

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

Convener
George Adam MSP

Vice-Convener
Jackson Carlaw MSP

Secretary
Amanda Ward
(Friends at the End)

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

**Tuesday 28th November 2017 at 6 pm
Committee Room 4, Scottish Parliament**

Present:

George Adam MSP (Chair)
Ivan McKee MSP
Patrick Harvie MSP
Michelle Ballantyne MSP

In Attendance:

Mary Blackford, Ben Colburn, Karin Currie, Gordon Drummond, Sheila Duffy, Jim Dyer, Douglas Hall, David Harper, Mark Hazelwood, Geoffrey Hillyard, Scott Kennedy, Julie Lang, Tom Lorimer, Lars Matersvedt, Gillian McDougall, Tom McKay, Harry McQuillan, Alastair Moodie, Gareth Morgan, Catherine Owen, John Raven, Jessie Reid, Tracey Taylor, Adrian Ward, Amanda Ward, Grahame Wear, Guineer Williams, Heather Williams, Hugh Wynne (29)

1. Welcome, introductions and apologies

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

2. AGM and Summary of work

GA gave a summary of the groups work since its first meeting in December 2016 and formal establishment in February 2017. In December 2016, the group heard from Professor Alison Britton about Commonalities in the Assisted Dying Debate. In March 2017, Professor Celia Kitzinger spoke about Advance Directives and gave advice on how the group can influence policy in this area. Tracey Lorimer also spoke to the group about her mother Flora's death and gave a very moving account of how they as a family coped with this. Tracey and her family continue their campaign 'Floras Voice' in Floras memory.

It was agreed to take Advance Directives forward as the group's first major project and Amanda has had meeting with various people including the Scottish Government and OPG. The Scottish Government is due to go to consultation on revisions to the Adults with Incapacity Act in January 2018. Amanda will put in a response from the CPG when this is released and those present were encouraged to respond.

As a new group, Amanda has had various meetings with MSP's to try and encourage support. GA expressed that it has been a good first year, getting the group off the ground and we look forward to moving our work programme forward and engaging with people out with the group.

3. Election of Office Bearers

Convenor George Adam MSP nominated by Patrick Harvie MSP and seconded by Ivan McKee MSP

Vice-Convenor Jackson Carlaw MSP nominated by Patrick Harvie MSP and seconded by Ivan McKee MSP

Secretary Amanda Ward nominated by Patrick Harvie MSP and seconded by Ivan McKee MSP

4. Minutes of previous meeting, 27th March 2017

The minutes of the previous meeting held on 27th March 2017 were approved with no amendments. Hugh Wynne asked that number of people in attendance be minuted from now on and this was agreed.

5. Matters Arising

There were no matters arising

6. Presentation and Discussion:

Adrian Ward, TC Young Solicitors and renowned Scottish Incapacity expert

- Adults with Incapacity Act (Scotland) Act 2000 (AWIA) was the first major piece of legislation for the re-formed Scottish Parliament
- Scotland are viewed as world leaders in this area, which is not always recognised
- Adrian Ward (AW) is a consultant to the Council of Europe and submitted his report on Advance Directives (AD's) last week
- Adults with Incapacity Act (AWIA) was basically the Scottish Law Commission 1995 report with the omission of Clause 40 proposed statutory regime for advance statement and Clause 41 statutory regime for withholding or withdrawing life-saving treatment
- Believes the law in Scotland is similar to England and Wales. If a person was competent at one point and there hasn't been a change in circumstances, then this should be accepted
- Review of AWIA is needed given the need to comply with article 5 of ECHR, review needs to cover mental health and adult support and protection legislation
- Need to ensure that the review looks to ensure any legislation complies with Disability Convention
- Consultation promised in January 2018, hopefully the two clauses (40 & 41) will be included
- Advance Directives can state not to do things (refusal) but also state that they want certain things to happen (positive treatment), they can be much wider than first thought
- AW sent questionnaires to all 47 member states of the Council of Europe as part of his COE research
- Report on voluntary measures in Europe – presented last week

- Voluntary measure is something I do for me, I enter in to something, involuntary is where someone else makes decision about me – concept of terminology has found favour and the Bioethics Committee of Council of Europe acknowledges the need to push towards the voluntary as opposed to the involuntarily (Convention of Human Rights and Biomedicine)
- Advance Statements in Europe are relatively underutilised. In Scotland, Power of Attorney is well used and accepted but there is a need to get more recognition for Advance Directives
- Are opinions from other European Countries totally in favour or are there any objections
- States should consider whether an AD should be recorded - what other mechanisms are needed to ensure these are considered
- Undue influence. AW was invited to speak to parliament re Margo's Bill. How do we know undue influence is present? Huge amount of experience in dealing with this re power of attorney – in Scotland there is a certification process and one must certify that there is capacity and it is without undue influence
- Any recommendations on AD's needs to include process of registration and a public register depository - experience from EU states shows there is no point having if this is not followed through with
- Is it a fair assumption that an AD is only needed where the person isn't in a position to consent? UN Disability Convention requires everyone is given the support they need to exercise their legal capacity. There are issues when someone no longer has capacity and changes their view on what they had said when they had capacity
- Does the need for involuntary measures conflict with the UN disability Convention? Need to have clear distinction re what convention and committee say (3 jurisdiction's report) drafting committee would neither stop nor support substitute decision making, committee not keen on involuntarily measures. German court overrode woman's decision not to undertake treatment for breast cancer, Finnish court upheld decision of guardian to go against persons wishes. Make maximum use of voluntary measures.

Amanda Ward, CPG secretary, PhD researcher on Scots Law on Assisted Dying and CEO Friends at the End (CPG sponsor)

- Amanda Ward spoke about her recent research trip (March 2017) to the USA where she visited various States interviewing stakeholders on Assisted Dying
- 10 in depth qualitative interviews over 12 days with 6 stakeholder groups. These included Medical Practitioners (Dr Ira Byock, Dr Lonny Shavelson, Dr Nick Gideonse), Universities (UCLA Health Policy Dept, Cleveland Marshall Law school), Legislators (Senator Bill Monning who passed the Californian Aid in Dying Bill), Governing Bodies (Oregon Health Authority, Oregon Medical Association) as well as lawyers acting for the government and campaign groups
- AW gave an overview of where Assisted Dying is legal in the US (now 8 jurisdictions) and that over 60 million Americans have access to it
- AW compared legislation in Oregon (where AD has been legal for 20 years) and California (the most recent state to legislate for it). Differ very slightly based on jurisdictional context i.e. California has a diverse population with many mixed nationalities, so interpreter provision necessary in Bill. Stressed importance of legislating for specific landscape and not parachuting in what other countries/states have.

- Interesting finding from medical practitioners was an alliance with hospice once the legislation has passed. Religious healthcare organisations remain officially opposed but at grass roots level, patients are requesting AD and institutions are allowing willing doctors (those with no Conscientious Objection and not employed by the religious hospices) to carry out AD for their patients
- Doctors felt that prior to AD laws being passed, EOL practices such as terminal sedation were more common and likely to be taken without the patient's pure consent. Medical practitioners interviewed believed that AD was happening in countries who did not have AD laws, such as Scotland, and were 'positive that some doctors facilitate it for certain privileged patients, with it happening in an uncounted amount, with questionable ethics and potential legal fear on the part of the families, patients and physicians'
- AW spoke about competency in detail and one doctor provided a framework for people with dementia. Medical Practitioners interviewed did not see competency as a difficult assessment, as they are trained in the elements of this and use it on a daily basis. The legislators in Oregon evaluated a mandatory psychiatric assessment as placing an undue burden on sick people.
- AW spoke about how AD works with palliative care and is seen as another choice at the end of life, not separate from the other options
- Access Issues: During Margo's Bill there were concerns that remote parts of Scotland would not be able to access AD if it became legal. California is a far vaster place than Scotland and has addressed this via willing doctors travelling and campaign groups helping with foreplanning
- Implementation – reason many doctors in California not doing it is that it is a new law and they do not know how to navigate the red tape. Lonny and other doctors are running courses to train physicians on how to carry out AD in accordance with the law. Training programme's following legalisation are essential.
- All medical practitioners interviewed who carried out AD, insisted that the patient had to be in hospice or receiving palliative care and that all other options had been explored, so that AD was not an alternative to poor health/social care
- Waiting period: 15 days – 48hrs is considered an 'undue burden' with abortion so why this long with AD? No other medical procedure asks a patient to wait this long. Patients consider AD when they realise they are very near death and things are becoming unbearable, often after 15 days the patient has become so weak/confused that they can no longer access AD due to self-ingestion and competency requirements
- Dr Ira Byock felt that AD was 'bad social policy' as the health/social care system in the US is very poor. He said, 'people are angry, fed up with the authorities saying they are going to make things better and they don't. Assisted Dying seems like freedom in a failing health and social care system'. He was aware that Scotland and the UK had the best palliative care in the world.
- Campaigners for the law in California felt the 'breakthrough' came when the Californian Medical Association (CMA) moved to a neutral stance. This was a result of the politicians meeting with the CMA to discuss working together given the public's support for it. The large campaign group Compassion in Choices funded a lot of the process whilst the Death with Dignity Centre, a smaller more specialist group, helped legislatures draft the laws.

- Death Certificate – AD does not appear on the death certificate as this is a public document. Like patients who refuse food and fluid or are palliatively sedated at the end of life, the underlying condition is noted instead. Doctors filing the AD paperwork is how AD is monitored for public health records
- Loss to follow up – suggestion that instead of having to return medication that has not been used within a certain time frame (such as Margo’s Bill proposed) the prescription is kept at the pharmacy and not filled until the day before person is ready to take it
- All participants interviewed agreed that AD being considered had opened up conversations around death and dying in society generally and had a diffusion effect for those who used it i.e. the families, health care practitioners etc. involved also felt the benefits of the person having a ‘good death’

Group discussion followed and included the following issues:

- Former psychiatrist: does not accept that all suicide attempts are irrational. Patients find the use of word suicide offensive to themselves and their family due to stigma that surrounds this. Amanda advised that in the US, legally Assisted Dying it is not suicide as the US definition of suicide involves ‘an irrational act’ which by following the steps in the law it is not as competency is assessed and present. Kinder language to call it assisted dying as opposed to suicide as majority of people using such laws are already dying so not a choice between life and death
- Solicitor: Medical ethics on withdrawing from caring for a patient who wants to have an AD? As a solicitor we can’t abandon clients, is there an equivalent for Drs? Amanda advised on principles of conscientious objection, referrals to willing doctors and ‘opt out’ clauses in Bills. This could not be included on the face of Margo’s Bills as it is a matter reserved to Westminster. Had the Bills got to stage 2, this would have been included by a Westminster minister and the group stressed how they fully support opt out clauses for doctors, such as that seen with abortion
- Ingestion of medicine was discussed. In US must be voluntary act by individual (swallowing/IV release). Euthanasia, where a third party, usually a medical practitioner administers the life ending medication is not permitted
- Adrian Ward: Single best thing done in the AWIA was the implementation of a steering group which had an overview of how it was implemented. If there is new legislation then there needs to be a multi-disciplinary implementation group
- Adrian drew on Council of Europe work, best regime in France, multi-disciplinary working co-ordinating the whole issue and drew whole lot together in a provision
- Hugh Wynne: Suicide not right word Dignicide is a better word, final act by the individual important part of regulations
- Douglas Hall: Estimate of 130 people who would die by Assisted Dying in Scotland if it became legal, tobacco deaths over 10,000 per year is ironic
- No fixed limit on human lifespan scientists suggest, if its legal for scientist to increase lives by decades then it should be legal for people to say ‘I have had enough’
- GA: Important that we are careful of the language we use as we may be accused of

hiding behind language. Stressed that preference in Scotland is to call it assisted suicide

- How did Dr Lonny build up relationship with hospices? Amanda: Patients began requesting it once the law passed. Doctors and hospice administrators said 'No, we don't do this', so as patients with private health care, they began requesting to be moved elsewhere to another facility that would grant them their right. There was also a push from nurses who were caring for patients and wanted to be present with them when they died.
- In Oregon became accepted and such a small amount of people having an assisted death (just over 1000 in 20 years) that is it tolerated and therefore facilitated
- Lars Matersvedt: comparing Oregon model with the Flanders model – area loaded with language which can turn things both way. Amazed doctors discussing issue re patients swallowing or not, would have thought that suicide machine used in Germany and Australia would have been legal in US. Legislation is self-administration. Language strange in talking about it as medical treatment. The Dutch Medical Act not medical treatment – 'when he performs euthanasia he stops being a doctor he is doing a medical act but not treatment'. Amanda responded that in the States it is seen as medical treatment because in the same way that palliative care is not itself *curative*, it is still treatment. The patient knowing they have the choice of an AD is in itself palliative to patients and many do not go on to use it
- Drugs: Opiates not proven to end life, they can prolong. Amanda advised that it is not just opiates that are used but a mixture of medication, all of which are readily used and available in society – it is the quantity that ends the persons life
- Gordon Wyllie: Current Pope has expressed himself on these issues in a book he wrote. He makes it clear that it is not part of catholic doctrine to struggle to keep someone alive once it is clear what the outcome is going to be, that you should keep that person comfortable but not prolong. Catholic church may see a way to reconsider its position on these issues
- GA: Interesting when we convened this group that the local catholic observer published a story on it which was fair.

7. Any other competent business

George Adam thanked the attendees.

8. Date of next meeting:

Wednesday 18th April 2018, 6 pm.