

**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 28th March 2017 at 6 pm  
Committee Room 1, Scottish Parliament**

**Attendance**

George Adam MSP (Chair) (GA)  
Patrick Harvie MSP (PH)  
Gordon MacDonald MSP (GM)  
Liam McArthur MSP (LM)

**Apologies:**

**1. Welcome, introductions and apologies**

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

**2. Note of formal establishment**

George Adam MSP met with the Standards Committee on 9<sup>th</sup> Feb 2017 and the group was formally approved.

**3. Minutes of previous meeting**

The minutes of the previous meeting held on 6<sup>th</sup> December 2016 were approved with no amendments.

**4.**

**Presentation and Discussion:**

Tracey Taylor, spoke about the death of her mother Flora:

- Flora contracted pneumonia in December 2016 after battling MS for 40 years, bed bound she suffered pain from ulcers and eventually could neither speak nor swallow.
- In the last two years of her life she expressed her wish to die and asked her family to help. Flora's family feel that death came too late, instead they live with the horror of her death and the feeling that she was denied a basic human right to die at a time and place of her choosing.
- In questions and discussion, the absence of appropriate palliative care (PC) was noted, that palliative care should be available to everyone with chronic and life limiting conditions and not just at the end of life. Others argued that access to PC was not the issue, rather the obligation on health professionals to prolong life. There should be better education: that the debate is not a choice between PC and assisted dying (AD) but about proper access to both, and about the importance of living wills. In summing up the Convener noted the group's wish to work closely with the CPG on Palliative Care.

## **Professor Celia Kitzinger**

Professor Kitzinger spoke about Advance Directives;

- Terminology varies but an Advance Directive (AD) is defined as “A record of your decision to refuse particular treatments – made at a time when you have the mental capacity to make this decision for when you can no longer make or communicate such decisions.”
- AD’s are massively under utilised (2% take up in Wales, 4% in England and unknown in Scotland). Professor Kitzinger was commissioned by the Welsh Assembly Government to research the low take up there and propose options to promote their wider use. She also highlighted the legally ambiguous nature of AD’s in Scotland where they are described in the Adults with Incapacity (Scotland) Act 2000 Code of Practice as “potentially binding” (para. 2.30)
- Professor Kitzinger proposed a form of words that is binding in England and Wales if signed and witnessed. The existence of an AD is not sufficient legally however, if medics and paramedics are unaware of it or its contents. Further, AD’s can only cover treatment that has been refused, not for example treatment that was not available at the time of their making. Doctors must have regard to the expressed wishes and feelings, past and present of the patient. AD’s cannot require doctors to act illegally.
- Professor Kitzinger noted recent medical concern with the issue of non-beneficial treatment and increasing interest in understanding the level of interventions that do not and cannot improve quality of life. Philosophically, the discussion on ADs must recognise different values but also the individual’s autonomy as well as the practical difficulty of deciding for a future self in uncertain circumstances. People change their minds and the reality of end of life might not match the circumstances envisioned at the time of making an AD.

### **Group discussion followed and included the following issues:**

- Clarification of the law – CK noted that there was pressure to amend the Adults with Incapacity Act which is currently seen as incompatible with the UN Convention on the Rights of People with Disabilities and any such revision would provide an opportunity to clarify legislation in Scotland since people who don’t have mental capacity are considered disabled people.
- Research and Capacity – The meeting noted the need for further research on uptake and awareness of AD’s and queried whether such research should be undertaken by the Scottish Government, whether information was already available to independent academic researchers, and what capacity existed to promote their uptake. Professor Kitzinger’s view was that information was unlikely to be available in any organised form and a process of outreach to numerous stakeholders would be necessary to begin to collate relevant data. It was suggested that if the Health and Sport Committee is to review the Adults with Incapacity legislation then an approach to SPICE might establish what information is currently available.
- Training of medical students was discussed, as well as the need to involve pharmacists in the debate about possible end of life interventions.

## **5. Any other competent business**

George Adam asked the group if they would agree for the CPG to take forward the issues spoken about tonight as a working project for the group. The first task is for the group secretary to contact the Health and Sport Committee to see if they have this on their agenda.

George Adam thanked the attendees.

- 6 Date of next meeting:** 6<sup>th</sup> June 2017, 6-8 pm. This date was subsequently been rescheduled for Wednesday 13<sup>th</sup> September 2017 and then 28<sup>th</sup> November 2017.