

We need to talk about Palliative Care

COSLA

Introduction

1. Local government recognises the importance of high quality palliative and end of life care if we are to give people greater control over how they chose to die, and, more importantly, how they chose to live while they are dying. We believe that much progress has been made in recent years, however, we also recognise there are challenges in relation to access to palliative, as opposed to end of life care, and particularly for those suffering from multiple conditions which may or may not include cancer. Indeed, for a number of years palliative care has been subject to a growing level of focus by charities, inspection agencies, professional groups, Scottish Government, The Scottish Parliament and the public. The Committee will be aware that there have been a number of recent reports which have provided an overview of the issues relevant to Scotland including the Audit Scotland report 'Review of Palliative Care Services' (2008); the Scottish Government's report 'Living and Dying Well '(2008) as well as its review 'Reflecting on Progress' in 2012. COSLA welcomes the opportunity to discuss the issues these raise with the Committee in more detail during the upcoming oral evidence session.
2. Scottish local government already plays a key role in delivering many aspects of palliative care, care at home, residential care, support packages for those with learning disabilities and incapacity, and meeting the needs of children and young people with life-limiting illnesses. Local authorities are also instrumental in supporting families and carers with bereavement after death. More recently and at the national level, COSLA has participated in the Palliative and End of Life Care National Advisory Group and has agreed to work with the Scottish Government on their commitment to develop the Palliative and End of Life Care Strategic Framework for Action. Local authorities are also significant purchasers of palliative care for children and young people, and COSLA renewed its national funding agreement with the Children's Hospice Association Scotland (CHAS) for a further three years.
3. Much has been done in recent years to highlight the needs of people with life-limiting illness, along with the gaps in provision and to change systems and behaviours required to better support the dying and their families. However, many of the findings of the Audit Scotland report in 2008 are as true today as they were then and COSLA recognises there is still much to be done to provide more person-centred and holistic palliative and end of life care to the people of Scotland.

Key issues

Definitions

4. Definitions have perhaps caused many to unhelpfully equate palliative care with end of life care, and while one may flow into the other, we do not believe they are the same thing. The Scottish Partnership for Palliative

Care and the ALLIANCE have both noted that a more staged definition would help with the journey from ill health or aging into needing end of life support.¹ They have argued that palliative care needs to be understood in terms of generalist palliative care, specialist palliative care and end of life support. COSLA supports this view and believes that this might be helpful in identifying and improving upon the role played by local government in the different stages of palliative care when all too often the focus is on the highly medicalised, acute end of provision prior to death.

Anticipatory Care Planning

5. Anticipatory Care Planning (ACP) allows for a record of a person's views and wishes about how and when they might wish to die. This includes clarity on resuscitation and the ongoing involvement of family members and carers in their treatment and care. It is understood that those who die with an ACP are likely to have had a better experience of support and respect for their views and choices than those without an ACP. This is precisely because an ACP requires those views to be formed, known and recorded. The ACP has therefore also acted as a trigger for better communication and involvement of families and carers in decisions about palliative and end of life care.
6. It is to the credit of local authorities and care homes that the number of older people who die in residential care with a ACP is increasing and in 2014 was at 62%. However more could be done to improve the number of care home residents with an ACP and specifically to improve the use of ACPs for older people who live at home or in supported accommodation.
7. ACPs could also have a wider role in supporting an individual through care pathways if there were better mechanisms for ensuring that the documentation and information could be shared between health and social care. The integration of health and social care will help to address these issues and the new Integration Joint Boards (IJBs) are currently considering their arrangements for sharing information, including data-sharing protocols; however it needs to be recognised that we are in the shadow year in terms of the establishment of IJBs and so this work will take time to fully bed in.

Training

8. The point at which social work and social care shifts from supporting the holistic needs of an individual into generalist palliative care, and from there to involving specialist palliative care onto end of life, will be different for every individual. Only better training and support for our staff – whatever the setting- will improve when and how this is done, and it needs to be recognised that this comes with a cost attached at a time when public sector funding is reducing while demand is increasing. We therefore need to identify the most cost-effective ways of improving staff knowledge and skills and it is worth considering, for example, the recommendation made

¹ Written evidence submissions to the Health and Sport Committee, 2015, <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/91550.aspx>

by some charities to include death, dying and bereavement in the undergraduate education of all health and social care professionals. It is also worth focusing on ways of improving the skills and confidence of non-health professionals to recognise some of the health needs of patients being given palliative support or who may not yet have been identified as needing palliative support. This earlier identification of need could prolong life and should lead to better outcomes at end of life.

9. More is also needed to ensure joined up and multi-agency training and to support the development of multi-agency tools. We recognise that in terms of home care and residential care, this may present a financial burden that is difficult to manage given the high number of staff such training would involve. Furthermore, difficulties with recruitment and retention of home care staff, especially in more rural areas, mean that for some partnerships it is simply not possible to meet palliative care need by increasing the responsibilities of home care staff (for example in relation to administering medication) – care at home operates within a low-wage culture and it is difficult to increase the medical responsibilities of these staff without also addressing pay.
10. COSLA is currently in negotiation with the Scottish Government to identify funding to raise pay within the home care sector to living wage levels, however we still face challenges attracting staff to roles with increased responsibilities when the living wage is also being offered by, for example, some major supermarkets and coffee shop chains. This is not something that IJBs alone can solve and speaks to the urgent need to have a broader debate about our tendency to invest in healthcare at the expense of funding to local government, and therefore to social care. This is why COSLA is calling for the 'National Conversation' to have a much more explicit focus on social care, and how much we as a society are willing to pay for social care into the future.

The complexity of need

11. For many the journey on a palliative pathway of care is not linear. Illnesses - while life limiting - can also improve and regress and often there is little to distinguish between an episode which may improve and one which may lead to death. This is particularly true for those who have degenerative diseases or organ failure. The difference in people's needs can vary widely and relate to their personal circumstance and the type of illnesses and diseases they have.
12. How we respond to the needs of cancer sufferers is arguably well developed in comparison to other diseases which is why there is such a strong call from many stakeholders to ensure an appropriate balance of support to people with other types of disease and illness. The complexity of the needs of those who are dying from a range of illnesses is further compounded by age and the particular the effects of frailty and dementia. The type of condition someone has can significantly influence where someone is cared for, their referral pathways, who funds their support and accommodation, and therefore overall, the support they can access.

People with cancer are much more likely to get the palliative care support they need than people with non-malignant conditions (including frail older people with multi-morbidities and dementia), and this applies both to specialist palliative care and generalist palliative care support.

Marginalised groups in society also tend to have worse access (e.g. people experiencing homelessness, prisoners, people with learning disabilities).

13. We recognise that care homes are often the providers meeting these complex needs, and that they are seeing a growing number of residents with different degrees of dementia, including severe dementia. This presents a challenge for care homes and for IJBs as they develop their strategic commissioning plans, and securing more (and more flexible) NHS input to care homes requires to be developed in order to avoid multiple hospital admissions in the later weeks of life. Indeed, if we are to redesign services so that people are able to live at home, or in a homely setting, for longer and potentially in the very late stages of life, we need to ensure the required healthcare services are available in a wider range of settings.
14. How residential provision is registered can also present a barrier to the development of appropriate support as provision for severe dementia and for other illnesses often need to bridge the gap between nursing homes and residential homes but must be classed as one or the other for registration purposes. This impacts on policies, practice, financing and outcomes for people. This is an issue which could be helpfully reflected upon in the review of national care guidelines and more generally by the Care Inspectorate and HIS. It can also be addressed by the development of different models, such as extra-care housing, and again, this requires a significant shift of resource from acute to community settings and in many areas significant additional investment. This is an area COSLA continues to focus on in working with our partners to implement the recommendations of the Residential Care Taskforce.²

Strategic Commissioning

15. The position of IJBs to plan local provision more strategically to resolve some of these tensions is worth highlighting. This is also true when it comes to the better and more joint planning and commissioning of care homes and care at home in the drive to reduce unnecessary hospital admissions and timeous discharge and is very pertinent to the debate about palliative care and end of life.
16. Specifically, the ways in which individuals, communities, third sector provision and local authority services can link with, and make use of, specialist and out of hours support needs to improve. Failing to address this will result in continued unnecessary use of emergency and hospital services as well as unnecessary admissions and delays in discharging. Rapid response capabilities within communities as well as the availability

² *Recommendations for the Future of Residential Care for Older People in Scotland*, COSLA and The Scottish Government, 2014, <http://www.gov.scot/Publications/2014/02/6217/4>

of support after hours on Monday – Friday and at the weekend needs to be addressed.

17. Again, IJBs are in a unique position to be able to address these barriers in terms of service design and financing and to create a holistic pathway of care that supports person centred and self-directed support. However, this requires that the national change agenda makes a shift from a health-focussed approach, to one which considers issues in relation to social care. COSLA continues to work with the Scottish Government to ensure change programmes such as the Transformation of Primary Care and the Sustainability & Seven Day Services Programme also take account of the role played by social care as simply inviting IJBs to engage with a health-dominated agenda will not achieve the change we jointly desire.

The palliative care needs of those with Learning disabilities

18. It is also worth drawing out the specific needs and circumstances of those with Learning Disabilities within this paper. A report by former social worker Linda McEnhill on behalf of Help for Hospices UK, details some of the specific challenges, needs and complexities in supporting this group of people in a way that fully respects their human rights. It is clear that people with learning disabilities have a large and variant disease profile which often makes their care a complex matter.
19. How these needs are dealt with as part of palliative and end of life care requires serious thought as does how we ensure that we support, empower and deliver real choice in this context. Councils often face real challenges in identifying age-appropriate, cost-effective provision for this group. This is something that COSLA and Social Work Scotland have sought to address through work on a national framework for purchasing specialist adult residential care, however we face similar challenges to those outlined above in ensuring flexible health and other services are able to 'reach' into the residential setting to avoid multiple hospital admissions.

Choice

20. Many people, if an illness permits, would prefer to die at home or in a homely setting; however, if we wish to provide people with, and respond to, people's choices as to where they die - as well as how they die - then we need to more actively shift the balance of resources from health settings to social care and specifically home care and residential care. While IJBs have a specific role to play in this it is also a point which should be considered by the Scottish Government as they develop the Palliative and End of Life Care Strategic Framework for Action and commit any supporting resources.
21. Councils are committed to ensuring people who receive social care services have choice and control over the type of provision they receive, including how and by whom it is provided. Self-directed support (SDS) is the method by which people are given this control, however we need to recognise that, in some cases, choices may be constrained by the type and severity of illness that people have and therefore what is physically

possible for them. However, it is also constrained by the availability of services and councils are working with providers to develop more innovative, flexible and outcomes-focused provision as part of their SDS implementation strategies.

22. While people have a right to choice and control in relation to services to meet their social care needs, the SDS duty falls on councils only, and so people do not have a similar right in relation to services provided to meet their healthcare needs. In a post integration world it is worth asking how we can ensure that people can exercise appropriate levels of choice and control over the entirety of their care package to ensure that the whole pathway of care is very much person centred and joined up. This would be helpful to those with long-term but life limiting illnesses and for older people with varying stages of dementia.

Children, Young People and Young Adults

23. The Children's Hospice Association Scotland (CHAS) is the sole provider of children's hospice services in Scotland. CHAS support children from every local authority in Scotland by providing hospice services for children and young adults with life shortening illnesses and COSLA has agreed a joint funding position to support the charity's work. This service is provided by two hospices, Rachel House in Kinross and Robin House in Balloch, West Dunbartonshire, and through the CHAS at Home service which is provided across the country to children in their own homes. In 2013/14 CHAS supported 378 children across Scotland, and COSLA has recently renewed its national funding agreement with CHAS for a further three years.

Conclusion

24. How we understand and define palliative care is critical if we are to fully value the early stages and preventative role of generalist provision. For too long, palliative care has been dominantly about how someone dies, rather than also about how they live while they are dying. It has also been largely about the role of GPs, nurses, consultants, psychiatrists and not about social work and care provision, bereavement and community support. COSLA would support a broader understanding of palliative provision which takes account of the wider groups and professionals involved in supporting people.
25. COSLA would also promote a more honest conversation with people in need of palliative care about their choices. If their choice is to be supported and to eventually die at home or in a home setting, we should be prepared and able to meet those requests. However, in order to do this we need better training for our staff and a strategic commissioning model which shifts resource as well as the balance of care to the community.

COSLA