

**Assisted Dying: What are the Issues and Options for Scotland?**

Inspired by Killing Roger, Sparkle and Dark and the Mason Institute at the University of Edinburgh held a public panel discussion on Assisted Dying: What are the Issues and Options for Scotland? The event was well attended by a broad spectrum of people including members of the public, practitioners (including GPs, medical lawyers, pharmacists, palliative care specialists), academics, and representatives of a number of advocacy groups.

The event was chaired by Sheena McDonald. Patrick Harvie (MSP and secondary member to the Assisted Suicide (Scotland) bill), Professor Calum McKellar (Director of Research at the Scottish Council of Human Bioethics), Professor Graeme Laurie (Director of the Mason Institute) and Lawrence Illsley (Writer, Poet and Musician for Sparkle and Dark) sat on a panel to answer questions from the audience.

The format was a question and answer style, largely discursive in order to have a fully interactive event. The panellists were given the opportunity to present briefly who they were and their reason for being on the panel.

The discussion was sparked by a new play, “Killing Roger” by Sparkle and Dark, funded by the Wellcome Trust. There were two philosophical questions that formed this play - “Could you kill someone?”, “Well what if they asked you?”. The play presented a situation of a lonely gentleman who is very ill and someone comes into his life to care for him. A very real social issue underpinned this art. Over the course of the 9 months of the project that Sparkle and Dark undertook, it became clear how important this debate is to people and how complex it is. The show itself presents one specific story; it does not show the full range of ethical dilemmas involved in assisted suicide.

Key themes and discussion points

The discussion covered a number of areas related to assisted suicide and the issues and options for Scotland as follows -

Dignity/Choice/Free Will

* The importance of choice, free will and autonomy
* That every person has inherent dignity, but the difficult of defining what dignity (and who gets to define it) and that there are different kinds of dignity
* The claim that every life is meaningful and worthwhile, and has equal value

Compassion and Suffering

* Role of palliative care to address different kinds suffering
* Suffering (physical/psychological/existential) and whether assisted dying can address any or all of these
* Palliative care seeks to address all the different kinds of suffering
* The limits of palliative care and the residual role for assisted suicide
* From a certain perspective of dignity it is not dignified to suffer

Communication and Cultural Change

* The reality that death is an issue faced by everyone, people are scared of dying and death – or at least are afraid of a “wild death” (Callahan)
* The importance of considering assisted suicide while competent – not only when near the end of life, in alien world, or when capacity might be questioned
* Art can inspire people to think about and consider issues to create a more enlightened and engaged society
*

Protecting of vulnerable people

* When is someone vulnerable?
* What are permissible safety nets and when do these become paternalistic?
* Where will the change in law lead to?
* The need to acknowledge that cases are rarely black and white

Burden

* No one should be made to feel a burden to family, finances
* If the law changes to allow assisted suicide, people may start to believe that their lives become a burden
* The burden to those involved in the act of assisted suicide
* The burden of living with dying
* The question of whether law should intervene to allow assisted dying, and if so, how it can do so in a safe and socially-acceptable manner.

The discussion spent time also defining what the terms of bill might be, what are the current distinctions in the law – for example between acts and omissions that lead to death - and the terms related to assisted suicide.

The definition of the term assisted suicide in the draft bill to be introduced by Margo Macdonald – will set out a process where people can make a series of requests. It will be set up so people can assist but not perform the final act, so that people take their own life. In this sense, the Bill will not be an example of physician-assisted suicide. Indeed, the proposal is likely to involve procedures that create new roles for non-medics to assist people to die. The bill is limited to people who have terminal illness/condition - so it would not help some of the high profile cases such as Tony Nicklinson). This begs questions about what is meant by ‘terminal’ and whether this is a just and fair basis for a law on assisted dying. The law would have repeated requests to demonstrate a person’s “settled view” and to ensure that they are capable of consenting using existing laws around capacity.

In law, the courts are clear that an act to bring about death is illegal. In contrast, an omission of treatment deemed by the medical profession to be futile is lawful. The fine line of act/omission distinction is very important in law, but many question whether it is defensible or philosophically meaningful. Everyone, in law, has the right to refuse care including feeding and hydration – no reason is needed. Additionally, physicians can provide treatment that might hasten death when their intention is to alleviate suffering directly related to an existing condition (called the “double effect”). Law does not promote unconditional sanctity of life and it can support decision that will allow someone to die. It does not, however, sanction intentional acts to bring about the death of others. Prosecutions service must now be clear about the circumstances in which they are (or are not) likely to prosecute people who help others to die. This is a requirement of human rights – the law must be clear and knowable, but a state like the UK – or Scotland – can continue to prohibit assisted suicide to protect ‘vulnerable’ persons.

Feedback and the Future

The event was well attended. Over 90 people registered for the event and a lot of other interested people had tried to register. Due to the festival taking place in Edinburgh, the organisers were limited as to room availability but it was clear that it could have taken place on a much larger scale.

We asked the audience for their feedback (available in Appendix 1). Only 12 people provided feedback as per expectation with these types of events. The feedback was to gain insight into if people had been engaged with the event and found it useful, to find out where they had heard about it and to identify what could be done to make it better. It was clear given the feedback from the minority who did feedback that they had been engaged in the event, with 11 out of the 12 going on to tell someone else about the event. Future events might want to consider having more of a balanced panel. Overall, we are happy with the mainly positive feedback that was given and how people had felt interested in the event.

There are two follow on events being planned. One is by a local minister who is planning to do a similar event in her constituency to discuss the issues. The second is the Mason Institute were approached by an Advocate, David Stephenson, QC, to undertake similar events for practitioners (including lawyers, physicians, nurses, pharmacists, social workers etc), working in the area. An event will be planned around the time when the draft bill is submitted to the Scottish Parliament and will be in partnership with some of the Royal Colleges.

The Mason Institute and Sparkle and Dark will continue to work together where opportunities present themselves in the future. The Mason Institute is happy to support Sparkle and Dark in pursuing similar events in other parts of the UK through its network of academics and to continue to support the Art and Bioethics work. Finally, the Mason Institute is bidding to host the 2016 International Association of Bioethics Conference and Sparkle and Dark have agreed to show their production, which sparked this discussion, Killing Roger at this conference.

The Mason Institute and Sparkle and Dark would like to thank the Wellcome Trust for supporting this event which is leading to other opportunities and public engagement work in this specific bioethical issue. In addition, the Mason Institute and Sparkle and Dark would like to take this opportunity to thank Sheena McDonald for chairing the event and the panellists and audience for their participation in the debate.

Links and other resources

The podcast for the event can be listened to here:

<http://www.masoninstitute.org/wp-content/uploads/2013/08/bristo%20square%20lt3%20140813.mp3>

In addition, there were some commentaries before and after the event which can be found here:

Dr Iain Kerr, Retired Physician: <http://masoninstitute.org/commentaries/4/>

Lawrence Ilsley, Sparkle and Dark: <http://masoninstitute.org/commentaries/5/>

And Sparkle and Dark’s blog: <http://killingroger.wordpress.com/>

Hazel McHaffie blog: <http://www.hazelmchaffie.com/blog/tag/assisted-dying/>

Gill Haddow’s commentary: <http://masoninstitute.org/commentaries/6/>

**Appendix 1 - Feedback: Assisted Dying: What are the Issues and Options for Scotland?**

**These are taken from Survey Monkey**

**How organized was the event?**

* **Answered: 12**
* **Skipped: 0**

| **Answer Choices** | **Responses** |
| --- | --- |
| **Extremely organized** | **50%**6 |
| **Very organized** | **50%**6 |
| **Somewhat organized** | **0%**0 |
| **Slightly organized** | **0%**0 |
| **Not at all organized** | **0%**0 |
| Total | 12 |
| Comments(0) |

**Had you been to see Killing Roger?**

* **Answered: 12**
* **Skipped: 0**

| **Answer Choices** | **Responses** |
| --- | --- |
| **Yes** | **41.67%**5 |
| **No** | **58.33%**7 |
| **No, but I have arranged to see it** | **0%**0 |
| Total | 12 |
| Comments(0) |

**Overall, how would you rate the event?**

* **Answered: 12**
* **Skipped: 0**

| **Answer Choices** | **Responses** |
| --- | --- |
| **Excellent** | **66.67%**8 |
| **Very good** | **25%**3 |
| **Fairly good** | **8.33%**1 |
| **Mildly good** | **0%**0 |
| **Not good at all** | **0%**0 |
| Total | 12 |
| Comments(0) |

**Do you have any suggestions about how it could be improved?**

* **Answered: 5**
* **Skipped: 7**

Showing **5** responses

More balanced questions. I felt the discussion ended up being quite one sided.

9/10/2013 11:01 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2804397445)

A well organised event, no suggestions for improvement.

9/2/2013 1:25 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2790858161)

More time for discussion

8/29/2013 1:15 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2786108534)

Perhaps we could have submitted questions before the event.

8/21/2013 10:23 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773138958)

Although I was surprised that the majority of the audience like myself supported some form of assisted dying I wonder how aware you that this was likely to be the case and if so whether it might have been better to more then one panelist who was anti.

8/20/2013 10:34 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2772462611)

**Are there any questions you would have like to be addressed at this event?**

* **Answered: 6**
* **Skipped: 6**

Showing **6** responses

The methods by which assisted suicide would be carried out

9/10/2013 11:01 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2804397445)

No. Felt the discussion included all the issues we had in mind.

9/2/2013 1:25 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2790858161)

More time to challenge Professor MacKellar

8/29/2013 1:15 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2786108534)

At the age of 76 It seems clear to me that if this latest bill is rejected there is no possibility of the law being changed in my life time. I Would have liked some discussion on where this disappointment would drive such as me.

8/21/2013 11:39 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773201892)

I was able to ask some questions of one speaker after the event; that was very helpful for me.

8/21/2013 8:21 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773043044)

It

8/20/2013 10:34 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2772462611)

**Did you tell anyone you had been to the debate? If so, what did you say?**

* **Answered: 12**

**Skipped: 0**

| **Answer Choices** | **Responses** |
| --- | --- |
| **Yes (if so, please complete the Other box below)** | **91.67%**11 |
| **No** | **8.33%**1 |
| Total | 12 |
| [Comments](https://www.surveymonkey.com/analyze/?survey_id=43691905&OPT=NEW)(10) |

That I had found it very interesting.

9/10/2013 11:01 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2804397445)

People have a mixed reaction to the subject, but raising awareness allows them to reflect and hopefully become more open to frank discussion. Does not mean they have to take sides on views but allows people to think about a very pertinent topic in today's culture

9/2/2013 1:25 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2790858161)

We related how pertinent and interesting the event was to our lives

8/23/2013 8:54 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2777702802)

Said it had been really interesting - great panel and interesting, varied audience

8/21/2013 5:57 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773820668)

It was a very interesting discussion and I am sure it was thought provoking for those who had very little knowledge of the subject.

8/21/2013 11:39 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773201892)

I discussed the event and subject matter with some friends who I met after the event.

8/21/2013 8:21 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773043044)

I was very positive about it to a number people saying that it made me think more deeply about the questions involved

8/20/2013 10:34 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2772462611)

very interesting discussion.

8/20/2013 7:43 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2772141531)

Spoke about how extremely interesting and thought-provoking the debate was. Also, that I had found the Professor of Bioethics' (sorry I forget the name) arguments terribly abstract and as such really quite meaningless in this debate, not doing his side of the 'camp' any favours in the process. Others were interested in the general opinion in the room, so I related the 'aye' or 'nae' poll outcome.

8/20/2013 4:56 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2771826158)

Said it was interseting debate on the issues surrounding assisted dying.

8/20/2013 4:51 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2771815877)

**Would you like to hear more about the Mason Institute or Sparkle and Dark Theatre company? If so, please provide an email address.**

* **Answered: 5**
* **Skipped: 7**

Showing **5** responses

s1037343@sms.ed.ac.uk

9/10/2013 11:01 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2804397445)

eileen.peebles@nhs.net

9/2/2013 1:25 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2790858161)

Muchalls1@yahoo.com

8/21/2013 5:57 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773820668)

tonalarts@gmail.com

8/20/2013 10:34 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2772462611)

delogie@gmail.com

8/20/2013 7:43 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2772141531)

**Q8**

**How did you hear about our event?**

* **Answered: 12**
* **Skipped: 0**

Through the University of Edinburgh, School of Law

9/10/2013 11:01 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2804397445)

Throught being a member of HPAD

9/2/2013 1:25 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2790858161)

Cannot remember!

8/29/2013 1:15 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2786108534)

Eventbrite mailing list

8/23/2013 8:54 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2777702802)

Eventbrite

8/21/2013 5:57 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773820668)

Member of Friends At The End.

8/21/2013 11:39 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773201892)

Pathways to Law

8/21/2013 10:23 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773138958)

Eventbrite emailing

8/21/2013 8:21 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773043044)

Eventbrite I thnk

8/20/2013 10:34 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2772462611)

advertisement

8/20/2013 7:43 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2772141531)

Forwarded University email

8/20/2013 4:56 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2771826158)

Mason Institute

8/20/2013 4:51 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2771815877)

**Q9**

**Do you have any further comments?**

* **Answered: 5**
* **Skipped: 7**

Showing **5** responses

Thank you for the opportunity to participate.

9/2/2013 1:25 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2790858161)

No

8/29/2013 1:15 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2786108534)

We were sorry we were unable to attend your meeting yesterday. We're very keen to be kept in the loop. Thank You!

8/23/2013 8:54 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2777702802)

It was really interesting having the reception afterwards as it continued the debate, and enabled us to discuss it with other people (including speaking to people who'd raised points as the talk

8/21/2013 5:57 PM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773820668)

Wished it lasted longer!

8/21/2013 10:23 AM [View respondent's answers](https://www.surveymonkey.com/analyze/browse/?survey_id=43691905&respondent_id=2773138958)