

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's Society

Alzheimer's Society is the leading care and research charity for people with Alzheimer's disease and other forms of dementia, their families and carers. It is a national membership organisation and works through nearly 300 branches and support groups. The Society has expertise in providing information and education for people with dementia, carers and professionals. It provides a helpline and support for people with dementia and carers, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. It campaigns for improved health and social services and greater public understanding of all aspects of dementia.

There are 700,000 people with dementia in the UK and this is forecast to increase to 940,110 by 2021 and 1,735,087 by 2051. One in 3 people over 65 will end their lives with a form of dementia. People with dementia and their carers are significant users of health and social care services.¹

Two thirds of people with dementia live in the community either alone or with a family member.² As the condition progresses, a person with dementia will need increasing amounts of care and support from social care services, as they start to lose the ability to perform the tasks of everyday living. Eventually, many people with dementia will require long term care in a care home and one third of people with dementia live in care homes. In care homes at least two thirds of people have a form of dementia. High quality care services, provided by social care staff well trained in dementia care, can have a very significant impact on the quality of life of people with dementia and their carers.

Ethical dilemmas – a common occurrence

A person with dementia, their family and carers and health and social care professionals who work with dementia will find that ethical dilemmas arise in many different aspects of life. It can be a stressful and isolating time as people struggle to know if they are making the 'right' decision or approaching a situation in the 'correct' way. Alzheimer's Society welcome the Nuffield Council's work on dementia and ethics. People must have as much support as possible when facing these types of dilemmas.

It's important to realise that in a great deal of situations, there is no 'correct' way or 'right' answer, and nobody should feel guilty about decisions they have made with the best intentions. Dementia can mean that people find themselves in a range of situations they never thought they'd be in and never planned for,

¹ Alzheimer's Society (2007) *Dementia UK*, a report to the Alzheimer's Society by King's College London and the London School of Economics. Alzheimer's Society: London.

² Alzheimer's Society (2007) *Home from Home*.

meaning that things that were once unheard of are now the norm. The Society encourages the view that each situation is as unique as the people concerned and must be dealt with in this way.

Many health and social care professionals can expect to come into contact with people with dementia, whether as General Practitioners diagnosing early signs, as social workers providing support or as staff members in residential care homes. It's not only paid, professional people who perform a vital role supporting and caring for people with dementia. There are large numbers of people who are called upon to provide support and care as unpaid carers, often at all hours of the day with little respite. There are estimated to be 595,000 people in the UK acting as the primary carers for people with dementia and these unpaid carers save the state £6 billion a year. These people are primarily spouses and family members, but can also be friends and neighbours.³

Development of response

One of the greatest resources the Society has is the network of people with dementia, volunteers, staff and carers across the national branches. As people who live and work with dementia every day, their insights and advice on the crucial issues and dilemmas are invaluable. To write this response, Alzheimer's Society asked people with dementia and their families and carers what dilemmas have the greatest impact on their lives. The Society sought information through the website, staff intranet and online webforum 'Talking Point.' The Society are privileged to coordinate 'Living With Dementia,' a volunteer group of people with dementia, and members were able to offer their assistance.

A noteworthy feature of the responses received was the emotion and passion with which people spoke of their experiences, trials and triumphs. There were many anecdotes and stories, some of which appear in the Society's response, that helped to bring dilemmas to life. Strong messages emerged from people with dementia and their families and carers about what advice and assistance would help them when they faced these situations, revealing some key themes. From this, the Society has developed some overall principles that can help understand and resolve some ethical dilemmas. These are listed below, and the Society would like to note that they are similar to the principles of decision-making in the Mental Capacity Act (2005), which the Society supports.

Guiding principles:

- 1) **The importance of little, everyday things:** It is the small situations that people face everyday that give rise to some of the most common ethical

³ Alzheimer's Society (2007) *Dementia UK*, a report to the Alzheimer's Society by King's College London and the London School of Economics. Alzheimer's Society: London.

dilemmas. When we think about ethical dilemmas, often the major ones spring to mind first – whether to withhold medical treatment or deciding if a person lacks legal capacity. People with dementia and their families and carers tell us that they face a myriad of ethical dilemmas everyday, over seemingly-small matters. It helps to bear this in mind.

- 2) **No 'right answer:** A lot of the time, there will not be one correct answer or solution to a problem. Each situation is as unique as the individual involved.
- 3) **Involve the person with dementia and those who know them best:** Advice from people with dementia and their families and carers tells us that we should assume the person with dementia can express their own preferences, and where they can't, professionals should defer to a spouse or loved one who can offer an insight not available to other people.
- 4) **Plan in advance:** Many people mentioned that planning for a time when the person with dementia may lack capacity was valuable. It offers firm guidance regarding a person's preferences and can help to reassure carers that they are acting in accordance with a person's wishes.
- 5) **Support is crucial:** Carers, family members and people with dementia all mentioned the value of talking a dilemma over. The advice of an independent, objective professional was often cited as important for seeing a situation in a different light and removing some of the burden in cases where a difficult decision was required.

Structure of response

Some questions received far more attention than others when in consultation with people with dementia and their families and carers, such as those about stigma and the issues associated with truth-telling.

The Society's response focuses on the questions that received the greatest deal of attention from respondents as the Society believes this provides an accurate reflection of the issues that have the greatest resonance for the people it represents.

Questions are addressed under the following headings:

- What is dementia and how is it experienced?
- Person-centred care and personal identity.
- Making decisions.
- Aspects of care and support.
- Carers.

Alzheimer's Society acknowledges that all aspects covered in the *Dementia and Ethics* consultation are important and relevant, and is happy to discuss any aspect of your consultation with you in greater detail.

The Society provided substantial comment and input into the UK Ageing Research Forum response on the research section of this consultation. The

Society is happy with the UK Ageing Research Forum response and so will not address the research questions in this response.

1. What is dementia and how is it experienced?

Alzheimer's Society received a great deal of responses to questions in section one of the consultation document, and a lot of the more general discussion generated from people with dementia, their families and carers fits into the issues raised in this section. The Society's response to this section will address:

- Aspects of dementia that have the greatest impact.
- Particular situations.
- The importance of ethnicity, culture and social group.
- Diagnosis.
- Stigma and perception.

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

Most forms of dementia are severely debilitating. This means that dementia has a great impact on people with dementia, their families and carers, as well as society as a whole. With numbers of people with dementia set to increase a great deal, it can only be assumed that the impact will be felt all the more, with an increase in support needs to match. Responses received to this question were wide-ranging and numerous, providing strong evidence that nearly all aspects of dementia stand to have a major, and often devastating, impact across most areas of a person's life. Many respondents commented that the question would be easier to answer if it were about what aspects of dementia did not have a great impact! Although responses were varied, they have been grouped as either those relating to the symptoms of dementia, or impacts that resulted from understanding the nature of dementia. They are addressed under these headings, with discussion of support needs included.

1.1 Behavioural and psychological symptoms of dementia

The behavioural and psychological symptoms of dementia have a great impact on people with dementia, their families and carers. Symptoms can include difficulty in communicating, memory loss, mood swings and agitation. Many of these result in a gradual loss of independence, and the emotional and physical effects on a person who can no longer do what was once taken for granted is very upsetting for both the person with dementia and their family and carers alike.

A person with dementia may show behaviours such as hallucinations or shouting and screaming. Many of these result from feelings of frustration or anxiety, where the person with dementia is in a situation where their needs are not correctly addressed or understood. This has a significant impact on the person

with dementia's quality of life and physical and emotional comfort. Responding to these kinds of situations also has a significant impact on families and carers.

Practical assistance is one aspect of the support required by people with dementia. People with dementia emphasised the importance of support to remain in their own homes and to be independent. The nature of dementia means that as the condition progresses, a person loses the ability to perform everyday tasks and will need help with these. Such tasks include eating, washing, getting dressed and using the toilet. A person may have to move into residential care as their needs for practical assistance increase. At present, two thirds of people with dementia live in the community and one third live in care homes. Unfortunately, our research indicates that many people both in the community and in care homes are not receiving as much care as they require.

It is important to note that practical assistance is only one part of the support required by a person with dementia. There is also need for emotional happiness, stimulation and social interaction. Day centres and support groups (for example, initiatives like Dementia Cafes) can help provide this support, and it is important that they are easily accessible. Research indicates that constant human interaction can do much to alleviate agitation in people with severe dementia. This is also a strong need for carers. One family member and carer mentioned that the greatest impact of her husband's dementia was the loss of their ability to socialise as communication became more difficult – 'this produced a huge sense of isolation and depression.'

Several carers noted that it is very important to match a professional carer with the person with dementia – for person to receive good care, the person with dementia must feel comfortable with the carer, relate to them well and enjoy their company. Carers too have a strong need for support. Access to respite services is a lifeline for many people.

1.2 The nature of dementia

Understanding and explaining the nature of dementia can present a challenge. Dementia is not merely a normal part of the ageing process, and nor is it the fault of the sufferer. It is an organic disease of the brain with physical causes and effects. A person with dementia will experience a decline in their ability to reason, speak, remember and make decisions.

Many carers mentioned that explaining this to other people was very difficult, and that they were often met with a lack of understanding, for example the opinion that 'he doesn't look that bad.' This can be a particular problem in the case of early onset dementia. Even medical professionals can be hesitant to acknowledge a person's experience of symptoms as dementia due to their young age.

People with dementia and their families and carers need access to accurate information and resources concerning all aspects of their experience. This can

include access to an accurate diagnosis, information on social care packages and information on the availability of therapies or medication.

1.3 Particular situations

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

The majority of the situations that came up in response to this question stemmed from the fact that, due to the dementia, a carer or family member finds that they can no longer act towards the person with dementia in the ethically 'correct' ways they once took for granted. These situations will be dealt with in greater detail later on, as many arise under other questions in this consultation response. A great deal of the time, it is the seemingly-small everyday situations which give rise to some of the most common ethical dilemmas.

Some examples of answers to this question included:

- Intercepting the daily post to avoid a person with dementia becoming agitated and upset at bank statements they cannot fully comprehend;
- A big change in relationships, for example child now looking after parent;
- Hiding medication in food;
- Driving - going behind a person's back to revoke a licence; pretending that the car is with the mechanic or telling similar white lies to 'provide a dignified exit' from driving;
- Moving a person to a care home, which is against a person's right to choose to live where they want;
- Aspects of personal care that infringe on a person's right to privacy;
- Whether a person with dementia should be told their diagnosis, and how to do so;
- Telling the truth about major life situations, such as death of a loved one or sale of property.

1.4 The importance of ethnicity, culture and social group

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

'My Indian husband has taken 3 years to accept outside help. Even though he has lived in the UK for 53 years, he still has his cultural belief that family care for the old and sick without outside support.'

Carer

People with dementia and their families and carers report that cultural, ethnic and social groups strongly influence a person's perception and experience of dementia. Culture and ethnicity are very relevant to care.

Culture and ethnicity influence the recognition of the condition itself. Some cultures have no word for dementia, instead using terms such as 'older peoples' madness.' Another problem can be diagnostic tests, such as the Mini Mental State Exam (MMSE), which are biased towards people whose first language is English. This can have a great impact on a person's access to support. The person or their family may chose not to acknowledge the condition, meaning that the person does not receive a diagnosis, any treatment or any support from social care services.

Culture and ethnicity can also determine the way in which a person seeks help. As shown in the above quotation from a carer, not all people are comfortable with accepting help from outside the family. This is not restricted to culture alone. A coordinator from the Society's Living With Dementia volunteer group noted that generational attitudes could also affect whether a person feels comfortable accepting outside help, with many people preferring to manage alone. Situations such as these can put immense pressure on the primary carer.

Recognising a person's culture, ethnicity and social background are crucial to providing high quality care. All cultures have certain expectations of behaviour or routines that can be upsetting or offensive if not observed. In the Sikh culture, it is very important for men that long hair is covered. It is inappropriate for a woman to perform personal care tasks for a man or vice versa, both in many cultures and also in certain generations. People with dementia are particularly vulnerable in these situations as they may not be able to communicate their values or preferences.

A further consideration is that as dementia progresses, it is not uncommon for the person to experience their earlier memories more strongly, and in some cases use their first language exclusively. A carer from a different ethnic background may struggle to deliver sensitive care in this situation.

A significant problem concerning care that is sensitive to culture and ethnicity is the limited data on attitudes towards dementia of people from black and minority ethnic (BME) groups. It is estimated that there are about 11,000 people from black and minority ethnic (BME) groups with dementia.⁴ The proportion of older people from ethnic minority groups in the UK is small, but increasing steadily as this section of the population ages. It is therefore predicted that the number of people with dementia from BME groups will rise quickly. However, many services for people with dementia from these communities remain inappropriate and inaccessible. Information about the attitudes and experiences of people from BME groups remains a significant research need.

⁴ Alzheimer's Society (2007) *Dementia UK*, a report to the Alzheimer's Society by King's College London and the London School of Economics. Alzheimer's Society: London.

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

Find out as much about different cultures as possible...and this is VERY important. All 'Asians' should not be considered one group. There is a very big cultural difference between all people from Asia. They are of different race, religion and cultural background and should not be considered even similar....people from Europe are Europeans, but we know full well the cultural differences between, for example, the English and Germans.

Carer

Education and understanding are clearly very important when it comes to providing care that is sensitive to a person's culture, ethnicity and social background. The Society has run training workshops for councils and health and social care staff with the aim of improving awareness and understanding. The Society also supports the recruitment of carers from a wide range of backgrounds, as the availability of appropriate carers is crucial to delivery of quality care for all people. Specialised residential care homes exist, for example ones that have all-Gujerati staff and can speak to residents in their first language. Feedback from families suggests that this can help the person with dementia to receive a high standard of care.

1.5 Diagnosis

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?

The Society recommends that a diagnosis of dementia is made and communicated to the individual as early as possible. Diagnosis is crucial as only then can a person and their family access the support, care and treatments they need.

Alzheimer's Society has commissioned qualitative research on peoples' experiences of receiving their diagnosis of dementia and this is underway at the moment. The research includes focus groups and interviews with people with dementia. The Society would be happy to share the results of this research with the Nuffield Council, which are expected in October 2008.

The Society actively promotes awareness of early symptoms of dementia and encourages people to see their doctor where they have concerns about their memory. At present, the Society is running the 'Worried About Your Memory?' campaign to support diagnosis, providing literature in GP surgeries and information on our website. The campaign has proved to be enormously

successful so far, indicating that there is an appetite for early diagnosis and a growing understanding of its importance.

The Society offers the following points in support of early diagnosis:

- While there is no cure at present for most forms of dementia, the type of care and support provided can have a very significant impact on the quality of life of people with dementia and their carers.
- A diagnosis can help people to understand their condition and plan for their future long term care needs.
- It is important to diagnose the cause of the dementia, as some drugs are dangerous when used on certain dementias, for example antipsychotics.
- Professional training and awareness are crucial to increasing accurate, early diagnosis. On average, only 60 per cent of the GPs surveyed by the Audit Commission in 2002 felt that it was beneficial to make an early diagnosis and less than half felt that they had received sufficient training to help them diagnose and manage dementia.⁵

Communicating the diagnosis

Had she asked me outright "what is wrong with me", I would have told her. She never did and we always settled on 'memory problems'.

Carer

For some people, whether to convey the diagnosis to the person with dementia is a very real dilemma. The Society asked carers and people with dementia for their views about this and found that although most people believe that the person concerned should be told their diagnosis, the decision to tell someone was very troubling for many people. These included cases where dementia had always been a person's greatest fear and it was thought a diagnosis would create a huge deal of distress, or cases where the person's reduced capacity to understand their diagnosis would cause confusion, anger or humiliation for the person.

Carers suggested that, where this dilemma is faced, language can be tailored to help convey the idea with minimum distress, for example referring to 'memory problems.' An appreciation of the distinction between 'early' and 'timely' can be of assistance in this dilemma. For conveying a diagnosis to be helpful and appropriate, it must be timely, with benefits balanced against risks. Where a person stands to be distressed to the point where no benefit can be derived, then even an early diagnosis is perhaps not a timely one. Above all, the Society recognises the need to treat the person with dementia with respect and sensitivity, and sometimes this may involve finding different ways of approaching this issue.

⁵ Audit Commission in Wales (2002) Losing time. Cardiff.

Carers also mentioned the importance of having professional support in making decisions around diagnosis. It is crucial that GPs and medical professionals are trained to deliver a diagnosis in a sensitive manner.

1.6 Stigma and perception

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

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

People with Dementia are cut out of conversations and not allowed to speak for themselves.
Person with dementia

Until a family is faced with a loved one who has dementia, they can never appreciate that it is not simply 'forgetting things'

Carer

This question received a high response rate. Respondents felt strongly that stigma still exists around dementia, and that this has a deep effect on people's experience of the condition. As the number of people with dementia grows, it is critically important that there is an increasing awareness of the effect dementia has on peoples' lives.

The Society would like to draw attention to the important difference between 'awareness' and 'understanding.' There is already quite widespread awareness that dementia exists, however it is a deeper and increased understanding of the condition itself that will bring positive change and reduction of stigma.

Stigma can be felt in a variety of ways. As the quotation above demonstrates, people with dementia suffer social exclusion. Carers told of how invitations to socialise gradually dried up, in effect cutting people out of their former social circles. Some more extreme examples included situations where neighbours would not even speak to young children of families where a relative was known to have dementia. These examples are all very troubling. They prove that there is still a lot of work needed to eliminate the stigma of dementia, allowing people with dementia to live lives free from discrimination.

Stigma about dementia has an impact on people's access to and experience of support and care. Carers told of how stigma has led to the person with dementia feeling embarrassed about their condition, and refusing help and support out of a feeling that this would be demeaning. This affects not only the person with dementia, but also the people who are required to care for them without the full range of help, support and advice that is available.

Raising understanding to reduce stigma

A lot of the feedback on this issue indicated that a great deal of stigma results not from mere bigotry, but from a lack of understanding. One carer told of being asked 'How can someone so intelligent get it?' Others spoke of misleading labels such as 'old age mental decay.' Many respondents felt that the social exclusion they had suffered came from the fact that people simply didn't understand how to react to or communicate with the person with dementia. Any stigma is in itself a very negative thing. A lack of understanding, however, is something that can be addressed. It offers the potential to change the negative perceptions that currently exist.

A key source of general misunderstanding around dementia is that a person's capacity is 'all or nothing' – that is, dementia leaves a person with no capacity or capability at all. This misconception leads to the kinds of social exclusion and stigma discussed above. The Society encourages the message that a person is 'living their life with dementia' to demonstrate that a diagnosis of dementia does not mean a person has no capacity. Dementia does mean a person has reduced capacity, but this in itself does not need to be a barrier to many activities. A person with dementia commented that this way of thinking was an important break from a 'dark ages' mentality, where dementia meant institutionalisation.

An important group of people to target in increasing true understanding of dementia is professional health and social care staff, including General Practitioners, social workers and staff in residential care homes. This is one of the areas where stigma and misconceptions about dementia exists and stands to have a considerable impact on the care and support a person with dementia receives. The Society agrees with the Commission on Social Care Inspection's summary that 'training alone is not enough and good leadership, staff support and a culture within a care home of respecting and treating people as individuals have been shown to be essential components of good quality care.'⁶

Our respondents offered a range of advice on ways to raise understanding of dementia. Education is key to enhancing peoples' understanding of dementia, and should target a broad range of people, from children in schools to bank tellers and firemen. The Society has recently started producing cards for people with dementia that can be used to tell bus drivers or shop assistants of the person's condition. The Society hopes that the 'Worried About Your Memory' campaign raises understanding amongst all people, and in particular encourages GPs and GP surgery staff to increase their own understanding of dementia. One respondent felt that younger generations offered a chance to start education for real change, commenting 'there are some very knowledgeable grandchildren now, who have experience of dementia. This is the generation which might make things better for the sufferer.'

⁶ Commission for Social Care Inspection, *See me, not just the Dementia*, June 2008.

The Government's recent commitment to the National Dementia Strategy is very encouraging, showing that dementia is firmly in place on both the political and public agenda. Although the Society welcomes developments such as the National Dementia Strategy as a positive step in the right direction, the Society believes that a substantial and sustained work is needed to transform the lives of people with dementia and their families and carers.

2 Person-centred care and personal identity

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

My father has Alzheimers, but he is still a man with feelings and emotions. Above all he needs dignity and most of my decisions around his care are based on this.

Craig, carer

Alzheimer's Society promotes person-centred care. Recognising that each person's experience of dementia is unique to them and tailoring their care accordingly is a critical part of delivering quality care. The Society encourage a balanced approach in addressing a person's past and present when aiming to deliver person-centred care. It is important not to over-analyse a person's past at the risk of stirring up feelings or emotions that are not helpful in the present. Of course, a person's history can offer valuable insights in how best to care for them in the present and when addressed sensitively can contribute to person-centred care.

High quality care is a fundamental right and as such, Alzheimer's Society supports person-centred care. The Society does not think that any aspect of person-centred care itself presents an ethical dilemma. It is always unethical not to deliver high quality care or to fail to treat a person with dementia with respect.

Some key pointers in delivering person-centred care that the Society frequently offers include:

- Help the person feel valued
- Always use the appropriate name or title
- Respect the person's cultural values
- Act with courtesy – use 'please' and 'thank you'
- Respect their privacy
- Offer simple choices
- Always try to remember uniqueness

3 Making decisions

3.1 Situations that raise this issue

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?

My father can't consent to being dressed, my father can't consent to what he is going to eat today, what tv shows he is going to be subjected to, whether he is going to be seated all day...a great number of these decision we make are for his own good, and no doubt that does not cause any ethical questions to arise, but there are also many decisions that we have to make for him that we simply make based on what we think won't cause him harm, or that will cause him little harm but are for the greater good....we have to make a decision based on who we knew him as when he could have told us what he wanted...

Carer

The above quotation from a carer is an excellent illustration of the fact that many of the things that create ethical dilemmas are the little decisions we make every day and take for granted. The serious dilemmas such as selling property or refusing medical treatment arise and are very troubling. People report that in some ways, however, there is more help available for dealing with these situations, for example legislation. As one carer described to us, the difficult part about selling his father's house was not the decision to sell it or how to enable this when his father lacked consent – the legislation was very clear and offered appropriate guidance. The biggest struggle for him was deciding whether his father would want to know and would be able to comprehend the implications of the sale. The little things that ensure a person's happiness and comfort on a day-to-day basis can be much harder to determine for carers, and yet it can be these little things that have the greatest impact on the person with dementia.

The Society would like to highlight the importance in putting the person with dementia first when making decisions and gaining consent. As seen in the above quotation from a carer, sometimes a decision can be made when a person considers what the person with dementia would have said they wanted at a time when they could do so. This feeling is echoed in other responses, with a person with dementia recommending 'find out as much as possible about the person and then tailor the services to suit.' The Society recommends that doing this as much as possible can help to give effect to the person's needs and desires and reduce the dilemma for some carers some of the time.

The Society supports the five principles of decision-making set out in the Mental Capacity Act. The Society encourage awareness and understanding of these, with training and support wherever possible, however there needs to be a great deal more publicity regarding peoples' rights under the Act. Developments

in health and social care professions to assist professionals in helping people with reduced or fluctuating capacity to make decisions are encouraging, for example the General Medical Council's recent guidelines. The Society welcome the growing recognition that reduced or fluctuating capacity does not render a person unable to make a decision. It is pleasing to note the growing emphasis on supporting people to make their own decisions rather than the assumption that decisions must be made for them.

There are decisions about major life issues that present serious ethical dilemmas as well. To this end, the Society recommends that advance directives may be of assistance to some people, if they are comfortable making these at a time when they can do so. Advance directives will be discussed in greater detail in the next section.

3.2 Advance decisions and directives

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

Respondents to this question generally indicated that advance decisions had the potential to be useful, although many noted that choosing to make an advance decision was a personal matter and not every person would want to do so.

Alzheimer's Society supports advance planning of this kind provided the person with dementia feels this is appropriate. There are following benefits in advanced planning:

- helps to ensure that a person's treatment and care wishes are taken into account
- helps to open up a dialogue with doctors and nurses
- stimulate conversation with family and close friends, which can relieve them of the burden of decision-making at a distressing time.
- protects an individual's right to personal autonomy and choice.
- brings some reassurance to a person worried about their future care and allows them to put their financial affairs in order.

The Society believes that advance decisions should be regularly reviewed while the person still has capacity, because views and circumstances may change over time, and written following full consultation between a patient and doctor. It is important that they should deal with general, rather than specific, kinds of treatment to ensure that they are as contemporary as possible. It is also important to realize that most people who make an advance directive about a matter such as withholding medical treatment do so with great consideration and think about it very seriously, and as such, advance directives offer reliable guidance.

There are situations where advance decisions should not be too prescriptive or adhered to too dogmatically as doing so would not deliver good dementia care. Any person's tastes or desires can change over time, regardless of dementia. Sticking to a previous preference in favour of a more recently expressed one would not be delivering person-centred care. This can hold of seemingly-small matters, such as what a person would like for breakfast, but can also raise issues over much more major situations. One example given by respondents was the decision to use or remove a PEG for feeding. Decisions such as these are enormously difficult and upsetting for carers and families. The Society advises that each situation must be dealt with on a case-by-case basis, with the highest quality of care for the person with dementia as the central consideration.

The Society supports the use of the Preferred Place of Care Plan (PPC). PPCs allow people to record decisions about future care choices and the place where the person would like to die. Initially developed for cancer patients, the PPC is now a nationally recognised tool for all palliative care patients. The use of a PPC plan can offer greater choice in where people wish to live and die, and may decrease the number of emergency admissions of people who wish to die at home and the number of older people transferred from a care home to a hospital in the last week of life.

4 Aspects of care and support

4.1 Telling the truth

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

...without a doubt the most difficult was how to handle telling my father (who has Alzheimers) that the love of his life had just died (my mother died earlier this year). We decided to tell dad and to take him to the funeral. Telling dad was one of the most painful experiences of my life as he registered (albeit momentarily) and cried. He was confused, upset but could not grieve in the way he would have done without Alzheimers.

I spoke to many about this decision as you can't always rely on your gut feeling and we decided that someone with dementia has the right to know. Ethics probably won over emotions in this case. The decision was complicated by the issue that mum would have probably preferred dad not to know or even go to the funeral. Everyone knows how painful it is to go against your mother's wishes. He did not grasp the whole situation and even at the funeral I'm not sure what was going through his mind. However, I have absolutely no regrets about taking dad to the funeral.

The problem now is that dad occasionally asks why mum doesn't visit any more. He has forgotten the funeral (at least at the moment he asks the question)

and another dilemma is thrown at me. Is it cruel to keep drumming it in to dad that the love of his life is dead or should I gently change the subject and leave him in peace?

Craig, Carer

The ethical dilemmas raised by truth-telling and dementia received a great deal of attention. Nearly all respondents wrote about this issue and many carers indicated it was the most significant, challenging and frequent dilemma they faced. Dilemmas about telling the truth occur across the spectrum of situations and events, from something very serious such as the death of a spouse, as in Craig's example, to seemingly-small things that occur every day, such as pretending the post has not arrived when it in fact it has, and has been intercepted by family or carers.

Alzheimer's Society does not have one hard-and fast rule for these situations, and indeed it would be inappropriate to do so. Every person and situation is different, and it is very important that each case is judged on its merits and carers can make decisions on the best course of action for that time and situation. It is particularly important that carers do not feel guilty about this issue, or that there is a 'right' way of approaching this issue and that anything else is 'wrong.'

In our publication 'Making Difficult Decisions' the Society offers some advice that a carer, family member or health and social care professional may like to consider when they are faced with a dilemma about telling the truth. Asking the following questions can be helpful:

- Is the person with dementia likely to understand what they are being told?
- Are there ways of making it easier for them to understand?
- Would knowing the truth cause them significant distress? If so, would the consequences of telling the truth outweigh the need to tell the truth?
- Are there ways of telling the person that would be less upsetting for them?
- If the situation was reversed what would you want?
- Are there some things it is essential to tell the truth about?
- Will not telling truth make things more difficult in the long run?
- From your knowledge of the person, what do you think they would want?
- Does what you say meet two of three criteria of saying what is true, necessary and kind?

One piece of advice that came up many times hinged on the fact that the truth is not always a black-or-white matter. This can be very helpful where the direct truth stands to be unduly upsetting for the person with dementia. It is possible to convey a message without telling the plain truth or a direct lie and still obtain a result that is not deeply distressing to the person with dementia – described by one respondent as the difference between lying and 'bending the truth.'

Respondents gave many examples of the kinds of situations where this was appropriate and helpful. One carer described the following situation: 'When I leave my wife each time at her care home, I tell her I am 'going shopping'. She appears to understand that this means I will return, whereas if I say "I am going now" she shows signs of distress.' Although this carer was not telling the plain truth, the message he conveyed was true (that he would return) and this allowed the person with dementia to feel reassured.

Respondents also spoke of how thinking about what the person with dementia would have wanted has helped them to make decisions about telling the truth. One carer told us: 'My own mother brought me up to understand that sometimes 'little white lies' were actually 'kind' So my own conscience is clear about telling 'fibs' when I believed they have stopped her being anxious.'

Respondents were careful to point out that although bending the truth was in many cases appropriate, it would not be ethically acceptable to tell a lie or merely because it was an easier option.

The issue of covert medication is related to truth-telling, and is one that many respondents mentioned. The Society recommend some things that the person giving the medication could think about:

- Is the person with dementia's unable to make a rational decision about medication?
- Is the medication necessary to prevent them becoming ill?
- Will the medication improve their quality of life?
- What do other family members or professionals think about the situation?

4.2 Freedom and risk

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 risk?

It is too easy to become overly worried and thus restrict independence and a sense of achievement. As one example, my mother insisted for a long time that she could cook for herself (simple tasks like frying bacon or boiling eggs) ... having seen some burnt pans my instinct was to switch off the cooker at the mains and 'pretend' it was broken, but she delighted in being able to accomplish something for herself. An independent assessment confirmed that her sense of achievement outweighed the risks involved with smoke detectors etc in place to try to ensure her safety as best we could.

Carer

Presently, most social care services are skewed towards those with high needs. The Society believes greater attention to needs across the spectrum could have some very positive benefits. At present, the assumption that a person with dementia must be intensely supervised can lead to over-protection. This can

have far-reaching implications, for example people being admitted to residential care earlier than necessary. Assistance to help people in the earlier stages of dementia remain independent would have a positive impact on the quality of peoples' lives, helping to encourage understanding that a person with dementia is capable of living a satisfying life. It also making sense for the State in financial terms. Prolonging independence allows people to live in their own homes for longer and may delay the need for intensive social care assistance.

People with dementia and carers urged a common-sense approach to this issue, where severe risk is minimised, but with the emphasis on enabling independence. It was common for respondents to state that as soon as a serious risk of injury or death was posed to the person or another, then this was the time for intervention. The decision to revoke a driving licence was a common example. Many carers emphasised the importance of including people with dementia in such decisions and trusting a person's judgment wherever possible, with one carer commenting 'I allow my husband as much freedom as he needs. On the whole, he will not do more than he feels safe with.'

The carer in the example above suggested seeking a second opinion was very useful as often a family member was too close to the situation and may be overly cautious at the expense of the person's happiness. It must be remembered that there is no such thing as a completely risk-free environment for any of us and in the case of a person with dementia, some minor accidents are probably inevitable.

An interesting area that people are often unwilling to address is that of sex and relationships. This can include the development of new relationships or continuing the intimacy in an existing relationship. At present, this subject still makes many people uncomfortable. It is very important to consider risks and assess whether any imbalance of power or potential for abuse is present. Outside of this, however, there is not a clear answer to these kinds of situations. This issue is a good example of the need to balance independence and autonomy with risk, and promoting understanding that dementia does not mean a person lacks capacity to make decisions about their own life. The Society suggests that the principles in the Mental Capacity Act should be used as guidance where these kinds of situations arise.

4.3 Assistive technology

If some one can come up with an item that helps us retain our freedom, I am all for it.

Person with dementia

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?

Assistive technology is often raised as an example of a dilemma caused by the clash of the desire to minimise risk with a person's right to privacy and independence. We have found that people with dementia are often very supportive of assistive technology. Assistive technology can offer freedom for people with dementia and peace of mind for families and carers. It should only ever be used as an aid and not as a substitute for good quality care, and it is important to seek the opinion of the person with dementia before using assistive technology.

The Society suggest the following questions are considered when making decisions around assistive technology:

- Could technology replace more restrictive measures such as locking doors?
- When does technology stop being an aid to independence and become a restriction on autonomy?
- Would confidentiality and privacy be comprised? Who would have access to information if a person is tracked? Could a person with dementia be followed?

The main reason given by respondents as to why assistive technology is not more widely used was that it is too expensive.

4.4 Restraint

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?

People with dementia and their carers felt that restraint was permissible only under certain circumstances. It is very important to respect a person's basic human rights to dignity and respect. Inappropriate restraint not only contravenes these rights, but can also be a form of abuse. Restraint can take many forms, including the use of medication to sedate a person (such as antipsychotics), physical restraints on a person and less overt restraints, such as putting someone into a deep chair that they cannot get out of without assistance.

The behavioural and psychological symptoms that can occur as part of dementia often give rise to a perceived need for restraint. The most obvious of these is aggression, but also include shouting out, anxiety and restlessness. It is very important to realise that behaviours such as those described above are not merely symptoms of dementia. They are a response to other factors, such as pain, confusion or boredom. Responding to such behaviour with restraint fails to address the real cause, neglecting the person's needs.

The Society considers that staff training in dementia care is crucial and recommends the following:

- Clarity around what is restraint.
- Clarity around best practice.
- A care plan for each person.
- Guidance for informal carers.

In 2008, backed by the Society's research, the All-Party Parliamentary Group on Dementia presented the report 'Always a Last Resort.' This report revealed the widespread use of antipsychotics to deal with behaviour such as aggression or agitation, despite the devastating side effects. Inappropriate use of antipsychotic medication is a form of restraint that is very harmful to people with dementia. As a direct result of this report, the use of antipsychotics will be addressed in the National Dementia Strategy and subject to a separate review, which is currently underway with results due in October 2008. The Society looks forward to the results of the review.

5 Carers

As a carer myself, there is also another issue; I like many find it hard to think straight most of the time as caring grinds down your decision making skills. Please consider that our relationship with reality has also taken a beating.

Carer

There are estimated to be 600,000 people in the UK acting as the primary carers for people with dementia and these unpaid carers save the Government £6 billion a year.⁷ There is evidence to suggest that the carers of people with dementia experience greater stress than carers of people with other conditions, with high levels of depression, great physical burnout, interrupted sleep and no time for themselves.

Respondents tended not to address individual questions, but instead offered advice and their thoughts about what would help carers. The strongest message that came through was that carers need support. The suggestions gathered carry particular weight as the majority come from carers themselves. As such, they are a unique and valuable reflection of the challenges faced by people who care for people with dementia.

Peer support

Many carers cited burnout and feelings of isolation as major issues. The ability to meet and share was seen as very valuable – as one carer put it: 'those caring need support groups with others in the same position, and also the opportunity

⁷ Alzheimer's Society (2007) *Dementia UK*, a report to the Alzheimer's Society by King's College London and the London School of Economics. Alzheimer's Society: London.

to meet and talk about other topics, so that their whole life does not revolve round dementia.' Respite breaks are also very important, for both carers and people with dementia. Greater provision for respite breaks is necessary. Informal research by the Society indicates that many carers do not have access to respite care or do not know how to apply for respite care.

Professional support

As dementia progresses, the pressure on carers often intensifies. Carers will find that they must make increasingly difficult decisions and respond to more and more crises. A great deal of respondents mentioned that reliable, sensitive professional support would go a long way to helping them when they faced these kinds of situations.

Emotional support and objective guidance was sighted as one way in which professional support could help carers. One carer spoke of strong feelings of guilt when making some critical decisions. The advice of professionals helped to remove the burden on this carer, assisting the carer to see that her husband's statement 'never put me into a home' could be understood as 'please ensure I am well cared for.'

Carers also mentioned that an on-call professional, such as a care manager, who could offer reliable advice at any time of day or night, would be immensely helpful in terms of practical assistance.

Couple vs. individual

Questions around this issue were not addressed directly. However, most respondents indicated that although the needs and safety of the individual were central, many needs of an individual were tied to the fact that they were one half of a couple. To neglect this fact would be to neglect the individual's needs. One carer summed this up neatly, noting 'Consider the flipside – that there can be joint interests too that are missed if each is considered as an individual.'

Carers urged that professionals listened to their perspectives and opinions, noting that: 'There will be situations where the spouse/partner will know more than the associated professionals in this respect.'