

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

Ross Campbell and Ian Jamieson

## **Section 1 – The Experience of Dementia**

### **The Impact of Dementia**

#### **Q1**

**Ross** – the irregularity of my behaviour and the mood swings. I would not accept initially that there was something wrong. At the beginning I felt like a guinea pig. All sorts of medication were tried. It was difficult trying to get the balance. It took a while to get a diagnosis – partly due to the complexity of having several conditions but I still do not have a definitive diagnosis. When you have this diagnosis you find your true friends. I never hid the fact – facing the challenge. Some people avoided me – true friends stand by you.

**Ian** – I was a very angry man that this should happen to me. I had been used to lecturing and training. I did not think there was any thing wrong. It was my daughter who noticed and spoke to my wife. I then saw the doctor. It took a long time to come to term with things. Time has helped. At first I would not tell anyone and felt that it was the beginning of the end of all the things I was doing. Now I live okay with it with the help of the medication.

**Ross** – The support that I have from family – my wife and daughter is really important for me. And I could not do without them. The staff at the Joint Dementia Initiative have helped me. At the JDI you are treated as an equal – no one speaks down to you or over you. If you have a problem then people listen to you. If you have difficulties there is assistance to enable you to carry on with life as normal as possible.

**Ian** – The support of my family and my wife. I have always kept a diary and I find this helps. My wife keeps a joint diary and reminds me what I have on in the morning for that day. I am dependant on my wife and daughter and am very grateful. We are there for one another.

#### **Q2**

**Ian** – I was a church elder for 45 years. When I was diagnosed my minister visited once and that was it. I felt very disappointed by that especially as I had found it reassuring meeting with him.

### **Diagnosis**

#### **Q3**

**Ross** – Whenever a specialist diagnosis is made both the person and their partner should be told as long as the person is capable of taking the diagnosis.

**Ian** – I got a very early diagnosis. At first I withdrew then I thought to myself if I did not want this to happen to me then I was wishing it on someone else – and that was terrible. If my family had been told prior to me I would have been very angry. We never hid anything.

There are positives and negatives of being told too early as well as being told too late.

### **Person – centred Care**

#### **Q4**

**Ross** – Very useful. If it is a support worker and is usually the same person then you have confidence in that person. There is familiarity and trust in one person. This enables the person to be calm and have stability within themselves. Being there at your pace is important to enable the person to regain their confidence – because your confidence goes at first.

**Ian** – The person needs to get to know you and vice versa. Family provide person centred care.

### **Personal Identity**

#### **Q5**

**Ross** – That is very difficult to answer. It is dependent on what stage of the illness the person is at. I would like to think I would not. Are the changes people see over time just a different side to the person? There are always ways of connecting with the person i.e. talking mats. There is always hope. That is important as is the bond you have with your partner. If the time comes for a care home then shoot me first.

## **Section 2 How Society Sees Dementia**

### **Stigma**

#### **Q6**

**Ross** – A lot of people do not understand about dementia. People at my local shops know I have dementia because I told them. I think being open about it helps. When the film “Iris” was released it stimulated a lot of discussion with the staff at my local post office.

**Ross and Ian** - Better training for staff. The Mutual Support Group is about to publish a book written by people who have a diagnosis of dementia and their grandchildren. This book will be distributed to all the local primary and secondary schools in our area and hopefully will be used in the training of health and social care staff. We hope that by raising awareness we will lower ignorance.

Television programmes have included story lines about dementia. This is great as long as it is in a positive way.

#### **Q7**

**Ross** – Yes there should be more discussion and more awareness. Enabling people with dementia to be included in the training of staff. Consulting people with dementia to record their views and acting upon them.

## **The Government's Duty to Support People with Dementia**

### **Q8**

**Ian** – There should be nothing less than there is for who are sick and go into hospital. We should have the same support as anyone else in the NHS and Social Work. People need as much support in the early stages of their illness as people whose illness is more advanced.

**Ross** – The free personal care in Scotland was only given to people over 65 years. People under 65 develop dementia too – but this applies to all people under 65 who develop other conditions. This is discriminatory. There should also be no post coding and people should be treated equally in all aspects.

## **Section 3 – Making Decisions**

### **The Law on Making Decisions**

#### **Q9**

**Ian and Ross** – Advance directives. Make decisions specific. Welfare Power of Attorney. There should be more encouragement for the uptake of these. These should be advertised more. In fact these should be done as a matter of course. Present is more important – no one can foresee the future.

#### **Q10**

**Ian and Ross** – There should be joint discussions between the person, family and professionals to reach a solution. Financial and Welfare Power of Attorney should be in place.

**Ross** - For example if the person is spending too much money could it not be stipulated that the person can only have so much money per week?

### **Advance Directives**

#### **Q11**

**Ross and Ian** – Yes as a matter of course. It would stop disputes within families and reduce distress especially if a partner is left on their own to make a decision. I have discussed these things with my family and they know my decisions.

### **Welfare Attorneys**

#### **Q12**

**Ross** – The doctor is not always right.

**Ian** – Everyone should work together for the best interests of the person. If the person is a danger to themselves or others then it would need to be the doctor.

## **Section 4 – Dilemmas in Care**

### **Truth-telling**

#### **Q13**

**Ross** – You need to adapt the communication to the persons' needs i.e. taking time or talking mats. If you tell lies the trust is gone. Sometimes you need to look beyond what the person is saying. If you are going to tell lies you have to have a good memory!

### **Freedom of Action**

#### **Q14**

**Ross and Ian** – There needs to be a balance between what is good for the person and good for society in general. If the person decides to take risks then may need to be some boundaries imposed.

### **Restraint**

#### **Q15**

**Ross** – Try talking rather than restraining and that goes for drugs too. Take the time to find the problem. There is a place for restraint if the person suddenly becomes aggressive and is a danger to other people or themselves. Restraint should only be used as a last resort.

### **New Technologies**

#### **Q16**

**Ian and Ross** – We are in favour if it provides a better, safer life and benefits the person. Nothing can replace people. Decisions could be made by advance directive. Dementia dogs could be used – much more friendly.

## **Section 5 – Carers**

### **The Impact of Being a Carer**

#### **Q17**

**Ross** – When I go out with my support worker this gives my wife a break to herself. I also use the Mobile Emergency Care Scheme. This provides me with a smoke and gas detectors linked to a central control room. I also have a tilt monitor in case I collapse and a bed monitor that alerts my wife when I have a seizure. All these devices give reassurance to my wife and family.

### **Confidentiality**

#### **Q18**

**Ian and Ross** – There should be discussions with professionals about who to share information with. If in any doubt check.

## **Section 6 – Research**

### **Research Priorities**

#### **Q19**

**Ian and Ross** –

1. A cure
2. Ways of finding an early diagnosis
3. Is there a particular gene that would show dementia

#### 4. Stem cell research.

##### **Involvement in Research**

###### **Q20**

**Ian and Ross** – It should only be if the person is able to give consent – it would be open to abuse otherwise. The person should be able to stop taking part at any time. There should be a vetting process about the research itself and the researchers. There needs to be safeguards and also being able to opt out.

##### **Section 7 – Other Issues**

###### **Driving**

###### **Q21**

**Ian and Ross** – We feel that there are a lot of issues about driving. Should people be allowed to drive? If so when should they give up? Who makes this decision? It is an issue that distresses a lot of people but there does not seem to be a consensus among professionals. Some people ignore the issue totally. Are they hoping someone else will broach the subject? We feel that this is a very important issue that needs to be debated further.