



Care and support
through terminal illness

Dying to care

A report into social care at the end of life

In partnership with



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1 Introduction

Everyone is different; we all have our own opinions, perspectives, values, beliefs and preferences. This doesn't change when we reach the end of our lives.



Layton Thompson/Marie Curie

Being diagnosed with a terminal or chronic illness might limit our choices, but it shouldn't stop us living in the way we want to until we die. Some people will need help to enable them to do this. Specialist palliative care can treat symptoms and manage pain, and also helps with psychological or spiritual needs, but often it's the social aspects of care – bathing, cooking, and changing the bed – that can make all the difference.

This specialist care is provided in hospitals, hospices and at home, by people who are trained to care for people who need high levels of support. However, most people receive care at the end of their lives from generalists, such as GPs, district nurses, nursing home staff, hospital staff, social workers and others who may not have undertaken specialist

palliative care training – including their own families¹.

Good social care is fundamental to people achieving the outcomes they want as they approach the end of their life. These outcomes include being able to leave hospital, be cared for at home, maintain independence for longer or remain among family and friends. Social care must be responsive, easy to access and available for people at the end of their life.

Too many people in Scotland miss out on this care. As a result, people often die in hospital when they'd rather be at home. They also frequently use acute and expensive health services, such as accident and emergency and the ambulance service, which could be avoided if the right social care package was in place.

People's conditions can deteriorate more quickly when 'simple' needs are not met. There is a range of challenges that must be addressed if we want to ensure that people can live as they wish, until the end.

We are concerned that these many challenges cannot be met now, or in the future, solely by finding more money for more statutory services. Scotland faces a crisis in caring for older and dying people.

As health and medical advances allow us to live further into older age, greater proportions of the community will live with multiple and complex conditions for longer periods, and need medical and social care.

With increasing pressure already on public funds, we need to look at how more care can be delivered without additional funding. However, we also need to make sure we value the role of social care professionals, family carers and volunteers for the enormous contribution they make to people's lives and the effectiveness of the health and care system.

The Scottish Government published its Strategic Framework for Action on Palliative and End of Life Care in

December 2015. The main vision of this framework is that, by 2021, everyone in Scotland who needs palliative care has access to it. We welcome this commitment. In this report we look at current understandings of people's needs and the barriers to meeting them. We also make a case for new models of health and social care. Our vision is for a seamless health and social care support network for people at end of their life, including an integrated team all working together.

The solutions require creativity, innovation, and a co-ordinated response, across communities, statutory services, and private and not-for-profit sectors. We hope that this report will feed into the work needed to achieve the framework's ambition – that regardless of family support, where you live, or your financial position, everyone has the same choices and opportunities to live as well as possible for as long as possible, until the end.

2 What is social care?

Social care plays a significant role in supporting people with palliative care needs or those at the end of life. Without this support people are unable

to remain at home, get out of hospital, stay connected to their communities, live as well as possible before they die, or have the death they choose.

Statutory social care services that might support someone living with a terminal illness include:

- physical care – such as washing, cleaning teeth and dressing, helping someone get in and out of bed
- practical support – such as adaptations to living accommodation, meal preparation, shopping, prescription collection and small tasks around the home
- support for carers and families – such as helping a carer go out and complete tasks away from the home, or have a break to help them continue with their caring role.

Specialist social care services might include:

- palliative care social work support
- debt/income maintenance advice
- housing and advocacy support
- pre- and post-bereavement services
- advance care planning.

This support can often be overlooked by statutory services, especially with increasing demand on services, resources and budgets. However, it is

vital if we want to get support right for everyone. Social care is crucial at key points in people's care:

At diagnosis and post-diagnosis

supporting future planning and providing information and sources of support.

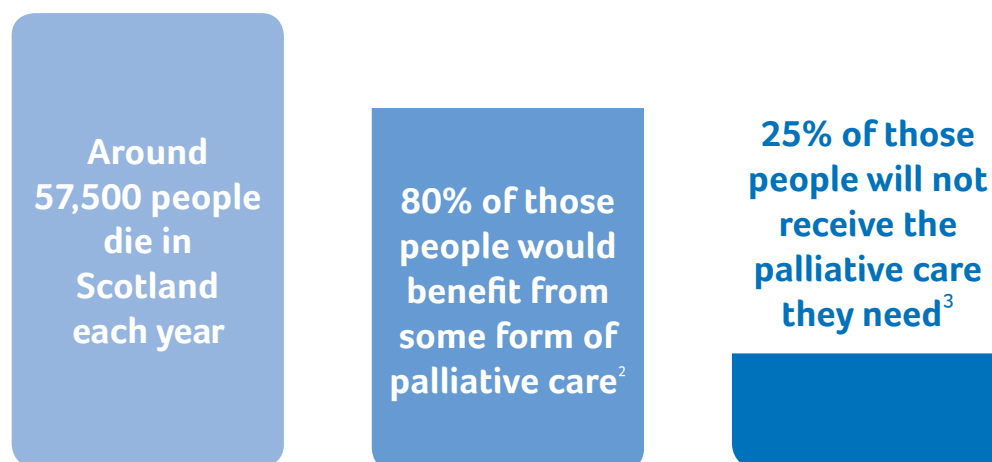
At hospital discharge

to ensure people have support to enable them to be discharged from hospital and live in their homes. At this point, future planning can be reviewed.

At key points throughout the course of their condition

particularly moments of crisis or deterioration, to ensure that plans are adaptable and people are able to continue to live as they choose.

3 Who needs palliative social care?



Scotland's population is aging. More and more people are living longer with increasingly complex conditions – 44% of adults in the last year of life have multiple long-term conditions – and the number of people dying each year is steadily increasing. Those factors mean that the need for palliative social care in Scotland is growing – and even current needs are not being met.

People may miss out on this care for a number of reasons, including the type of illness or condition they have, their age, where they live, household type – especially whether or not a person lives alone – ethnicity and socio-economic factors⁴.

Dying can be an unpredictable process, with numerous possible trajectories depending on a person's circumstances and diagnosis.

It may take years, months or days from when a condition becomes incurable to the end of someone's life. Care may

be needed in multiple settings and delivered in different ways, meaning a standardised approach is unlikely to help meet people's needs and help them achieve their specific aspirations.

Health and social care services are unlikely to cope with the effects of the changing population unless major changes are made to the way they are delivered⁵.

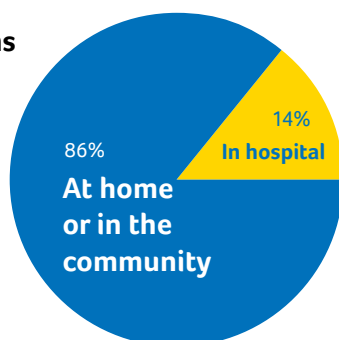
The Scottish Government's vision for health and social care is a shift away from hospital care towards quality community care. Good social care support has the potential to prevent people dying in hospital if they don't need to be there, prevent unnecessary admissions and tackle delayed discharges. All of these can result in savings in the acute healthcare budget. However, investment in preventive early intervention in social care and in NHS community services is required for this to happen.



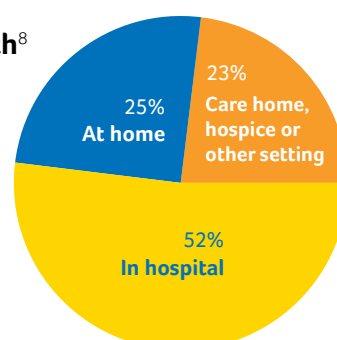
What do we know?

Most people in Scotland spend the last six months of their lives at home or in the community. Most people would also like to die at home, but the majority still die in hospital. In Scotland, on average, people spend 86 per cent of their last six months of life at home or in a community setting, with the remaining 14% of time spent in hospital¹. This is equivalent to each person spending an average of 25 days in hospital in the six months prior to their death².

Last six months of life⁶



Death⁸



Services provided in people's homes

- In March 2016, 59,780 people in Scotland were receiving home care services, of which 48,920 were aged over 65 and 53% of these people lived alone. 44% of home care clients over 65 are frail, 23% have a physical disability and over 6% live with dementia.

Care home services

- In March 2014 there were 902 care homes for older people (those aged over 65), providing 38,441 places to 33,187 residents, of whom 31,943 were long stay residents⁹.
- Between 2005 and 2014, the number of short stay and respite care residents increased by 58% from 789 to 1,244 people, highlighting an area of social care provision that needs to be addressed.

Hospices

Around 14,000 referrals are made to hospice palliative care services in Scotland each year, across hospice in-patient, day services and hospice at home/community nursing¹⁰.

Hospice care in Scotland in 2014-15¹¹:

- 240 inpatient hospice beds.
- 4,000 people were admitted to a hospice bed.
- 11,000 people were seen by community care and hospice at home.
- 65,500 home visits were made by charitable hospices.
- 2,400 people were seen in day hospice and outpatient care.
- 37,000 contacts with people in day hospice and outpatient care.

However, we don't know how many people in the last year of life are in need of social care, and who receives it¹².

With this information we could start to understand who is not accessing social care and why.

Recommendation

Scotland does not currently collect and analyse enough data to show the need for, and provision of, palliative social care across the country or the progress in improving access to this care for people living with a terminal illness. Addressing this will allow for more effective data sharing between professional and clinical staff. It will also allow for the development of tools for planning and commissioning effective integrated services; and

performance management and improvement work.

Health and Social Care Partnerships, tasked with delivering integrated health and social care, should:

- **develop a local assessment of need (including unmet need) in their areas to determine who needs palliative social care, and prioritise palliative social care in their locality planning and delivery.**

4 What gets in the way of good social care at the end of life?

Everyone is different, everyone has different things that are important to them, and everyone has the right to change their mind. That's why a responsive social care sector is needed, which has the flexibility to respond quickly if something changes. When people are dying, there is no time to get this wrong, and if it goes wrong it can never be fixed.

There are a number of ways services can improve to ensure that people get the care they need at the end of life.

Communication

Achieving a good death with dignity is possible for every person in Scotland. We need to have conversations with people about what matters to them early in their journey, and then support them to make choices that enable them to have the right care at the right time.

“There needs to be a consistent approach to advance care planning across health and social care. I set up a programme across the county to train health and social care staff about a standardised approach to advance care planning. The message that we all have a right to make decisions about our future under law has been one that has really resonated with the staff and with the public. This involved working with all areas of healthcare and adult social care to ensure that all staff are equipped to help people to make plans in advance if they want to. People are more likely to be informed

about their right to make decisions about their future care, and workers are better equipped to support them to record their choices appropriately if we work together.”

Palliative care social worker¹³

Many people have not thought about what they want at the end of their life or talked about this with their loved ones. Even if they have, their wishes may not be written down and even when they are, they may not be shared. We need to make sure that everyone involved in someone's care, including primary care teams, out-of-hours services and community teams, knows what they want, and that there are systems, such as anticipatory care plans, to support this. Social workers are key professionals in introducing advance care planning principles; they often support people for months if not years before other specialist healthcare professionals become involved¹⁴.



Recommendations

Health and Social Care Partnerships should:

- work in partnership to develop an integrated approach to anticipatory care planning for patients across Scotland that considers and identifies both health and social care needs,
- improve data sharing between health and social care professionals, with IT systems that facilitate close working relationships across services.

Rapid support

It is vital that people receive support quickly towards the end of their life. Delays in social care assessments, accessing care places, and accessing other aspects of social care mean people and their families can be left without support when they need it most.

How quickly people receive home care can depend on where they live. When there are long delays, this can sometimes result in people taking out loans or applying for grants to self-fund adaptations to their homes. In 2015, people in some local authority areas on average received their support the same day while people in other areas waited on average up to 12 weeks¹⁵.

It is important that people get care quickly, but this needs to be the right care. People can be ready to leave hospital, but be unable to do so as they are waiting for social care assessments, accessing care places, and other aspects of social care such as adaptations to their homes. People living in the community,

who don't have the right social care, can deteriorate more quickly than they should and can end up being readmitted to hospital.

“Adaptations to a person's home should be a ‘can do’ approach not ‘you can't get a stair-lift as you won't be walking soon’.”

Person with MND

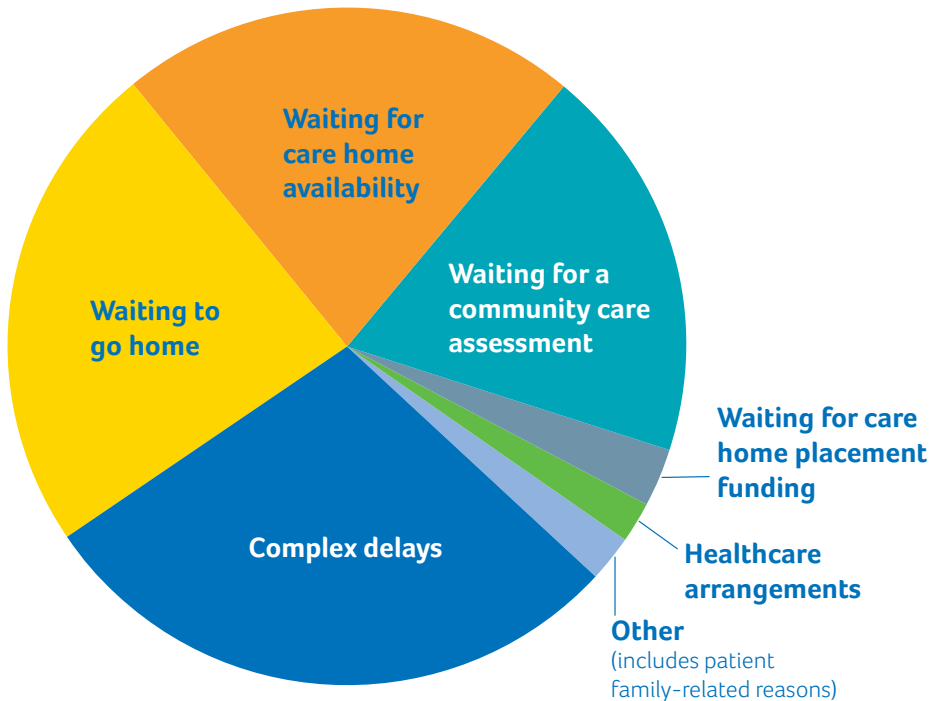
During 2015, one in 12 (8.2%) occupied beds in NHS Scotland were due to delayed discharges.

That's 567,853 bed days occupied by delayed discharge patients in 2015/16¹⁶. The reasons for these delays are shown in the chart on page 13.

Over 70% of bed days occupied by delayed discharge patients were for those aged over 75¹⁷.

There are services in the voluntary sector to help ensure the right support is available quickly, such as the Marie Curie fast-track service which helps prevent hospital admissions and get people home after being in hospital.

Reasons for delayed discharges 2015-16



“The Marie Curie Nurses were a breath of fresh air. It’s hard to put into words what an amazing service it is. We were left high and dry. We felt despair but everyone on the team went above and beyond. That meant we got to have precious time with Mum.”

Family member, commenting on the Marie Curie fast-track service

Delays while awaiting care packages and care home placements can also have an impact on hospices and voluntary sector services. For example, these delays meant that between March 2015 and February 2016, 66 people were delayed in leaving the Marie Curie Hospice, Edinburgh – that’s 654 hospice bed days in total across Edinburgh, Midlothian and West Lothian.

Despite these pockets of good practice throughout Scotland, it’s not enough.

“People are dying in conditions that they shouldn’t be in.”

Social worker, voluntary sector

Across Scotland in 2015, 276 people died waiting for their social care packages to start, while others waited over a year for their packages¹⁸. This isn’t good enough.

“There’s just not enough care out there and trying to access it quickly is one of the most time consuming and ultimately frustrating parts of the job. I’ve got one man who has been waiting in the hospice for a care package to get him home for over four months now; by the time the package comes up it probably won’t be enough to meet his needs. It’s heart breaking for him.”

Palliative care social worker

Recommendations

All local authorities and Health and Social Care Partnerships should:

- ensure there are no unnecessary delays between assessment and provision of social care support for people living with a terminal illness and their carers,
- ensure that services are in a position to change social care packages quickly to respond to a crisis, deterioration of the patient or the carer or if the person's wishes change.

Age appropriate support

People under the age of 65 can also face difficulties in accessing social care services. There are few resources in the community for people under 65 and often care home places are not appropriate for younger people. Finding appropriate places for younger people in care homes can be challenging and result in long delays.

Since 2002, people over 65 in Scotland have received free personal care – that's care provided by local authorities for people who need it at home.

However, people under 65, who require this same personal care, are financially assessed by their local authorities to determine their contribution.

The Convention of Scottish Local Authorities (COSLA) guidance for local authorities states that people who are

terminally ill should not be charged for personal care. MND Scotland highlighted that many people with motor neurone disease (MND) were being charged for personal care when it should be free. The First Minister responded by stating that COSLA guidance must be followed – if not the Government would legislate. It remains, however, that some terminally ill people do slip through the net and find themselves being charged¹⁹.

People over 85 can also face difficulties accessing palliative and social care. This can be down to a lack of a clear diagnosis of dying as people in this age group are viewed merely as 'old' or 'infirm'. This may lead to them not getting the most appropriate care²⁰.

Recommendation

- All local authorities and Health and Social Care Partnerships must follow the COSLA guidance stating that people living with a terminal illness should not be charged for social care. The Scottish Parliament should consider legislating to ensure this happens²¹.
- The Scottish Government should explore respite and care home provision for under-65s, which is often unsuited for their particular needs.

Social security

The welfare system in Scotland should enable people living with a terminal illness to enjoy the highest quality of life possible until they die. Benefits for people living with a terminal illness should be delivered quickly and with limited disruption to their lives. They should mitigate the cost of living with a terminal illness, and prevent any fall into poverty and social isolation at end of life.

Far too many people living with a terminal illness are not currently getting the benefits they need to support themselves, or receiving them as quickly as they should.

“Going through the protracted support/benefits system is unbelievably stressful just after you have been given such a devastating prognosis. Suddenly every moment

becomes precious and time spent on bureaucracy is resented.”

Person with MND

“The Special Rules for my Disability Living Allowance were a godsend; it made all the difference not having to fill in the whole form and having a reply so quickly. Everything else has been a total nightmare. I’m just a number and I don’t have the energy to argue; they don’t realise my number is nearly up!”

Person with cancer

The Scottish Government is currently working on developing a new system of social security following the devolution of a number of benefits for people with disabilities and their carers.

Recommendations

Scotland needs its social security system to be responsive to the needs of people living with a terminal illness, particularly for those near the end of their life. This needs to include a fast-tracking system for people with terminal and life-shortening illnesses, and their carers. Free personal and nursing care needs to be available across Scotland for all people living with a terminal condition. The Scottish Government should ensure that:

- a crisis grant is introduced for those with a terminal diagnosis,
- all devolved benefits continue to include fast-tracking for those living with a terminal illness,
- carers of terminally ill people are also entitled to fast-tracked benefits, such as Carers Allowance,
- any new benefit introduced includes fast-tracking for those who are living with a terminal illness,
- devolved benefits should be set at a level to offset the cost of living with a terminal illness.

5 Who cares?

Social care can be provided by a professional care workforce, informal carers such as families and friends, and smaller pockets of volunteers. In the future, to help meet demand, communities will need to come together to support people with palliative social care needs.

Carers

Family carers are key to supporting a person living at home. Having a family carer is the single most important factor enabling someone to die at home, whereas living alone, being unmarried or not having a carer increases the likelihood of a person dying in hospital. It is therefore crucial for social care services to ensure that carers get the support they need.

“There need to be skilled staff, in appropriate, local, environments to support families and carers who are currently left to meet the needs of their loved ones.”

MND carer

For people that do not have the support of an informal carer, local authorities need to ensure that social care services are in place to enable the patient to stay at home if that is what they would like.

The Carers (Scotland) Act 2016, due to be implemented in 2017-18, ensures that new support plans for carers will be fast-tracked for those caring for someone living with a terminal illness.

The Act includes access to respite care for carers to ensure that they are able to continue in their caring role, which is currently very limited and varies across Scotland. Any respite care developed in response to this needs to be able to be planned in advance, but also accessed quickly in the event of a crisis. The Scottish Government has stated it is fully committed to improving the quality and quantity of short breaks for carers and young carers²².

Recommendations

All local authorities and Health and Social Care Partnerships should:

- ensure there are no unnecessary delays between assessment and provision of social care support for people living with a terminal illness and their carers,
- ensure respite care can be planned in advance, but is also accessible during crisis points in someone's illness,
- ensure that services are in a position to change social care packages quickly to respond to a crisis or deterioration of the patient or the carer or if the person's wishes change.



Professional social care workforce

The professional social care workforce plays a vital role in communities, providing housing support, home care and care home services.

“We, as a society, do not value social care in the same way as we value NHS care. We are not willing to pay decent wages for social care, which causes problems with recruitment and retention in the workforce. Against that backdrop, it is difficult to upskill staff and ask them to take on more responsibilities that may be outwith their traditional professional boundaries.”

COSLA, 2015²³

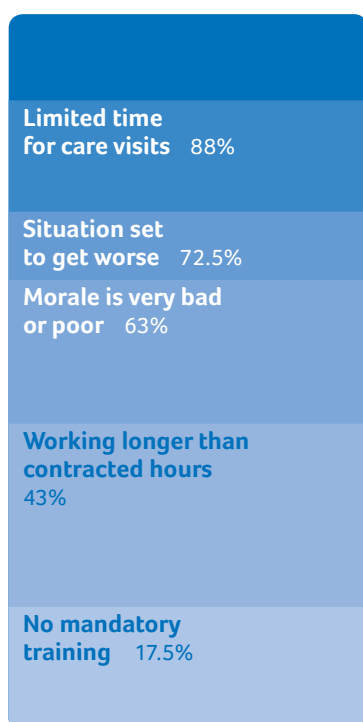
Lack of investment in the workforce can mean high turnovers and relatively inexperienced, low-paid staff

supporting the most vulnerable people through the most difficult times of their lives. The living wage for social care staff was agreed as part of the 2016 Scottish Government Budget. We fully support this commitment but also recognise the need to ensure that there are additional resources for organisations to be able to invest in their social care workforce. However, this isn't just about investing monetary resources; more support is needed for social care staff to maintain their high standards and ensure people get the responsive, flexible support they need.

“Sometimes I have four clients all with 15 min scheduled time in the space of one hour with no travel time to each one.”

Social care worker²⁴

Key issues for social care professionals



- Nine out of 10 paid carers report facing limited time for care visits with almost half of carers reporting they worked longer than their contracted hours to allow them to support people properly.
- One in five feel that they don't receive adequate mandatory training and many feel that cutbacks, an intensifying workload and reduced hours are having a negative impact on the people they provide care for and causing increased stress in the workforce.
- 72.5 per cent of paid home care workers think this is set to get worse
- 63 per cent said morale among their workforce is very bad or poor²⁵.

“The clients are getting more difficult to handle; what I mean by that is they are being kept at home with more serious illnesses.”

Social care worker²⁶

“People in need of palliative care need more than half an hour and it is getting more difficult to ask for time if things don’t go to plan; this service is not always the same as depending on health issues people need more care time.”

Social care worker²⁷

Palliative care training is not mandatory training for social care workers and many don’t have access to formal palliative care training.

While palliative care social workers do exist, they usually work as part of specialist palliative care services.

The principles of palliative care social work are not typically included in public sector training.

“...are (we) ready for the palliative end-of-life needs of our community? In some areas, the answer is yes; in other areas, the person who sits with somebody who is in their last few weeks of life is terrified because she or he is not trained, or not resourced, because their organisation cannot afford it.”

Donald Macaskill
Chief Executive, Scottish Care²⁸

The Scottish Government’s Strategic Framework for Action on Palliative and End of Life Care includes the development of a new palliative and end of life care educational framework. It is essential that social care teams and healthcare teams working in both community and acute settings are adequately trained and supported to provide palliative care and end of life care. This means person-centred care, with advance care planning.

People need access to social workers, who have the capabilities and resources to help them when they need it. All social workers should be able to help people, their families, and those close to them at the end of their life and during bereavement²⁹.

Case study **Marie Curie Lothian Care Assistant Development Programme**

As part of our palliative care redesign programme in Lothian, we provided an education programme for care home and home care staff working across the four Lothian councils. We delivered 36 one-day palliative care sessions to care home and home care staff, as well as an online training module.

The purpose of the programme was to increase the knowledge and confidence of social care workers caring for people with a terminal illness, within their scope of practice. It also helped staff identify who in their wider team could provide further support and information when needed.



Marie Curie

The programme is currently undergoing evaluation. You can find further information at **mariecurie.org.uk/lothianprogramme**

Recommendations

Staff need support to help them manage and navigate more complex care with increasing resource constraints and workloads. This should involve local authority staff, and those employed in the independent and voluntary sectors. It should include:

- palliative care and bereavement training, as a mandatory part of education across all social care curriculums including social work degrees, specialisms such as occupational therapy and physiotherapy, and core training for all care at home, nursing and care home staff,
- communication training for health and social care staff to support them in sensitive conversations about death and dying, as well as anticipatory care planning to ensure a person's preferences, choices and wishes are accurately recorded.



6 Opportunities

We need to ensure that people living with a terminal illness get the care they need, when they need it. People at the end of life can have rapidly changing needs and many do not have the time to wait for a delayed care package to support them at home; they will often need a quick or immediate response.

We know people would prefer to be cared for at home or in the community. However, with increasing demand for social services, limited resources, high workloads and a rapidly changing staff group, providing consistent social care services across Scotland can be complicated.

We need to assess need and unmet need in local areas. We need to make sure the right people are involved in the design, development and delivery of plans, and this includes

communities and third sector providers. Increasing social care will make it more likely for people to get the care they prefer during the course of their condition and at the end of their lives, and it will also ease pressure on acute services³⁰. But to do that, there needs to be increased co-ordination of end of life care in the community.

With the introduction of health and social care integration, we need to look at developing new efficient and sustainable models of health and social care. They need to be responsive to need and they need to be available when required. We also need early interventions to enable better planning to prevent admissions and facilitate discharges across Scotland.

Recommendations

The Scottish Government has committed to ensuring that everyone who needs palliative care has access to it by 2021. This should include timely access to appropriate social care services. We have identified a number of recommendations throughout this report to help it deliver on this ambition.

Locality planning

Health and Social Care Partnerships should:

- develop a local assessment of need (including unmet need) in their areas to determine who needs palliative social care, and prioritise palliative social care in their locality planning and delivery,
- work in partnership to develop an integrated approach to anticipatory care planning for patients across Scotland that considers and identifies both health and social care needs,
- improve data sharing between health and social care professionals, with IT systems that facilitate close working relationships across services.

Social care charging

All local authorities and Health and Social Care Partnerships must:

- follow the COSLA guidance stating that people living with a terminal illness should not be charged for social care.
- The Scottish Parliament should consider legislating to ensure this happens.

Social security

Scotland needs its social security system to be responsive to the needs of people living with a terminal illness, particularly for those near the end of their life. This needs to include a fast-tracking system for terminally ill people and their carers. Free personal and nursing care needs to be available across Scotland for all people living with a terminal condition. The Scottish Government should ensure that:

- a crisis grant is introduced for those with a terminal diagnosis,
- all devolved benefits continue to include fast tracking for those living with a terminal illness,
- carers of terminally ill people are also entitled to fast tracked benefits, such as Carers Allowance,
- any new benefit introduced includes fast tracking for those who are living with a terminal illness,
- devolved benefits should be set at a level to offset the cost of living with a terminal illness.

Care

All local authorities and Health and Social Care Partnerships should:

- ensure there are no unnecessary delays between assessment and provision of social care support for people living with a terminal illness and their carers,
- ensure respite care can be planned in advance, but is also accessible during crisis points in someone's illness,
- ensure that services are in a position to change social care packages quickly to respond to a crisis or deterioration of the patient or the carer or if the person's wishes change.

Professional social care workforce

Staff need support to help them manage and navigate more complex care with increasing resource constraints and workloads. The Strategic Framework for Action on Palliative and End of Life Care recognises this issue and it is hoped this will be addressed in the proposed education and development framework as part of this. This should involve local authority staff, and those employed in the independent and voluntary sectors. Support should include:

- palliative care and bereavement training, as a mandatory part of education across all social care curriculums including social work degrees, specialisms such as occupational therapy and physiotherapy, and core training for all care at home and nursing and care home staff,
- communication training for health and social care staff to support them with sensitive conversations about death and dying, as well as anticipatory care planning to ensure a person's preferences, choices and wishes are accurately recorded.

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The partnership

As organisations with an interest in improving care for people with all terminal and chronic conditions, we recognise a need for significant improvements in social care particularly when approaching the end of life. To support greater discussion and access on this important topic we set up a partnership to develop this report.

Marie Curie

Provides care and support for people living with a terminal illness, and their families and carers. Supporting over 8,000 people in Scotland through two hospices in Glasgow and Edinburgh, as well as community nursing services across 31 local authority areas, and four volunteer led Helper services. We also provide nationwide support through the Marie Curie Support Line and information topics on our website.

Contact: Susan Lowes
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Email: susan.lowes@mariecurie.org.uk
Tel: 0131 561 3902
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MND Scotland

MND Scotland is the only Scottish charity providing care and support to people affected by Motor Neurone Disease (MND), as well as funding research into finding a cure. To find out more about how we can help you, or how you can support us, please visit our website at mndscotland.org.uk.

Contact: Susan Webster
Head of Policy and Campaigns
Email: susan.webster@mndscotland.org.uk
Tel: 0141 332 3903
Web: mndscotland.org.uk

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

mariecurie.org.uk

@MarieCurieSCO



[mariecurieuk](https://www.mariecurieuk.org)

Charity reg no. 207994 (England & Wales), SC038731 (Scotland) B091

Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice care across the UK. Our aim is to make sure that hospice care is there for everyone who needs it and to improve everyone's experience of death, dying and bereavement.

Contact: Eilidh Macdonald
Policy & Advocacy Manager, Scotland
Email: e.macdonald@hospiceuk.org
Tel: 07852 244304
Web: hospiceuk.org

The Association of Palliative Care Social Workers

The Association of Palliative Care Social Workers is a national membership organisation that represents social workers working as specialists in palliative, end of life and bereavement care in the UK, alongside the people they work with and those close to them; their families, friends, unpaid carers and communities. The association's vision is that people will have access to a social worker with the capabilities and resources to help them when they need it, and support those close to them at the end of their life and during bereavement, and to get the support they need.

Contact: secretary@apcsw.org
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**Care and support
through terminal illness**