

*and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*³.

In this response, we take end of life care to mean care that is provided in the final hours or days of someone's life. Palliative care can be provided, to varying degrees depending on the condition(s) a patient is living with, for extended and unpredictable periods of time.

The challenges

Sue Ryder believes there are two significant challenges which need to be overcome to improve palliative care. Firstly, inequalities in access to palliative care for people with neurological conditions and other conditions that are not cancer need to be addressed. Secondly, communication needs to be greatly improved: what palliative care means needs to be better understood, health and social care professionals need to be better skilled at the 'initial conversations' about palliative care, and recording the outcomes of conversations and integrating records across entire care teams is vital if an individual's wishes concerning palliative care are to be met. These two themes underpin many of our responses to the questions posed by the inquiry.

Response to inquiry questions

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

Sue Ryder provides palliative and end of life care via our six hospices (in England) with hospice care in the community in many of these locations. We also deliver palliative care for people living with neurological conditions in our centres (including Deevie Court, Aberdeen), many of whom also ultimately die in our centres. Specific examples of the type of holistic service we provide are:

- The 'Vitrucare' digital palliative care pilot. We are carrying this pilot out jointly with Dynamic Health Systems in three of our hospice areas. The aim is to allow people to use a digital service to communicate with their families, carers and health professionals about their current and future wishes, thus allowing a personalised record, as well as getting advice on symptoms and discussing pain relief. Video links can be set up with carers and professional staff so anxiety and uncertainty can be greatly reduced (see Appendix A for more details).
- Online Community and Support. We provide a number of support services for carers and families. Funded by our partnership with supermarket chain Morrisons, we provide 24 hour support for people who care for someone who is dying or has died via our new online community and support service.

³ <http://www.who.int/cancer/palliative/definition/en/>

From expert Sue Ryder nurses on hand for advice, to support on how to deal with diagnosis and treatment, the service connects together those who are experiencing bereavement and provides support and advice to help them to better prepare for and deal with loss.

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?

The availability of personalised, holistic palliative care varies according to the condition(s) that a patient is living with. Colin Keir MSP alluded to this during the Health and Sport Committee's evidence session with representatives of the Care Inspectorate and Healthcare Improvement Scotland⁴. People with non-cancer conditions, including neurological conditions, are less likely to have access to palliative care⁵. This is because firstly, these conditions often have a less predictable disease trajectory than cancer which makes prognosis less certain and secondly, these conditions are less prevalent in the population so health professionals are less experienced in these conditions and find diagnosis more difficult as a result. This means diagnosis is often late, if it happens at all, and people with neurological and some other non-cancer conditions are much less likely to receive the level of support they would have been able to had they been diagnosed earlier.

In addition, prognostic indicators and an understanding of palliative care is generally better understood by oncologists than other specialists.

To address this inequality of awareness of neurological conditions and the support that can be put in place for people living with them, understanding needs to be greatly improved amongst generalist health and social care professionals. This would not only involve improvements to education and training across the workforce, it would involve outreach work by specialist providers to improve awareness of conditions and the services – including palliative – available to people living with such conditions. This would both drive up diagnosis rates, thus allowing better palliative care, and would improve standards in palliative care for people with neurological conditions.

The effectiveness of work in this area could be measured by data on the proportion of people with neurological conditions having advanced care plans (see response to question 9). However, in general, there is no data collected on the number of people in Scotland living with neurological conditions, other than an estimate for people living with

⁴<http://www.scottish.parliament.uk/parliamentarybusiness/report.aspx?r=9995&i=91755&c=1835397#ScotParIOR>, 2 June 2015

⁵ *Ways and Means*, Paget and Wood, Demos, 2013
http://www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165

multiple sclerosis (based on 'definite and probable' cases of multiple sclerosis in Lothian and Borders⁶).

A further measure to improve equity would be to ensure palliative care is available round the clock, rather than just during working hours. This was highlighted in Sue Ryder's recent *Dying doesn't work 9 – 5* campaign. Given that 50% of calls to our 24 hour palliative expert support service in Bedfordshire are overnight, it's clear that people need a dedicated and immediately available 24/7 service providing expert practical advice, emotional support and coordination for dying people and their families. This not only lessens stress and anxiety, it can improve the quality of a death at home and reduce unwanted emergency admissions to hospital. We want to see the new IJBs ensure that the palliative services they provide or commission are genuinely accessible round the clock. This should be a key aspect of palliative care provision to be taken into account by the Care Inspectorate and Healthcare Improvement Scotland's joint strategic inspections and there must also be clarity about it when the Scottish Government's current review of out-of-hours services concludes.

The Scottish Government recently changed its policy on NHS Continuing Healthcare, which has implications for people receiving palliative care. To ensure equity of access and that people with all conditions benefit from this policy, evaluation is necessary. On that basis Sue Ryder is pleased that the Cabinet Secretary for Health and Wellbeing committed to this in recent evidence to the Health and Sport Committee⁷. We hope that this evaluation takes into consideration the condition(s) that individual patients are living with.

While we understand the rationale for the changes being made to the National Care Standards so that they are human rights' based, the fact that palliative care will not be the subject of a specific standard means that the new inspection regime needs to find effective ways of ensuring palliative care is of a consistently high quality for all in all areas of the country. To some extent this will rest on the reliable collection of meaningful data, an area that the Health Committee is looking into separately as part of its inquiry. Use of specific examples where a palliative care service is based on a human rights approach, to spread best practice and to potentially use to inform inspections, would be welcome.

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

In addition to better diagnosis as set out in section 2, good communication and better information sharing is key to improving

⁶ <http://www.scotpho.org.uk/health-wellbeing-and-disease/multiple-sclerosis/key-points>

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<http://www.scottish.parliament.uk/parliamentarybusiness/report.aspx?r=9995&i=91758&c=1835477#ScotParlOR>

palliative care. Sue Ryder runs the Partnership for Excellence in Palliative Support (PEPS) in Bedfordshire, a service that has been funded by Bedfordshire Clinical Commissioning Group since 2012. The service entails coordinating 15 services across health and social care locally. This is a model that could be adapted by Scotland's IJBs to provide tailored support for people with palliative care needs. It helps ensure that dying people and their carers have easy and timely access to appropriate services and are supported around the clock. This has helped avert care crises by helping people to cope with increasing care needs at a very emotional time. It has also helped to deliver people's choices as the PEPS team have access to people's care records: one example of this is that more people than average have been enabled to stay in their preferred place of care. More recently PEPS has linked with the East of England Ambulance Service. This has included joining up data and systems so if a PEPS 'patient' calls the Ambulance Service there this will be flagged up and PEPS can then alert the Ambulance Service to people's preferences. If their preference is to be cared for and to die at home PEPS will work together to see whether additional services can be provided to enable someone to stay at home. This role helped discharge 112 people between December 2013 and September 2014 (see Appendix B for more details).

As identified in *Living and Dying Well*⁸, It is important that in addition to specialist palliative care professionals, all health and social care staff who work with people with life-limiting conditions are appropriately skilled in palliative care, so that they can provide holistic, person-centred care and have the initial conversations. An assessment of current pre-registration training for doctors and nurses in Scotland should be undertaken to ensure that all of these key professionals have the skills to be able to talk about death and dying.

As outlined in response to question 2, addressing inequalities in access so that whatever a patient's condition(s) they receive early, good quality palliative care, is essential.

As the Health and Sport Committee has already identified, there is currently very little data relating to palliative care. This is an area that needs to be addressed so that an accurate picture of current palliative care provision can be gained, and so that improvements can be both driven and measured.

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?

When a life-limiting condition is diagnosed, this should act as a trigger to put in place a plan to have a conversation – to be regularly reviewed – with that patient about palliative and end of life care. However, Sue Ryder concurs with Jaqui Macrae of Healthcare Improvement Scotland

⁸ <http://www.gov.scot/Publications/2008/10/01091608/4>

when she told the Health Committee: “A range of staff and healthcare professionals need to be skilled up so as to understand when the most appropriate time is to have the conversation. Different people will be ready—or not—to plan for the future and to have those conversations at different times during their illness.”⁹ Sue Ryder believes every individual is different in their approach and their wishes. It therefore takes a skilled clinician or social care professional to have this conversation, effectively and at the right time. Individual circumstances mean it may be different health and social care professionals, depending on their role and relationship with the patient, who have the initial conversation with a patient.

However, there should be one professional – for instance the GP given they hold the Key Information Summary – that has responsibility for ensuring the conversation takes place and is recorded, even if it is not the GP who has the actual conversation. And the importance of recording these conversations consistently, and sharing the outcomes with the wider care team, cannot be underestimated. It is unfair to expect people to have the same conversation over and over again about their ongoing palliative care needs and ultimate death with different members of their care team, simply because NHS, social care and other systems don’t ‘talk’ to each other. This will become increasingly important as people live with multiple conditions and so move, sometimes quite rapidly, between different care teams and professionals.

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

What works well is where clinicians feel confident to discuss death and dying and know how to have open and informative conversations with people where they can make clear what people’s options are¹⁰. Often this requires specific training. Acute consultants and other staff are not always aware of the availability of services in the local area, including those run by third sector organisations.

Another important point that contributes to good palliative care is a consistent approach to ascertaining a patient’s wishes about palliative care and recording this consistently, with regular reviews so that anticipatory care plans are kept up-to-date.

There are examples of excellent practice across Scotland but there is no consistent way of sharing these nationally. It is also difficult to get a national picture of access to and quality of palliative care due to the lack of nationally collected data. A way to share good practice should be identified by the Health Committee.

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<http://www.scottish.parliament.uk/parliamentarybusiness/report.aspx?r=9995&i=91755&c=1835336#ScotParlOR>

¹⁰ *Ways and Means*, Paget and Wood, Demos, 2013

http://www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

If more people are to be cared for at home or in another preferred place of care, anticipatory care plans are vital. There is a need for more quality end of life conversations and advance care planning needs to be reviewed regularly as people's preferences may change as their condition progresses. That is why good communication together with health and social care professionals being skilled in having conversations about palliative and end of life care, as outlined in response to earlier questions, is so important.

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?

As holistic palliative care doesn't just concern the person with the disease, but also their family and carers, it's important that information and services are available for families and carers too. It's in response to this, and the lack of round-the-clock care, that Sue Ryder provides a 24 hour online support community for the families and carers of people who are dying or who have died (outlined in response to question 1). As IJBs develop their plans for palliative care, they must take into consideration how they will make it as straightforward as possible for families to access information on palliative care in their local area. Sue Ryder understands that work is taking place in NHS Grampian with the third sector interface to develop a resource for anyone needing palliative care so they understand what level of care they should receive, what is available to them and are signposted to further resources and services for more information and support. The principles behind the PEPS model (outlined in Appendix B) could be adapted. If there was a dedicated resource such as PEPS for everyone who requires palliative care, this could also be a resource for patients and their carers to gain information on local services and options.

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?

Please see responses to questions 2, 3, 4 and 5.

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?

Healthcare Improvement Scotland set out four indicators for palliative care in 2013, due to be reported against from 2014-15 onwards¹¹:

¹¹ Palliative and end of life care indicators', NHS Healthcare Improvement Scotland, March 2013

Indicator 1: Increase in the number of people with palliative and end of life care needs who are identified

Indicator 2: Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan

Indicator 3: Increase in the number of electronic palliative care summaries accessed

Indicator 4: Place of death

This framework stated that indicator 1 could be measured by establishing the number of patients on a GP's register with a) cancer, or b) other long term condition, who are also on the palliative care register. However, the ISD 2013-14 review of the Quality Outcomes Framework (QOF) (where this information would reside) states: "This QOF prevalence of palliative care is unreliable as the judgement about who needs palliative care is subjective. Numbers are low as patients only receive palliative care for a short length of time."¹²

The framework states the indicators 2 and 3 should be measured by the proportion of people with a) cancer and b) other long term conditions having an electronic palliative care summary according to health boards' own records (assuming this would therefore mean the existence of a patient's anticipatory care plan). This data is yet to be published. Also, the fact that there is no data on people in Scotland with neurological conditions, i.e., 'other long term conditions' (as outlined in response to question 2), would be problematic in measuring this.

The final indicator would be measured by the number of people dying at hospital vs their normal place of residence. While this may seem straightforward, many people often use location as a proxy for achieving different factors that are important to them, such as being surrounded by loved ones or being pain free when they die. While most people prefer to die at home it cannot be automatically regarded as a good death. It delivers control on the setting of care and death, which is important but doesn't say anything about the quality of care or experience in that setting. We need to be able to assess this.

It is clear that the new palliative care strategy for Scotland must not only find ways to measure quality palliative care, it must ensure there is a way of collecting relevant data. We have concerns about the collection of data against the above indicators.

In addition, if care is to be truly patient-centred, views of patients' and carers' must be systematically collated, with key indicators used to drive improvements in performance.

¹² <https://isdscotland.scot.nhs.uk/Health-Topics/General-Practice/Publications/2014-09-30/2014-09-30-QOF-Report.pdf?43682497740>

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?

See response to question 3.

Sue Ryder

Appendix A

VitruCare digital palliative care pilot project

The 'VitruCare' palliative care pilot is being carried out in partnership with Dynamic Health Systems in three Sue Ryder hospice areas. VitruCare is an internet enabled digital health service and platform designed around the patient. It can be accessed on many devices including PCs, smartphones, tablets, smart televisions. It aims to provide patients with connection, choice and support when living with a life limiting condition. A series of individual apps have been designed, each performing a particular function for the patient, which means patients can use combinations of apps designed to meet their current needs.

The model aims to provide a person approaching the end of their life with connection by creating a personalised record reducing the need for them to retell their story in full on multiple occasions.

It provides choice – so people can express their current and future wishes and choices to the people caring for them. The service also provides support as people can request help through direct contact with their extended care team, or simply by recording the issue in their daily diary. For example they may need to discuss their current pain relief, or be experiencing particular symptoms they need advice on. In some cases the use of video links between patients and their carers will help to reduce anxiety and uncertainty by offering a near immediate access to support from friends and professional carers.

The pilot is due for completion at the end of 2015, and the outcomes will be shared in 2016.

Appendix B

Partnership in Excellence for Palliative Support

Sue Ryder's Partnership in Excellence for Palliative Support (PEPS) service in Bedfordshire is a partnership of 15 organisations which supports the patient and their family to stay in their preferred place of care. It has been in place for three years and evidence shows that nearly half (46%) of patient and carer calls were made out of hours (after 5pm, before 9am). Of these 79% of out of hours calls were made by a relative / carer and 21% by the patient. In the 12 months to end May 2014, 166 admissions have been recorded as being avoided

Since January 2014 the local ambulance provider has worked closely with PEPS to change their pathway, instead of taking patients straight to hospital they contact the PEPS service. This has happened as a result of the ambulance service receiving a feed of patients who have been referred to PEPS this is then entered onto their computer aided dispatch system. Should patients, family or friends ring for an ambulance, this then flags up that the patient is known to PEPS. The ambulance crew will attend the call as normal and following stabilisation of the patient the crew will ring PEPS for further

information which is held on the system, such as preferred place of care, and Do Not Attempt Cardiac Pulmonary Resuscitation status. PEPS will coordinate the patients care in the community dependent upon need and choice of the patient who may want or clinically need to be taken to hospital. A minimum of 2 admissions a week are being avoided through the link with the ambulance service computer aided dispatch system.