

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

Convener	Vice-Conveners	Secretary
Michelle Ballantyne MSP	Liam McArthur MSP/Jackson Carlaw MSP	Amanda Ward

### **Minute of the meeting and AGM of the Cross-Party Group on End of Life Choices**

Tuesday 13<sup>th</sup> November 2019 at 6 pm  
Committee Room 4, Scottish Parliament

#### **1. Welcome, attending and apologies.**

Michelle Ballantyne (MB) welcomed everybody in attendance. MB introduced herself and those around the table did so too.

Those in attendance were:

Michelle Ballantyne MSP, Amanda Ward CEO Friends at the End (FATE), Sophie Sellers, Office Manager at FATE, Lila Shellstrom – Member of a Death and Dying group in Glasgow, Heather Williams- FATE, Elin Lee, Gordon- retired Doctor and member of FATE, Julie Lang - Trustee of FATE and currently completing a PHD on how contemporary writers address death and assisted dying, Alistair Moodie – representing the Scottish Unitarians, Aileen Weiss – Pharmacist, Ally Thomson – Director of Dignity in Dying Scotland (DiD), Chris Doy –DiD group member, Rudi Vogels – Disability activist and member of FATE, John Raven – DiD Member, Stacey Adam, Gordon MacDonald, Harry McQuillan - Chief Executive of Community Pharmacy Scotland, Mark MacDonald MSP, Sorcha Hume- Researcher for Mark Macdonald MSP, Allan Rose, husband of guest speaker Dr Ellen Wiebe, Ben Colburn – Political Philosopher from the University of Glasgow, Dr Ellen Wiebe – Physician from Canada, Patrick Harvie MSP, Lynn Pratt –DiD Member, Heather McQueen - DiD Member, Mel McLeod –DiD member, Hannah Wilson - DiD Member, Norman Craig –DiD member, Simon Shearer –DiD member, James McCarthy –DiD member, Rev Lindy – Did Member, Rev C Dell – DiD member, Joyce Cowie – DiD member, Jessie Reid – member of FATE, Louis Farnley - DiD member, Linda Armstrong- DiD member, Bill Heim – DiD member, Anne Glase – DiD member, Bob Gleister – DiD member, Louis Waugh.

#### **MSPs in attendance:**

Michelle Ballantyne (Conservative)  
Patrick Harvie (Greens)  
Mark McDonald (SNP)

#### **Apologies:**

Jenny Gilruth  
Jackson Carlaw

#### **2. Minute of the CPG AGM meeting 27<sup>th</sup> November 2018**

The minute of the CPG AGM on 27<sup>th</sup> Nov 2018 was approved with no objections or amendments.

### **3. Matters Arising.**

MB provided a summary to attendees of events since the last CPG AGM.

Following the AGM on 27<sup>th</sup> November, Rev Scott McKenna spoke to the CPG about religion and assisted dying, he gave his insights into the lack of conflict between religion and assisted dying. He spoke about understanding this concept and understanding where belief comes from. MB reported this talk was a fascinating insight and was very much enjoyed by those in attendance.

On the 12<sup>th</sup> March 2019 Professor Harry McQuillan spoke to the CPG from Community Pharmacy Scotland, he spoke about how assisted dying can be supported through pharmaceutical solutions.

On the 10<sup>th</sup> of September 2019 Dr Mehrunisha Suleman, from the University of Cambridge, spoke to us. She illuminated the Islamic perspectives on death and dying. This was another fascinating and insightful talk. MB reported that Dr Suleman has been in touch since and is keen to stay in contact, she plans on returning to speak at another CPG in the future.

The timetable for a Bill was discussed and it was noted that the Bill will not be put forward in the 5<sup>th</sup> session. The aim is to put the consultation forward in the latter part of 2020. This will frame it to be in place for session number 6, starting after the May 2021 elections. The Bill will then be brought in Session 6.

Amanda Ward (AW), Ally Thomson (AT), Fraser Sutherland (HSS) and MB have been in talks and attending meetings with a steering group of MSPs, as well as working with other professionals. These discussions have covered assurances over safeguards for those seeking assisted death as a priority. There have also been various discussions with partners overseas regarding progress they have experienced since Assisted Dying was legalised in their respective countries.

MB added that on Wednesday 20<sup>th</sup> November 2019 at 1:30pm there will be an open meeting held in the Parliament where Prof Jocelyn Downie will speak about her experiences in Canada since assisted dying was legalised. This meeting is open and all are welcome. Anybody who would like to attend is to email Amanda Ward at FATE for further information.

### **4. Office Bearers AGM re-election**

Current positions are as follows:

**Convenorship** - Michelle Ballantyne

**Vice Convenor** – Jackson Carlow and Liam McArthur

**Secretary** – Amanda Ward, Friends at the End

MB proposes that this continue.

MSPs are happy with the proposed candidates; no nominations were given.

This concludes the 2019 End of Life Choices CPG AGM.

## **End of Life Choices Cross-Party Group Meeting**

### **1. Approval of the minute from the CPG meeting 10<sup>th</sup> Sept 2019**

Minute was approved with no corrections and complimented by MB for their accuracy.

### **2. Dr Ellen Wiebe – MAiD Canada**

MB welcomed our first guest speakers for the evening, Dr Ellen Wiebe who is a practitioner at Medical Aid in Dying (MAiD) Canada.

Dr Wiebe is a Clinical Professor in the Department of Family Practice at the University of British Columbia.

After 30 years of full-service family practice, she now restricts her practice to womens' health and assisted dying. She is the Medical Director of Willow Women's Clinic in Vancouver and provides medical and surgical abortions and contraception. She developed [Hemlock Aid](#) to provide consultations for doctors and patients about aid in dying, and to provide assisted death.

Assisted Dying was legalised in Canada in 2016, and Dr Wiebe spoke about her experiences and the challenges that she has faced since the law changed.

Dr Wiebe spoke about the case of Kay Carter, which then became known as the Carter decision which is the basis for Canada's Assisted Dying legislation. These terms for eligibility for MAiD are:

- Competent, of sound mind and 18+
- Ability to give consent
- Suffering with a grievous and irremediable condition
- Death is expected in the foreseeable future (without a time limit)
- Patient is in an advanced state of decline
- Two doctors/nurse practitioners must be in attendance.

*MSP George Adam arrived 18:18*

Dr Wiebe's talk included some comparative data which showed that Canada's assisted deaths make up 1% of all deaths after 18 months. Comparatively after 22 years, Oregon is approximately 0.5%

Dr Wiebe talked about the main reasons people choose an assisted death, which she cited as pain, loss of control and independence, loss of a meaningful life and loss of enjoyment, along with fears around future suffering associated with diagnosed conditions.

Dr Wiebe emphasized that a key benefit in this new law is the shift in people's ability to face the future. They feel that they can cope with what might be ahead, knowing that they have the safety of the assisted death if the development of their disease or condition becomes too much for them to bear. For this reason, although people often complete the paperwork for the assisted death at the time of their diagnosis, many do not go ahead with it; knowing that they now have a choice gives them the strength keeping living.

In Canada, not only GPs, nurses and MAiD specialists are trained to carry out the assisted death. This contrasts with the Netherlands, where it is usually carried out by a patient's own GP. At present, Canada is the only country which allows nurses to carry out the procedure. In Canada, any medical practitioner can decline a patient's request for an assisted death (at any stage), but law requires them to provide an effective transfer of care to another practitioner who can assist them with their request. Obstructing patients' requests is against the rules and unfortunately does happen.

Dr Wiebe reported that malignant tumours are the most common reason for the request for an assisted death, followed by organ failure. The most common reason for a rejected request is that the natural end of life is not foreseeably soon.

The assessment criteria state that the individual's suffering must be grievous and irremediable. If there is any evidence of a relief option that has not been taken, or if the person appear to have been coerced, then their request will be declined. This is especially difficult in the case of elderly couples choosing to die together. The criterion of death being reasonably foreseeable has recently been debated and changed. . Initially the period was set at 6 months, but due to an appeal citing the Carter case, this has since been voted as unconstitutional and the 6-month law must be changed within the next 6 months. It is not the responsibility of the individual to prove his or her capacity, rather the assessor must prove that they do not. The criteria for this are the same as other pre-existing medical criteria, such as turning off life support.

Dr Wiebe talked about some difficulties, using case studies of patients that she has helped. In the beginning, she described difficulties with the very basic practical arrangements - there was no place to carry out the assisted death, as nursing/care homes would not let it happen on the premises. Pharmacies would not assist in dispensing the drugs as they had concerns about the law and what they were permitted to do, and nurses would not assist for these reasons.

Dr Wiebe reported that in Canada, there is the option to ingest a fluid, or have IV administration. (Unlike Switzerland at Dignitas, where only the enteral (by way of the digestive tract) method is used). To date thousands of Canadians have had an assisted death, of which only 16 were oral. IV is by far the most popular method as the drink is unpleasant, death can take up to 24 hours and patients experience the unpleasant 'death rattle'. IV in contrast is much faster, without these side effects. Dr Wiebe explained that while the oral method offers more autonomy, it comes with many more complications. Dr Wiebe believes that the personal autonomy comes for many with having the choice, rather than the method.

Dr Wiebe discussed the safeguarding and paperwork which is required in Canada. This involved 18 pages of documentation. Failure to comply with these strict requirements is punishable with 2 years in jail. Safeguards include;

- 2 witnesses
- 2 independent clinicians
- 10 day wait period
- Day of death consent
- Death must be foreseeable or patient in an advanced state.

The required 10 day wait period can only be overruled if a patient is expected to lose capacity or die within the 10 days.

Dr Wiebe added that in Canada, co-ordinating centres were not set up quickly enough for vulnerable people needing help with these steps, or to provide assistance and information for those who wanted an assisted death. Setting up appropriate infrastructure in Canada took 2.5 years. This was detrimental to patients, as many people who need help are often isolated, not on the internet and unable to travel.

Dr Wiebe finished by adding that she firmly believes in assisted dying, and feels it is her best work in 4 decades of being a GP.

MB thanked Dr Wiebe for her informative talk and insights, and added that as a country looking to legalise assisted dying it is good for professionals here to learn from and understand the challenges and pitfalls that Canada faced, so that Scotland and the UK can learn from them before our legislation changes.

Dr Wiebe opened up the room to questions.

“How do medical professionals respond to this?”

Dr Wiebe explained that most providers of assisted dying are GPs. The regulating body (The Canadian Medical Association) were at the time very reluctant and working with them at the time of changing the law was difficult, in part as their head is a Catholic who held opposing views. GPs from within pushed for this legislation in the beginning, and Dr Wiebe reported that there has been change in the past years. In the 3 years since the legislation changed, Dr Wiebe now reports that assisted dying in Canada has majority support from GPs.

“Did Pharma have some catching up to do, and were the public ready?”

Dr Wiebe explained that the public were communicated with about this via the media. One of Dr Wiebe’s case studies, Hanna (the first person) went public with her story before her death. Stories such as these touched hearts and minds, which lead to the public and media being supportive. The media was the main source of information, rather than a public information service.

“In Switzerland the patient is able to press a button which self-administers the IV optionally, is this the same in Canada?”

Dr Wiebe reported that in Canada, there is the choice for this option, but nobody has chosen it. The drugs which are used in Switzerland are different from those used in Canada. The specific drug is not available (due to extremely prohibitive costs) in all of North America.

The price of the drug has risen from a matter of pounds, to thousands per dose, so it is only used in veterinary medicine in Canada now (which is licenced differently). In Canada an overdose of general anaesthetic is used.

“Is there is a time limit to using the medication once it has been approved?”

Dr Wiebe confirmed that there is not a time limit in which it must be used at present, however this may change in light of the recent unconstitutional ruling. Prime Minister Trudeau has confirmed that the legislation will be re-written to remove the ‘reasonably foreseeable’ clause and add in other safeguards instead. There is not expected to be a time limit within the law, but Dr Wiebe hopes these new safeguards to be along the Belgian model which states that if the condition is not terminal, safeguards will include a longer wait period and more assessments.

“What is the availability of emotional and bereavement support for practitioners and volunteers?”

Dr Wiebe explained that 3 comprehensive studies have been conducted with providers and the effects of working with assisted dying; the response has been incredibly positive. Medical providers are used to death, and find dealing with this aspect of death to be rewarding. Colleague support made the biggest difference to practitioners’ emotional wellbeing. There are also supportive groups available to those who are involved. Volunteers reported that they did not need support personally, due to the fact that that most people who are involved with assisted dying have already worked in end of life care, hospices etc. it is not a big change for them in terms of emotional impact. For those who need it, there is support with MAiD available.

“I’m a pharmacist. It is compelling to hear how many people choose IV, I wonder how effectively the transfer of care works. Legally, who must be present at the death?”.

Dr Wiebe confirmed that the provider of the drug must be present for the assisted death, this would be a doctor, nurse or MAiD practitioner.

“How does the assessment of patients work in practice?”

Dr Wiebe explained that she would ask patients about how they came to their decision, what suffering means to them both physically and mentally, adding that having chronic pain is not acceptable under the law so patients are refused on this basis. Dr Wiebe added that in querying the concept of ‘life changing’ in the context of not wanting to live, this is difficult with (often) men who are quadriplegic. They could live with good care for decades, but they consider such a life not worth living They frequently suffer from depression. Becoming quadriplegic is in effect, a fatal condition as patients would need medical care to survive, which they have the right to refuse. Dr Wiebe added that these cases are difficult, and a change in the law with the 6 months limit will really impact cases like these.

In the Netherlands, doctors must be personally satisfied that the criteria have been fulfilled in cases like these. Dr Wiebe agrees that personally you must believe it is the right thing on a person by person basis. Even when taking difficult cases like these into consideration, on balance for society, having the option and a right to an assisted death with MAiD is still better. Patients are able to die at a time of their choosing, with their family around them; they often throw a party and make an event of it. All of this is impossible if people are forced to

take matters into their own hands and die by suicide, or travel overseas, with any family involved possibly facing prosecution.

### **3. Dr Ben Colburn – Professor of Political Philosophy at Glasgow University**

Ben Colburn is Head of Philosophy at Glasgow University. He has worked at Glasgow since 2010. Before that, he studied and worked in Cambridge University, receiving his PhD in 2008, and holding a research fellowship at Corpus Christi College from 2008 to 2010.

His main research interests are in political philosophy and ethics, with a particular interest in the nature and value of autonomy and its importance in liberal political philosophy. He is currently writing on various topics in this area, including the nature of responsibility and its role in distributive justice; the moral foundations of the free market; and the conditions of independence and authenticity.

Dr Colburn has a further interest in exploring how foundational philosophical ideas (like autonomy and responsibility) can be put to use in policy and practice. He has a number of ongoing collaborative research projects along these lines, including work on refugee education, on palliative and geriatric care, and on architecture and urban design.

Dr Colburn spoke about autonomy and choice, breaking down what is true autonomy. He also discussed legitimacy and disagreement. This is the argument that people are prone to buying into the conflict between palliative care and Assisted Dying, when they should really be mixed/blended together as part of a comprehensive palliative care package. They are not, and should not, be seen as opposing stances.

Dr Colburn explained that the opposition/discussion/debate should be on opposing the legal details instead of the principled engagement. So far, all attempts, and activities aimed at changing the minds of the lawmakers have failed. Dr Colburn recommended, as his work as a political philosopher that these key tools be used:

Begin by excavating a shared underpinning value:

1. Inform the basis of public policy with the excavation of human values i.e. what is important to people – autonomy, dignity etc. Then, those who object in good conscience cannot as the policy is, at base, express a concern for peoples' autonomy. The aim should be to build a course of action that's objective in order to respect autonomy.
2. Currently, the situation appears as interpersonal conflict and intergenerational justice which in turn appears as antagonism between generations. There is a need to rephrase this antagonistic framing. When looking at arguments of opponents of assisted dying, these point to the interests of those who don't want to die, or who are vulnerable. Interpersonal conflict is dominant at this moment. Detailed research in the past shows how this vulnerable framing is an illusion. If one considers an area of law where there is interpersonal disagreement (between individuals) and instead model it as intrapersonal (in one's own mind), in doing so we frame it for ourselves i.e. personal autonomy is at the forefront. Instead of balancing interests of competing and opposing groups i.e. those who want to die as opposed to vulnerable people who don't – we do

not know which one of these we might become. Without this prior knowledge, we need a framework that would empower individuals to make their own decision about themselves, at the time. This is about empowering everybody, despite their beliefs. In doing so, this strategy removes the problematic framing.

3. Finally, working to find overlapping consensus which both respects and brackets disagreement, we need to respect the huge moral differences that exist in society, but bracket them to find a way to move forward.

Liberal autonomy can be clarified:

Individual autonomy is an idea that is generally understood to refer to the capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own and not the product of manipulative or distorting external forces.

In line with this, people should have control over the time and manner of their own deaths. Autonomy is not respected if this is not adhered to, and we in effect, interfere with others' deaths. The choice to have an assisted death gives people even more autonomy.

The autonomy of people who do not want to die is also respected, as the principle of autonomy equates with voluntary decision making. Autonomy is undermined when a choice is forced by there being no acceptable alternatives. Acting non voluntarily is therefore not having your life in control.

End of life situations are often characterised by a lack of alternative options. Assisted dying can give those who want it, an acceptable, alternative option. In doing so, assisted dying can transfer a situation which benefits both those who want to live, and those who want to die.

Ben spoke about Melanie Reid, who was paralysed in an accident 10 years ago. She is a columnist for *The Times* and is supportive of assisted dying. Melanie Reid's stance is that having assisted death (namely Dignitas) as an option is transformative. It gives her the choice in her life, lets her keep control and this in turn is the strength which keeps her going. Continuing to live is her choice, without assisted dying there would be no choice as she would be forced to live. Without the choice she would be trapped in her own body.

Assisted Dying transforms the choices and may actually help people live longer without the fear that their future is non voluntary. Having the option expresses autonomy.

MB thanked Ben for his informative talk. MB adds that with her nursing background she personally experienced people saying to her that they could bear the problems if they knew they had control over their life.

MB opened the meeting for questions to both speakers.

“Dr Wiebe, do you have concerns that the law in Canada may be repealed?”

Dr Wiebe explained that the law will not be repealed as this is a constitutional issue, but more safeguards could be put in place. Dr Wiebe expressed concerns that a conservative government could make psychiatric analysis requirements mandatory, which is a huge hurdle because of a lack of qualified professionals in Canada. This would likely not be deemed

unconstitutional. At the moment, a liberal government is in place for the next few years, so this is a possible concern for the future.

“What is the cause of death listed in a death certificate if a patient has an assisted death?”

Dr Wiebe stated this varies by province. She feels personally that it should be the primary illness. In Dr Wiebe’s province, MAiD is the primary cause of death, followed by the medical problem as a secondary cause of death. This does vary across Canada, however in the USA it is universally the underlying disease which is cited.

“People coming from less affluent backgrounds tend to be a higher risk of cancer, so why are these people statistically less likely to have an assisted death?”

Dr Wiebe reported that there is ongoing research in this field. The understanding is that indigenous and poorer people know less about the options available to them. As a result, access to any medical care can be problematic. People from these communities often do not trust doctors, have little medical knowledge and are less able to advocate for themselves. Typically, they are less used to making choices for themselves and are less likely to access an assisted death, this pattern continues into general access of medical care.

This issue is furthered by campaign groups spreading the word about assisted dying via the media, and not through an organised initiative by the government or the health service, so those who are cut off from modern media are the least likely to get the information that they would need. Dr Wiebe said that if all GPs became more engaged in this issue then this would increase accessibility for the vulnerable.

Dr Colburn added that some people in these communities see assisted dying as a bad thing, that it forces people to make a choice that they might not want. Dr Colburn said instead that we cannot respond to danger by taking away empowerment. When having a dangerous operation, you empower people to make the decision by explaining the risks and procedure. You would not take away the operation, due to the risks. Responding to vulnerability in this way, by taking away choice is perverse. The appropriate reaction is to ensure safeguards, empower and inform.

A psychiatrist, expressed his unease, stating that mood can change in just a few minutes. His concerns are that people lack effective choice in terms of mental health. In turn, this narrows the perception of help available for maintaining quality of life. He added that the choice needs to be broadened especially in more deprived situations. This would include access to resources, social support etc. as destitute people may feel life is not worth living.

Dr Colburn acknowledged that it is easy to think adding the option will fix things, but we must remember that the advocacy of assisted dying needs to support other changes too, which include better support for those suffering with mental health conditions, ongoing improvements to palliative care etc.

“Could Dr Colburn’s strategy of pointers (as seen above in his talk) be used in the consultation process as a way to help politicians, professionals and lawmakers understand the benefits?”

Dr Colburn advocated using the strategies as he suggests, along with pointers from other countries. There are various ways of framing consultations and there can be ways that are problematic because they do not embody these strategies.

MB added that Amanda Ward (AW) is currently drafting ideas for the consultation as part of her PhD. The language used in this, along with the phrasing of our objectives, and addressing arguments will all be extremely carefully considered, and will capture both Dr Colburn and Dr Wiebe's comments.

George Adam MSP added that for politicians this needs to be framed differently from how it is framed for the public. In parliament is it very black and white, for and against, with people opposing assisted dying being trapped in the same old arguments. It is hard to expose the reality, and capture the support of the public in a Parliamentary setting.

“The last Bill was hugely flawed, and that this time any Bill would need the support of doctors, nurses, pharmacists etc. How will we get there?”

Patrick Harvie MSP Addressed this by saying that while this is true, there are flaws in all legislation. However, the second attempt at a Bill was an improvement on the first, and things have continually evolved and improved. This might be our last chance for some time, so it is essential that this is right this time. He added that the key is engaging with politicians as the public are already largely in support.

MB added that a key change since the last Bill is that assisted dying is now legalised in many countries and provinces across the world. There has been a lot of learning, and many changes. Now we have lots of real-life evidence, results and reactions.

An attendee, Rudi Vogels, who is an active disability and assisted dying activist commented that there is a need to understand the opposition to prevent the Bill falling. He added, some people will reject it on religious grounds; however, their religious beliefs should not be pertinent to others. Palliative care should go hand in hand with assisted dying, free to use for all. He has had a full life, but currently he has no choice and no rights as his only options are suicide or going to Dignitas in Switzerland which is costly and not an option for all.

A member requested a copy of Dr Wiebe's presentation be distributed with the minutes; this was agreed.

#### **4. Date of next meeting**

The date is set for the next CPG meeting to be held on the 13<sup>th</sup> May 2020.