

London Quaker Dialogue, 8/5/2010 – introduction

What motivated our group, the Quaker Concern on Death and Dying, to spend regular time pondering this subject? It was a Friend in Macclesfield who kicked the ball onto the pitch – Nancy Mottram wrote two years ago to the Quaker journal, *The Friend*, telling the story of a friend of hers who died in a way that she wouldn't have wanted and that was extremely distressing to her family and friends. There were various responses, and one was a letter from me. I suggested that just as during the late-1950s/early 1960s a group met together to discuss a difficult subject – sexuality – and eventually come up with their collected thoughts on the subject – *Towards a Quaker View of Sex*, so, now, we might have a group to get together to think about death and dying and, perhaps, if it seemed right, think about compiling some kind of *Towards a Quaker View of Dying*. More than 60 Friends signed up their interest. In May last year we held our first gathering for two days at the Quaker Study Centre, Woodbrooke, in Birmingham, and we've held two more gatherings since then.

The prospect of publishing our findings has vanished into the distance, and at the moment it's the exploration of this vast topic which is our main thing.

We're not alone, of course, in our concerns about death and dying in the 21st century. Good public health and medical science have made us healthier and enabled us to live much longer lives. Over the past few years, the subject of choices in dying has become one of the biggest of the ethical issues facing us - in particular, the assisted dying debate. The number of those going to Dignitas in Switzerland for the death of their choice... The fact that those who accompanied them were breaking the UK law, but none were prosecuted... Debbie Purdy's fight for clarity and the ensuing guidelines from the Director of Public Prosecutions... the freeing of Mrs. Gilderdale who helped her daughter to die... All these have aroused intense public interest and comment.

Our group didn't just want to look at Assisted Suicide, or as most of us prefer to call it, Assisted Dying. We wanted to take an exploratory, open-minded look at the last stages of life and the end of it.

Our first task was to discover what death and dying meant to each of us. Why had we come to Woodbrooke to talk about this? What aspects were we aiming to take a deeper look at?

We came up with a list:

- * How can we, as lay people, work effectively with health professionals, and if necessary challenge their assumptions about what we might want at the end of our lives?
- * We realised that we ourselves need to learn how to communicate sensitively and knowledgeably with those who are dying and with those who are bereaved. This connects with 'soul midwifery', which we'll hear about later from Hazel.
- * How can we make a place for bereavement, grief and mourning in our lives? People are often expected to get over it, get back to work or to normal. But this isn't healthy. What's the alternative?
- * Then there's the massive issue of how we care for elderly and frail people. Can we acknowledge how difficult that caring may be for the carers? How do we deal with the 'post-code lottery' that gives such a dramatic variation in the level of care?

* Then there's question of 'life after death'. Our group haven't had time for this, and I'm especially interested in it, so we're including it today.

* Yes, there was 'Assisted Dying' – the issue of whether there could be more choices about when and how to die, and looking squarely at the implications of these choices. We're including this today too, particularly with Val's talk.

* At our second meeting, we began to think ahead to our own death. Practically:

i) how to de-clutter and downsize as we grow older
ii) making a Will (is there a quick intake of breath here, from those of you who haven't made your will yet?)

iii) drawing up a Power of Attorney in case we become incapable of managing our affairs

(iv) making a 'Living Will' / Advanced Directive so that medics will know what our wishes are even when we can't express them

* And also the emotional side, including talking with our family and friends about our deaths – which is often a difficult thing to do. Jill will touch on this in her talk about contemplating her death.

* Finally, there came the 'why?' question – what about 'the will of God'?

At our third gathering, a couple of months ago, we concentrated on the huge area of 'Choices in old age and dying'.

Over our three gatherings, we've discovered that each of our personal experiences and decisions have wider implications. If I list them for you, it might help to clarify our thinking today. All the issues are linked, so it's easy to go round in circles. But we do need to try and disentangle them.

- **Legal issues.** Who has the right to choose to die, and when, and how, and with whose help?
- **Political issues.** Is it those with the loudest voices or those with the most political clout who make decisions about life and death on our behalf? Can we reclaim those decisions for ourselves? Would that fragment the basic shared values of our society?
- **Philosophical issues.** Is life itself a paramount good? Could allowing people to make their own choices, or be helped by others to die, be the first step on a slippery slope towards a devaluing of life itself? How can we distinguish between 'life' and 'mere existence'?
- **Medical.** How does medical practice help or hinder our choices? When we have a heart attack and the paramedics rush to the door with sirens blaring, is there time, then, to ask 'What do I want to happen now?' If I've made a clear choice and let it be known, what if I change my mind?
- **Religious.** We live in a multi-faith, multi-cultural society, and each faith, each culture, has its own ways of dealing with issues of death and dying. How do we communicate across these chasms?
- **Generational.** Every generation grows up with attitudes that may persist, even when other generations have passed those attitudes by. For instance, friends of mine are living alongside a relative aged 102 while she longs to die. But she's ashamed of longing to die, because she grew up in a time when suicide was illegal,

immoral. I suspect that we all have assumptions that lie as deep as that, and are as difficult to get at.

- **Economic.** I remember the point in my aunt's last years when I dreaded the moment when her own funds to pay the nursing home ran out. Then the Social Services would have to take over the cost of keeping her alive – just, and having worked myself with children in care, I knew how much good that money could do for a child's growing life. Thankfully, that moment didn't come, with my aunt. But how long can we afford to keep people alive? ...That's about as uncomfortable – unacceptable – a question as you can get. It's maybe only in fantasy or 'future' fiction that such a question can be explored.
- Connected with this is the **Environmental** – the issue of finite planetary resources. In the western world, we've been over-consuming resources, and other parts of the world are now asking us to change our ways. How might we have to choose? Again, an almost unacceptable question.
- **Historical.** In our culture, we're now living the longest and healthiest lives in the history of this planet. Can we go on living longer and longer? Are there diminishing returns on this journey? Is it possible, or desirable, to reverse this runaway train?

One telling moment in our recent gathering illustrated some of the problems at the end of that list. A vet told us that if she allowed her animal patients to go on living in the state some human beings live, in some poorly equipped and staffed hospitals and nursing homes, she'd be struck off her professional register. But she also knows that if doctors did what she does – end the lives of those who are suffering unbearably or have no quality of life left – then *they* would be struck off *their* professional register.

I think we need to take a journey around our minds and our souls. Try not to stop ourselves thinking and speaking because we are afraid, or because a certain thought is unacceptable to us or to other people. We need to think, set the thought aside, pick it up again, think again, set it aside – and allow these many thinkings to become part of how we live.

Recently, I was talking about dying with my sister, and we realised – suddenly, unexpectedly – that our fears about dying were opposite. She was afraid of dying alone, I was afraid of dying among strangers. She'd rather be with someone, even with someone she didn't know, on that last journey, whereas I'd rather be alone than with people I don't feel comfortable with. We've known each other 66 years, but we didn't know that.

When we got together to discuss today's occasion, we realised that we must try to distinguish between two things:

- One, our personal experience, our passionate fears and wishes.
- Two, the issues which face our society in relation to enabling people to end their lives with love and dignity, with safety and support.

All of you, like us in our group, will have had experiences that make you hope this, or dread that. Some of your hopes and fears will be the same as some other people's; some of them will be quite different. So we would ask you to bear this in mind as we talk this afternoon. Please be sensitive to which part of your story is for yourself only, and what may be helpful to others.

Now at last we come to the spiritual side of death. Take this question of 'Whose life is it anyway?' – the God Question – the issue of how life is given and by whom it can be taken away.

Towards the end of our last gathering, we gave time to this question in a slow go-round of worship-sharing, and we started to say things we didn't know we thought or felt until we heard them coming out of our mouths.

A summary of what we came up with went like this:

- Our lives, now, may be given and taken away by medical science, rather than by God.
- When we ask, 'whose life is it anyway', we tend to assume that if our life is owned by God, then that God is the old, Old Testament God who is determined we shall do His will, and not what we really want to do.
- We don't actually believe in this God any more, in the rest of our lives. So why should we give look to this God when we think about our deaths?
- As Quakers, the value that underpins our approach to life is that of love.
- So the value underpinning our spiritual approach to death should also be that of love. As one Friend said, 'When someone is in pain or dying, they need a simple loving tenderness, care and presence.' The question we should be asking, in our care for others and in our decision-making about ourselves, needs to be – "What does love require of us in this situation?"

This felt like a kind of revelation. A liberation.

Asking what love requires of us, though, is no quick litmus-test solution. Love is more than a general benevolence. It needs courage, and attention, and a willingness to set aside preconceptions and preconditions. It requires us to live in a situation as it is, not as we would wish it to be.

We're back to the first of the Quaker *Advices and Queries*: 'Take heed, dear Friends, to the promptings of love and truth in your hearts.'

Love connects us with all the issues in the rest of our lives, its relationships and decisions. We don't have to think of death and dying separately from everything else.

For each of us, these decisions, these movements and hopes and fears, will be sometimes the same as, and sometimes different from, what they are for each and every other person. And they'll differ in each of us from time to time.

As we hear the other talks in this presentation and move towards our discussions together, I hope we can listen as much as talk, think freshly as much as rehearse our fixed opinions, and find at the end that we have given and gained in equal measure.

Alison Leonard.