

We need to talk about Palliative Care

Health and Social Care Alliance Scotland (the ALLIANCE)

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. It brings together over 1,200 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.

The ALLIANCE's vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE welcomes the opportunity to respond to the Health and Sport Committee's Inquiry into Palliative Care in Scotland. On August 5 2015, the ALLIANCE and the Scottish Partnership for Palliative Care¹ jointly hosted a session for members to input their views on the inquiry and much of our response has been informed by the discussion on the day.

Terminology

Before turning to the questions set by the committee, it is important to highlight the importance of terminology in relation to this inquiry, and the need for the Committee to be clear what it means when it uses terms such as 'palliative care' and 'end of life care'. At present in Scotland (and across the UK) there are inconsistencies and misunderstanding in how these terms are used, and the Committee can help by being consistent in its own work.

For many people, the word 'palliative' is associated with the last days or weeks of life, or with cancer, or thought to only refer to specialist services. However, palliative care can be appropriate alongside active treatment, from diagnosis onwards, and for people with non-malignant conditions. Much palliative care is provided by generalists, in care homes, hospitals and in people's homes.

Misunderstandings over what is meant by 'palliative care' can present barriers to people receiving care that would support their wellbeing. It is therefore important that the Committee is clear and consistent in its use of terminology throughout this inquiry. Using the phrase 'palliative care' without an accompanying definition opens the ten questions up to various interpretations.

We would suggest the Committee refers to the Scottish Partnership for Palliative Care for a considered approach to appropriate terminology, including terms such as 'generalist palliative care', 'specialist palliative care' and 'end of life care'.

¹ <http://www.palliativecarescotland.org.uk/>

Questions

1. What has been your experience in terms of access to palliative and end of life care?

Recent research, carried out by the London School of Economics (LSE) and commissioned by Marie Curie, suggests that nearly 11,000 people who need palliative care in Scotland each year are not accessing it².

While Cancer is often seen as synonymous with palliative care, it is critically important to recognise that people living with a wide range of long term conditions can significantly benefit from palliative care. Despite this being the case, people living with long term conditions such as dementia, chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND) or multiple sclerosis (MS) are much less likely to get the palliative care they need³. This can be due to a number of factors, including a lack of understanding around what palliative care is and can do, prognostic uncertainty, a reluctance to identify some conditions as terminal and under developed links between health and social care professionals⁴.

Difficulties in obtaining a diagnosis are often faced, particularly for neurological conditions or illnesses when symptoms may be hidden. For example, in a survey conducted by the Dementia Carer Voices project, 39% of people waited 6 months or more for a diagnosis of dementia, with some reporting waiting several years.⁵ It is therefore important to recognise the importance of improving diagnosis times in order to ensure people are provided with palliative care at an appropriate time.

During our recent roundtable event held to explore the issue, members highlighted that further work is also required on making sure that people with learning disabilities are supported to access palliative care⁶.

2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

² Dixon J, King D, Matosevic T, Clark M, Knapp M (2015), Equity in the Provision of Palliative Care in the UK: Review of Evidence, PSSRU Discussion Paper 2894, London School of Economics

³ Zheng L, Finucane A, Oxenham D, McLoughlin P, McCutcheon H & Murray SA. How good is UK primary care at identifying patients for generalist and specialist palliative care: a mixed methods study. *European Journal of Palliative Care*, 2013;20(5).

⁴ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf>

⁵ http://www.alliance-scotland.org.uk/download/library/lib_55487edc0c2bc/

⁶ Further information on this theme can be found within 'The Same as You' 2000-2012, Evaluation of progress from the perspectives of people with learning disabilities and family carers, the Scottish Government, 2012. (Page 146)

Palliative care can be provided by generalist (those who provide day-to-day care to people with advanced illness and their family and friends) and specialist (such as consultants in palliative medicine or clinical nurse specialists) professionals across a range of settings including, hospitals, care homes, hospices or in people's own homes.

One of the main opportunities for improving access to palliative care for people with all conditions across Scotland is to ensure that health and social care professionals have access to generalist palliative care training and, importantly, see it as an integral part of their job. At our roundtable event, one attendee spoke of an individual whose mother had dementia, and who was very distressed. When she inquired about palliative care for her mother, she was told "no such thing exists for dementia". Training should therefore encompass generalist skills, coupled with an awareness of and signposting to specialists to ensure equality of access to palliative care.

Within our roundtable event, the provision of support and training for care workers who are increasingly supporting people at the end of their lives in care homes and through care at home services was highlighted by a number of members as an issue of key importance.

Central to accessing good, timely support for palliative care at home is the recognition that Self-Directed Support can be an invaluable tool for insuring people who have choice and control over how their support is delivered to them throughout their treatment of their long-term condition and in the final stages of their lives. With the integration of health and social care, there is an opportunity for palliative care to be transformed into a joined up service that is backed by both health and social care services. In doing so people who require palliative care can be far more directive over the type of care they receive. The ALLIANCE would go further to support joined up individual budgets, including contributions from health, for people who require palliative care in order to arrange support around their personal lives and enables their end of life care to be as individual as the rest of their lives.

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

A common theme which arose throughout the discussions was the relationship between support, communication and culture.

“When the conversations break down, so does the support”

If people are unable to talk about deteriorating health and death, then it is very difficult for them to make plans and access the support they need. Currently many people are reluctant to discuss death and dying – whether as individuals, professionals, family or friends.

One participant, reflecting on their experience as an unpaid carer noted that the difficulty they had encountered when trying discuss end of life care had impacted negatively on the care received by his mother.

“My mum had a right to live well but also a right to die well. I found the last six months of my mum’s life dreadful – just trying to have a conversation with anyone about the end of her life. Every time the conversation was “it’s the dementia”. But it wasn’t. I knew my mum was dying but even in the last week of her life but I still couldn’t have a conversation with a nurse about bringing her home to die.”

Key to improving communication in this regard is initiating a culture shift in Scotland. We need to normalise these kinds of conversations, giving professionals and the public the confidence and support to be open about these issues.

Though many specific communication issues exist, most are related to this, and cultural factors are currently a limiting factor in service improvement. This is a public health issue, as has been recognised by the Good Life, Good Death, Good Grief⁷ alliance who have been leading the way in addressing this issue in Scotland, and whose work should be scaled up.

In addition to communication and culture, identified priority areas included;

- Educating and supporting generalist staff to provide palliative care alongside curative care as appropriate
 - Addressing the need for support and training for care home / care at home staff
 - Anticipatory care planning - providing people with opportunities to talk about their potential future needs and preferences while they are well enough to do so
 - Supporting and enabling staff in very busy acute hospital settings to provide quality end of life care
4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

The fact that each person’s preferences and circumstances are different mean that it is not possible to provide a single definitive answer to this question.

This dynamic is highlighted by the experience of one person who attended our members’ roundtable event, who noted;

“I would like to talk about my situation and my changing condition but my husband doesn’t want to go there.”

A discussion about options for palliative care may cover a range of different things depending on the condition and stage. For example, it may be appropriate to have a discussion about optimising symptom management at a very early stage, but it might not be appropriate to be having a detailed discussion of end of life care wishes. However, having a plan in place for

⁷ <http://www.goodlifedeathgrief.org.uk/content/about/>

when to have those conversations would help to ensure that rather than having on an 'if and when' basis, or at a point where it is very close to the end of the person's life when they may not be in a position to make the decisions they otherwise would have. For example, people living with dementia may not retain their capacity to make informed decisions, and so establishing their wishes and preferences earlier on is crucial to ensure that their wishes are followed. There are clear parallels between these conversations and Power of Attorney and Wills, where public awareness campaigns have made considerable impact in increasing people's awareness of the importance of advance planning.

Discussions about palliative care need to be initiated and carried out in a truly person centred manner. The role of professionals in this regard must be to ask people what matters to them and who matters to them, and then work in a flexible and responsive way to ensure that their personal preferences are at the forefront of the approach that is taken. In some cases this must involve independent advocacy support to ensure that the person's views are well represented.

Additionally, the role of families and carers should be a key consideration when talking about palliative care. Families and carers should be involved in discussions around palliative and end of life care, as often they are well placed to support their loved ones to make informed decisions, and often will be involved in delivering care at home.

Sue Ryder's [PEPS service](#) in Bedfordshire has been highlighted as an example of good practice in which a multi-disciplinary team take a more holistic approach and build support around the person. This includes having a system in place whereby when an ambulance is called, it triggers a group response from their support team, thereby reducing admissions to hospitals through greater use of technology and effective communication.

5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

Good communication between professionals and people who live with long term conditions is vital to ensuring that people receive the type of care they need to support them. This must include:

- Early planning for possible future deterioration in health
 - Better sharing of information across settings (including third sector organisations). It is difficult for professionals to provide the right support if they're unaware of previous discussions and decisions
 - Support and training for care workers who are increasingly supporting people at the end of their life in care homes and through care at home services.
6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

Anticipatory care planning including the Key Information Summary have an important role to play in supporting people who may require palliative care. Data included in such plans needs to be well completed, updated on a regular basis and be available at the time when it is needed. These often work best when the information is not “medicalised” and involves family members and unpaid carers. Often such plans are paper based and held in the home which is not ideal.

7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

Supporting people to have early conversations about possible future care needs and preferences is key to helping them (and those around them) to maximise their wellbeing even as their health deteriorates. Within this context, it is reasonable to expect that people will have the opportunity to sit and talk about their condition, their future and what they can expect with health and social care professionals who have the skills and knowledge to support this conversation. Again, there is no one size fits all approach, and it is important that the steps taken recognise and accommodate the unique wishes and circumstances of the person in question and those around them.

It is also important to recognise that carers need to be involved in a different conversation. At the roundtable event, it was suggested that further information is available at carers centres, including having the opportunity to speak to professionals about palliative care and what this means for the person they care for, and themselves in their caring role.

8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?

There is a significant amount of work going on across, and in conjunction with, the third sector to support health and care staff to discuss palliative care with people and their families. Some examples include:

- As an element of their free online stroke training resources **Chest, Heart and Stroke Scotland** have developed e-learning modules for healthcare professionals which include an end of life care module and palliative care module. Healthcare staff can complete module tests to show evidence of their learning.
- The **Learning Disabilities and Palliative Care: Building Bridges, Supporting Care** project is working in Greater Glasgow and Clyde to support staff in the provision of best quality care for people with learning disabilities who have palliative care needs. The key aims include developing a high quality care pathway and linking with clinical workforce teams to build knowledge, skills and confidence to ensure high quality palliative care is available for people with learning disabilities.

- **NHS Grampian, with support from MS Society Scotland,** are developing a short document outlining what their rights are in terms of palliative care and what to expect. The purpose is to begin to enthuse people about their care and empower them to take control over the support they need in the future.
9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

Supporting people to have early conversations about possible future care needs and preferences is key to helping them (and those around them) to maximise their wellbeing even as their health deteriorates. As highlighted in our response to question 4 however, the definition of the “right time” is likely to vary from person to person and therefore requires a flexible and person centred approach. Health and Social Care organisations can support this by ensuring that their staff have the skills and support in place to identify when a palliative care approach is required.

10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

Similarly to the issue of communication between professionals and people who use support and services, the extent to which professionals communicate with each other is also crucially important.

One of the key related issues highlighted during our members’ roundtable event was the impact of the differing IT systems used within primary and secondary care and within different providers, which pose barriers to accessing and sharing information. For example, the different electronic systems used to record information across public, independent and third sectors and between primary and secondary care do not automatically connect to the Key Information Summary (KIS), requiring GPs to re-enter details received from consultants which can be time consuming and therefore not completed. Investment in effective ICT infrastructure has the potential to significantly improve the reliability of information sharing across settings and the ability for it to be updated rapidly.

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