from lack of domiciliary care packages, 2017–18**

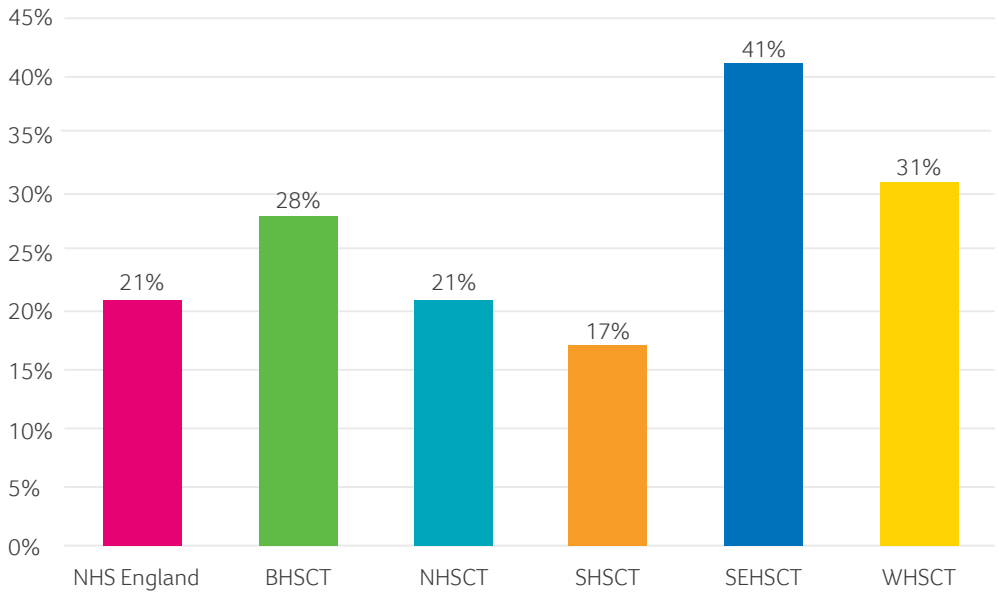
Health and Social Care Trust	Delayed beds because of lack of domiciliary care packages
Belfast Trust	5,066
Northern Trust	1,773
Southern Trust	669
South Eastern Trust	2,279
Western Trust	3,153
	Total: 12,940

The shortage of domiciliary care packages is caused by two main factors: lack of funding for the packages needed and a shortage of staff to fulfil packages.

As the local population has grown older and its health needs more complex, demand for domiciliary care packages has risen, and Trusts have been unable to meet this demand. This is reflected in growing waiting lists across the health service. For example, while there were nearly 700 people in Northern Ireland waiting for a domiciliary care package at the end of 2016, this increased to more than 1,200 in 2017–18, with over 600 people waiting in the Belfast Trust alone.[10]

It is illuminating to compare the impact domiciliary care shortages are having on hospital discharge in local Trusts with the health service in England. Only the Southern Trust fares better than NHS England, with lack of domiciliary care packages accounting for either the same or a higher proportion of delayed discharges in the other four local Trusts (Chart 5). This is despite local authority spending on adult social care falling by 10% in real terms in England between 2009/10 and 2014/15.[11]

Chart 5: **Proportion of discharge delays as a result of lack of domiciliary care packages in Northern Ireland versus NHS England, 2017–18**



Source: FOI data and NHS England (2018). Delayed transfers of care statistics for England 2017/18.

The Northern Ireland Social Care Council predicts that a further 4,050 care packages will be needed in 2020 to meet demand,[12] so a mature conversation is needed around how to improve domiciliary care provision for everyone who needs it and, crucially, where the money will come from for this.

The *Power to People* report – commissioned by the Department of Health and published in 2017[13] – raises the prospect of charging for domiciliary care in the future, but we would have concerns about the impact this may have on people with terminal illnesses.

As we have noted, domiciliary care plays a key role in facilitating care for terminally ill patients in their own home. We do not want to be in a situation where someone is unable to remain in their home, or unable to be discharged from a hospice or hospital, because they cannot afford a domiciliary care package.

Beyond the obvious negative impact this would have on patients, such a scenario would be counter-strategic from the point of view of the health service because it could lead to more patients staying in hospital for longer and even more delayed bed days, at a greater cost.

If the direction of travel is to begin means-testing for domiciliary care, the Department of Health would need to publish further details on how the new system might work – with full analysis of the likely impact on different socio-economic and patient groups – before any further steps are taken. It would be important for this system to take into account the significant costs associated with living with a terminal illness, both those already incurred by patients and those that they will incur in the future, including travel costs for frequent medical appointments, lost earnings from having to leave work and the cost of medical equipment/home adaptations. For example, research from Demos suggests that people living with motor neurone disease and their families spend over £9,600 per year in costs as a direct result of the condition.[14] Other research shows that three in four people with cancer in Northern Ireland are financially affected as a result, at a cost of £290 a month on average. One-third of people with cancer also experience loss of income as a result of their diagnosis, with those affected losing on average £860 a month.[15]

The proposal to means-test domiciliary care should not be considered in isolation, but as part of a broader scoping exercise on the potential benefits of other revenue-raising measures.

Beyond this, we also see the logic in making an additional upfront investment in more domiciliary care packages. This would reduce the number of delayed bed days across the Trusts, with the money saved helping to offset the initial investment. Ideally this would be part of a more strategic, longer-term budget and planning process, because the current model in Northern Ireland – short-term budgets propped up by non-recurrent, in-year funding – is not working.

We saw the negative outworkings of this model in 2017, when each HSC Trust was mandated to draw up in-year savings plans to reduce spending across the health service by £70 million. A number of Trusts proposed cuts to areas such as domiciliary care and care home placements, which would have had a massive impact on the most vulnerable patients if it were not for additional money being made available by the Department of Health to mitigate the cost pressures facing the system.

Without a longer-term budget-setting process, we will keep finding ourselves in similar situations in the future. This is likely to be exacerbated by the ongoing political situation in Northern Ireland.

Social care staffing issues

It is important to remember that, even if Trusts had enough money at their disposal to fund all of the packages needed, pressures will persist unless steps are also taken to address social care staff shortages.

Care providers across Northern Ireland are struggling to attract and retain staff because of a combination of low pay, poor conditions and inadequate opportunities for career progression. The extent of the problem was most recently laid bare in the *Power to People* report, which highlights a destabilising 'churn' in the social care workforce. This has consequences for providers' ability to fulfil domiciliary care packages and for ensuring continuity of skilled and experienced staff, which we know are priorities for patients.[16]

Part of the problem lies with the social care commissioning model in Northern Ireland, which forces independent providers to compete for contracts largely on price, creating a 'race to the bottom' where staff wages and costs are squeezed to keep costs low. Furthermore, terms and conditions for staff in the independent sector may be much less favourable than in the statutory sector; 'as and when' contracts, unpaid overtime, unpaid training time and no/limited travel expenses are common.

All of these issues have a real impact on patients, with staff shortages leaving care providers unable to fulfil packages of care for people in their own home. The result is that patients end up stuck in hospital when they do not need to be.

Again, the situation will only get worse without action. Research suggests that an additional 1,400 care workers will be required each year in Northern Ireland to meet demand.[17] The *Power to People* report called for social care workers to be fairly paid for the difficult job they do, and set out actions to help elevate the status of social care and ensure staff have genuine and attractive career pathways.

We also need to see a greater commitment to providing training and education opportunities for domiciliary care staff, including in palliative care, because evidence shows low levels of vocational qualification attainment among the domiciliary care workforce in the independent sector.[18]

Finally, policy makers need to ensure the future Brexit settlement does not act as a barrier to people from European countries working in Northern Ireland. European nationals represent nearly 10% of the social care workforce here,[19] and the sector cannot afford to lose these workers when it is already facing staffing pressures. Action in these areas is the only way to ensure that Northern Ireland has enough skilled and experienced social care staff to meet the needs of terminally ill people now and in the future.

Care planning issues

Broadly speaking, care planning is the process where a patient's care manager or key worker will work with them (and their loved ones) to agree and arrange the health and social care services that they need to be discharged home or into the community. For instance, this may include arranging a suitable domiciliary care package for a patient or identifying a suitable nursing home for them to move into.

Breakdowns or issues in care planning are causing a significant number of delayed bed days across local hospitals, accounting for over 10,000 delayed days in 2017–18. (Table 4).

Table 4: **Delayed bed days resulting from care planning delays/issues, 2017–18**

Health and Social Care Trust	Delayed beds resulting from care planning delays/issues
Belfast Trust	4,605
Northern Trust	1,753
Southern Trust	874
South Eastern Trust	135
Western Trust	2,815
	Total: 10,182

There can be a breakdown or delay in care planning for a variety of reasons. The workload facing hospital staff as a result of the volume of patient admissions means that they simply may not have the time to access and arrange care packages for every patient as quickly as they would like to. Practical issues such as delays in putting care packages in place at the weekend and lack of integration and communication between hospitals and social care services are additional factors.

We also know that assessing community care needs for people living with one or more terminal illnesses, and arranging a suitable package, may not be straightforward. These patients often have multiple and compounding complex needs that require similarly complex care packages to allow them to leave hospital. If the expertise, time and resources are not available for this level of care planning, patients may find their discharge delayed.

One potential solution is the embedding of specialist palliative care 'hospital-to-home' discharge teams across Northern Ireland's hospitals. These teams would lead or assist with care planning for terminally ill patients who are ready to be discharged, using their expertise to help assess the complex community care needs of patients and agreeing a suitable package of care. The teams would be fully integrated with local community services, helping to tackle some of the barriers between acute and social care. Similar models to this exist successfully elsewhere in the UK (Box 1).

Box 1: **Hospital Palliative and End of Life Care Liaison Teams, Northumbria**

Marie Curie's Hospital Palliative and End of Life Care Liaison Teams were formed as part of a partnership with Northumbria Healthcare NHS Foundation Trust. Operating in three hospitals across Northumbria and North Tyneside, the teams provide expert clinical care for patients with terminal illnesses and support ward staff in arranging their discharge with community nursing teams. Each team consists of clinical nurse specialists, Marie Curie Nurses and palliative care consultants. When a patient is discharged, nurses often accompany them to provide a face-to-face handover to the community nursing teams, easing the transition from hospital to home and ensuring a good communication flow.

"An important part of our role is to work collaboratively with community teams to ensure a safe and timely discharge for patients. We often accompany patients during their transfer out of hospital, and this can be very reassuring for them and their loved ones – helping to provide seamless care and continuity. Our team works to ensure patient's wishes around their place of care and death are achieved wherever possible, and that they enjoy the dignity and best quality of life possible during the time they have left."

Senior Palliative Care Nurse, Hospital Palliative and End of Life Care Liaison Team.

Katie Hyams/Marie Curie

Lack of available care home places

The lack of available care home beds (nursing, residential and Elderly Mentally Infirm [EMI] beds[20]) in Northern Ireland is another big contributing factor to delayed transfers of care, especially for people living with terminal illnesses. Across the health service, lack of available care home beds resulted in 7,775 delayed bed days in 2017–18 (Table 5). Lack of available nursing home beds accounted for 5,107 of these delayed days; 1,186 delayed days were caused by lack of available residential home beds, and lack of available EMI beds accounted for 1,482 of the delayed days.

As with domiciliary care packages, demand for care home beds has risen significantly as a result of the growing number of older people living with long-term and chronic illnesses, increasingly including dementia (Box 2, page 22). Over four-fifths of residential and nursing home care packages in Northern Ireland are used for those in the Elderly Care category. As we have seen, our older population grew by over 25% between 2007 and 2017 but, during this same period, the number of available residential beds in Northern Ireland actually declined by nearly 6%. While the number of available nursing home beds did increase, it did so by 11.7%, which is less than half the rate of growth in number of older people (Chart 6 and Chart 7).[21]

Demand has far outstripped supply, and this has resulted in more and more older people being stuck in hospital because there is no suitable care home bed for them to be discharged to.

Table 5: **Delayed bed days resulting from lack of available care home beds, 2017-18**

Health and Social Care Trust	Delayed beds because of lack of available care home beds
Belfast Trust	3,339
Northern Trust	1,621
Southern Trust	280
South Eastern Trust	1,013
Western Trust	1,522
	Total: 7,775

Chart 6: **Number of older people and available residential care home beds in Northern Ireland, 2007–17**

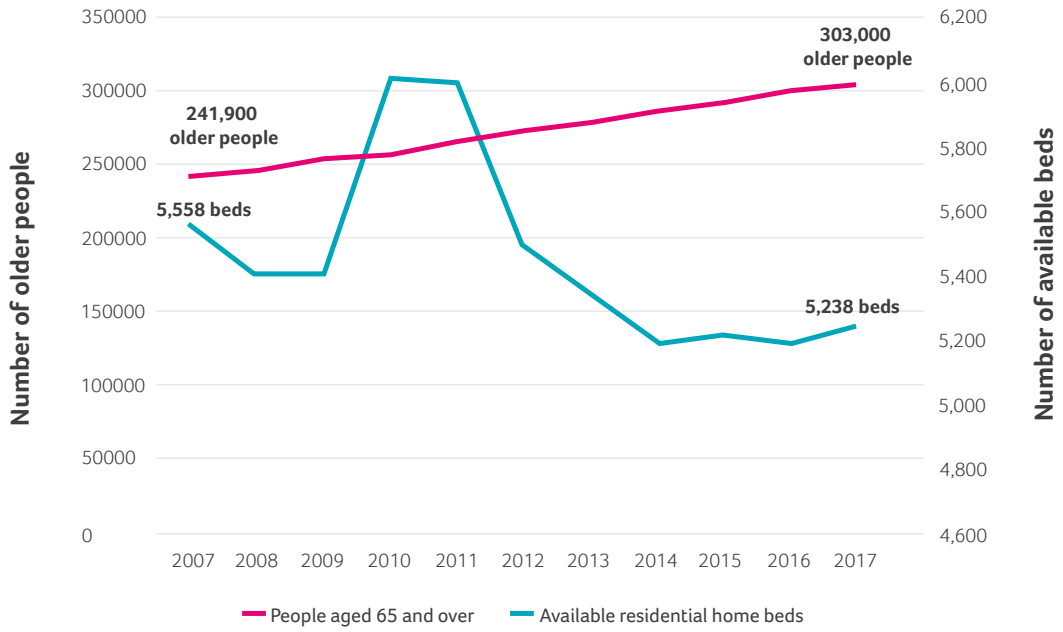


Chart 7: **Growth in number of older people and available nursing home beds in Northern Ireland, 2007–17**

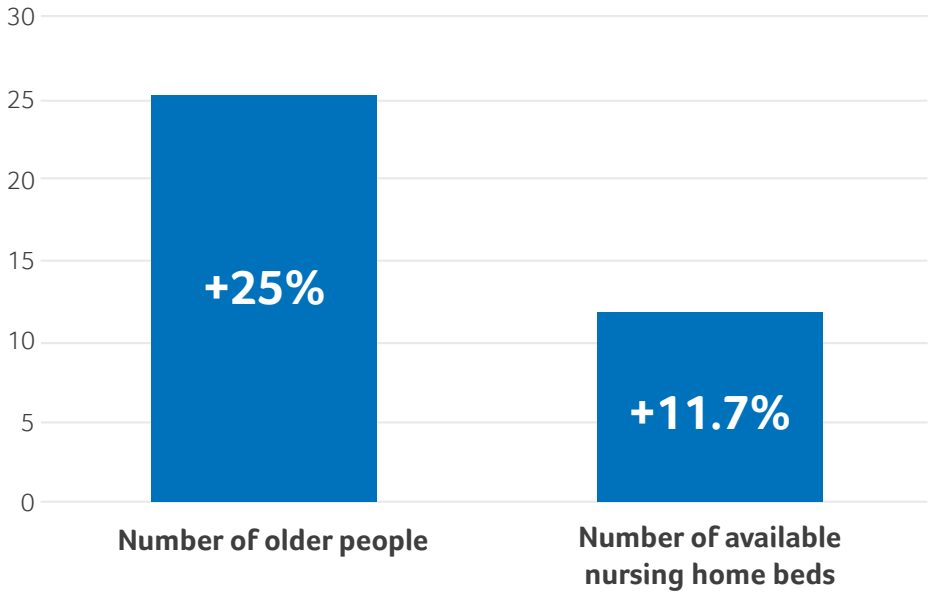
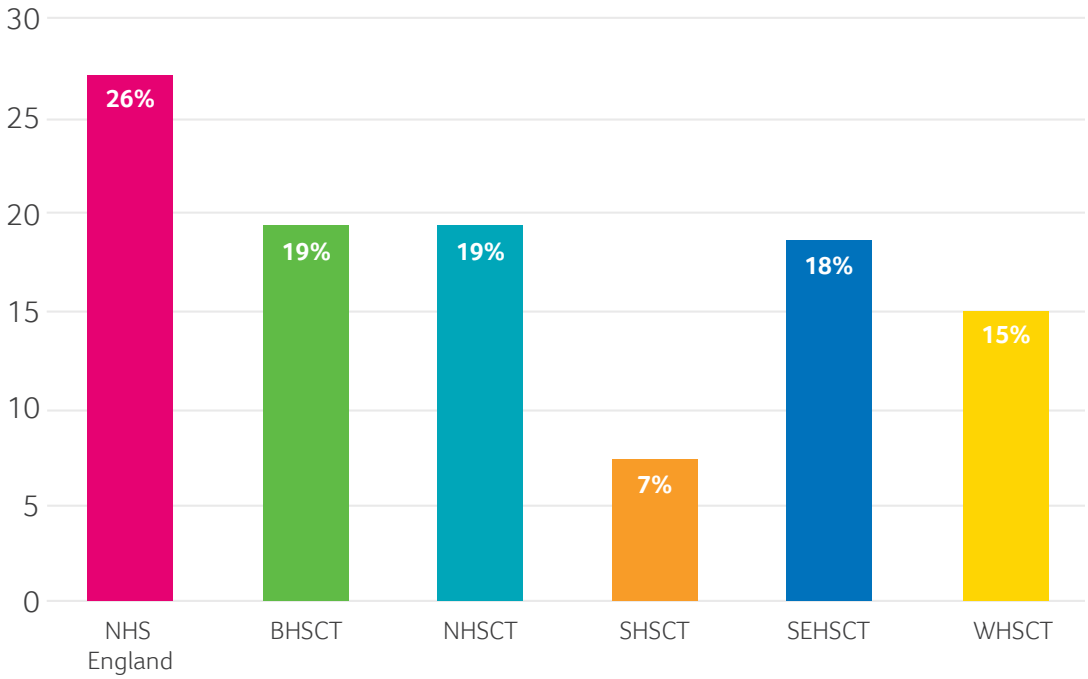


Chart 8: **Proportion of discharge delays as a result of lack of available nursing home beds in Northern Ireland versus NHS England, 2017–18**



Source: FOI data and NHS England (2018). Delayed transfers of care statistics for England 2017/18.

Again, it is interesting to compare the number of delayed bed days caused by lack of available care home beds in Northern Ireland and England. Local Trusts compare much more favourably here, with the lack of available care home spaces accounting for a smaller proportion of total delayed bed days in every Trust compared with NHS England (Chart 8).

As well as having enough beds available, we also need to ensure that care homes have the skilled and experienced workforce required to provide the complex care that people with terminal illnesses need. Unfortunately, this is not always the case.

Care homes face the same difficulties attracting and retaining staff as domiciliary care providers, and this high level of workforce turnover is not conducive to ensuring care homes have experienced and skilled staff available to care for terminally ill residents.

There are well-documented issues with educational gaps among care home staff, in terms of both formal qualifications and training. In 2014, the Northern Ireland Social Care Council surveyed social care workers in domiciliary care, nursing and residential home care, and supported living settings in the independent sector. The survey found that only 51% of staff held a health and social care qualification, with the nursing home care setting being among the two service areas where the fewest number of care staff held a relevant qualification.[22]

One of the biggest challenges facing care homes is ensuring staff are properly trained to plan and deliver care to people with complex needs. While evidence suggests that care home staff often want to take part in training, a number of barriers exist, including insufficient staffing levels to cover attendance at training or an expectation that staff attend training outside of work hours.[23]

If we look specifically at competency in caring for terminally ill people, there is also worrying evidence that knowledge levels aren't always what they should be, even among senior care home staff. In 2016, Mitchell et al. conducted research into the level of knowledge and understanding of palliative and end of life care among care home managers in Northern Ireland using the palliative care quiz for nursing, a 20-item test of knowledge relating to palliative care. The average score among the nursing home managers was less than 13 out of 20; that is, the average manager answered more than one-third of the questions incorrectly.[24]

Within this context it is worth noting that the figures in Table 5 do not include delayed days resulting from care home resistance, which caused nearly 750 delayed bed days across the health service in 2017–18. It is likely that some of this care home resistance to accepting new patients from hospital arises from concerns about their complex needs and whether these needs can be met within the care home.

Many care homes provide excellent care for residents, but this is not universal. Transformation Funding has been allocated to help improve quality and safety in care homes across Northern Ireland. Proposals are being developed around issues including recruitment, retention, education and training of staff. It is vital that improving knowledge and competency in palliative care and supporting people with terminal illnesses is included in these initiatives.

Box 2: **Dementia in care homes**

Dementia is a progressive, neurodegenerative condition with a wide range of effects on cognitive function, speech and behaviour. Someone with dementia will require more support as their condition progresses and will develop significant care needs as they approach the end of life. As a result, many people with dementia will eventually move into a care home.

Estimates suggest that the average prevalence of people with dementia in care homes is around 69%.[1]

In 2017, 62% of deaths registered with an underlying cause of Alzheimer's disease or dementia did so in a nursing home.[2]

There is worrying evidence that many dementia patients are receiving inadequate levels of care in care homes. Some of the common issues identified are poor pain management for residents with dementia, the failure of staff to commence or maintain advance care plans, inappropriate or unnecessary hospital admissions for dementia patients as they approach the end of life, and educational gaps in palliative care among staff.[3]

Over 20,000 people are living with dementia in Northern Ireland today, and around 60,000 people are expected to be diagnosed with the disease by 2051.[4] It is anticipated that there will be a corresponding increase in the demand for care home places, together with appropriately skilled staff, in line with this growth in dementia patients. It is imperative that steps are taken to increase capacity in care homes and ensure that staff are properly trained to deliver compassionate, high-quality care and support – including palliative care – to dementia residents through to the end of their lives.

1. Cited in Alzheimer's Research UK. Dementia Statistics Hub: Care services. Available at: https://www.dementiastatistics.org/statistics/care-services/
2. Data obtained from Northern Ireland Statistics and Research Agency, Births, Deaths and Marriages division.
3. Brazil, K et al (2012). Knowledge and perceived competence among nurses caring for the dying in long-term care homes. *International Journal of Palliative Nursing*, 18 (2).
4. Department of Health (2011). Improving dementia services in Northern Ireland: A regional strategy.

Kieran Dodds/Marie Curie

Other factors contributing to delayed discharge

A number of other issues account for fewer, but still significant, numbers of delayed hospital bed days.

Shortage of step-down beds

The provision of step-down beds – as part of the overarching intermediate care process – can play a vital role in helping to get terminally ill patients out of hospital when they are ready, meeting any shorter-term care needs they may have, eg rehabilitation, before returning home. Step-down services are provided by both the independent and statutory sectors. The Inver Intermediate Care Unit at Moyle Hospital and Robinson Hospital in the Northern Trust are both examples of intermediate care units that offer step-down beds for a range of patients, including those with palliative care needs.

The unavailability of step-down beds is a significant contributing factor to delayed discharges across the health service, accounting for 3,500 delayed bed days in 2017–18.

Equipment and home adaptations

Someone with a terminal illness may require a number of adaptations to their home. These might include handrails, ramps, lifts and widened door frames for wheelchair access, or an intercom system for answering the door. They may also need equipment such as bath lifts, alternating pressure mattresses and mobile shower seats. These adaptations and pieces of equipment not only ensure that people with terminal illnesses can be cared for at home, but that they can enjoy the best quality of life possible.

The lack of availability of essential equipment and/or adaptations accounted for 1,146 delayed bed days across the Northern Ireland health service in 2017–18, and varied widely between Trusts. On the face of it, the logistics of equipment provision would appear to be a more straightforward problem to solve than some of the other issues discussed, given that there are fewer dependencies on systematic health service issues.

The impact of delayed discharge on terminally ill people

Most terminally ill people want to be cared for and to spend their final days at home. We know this anecdotally, through conversations with patients and their loved ones, and from statistical research into preferred place of death among people with terminal illnesses.[25] Despite this, around half of people die in a hospital in Northern Ireland every year.[26]

For some terminally ill patients, being admitted to hospital may be essential. Hospital may be the only place where their symptoms can be effectively managed, or the level of community care that would be required to keep them at home may not be feasible. However, for many other patients this isn't the case, and these patients should be supported to remain in their preferred place wherever possible.

Hospital stays can be incredibly distressing for people with terminal illnesses, where they are in unfamiliar surroundings and are not able to be with their loved ones. Hospitals are also uniquely ill-suited care settings for people with dementia, with research linking stays in hospital to delirium, functional decline and greater institutionalisation post-discharge among dementia patients.[27] [28]

Hospital stays also increase the risk of hospital acquired infections, and research suggests that older people can lose 5% of muscle strength per day while lying in a hospital bed,[29] with serious consequences for quality of life when they leave.

In the extreme, some patients even end up dying in hospital while waiting to be discharged.

When someone has a terminal illness, especially as they are approaching the end of their life, every moment matters. Time spent at home or another preferred place of care, surrounded by their loved ones, is precious. It is unacceptable that terminally ill people in Northern Ireland are being kept in hospital unnecessarily, unable to be discharged, because of the issues discussed in this report.

Palliative and end of life care includes respecting people's wishes wherever possible and ensuring they can enjoy the best quality of life during the time they have left. Keeping people in hospital if they do not want or need to be may deny both to patients at the end of life.

Elizabeth's dad Patrick had terminal lung cancer. The whole family knew how important it was to him that he be cared for at home.

"During the last 12 months Dad was admitted to hospital a handful of times. He absolutely hated being there and couldn't get back out again fast enough. He much preferred being looked after at home, with his family around him, and was very clear with all of us that he didn't want to spend any time in hospital if it could be avoided. That was very important to him."

Brenda's husband Richard had prostate cancer. After what turned out to be his last admission to hospital, it took six days to put an appropriate care package in place so that he could be discharged.

"He came out of intensive care and we knew that there was nothing else they could do for him in hospital, but he spent a week on a ward waiting for this care package to be set up... Think of the cost to the hospital of having him for those extra six days. And for us – when you don't have very much time left, every day, well every minute, yes it matters. Six days is a very long time in that context. You don't want a moment's delay. Every hour is stressful and he found it hard, waiting and waiting."

Marie's mum Chris had COPD. The time she spent in hospital before she died was very traumatic for her and her family.

"Mum was in and out of hospital when she was ill, which was a very traumatic time for the whole family. She had a heart attack in September 2015, and was admitted for about a month after that. It was heart-breaking... All of that period when she was in hospital after the heart attack was worse than her death in some ways."

Conclusion and recommendations

This report has laid bare the impact that social care pressures, care planning problems and other issues are having on the timely discharge of patients from Northern Ireland's hospitals, with specific analysis on the impact on people living with terminal illnesses. As the population gets older and the prevalence of terminal illness grows, demand for services will increase and these pressures will only get worse, so solutions are required to ensure the necessary resources, capacity and skills are available to meet this need.
To this end, we have set out a number of recommendations below. None of these policy ideas should be seen as a fully developed solution. Rather, we hope they will feed into a wider conversation around how health and social care providers across all sectors can work together to address the growing problem of delayed hospital discharge in Northern Ireland, and the profound impact it is having on terminally ill patients. The key context to our recommendations is the lack of sitting political institutions at Stormont, which needs to be addressed if the promise of the HSC transformation agenda is to be realised.

Ben Gold/Marie Curie

To help put the funding, commissioning and planning of social care services in Northern Ireland on a sustainable footing,

1. The Department of Health should work with the Department of Finance and other stakeholders to scope out the potential benefits of a range of funding measures for social care. There should also be a move away from short-term financial planning, in favour of longer-term budget setting, so that services can be commissioned and planned in a more strategic way.

To ensure Northern Ireland has the social care workforce necessary to meet growing demand and provide high-quality care for patients with complex needs,

2. Steps should be taken to ensure social care workers are fairly compensated for the difficult job they do, to elevate the status of the social care profession and to ensure staff have genuine and attractive career opportunities/pathways. Making social care a Living Wage sector is an important first step in achieving these aims.

3. A bigger commitment to training and continuing professional development for social care staff is needed. This should include full palliative care training for relevant roles, especially those working in care homes. The Department of Health should convene a Northern Ireland-wide forum with relevant stakeholders to discuss how independent sector social care providers can be better supported to provide training and development opportunities to staff.

To improve care planning in hospitals and support the timely and smooth discharge of terminally ill people back into the community when they are ready,

4. HSC stakeholders – in partnership with palliative care providers such as Marie Curie – should look at the potential for new specialist 'hospital-to-home' discharge teams, following best practice from elsewhere, including Marie Curie's Hospital Palliative and End of Life Care Liaison Teams in Northumbria.

APPENDIX 1: Reasons for discharge delays across Northern Ireland's hospitals

Marie Curie sent Freedom of Information requests to each Health and Social Care Trust asking for the following information:

Number of lost bed days in each Trust due to delayed discharge during the 2017-18 financial year, broken down by the reason discharge was delayed.

The table below provides all of the data that we received in response. Please note that some of the reasons for discharge delays were not cited by every HSC Trust.

Reason for discharge delay	Number of delayed days					
	BHSCT	SHSCT	NHSCT	SEHSCT	WHSCT	Total
No domiciliary care package available	5,066	669	1,773	2,279	3,153	**12,940**
Care planning	4,605	874	1,753	135	2,815	**10,182**
No nursing home bed available	2,588	198	937	525	859	**5,107**
No suitable step-down bed available	1,256	5	723	673	843	**3,500**
Other complex delay reason	878	745	851	110	420	**3,004**
Patient/family resistance	227	428	958	545	113	**2,271**
Hospital assessment	473	108	583	13	717	**1,894**
No EMI bed available	289	47	305	316	525	**1,482**
Community rehabilitation	1,242	2	3	-	185	**1,432**
No residential home bed available	462	35	379	172	138	**1,186**
Essential equipment/ adaptations not available/ complete	214	200	90	415	227	**1,146**
Nursing/residential home resistance	283	88	35	245	92	**743**
Patient/relative choice	43	154	74	37	18	**326**
Palliative inpatient based	132	-	8	-	21	**161**

Table continued on next page

Reason for discharge delay	Number of delayed days					
	BHSCT	SHSCT	NHSCT	SEHSCT	WHSCT	Total
Palliative care community/ home based	74	-	-	64	19	**157**
Funding issues	-	-	80	-	49	**129**
Awaiting ambulance	-	71	-	-	-	**71**
Awaiting transport from family or friends	-	71	-	-	-	**71**
Training related delay	6	20	27	8	7	**68**
Principle reason for delay unknown	43	4	-	-	19	**66**
Simple community package	-	51	-	-	-	**51**
Pharmacy awaited	-	48	-	-	-	**48**
Transport delay	6	5	-	10	7	**28**
Awaiting secondary care bed	-	28	-	-	-	**28**
Simple items of equipment not available	-	22	-	-	-	**22**
Other simple delay reason	-	17	-	-	-	**17**
Oxygen delay	-	-	12	-	-	**12**
Awaiting tertiary care	-	4	-	-	-	**4**
Discharge summary awaited	-	1	-	-	-	**1**
Ward originated delay	-	1	-	-	-	**1**
TOTAL	**17,887**	**3,896**	**8,591**	**5,547**	**10,227**	**46,148**

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