

Cross-Party Group on End of Life Choices

Tuesday 26th April 2022 at 6pm

Minute

Present

MSPs

Rona Mackay MSP (RM), Elena Whitham MSP, Joe Fitzpatrick MSP, Karen Adam MSP, Collette Stevenson MSP, Audrey Nicoll MSP, Liam McArthur MSP.

Invited guests

David Obree, Sarah Kelly, Kathy Strachan, Edwin Jesudason, Louis Resnick.

Non-MSP Group Members

Ben Colburn, Scott McMurray, Gordon Drummond, Moira Mather, Lin Li, Alastair Moodie, Charles Warlow, Catherine Owen, Lewis Waugh, Hugh Wynne, Kathryn Taylor, Serge Madrigal, Chris Doye, Julie Lang, Moira Symons, Kenny Steele, Mark Hazelwood, Kenny Steele.

Apologies

Jackson Carlaw MSP, Rachael Hamilton MSP, Mercedes Villalba MSP.

1. Welcome, introductions and apologies

Rona Mackay MSP welcomed everyone to the meeting. Apologies were noted as above.

2. Minutes of previous meeting (Tuesday 25th January 2022)

Convener Rona Mackay MSP (RM) asked if anyone proposed any changes to the minutes of the previous meeting. The minutes were agreed in full. Proposed by Hugh Wynne and seconded by RM.

3. Matters arising

-Assisted Dying for Terminally Ill Adults (Scotland) Bill

Liam McArthur MSP provided a brief update on the Bill process. He has been involved in a number of meetings with a medical advisory group, which pulls together a cross section of experts in medicine, nursing, pharmacy and others to tease out some of the details. Further conversations have taken place between campaign groups and MSPs with positive outcomes. Work on processing consultation responses continues; any small changes in the proposal can mean substantial work in terms of the overall narrative so the timeline is uncertain at present. RM commented that the process will take as long as it takes and that it is most important to get everything right.

4. Presentations and discussion

Presentations from:

Dr David Obree (DO)

Dr Sarah Kelly (SK)

Further input from:

Dr Louis Resnick (LR)

Dr Edwin Jesudason (EJ)

Dr Kathy Strachan (KS)

David Obree (DO) is the Archie Duncan Fellow in Medical Ethics and Medical Education at the University of Edinburgh Medical School with responsibility for teaching medical ethics and law to undergraduate medical students. He was previously an honorary lecturer at the University of Bristol and has taught end-of-life ethical issues for 12 years.

Students are taught medical ethics, including end of life issues, as part of their undergraduate medical degree. The teaching aims to be balanced and encourages students to be pluralistic in their outlook, to understand each other's views and be prepared to have their own views challenged.

Assisted dying and autonomy – there is a right to self-determination but also a contradiction between autonomy being prized but also denied at life's crucial junctures. There is a need to consider external influences e.g. voluntariness, and internal conflict e.g. buyer's regret. Humans are unreliable decision makers.

We often think of our patients as autonomous agents; that they are educated, rational, determined and settled, but often patients find decision making difficult. With the pressure of the responsibility to make particular decisions, patients often look to their doctor to make the decision for them, and this can be problematic. Free will requires the availability of choice, but choices are already limited for someone with a terminal diagnosis. There is an inability to provide (fully informed) consent as there's no data on what dying is like from the point of view of the patient. How can we reliably inform patients of 'what dreams may come'?

Autonomy is one of the four principles of medical ethics, which are: autonomy, beneficence, non-maleficence and justice. For pedagogical reasons, we set up the assisted-dying topic as a 'for' or 'against' debate. Perhaps we need to revise this approach when we are trying to seek change or compromise; the reasons are often not as binary as they first seem. The philosophical origins of respect for autonomy and sanctity of life are quite similar: respect for the person and respect for humanity.

Students often have difficulty with sanctity of life arguments. It is often conceived as solely the preserve of theologians or religious groups. Pagans or 'enlightened heathens' might bristle at the thought of being told what to do or what not to do by a values based system that they don't subscribe to. However, you don't need a deity to understand or appreciate that human life is valuable. The sanctity of life concept has a strong secular presence in philosophy, the law and human rights (Article 2 of the Human Rights Act). The concept is dismissed readily on page 18 of the proposed Bill consultation as it has been incorrectly transcribed from the Omid case which states: "there is no moral or ethical basis *a priori* for the blanket ban on assisted dying based on sanctity of life."

Sanctity or inviolability of life is discussed well in Richard Huxtable's book 'Euthanasia, Ethics and the Law: From Conflict to Compromise?' which points out that the debate has rumbled on for many years with little change. He argues that autonomists need to give sanctity of life more credence and sanctity of life proponents need to consider autonomy more seriously or progress won't be made.

The terminology of accelerated dying is a mess. Whilst LM's introduction includes a clear definition of the bill's proposal; in other areas (newspaper reports & TV) more loosely applied language is used which can confuse the general public. It is important to have accurate, precise and consistent terminology. For example, euthanasia can be reported as always being compassionate however it should be remembered that involuntary euthanasia is murder.

Euthanasia comes from the Greek *eu-* good and *Thanatos-* death. Concerns about terminology are common amongst academics such as John Keown who states: "Given the absence of any universally agreed definition of 'euthanasia,' it is vital to be clear about how the word is being used in any particular context."

Mary Warnock notes that "no Bill with euthanasia in its title would have much chance of finding its way onto the statute book at the present time" but the term still exists in academia and so it needs to be defined. Active euthanasia is when medication is given, and passive euthanasia is when treatment is withdrawn. Euthanasia can also be voluntary (patient is competent and makes request), involuntary (patient is competent but does not make request i.e. murder) or non-voluntary (patient is not competent e.g. is in a coma and cannot take part in decision). Passive, voluntary euthanasia is now legal in England following the case of Miss B. Passive, non-voluntary euthanasia is now legal following the tragic case of Tony Bland.

'Voluntary' means that a competent patient asks for/requests/chooses and therefore consents and 'active' means that a medication or action is taken. If the final act is patient administered, we may call it voluntary, active euthanasia or 'auto euthanasia'

but is more likely to be called assisted dying or assisted suicide. If the final act is physician/doctor administered, this is more likely to be called voluntary euthanasia.

Physician assisted dying/suicide, as referenced in the Bill proposal, usually defines the role of the patient as making the final act e.g. pushing a button or taking a tablet. Therefore, this could be called 'patient-administered physician-assisted suicide/dying' OR 'patient-administered, physician-assisted, voluntary, active (auto) euthanasia.' This may sound pedantic, but it is important to have very clear and consistent terminology. Another question that might be asked is what is the moral difference between the patient making the final act or the doctor doing so?

DO looked at the definitions and terminology used on different campaign groups websites and encouraged Friends at the End to expand upon their definition of euthanasia as it is currently too narrow.

First year medical students who chose assisted dying as the topic for their medical ethics module (25% of the year group) held the following views on assisted dying: 70% in favour, 25% against, 5% undecided or neutral. The recent BMA survey of medical professionals showed that 53% of medical students supported a change in the law, compared to 40% of all BMA members.

Atul Gawande, in his book *Being Mortal*, says that at its "root, the debate is about what mistakes we fear most; the mistake of prolonging suffering or the mistake of shortening valued life."

Dr Sarah Kelly is a Year 2 Foundation Doctor in South East Scotland. She is also a trained bioethicist and is interested in the translation of moral theory into the everyday practice of medicine. She studied at King's College London where she focused on the ethics and law of assisted dying and prison healthcare. Subsequently she received a Master of Bioethics degree from Harvard University where she worked on issues regarding medical error and broader questions of justice in clinical medicine. Sarah teaches medical ethics and law to medical students at Edinburgh Medical School and she sits on the School's Research Ethics Committee.

The morality of this discussion lies not only on the broad level of 'should assisted dying be 'legalised in any capacity,' but in the practical, granular level of detail in how this might be done. Having spoken to a lot of junior doctor colleagues about this proposed Bill, very few were even aware of it. Most doctors I spoke to were in favour of some change, albeit with questions about its practical applications.

The current process of end-of-life care is not perfect. Whilst good palliative care can make the dying process much more bearable, there are some for whom the end of life brings a lot of suffering, including loss of dignity and autonomy. From a medical perspective, there can be a lot of moral harm to professionals from not being able to alleviate suffering. There has been a shift from doctors in recent years from a position of opposition to neutrality, as evidenced by the recent BMA survey and subsequent vote on the topic. Medical professionals who support a change in the law frequently highlight that they want to see clear legislation and guidance for doctors as to how the law would be applied in practice.

The first question to consider is who should initiate a conversation about assisted dying – should it come from the patient or the healthcare professional? While some people would welcome the discussion, others may feel threatened just by the mention of assisted dying. Throughout the pandemic, there has been controversy about DNACPR conversations, with some patients offended by discussions around ceilings of care. So much of advanced care planning is still done on an ad hoc basis in the context of acute deterioration and admission to hospital. These conversations by their very nature are emotional and difficult and that will remain the case even if assisted dying is legalised. Thought therefore needs to be given to who is the most appropriate person to have these discussions.

In last year's BMA survey, only 36% of doctors said they were willing to take part in the process, which is a minority of doctors and covers all grades. There needs to be clarity in any Bill about what grade of doctor would be involved in the process i.e. in this Bill 'fully registered doctors' are mentioned which covers all doctors after their first year of qualification. Much of the hands-on care in hospitals is delivered by doctors in training but I suspect that junior doctors will not feel that they have the specialist knowledge and skills to adequately support patients through that process. It therefore seems appropriate that consultants in oncology, neurology and palliative care for example would be best placed to engage with patients in this decision-making process as part of wider end of life care planning. Interestingly, in the BMA survey, these specialists were amongst the most opposed to a change in the law.

It is important to ascertain even senior doctors' comfort with assessing capacity in this context and to consider whether other specialists such as psychiatrists or psychologists might be able to support doctors when capacity isn't necessarily clear cut. We need to make sure that there is training and support for doctors to carry out this work well. Data shows that many doctors are still uncomfortable with the idea of participating in the process and we already know that many junior doctors feel unsupported and ill-equipped to deal with end-of-life issues. A recent meta-analysis highlighted a lot of opportunities to improve skills and knowledge in this area, including role playing scenarios, observing senior colleagues and building reflection into practice. If there is to be a change in the law, these kinds of techniques should be considered to allow doctors to best support patients at the end of their lives.

Key points from Q&A:

- Training of healthcare professionals is key: difficult conversations can be done differently and better.

- Nurses are a fantastic resource that should not be overlooked.

How far should legislation go in terms of qualifying criteria? Legislation in the USA only allows a certain subset of people to have an assisted death, for example the Oregon law requires self-administration and is generally used by middle class, affluent people with cancer or neurological diseases. Is there some class discrimination?

- Accessibility is a health service wide issue, not unique to assisted dying.

- Patients already discuss difficult choices with their clinicians e.g. those with motor neurone disease who may require ventilation.

- Many patients are able to operate switch gear with their eyes or breath; technology may allow those even with profound disability to access assisted dying.
- Language is very evocative and needs to be correct.
- BMA survey didn't delineate between seniority of doctors, only doctor vs medical student opinions. Higher levels of support in medical students could be due to a variety of reasons e.g. changes in palliative care teaching, generational shift, broader political views.
- Doctors are drawn to a speciality for societal and cultural reasons which may explain why many palliative care doctors are opposed to assisted dying e.g. cardiothoracic surgeons were upset when stenting was invented for coronary artery disease as they believed that the only treatment was surgery. Difficult transition.
- Assisted dying should be an option within palliative care.
- One of the strengths of the Bill is that people will talk about dying earlier in their lives. Patients can exercise autonomy in lots of ways already with options for treatment, admission to hospital etc.
- Legislation needs to be watertight with strong safeguards e.g. in Hawaii, a third assessment is required from a mental health practitioner.
- Could consider videoing assessments to give assurance/be reviewed by senior clinicians and used for training purposes.

5. Any other competent business (AOCB)

N/A.

6. Date of next meeting

Tuesday 27th September 2022 at 6pm.