

Cross-Party Group in the Scottish Parliament on End of Life Choices

Convener
George Adam MSP

Vice-Conveners
Jackson Carlaw MSP

Secretary
Amanda Ward

Minute of the meeting of the Cross-Party Group in the Scottish Parliament on End of Life Choices

**Tuesday 4th September 2018 at 6 pm
Committee Room 3, Scottish Parliament**

Attendance

George Adam MSP (Chair) (GA)
Jackson Carlaw MSP (JC)
Patrick Harvie MSP (PH)
Michelle Ballantyne MSP (MB)
Rachel Hamilton MSP (RH)
Liam McArthur MSP (LM)

And an additional 31 members of the group.

1. Welcome, introductions and apologies

George Adam (GA) welcomed everyone to the meeting and apologies were noted.

2. Minutes of previous meeting

The minutes of the previous meeting held on 18th April 18 were approved with an amendment under item 4 bullet point 1 quotation marks added around 'the law in the UK Is broken'.

3. Mark Hazelwood Presentation

Mark Hazelwood from the Scottish Partnership for Palliative Care provided the group an input around Palliative Care in Scotland

- Mark provided a definition of what Palliative Care is 'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' And explored what it is in terms of when it starts, whether it is just terminal care.
- SPPC definition from Grasping the Nettle "one way of thinking about 'palliative care' is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making. However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances."
- Mark spoke about the difficulty of defining End of Life Care as this is seen as something which happens during the last year of life but because this is only known in retrospect can't always define when someone is receiving this. He gave the following definition "End of life care is that part of palliative care which should follow from the diagnosis of a patient entering the process of dying, whether or not he or she is already in receipt of

palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.”

- Mark gave a short history of Palliative Care and how Scots have been important in its development citing Hugh Noble, Frances Davidson, Hill of Tarvitt, Controlled release morphine and Derek Doyle
- Mark then gave an overview of the challenges Scotland faces in providing Palliative Care these are Scale and Complexity, Measuring Quality of Care and Experience, Reticence about talking about death and dying, Lack of staffing
- Mark spoke about a number of pieces of work taking place in Scotland to help deal with these challenges this included:

SPICT - the Supportive and Palliative Care Indicators Tool which helps the identification of people in any setting with palliative care needs

EC4H – Effective Communication for Healthcare is an evidence-based approach to equipping health care professionals with the communication skills required for sensitive conversations

KIS – the Key Information Summary is providing a basic infrastructure to share essential information about a patient’s healthcare and individual preferences across settings.

SPSP – Scotland’s national patient safety programme includes a structured approach to prompting important conversations with patients (and family) where their condition is deteriorating, and the outcome is uncertain

The Scottish Palliative Care Guidelines – provide evidence-based practical guidance (via web and app) to on-specialist practitioners in all settings

- Mark then looked at how Good Palliative Care was in Scotland and said it was difficult to provide an overall picture as there was no national data but that at times they got it right and at other times it could be better

Group discussion followed and included the following points:

- Families role as care team and the need to look at how we empower families, need for education about the dying process and what is normal to prevent over medicalisation
- Death has become institutionalised since the end of the 2nd world war, language used by professionals and lack of honest communication about what is happening to individuals doesn’t help
- As an adult social carer, it was difficult being unable to talk to people about the end of their lives (I would have wanted palliative care but also want to be able to say enough is enough)
- GA asked is not having a position on Assisted Dying is not part of the problem in terms of people not talking about death, Mark recognised that the debate on Assisted Dying is an important part of the civic discourse important that Palliative Care providers don’t sit off to one side of the debate
- People no longer talk about death, we don’t know what the normal dying process is need to counter fear of the unknown
- Need to teach health professionals how to initiate conversations on death and dying
- There was a query re the definition used by Mark, as they are very wide, they were trying to recognise something distinctive from last days of life as many people are recognised as dying too late

- Question was asked about how consistent Palliative Care is as well as how good, need to help family to be able to speak about 'treatment not working' when they see a deterioration

4. Dr Lonny Shavelson Presentation

Dr Shavelson from Bay Area of End of Life options spoke about his experience of providing medical aid in dying (MAID)

- California passed Legislation in 2016 since this time Lonny has had 700 enquiries about MAID and has carried out evaluations on 300 people and has been at the bedside of 102 people as they have used MAID
- Lonny started considering MAID in 1996 needed to know how it was happening without law (family and friends hoarding medication and medical professionals giving doses of morphine), this resulted in people being given the wrong medications at the wrong time which didn't work and left people worse off, he concluded that it needed to be brought out of the darkness
- In America the decision on MAID was passed to states as there is no constitutional right to aid in dying but also no constitutional basis that doesn't allow it
- In California they are not allowed to use the term suicide for MAID, this is not a term used anywhere in America
- Lonny believes replicating the Oregon law was a smart political decision but a bad medical decision
- California had 5 attempts to change the law with 4 turned down but each one moved the case forward
- Lonny spoke about how the Brittney Maynard case had been a turning point in California wither moving to Oregon to access MAID, the California Medical Association moved from negative to neutral which influenced legislators
- Lonny spoke about how the AMA committee are considering their negative opinion on MAID, 20% of the US population currently have access to MAID
- Lonny spoke about the need to swallow the medication used in MAID being a political rather than a medical decision and that this had implications for those who could access MAID (the sicker the person is the harder it is to use oral medications, those with gastro intestinal issues found it hard to use oral medication, these with neurological disorders can have difficulty swallowing.
- In California there is a 15-day waiting period to access MAID medication this results in 30% dying during the waiting period as most who are considering this option will have spent time contemplating it), Lonny believes this waiting period is too long that the maximum needed is 48 hours
- 2 independent doctors having to collaborate and agree to request is good thing, he does however feel that psychiatric evaluation is another hoop that is not needed and is one which is burdensome to the patient – Drs do capacity checks all the time formally and informally)
- Lonny spoke about hospices being traditionally against MAID – their ethos is not to hasten death and they believed good palliative care meant there was no need for MAID, Palliative Care even when it works isn't what everyone wants, you can do palliative care well, but someone will still say enough (usually because they are tired you can try to palliate this but it's difficult to do)
- Hospices will not abandon their patients which is why they are now supportive where MAID is legal, hospice care can't exit without MAID as patients want this & MAID can't exist without palliative care/Hospices
- Lonny says that an area of difficulty since MAID became legal in California is that Drs didn't know what to do as this had never been part of their training as such there are access problems, Drs only do things they have been trained for. Lonny suggests when it becomes legal in Scotland there should be a delay in it becoming law to allow the

Medical Profession to be trained

- Lonny believes the law needs to work medically as well as politically and as such should look at the need for patients to take medication orally, not have anything more than a 48-hour period (and in certain circumstances Drs should be allowed to overrule this), he also believes the physician should follow the patient and not just prescribe medication.
- Lonny believes hospices being against this is fine but that when it is legal they will come on board as they are good clinicians and they care
- Lonny believes there should be a medical professional at the persons bedside not ok to ask family/friends
- Lonny stated that as patient autonomy increases and there is a decrease in paternalistic medical care MAID becomes inevitable as it is just another example of shared decision making (just like in any other part of medicine)
- Lonny stated you don't need a large number of Drs willing to take part as only 1-3 deaths out of every 10,000 use MAID and you are better having a small number of doctors who do this frequently.
- As well as Drs input also required from pharmacists

5. Any other competent business

6 Date of next meeting 27th November 2018, 6-8 pm in CR3.