

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.

Alzheimer Scotland

Introduction

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people with dementia and carers in getting their views and experiences heard. We provide specialist services such as day care, home support and carer support (through training programmes and support groups) in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications. Our values and principles are set out in Appendix 1.

We welcome the opportunity to respond to the consultation on ethical issues facing those caring for people with dementia. Ethical dilemmas emerge not only from the impact of the illness on the autonomy and independence of the person with dementia but from past and present relationships between the person with dementia and the primary carer and because both have different sets of needs, which may come into conflict. Problems may also be exacerbated by the limited choice and quality of services available; and sometimes by the lack of understanding about the illness by other family members and the community. Carers and family would benefit from guidance on how to respond to these issues and the difficult decisions they have to make.

Alzheimer Scotland has focused on rights and legal protection issues and campaigned for legal reforms over many years. Our response to your survey is informed both by this work and responses we invited from our members, branches and staff to your questionnaire.

Dementia in Scotland – prevalence, legislation and policy

There are currently 59,000 to 66,000 people with dementia in Scotland, 1,350 to 1,650 of whom are aged under 65. As our population ages there is projected to be a 75% increase in the number of people with dementia in Scotland by 2031.

In Scotland we now have in place comprehensive legislation to support the rights of people with a mental disorder who are unable to make some or all decisions for themselves, to give authority to others to make welfare and financial decisions on their behalf and to protect those at risk of harm i.e. the Adults with Incapacity (Scotland) 2000 (AWI) the Mental Health (Care and Treatment) (Scotland) Act 2003 (MHA) and the Adult Support and Protection (Scotland) Act 2007 (ASP), the Protection of Vulnerable Groups (Scotland) Act 2007 (PVG). People with dementia and their carers are the largest group to benefit from these legal reforms. The following principles, which are close to those in the Mental Capacity Act 2005, provide a helpful guide to the 'process' that carers need to apply when faced with making difficult decision/s

- benefit the person in a way that cannot be achieved otherwise;

- be the least restrictive option in terms of the person's freedom;
- must seek the persons past and present wishes, with the aid of assistive technology, and/or specialist professional help as appropriate;
- take into account the views and wishes of others with an interest in the person (where reasonable and practicable to do so);
- encourage continuing use of the person's existing skills and, where possible, learn new ones.

Another significant policy development is that the Scottish Government has made dementia a clinical priority. We know that only about 50% of people with dementia have a formal diagnosis. The government has set targets to increase diagnosis and is providing funding for the piloting of post-diagnostic support services; priorities for dementia care are set out within Standards for Integrated Care Pathways for Mental Health (December 2007). Government has also invested in the provision of 80,000 guides for carers 'Coping with Dementia – a handbook for carers' and guides for people facing dementia themselves, both developed in collaboration with Alzheimer Scotland. We have also initiated a project to produce information guidelines for professionals, including an information 'grid' which sets out published information available to carers and people with dementia appropriate to their information needs at different stages of the illness.

The experience of dementia

Q1. What aspects of dementia have the greatest impact on the lives of people with dementia and their families, their carers and society more generally? What kind of support is needed most by people with dementia and those caring for them?

The progressive nature of dementia means that the aspects of the illness that have the greatest impact change as the condition progresses. For the person with dementia the early stages of the illness are a frightening time; learning that he/she has a progressive terminal illness and worrying what the future holds can be devastating. As the illness progresses the greatest impacts include the loss of independence and having to rely on others to meet the needs of everyday living, feelings of insecurity, frustration, which can affect individuals differently e.g. becoming frustrated, agitated or withdrawn.

Dementia also has a significant impact on the families, particularly the primary carer. This includes unpredictability and changes in the behaviour of the person with dementia, enforced change of lifestyle e.g. giving up work or changing to part-time work and having to live on a lower income as well as dealing with additional costs of caring; having to plan ahead, worry of doing things right, loneliness and lack of understanding from others. Research suggests that behavioural changes e.g. turning night into day, personality changes and double incontinence are the most stressful and the most likely to affect the mental and physical health of

the carer, leading to placement of the person with dementia in a care home.

In terms of support, the over-riding issues for carers are the need for:

- clear information about the illness and services available to help;
- speedy referral and assessment;
- services which are flexible in terms of when, how and where they are provided;
- services that are well co-ordinated throughout the illness as changes occur;
- services that are consistent and reliable;
- delivered by a dedicated staff team, trained in dementia care;
- ready access to specialist help when needed e.g memory training; continence management; behaviour management.

The type of support needed will change and increase as the illness progresses. It is estimated that approximately 60% of people with dementia live at home, and that about a third live aloneⁱ. Initially there is a need for information about the illness, legal and financial implications and sources of support. As the illness progresses, access to good quality community health and social support is vital; this includes day care, home support, respite and continued involvement from the GP and other health care professionals. Anti-dementia drug treatments can make a significant improvement in the quality of life for some people with dementia. In the later stages of the illness people will need full time care, with approximately 40% of people with dementia living in care homes. People with dementia are known to function best when accommodation is provided which meets 'dementia friendly' design principles, inside and outside the buildingⁱⁱ; provided in small, local, domestic-scale units close to where people live, and provided by dementia care trained staff who are able to support the person's changing needs and respond positively to any desire by family and friends to continue to be involved in the person's care.

Q2 From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

Ethical dilemmas will occur throughout the illness, in particularly when the person with dementia becomes less able to communicate their wishes and/or make some decisions for themselves. Carers would benefit from guidance to help them negotiate these issues, including consideration of the need for legal authority to act on behalf of the person. Those contributing to our response raised the following situations from their own personal experience:

- conflict of needs between those of the carer and those of the person with dementia e.g. whether to struggle on caring for a relative at home whose needs have become too demanding for the

carer to cope with, or to seek a place in a care home against the person's wishes;

- whether to accept respite care when past experience has been poor;
- whether to tell the person their diagnosis when the doctor has not done so; or to remind the person with dementia of their diagnosis when things go wrong;
- whether to assist with feeding in the later stages of the illness – where the carer considered this to prolong an unsatisfactory life;
- whether to donate the person's body for medical research after death – where the person with dementia supported medical research but did not leave specific instructions.
- Family conflicts over what is 'best' for the person with dementia; and the level of risk that different family members feel able to tolerate at the expense of the liberty of the person with dementia.

Q3 From your experience, do different ethnic, cultural or social groups have different understanding of dementia? If so, are these different understanding relevant to the care of people with dementia?

Alzheimer Scotland recognises that the symptoms of dementia may be regarded differently by different cultural groups, for example, as a normal part of ageing. As an organisation, over the last 10 years we have targeted projects to different black and ethnic minority groups. Our first was to work with the community leaders of the Indian and Pakistani communities, to raise awareness of the illness and provide information on help available. However, in the south east of Scotland the largest minority ethnic groups of older people are from Eastern Europe i.e. Poland and the Ukraine. We currently provide support services to these populations and to health and social care professionals who work with them.

As an organisation we have experience of delivering care in many island and remote rural communities. The experience of one of our island based services is that GPs are reluctant to diagnose dementia because of the stigma that is attached to it. The island communities are generally more self-sufficient and reliant on traditional extended family to cope with difficulties. Outside support is usually sought as a last resort and then usually home support is preferred to attendance in a day care centre.

However, it is likely that, similar to younger people with dementia, people from different cultural groups will face problems in having their specific needs recognised because of the low numbers.

Q4 What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

Care and support should be sympathetic to the traditions and values of different cultures. Services should be flexible to accommodate these and able to respond, for example, to the dietary, spiritual and hygiene needs of individuals, including the appropriateness of having a male or female care worker.

In 2001 there were 101,677 people in Scotland from black and minority ethnic communities; equivalent to 2% of the population of Scotland at that time. In 2004 it was estimated that 228 people in this population had dementiaⁱⁱⁱ.

Q5 What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

Advancements in medical treatments for people with dementia pose ethical considerations for the care and treatment of people with dementia. It is already the experience that drug treatments for people with dementia are denied to those in the early stages of the illness on the NHS due to cost. Further developments in medical treatments are likely to intensify further rationing with Quality of Life (QOL) formula, which is not a helpful tool in the case of dementia where benefits can be subtle but equally important. The most significant scientific development relates to the announcement of a phase 2 study in relation to a new treatment which aims to halt the progression of Alzheimer's disease (Aberdeen University with TauRix Therapeutics LTD).

Q6 Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

As an organisation we promote early diagnosis of dementia by an appropriate professional^{iv}. We acknowledge that making a diagnosis and telling the patient is often difficult, particularly in the early stages. However the risks are well understood i.e. misdiagnosis can be avoided given the availability of specialists with access to sophisticated diagnostic techniques; the risk of knowing the diagnosis leading depression or suicidal thoughts – which can be anticipated and countered by giving information about the illness sensitively and providing emotional support before and after diagnosis, including the offer of counselling. Many people with dementia express their relief at being given the diagnosis because they knew from the reactions of others that something was wrong and they felt they were 'going mad'. The earlier a person is diagnosis the sooner they can come to terms with the illness, start treatments which may (in some cases) slow progression, make plans for the future and access services that can help.

The majority of those who contributed to our response were in favour of early diagnosis for the reasons outlined above. However, there were some who were not in favour of early diagnosis because dementia is a degenerative illness with no cure. We know that some GPs also hold this view, but we believe it is misplaced. In some areas GPs are the

gatekeepers to specialist dementia care services which can provide practical and emotional support.

"The diagnosis should be communicated to the person by an appropriate professional who can answer the person's questions and provide signposts to further information and support. The person should have the opportunity to have a person of their choice present at the diagnosis."
Person with dementia

Q7 In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how?

Many of those who contributed to our response felt there had been improvement in awareness of dementia in the general public in recent times. However, there are still misconceptions in society and much work still needs to be done to inform society that dementia is not a natural part of ageing. In Alzheimer Scotland's public awareness survey 30% of respondents considered dementia to be a natural part of ageing, with 32% believing that the majority of people with dementia lived in care homes^v. It is important to promote a better understanding of dementia so that: symptoms are recognised early and acted upon so that the person will feel able to seek a diagnosis, without fear of stigma; and be offered information (including legal and financial) and emotional and practical support; so families respond appropriately when worried about the person and encourage medical intervention; so individuals and carers can access services to enable both the carer and the person with dementia to carry on living as normally as possible for as long as possible; also with support and understanding from the local community e.g. shops, leisure centres, cafes, faith communities etc. It is also important that the general public are informed of how they can reduce their risk of getting, for example, vascular dementia.

A key objective of Alzheimer Scotland is to raise awareness of dementia through the media and publicity campaigns, as well as our 'Creating Dementia Friendly Communities' programme (which includes a schools pack). However, raising funds for such activity is difficult. We believe the way forward is through a government funded, multi-stranded national strategy with specifically targets public attitudes to dementia (the general social inclusion policy is not rigorous enough). We have welcomed the Scottish Government's commitment to working with stakeholder groups, and its recent provision of funding to enable the development of a publicity programme (which is still at the embryonic stage).

The mass media has an important role to play in providing accurate information about dementia and in changing attitudes/reducing stigma.

Q8 What part, if any, does stigma play in the process by which people seek care, treatment and support for dementia?

Fear of dementia and concern over the stigma that the illness carries can often make people unwilling to speak to their GP about worrying symptoms. Dementia is often a taboo subject even amongst friends and

family. An unpublished survey by the organisation a few years ago indicated a delay of between 6 months and 2 years before seeing the doctor about symptoms. A main factor was that the onset was gradual and assumed/hoped to be a normal part of aging.

Q9 Should more be done to include people with dementia in the everyday life of communities? If so how, and if not, why?

Many people with dementia and their carers suffer from social isolation because of the difficulties they face in going about their daily lives. However, social contact and activity is important for people with dementia to maintain skills and remain independent for as long as possible. Lack of stimulation and activity may result in premature decline and depression.

The majority of those contributing to our response were in favour of the person with dementia being encouraged to continue to participate in community life. It is important that activity is within the persons capabilities, focusing on what the person can still do. The decision to participate in community activity should be a matter of personal preference for the person with dementia.

There are a number of measures that can help people with dementia and their carers feel they are still valued members of the community including:

- Public service staff and others serving the public should receive disability awareness training that includes dementia
- Customer care policies that take account of the special needs of people with dementia
- Local community groups should inform themselves and disseminate information amongst members
- Specialist community-based projects to provide support workers for people in the early stages of dementia.

Alzheimer Scotland's guide on *Creating dementia-friendly communities*^{vi} aims to increase public understanding about dementia and sets out ways in which the whole community can best help people with dementia and their carers to remain part of the community.

Person-centred care and personal identity

Q10 Is the idea of *person-centred care* helpful, and if so, in what way?

The concept of person-centred support, or 'personalised' care as the term currently used, is of central importance. In practice it means that the needs of the whole person should be assessed and services provided which are responsive to the needs of the individual. Fundamentally, Single Shared Assessments should be comprehensive, with a rehabilitative philosophy: to include an assessment of the person's physical, social, psychological, and spiritual needs. Service provision should be flexible in order to provide care that is suited to the individual's needs rather service expediency. In practice people often have to fit the service. Alzheimer

Scotland's recent research on community care services for people with dementia highlighted inflexibility of service models^{vii}.

Q11 In your view, to what extent is it correct to say that dementia changes a person's identity?

The majority of those who contributed to our response felt that whilst behaviour changed, at least some of the person remained. In the latter stages of dementia carers still talk about experiencing glimpses of who the person was. The long-term memory of people with dementia is often intact and the use of reminiscence to evoke positive experiences and memories from the past can help to reinforce the person's sense of self amongst the confusion of the present. The creation and use of 'Life Story Books' with the person with dementia have proved to be of value for staff in care homes as well as relatives in keeping hold of their own sense of the individuality of the person being cared for.

Dementia affects a person's ability to communicate as they would have in the past and it is important that those directly involved with the care of the person learn communication skills and find new ways of engaging with the person to understand their needs and wishes.

So-called 'personality change' e.g. the person becomes apathetic or aggressive - may be exacerbated by triggers in the environment or caused by depression or paranoia caused by the dementia. It is important that such symptoms are drawn to the attention of a specialist dementia nurse, psychologist or consultant in old age psychiatry so that they can be addressed.

Q12 What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?

Many carers find changes in the behaviour of the person with dementia extremely difficult and often feel guilty seeking professional help when they can no longer cope; learning to understand the meaning behind the actions will help with responding to challenges. Carers can feel abandoned by family and friends who are not able to cope with the changes in the person with dementia or do not recognise that the person's behaviour is caused by their illness.

Making Decisions

Q10 What do you think family or friends should do if they are worried about the decisions a person with dementia is making? (short version of consultation)

This will depend on a number of factors. It would help for the family to ask themselves a series of questions e.g. is the person acting 'out of character' and making the sort of decisions that they would never have made in the past? Has the person always enjoyed taking risks or taking unusual decisions? Are the decisions the person is making against his/her own interests/creating risks? Simply because the person has a diagnosis

of dementia and may lack competence to make some decisions, does not mean that they are incapable of making others.

However, if there is a marked change in behaviour or the person appears to be unaware of, or lacks understanding of the risks then it would be wise for the family to seek advice from the person's doctor.

Action which might be taken by family and friends will also be conditioned by whether the person has been told of their diagnosis, has accepted it, and has some understanding of the impact the condition may have on his/her behaviour. If this is the case then, in the first instance, it will be important for those closest to the person to talk sensitively to him/her and discuss the possibility of appointing a welfare and/or financial power of attorney. The person needs to understand the implications of doing so. This is quite possible even though they may be losing or have lost competence in the areas of decision-making that others are concerned about.

If the person lacks competence to instruct a power of attorney, and the specific decisions the person is taking are putting him/her at risk of harm, the family should seek advice from a health or social work professional. If the person is assessed by the GP as lacking in competence in specific areas e.g. managing money, then the family should consider applying for authority to act on behalf of the person:

'In Scotland we have an excellent piece of legislation which directs this i.e. Adults with Incapacity Act' Alzheimer Scotland Branch

Q13 When judging the best interests of a person with dementia who lacks capacity, how should the person's past wishes and values be balanced with their current wishes, values, feelings, and experiences?

First a comment on the use of the term 'best interests' within capacity legislation north and south of the Border. In Scotland the AWI uses the test of 'benefit' rather than 'best interests,' as, at the time of consulting on the legislation, the latter has been criticised as being too paternalistic in the context of adult welfare, and thought not to give enough emphasis to the views, wishes and feelings of the adult. Benefit is not simply what might be in the adult's best interests but encompasses what the adult could reasonably have expected to have chosen to do if capable, even if it is of an unselfish nature. Taken together the principles mean that a decision on behalf of an adult takes account of more than just what is 'best' for him or her. To quote Hilary Patrick^{viii} 'this approach reflects good practice and reflects current concerns about human dignity and autonomy'. Secondly, capacity is not all or nothing. Where the person understands the options and consequences of their actions or decisions, their present views and wishes should be respected, even if they differ from the past. However, if his/he current wishes and values are totally at odds with the past, then it would be helpful to try to understand the change, for example, whether it is based, for example, on a sense of insecurity, fear or as a consequence of the illness e.g. disinhibited

behaviour; or because the person is genuinely enjoying doing things differently.

Our respondents, including people with dementia, all stressed the importance of communication and the need to explore the person's current feelings. Family carers or paid carers should not assume that they know best. It is important that the person with dementia feels happy now. It is important to listen to the person with dementia.

It is dependent on individual circumstances, which should be assessed in each case. Past wishes have their place and it is important to be supportive in maintaining dignity for who the person was. However, present wishes are also important and the person with dementia should feel happy now... the here and now matters. Carer

Q14 What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just?

We are not sure what is meant by 'only just'. An assessment of capacity must be decision specific and subject to the tests set out in AWI. AWI principles must be applied to any decision by others on behalf of the adult. The individual must be supported to communicate their past and present wishes by all means possible i.e. with the aid of assistive technology, specialist professional such as a speech and language therapist, independent advocate. Capacity of someone with dementia can fluctuate over the course of the day e.g. the person may have times when they have clarity but other times, due to tiredness or medication; their views should be sought when the person is at his/her best and if necessary on several occasions where there are memory problems. This can provide a good test of consistency in relation to wishes with regard to a specific decision. If the person has recently lost capacity to make some decisions then the possibility of the person appointing an attorney should be explored. A recent guide, 'Adults with Incapacity Act: communication and assessing capacity' although targeted to health and social care professionals has been found to be helpful by carers.^{ix}

Q15 How should a diagnosis of dementia influence decisions about best interests and appropriate care in connection with life-sustaining treatment?

In the final stages of dementia patients may not be able to recognise food, may be unable to chew or swallow and may lose weight very rapidly. In severe cases, where a patient cannot accept food by mouth, then in order to avoid starvation and dehydration, nutrition may be given by another route i.e. either PEG feeding or nasogastric feeding. The patient with dementia will never recover or regain the ability to feed themselves. The ethical question is around the use of these methods as a permanent method of feeding. We have experience of cases where a

doctor in an acute ward has insisted on introducing PEG feeding of a patient with very severe dementia against the wishes of the family. In one situation the carer was an attorney with medical decision-making powers but was not informed of her right to seek a second opinion.

As with any other major decision, the AWI principles are extremely helpful in deciding what to do where quality of life becomes a predominant issue. Even someone with severe dementia may still be able to communicate his/her feelings, possibly non-verbally. The person's advance statement, if there is one, must be taken into account, although his/her current views must over-ride this.

Q16 What role do you think welfare attorneys should play in making healthcare decisions on behalf of people with dementia who lack capacity? How do you think both minor and more significant disagreements between attorneys and health professionals over the best interests of the person with dementia should be resolved?

In Scotland, welfare attorneys can only make health care decisions where this is specified in the power of attorney document. However, even where the person with dementia has a proxy decision-maker, the doctor must assess their capacity to consent to the treatment in hand. If the person lacks capacity then the attorney becomes the decision-maker on behalf of the adult and the doctor must seek his/her consent (so far as is reasonable and practicable). Ideally disagreements will be resolved through dialogue between doctor and proxy. But where this is not possible then either the doctor or the proxy can seek a second opinion from a list held by the Mental Welfare Commission for Scotland. In this case if the 2nd opinion doctor agrees with the responsible medical practitioner then the proxy must abide by it and vice-versa, if the 2nd opinion doctor agrees with the proxy then the patient's doctor must abide by the proxy's decision. However if disagreements continue then either party, or indeed anyone else with an interest, can appeal to the court of session.

The general response from our members was that where the attorney has been entrusted with medical decision-making power then they have a right to make the decision.

However, beyond that, responses indicated a lack of knowledge amongst carers about their rights under AWI. In fact the law gives carers and any one with an interest, a **right to be consulted** with regard to care and treatment matters (where reasonable and practicable) and same right as legally appointed proxies to a 2nd opinion and appeal to the court of sessions. This information gap for carers is currently being addressed by the Scottish Government and a booklet for carers on consent under AWI is being prepared.

Q17 What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?

In Scotland, under AWI, advance directives don't have the force of law, but must be taken into account as an expression of the person's past wishes. There would have to be good reason as to why their wishes should be over-ruled. Under the MHA advance statements are legal in so far as they relate to treatment for mental health and must meet certain specifications to be regarded as valid.

Most respondents felt that people should be encouraged to make advance directives and considered them to be beneficial, with the qualification that they should be reviewed at regular intervals. The person's current wishes were felt to paramount.

Q18 What are your views about the effect of the *Adults with Incapacity (Scotland) Act 2000* or the *Mental Capacity Act 2005*, or both, on the care of people with dementia? Has the introduction of these Acts made it easier, or harder, to support and care for people with dementia?

Prior to AWI the law was fragmented, limited and cumbersome; incapacity was regarded as 'all or nothing' and people with incapacity had little or no rights. Carers had great difficulty in providing support to their relative with dementia, especially in terms of being able to manage their finances. There was no legal mechanism for dealing with family conflicts over care decisions and it was often whoever shouted loudest who took over control, with no checks or balances.

The Act, and associated changes, has made it easier for carers to provide support. In terms of financial management, a joint 'either or survivor account can continue to be used when one of the signatories has lost capacity – in the past the account would have been frozen. A new provision called 'Access to Funds' aims to support those with modest or uncomplicated assets and income through an application which can be made by a carer, or in the absence of a carer, an organisation, to the Office of the Public Guardian. Where funds are significant and asset management is required, then an application for financial guardianship may be made to the sheriff court. Families can also apply for welfare guardianship where important and ongoing decisions need to be made regarding the welfare and health of the person with dementia. Applicants for welfare or welfare and financial guardianship are entitled to free legal aid. Since 2002 approximately 900 private guardians have been appointed.

It is not always necessary to seek the appointment of a welfare guardian where the person with dementia is unable to consent to community care services which they have been assessed as needing. In Scotland local authorities have the power under the Social Work (Scotland) Act 1968 to provide services in circumstances where there is agreement by carers and

professionals on the best course of action and where the person with dementia is not resisting. This power was clarified with an amendment passed through ASP in March 2007.

AWI introduced welfare powers of attorney and enables the appointment of joint welfare and financial powers of attorney, with enhanced safeguards. Alzheimer Scotland encourages the up-take of powers of attorney by people in the early stages of dementia and promotes information giving about powers of attorney to professionals involved in giving a diagnosis and post-diagnostic support. It is interesting to note that the uptake of powers of attorney within the general population has mushroomed.^x

Aspects of care and support

Q19 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

If the person with dementia has capacity to understand then it should never be permissible not to tell the truth. However where capacity to understand is compromised by the illness there can be no hard and fast rules. The person with dementia may be distressed by the truth whereas not telling the truth may result in increased confusion. Where the person, for example, is constantly seeking out a deceased spouse, it may be, more appropriate to recognise the person's sense of loss, empathise with their feelings, and perhaps look at old photographs, rather than simply repeating the stark truth. People with dementia have their own rational and often make sense of the present by relating back to the past. Again a helpful response might be to confirm similarities between present and the past familiar situation without colluding.

Q20 In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

Every individual should have a care plan which addresses quality of life issues and how risks for that individual can be managed. The Mental Welfare Commission's Good Practice Guide: Rights, risks and limits to freedom (2006) very helpful for carers as well as practitioners.

In general, responses received reflect the following: it is thought important for the person to be encouraged to continue doing things for themselves and that risks should be managed. It is more important to review tasks and the environment of the person with dementia to try to prevent accidents rather than limit activity. Quality of life is important.

'It is better to err on the side of risk if it improves the quality of life for the person with dementia' Carer

The predominant concern is about risks in the environment for people with dementia who want to walk and may get lost, have an accident or be at risk of abuse from others.

'My father wanted to go out every day and wander about Edinburgh, it got to the stage that my mother was worried sick about what might happen to him; but he was determined so she put up with that risk. People are different and have different risk thresholds.' Carer

However, the carers anxiety and risks might have been reduced if the care plan had identified the need to find a volunteer befriender to accompany the husband on his walks.

Cares and practitioners recorded a variety of attitudes to risk and risk management, despite the use of the Single Shared Assessment tool. Legal departments of health and social work authorities tend to be 'risk averse' to the extent that it may lead staff to be over-cautious and unnecessarily limit the freedom and quality of life of people with dementia. Limitations are often caused by lack of resources to provide the necessary supports e.g. to go out walking in the evenings when someone is restless; or a lack of understanding about what practical measures might be put in place to reduce risks. Carers can also be over-cautious and this view was reflected by some of our support staff. However, staff also felt that insufficient attention was given to the introduction of risk-reduction measures (SMART technologies) and other forms of support, by some local authorities, and that the stress and anxiety experienced by cares could be reduced.

Q21 Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

AWI does not allow the use of force or detention, unless it is immediately necessary and only for so long as it is necessary in the circumstances i.e. to protect the person from harming themselves or others. This was also the consensus view of our respondents. Better staff training and awareness of needs of people with dementia was regarded as important with an emphasis on training for those administering restraint.

Some carers felt that there may be a need in the persons own home to also use some mild form of restraint: e.g. where the person with dementia wanted to follow the carer into the kitchen whilst she was cooking and afraid of risks, the carer resorted to converting her kitchen door into a 'stable-door' so that the person could see her and they could talk in safety; persuading the person the sleep in a separate bed at night (where the couple had previously shared a double bed).

Guidance from the Mental Welfare Commission is helpful for carers as well as paid staff. If someone needs to be restrained on a regular basis then the carer (paid or family carer) should call for an immediate review to assess the situation and find ways of managing by using psycho-social interventions in the first instance. If the person with dementia is refusing medication then this should be addressed by the professionals and carers

involved with the care of the person to assess the problem and find a resolution which does not require the use of restraint e.g. in certain circumstances the use of covert medication may be agreed.

Q22 Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?

Carers are faced with making very difficult decisions where the physical and mental abilities of the person with dementia are failing. They are faced with many difficult dilemmas including conflicts of interest within the family about what is best for the person. The application of the AWI principles can be very helpful in such circumstances but carers need to be aware of what these are and how they can be applied. Carer education/training programmes could include specific sessions on ethical decision-making and empowerment for the person with dementia. Scotland has carer training programmes and support groups in place and these issues arise from time to time. In response to this question, our carer support staff felt that it is something that carers would welcome, but probably find too difficult to initiate a request on this uncomfortable topic themselves. It was agreed that training for carers support staff and their line-managers would be essential.

'It is an important issue. I know not everyone feels able or comfortable being involved in these "deep" topics but it is important. Carers often want to know and we should be able to discuss openly and support them'. Carer Support Worker, Alzheimer Scotland

Statutory funding could be made available through the national carers strategy, and in particular through carer information strategy of each health boards to develop training and support materials and pilot sessions on decision-making and dementia for staff (statutory and voluntary) who provide support and information to carers; and to develop a specific session for carers as part of carer training programmes.

Q23 What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?

New technologies, such as sensors and memory aids, can give the person with dementia confidence and enable them to retain a level of independence for longer than would have otherwise been possible. They may also allow carers to monitor the person remotely, offering help when it is needed. However, the benefits must be balanced with the loss of privacy and negative impacts. For example a voice through a speaker system into the home from a remote location may increase confusion in the person with dementia. The use of such technologies should always be part of a care plan and the person with dementia involved in the

decision. The use of such technologies must never compromise the dignity of the person or be a substitute for human support. Mental Welfare Commission, Good Practice Guide: Safe to Wander, is very helpful.

Q24 What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

The state has a responsibility to ensure there is an equitable system of health and social care for people with dementia and support for their carers. It should

- ensure that people with dementia are treated as equal citizens and not discriminated against;
- to ensure the full implementation of legislation to promote and safeguard the rights of people with dementia;
- a duty of care towards people with dementia;
- a duty to support carers as equal partners in the provision of care for people with dementia

Dementia is a long term progressive, terminal illness. The state has a responsibility to ensure there is effective strategic planning and funding in place to respond to the needs at a local level.

Needs of carers

Q25 How can conflicts between what is best for the person with dementia and what is best for the family carer(s) be resolved, especially as dementia progresses?

The person with dementia and the carer both have a right to have their needs assessed independently; the views of the carer as well as the views of the cared for person should be taken into account by local authorities before deciding on services to be provided^{xi}.

Support services that respond to both the needs of the person with dementia and the carer can help to resolve conflicts. For example overnight respite should be seen as providing a beneficial service to the person with dementia as well as the carer.

Q26 What role should health or social care professionals play in helping resolve such conflicts of interest? What ethical dilemmas do they experience when helping families with a family member with dementia?

Health and social care professionals have a role to play in resolving conflicts of interest when the carer is having difficulty coping or the person with dementia cannot express their views. Advocacy for the person with dementia can support them in making sure their views are represented. Carers, especially those who are elderly or with a disability themselves, may also benefit from having an independent advocate. However carer advocacy services not available in many areas.

It can be difficult to resolve conflicts to the satisfaction of both the person with dementia and the carer; professionals may face the dilemma of prioritising the needs of one ahead of the other. For example they may be placing the person with dementia in respite care knowing that it is not in their best interests, but the carer is in desperate need of a break from their caring role.

Q27 In what circumstances might it be appropriate for health or social care professionals to make judgments about the best interests and needs of a *couple* (or of a household), instead of concentrating solely on the interests and needs of the individual?

The majority of people with dementia live at home with the majority of care giving provided by family members. The quality of life of the person with dementia and their primary carer are mutually dependent. It is important for health and social care professionals to take a *relationship-centred approach*, viewing the person with dementia within the context of important and significant relationships^{xii}.

As dementia is an illness that largely affects older people the primary carer may also have care needs of their own; older couples often support and complement each other.

“My husband and I continue to support each other, my physical problems increase as his cognitive facilities decrease” Carer

It is appropriate to make judgements about the best interest of the couple (or household) to ensure that both needs can be addressed in the same location; enforced separation can be devastating for older couples. This may mean providing additional support to the couple to remain living at home or sourcing long term care that meets the needs of both. More provision of both sorts should be made available.

Q28 From your experience, do you think that concerns about patient confidentiality result in family carers being given too little or too much information about the person they care for? How should a professional caregiver decide how much information to share with families?

Family carers are crucial to the care of people with dementia. Under the Health and Community Care (Scotland) Act 2002 carers who provide a regular and substantial amount of care are to be regarded as partners in the provision of care. This has clear implications for the sharing of information. Carers will know the person best and well are well placed to advise and inform professionals. They will want to ensure that the person is receiving the care they need. However, friction can arise when family carers feel they are not given the information they need to help care for the person. Where the person with dementia lacks capacity to consent the AWI principles are very helpful. In addition, government guidelines advice is to share information on a ‘need to know’ basis with carers.

If the person with dementia is able to give or withhold informed consent then their wishes must be respected. However they may be counselled

that, because the illness is progressive, they may wish to agree to sharing information at a later point.

Research

Q29 What should research into dementia be trying to achieve? On what basis should funding be allocated?

It is important that research into dementia achieves a balance between developing treatments, looking for the causes of dementia and understanding how to best care for people with dementia.

Priorities for dementia research:

- the causes of dementia
- factors that reduce or increase risk of developing dementia
- development of tools for assisting in the early accurate diagnosis and monitoring of the disease progression
- pharmacological and therapeutic treatments
- development of social care and support.

The level of research funding given to dementia research in the UK as a whole does not reflect the prevalence and cost of the illness. The amount of research funding is 3% of that spent on cancer research^{xiii}.

Q30 What is your view on involving people in research if they lack capacity to give consent themselves? Under what circumstances, if any, should such research be permitted? What safeguards would you choose and why?

In Scotland this question is answered by AWI Part 5, Medical Treatment and Research. It mirrors the European Convention on Bioethics and Research on adults who are able to give informed consent. There was a strong consensus amongst carers and professionals on this part of the legislation during the consultation period. The conditions are:

- the research is likely to produce real and direct benefits to the adult
- the adult does not indicate an unwillingness to participate in the research
- the research has been approved by the Ethics Committee
- the research entails no foreseeable risk, or only a minimal foreseeable risk to the adult
- the research imposes no discomfort, or only minimal discomfort to the adult;
- consent has been obtained from any welfare guardian or welfare attorney who has powers to consent to the adult's participation in research, or where there is no welfare guardian or attorney, from the adult's nearest relative.

Where the research is not likely to produce real and direct benefit to the adult, it may nevertheless be carried out if it will contribute to a significant improvement in the scientific understanding of the adult's incapacity to the attainment of real and direct benefit to the adult or to another persons having the same incapacity, provided the other circumstances or conditions mentioned above are fulfilled.

The proxy or relative must take into account the past and present wishes of the adult.

Q31 Does the current legal position, together with the requirements for independent ethical review of research projects, prevent any research which you believe would be valuable? If so, could any changes in the regulatory framework be ethically justified?

An issue of concern for us that has been raised by social researchers is the difficulty they have in getting psycho-social research. However, we understand that this issue is currently being addressed.

Other Issues

Q32 Are there any other ethical issues relating to dementia that we should consider?

- Sexuality and dementia, including ethical issues that occur for existing relationships and new relationships.
- How older people are treated in society compared to other age groups in relation to health, social care and the benefits.

ⁱ Alzheimer Scotland (2007) *The Dementia Epidemic – where Scotland is now and the challenge ahead* Edinburgh

ⁱⁱ Alzheimer Scotland (2000) *Planning signposts for dementia care services* Edinburgh

ⁱⁱⁱ Alzheimer Scotland (2007) op cit

^{iv} Alzheimer Scotland (2005) *The right to know*.

^v Public opinion survey carried out for Alzheimer Scotland by Market Research UK Ltd November 2007

^{vi} Alzheimer Scotland (2001) *Creating dementia-friendly communities: a guide* Edinburgh

^{vii} Alzheimer Scotland (2008) *Meeting our needs? The level and quality of dementia support services in Scotland* Edinburgh

^{viii} Hilary Patrick (2006) *Mental Health Incapacity and the Law in Scotland* Tottel Publishing

^{ix} Scottish Government (2006) *Adults with Incapacity (Scotland) Act 2000, Communication and assessing capacity. A guide for social work and health care professionals*. Webbased publication only: www.scotland.gov.uk/justice/incapacity

^x Office of the Public Guardian website www.publicguardian-scotland.gov.uk

^{xi} Community Care and Health (Scotland) Act 2002

^{xii} Ryan T et al (2008) Using the senses framework to achieve relationship-centred dementia care services.

Dementia – the international journal of social research and practice 7(1) 71-92

^{xiii} Alzheimer Research Trust <http://www.alzheimers-research.org.uk/>

Other references: Mental Welfare Commission guides

Nutrition by artificial means (March 2007)

Cover Medication- a legal and practical guide(November 2006)

Rights, risks and limits to freedom (2006)

Safe to Wander (2005)

Cares and confidentiality (2006)

Deprivation of Liberty – forthcoming

Appendix 1

Values and Principles

These values and principles are intended to act as a constant reminder that values should always illuminate the way we undertake our work and our choice of activities. In practice a number of these values may be in conflict with each other and a careful assessment of the issues will be required in order to mediate differences of opinion.

People with dementia are entitled to:

- a diagnosis and information about the illness
- the same respect and regard for dignity and privacy as anyone else
- the same range and quality of general services as other citizens but delivered with sensitivity to their needs
- specialised services tailored to their individual needs
- live as independently as they wish to and in familiar surroundings for as long as possible
- medical care for other health problems
- services which recognise and provide for the support needs of their carers, whose goodwill must not be exploited.

The carers of people with dementia are entitled to:

- access to adequate information and support (emotional, financial and practical) to empower them to care in the way that they believe to be most appropriate and for as long as they are able and choose to do so
- recognition by public policy makers and all service providers (whether public, voluntary or private) of the care which they provide
- full involvement in the preparation of individual care plans
- an assessment of their own needs if they wish
- continuing support after bereavement.

People with dementia and their carers are both entitled to:

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- opportunities to enhance their abilities
 - participation as far as practicable in decisions affecting their daily lives and future care
 - access to independent safeguards against infringement of legal and civil rights, including advocacy services
 - not be disadvantaged by the illness
 - opportunities to participate in the wider community
 - objective assessment of their general, social and medical needs.

Alzheimer Scotland - Action on Dementia is committed to the improvement of services for all people with dementia and their carers throughout Scotland. We will co-operate with public, private and voluntary agencies to achieve this end.