

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.

Stockport Dementia Care Training
(Consultation Session)

Q1

You don't realise when a person is diagnosed with dementia what impact this will have on your life. You need a great deal of support

There needs to be dementia nurses like Macmillan cancer nurses

The dementia nurses could go into nursing homes and train staff

I forget what I learn on dementia course 3 or 4 years down the line

Q2

Physical treatment – have to fight for it. Help needs to be available to make best interests decision

Respecting individuality – within care package/services

Q6

Earlier the diagnosis the better

Carry on as normal, treat them the same

Initial approach, not to tell the person

Patient has the right to be told of diagnosis

Who decides, who should tell the person, should it be GP or carer

Some are able to be told

Is person able to understand and able to accept what is happening to them

Impact of a label

All agreed very crucial

GPs not always "spot on" – very patchy care

Other pathway?

More training

General screening

Helpful way of patient understanding the problem

Access to medication benefits

Early diagnosis important

Patient more able to understand problem at early stage

Time for decisions to be made

Communication to individual is important if early diagnosis given

Q7

Don't feel society respects people with dementia (funding)

People aren't given the same treatment by society as someone with a physical condition

Forewarning other people about the person's condition can help how the person is treated – in shops etc

Is this labelling the person

Healthcare professionals can blame other problems on dementia eg bowels

Bringing dementia onto TV and radio documentaries the more people talk about it the better

You need to give people the skills to know how to talk to people with dementia – helping to educate people

With embarrassment

With fear (and these two are often interlinked)

Most people don't know how to react or how to approach someone with dementia

I often feel under the spotlight – and I don't like having to justify his illness or his behaviour

Sometimes, people react with disbelief – 'Surely not you? But you seem so normal!' (This group contribution was from someone who has Alzheimer's)

People have had very varying experiences with friends when they discover that the person has dementia – some friends had been very supportive and had adjusted their behaviour and actions in order to still include the person and to be supportive to them and their carers. Other peoples' experiences had been quite the reverse, with long-standing friends suddenly cutting them off. Some people with the latter experience described the importance of having made new friends through support groups or dementia/carers organisations who understood the issues they face.

There's a lack of understanding

You would think it was catching, the way some people react!

Education in its' broadest sense – using the media effectively to portray more positive images as most coverage in the press is either negative or sensationalist or both.

Education in more specific sense – starting with school children (positive attitudes and information about ageing in general and also about dementia being part of the curriculum). Also ensuring that dementia and the person-centred approach are substantial elements of professional and vocational training in health, social care and education

Positive role models such as The Pointons and Iris Murdoch and her husband

The group recognised that more and more people are likely to come into contact with people who have dementia as the decades roll on and the population ages. This will make it less easy to ignore and more 'normal'

Most people in the group thought the word 'dementia' itself was scary and had very negative connotations and that an alternative was needed

Q8

Affects family

Symptoms may be confusing to others

Stigma affects patient
People fear patient
May prefer to remember them "as they were"
Care staff and nurses not always well trained to deal with dementia
Recruitment issues
Relatives need information
More positives in media

Carers all felt they had enough to think about not to worry about others' opinions, but were aware that people often shun them and the pwd in social situations.

However the pwd dementia often refuses to let carer tell others because they anticipate stigma.

The group generally felt that it should be in the open especially for safety reasons and cited examples of when neighbours had discerned or found out through an incident that there was a lot of help and support if the pwd wandered.

The group member with dementia feels it is important to be totally 'modern' and up front about his condition and finds people accepting.

Q9

People in community/public area don't expect to see people behaving differently – can be embarrassing for carer – eg behaviour in restaurant or using wrong gender public toilets

Difficult person with dementia is disabled but not always evident. Differing views of if apologise for behaviour or not

Public don't always understand what dementia is

Need more general publicity – raising awareness – more on TV

Some carers have experience of real courtesy when out in the community

Community needs to understand issues better – if don't go into community how will people know/understand

Some carers use strategy of only going to familiar places where community know the person with dementia

You have to look at the consequences – depends on the situation

Some things there is a moral right for the person to know the truth eg if a person is asking what is happening and they have insight/comprehension for it It's important also the approach and the way you tell the truth. Deliver in positive way without false hope.

Q10

Person centred care is essential to preserve individuality and give the best quality of care for a person in their circumstances.

Importance of planning future eg accommodation

When do needs of carer overtake those of cared for

Q11

Some parts do remain the same

Some aspects have changed, depending what dementia they have

Some can become very nasty

Enormously, perhaps the most important, issue to come to terms with

A major factor

Q13

We all change over the years – people's views change

It's important to have a history of a person so you can promote their wishes

Dementia is a growing problem – we need to deal with it now

Tablets – doing them correctly - try different approaches to get the person to take them – you may need to hide tablets if it's in the person's best interest

Our discussions on this were a lot less focused – many of the group reported their concerns that if a person had made an advance directive but in the later stages of dementia when they no longer had capacity they seemed to have changed their views, would this be listened to and worked with?

All agreed that the key to balancing these things was knowing the person well and their ways of communicating. Also knowing what experiences and beliefs had shaped their lives and their preferences in the past. The role of carers in helping professionals understand all of this was high on peoples' list of important things – and professionals giving enough time to hear and understand these things.

Q14

Involve person

Everyone involved - family, carers etc

More info about condition – all facts and needs, everything about the person

Really comprehensive overview

Discussion beforehand

Live wills useful

Carers should have major say and all professionals must consult with the carer (group thought most do). Strong feeling they are the decision makers and always do their best for the person.

There will always be grey areas and unpredictability of behaviour and perceptions is the major issue so carers choose the time to talk to pwd.

Any professional decisions must be transparent and back by written reasoning and proof of costings.

Group inc the pwd adamant that professionals always see the best of the pwd as they can all sustain an effort for a short time and professionals should take this into account.

Q15

Carer told would not resuscitate because of dementia – carer did not agree
Where do you draw the line if you choose not to sustain life
Issues ie quality of life and decides on quality of life – person with dementia may feel differently
Other carer's husband is not eating – in residential care – putting supplements in drinks to sustain
Ethically person needs to be cared for as they used to chose to dress etc – eg putting crease in trousers

Q16

Need more views of carer taken into account re medical issues

Q19

All said it is necessary to bend the truth, but debated how far this should go from omission to white lies; one member feeling he had to say whatever it took to maintain tranquility. Quite a bit of discomfort around this one with requests for further refreshers to look at coping strategies and 2 very specific requests seemingly supported by others to have anger management to help them control themselves.

Advanced Directives

Quite a bit of uncertainty here. All interested and feeling it to be essential, though real concerns about later changes of mind and how it would really work in practice.

Q20

Promote independence

Intervene if we thought there was a risk

Every day you assess risks, do it automatically

Individual likes and needs

Can't eliminate risks in every day life

Safety of individual paramount – this could/can lead to conflict

Q21

Other people's and person with dementia's safety versus sedation and restraint
Actions can be a cry for help

The person in our group who has dementia said 'I am used to being in control of myself and other people and hate the idea of someone having to control me'

The carers in the group felt that there were times when restraint was inevitable and that it all hinged on what was 'reasonable and proportionate'

There was also some discussion about the need for training for staff and carers alike about safe techniques for restraint (or better still de-escalation)

Q22

Question divided the group. Some feeling that it would do no good as you can only do what you think right for your loved one. Others would welcome more space to explore issues and possible consequences, either in occasional one off sessions like today or more incorporated into the Carers group training. Refreshers were requested and evening sessions like today.

Q24

Social can help resolve – family disputes/conflict

Financial support required

Day care really good – allows respite

Acknowledge social services have offered good services – person care and day services

State should pay towards all respite care – as Scotland (standard payment)

Q26

Weigh up priority of everyone involved and also risk

Communication and close networks are important

It's difficult to know when to try and resolve things

It's important to think ahead and plan

Q27

Don't listen to the carer/partner

Don't ask the opinions of partner sometimes

Invasion of privacy

Interest of everybody that all should be communicated because the two cannot be separated

If carer's health is compromised it then has an effect on the person you are caring for

Carer needs help, but they often don't know where to get the help from

Opinions would help – recommendations from professionals advantageous – final decision must be with family

Professionals should not make recommendations that may rely on funding from local authority
Always. No debate needed.

Q28

Carers felt health not giving all information
GPs very in terms of how much medical info is shared
General agreement that carers are advocates for person with dementia and should be told medical information about person with dementia
Alzheimers/Dementia clinics at GPs would be good idea to review dementia conditions if nurse to come to home to review 6 monthly
Carers so involved in caring often don't see issues with own health as so involved with person caring for
Companies are hard to deal with – gas, electric, banks – if you need to sort things out with them for a person with dementia. These companies need a written code of practice in this area to make it easier for people
It's difficult discussing things with a doctor due to confidentiality
Data protection act makes it too difficult to help a person – something needs to be written into the act to help carers
This was a good news scenario! All members of this group had only positive stories to tell about the way in which information was shared with them by all the professionals they had come into contact with in Stockport.