Scottish Parliament's Health and Sport Committee's social care inquiry

A joint response from Hospice UK, the Association of Palliative Care Social Workers, Carers Scotland, Children's Hospices Across Scotland, Marie Curie, MND Scotland, Scottish Care and Sue Ryder

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Introduction

This is a joint submission from Hospice UK, the Association of Palliative Care Social Workers, Carers Scotland, Children's Hospices Across Scotland (CHAS), Marie Curie, MND Scotland, Scottish Care and Sue Ryder.

As organisations with a shared interest in delivering or supporting the delivery of palliative care in Scotland, our response focuses specifically on meeting the social care needs of people affected by terminal illness in Scotland.

A terminal illness is a disease or condition which cannot be cured and is likely to lead to someone's death. It is sometimes called a life-limiting or life-shortening illness. Palliative care is treatment, care and support for people with a terminal or life-limiting illness, and their family and carers. Social care support is one element of palliative care, alongside managing physical symptoms such as pain, and emotional, spiritual and psychological support.

Every individual has the right to access appropriate palliative and end of life care and support, regardless of circumstances, age, status or geographical location. The Scottish Government has committed that everyone who needs it should have access to palliative care in Scotland by 2021. The number of deaths each year in Scotland is rising, along with an increasing need for palliative care. In addition, people's needs are becoming increasingly complex as more people are living with multiple conditions. Currently it is estimated that one in four people do not receive the palliative care they need[1]. By 2040 it is estimated that over 50,000 people who die each year will need palliative care[2].

Qu. 2 How should Integration Joint Boards commission and procure social care to ensure it is person-centred?

The commissioning and contracting of social care must be based on a robust understanding of need, be focused on person-centred outcomes and support services to be person-led, flexible and responsive to the changing needs of people with a terminal illness, their families and carers.

Responsive care and support is embedded within the principles of the Health and Social Care Standards. The commissioning of social care must support services to be flexible and agile enough to respond quickly when someone's needs change. Strategic planning and commissioning, alongside integrated workforce planning, needs to ensure that there are services available with sufficient capacity and expertise to provide the right type of support for people with complex palliative needs now and into the future. It also needs to ensure there is appropriate support for families and carers.

"The system isn't responsive enough to the changing nature of palliative care and the complexities of patients now" Palliative care social worker

Every individual with a terminal or life-shortening illness is different. With progressive conditions, care needs can rapidly change, fluctuate or gradually get worse over time. Someone with Motor Neurone Disease, for example, can quickly go from requiring one carer twice a day, to needing two carers visiting four times a day. With a terminal illness, time is of the essence and there is only one chance to get care right. Care which goes badly at the end of life can have a profound impact on family and loved ones, as well as having a significant impact on the wider health and social care system.

Current commissioning of adult care at home services, provided under the generic homecare framework, is focused on time and task. Carers often have visits of a set length to complete specific tasks such as helping someone to get washed and dressed. In some areas, carers are required to phone in at the beginning and end of a visit to monitor the time they have spent with someone. Over a third of publicly funded adult care packages are commissioned for visits lasting under half an hour[3] and social care staff have reported the use of 15 minute visits to support people at the end of life.

Time and task commissioning is driven by cost, and has created a system that is too rigid and inflexible to meet people's care needs, particularly the changing complex needs of someone with a terminal illness. It does not allow person-led care. Commissioning and procurement need to be focused on quality and person-centred outcomes, and allow care providers the time and flexibility to support the holistic needs of each individual they are caring for.

The current commissioning arrangements for adult social care are also putting providers at risk. Data from Scottish Care shows that 86% of care at home providers are worried about sustainability and survival, with 24% extremely concerned[4]. Some voluntary sector providers are having to withdraw from contracts because they are running at significant financial deficits and the terms of the contracts are incompatible with their values and standards around providing quality care[5].

Though this inquiry is focused on adult social care, it is helpful to note that given the highly specialised nature of children's palliative care needs, there are separate national arrangements in place which work well through a Scotland-wide model of palliative and hospice care for babies, children and young people. This national approach allows nursing, medical, social work and social care staff to work together in an integrated way.

What change is needed?

- Strategic planning, commissioning and investment in social care services needs to be underpinned by a robust understanding of need and unmet need. Integration Authorities need to demonstrate how services will meet the projected increased need for palliative care. All sectors, including the voluntary and independent sector, need to be engaged as equal partners in the strategic planning and commissioning process.

- Time and task commissioning needs to be replaced with a person-led, rights-based, outcomes-focused commissioning process for adult social care. There need to be specific commissioning arrangements to support fast access to responsive and flexible social care for people with complex palliative care needs. This needs to recognise that good palliative and end of life care may require a wide range of public, voluntary and independent agencies to work together around an individual person's needs.

Qu 3. Looking ahead, what are the essential elements in an ideal model of social care (e.g. workforce, technology, housing etc.)?

For social care to meet the needs of people affected by terminal illness, it has to be proactive, with a focus on planning ahead and early intervention. It should be easy to access, without delay, and be flexible enough to respond quickly if someone's needs change. It should be provided by a skilled and adequately rewarded workforce, who have appropriate time to care, and the care provided should fully meet someone's needs. Care should be person-led, with an emphasis on the rights and choices people have, and should value the relationships with the person's family, carers and wider support network.

To achieve this, there needs to be a focus on the following:

Anticipatory care planning and early intervention

People with palliative care needs must be identified as early as possible, to make sure they can access the support they need across services. Anticipatory care planning is a person-centred, proactive, 'thinking ahead' approach, with health and care professionals working with individuals, carers and their families to make informed choices about their care and support, in line with the realistic medicine[6] ethos. It is vital for people with a terminal illness where conditions can change or deteriorate quickly. Work from Sue Ryder has shown how taking a proactive approach to care results in better quality and longevity of life, as well as delivering savings to the wider health and care system[7].

Anticipatory Care Plans (ACPs) need to be developed as early as possible and be reviewed and updated regularly. ACPs are often seen as a 'health document', focusing on clinical needs. ACPs need to be integrated, consistent and transferable across sectors. They need to be embedded into social care, and focus on health and social care needs and outcomes.

Edinburgh Health and Social Care Partnership's ACP team has been training staff in care homes across Edinburgh in having anticipatory care planning discussions and how to use completed ACPs in an emergency. The project has reduced the number of avoidable admissions to hospital by 56%[8]. Care home staff have become more confident in managing conversations on future health and care wishes for residents and relatives.

Children and young people living with life-shortening conditions can have particularly complex health and care needs, and may require hospice and palliative care for many years. To support young adults with life-shortening conditions to live as independently as possible, services need to be co-ordinated and focus on their needs as a whole, along with those of their family[9]. An important part of this is anticipatory care planning. CHAS, in partnership with Healthcare Improvement Scotland, has developed a national ACP for babies, children and young people.

The number of young people with life-shortening conditions living into adulthood is increasing in Scotland[10]. This means more young people will need specialist support as they transition to adult services. They may experience particular challenges, such as changes to the social care support they receive, because the availability or criteria for adult services are different to children's services. Transitioning to adult services can add another layer of uncertainty to living with a life-shortening condition, which can impact on an individual's emotional and mental wellbeing. To support young people transitioning to adult services, planning needs to start early and should continue even into adulthood. It should be carried out in a person-centred way and take into account the needs of parents, families and carers[11].

There also needs to be more effective transitions for people moving between services for adults and services for older people, particularly in relation to removing resource inequality based on age.

What change is needed?

- Improve earlier identification of people with palliative care needs
- ACPs need to be embedded as a core component of social care, with staff supported and trained in anticipatory care planning approaches
- Increased support and planning for young people with a life shortening condition transitioning from children's to adult services, and for people transitioning between adult and older people's services

Maximise the potential of technology and information sharing to enable effective partnership working

Good relationships and partnership working across sectors and agencies is vital to being able to effectively meet someone's needs, and make best use of resources. Technology needs to support information sharing across sectors and agencies, and not be a barrier.

Information in ACPs needs to be communicated and transferable across different health and social care sectors. A Key Information Summary (KIS) is an electronic care planning record, and is a way of sharing vital information about a person to help decision-making if that person needs emergency or out-of-hours care. Recent research by Marie Curie[12] has shown there is good progress with using KIS, with 69% of people with an advanced progressive illness having a KIS in place.

However not everyone has access to information in the KIS, including social care staff. This means, for example, if a person in a care home deteriorates, they may end up in hospital because staff were unable to access and follow the information in the KIS. Having access to the KIS could help the person be supported within the care home, enabling them to stay in their home environment with staff who know them and their needs.

We need to maximise the potential of technology. There is important work happening around the use the of the ReSPECT tool to help people get the right care in an emergency and the development of the new National Digital Platform. This needs to link in and complement existing processes around anticipatory care planning and be a true health and social care platform, which all sectors can access, enter and update information on it.

What change is needed?

- The National Digital Platform needs to be a fully integrated health and social care platform that supports all services to deliver joined-up care
- There needs to be support for providers to ensure compatibility of technology and systems

Fast, streamlined access to care

People living with a terminal illness need fast and easy access to social care that fully meets their needs and can quickly change when they need more support.

National eligibility criteria[13] set out how long someone should wait to access social care based on any potential risks to them, categorised into critical, substantial, moderate and low risk. The 'critical' and 'substantial' criteria do not explicitly reference people with a terminal illness. Local authorities should use the national framework to determine their local eligibility criteria. However practice appears to vary in how local authorities determine and implement eligibility criteria locally and whether or how they prioritise someone with a terminal illness within this. Feedback from social care staff suggested that prioritisation does not always happen or is difficult to achieve in practice as services have many competing priorities, such as reducing delayed discharges from hospitals.

Long delays mean that by the time the package is in place, a person's condition may have deteriorated so much that more care is already needed. 43% of older people assessed as needing substantial or critical care in 2018 waited more than six weeks to get social care needed[14]. The average waiting time for an assessment was three weeks, with the average waiting time to receive care 2.5 weeks. Most local authorities were unable to provide information on waiting times specifically for people with a terminal illness[15]. However, from those who did there are examples of people with a terminal illness waiting for an average of 16 days to receive an assessment and 5.5 weeks to receive care.

Feedback from palliative care social workers emphasised the time constraints and the lengthy and complex nature of referrals and assessments, sometimes duplicating

work unnecessarily during a time-sensitive situation for the individual and their needs. For example, when local authorities do not accept an assessment carried out by a social worker in a hospice.

"I thought my job would be softer, but I'm actually navigating this complex, unworkable, cumbersome system" Palliative care social worker

Social workers talked about having multiple complaints from families after their relative died in hospital, against their wishes, because they were waiting for a care package. Across NHS Scotland in 2018-19, approximately 400 people died in hospital while waiting to be assessed for a care package or for care arrangements to be put in place[16]. Sometimes families would step in and take their relative home and provide the care themselves until a care package could be put in place. But then they struggled to provide care and the person had to be readmitted to die in a hospital or hospice.

What change is needed?

- Fast track access to a streamlined process for the referral, assessment and delivery of social care support for people with complex palliative care needs

Responsive, person-led care that meets needs

The Health and Social Care Standards are clear that people should expect *"care and support meets my needs and is right for me"* as well as "*consistency and continuity*" from people providing care. We know that people receiving care want longer, more flexible visits, with carers that they know and have built a relationship with.

There are examples of people with a terminal illness having different carers for each visit, having 15 or 30 minute visits and being put to bed at 7 or 8pm because carers are not available later in the evening.

The system needs to respond quickly when people's needs become more complex and they need more support. Currently if someone is receiving a care package and their needs change, they need to have another assessment. This can be a slow process and the family is left struggling in the meantime.

"People are waiting too long and having to be reassessed multiple times due to their condition or circumstances changing in that time" Palliative care social worker

There are positive examples of responsive, flexible, social care services that support people at the end of life in their own home. For example, the North West Edinburgh end of life home care team and the Hospice@Home service from Strathcarron Hospice, which provides personal care and emotional support to people at the end of life and their families, through a small team of health care assistants with specific training and experience in palliative and end of life care. An independent evaluation of Strathcarron Hospice's Hospice@Home service shows that the service reduced hospital admissions and reduced bed days[17].

If people do not receive the right social care support at home, their needs can quickly escalate and they can reach crisis point. Nearly half (48%) of carers caring for someone with palliative care needs reported that the person they cared for had an emergency admission to hospital in the last 12 months[18]. Over a quarter (29%) felt that the emergency admission could have been prevented if the person they cared for had received more support. This may have meant more hours of care, more flexible support, or better integration and responsiveness of services around an individual and their home care package.

People are also going in and out of hospital multiple times in their last few weeks of life, which suggests they are unable to access the support they need at home or in the community. Across Scotland, in 2018-19, over 2,300 people had three or more emergency admissions to hospital in the last 90 days of their life (figures exclude the largest health board, NHS Greater Glasgow and Clyde, so will be higher)[19]. In some cases people were being admitted to hospital eight or nine times in these last few weeks. This will have a profound impact on the person receiving care and their families, as well as the wider health and care system.

What change is needed?

- Social care services need to fully meet an individual's needs and quickly respond if their care needs change, without having to have multiple reassessments or long delays

Increase capacity of community services

The capacity of community support needs to be increased. This includes care at home services, care homes, day to day respite services, and support, advice and information for carers. Initiatives such as compassionate community projects are also important to provide support to people before they need formal care services, or in addition to support they receive from social care.

Delayed discharges are increasing[20]. In 2018-19, 35% of delayed discharges were caused by people waiting for care arrangements to be complete; 26% were waiting for a care home place and 16% were waiting for a community care assessment.

"The health and social care system is creaking" Palliative care social worker

Investing in palliative care services in the community can help make savings and reduce demand on hospitals[21]. In 2016, the Scottish Government committed to doubling the provision of palliative care in the community by 2021[22]. This has yet to be realised. If there was a clear implementation plan, funding mechanism and workforce plan to realise this commitment, palliative care providers would be able to increase their capacity and support more people with palliative care needs, in a way that is cost-effective and meets a clear public need.

Scottish Government's ambition is to shift the balance of care from acute to community settings, to support more people to die at home, where most people frequently say they would prefer to die. Recent research shows that, by 2040,

community settings could feasibly account for two-thirds of all deaths in Scotland[2]. However, this is very unlikely to happen, unless community support and capacity is radically increased and existing support is made more sustainable.

We know that the voluntary sector provides excellent social and economic value in the delivery of palliative care. Though specific to children's services, research from York Health Economics Consortium shows that for every £1 of public funding for children's palliative care in Scotland through CHAS, £5.12 of economic value is created including through voluntary income, reduced demand on the health service, and the increased economic activity from supporting people to be resilient even in the hardest of times[23].

What change is needed?

- Invest in and increase full range of support in the community
- Be more proactive and less risk-averse in enabling communities to realise their own assets and support people affected by terminal illness

Embed principle of choice through self-directed support

Self-directed support (SDS) is about embedding the principle of choice and control over what an individual's social care support looks like and how it is delivered. Having more control over decision-making can help ensure that the care received best reflects an individual's wishes and preferences. This can be hugely important for someone who is living with a terminal illness.

Individuals can choose how to receive support from four options, from having their own personal budget as a direct payment, to having the local authority arrange services for them.

The feedback we received from social care staff and people accessing support is that SDS, particularly the use of direct payments, is not working for people with a terminal illness. The process was felt to be too long and complicated, with direct payments taking up to a year to put in place. In general, it was felt that there was a lack of support in place for people, though there were positive examples of third sector organisations, such as Cornerstone, providing dedicated support to people accessing SDS.

This aligns with the Care Inspectorate's recent review of SDS[24] which found that front-line health and social care staff are not yet actively engaged in SDS and that the information being given was not consistent. As a result, all four options were not available consistently to people. In addition, personal budgets were taking a long time to be approved.

Most local authorities are unable to provide data on the number of people with a terminal illness accessing SDS under each of the options[25]. Out of the five local authorities who could provide this information, the majority of people accessed SDS through option 3, the traditional route of the local authority organising services on the individual's behalf. In four out of five local authorities, nobody with a terminal illness

used the direct payment option. In the fifth local authority, just 6% of people with a terminal illness accessed a direct payment.

There also needs to be more support to use direct payments to pay family members for providing care, as the system does not easily allow this. It can be hard to recruit someone as a personal assistant to provide care to someone with a terminal illness, especially in rural areas. There is also the risk of the person employed leaving at short notice, and there being a gap in care provided. Family members who are caring for their relative often have to give up work because they are unable to juggle the demands of caring with employment. Being able to use direct payments to pay family members would mean some of that financial burden is lifted from carers, while also providing person-centred care from someone who knows the individual best.

What change is needed?

- More training for front-line staff on SDS and more support for people with a terminal illness so that they can access the SDS option that best suits their needs
- Introduce a fast-tracked, streamlined process for people with a terminal illness wishing to access direct payments
- Simplify the process for direct payments to be used to employ family members as carers

Supported and skilled workforce

None of the above points can happen without the right workforce in place. The social care workforce needs to be supported and valued, with the right number of staff, in the right place, with the right skills and training to meet the changing social care needs of people with a terminal illness.

Under the Health and Care (Scotland) (Staffing) Act 2019, there will be a duty on NHS and social care providers to have sufficient, suitably qualified staff to ensure the health, wellbeing and safety of people using their services, the delivery of high quality care and the wellbeing of staff.

To achieve this, there needs to be a focus on recruitment and the supply of people into caring roles; and retention and support for people once they are in the role. This needs to be supported by adequate investment and resourcing, and long-term integrated workforce planning.

Some areas of the social care workforce in Scotland are experiencing significant challenges around recruitment and retention, particularly in care homes and care at home services. As at December 2017 (the latest available data by Scottish Social Services Council (SSSC) and the Care Inspectorate), 62% of care at home services, 59% of care homes for older people and 53% for care homes for adults reported vacancies[26]. This is significantly higher than the 38% national average across all registered care services. Vacancies also varied across Scotland, for example 87% of care homes for older people in East Renfrewshire reported vacancies. Nearly half (46%) of care homes for older people reported vacancies for nursing staff.

Vacancy rates have increased from 2016 to 2017[26]. The percentage of whole time equivalent vacancies (as a proportion of the workforce as a whole) increased from 7.8% in 2016 to 8.2% in 2017 for care at home services. For care homes for older people, the percentage increased from 4.3% in 2016 to 4.8% in 2017. The rate of vacancies in care homes for adults rose from 6.6% in 2016 to 7.3% in 2017.

While there is currently a national recruitment campaign for frontline workers in adult social care, the impact of this will need to be evaluated, alongside parallel work to support and improve working conditions so that care staff want to stay in the sector and are supported to do so. In some areas, the adult social care sector is competing with other sectors, such as retail, with better terms and conditions.

Care staff delivering palliative and end of life care have a complex, challenging and emotionally demanding role. As well as personal care, they provide emotional and social support, care for the dying, respite care for family members and domestic support[27,28]. There are particular challenges such as emotional attachment and grief after bereavement; feeling isolated, unprepared and insufficiently trained for end of life care; and a lack of clarity about the boundaries of their role compared with other health and care staff[27,28,29].

To effectively support the key contribution of the front line workforce in palliative and end of life care, employers need to feel valued and have sufficient investment in their services to implement training, learning and innovation, all of which enhance the 'wellness' of their employees. There needs to be a better understanding of what organisations and employers need in order to support staff in a consistent way.

There are positive examples of support available for employers, such as Hospice UK's Compassionate Employers scheme, that helps organisations to support employees who are affected by terminal illness, caring and bereavement.

Effective and appropriate learning and development for front line support workers is central to the delivery of person-centred palliative and end of life care. Hospice care providers play a key role in education, with 90% of charitable Scottish hospice care services providing education and training to health and social care staff, including care home staff and community teams. For example, Project ECHO[30] uses videoconferencing technology to bring together clinical specialist teams in hospices with staff in care homes.

SSSC has published a framework for palliative and end of life care, though it is not clear to what extent, or how consistently, this has been implemented. Effective training and development is especially important in the context of changing demographics, with people going into care homes later in life and the increasing complexity of people being cared for at home or in care homes. This means that social care staff will increasingly have to support people with palliative and end of life care needs in the coming years.

What change is needed?

- Adequately resource, support and value the social care workforce to address issues in both recruitment and retention

- Closer working between SSSC, NHS Education for Scotland and social care employers to deliver and evaluate effective training and education to the social care workforce to meet the growing need and complexity of palliative and end of life care
- Support for the wellbeing of staff and acknowledgement of the particular challenges that working around death, dying and bereavement can bring
- Monitor implementation of the Health and Care (Scotland) (Staffing) Act 2019

Supported carers

Family and other informal carers are hugely important in the support they provide to someone with a terminal illness, and play a key role in co-ordinating and linking in with formal services. Having a family carer is the single most important factor to enable someone to die at home, if that is where they wish to die.

The impact on people caring for someone with a terminal illness can be huge. Feedback gathered by Carers Scotland from 163 carers caring for people with palliative care needs, found that the vast majority of carers (82%) provided over 20 hours of care a week, with 70% providing over 50 hours of care a week[18]. A third had given up work to care and almost half were struggling to make ends meet, with nearly a quarter cutting back on essentials like heating and food. Nearly a quarter described their physical health as bad or very bad, and almost a third said the same about their mental health. 81% reported feelings of loneliness. We also know that for carers of children who will die young, caring responsibilities can last for years, be intense, and impede employment and engagement with friends and families.

Yet despite the massive impact on carers caring for people with palliative care needs, the majority of these carers (71%) reported they had not had their needs as a carer assessed[18]. The Carers (Scotland) Act (2016) places a duty on local authorities to prepare an adult carer support plan (ACSP) for anyone who identifies as a carer or any carer that requests one. The legislation will set out timescales for preparing ACSPs for carers of those in the last six months of life, but this has not yet been implemented.

Timely intervention is crucial to ensure that carers feel supported to live well and to carry out their caring role[31]. Many informal carers supporting people at the end of life go unidentified and unsupported. This can lead to prolonged and complicated grief, including a sense of guilt.

A lack of support can put both the carer and the cared-for person at risk of reaching crisis point, resulting in a breakdown in care. ACSPs need to consider the need for support in an emergency, however only 30% of carers who had their needs assessed were provided with this[18]. A quarter of carers felt that an emergency admission to hospital could have been prevented if they had received more support as a carer, such as breaks from caring or more ongoing support.

Support for carers includes regular respite support, advice, information and support from carers centres/groups, and bereavement support after the person being cared

for has died. Research by Sue Ryder and Hospice UK found that a quarter of bereaved people in Scotland who said that they would have wanted bereavement support reported that they were unable to access it[32].

Effective hospice care, which is designed to support people dying and their families, can play a huge role in supporting carers before death, in bereavement, and during times of crisis.

Financial support is also key. For carers who had to stop working in order to manage their caring responsibilities, this includes support to help them get back into work, once they are ready. Currently, working age carers on Carers Allowance only have eight weeks before they may be expected to seek employment or decide what they will do now. This can add further pressure to someone caring for someone with palliative care needs.

What change is needed?

- Improve identification, assessment and support for carers and young carers who are caring for people who are terminally ill
- Implement timescales in the Carers (Scotland) Act 2016 to ensure faster access to support for carers who are caring for someone who is terminally ill
- Effective implementation and ongoing evaluation of the new Benefits Assistance under Special Rules in Scotland (BASRiS) for fast tracked access to devolved benefits for people with a terminal illness
- Sustainable funding for carers centres and bereavement support services
- Evaluation of implementation of the Carers (Scotland) Act 2016 to assess the difference it has made and where more work is needed
- More support for carers when their caring role ends, to help them adjust to their change in circumstances

In summary, people who are terminally ill do not have time to wait for care. They want to live as fully and independently as possible to the end of their lives, however long that may be. They need a social care system that is proactive, flexible and responsive, which delivers joined up care that fully supports them, and those closest to them, when they need it most.

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