

End of Life Focus Groups – Initial Results

There were 55 (33 women and 22 men) who participated in the FG, less than the 97 (60 women and 37 men) who answered the questionnaire. The questionnaire probably took around 20 minutes to complete, a notional 1940 minutes of input. Each FG lasted for around 90 minutes, a notional 90 x 6 or 540 minutes input for the FG. Inevitably the FG participants were restricted by the conventions of conversation. The questionnaire did permit qualitative contributions at any stage if the participant decided to write anything. The quantitative evaluation of the FG was considered largely irrelevant, though it was useful in the early stages of the analysis to see what subjects were discussed more frequently.

There was an overwhelming amount of data from the six focus groups; firstly an analysis was made of substantive topics, and a qualitative comparison made across the FGs. 30 different themes or modifiers were identified and tabulated for each focus group. The table of themes is included for the sake of completeness (Appendix XX). This had the advantage of allowing total familiarisation with the transcripts.

A decision was made to restrict the number of themes for discussion. The major task was to analyse the Quaker view of assisted dying. However, as the questionnaire asked things concerning Quaker practices and looked at some emotive issues these could not be ignored. It was important to ascertain the complete **range of views** on AD and, if possible the **reasons** for the views, thus the thematic analysis was of limited value.

However, and unsurprisingly, of most interest was the **theme of assisted dying** itself, with the majority of comments in favour: “AD should be a right”, “it’s an expression of personal autonomy”, “people should have a choice”, “AD should be part of palliative care”, “I believe in euthanasia”. One person said “I haven’t heard any real opposition though some in area meeting are opposed”.

Very few were against, though one was adamant “I am totally against AD” while another had a “gut feeling against it but believe it will be ratified”. Some said their

minds were not made up: “my views are fluid”, “I see the benefits but have some reservations”.

Most people felt the option should be available even if they did not want to make that choice for themselves, recognizing that “not all would want AD even if it was legal”, “there should be an option”, “people should be allowed to die when the time is right”.

Some of the debate was around factual information in the UK, Switzerland, Belgium and USA (Oregon) with some people showing considerable knowledge. It was recognized that no one should be allowed to ask for AD if they were depressed, or without mental acuity.

The majority of the debate was about any change in the law needing to include safeguards to prevent abuse of the system. There was concern that any change in the law should recognise the range of cultural views in the UK as a whole. Another concern was about those unable to commit suicide through disability “because of your incapacity you should not have less choice”.

Areas of agreements were

- the recognition that a change in the law in favour of AD would need to happen in parallel with an increase in the availability of palliative care;
- people should be encouraged to develop their understanding of death and dying, and to make what provision they could for it, and
- the need to communicate well with families and doctors.

Some debate revolved around the withdrawal of nutrition and hydration as well as the withdrawal of treatment suggesting that at times it was not a sufficiently transparent process, raising ethical questions as to **who makes decisions** and how those decisions are made. Patient participation was considered vital.

Another useful thematic examination was that concerning **the law** where nuanced opinions were voiced along with categorical declarations both for and against a change.

It became clear that the conference held in May 2012 had been very helpful in informing people of the process of AD used in the Benelux countries and the law as it affects those in England. The “concept of a good death and what that means and how the law could protect as well as support people” was stated as an important learning point. There was also almost a sense of yearning in the statement “we should have laws – other countries have them” to allow AD, together with a belief that “public opinion will push us in that direction....it will take care of itself”.

There were subtle comments about **rights** and the bold question “Is it right that the law should dictate something so crucial to our whole life?”. Another wondered “it’s a right, so does it have to be put into law?”. Allied to this was the comment that the British Medical Association would not comment on AD since it was not legal saying that it was Parliament who made the laws and the BMA acted within those laws. Because this was the stance of the BMA it was thought that the question of AD was firmly placed within the sphere of the social, i.e. society or community, rather than the legal or political spheres. The suggestion by some that public opinion would drive the legislation would echo this.

AD was believed to happen now despite the lack of legislation permitting it. Some people felt that because of this, there was no need to change the law while others felt that a law permitting AD would make the whole process more transparent and that by doing nothing it would let the present, covert, practice continue.

Concern was expressed about issues around ‘Do Not Resuscitate’ (DNR) directives in use in hospitals. They questioned both whether DNR was put on people’s notes without consultation and, without such a directive, whether the medical team was legally required to attempt resuscitation ? This led to questioning the status of an advance directive in law as well as a different perspective on who should make decisions.

There was recognition that doctors would be an integral part in any procedure for AD if the law was changed. People questioned how they would interpret the **Hippocratic Oath** and assumed there would be a clause to allow them to refuse to administer AD in parallel to the exclusion clause of not being involved in

abortions. There was also an understanding that the public would have to have **confidence** in their doctor and other medical practitioners if AD was legalized, though the degree of confidence was questioned by others. The experience of other countries which had allowed AD was considered a possible indicator as to areas where the law is weak or has been abused and thus something from which our legislators could learn.

Perhaps the most distressing comments were those around the **suffering** witnessed when AD was not available and treatment for pain was inadequate.

“I know she was in terrible pain. Between these bouts of morphine she used to get very agitated before it was time for her to have it. And that made her death and everything about it really hard”.

“I found it unbearable to see her suffering “

Even more distressing was to hear someone admit they wish they had broken the law :

“My wife was crying out for the last three days and looking back I wish I had done what I shouldn't do in law. It was so painful and ...as xxxx said, you wouldn't let an animal go through that.”

This last statement indicates strongly that considerations of this issue “cannot be divorced from one's own circumstances”.

When a decision was made to change from looking at subject themes to **modifying statements** a different but parallel perspective was revealed. Inevitably these were more personal statements and as such more revealing of feelings and states of being, often giving reasons for the way they felt.

Looking at the spectrum of subjects revealed by finding “think” or “believe” there is the heartfelt

“I think we felt helpless because each time we visited this particular friend she said to us “Please help me to die. I want to die.” And that’s why I just feel helpless.”

And the dawning of realization:

“We have this image of how we think it is going to be and more often than not it isn’t . I think that was very revealing, for me to face up to what might be ahead”

Complex thoughts, which could not possibly be catered for in a questionnaire, were also articulated: how should society confront the “huge powerful professions” of medicine and law which would inevitably be responsible for much of the legislation ? The statement was perhaps an extension of the Quaker tenet of “**speaking truth to power**” (Ilkley, lines 49 – 54). Another group thought “the medical profession needs to look at its services”.

One of the problems which was recognized was not only the need to talk with one’s children but also the difficulty of doing that.

“Children don’t want to discuss it I find. There is a huge resistance. Don’t talk about it. Please, I can’t bear to think about it. And this is quite difficult to come to terms with. I have tried but I obviously haven’t found the right moment, the right time.”

Another person responded by saying:

“I think partly we have the responsibility, as the older generation, to create the conditions where we can have that discourse”.

Concerning the matter of **choice** in AD, one person made the statement :

“The inner light, the in-dwelling light and the idea of God within us....

Is really something about us, as individuals, seems to me to keep us free to welcome, to accept such a choice, if it is made available and to do so reflectively.... even as we sit in meeting with each other in silence, (there)is something about the Quaker way which seems to me inclined towards accepting this greater choice”.

This seems to clarify a traditional, strong, Quaker stance of allowing *individuals* to **accept responsibility** before God for any choice that they make, knowing that they will be supported in their choice by the *community* of Quakers around them.

This being part of a community was reiterated for society as a whole:

“society, not the Society of Friends,we have got to work out a collective perspective on this very complex issue...I don't think we want to end up as atomized individuals where a, b and c do their own thing”.

With another wondering whether it was a question of: “compare and contrast freedom and responsibility. Can that be individualized?”

With a more spiritual contribution the statement was made :

“I don't know whether there is something beyond me which helps me make that decision. Whether it is my relationship with God, a higher power, or my spiritual welfare ? ...my family and my community (help) in making that decision for me. (I wonder) whether I would trust to put myself in God's will. I think that's part of it. I am not sure that it has anything to do with (the) corporate, but it does have to do with the individual. (The) right to make

their own choice, in their own way (as to) what happens next”.

It cannot be deduced directly from the context whether the final comment about “what happens next” relates to asking for AD or whether it refers to an after- life. However, this was considered directly by one participant who stated “there is a religious belief..... that there are going to be consequences beyond our ken” but it was pointed out by another “ the choice is always that of the person therefore if they believe there may be consequencesthey won’t allow it to be taken”.

The responsibility of the **medical profession** and the burden they would take on if the law was changed was an issue for some people as they considered if it was possible for “emotionally and personally (to) combine a total commitment to the preservation of life with having part of your practice which ends life”.

Problems allied to **demography** and the **NHS** were also considered in the context of care for those at the end of life.

“The whole thing needs quite creative thinking through, doesn’t it ?

Where people are going to end up, living in community may become much more significant in the future. How do we cope with that ?”

And again

“there is a challenge to palliativecan they rethink it to deliver it in different ways, not in institutions”.

Learning from the conference, one person referred to Debbie Purdy, the campaigner from Pudsey with multiple sclerosis who took her case to the European Court in an attempt to get reassurance that her husband, Carlos, would not be prosecuted if he accompanied her to Dignitas for PAD. The participant said:

“I think it was Debbie Purdy who said that she thought for people to know that they had the choice actually **empowered** them to carry on and I quite understand how you could know there is a way out but

not actually choose it. Somehow they found that individuals in great pain, for them to know there was an exit, enabled them to be stronger, to deal with what they had to. I had not thought of that before but I think it was very touching”.

This was articulated clearly by one participant:

“if I were in pain I might want to be euthanased. But ideally, I would rather not, I would rather be helped to cope with the pain as long as I could stay conscious. At least I think I would.”

There was a recognition that **suicide** is now legal so a person has a right to end their own life. There were several suggestions that the choice issue around abortion is reflected in choice concerning AD. It was pointed out that

“now, if someone attempts suicide they are supported and helped and cared for. So the whole approach and the menace of suicide has changed”.

While someone else thought “the whole question of suicide was covered up” and another opined that it “sometimes takes us quite unawares....we think we should have known” and thus there is a sense of guilt.

Observing the dying of someone we love is still very much removed from the experience of dying itself:

“whilst we may think they were having a really bad time towards the end, they were hanging on..... in there for something worth doing”.

“He enjoys life and savours it in so many ways”.

In summary to much of the discussion

“ it would be lovely to think that society had moved to the point where people were able to acknowledgethat you had (had) a good life ...and you could see what might be coming round the corner and were not happy about it and this was a good time at which to die.”

Dependency was an issue that did not crop up as often as expected but when it did it was important, generally around the question of dependence versus independence :

“The other big issue is our fear of dependency and I think it comes in two flavours. When it is you who becomes dependent and it’s also a question of the dependency of someone you have to care for. I think both those can muddy the waters”.

Additionally, it was thought to be involved in making a decision for AD (or turning off life support ?) for your child as well as how your children would deal emotionally with your decision to go for AD.

It was thought that we needed to “discuss as a society what value we place on independence....I think a lot of it is about **control**”. The same participant said “we are not prepared to go out and engage in the **context**....I would like to see the Society of Friends talking about the context”. A different FG contributed the thought

“Why is now – our generation – is it such a burden ? Why is it so difficult ? I think that is part of the contextual thing”.

Two reasons for the question of AD being so important at present were considered to be

“the lack of a cohesive familythey are not able to do the caring that was traditional 50 years ago” and “the medicalisation of death..... if the medical interventions are there it takes longer to die”.

“There is the very important issue that people are allowed to die when it is their time...that people are not kept alive artificially”.

It was acknowledged that it

“hasn’t been easy to address this topic....but I was left with a very positive feeling.....it was very life affirming. I don’t think there is anything paradoxical ...it has actually been a joy to be part of this discussion”.

Attention was drawn to Advices and Queries 29 and 30 “accepting the fact of death we are freed to live more fully” (A&Q , 2010, 13).