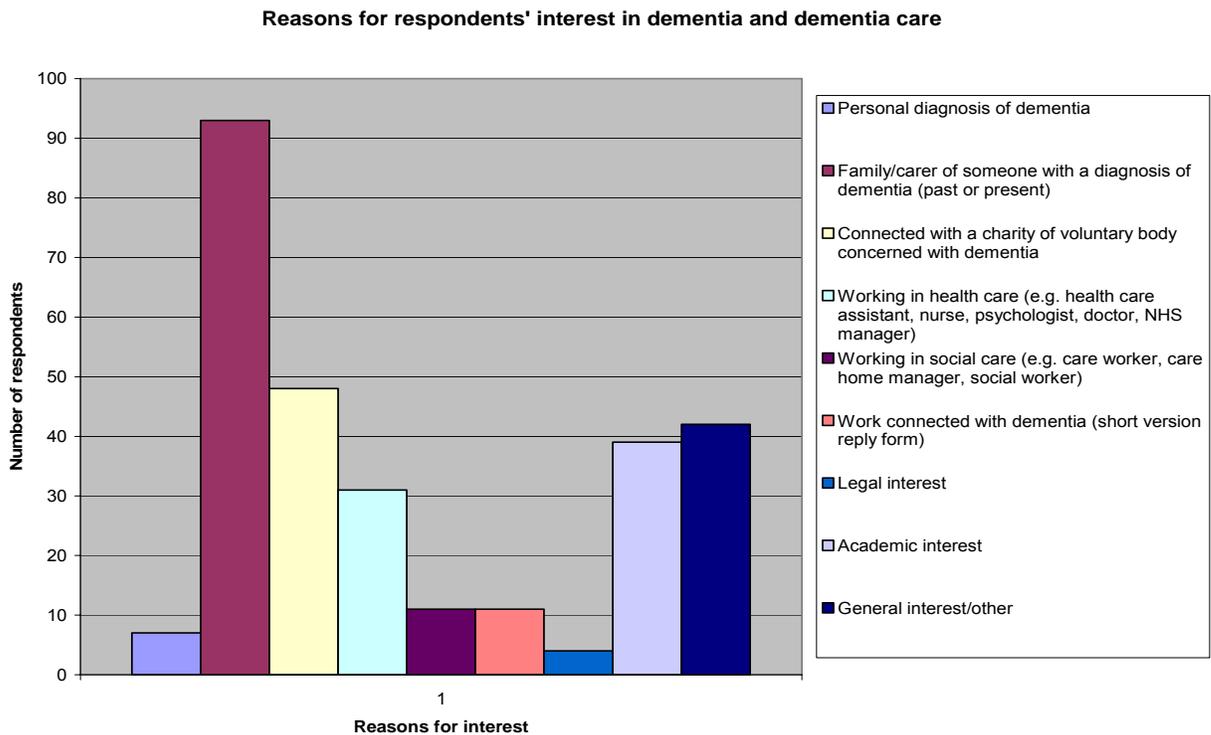


Dementia: ethical issues – summary of public consultation

Wider consultation

A public consultation was held between 14 May and 31 July 2008. A consultation paper prepared by the Working Party contained background information and questions for respondents to answer as many or as few questions as they wished. The document was disseminated to individuals and organisations relevant to the field, and it was also available online. As well as the main consultation document, respondents were also offered a shorter version of the document containing 21 questions instead of 32, and also a large-print version of both the shorter and the full-length document.

Two hundred individuals and organisations took part in the consultation, and responses received by the Secretariat were sent to members of the Working Party and discussed in meetings. Of these 200 responses, approximately 70 per cent were from individuals; 23 per cent were from organisations; and seven per cent came from organisations who arranged for discussion events to take place, with the focus of debate on the Working Party’s consultation paper. One hundred and seventy nine respondents stipulated a reason or reasons for their interest in dementia and dementia care, and these are illustrated in the diagram below:



The Working Party and the Council are grateful for such a diverse range of responses and found them to be insightful, helpful, and very useful. The questions, the summary of responses and the list of respondents are provided in this Appendix. The views that have been included in this summary were selected either to display the range of different comments or where the comment clearly encapsulated a particular viewpoint. The summary is not intended to form a quantitative survey. Responses were not taken from a representative sample, and should not be treated as such. Many respondents agreed to make their submissions available publicly and these can be found on the Council's website.¹

¹ See: <http://nuffieldbioethics.org/go/ourwork/dementia/introduction>.

Summary of responses

Section one: What is dementia and how is it experienced?

1. 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 by most people with dementia and those caring for them?

(Short version question: 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?)

Impact on the lives of people with dementia and their carers

The notion of 'loss' was prominent in respondents' comments. A significant number referred to a loss of identity, dignity, mental ability, memory, employment, awareness, confidence, self-esteem and personality as factors that impacted on the lives of those with dementia. Others referred to having to deal with ignorance of the condition, and the social isolation that may occur if a person develops dementia.

'Fear' was also mentioned several times by respondents. Some recounted a fear of being written of as worthless, others of the future burden of care and the loss of independence, and one person with dementia expressed their fear about telling others of their condition.

Some respondents also noted the progressive nature of dementia and the difficulty of a transition from people with dementia being able to look after themselves, to needing full-time care.

A number of respondents also felt that, for both the carer and the person with dementia, very difficult aspects of the disease to deal with were emotional changes, and subsequent damage to relationships and, potentially, detachment from well-established familial relationships. One anonymous respondent told us that "I have no time for myself due to the selfishness of my wife who is suffering from dementia."

Addressing the issue of the impact dementia has on carers specifically, 'loss' was again a prominent theme. Respondents commented on experiencing the slow, gradual loss of their family member with dementia and grieving for their relative before their death.

Support for people with dementia

Respondents cited a need for more funding for dementia support; support in the early stages of the disease; time and emotional support in order to come to terms with the diagnosis; support to facilitate the protection of relationships; more support to encourage continual community living; and to have dementia support centres in every locality.

One respondent also specifically cited a need for Admiral Nurses to be available to people with dementia and their carers at a nationwide level.

Support needs of carers

A significant number of respondents felt that there was a need for further effective and timely respite breaks that also ensured that disruption to the person with dementia is kept to a minimum. Other respondents also cited the need for regular good-quality support for carers both in terms of day care and at-home support. One respondent also drew a comparison with the support given to single-parent families.

A number of respondents referred to the need for carers to receive training, in order for them to understand how dementia will progress and impact on them, and enabling them to cope with symptoms such as agitation, wandering, toileting, dressing and delusion. A need for further information about how carers should approach financial matters and support was also brought up by respondents.

The impact on society

Few respondents directly responded to this part of the question, with comments focusing on how society perceives the person with dementia, rather than the impact dementia has on society. However, one respondent noted that the plethora of information that informs the public about the economic impact of dementia may serve to instil a culture of fear and rejection in relation to the disease.

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

A range of situations where ethical problems may arise were raised by respondents. A number of responses showed concern for situations where the person with dementia may be lied to, or have the truth withheld from them, particularly in the context of covert medication. Related to this point, other respondents felt that revealing a diagnosis to family members, and not to the person with dementia, was ethically problematic, as was the dilemma of how and when to reveal to the person that they have dementia, if at all.

Another situation which raised ethical concern amongst some respondents was how to decide when it is appropriate for a family member to be moved to a residential care home, and also how the person's finances should be dealt with to manage care costs.

The need to balance extremes also arose in a number of responses. For example: balancing the need for freedom for the person with dementia against the concern that in having that freedom, they are exposed to risk; balancing the needs of the person with dementia and their family carer; and implementing technological developments whilst trying to maintain good levels of personalised care.

Two respondents also raised the issue of when, if at all, the prospect of donating their relatives' brains for research should be discussed with family carers, with others raising the issue of when to specify what should be done as the person with dementia approaches the end of their life, and the role advance care planning should play in such situations.

3. 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?

(Short version question: What difference (if any) does a person's religion, culture or family background make?)

Do different ethnic, cultural or social groups have different understandings of dementia?

Opinions were divided amongst respondents, between those who did think that different ethnic, cultural or social groups have different understandings of dementia, and those who did not.

Of those who were in the former group, comments centred on providing anecdotal references to how certain ethnic and social groups understood dementia. For example, some respondents referred to the possibility of a traditional Caribbean view that holds that people with dementia are cursed and need to be cleansed spiritually. It was noted, however, that even if there are perceived to be differences between ethnic, cultural, or social groups, these differences should not be assumed to be homogenous.

Other respondents noted that different understandings of dementia may exist between the sexes: one respondent, himself a carer, commented that he found that male carers avoid or are resistant to bringing their wives - who have dementia - to a communal support group. The respondent also commented on how there is a lack of availability of male-focused social groups they, as men with dementia, may attend. This was compared to how

women with dementia may continue to be part of social groups such as the Women's Institute.

The Royal College of Physicians made the point that attitudes of first generation immigrant groups may become modified towards those of the host community in succeeding generations. Another response, from Alzheimer Scotland, noted that in the Scottish Islands, communities are generally self-sufficient and rely on extended family to cope with difficulties raised by dementia.

However, a significant number of respondents who addressed this question thought that belonging to a specific ethnic, cultural or social group did not make any difference to understandings of dementia. Of these respondents, some went on to comment that it is acceptance of the disease that matters, not who has the disease.

Some respondents wrote that they felt unable to comment on the issues raised as they had little experience of dementia in ethnic groups other than their own.

Are these different understandings relevant to the care of people with dementia?

Of those respondents who directly addressed this question, the majority felt that different understandings arising from ethnic, cultural and social groups were relevant to the care of people with dementia.

One respondent took the view that professionals who engage with the families of people with dementia should give careful consideration to a particular family's circumstance. This may, of course, include the family's religious or ethnic background, but the 'whole' family picture should be what is addressed first. Another respondent argued that cultural differences did not have an effect that was any more significant than the quality of individual family relationships.

A handful of responses held that different understandings only held relevance to the family of the person with dementia. Several respondents felt that the ethnic, cultural or social situation of a person with dementia could offer comfort and security to family carers, especially as the disease progresses. However, other respondents thought that the rituals and familiarity of a person's religion could also offer comfort to the person with dementia themselves.

Other respondents felt that differences to care were made through the opportunity to personalise the care of the person with dementia. The

Guideposts Trust, for example, emphasised that care should be tailored to accommodate the beliefs and standpoints of the individual person with dementia.

From a more pragmatic perspective, some respondents felt that a person with dementia's cultural situation could impact on their care because of difficulties with language, and several respondents felt that using friends or family members as interpreters for the person with dementia could compromise confidentiality or influence a health or social care worker's assessment of the person.

Another point raised in responses to this question addressed the need for care homes to be sympathetic towards how people with dementia felt it was appropriate to dress *before* being admitted to a residential home, for example, by maintaining body coverage (Medical Research Council and the Economic and Social Research Council), and also the need to respect cultural norms that the person with dementia has always adhered to.

Concern was expressed that cultural differences can create disharmony, misunderstanding and mistrust between care-givers and recipients and their families, and also for the need for person-centred care to be culture specific. For example, Ms Lesley Perrins made the point that "a day centre singing songs about the war or reminiscing about life in 50s Britain can further confuse and distress an Asian person with dementia."

Of those respondents who felt that differences were *not* relevant to the care of the person with dementia, reasons cited included: human needs are universal, and are not relative to a person's ethnic, cultural or social situation; there can be as many differences between people of apparently the same culture, as between those of different cultures; and that the more important issues are *acceptance* of the illness and support for both the person with the dementia and their family carers. Age Concern Leeds urged caution in "assuming that black and minority ethnic groups require different services. In particular, there is a danger of assuming that some groups 'look after themselves' and have stronger family structures, so do not welcome outside help."

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

Few respondents referred specifically to *ethical* questions that are raised by care in a multi-cultural context. Of those who did, the majority were concerned with respecting the person with dementia's preferences and wishes before mental capacity was compromised by their disease.

One individual respondent urged carers to consider a person's religious needs, such as prayer ritual, a point which was supported by Admiral Nurses – for dementia who raised the point that food requirements should also be taken into consideration, in accordance with that person's religious belief. Mrs Penny Hibberd, an Admiral Nurse and Senior Lecturer at Canterbury Christchurch University, raised the scenario where "the person with dementia has 'forgotten' their background or a certain way of practising. For example, eating a certain diet or dressing in a certain way." A similar concern was again raised by Admiral Nurses – for dementia where a person with dementia may participate in a religious service that does not celebrate his or her own faith.

Colin Isaacs noted that "like many older women, my mother views caregivers of visible minorities as different from her. My mother believes that visible minorities provide my father with inferior care. She is 88 and it is unlikely that we will ever be able to persuade her differently [...] this could be partially addressed by better communication between the care team and my mother." This response was one of the few that addressed the issue of how ethical questions that may arise in multi-cultural contexts of dementia care may be addressed.

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

A number of key research organisations and funding bodies responded to this part of the consultation.

For example, the Alzheimer's Research Trust highlighted two areas of scientific development that show promise for translation into improved care and treatment for people with dementia:

- Recent developments in biomarkers, resulting from progress being made in neuroimaging, including both structural and molecular imaging, and from gene and protein based studies in blood and cerebrospinal fluid; and
- The use of large-scale genetic studies to try to elucidate the causes of Alzheimer's disease.

The Medical Research Council (MRC) and the Economic and Social Research Council (ESRC), in their joint response, felt that few new treatments were likely to come about in the next five years, a view echoed by the Royal College of Physicians, which took the view that it was "not aware of any major scientific advances that hold the *early* promise of a major advance in

our treatment of dementia.” However, the MRC, drawing on its own review of future research opportunities for neurodegeneration, noted that there were opportunities for investment in programmes for this area of research which could take place in the next five or ten years for the purposes of future development:

Investment opportunities for research within 1–5 years:

- Whole genome analysis and the assembly of gene products and regulators into disease pathways – identification of new therapeutic targets.
- Research to improve understanding of mechanisms and pathogenesis of neurodegenerative diseases – validation of new therapeutic targets.
- Research to better understand the role of cognitive dysfunction in the full range of neurodegenerative disease.
- Stratification of patient subgroups and population risk, identification of key time-windows for intervention – increasing the informativeness of clinical trials and the effectiveness of use of new medicines.
- Clinical research into symptomatic management – using science to improve quality of life.
- Better ways of assessing safety of new therapies given initially at early (or presymptomatic) disease stages, and taken for 10 or 20 years.

Investment opportunities for research within 5–10 years:

- Improved biomarkers, especially presymptomatic markers of early disease states, to allow more powerful clinical trials.
- Exploitation of new epidemiological opportunities provided by the outcome of whole genome analyses and cheaper genotyping, to better predict risk and identify factors that may allow very early, presymptomatic intervention.
- Moving towards the second generation of new therapies - addressing key mechanisms in the light of the outcomes of trials of interventions and delivering the potential of stem cell, gene and antibody (fragment) therapies.

In addition, the Academy of Medical Sciences told us that developments on the horizon in clinical research may arise from current efforts to find effective anti-inflammatory agents, reduce the production of A β , reduce the phosphorylation of the abnormal tau protein, and to target the tau and α -synuclein proteins, which are most closely associated with neuronal loss.

The Wellcome Trust drew our attention to developments in animal modelling:

“Developments in animal modelling of neurodegenerative diseases play a key role in gaining insight into dementia. Although mice are most commonly used in animal modelling studies, there are concerns about the scientific value of mouse models in certain types of dementia research. Dementias are varied and have different (sometimes multiple) causes, and therefore some researchers have expressed a need to develop and refine the animal models currently in use, and to explore possibilities for new, more complete modelling techniques.”

A similar point was made by the Alzheimer’s Research Trust, which stated that “models of Alzheimer’s disease are based almost exclusively on inducing autosomal dominant mutations in AD-related genes into mice. The results, however, have shown that the ensuing phenotype does not match the human condition.”

The Wellcome Trust also noted that improvements in imaging technology, ranging from molecular imaging to gene and protein-based studies, have led to the development of biomarkers that allow an earlier, and potentially improved, diagnosis of dementia. Also, it stated that:

“Current treatments focus on symptom mitigation. The advent of therapies that address biomedical causes of dementia is likely to be a major imminent development.”

Alzheimer Scotland suggested that “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)” was the most significant scientific development.

A number of individual respondents who identified themselves as carers and/or family members of a person with dementia, or connected with a charity or voluntary body concerned with dementia, also commented on what they felt to be significant developments in the scientific understanding of dementia. These included:

- The further use of donepezil;
- The use of stem cell research;
- The injection of Etanercept – a drug normally used for the treatment of rheumatoid arthritis – into the spine of a person with dementia;
- The use of Snoezelen, a controlled multisensory treatment.

6. 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? (*Short version question: When do you think a diagnosis of dementia should be made?*)

Respondents expressed strong opinions on the subject of early diagnosis for dementia, with some vehemently in favour of it, others against it, and some feeling that the timing of diagnosis depended on other factors. Answers therefore fell into three broad categories:

i. Early

One of the reasons most often quoted by respondents who favoured early diagnosis was that it gives both the person with dementia and their carers time to plan and make arrangements for the future, and adjust to their diagnosis. One respondent, with a diagnosis of dementia, stated that "early diagnosis is so important, so that I am involved in planning my future." Another noted that it would also offer more time for an advance decision to be made by the person with dementia.

A connected point on when a diagnosis should be communicated was made by one respondent who felt failing to impart a diagnosis could lead to the person with dementia experiencing feelings of mistrust and suspicion.

A significant number of respondents who answered this question felt that a dementia diagnosis should be treated no differently to other illnesses. Barbara Pointon stated: "People have learned to accept other life-threatening diagnoses, provided they know that support and treatment are available, and it should be the same for dementia." On a similar theme, H. A. Carsley felt that "a society where people with early problems are aware and can share their experiences also reduces taboos a little."

The feeling that 'knowing is a relief' also arose in a number of responses, including Friends of the Elderly, which stated that "early diagnosis may be a relief to certain people as many people are not sure what is wrong with them and are very worried that they are going mad."

It was also suggested in a joint response from the Economic and Social Research Council and the Medical Research Council that "there would be a clear medical benefit of early diagnosis since for the majority of cases, clinical presentation is at a point where irreparable damage has been done."

ii. Conditional upon certain factors

A number of respondents felt that a diagnosis should not be made until the relevant clinician has confidence, or certainty, that the patient has a form of dementia. One reason cited for this stance was that, at present, there is a lack of disease-modifying treatment, so diagnostic certainty should be

encouraged. One respondent, who wished to remain anonymous, commented that “the value of early diagnosis is in direct proportion to the efficacy of remedial or suppressant medication/therapy available ... There seems no point in providing a diagnosis that will only add to the sufferer’s anxiety without offering any potentially positive prospects.”

Other respondents felt that a diagnosis should be sought when concerns arise, and when changes in behaviour occur in a patient. In contrast, Bill Drake felt that diagnosis should not hail from a one-off event, but rather from a “progressive exercise over a period, so that adjustment is a natural development in which patient and carer may begin to accept change.”

Other respondents argued that the timing of the communication of a diagnosis should depend on the individual concerned, with decisions made on a case-by-case basis. Several respondents thought that there needed to be a solid understanding of the person’s history, support network and previous coping abilities.

One respondent highlighted the relevance of the stigma and fear attached to a diagnosis of dementia, and also the lack of a hopeful model of what it would be to live well with dementia.

iii. Later

A number of respondents felt that diagnosis could be offered too early. An anonymous respondent stated that “my mother was 95 years old when her troubles started and if she had been told at the outset, she would have been very frightened by the knowledge.” Ernie Allan similarly noted that “I was told very early that I have dementia. It was too early. My life would have been much easier without knowing my diagnosis. I find myself looking for new symptoms and some people don’t believe I have dementia because I can still function relatively independently. That causes me distress and agitation which in turn affects my relationships with others.”

Other respondents were concerned about misdiagnosis, especially where depression is originally diagnosed at an early stage of dementia. One anonymous respondent went as far as to say “early diagnosis is desirable, but an erroneous diagnosis may be a disaster ...”

Other points

Respondents also took the opportunity to comment on other issues surrounding early diagnosis. For example, some felt it vital for a support pathway to be in place for when a diagnosis of dementia is made with the possibility of pre or post diagnostic support and counselling. One health care professional, for example, felt that guidelines should be established for those

in a position to disclose a diagnosis of dementia, and also asked what should be done by health care professionals when a relative of a person who has been given a diagnosis of dementia insists that the person should not be informed of the diagnosis. Ian Jamieson, in answer to such a question, told us that “if my family had been told prior to me, I would have been very angry.”

Admiral Nurses – for dementia noted that it “was not so much about when the diagnosis was imparted (although we are clear it does need imparting as soon and as early as possible) it was more *how* it is imparted and how the person with dementia and their family are supported emotionally.” The same respondent also warned that there should be an awareness that not all people with dementia actually *want* a diagnosis.

The fear of being diagnosed also arose. For example, the Scottish Dementia Working Group thought that “...getting an early diagnosis will have an almost instant impact on many, if not all, aspects of a person’s life...it is therefore not surprising that some people will do anything to avoid confronting a diagnosis.” Perhaps in answer to such a point, the Christian Medical Fellowship felt that it was important for diagnosis to be discussed, and for any misunderstandings to be allayed.

7. In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how? (Short version question: in your experience, how do you think society perceives dementia? How could we promote a better understanding of dementia?)

Perception of society

Responses were primarily – but not exclusively – negative on the question of how society perceives dementia.

Dr Hazel McHaffie felt that “society perceives dementia as something which is to be feared, dreaded, hidden; a form of madness which also leads to a loss of inhibition and unsocial behaviours.” Bill Drake also found it regrettable that “much of the public awareness comes from publicity given to cases of the bad treatment given to dementia patients in hospitals and care homes.”

Several respondents referred to a lack of understanding of dementia amongst society. For example, one anonymous respondent held that “a lot of people are simply frightened of it, and don’t know how to communicate with those with dementia – they therefore try to avoid contact.” This point, regarding fear of dementia, was one echoed by a number of respondents.

Some respondents felt that despite dementia receiving more press coverage over the past few years, it was still misunderstood, and therefore that the public perception of dementia remained poor. One anonymous respondent told us that care assistants “treated my father as if he were simply an old man without illness, and even sought to blame his relatives for his distorted perspective.” On a similar point, an anonymous respondent noted that “it is not unusual for careworkers on training courses to say that they would commit suicide if they had dementia – what does that say about how they value others?”

Miss Gill Taylor similarly noted that she had to apologise for or “justify my father’s condition to society as well as dealing with my father.” This view was echoed by a participant in Stockport Dementia Care Training’s consultation session, who state that “I often feel under the spotlight – and I don’t like having to justify his illness or his behaviour.” The theme of justification was picked up by another respondent who told us that “we were viewed with curiosity, as though we were somehow responsible for him behaving in the way he did.”

A handful of respondents felt that a misunderstanding of the condition was particularly prevalent amongst younger people. For example, Findlay McQuarrie suggested that “there is little or no understanding among most younger people.”

Mrs Lesley Perrins thought that society’s perception was split between underestimating the impact of the disease, with statements such as “it’s only about not remembering things”, or over-emphasising certain (perceived) aspects of dementia, with statements such as “they all get violent, don’t they?”

Other respondents referred to society’s attitude to difference generally. For example, the Royal College of Nursing told us that “society is generally negative about areas of health care that deal with stigmatising conditions and spoilt identity.”

Other comments were also made in response to this question, including the observation from John Shore that “respect for elders, patience, and support for old people with physical or mental limitations are qualities sadly lacking in the UK today.”

Respondents who work in the field of dementia care provided a range of views. For example, Professor C. G. Swift reported that “avoidance, uneasy humour, and stigmatisation” existed in societal perceptions of dementia,

adding that “sadly, these perceptions pervade politics, health economics, and to a significant degree my own profession (medicine).”

Alongside the view expressed by Professor Swift, Professor June Andrews, head of the Dementia Services Development Centre at Stirling University, stated that there is “a very negative perception of dementia, equating it with decay, shabbiness, and ultimately horror. I say this while reflecting on the response of everyone from taxi-drivers to relatives when I tell them that I am a professor in this subject ... But it is getting better.”

The Royal College of Physicians felt that it was “hardly surprising that dementia has negative associations. It is a largely negative condition, i.e. associated with loss and with few, if any, compensations.”

A handful of respondents felt that dementia is seen as something that is an inevitable part of ageing; something that ‘just happens’ to older people. Dr John Kelly, for example, told us that dementia is “perceived as a ‘normal’ and inevitable part of ageing by some patients and public alike, promoting a passive acceptance of those diagnosed.”

In comparison to the number of respondents who commented on negative aspects of society’s perception of dementia, relatively few felt that society perceives dementia in a positive way.

For example, Linda Tolson told us that she had “no evidence that society perceives dementia in a negative way. We took my parents into restaurants and to the theatre for as long as we could and they were always treated with respect and kindness.” An anonymous respondent, in answering question nine of this consultation, on the issue of community inclusion for people with dementia, felt that “it might be perfectly possible to go to a carol service concert but not to a theatre play.”

The view that society does perceive dementia positively was supported by a handful of other responses, including H.A. Carsley who similarly related an anecdote from personal experience, telling us “when I am out with my mum and apologise or attempt to explain some slightly quirky behaviour, many people are very understanding and make allowances or offer to help.”

This view was supported by that of Daphne Sharp: “dementia was always a taboo subject, but it now seems that the country has woken up to the fact that it needs to address the issue of an ageing population.”

An anonymous respondent summed up two perspectives, writing “some people perceive [dementia] as an entirely negative disease, others see some

aspects of dementia as beneficial (mental decline results in [a] lack of worrying about oneself and sometimes [adopting a] more humorous approach to life)."

Promoting a better understanding of dementia

Answers to this section of the question fell into five broad categories.

i. Community involvement

Several respondents felt that a better understanding of dementia could be brought about through education in a school or college environment. The AAC Research Unit from the University of Stirling, for example, stated that "if we can teach children the facts about dementia and help them to understand changes in behaviour, perhaps this will alleviate some of the fear and help to combat the ignorance of future generations."

Another respondent felt that promotion of voluntary schemes could "demystify" people with dementia, additionally suggesting that if each community centre "could also cope with the needs of dementia as well as physical disabilities/young children, this would be helpful." A broader aim of increasing support and understanding in local communities through using pre-existing community focal points such as shops, leisure centres, cafés, and faith networks was also suggested by Alzheimer Scotland.

ii. The contribution of the health care community

There were several suggestions from respondents about the role of the health care community in promoting a better understanding of dementia. For example, a handful of respondents felt that understanding could be improved if GPs more frequently identified dementia as a primary cause of death on their patients' death certificates. Another anonymous respondent felt that GPs should provide leaflets on dementia in their surgeries.

Training for the health care professions was also seen as an issue by Ann Yourston, who highlighted that "in dementia care some staff are still not sufficiently trained in specific dementia care and can go into the job not realising how this is different from geriatric care."

iii. Use of the media

A significant number of respondents referred to the media as a source where a greater understanding of dementia could be encouraged. Forms of media including theatre, television, print and broadcast journalism and film were all mentioned by respondents. For example, Claire Biernacki thought that "more positive portrayals in the media are required so that the doom and gloom that is associated with Alzheimer's and dementia can be balanced against the positive experiences of many living day-to-day with dementia."

In referring to more specific aspects of the media, such as soap operas, one respondent felt that where these dramas portray a person with dementia, they should not be portrayed as 'sufferers'. Continuing with this point, John N. Laurie told us that "Coronation Street did more to promote general public understanding than all the excellent publications by Alzheimer Scotland." However, another respondent thought that real people with dementia should be involved with media rather than using soap plots.

Several respondents commented that understanding of dementia may increase when famous people with dementia 'go public' whilst another respondent felt that there was a need for positive role models in the media. Similarly, other respondents, including Chreanne Montgomery-Smith thought that more should be done "to illustrate people with dementia enjoying a good life." Another view propounded by Guideposts Trust was that obituary writers should be encouraged to acknowledge the role dementia plays in a person's life.

However, other respondents acknowledged the negative part the media may play in understanding dementia. For example, an anonymous respondent thought that work needed to be done to combat "erroneous and sensational health information [that] can appear in the press."

iv. State involvement

A wide range of suggestions were made by people regarding the role of the state in furthering an understanding of dementia. A large portion of these centred on education and training: it was suggested, for example, that training sessions should be introduced for anyone coming into contact with dementia in any capacity. Other respondents made similar points, and gave examples of professionals such as police officers, fire-fighters, and bank tellers as people who would probably come into contact with someone with dementia from time to time. In terms of educating younger people about dementia, one respondent suggested that before anyone leaves school, they should do a work placement in a care home with dementia, while a participant in Stockport Dementia Care Training's consultation session thought that both ageing in general and dementia in particular should be part of the school curriculum.

In terms of what type of information should be disseminated about dementia, suggestions included that given by Barbara Pointon, who told us that "there needs to be a national public health campaign to inform, educate and reassure [people affected by dementia] that help and support is available." Other respondents also felt that the state had a duty to inform people that dementia is not a natural part of ageing. For example, Moira Livesey stated

that “we need to communicate to everybody that dementia is an illness that everyone can get and should be treated with care and sensitivity.” The Christian Medical Fellowship expanded on this theme, in telling us that the population should be “important to try to persuade the population that people with dementia enrich society.”

Suggestions for state involvement that did not focus on education and training included the idea that there should be more government funding of organisations focusing on the needs of people with dementia and their carer(s). Ann Yourston, for example, thought that “there should be more public/government funding of organisations like Alzheimer Scotland.”

v. Reconsidering terminology

A handful of respondents felt that understanding dementia would be better if it were referred to in more ‘public-friendly’ terms. Bruce Bovill, for example, suggested that ‘cognitive cancer’ should be used instead of dementia because the “public understands more of the seriousness of cancer, and nobody jokes about it, unlike dementia.”

8. What part, if any, does stigma play in dementia care?

Very few respondents felt that stigma played no part in dementia care. Of those who did, one respondent, Professor Martin Raff, commented that “there seems to be relatively little stigma associated with dementia these days, as it is so common.” Another anonymous respondent, although not going so far as to say that stigma plays no part in dementia care, did think that people with dementia “seem not to be aware that they have it, and are therefore blissfully ignorant of any difficulty or stigma that is attaches [itself to it].”

However, the vast majority of respondents who answered this question felt that stigma *did* play a role in dementia care.

A significant number of responses focused on the idea that dementia is accompanied by shame and embarrassment. Daphne Sharp, for example, felt that “many people are ashamed to admit they have a family member with dementia.” The European Care Group similarly noted that dementia maintains “a strong taboo.”

A number of respondents also thought that stigma surrounding Alzheimer’s had a negative impact on enticing people to work in the field of dementia care, and also that the low pay and status for care workers encouraged a type of ‘stigma by proxy.’ Professor June Andrews also noted that stigma stops people recommending dementia care as a career.

Some respondents also referred to the difference between care provisions for children and those for older adults, with moral outcries for failures in the former, but not the latter. Coupled with this, other respondents noted that society generally tends to fear mental illness and old age, and that dementia encompasses both of these fears.

Several comments were made by respondents who felt that the impact of stigma stemmed from the caring profession itself. For example, Mrs Lesley Perrins told of how she had heard about families calling residential homes to inquire about a room for a person with dementia, only to be told that “we’ll take dementia, but not Alzheimer’s.” Age Concern Camden took the view that stigma arises from the attitude and behaviour of care professionals, and cited in its response the example of care home staff insisting on using separate crockery and toilet facilities to those for whom they care.

Another anecdotal example was provided by a respondent who told us that “I was shocked to be refused travel insurance for my mother- no questions were asked about the severity or anything else, just a bald statement that dementia is ‘one of very few diseases our underwriters will not accept’.”

9. Should more be done to include people with dementia in the everyday life of communities? If so how, and, if not, why? (Short version question the same as full version)

More should be done

A large proportion of people who answered this question felt that more should be done to include people with dementia in communities.

Several respondents highlighted the detrimental effect of people with dementia being hidden away, both for the person with dementia, and on public understanding. Algy Keuneman, for example, told us that “being hidden away is so detrimental to the person, taking even more hope and enjoyment from them.”

Daphne Sharp took the view that communities need to embrace people with dementia, and the European Care Group, on a similar point, thought that “if dementia was promoted as an everyday experience of many families and communities, barriers would fall.” Other respondents added that being more open about dementia would reduce fear of it, in its current state of being ‘hidden away.’

Some respondents thought that inclusion should be encouraged for the good of people with dementia themselves. For example, the Alzheimer’s Research

Trust took the view that “people with dementia should be included in everyday life as much as possible for social, emotional, and mental stimulation.” Similarly, Professor David A. Jones commented that “what is suffered is as much an alienation from the life of society as an alienation from the individual life of the mind.”

Several respondents also referred to the fact that communities offer opportunities for relation-building and personal growth. On such a point, Susan M. C. Gibbons told us that “our relationships with others are central to our personal ‘identity’ and to our ‘sense of selves.’”

A cautious approach to community inclusion

A small number of respondents took a cautious approach to community inclusion for people with dementia, emphasising the importance of individual choice. The AAC Research Unit, at the University of Stirling, for example, noted that more should be done to include people with dementia in community life, “but only if the person with dementia wants” it. Findlay McQuarrie also noted that “the decision to participate in community activity should be a matter of personal preference for the person with dementia.” Fiona McMurray told us that if more is to be done, then it should be done “carefully, so as not to make a spectacle” of the person with dementia. Nancy McAdam told us that “I need opportunities to join in with everyone else but I also need the chance to meet socially with others like me (with dementia).”

How should more be done?

In addressing how more should be done to include people with dementia in everyday communities, a general point was made by the British Geriatrics Society, which stated that what was needed was a “challenge to the perception that those with a diagnosis of dementia are burdensome to society with little to contribute.” Professor June Andrews also urged that the public should be generally more “aware of the problems of the person with dementia so that they are not afraid to help and have the skills to help.”

Some respondents felt that a good way of opening up opportunities in the community to people with dementia was through encouraging contact between older and younger people in a *general* way. Rebecca Taylor, for example, thought that a good way of doing this would be through encouraging school children to visit care homes. This viewpoint shared by a number of respondents. However, other respondents felt that community inclusion and openness also depended on the attitude of the family of the person with dementia. One such view was offered by Jan Lethbridge, who thought that “I would hope carers would continue to take their ‘charges’ out into the community as much as possible.”

Other suggestions for community initiatives included art, music, and dance classes, coffee mornings, and making further use of faith communities. For example, Ann Yourston told us that “I used to take my mother to the local church ... for the last half hour of the service we would slip in and sit near the back then join the congregation for coffee afterwards – we were always made very welcome.”

More generally, other respondents felt that people with dementia should be encouraged to continue to use their existing skills. Other respondents raised a similar point when they suggested that people with dementia should be given the opportunity to run day centres themselves, or do voluntary work so that they can make a contribution. The Scottish Dementia Working Group raised the point that “it’s important to realise that people with dementia can still learn new things, i.e. computer, internet and email skills. Courses catering specifically for groups of people with dementia would be useful so that everyone is at the same level.”

If more should not be done to include people with dementia in everyday community life, why not?

A significant number of respondents felt that people with dementia should not be further included in everyday life. Of these responses, nearly all focused broadly on ideas of harm, annoyance, adverse reactions of members of the public, risk, and stress.

For example, one anonymous respondent stated that they could not “see how people with dementia can be included in everyday life, as they need 24-hour care and can harm themselves if not watched.”

Other respondents, such as H. A. Carsley felt that a different approach was needed when addressing early and late stages of dementia: “later in the illness, community living can be less possible because of the physical risk of the environs, and unpredictable behaviour of the affected person towards others.”

Some respondents chose to focus on the effect further inclusion would have on others. For example, one respondent thought that carers would be under more stress to regulate the situation, whereas an anonymous respondent told us that “it’s not fair to expect others to cope with the inevitable problems that result from patients with dementia wandering around.” A. G. Wright also commented that people with dementia “act oddly. You have to know what to expect and not many do.” Drawing on this theme the Guideposts Trust stated that “involvement with the wider community, unless it is carefully planned and monitored, could inadvertently create stigmatising

responses.” Relating to this point, another respondent thought that “the presence of a person with dementia can stir up quite a lot of anxiety and hostility among other elderly people.”

Section two: Person-centred care and personal identity

10. Is the idea of person-centred care helpful, and if so, in what way? (Short version question the same as full version)

Responses to this question were fairly evenly split between those who thought person-centred care to be helpful, and those who did not.

A large number of those who felt that person-centred care was helpful referred to the oft-cited mantra that it is a good thing to ‘see the person, not the dementia.’

In its response, The Ethox Centre framed person-centred care in terms of legal necessity: “What is *non*-person-centred care? ... [It is] reflected in the Mental Capacity Act by the best interests test which takes into account the values and beliefs of the individual and so an additional label or test is not necessary. Person-centred care would therefore seem to be legally mandatory, not just desirable.”

Focusing on practical ways in which person-centred care is helpful, Robert Steward told us that “discovering their past interests and encouraging them to participate in such interests ... is both reassuring and relaxing, but also stimulating for person with dementia.” This assertion was supported in the response of Margaret Barbour who thought that reassurance and calm could be found from hearing “a word from their working life; a little music that was very much loved.”

Commenting on a practice that has been extinguished by the advent of person-centred care, Claire Biernacki stated that “[it] has led to the cessation of many undesirable practices [such as] bathing people in rows of baths.” An anonymous respondent commented that “when seeing dementia patients in a group it is quite clear that they are all individuals and different from each other and these characteristics should be respected and nurtured.”

However, some respondents, although clearly of the view that person-centred care itself was a good thing, thought it may be improved upon. For example, in commenting on personhood more generally, Canon Professor Robin Gill thought that “more might be added about the social and spiritual aspects of personhood. It is not just inner experiences that make someone a person but also the love of other people that makes someone a person. We are made fully a person because we are loved by others.” Colin Isaacs

highlighted the need for further use of person-centred care in recounting his father's experiences in a residential home: "all of the things which his – mostly much younger – care team think of as violent hallucinations may in fact simply be part of the fact that, as a result of his Alzheimer's, he is mostly revisiting and thinking he is living in his youthful past (as a soldier)."

Taking a more cautious approach to person-centred care, Chreanne Montgomery-Smith, along with a number of other respondents, thought that person-centred care was put into care home brochures, "but not much into their practice." The European Care Group offers a potential explanation for this, saying "it is a vague concept and has proven difficult to grasp at shop floor level." Professor June Andrews commented to us that "It is no longer as helpful as it once was. It is now 'jargon'. It was an inspirational idea from Tom Kitwood when he was relatively young and he would have developed his thinking since then if he had been spared. His brilliant idea is now abused and has been exhausted by overuse."

Some respondents thought that person-centred care held negative connotations for family members and carers. One response held that it "seems to overemphasise the role and importance of the patient as if they are not ill, and at the expense of the interests and wellbeing of others around." This assertion was supported by another response, stating that "as a carer I feel my needs or feelings were not taken into consideration." This point was noted further by The Ethox Centre: "[it is] problematic to think of the family and the individual as being separate. Potentially, carers could be excluded if care is defined as being 'person-centred' only"; the person with dementia should be considered in a more communitarian sense, located at the centre of a network."

A further cautionary note to this question was raised by the Alzheimer's Society: "It is important not to overanalyse a person's past at the risk of stirring up feelings or emotions that are not helpful in the present."

11. In your view, to what extent is it correct to say that dementia changes a person's identity? *(Short version question: do you think that dementia can change people so much that they actually stop being 'themselves'?)*

Many respondents answered this question, with answers evenly spread between those who vehemently defended the notion that a person's identity does not change with dementia, and those who thought that it may, or definitely does.

Of respondents who thought that dementia did not change a person's identity, reasoning included that a personality shift does not change a person's identity; that dementia *obscures* the person's identity but does not change it; and that the person is still situated in familial and other relationships - "they are still someone's spouse, mother, father, relative or friend" (respondent Jean Burnard). A précis of this view was offered by one anonymous respondent who told us that the "person is the same person, but one who has dementia." Canon Professor Robin Gill saw dementia as a contribution to evolving identity for the person; that "dementia changes the person's biographical 'story' and thus contributes to the person's evolving identity."

Other respondents sought to normalise changes in personality, arguing that each person, whether they have dementia or not, changes over time. On a similar point, The Ethox Centre told us that "care should be taken not to assume that there is a monolithic entity – a 'normal' person's 'identity' – which is potentially under threat in dementia."

The Scottish Dementia Working Group asked us to consider that apparent changes "may in fact be a frustrated reaction to the changes/circumstances that the dementia sufferer is now experiencing." Similarly, an anonymous respondent felt that the question of identity could be determined by interactions with others.

One of the most vehement responses we received was from Margaret Barbour, who told us that "the beast can never fully take over the spirit," with Agnes Charnley, in a similar vein, commenting "never think that the person has gone for good; so often they will surprise you, if you have the time and patience to see it."

Other respondents appeared to be less certain that dementia does not change a person's identity. Age Concern Leeds, for example, whilst stopping short of saying that identity itself is changed, did note that "emotional, psychological, and relational responses may be." A similar response was offered by an anonymous respondent: "certain aspects of him/her may be 'wiped out' and other aspects will then become stronger and more noticeable."

Some respondents looked to the behavioural actions of the person with dementia in order to come to a conclusion on the point of identity. For example, Colin Isaacs stated, in referring to his father, that "his spoken thoughts are so muddled it is difficult to know who he is." A comparable response from Peter Hindle related how, in caring for his wife "we see less

and less of that person (in all sorts of ways) and we see behaviours that are totally alien to her as she was before the disease.”

12. 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?

A significant number of responses to this question cited aggression as having a significant effect on relationships. One anonymous respondent raised a particular point in regard to relations between grandparents and grandchildren: “[It is] very challenging particularly when ‘Nanny’ can no longer control her temper and frightens younger relatives that they will no longer visit her.” Similarly, H. A. Carsley told us “mother lost touch with friends as they were offended when she made arrangements to meet and then repeatedly forgot.”

Barbara Pointon attempted to rationalise her partner’s aggressive behaviour. She said: “he became aggressive towards me, but I reckon with hindsight that it was because I had overstepped the fine line between caring and controlling.” This illuminates another point made in a response from the Christian Council on Ageing and Faith in Elderly people, Leeds, who told us that implications can be “considerable, especially if it is not understood why a person’s mood or behaviour has changed.” One of these implications may be that relatives distance themselves from the person with dementia, as suggested by the Royal College of General Practitioners: “It may mean that both carer and person with dementia end up living with ‘a total stranger’, despite having spent years together as a couple.” A caveat to such a point was offered by an anonymous respondent, who noted that “relationships may have broken down prior to the onset of dementia.” However, a contrary view was taken by Jim Ellis, a member of the Alzheimer’s Society, who thought that “sometimes, it can result in greater bonding, e.g. with a man and wife.”

In terms of respecting values and wishes held *before* the onset of dementia, the British Geriatrics Society commented that “under the considerable stress of caring, emotion may lead carers to misrepresent the former views of the person they care for.” The difficulty of the situation carers may find themselves in was also highlighted by the AAC Research Unit from Stirling University: “Often the children of individuals with dementia are torn; they were raised with, and remember their parent’s values and beliefs prior to the onset of dementia, but can find it difficult to encompass these values and beliefs when trying to make the right decision about their parent’s care.”

Section three: Making decisions

13. 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? (*Short version question: How do you think a person's past wishes and feelings should be balanced with their current wishes and feelings, if these seem quite different? Is the past or the present more important?)*

Responses to this question fell into three categories:

i. Past wishes trump current ones

Several respondents thought that a person's wishes when they had full capacity were more important than their contemporaneous wishes.

There were a variety of reasons respondents offered to support this view, including the suggestion that significant changes in decisions may mean that the disease is 'taking over' the person, and that if a person felt particularly strongly in the past it is probably what they *always* would want. Janet Wilkinson referred to the person's cognitive abilities as a reason to prefer past wishes: "from my experience my mother can no longer comprehend and grasp questions like 'do you wish to be resuscitated?', therefore her past wishes and feelings are what count." Similarly, an anonymous respondent thought that any personality changes arising with dementia have an impact on whether past or current wishes or feelings should be balanced: "the illness ... has changed the personality and they can't really make the decision."

Dr Jacqueline Atkinson, from the Department of Public Health and Health Policy at the University of Glasgow expressed a view in regard to the religious values of a person: "[it] might be considered unfortunate if strongly held religious beliefs and observances were to be ignored or overridden because the person had lost the intellectual capacity to understand them." Such a stance was supported by the view Angela Melamed, who wrote that there is "no way to compare a lifelong held belief with the answer to a question that may not have been fully understood or would probably have been answered differently before or after a meal or perhaps with or without music playing."

ii. Current wishes trump past ones

A number of respondents felt that current wishes should take precedence, and cited a range of examples for taking this view.

The difficulty of the issue raised by this question was raised by the European Care Group: “preventing someone from taking actions that make them happy now because it may not have made their old selves happy is difficult.” The Inverness Dementia Group also recognised it to be “important that the person with dementia feels happy now.”

Alzheimer Scotland raised a concern that, in failing to explore current wishes, carers may take on an ‘I know best’ attitude to the person.

Perhaps from a practical point of view, Dr Ian M. Jessiman thought it to be “impossible for any person to judge what another ‘would have wished’ in their present circumstances.” Reaching the same conclusion but for a different reason, John Shore simply did not like the idea of “someone else dredging up what *they* thought would have been my wishes at some unspecified point in the past.”

iii. A combination of past and current wishes

A significant proportion of answers to this question fitted into this ‘combination’ category, which is perhaps best described by a response from the Office of the Public Guardian (Scotland): “The adult’s past wishes cannot, in isolation, be the focus; past wishes often do not cover the particular current situation. Likewise however, the focus cannot be entirely on the current situation. The ideal is a proportionate balance of the adult’s past wishes and current wishes.”

A number of respondents also took the view that the observance of the person’s past or current wishes should be *conditional* upon certain factors. For example, one anonymous respondent thought that it was “neither possible nor sensible to lay down hard and fast guidance on their comparative weight as this is likely to be very fact specific – e.g. what sort of decision it is, how clear and coherent the views both past and present are, where the decision-maker thinks the person’s best interests lie and why.” The Ethox Centre similarly thought that “the key question is perhaps this: how accurately can we determine what is in the mind of the person with dementia?” Another condition suggested was how *risky* the outcomes of the decisions are perceived to be.

14. What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just? (Short version question: What do you think family or friends should do if they are worried about the decisions a person with dementia is making?)

In regard to *who* should be involved in borderline cases of legal capacity, only a handful of respondents felt that using substituted judgment as a sole

instrument of decision making was the best way of addressing the dilemma raised by this question.

A greater number of respondents thought that *joint* decision making was the best approach to take in cases of borderline capacity. Colin Isaacs, for example, felt that “there should be a stage before enduring power of attorney where the person with dementia and one or more designated family members are given the power of joint decision-making.”

Other respondents focused on *when* assessments of capacity and the issue of best interests should be addressed. Answers here focused almost exclusively on choosing a time when the person with dementia is best able to participate in a decision; the Ethics Department of the BMA wrote that “all efforts should be made to enhance individuals’ capacity, by assessing them at their best time and in familiar surroundings.” Adding to this view, Alzheimer Scotland stated that assessments should be made, “if necessary on several occasions where there are memory problems.”

Some respondents also referred to the need to make information accessible to the person with dementia. Bromley PCT commented that there is a need to break down “information into manageable chunks.” Similarly, the National Prion Clinic called for “a structured, clear approach” to situations where decisions need to be made.

A handful of respondents objected to the notion of ‘only just’ lacking legal capacity. For example, John N. Laurie told us that the idea was “nonsense, legal capacity is an absolute.” Dr Ian M. Jessiman also expressed feelings of discomfort with the notion, for the reason that “it creates an impossibly woolly situation.”

The majority of the answers to the ‘short version’ of this question cited the need to discuss their concerns with a health professional.

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

Responses were split between those who took the view that a diagnosis of dementia should not have influence in the areas raised by the question, and those who thought that it should have an influence.

Of those who fitted into the former category, reasons cited by respondents included that “every patient has a right to good treatment and this should

not be different because a patient has dementia” (anonymous respondent). Another anonymous respondent felt that in considering a patient’s dementia when making decisions regarding life-sustaining treatment, a value judgment was being made: “The equal value attached to each human life does not have to be earned. Ethically, and quite possibly legally, the doctor should not be making judgments about the objective value of a person’s life.” This, and the majority of other responses to this question, alluded to the view that the person with dementia should be treated as a *person* first, with their whole situation being considered rather than just their dementia.

However, another smaller group of respondents felt that dementia *should* influence decisions about best interests and appropriate care in connection with life-sustaining treatment. One argument raised by John N. Laurie was that “life-sustaining treatments should be reserved for patients who have the capacity to lead a good quality of life for a reasonable time.” However, others focused on practical difficulties that may arise as part of a diagnosis of dementia. One specific example, provided by the British Geriatrics Society referred to the use of CPR (cardiopulmonary resuscitation): “Cardiopulmonary resuscitation in frail people with advanced dementia has a very low chance of success for instance in care homes. It is clearly not beneficent to provide an intervention with a low chance of success which could also be burdensome for the individual.” Barbara Pointed suggested to us that her answer to this point was guided by an entry in her husband’s diary, which stated: “So it’s Alzheimer’s. When the end comes, I hope it isn’t too messy.”

A range of other issues were also discussed in response to this question. In particular, respondents referred to the potential for discrimination and stigma that may arise from a diagnosis of dementia and impact on decisions made in connection with life-sustaining treatment. For example, Professor David A. Jones noted that “stigma associated with dementia makes this group very vulnerable to wrongful and lethal discrimination in relation to life-sustaining treatment.” The Ethics Department of the BMA added that particular care should be taken “to ensure that decisions for people with impaired capacity are made fairly and without discrimination.” The same respondent went on to opine that reasons for withdrawing treatment “should be carefully explained so that it is not interpreted by relatives as abandoning the patient.”

- 16. 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? (*Short version question: What do you think should happen if the welfare***

attorney and the doctor disagree over what is right for the person with dementia?)

The role of the welfare attorney

Very few respondents specifically chose to answer the first part of this question. Bromley PCT however offered the view that “they should work as part of the whole multidisciplinary team, and not in isolation from it.” Similarly, Canon Professor Robin Gill noted that in situations where a person is appointed to make decisions for the person with dementia, “it is important that all those involved – the attorney and health care professionals – work in full cooperation in order to reach joint agreement on the patient’s best interests.”

How should disagreements be settled?

Many respondents approached the issue raised in the second half of the question in terms of whose view should take precedence: the welfare attorney, or the health professional.

- The welfare attorney’s view takes precedence

Of these respondents, most thought that the welfare attorney’s view should take precedence. The Office of the Public Guardian (Scotland) was one such respondent, explaining its view by stating that it “defeats the purpose of the law if the role of a proxy is fettered.” Other views offered by respondents, especially by those who are carers of people with dementia, expressed the view that the welfare attorney’s view should take precedence as they know the person best. Nancy McAdam, in answering this point, stated that “I would give more weight to my two daughters acting as welfare attorneys because they know me.”

However, Barbara Pointon qualified such a stance with the requirement that the welfare attorney’s view should “be given due weight, unless there is evidence that the attorney has not been in contact for some considerable time.”

A different qualification was made by the Royal College of Nursing; that the welfare attorney may be the best person to make the decision “if the matter is *not* one of clinical judgment.”

Other respondents referred to the notion of autonomy in order to justify this view. For example, the British Geriatrics Society told us that “respecting the older person’s autonomous decision to appoint a proxy *ipso facto* entails respecting that proxy’s subsequent decision.”

- Health professionals’ view takes precedence

Of respondents who felt that health professionals' views should take precedence, almost all of these referred exclusively to doctors. One such view was adopted by the Falkirk Branch of Alzheimer Scotland – a group of former carers, professionals and ex-professionals and people interested in dementia care. They told us that “the doctor should have the final say depending on circumstances.”

Other respondents chose to approach this section of the question by referring to *how* disagreements should be resolved, not to whose view should take precedence.

For example, a significant number of respondents felt that the issue of potential disagreements should be discussed *before* the issue arises. The Office of the Public Guardian (Scotland), for example, thought that it was “important to have early, full and frank exchanges of views between the adult and those closest to him in order that the adult’s wishes can be represented accurately and comprehensively by the proxy. A record of any such conversations should be maintained.” Angela Melamed similarly expressed the view that “conflicts are less likely to arise when a relationship of trust has built up between the WA and the professionals and it is important that the professionals give enough time for this.”

- Arbitration

A handful of other respondents thought that an independent body or arbiter would be of use in such cases. Moira Livesey, for example, thought that a “mediation panel made up of people who understand dementia and who have been through the same sort of things with their family” would be a useful body of people to employ where such situations arise.

Similarly, the Royal College of Physicians suggested that “each trust could have a standing body or group of nominated individuals, both professional and lay, to play a role here. It might be worth exploring whether clinical ethical committees might have an advisory role in this area.”

Concerns

A number of concerns were also voiced in response to this question. For example, the Office of the Public Guardian (Scotland) noted that “one must be satisfied that the proxy is representing the views of the adult and not their own views for the adult.” This point was also made by the British Geriatrics Society: “a welfare proxy may, even in good faith, make a decision which is contrary to the person’s best interests or motivated by their own agendas.” These views added to those of a number of respondents who were equally concerned about the potential abuse of power. On a related

point, Dr C. A. Trotter commented that there needed to be improved *training* for welfare attorneys.

On a similar vein, the National Prion Clinic express a concern that “there is a conflict of interests in the representation of people with dementia through solicitors. They are often acting for the family and not the person with dementia, unless an advance directive has been set up by the individual.”

Another concern was raised about the attitude of some welfare attorneys. For example, the Christian Medical Fellowship noted that “well-qualified welfare attorneys can be helpful but those simply ‘on a mission’ are usually unhelpful.”

Concerns were also raised by some respondents about the time that arbitration activities take to come about. The British Geriatrics Society thought that “if independent legal arbitration is to be employed this needs to be provided very rapidly,” a point which the Christian Medical Fellowship also picked up on: “there needs to be a clearly demarcated route for disagreements to go to arbitration quickly.”

- 17. What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives? (Short version question: Should people be encouraged to write advance directives? How should they be used?)**

The role advance directives play

Responses to this part of the question focused primarily on how advance directives should be used, and the weight that should be placed on their contents. Some respondents felt that a directive should always be adhered to; others that it should be one of several considerations; and some that they should not be used at all.

Always adhered to

There were a considerable number of respondents who felt that the provisions of an advance directive are absolute. Of these, several respondents thought that they should always be observed, because making the directive would otherwise, in effect, become a futile activity. As one respondent noted, “what is the use of making them otherwise?” Angela Melamed similarly commented that it would be a “serious abuse of trust to impose our ideas rather than respecting their wishes.”

In their response, Dignity in Dying recounted one of their member’s experiences of advance directives in relation to her own mother. This person said that “my mother died peacefully because she had an advance decision.

She had been transferred from her nursing home to the local hospital ... fortunately, the nursing home had faxed through a copy of my mother's advance decision".

Other respondents felt that the use of advance directives had a secondary result of reducing any feelings of guilt that may arise when decision-making issues arise.

One of several considerations

A larger proportion of respondents thought that advance directives should be one of *several* considerations in decision-making. One of the reasons respondents thought that this was the correct approach to take was due to a worry that advance directives could be interpreted as a substitute for effective communication. A similar point was made by Professor C. G. Swift, who thought that advance directives should never "take the place of the immediate ethical duty of care at the time, and their use for 'defensive' purposes should therefore not be encouraged."

Other respondents thought that advance directives should not be followed absolutely because they could conflict with what is in the patient's best interests at that time. Mr Keith Chard thought that "greater weight should be given to other considerations, such as whether the person appears to be generally happy." This point was supported by Dr Jacqueline Atkinson from the department of Public Health and Health Policy at the University of Glasgow, who thought it "perverse to allow someone who appeared relatively happy and content with their current lot to die because of a decision made before the new circumstances had been experienced..."

The Alzheimer's Society took the following view in its response:

"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 preference in favour of a more recently expressed one would not be delivering person-centred care."

Should not be used

Dr Jacqueline Atkinson, in adding to her response to this question, noted that advance directives were "likely to be as problematic as helpful in many cases because they are either too prescriptive or not prescriptive enough." Another respondent thought that a "statement of 'wishes and feelings'" should be used instead.

Others thought advance directives to be simply unnecessary if a good relationship, with clear communication, exists between doctor and patient.

Some respondents were concerned about opportunities to review the directives at the time when they would be used. For example, Professor David A. Jones thought advance directives to be an “unnecessarily strong and dangerous law by which people can make unwise life-threatening decisions without any chance to review them at the time they will come into force.” Also, in a response from Stockport Dementia Care Training, who held a discussion group based on the consultation, concerns were expressed about situations where a person with an advance directive appears to change their mind at a later stage.

Should people be encouraged to complete advance directives?

Firm views were expressed both by respondents who thought that people should be encouraged to complete an advance directive, and those who thought they should not be encouraged.

The completion of advance directives should be encouraged

A considerable number of respondents felt strongly that making an advance directive should be standard practice. Some, such as Professor Martin Raff, thought that making an advance directive should be standard practice for all middle-aged people. Dr James Warner took the view that there should be widespread advertising for advance directives. A different approach was offered by an anonymous respondent who thought that advance directives should be mandatorily “incorporated into post-diagnostic support.”

Reasons offered for why people should be encouraged covered a wide range of topics. For example, one anonymous respondent thought that advance directives were “a great help to know what their feelings are.” The British Geriatrics Society thought that advance directives help professionals “who would otherwise struggle to ascertain that person’s former wishes and views about medical intervention and future care.” This was an opinion which was echoed by a number of respondents to the consultation.

In its response, Dignity in Dying thought that more should be done to raise the awareness and effectiveness of advance decision, and that a central register for advance decisions would ensure that health professionals become aware of the existence of an advance decision, and hence be in a position to respond to it. A further point was made by Lukas Kalinke who suggested that it would be “useful to have an audio file” of the person with dementia stating their wishes as “hearing them say it holds greater weight seeing it written down.”

Advance directives should not be encouraged

A significant number of respondents expressed their unease at the idea of encouraging advance decisions.

For example, The Ethox Centre made the point that it seemed “strange and potentially dangerous that advance directives should be positively ‘encouraged,’ especially when it remains so unclear as to the circumstances in which an advance directive should be accepted or not, and upon what grounds.” This point was made by other respondents, some of whom work in the health care arena, and thought that some of the scenarios that may be put forward by advance directives may not echo the reality of a situation as it occurs, and therefore be of little tangible help for decision-making in cases of dementia.

Another concern which was frequently raised by respondents was in relation to the party who had made the advance directive changing their mind. Charlotte Rowley made such a point, observing that although advance directives are a good idea, “people change their mind and may not realise how later stages of [the] disease will affect them.”

A further cautionary note was raised by several respondents, who thought that the person with dementia should have their condition properly explained to them before they decide whether to write an advance directive.

Other considerations

The Medical Research Council and the Economic and Social Research Council highlighted a current gap in the way advance directives are used: “it would be helpful if the directive explicitly included a statement about the person’s willingness to participate in research should they lose capacity.”

18. 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 the Acts made it easier, or harder, to support and care for people with dementia?

Many respondents who answered the first part of this question were largely positive about the impact of the Acts. The British Geriatrics Society, for example, told us that it is “useful that health professionals are clearly encouraged to assess capacity, specific to each decision to recognise that capacity is not static” and a “useful defence against pressure or threats of complaint/litigation from family members.” Dignity in Dying thought that the Acts empowered people “by starting from the presumption that everyone can make their own decisions.”

A response from Alzheimer Scotland also highlighted a positive impact that the Adults with Incapacity (Scotland) Act may have had. They state that “it is interesting to note that the uptake of powers of attorney within the general population has mushroomed since the Act’s inception.”

However, a number of concerns were also voiced by respondents. The United Kingdom Psychiatric Pharmacy Group and The College of Mental Health Pharmacists, for example, felt that the Acts could be “more prescriptive about the banning of inappropriate prescribing of medication which increases morbidity and mortality in this age group.” Another comment about an omission (specifically an omission of the Mental Capacity Act), was made by Medical Research Council and the Economic and Social Research Council who told us that “for research that is not a clinical trial, the MCA does not specify what steps should be taken if capacity is lost following consent to participate in a study.”

Several respondents also highlighted the cost and complexity of creating a lasting power of attorney, while others felt that the Acts had made it harder to provide care and support for people with dementia. For example, Colin Isaacs told us that “legislation puts too much responsibility on the medical and legal systems and takes too much power away from the family [of the person with dementia].” Others felt that the Acts had made the support and care of people with dementia easier. Of this group, Admiral Nurses – for dementia for example, took the view that “professionals are able to make clinical judgments and the need to wait for the consultant’s opinion is reduced.” Similarly, Bromley PCT stated that the Acts “raised the profile of what it means to lack capacity and how this is no longer something for a single discipline to decide.”

The importance of adequate training to enable care staff to have a good understanding of the requirements of the Acts was emphasised by a number of respondents. For example, Bromley PCT made the point that “the quality of the decision depends upon those making the assessment, and some people still do not understand that capacity is decision specific.” The British Geriatrics Society similarly stated that “without the right training and protocols, staff may not feel confident in making assessments, or may, on the other hand, make superficial and inadequate assessments of capacity.” A relevant example to illustrate this point was made by Dr C. A. Trotter who stated that “ambulance personnel are uncertain and have been declining to take very ill and confused elderly to hospital in the absence of consent using the MCA.”

Several respondents also thought that mental capacity legislation brought with it ‘bureaucracy.’ For example, the Christian Medical Fellowship reported

that one of its members it consulted before submitting its response to the consultation, took the view that “Independent Mental Capacity Advocates [IMCAs] have made life difficult; they add another, often poorly accessible, link into the chain of care.”

Section four: Aspects of care and support

19. Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why? (*Short version question the same as full version*)

The dilemma this question raised was summed up by the Alzheimer’s Society, quoting one of its members: “Is it cruel to keep drumming it into dad that the love of his life is dead, or should I gently change the subject and leave him in peace?”

A minority of respondents opted to take a straightforward yes or no approach to this question, with the majority opting for a ‘sometimes, in certain circumstances’ stance.

Of those who thought that it was permissible not to tell the truth when responding to a person with dementia, most cited the need to avoid causing distress, emphasising how such distress would be a regular and fruitless occurrence, if telling the truth was deemed to be the right course of action in *all* situations affecting people with dementia. For example, Miss Janet Wilkinson told us that you “would cause hurt, pain, upset and after she would not remember what you had told her.”

An anonymous respondent cited their own personal experience of truth-telling: “He refused to believe that she had died, accused me of lying to him, wanted to know why I insisted on saying these things and became very distressed and tearful. What possible benefit could accrue from insisting on the truth under these circumstances?”

Angela Melamed thought that telling a lie ‘under these circumstances’ is in fact different to most other types of lie. She said that “unlike most lies, they are told to reduce suffering, not for the gain of the lie-teller.”

The respondents who stated that it was permissible not to tell the truth offered us the richest source for answers to the question of ‘under what circumstances and why’. A sizeable proportion of these respondents stated that it would be permissible in order to *protect* the person with dementia from distress and anxiety. For example:

"I felt fully justified in telling lies if it prevented my mother going through even more distress."

Mrs Linda Tolson

"[It is permissible] at all times to protect the health, safety, and general well-being of the person with dementia..."

Anonymous consultation respondent

"The only lie which is permissible is where it is done to save a person's feelings."

Martin Swann

"There would be very few circumstances where it would be morally permissible to lie to a patient. Truthful information is a precondition for respect for autonomy and for consent to treatment and could only be overridden if it could be demonstrated that lying to the patient was a lesser harm or provided a greater benefit than this fundamental breach."

British Geriatrics Society

However, others felt that *not* telling the truth was permissible in order to make life 'easier' for carers. An anonymous respondent thought that not telling the truth could "prevent anxiety and difficult behaviour." This view was supported by Robert Steward, himself a family carer: "[It is] much easier to work around mum's anxieties and agree with her, even if the facts are wrong."

Other respondents strongly emphasised that truths should *not* be withheld from the person with dementia in order to make things easier for carers. For example, the Alzheimer's Society, citing views of its members, stated that "it would not be ethically acceptable to tell a lie ... merely because it was an easier option." The Christian Medical Fellowship adopted a similar view: "[It] depends on the intention behind the deception: is it just for my convenience? Or does it have the patient's best interests at heart, in diverting them from a troublesome concern?" A caveat was also offered by the Ethics Department of the BMA: "If the truth is not told to a person with impaired capacity in certain circumstances, it is important that this should not become routine or used as an excuse to avoid discussions that patients want to have which could be distressing for themselves or others."

However, the Alzheimer's Society stated that "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.'" This view – that

there is no 'right' way of approaching the issue – was a view taken by a number of respondents.

However, a handful of respondents thought that people with dementia should *always* be told the truth. The reasoning behind this view often focused on the notion that 'it is not helpful to lie about anything.'

A possible justification for such a view was offered by the Royal College of General Practitioners as part of its summary of the issues this question raises: "given that one of the main symptoms is loss of short term memory, any distress caused by truth telling may be so transient that it could be considered insignificant."

Several respondents referred to the need to learn from experience whether to tell the truth or not. For example, Agnes Charnley stated: "I told him he was dead ... He was devastated and broken-hearted. I learned from my mistake. You have to be sensitive and feel for an answer. Ask what they think."

A similar view was also expressed by Jan Lethbridge: "The most important bit of advice I was ever given as a carer was that 'You cannot win.' It's probably worth remembering how we approach truth with children. We keep it simple, avoid unnecessary harrowing details and try to gauge how much they can cope with."

A considerable number of respondents felt that whether the truth should be told depended on what *stage* of dementia the person had reached. An anonymous respondent summed up this point: "a person with dementia who knows they have dementia has a right to a truthful response. A person who has dementia but has forgotten they have it can usually be distracted by talking about some aspect of the issue they've raised."

A considerable number of people referred to diversionary techniques as potential solutions to this quandary. For example, John Major of Bournemouth referred to the fact that it "may [be] better to introduce a conversational diversion rather than deliver incorrect or potentially disturbing information." A handful of other respondents referred to the perceived usefulness of validation therapy in cases where truth-telling dilemmas arise, a therapy based on the general principle of validation, the acceptance of the reality and personal truth of another's experience. For example, the Friends of the Elderly noted, in referring to current methods of training, that carers are taught to "look at what is actually being expressed by a person's communication and respond to that rather than attempting to correct their perceptions."

20. 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? (*Short version question: Do you think that those who care for people with dementia are too worried about risks, or not worried enough about risks? How should freedom of action be balanced against possible risks?*)

Most respondents took the view that carers err too much on the side of caution. A good summary of this view was offered by H. A. Carsley: "Generally, in my experience as a carer and as a GP, carers overestimate risk. When you accept responsibility for another person you tend to over-compensate, seeing adverse events or possibilities everywhere." A similar point was made by Claire Biernacki "as a nurse my experience is that nurses are defensive. Most would rather justify a restrictive action taken in their best interests than try to justify a negative outcome that was based on enabling freedom."

In contrast, very few respondents felt that carers did not consider risk enough. One such point was made by Mrs Jaki Evans who commented that: "some are negligent" while others are "overprotective."

A wide-range of comments were offered in response to the second part of the question concerning balancing risk against freedom of action for the person with dementia. Some chose to focus their answer on the person with dementia themselves. These responses included:

"Freedom of action should be permitted within the boundaries of reasonable safety and where possible the person with dementia should be supported to facilitate extension of their boundaries".

Dr Hazel McHaffie

"If it makes the person with dementia happy, then to hell with the risks."

Margaret Barbour

"I allow my husband as much freedom as he needs. On the whole, he will not do more than he feels safe with."

The Alzheimer's Society, citing one of its members

"[There is] too much emphasis on risk assessment. Why can't we use common sense to assess whether a situation is safe or not?"

Mrs Jacqueline Baldock

These respondents, and a significant number of other respondents who also answered this question, felt that, generally, freedom should out-weigh risk. One stark observation was offered by Chreanne Montgomery-Smith: "Protection of people can become an end in itself which is disrespectful. It is not living." Indeed, in its response, the Alzheimer's Society quoted a carer who highlighted her mother's desire to continue to accomplish tasks:

"My mother insisted for a long time that she could cook for herself ... 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."

However, a different style of approach was offered by Alzheimer Scotland, reflecting the views of its members who had been consulted on this question: "It is more important to review tasks and the environment of the person with dementia to try to prevent accidents rather than limit activity."

Other respondents emphasised the importance of considering the possibility of harm to others within any calculation about freedom and risk. For example:

"Institutions owe a duty of care and must take appropriate steps to facilitate individuals' freedom as much as possible. Restrictions of liberty must be based on an assessment of best interests and the potential for harm to other people."

Ethics Department of the BMA

In terms of the practicalities of balancing freedom and risks, a number of suggestions were made by respondents, including further use of personalised care plans and using advance directives to stipulate the risk the individual feels is acceptable. The latter view was offered in a response by Admiral Nurses – for dementia:

"The admiral nurses felt that it was interesting to note that advance care plans in [the] USA and Canada have a section that acknowledges a person with dementia to state that, for example, 'if I start to wander I only want [an intervention] if I am a risk to others.'"

21. 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? (Short version question: should any forms of restraint be allowed? If so, when?)

Responses to this question were balanced between those who thought that particular forms of restraint *should* be permissible, and those who thought they should *not*.

Restraint is permissible

A handful of respondents felt that restraint could be necessary in order to calm situations. Ernie Allan, for example, taking care to distinguish between physical and chemical restraint, noted that: "Medication could be used in extreme cases to calm situations."

A larger number of respondents thought restraint to be permissible in situations where the person with dementia may harm themselves or others around them. In referring to possible harms caused to other people, one anonymous respondent asked "what else would you do if a patient was assaulting another patient?" The Christian Medical Fellowship brought up a difficult point in relation to the use of anti-psychotic drugs and harm: "The key justification for 'restraint' is harm to the individual, and is an interesting issue with regard to the use of antipsychotic medication in dementia ... If antipsychotic medicines are the best way to reduce distress in an individual with dementia, are they justified by that gain despite the known risks of harm?"

Another group of respondents focussed more on the *procedures* to be followed in using restraint. This group took the view that restraint should only be permissible if a restraint policy or framework existed for the institution that took the measure of restraining a person with dementia. One anonymous respondent, for example, held that it is permissible "only if there is a clearly outlined framework of how and why [it should be used] and what reporting should follow [its use]." In a similar vein, Bromley PCT stated that "any decision about using restraint should be individual to a particular patient at a particular time and not a blanket decision."

A further condition some respondents felt should be met in order for restraint to be carried out was that *approval* should be sought. An anonymous example told us "I would hope that outside agencies, authorities and the individual's family would be involved in approving such restraints. This would

help to avoid private cruelty, when a person is unable to ask for protection from harm for themselves.”

A large number of respondents highlighted their belief that restraint should be a short term measure, and also a last resort. Chreanne Montgomery-Smith for example stated that “very short-term restraint might be necessary until other attempts at ameliorating the situation may start.” An anonymous respondent told us that “chemical constraints [or] sedatives can have a place but only with ethical medical supervision – not just to make life easier for carers [or] care staff.”

Restraint is not permissible

A number of respondents felt that restraining a person with dementia should not be permissible.

Of these respondents, several expressed strong views about situations where restraint was, they perceived, “more for the benefit and safety of staff” (anonymous consultation respondent).

Some distinguished between different ‘types’ of restraint, although, overall, there was no consensus on which types of restraint were permissible and which were not.

H. A. Carsley, for example, stated that physical restraint such as tying a person to a chair is never acceptable, whereas “sedation, if managed well, can be a component of enabling good care to continue.” Others however took a strong stance against the use of ‘pharmacological restraint.’ Fiona McMurray, for example, stated that drugs with the aim of restraining a person with dementia should not be used, “as these are often given too easily, and further diminish the quality of life.” An example of such a situation was offered by an anonymous respondent who told us of a relative who behaved “quite badly,” entering other patients’ rooms and pulling their hair. The respondent then recounted how their relative “was given some calming tablets” that “made her into a zombie, who did not speak or interact.”

A different stance was offered by the Ethics Department of the BMA who referred to the *proportionality* of the response of restraint:

“Restraint which is disproportionate to the threat or is routinely used without assessment of the need for it is not permissible [...] measures of restraint have included ‘cocooning’ them in sheets so that they cannot remove incontinence pads and all their movements are

restricted. We would consider such measures disproportionate and therefore not permissible.”

A different approach was offered by other respondents to this question, who took the view that people with dementia should be treated how one, oneself, would want to be treated. For example, a participant in a consultation session organised by Stockport Dementia Care Training stated: “I am used to being in control of myself and other people and hate the ideas of someone having to control me.” A further example was relayed by anecdote was offered by an anonymous respondent:

“It should not be acceptable for hospitals to treat a distressed person with dementia as though he or she were some sort of delinquent or violent offender. For example, one evening my father was moved without warning from one acute ward to another, and he naturally became distressed, and complained loudly. The reaction of the nurses was to surround him with furniture, and get security staff to stand over him.”

A linked point, raised by a small number of respondents, referred to their concern in not being able to stay in hospital with their family member, offering reassurance and comfort, and hence possibly avoiding the situation leading up to the use of restraint in the first place.

On a similar point, CARE stated that “using restraint can frequently lead to distress and exacerbate a situation when the reality is that most patients need space and freedom.”

Who should decide?

Few respondents chose to answer this section of the question. However, of those who did respond, two different views were expressed. The first view focused on care staff’s obligation to decide on issues of restraint, whereas the opposing view offered by respondents was that the decision as to whether to use restraint or not should rest with the family of the person with dementia.

Does the law help or hinder?

Again, few responses were offered in response to this part of the question. One comment from Dr Hazel McHaffie raised the issue that, “in drawing attention to the issue, the law raises awareness of the undesirability of restraint but it provides little guidance as to the level and nature of appropriate restraint or circumstances in which it might be used.” The British Geriatrics Society, on the other hand, felt in relation to physical restraint that “the Mental Capacity Act seems to have this at about the right level i.e. that

restraint should be a last resort and not merely a proxy for inadequate levels of assessment, nursing care, medical treatment." An anonymous respondent however pointed out that the Mental Capacity Act holds "room for argument about what constitutes a restraint: section 6(4) may need further interpretation."

A derogatory view of the law was offered by a separate anonymous respondent: "The law is, as ever, desperately unhelpful in its prescriptive attempt to foresee every situation, whilst devaluing reliance on an informed, compassionate and intelligent response to the circumstances." The same respondent took the view that "at the expense of ever more bureaucracy, a log of each incidence of restraint and sedation might help to maintain an overall picture of the care home's general ethics." The Older People and Disability Team from the Social Care and Learning Department at Bracknell Forest Council adopted a similar view, suggesting that "there should be record proving that restraint is justified and all other means of prevention have been tried first."

22. 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?

Reactions to this question were generally positive about the idea of education in ethical aspects of decision-making. Claire Biernacki commented that "some practices in some care areas are so ingrained that carers don't even realise that their practice is open to question and that there are other potentially 'better' ways of working." In support of this, the European Care Group made the point that the "ethical use of power and the realisation of moral aspects of the care should form the lynchpin of all training programs." The Guideposts Trust felt that if such training were to be employed, that there should be "greater emphasis on 'everyday' or 'mundane' ethics: it is these which influence the quality of life as it is experienced by patients on a daily basis."

Those who thought an ethical education for those providing front-line care would be positive expressed the view that this sort of education would lead to better care and more respect for patients. A handful of respondents, such as Spiritual Care for Older People (SCOP) in the Diocese of Oxford, took the view "nothing more than a general awareness of the issues is needed on a shop floor level, but it ought to be part of 'managerial' level training perhaps via NVQs."

However, a significant number of respondents thought that education in ethical aspects of care was not required as a support for those providing

front-line care at all. Most views on this point suggested that ethical education was something else to add to the workloads of those providing care. Some of the comments included:

“I have found the professionals engaged in [the] care of my dad to be pretty good in their understanding of these issues. It has been legislation and their workload that cause problems, not the professionals’ level of ethical education.”

Colin Isaacs

“Most of those who care need clear guidelines and boundaries as to what is permitted. They do not need ethical debates in the heat of the moment.”

Angela Melamed

How could it be provided?

Responses to this part of the question were split between those respondents who suggested using pre-established initiatives, and those who thought that, if ethical education was to work, that a new initiative would have to be provided. Examples for each category are offered below:

Established initiatives:

- Extending the use of local support groups and community centres which may offer carers an opportunity to meet, receive training, and debate ethical issues.
- Using hospital facilities and residential care homes as places to discuss ethical issues, with training assistance from carers’ associations.
- Providing ethical education at PCT level for primary health care staff.
- Considering the use of NVQ qualifications, questioning whether they could place more emphasis on ethical issues facing those providing care.
- Considering whether the Care Quality Commission could further encourage ethics training.

In terms of the content of an ethical education for carers, a response from the Guideposts Trust illuminated the breadth of ethical issues that would need to be addressed:

“There is a tendency among those interested in practical ethical issues to concentrate on difficult or challenging cases (sometimes referred to as ‘quandary ethics’) and use them as a basis for discussion, training and consciousness-raising. This is in itself excellent prudential preparation for the time when they occur but when one is considering the ethical framework which

ought to inform theory and practice in the provision of regular daily personal care, the focus on specific discrete problems can divert attention from the need to develop sustainable ethical culture in the direct caring environment ... suggesting that there should be a greater emphasis on what might be called 'everyday ethics' or 'mundane' ethics': it is these which influence the quality of life as it is experienced by patients on a daily basis."

New initiatives

- Using travelling workshops in ethical aspects of care
- Developing a code of practice which "spells out in unequivocal terms the ethical parameters which ought to inform the personal treatment for patients [with dementia]." (*Guideposts Trust*)
- Developing specific courses for all levels of carers that would include specific and extended sessions on ethical decision-making.

- 23. 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? (Short version question: Do you think new technologies such as smart homes and electronic tagging raise any ethical problems? If so, what should be done?)**

Ethical issues were addressed by the majority of respondents in terms of positive and negative impacts.

Positive impacts

Some respondents referred to the technology enabling the person with dementia to have a better quality of life. For example, Colin Isaacs noted that "once a person reaches a point where they are no longer able to make decisions about their own care then any electronic device helps to maintain the highest possible quality of life consistent with safety to themselves [the person with dementia] and others should be employed." However, some, such as Professor Roger Orpwood, Director of the Bath Institute of Medical Engineering, cautioned that an ethical issue arose about who *actually* benefits from the use of the technology, and that it should be the person with dementia who benefits primarily.

Addressing the argument that assistive technologies could undermine a person with dementia's dignity or autonomy, the British Geriatrics Society commented that the notion of *proportionality* should be invoked. It commented that "being on the floor with a serious injury, becoming ill because of failure to take one's medication, putting oneself at risk from appliances might be considered equally more undignified and harmful than the

alternative of using the technology.” The Society also commented that if the technology is not burdensome, and coercion to use it is not needed, then its use is morally permissible.

The notion of ‘freedom’ was raised by the Alzheimer’s Society, quoting one of its members: “if someone can come up with an item that helps us retain our freedom, I am all for it.” Other respondents referred to the wider aim of keeping people with dementia at home and in the community and how assistive technologies may assist in this aim.

Other respondents opined that the technologies were useful in offsetting vulnerability. For example:

“GPS tracking devices are successfully used to keep watch on/locate vulnerable children. I think it is sensible to use technology to help a vulnerable person.”

British Geriatrics Society

“Paradoxically, whilst some older people may feel that the very use of walking aids, social services, or assistive technology solutions may compromise their independence or “label” them as old, these may be the very things which enhance their capability to remain living independently.”

British Geriatrics Society

Ross Campbell and Ian Jamieson, in their joint response to the consultation, stated that “we are in favour if it [assistive technology] provides a better, safer life and benefits the person.”

Impacts that raise concerns

Most respondents who felt concerned about the use of new technology for the care of people with dementia focused on the possibility of it being a replacement for human care and the worry that the person is deprived of their liberty and privacy if they are subject to such technology.

Respondents who felt that assistive technologies could be seen to be a replacement for human care included:

“It is fine for a light to automatically come on to illuminate the way to the bathroom but it’s what happens next [that] there is no technology for. Mopping up, cleaning up. These technologies are intended as aids to, and not substitutes for, caring.”

Anonymous consultation respondent

"If smart homes mean that people can safely remain in their own homes for longer, then that can only be good. But it must not mean that people don't have personal visits; electronics can never replace human contact."

Hazel Simpson

"Just as drugs may be abused to keep the elderly sedated, so electronic constraints may be used to control people and reduce staff costs."

Anonymous consultation respondent

"It is important that new technologies should not be applied too mechanistically, reducing the human approach."

Bromley PCT

However, a different stance was adopted by Professor Roger Orpwood, Director of the Bath Institute of Medical Engineering:

"Those of us involved in developing such equipment see it more as augmenting human care rather than replacing it. However, there are some things technology can do that are better than human support. It doesn't get tired or frustrated, it can operate 24 hours a day, and it clearly doesn't get upset by the behaviour of the person with dementia."

In regard to the argument that the use of technology amounts to a deprivation of liberty and privacy, respondents referred to the perceived intrusiveness of assistive technology; that the technology is a form of restraint; and that the technology may not be used sensitively.

For example, the Alzheimer's Society raised the question of "when does technology stop being an aid to independence and become a restriction on autonomy?" An anonymous respondent, addressing such a point, stated that "restriction of liberty needs to be weighted against what would happen if the PWD did not have access to the technology."

However, Professor Roger Orpwood again made the point that ethical issues arising from the use of assistive technology stemmed from the way in which it is *interpreted*: "If carers are told 'now he is in bed, and now he is out', etc that is intrusive, but if they are told 'the client has had a poor night's sleep' I would be less concerned, and given the impact it can have on the client's well-being I feel this intrusion into their personal world is acceptable ethically."

The way in which assistive technology is used was another central point of Professor Orpwood's response:

"Cameras concern people because they mean "someone can see what I am doing", but all sensors are basically building a picture of what people are up to. The key ethical concern is how this sensor information is used. If other human beings are directly watching video output, or are able to see from the detailed information that someone is in the toilet then this is an unacceptable intrusion of privacy."

The Guideposts Trust took the view that although the use of technology, and specifically surveillance, could be seen to be invading a person's privacy, it could also liberate "the person from the shackles of a very restricted lifestyle by allowing them to move about freely and alerting others when care is needed."

A response from the Older People and Disability Team at the Social Care and Learning Department of Bracknell Council raised a separate concern that the justification for use of assistive technology could be primarily financial: "[It] removes responsibility from the government for providing person-to-person care, thereby resulting in a money-saving exercise."

Relatively few respondents commented on the argument that the use of such technologies could bring about stigma. However, Agnes Charnley, one of the few respondents who did take such a view, stated that "electronic tagging puts them in line with criminals. A name and address placed in a pocket or wallet seems a better idea." Similarly, Rebecca Taylor commented that its use could make the person with dementia "feel like second class citizens." However, these comments were mainly confined to electronic tagging devices.

Why technologies are not more widely used

This part of the question received less attention from respondents. However, a large portion of those who did choose to address this issue referred to the *cost* of assistive technology.

One anonymous respondent, for example, told us that "resources [are] needed to make any technology effective – if someone is tagged, who is watching and tracking?" A similar point was raised by H. A. Carsley: "knowing someone has left a building, and is off down the main road is not a lot of use if they are then knocked down: we need people to supervise in a timely fashion."

Other respondents drew attention to the *timeliness* of the technological intervention, and that a tipping point occurs in dementia where the person becomes less able to learn anything new, and also that “[at] times, technologies are introduced too late for the person with dementia to learn how to use it or get used to them” (Mrs Penny Hibberd, Canterbury Christchurch University, Admiral Nurse and Lecturer). A complementary point was made by Jan Lethbridge who thought that the time taken for assessments and referrals for assistive technology was the reason that it was not more widely used. Also on the issue of time, Professor Bob Woods told us that “often the rate of progress of the person’s condition means that the technology cannot keep pace with the person’s changing needs.”

Respondents also felt that some technologies may *frighten* the person with dementia:

“Certain sorts of technology might actually be frightening. Listening to a (non-embodied) voice, for instance, might be quite confusing for someone who is already confused.”

Anonymous consultation respondent

“...some of the smart house suggestions cause me concern – the idea of piping a voice into someone’s home in the middle of the night to encourage them to go back to bed and orientate them to time is very Big Brother – were it me, I would be looking for the source of the voice, particularly if the voice were of a family member.”

Claire Biernacki

“...how would a confused person react to a disembodied voice from the wall asking why they are opening the door?!”

Age Concern Leeds

A small number of respondents focused specifically on the effect of assisted technology on professional carers. Professor Roger Orpwood, Director of the Bath Institute of Medical Engineering, for example, referred to a “reluctance on the part of professional carers to make what are perceived to be major changes in their approach to caring.”

24. What duties do you think the state owes towards people with dementia and their families, and on what ethical basis? (*Short version question: What duties do you think the government owes towards people with dementia and their families, and why?*)

Answers to this question fitted into five main categories:

1. A duty to give financial support

Several respondents referred to the funding split between health care and social care. As one anonymous respondent noted, “a person with a physical illness is automatically cared for under the NHS free of charge regardless of that person’s financial status. A person with dementia is said to require state social care only if their family cannot provide care for them.” A significant number of other respondents also felt that means-testing for the care of people with dementia is unfair, impacting on the lives of the person with dementia and their carers, sometimes forcing homes to be sold in order to pay for care.

The theme of financial support was also raised in the context of wage levels for those working in dementia care. Mrs Jacqueline Baldock, for example, felt that carers should be paid enough “so that others are attracted to care work.”

2. A duty to provide information about dementia, raising awareness

This view is illuminated by a response from an anonymous respondent who told us “most have to rely on word of mouth, chance, or very helpful charities if [they are] known about.” Mrs Debra Catton echoed such a view, calling for more information to be provided by social workers, particularly at times when care homes need to be chosen and decisions made about continuing care.

The need for the public to be informed about what dementia actually is was raised in response to this part of the consultation. Charlotte Rowley, for example, stated that “dementia needs to be promoted as a clinical disease and that behavioural changes are due to biological changes in the brain.”

3. A duty to give further community support

Several respondents also thought that the state had a duty to support care in the community schemes, for example with more care centres being opened. Chreanne Montgomery-Smith highlighted how ‘community’ support can extend beyond health and social care services: “The state needs to look to existing resources which are underused, like village halls, church halls to build community health and well-being.” Other respondents made similar points, with calls for pre-existing institutions such as banks and shops to tailor their services to accommodate a person with dementia.

4. A duty to fund research

A full discussion of the issues surrounding research funding is given at question 29. However the main point raised here concerned the distribution of the government’s medical research budget. For example, in its response,

the Academy of Medical Sciences told us: “at present, the Department of Health allocates three per cent of its research and development budget to dementia research.”

5. Further support for dementia in the NHS

Two clear lines of argument appeared where respondents lobbied for further NHS support.

The first involved the use of a specialist GP or dementia nurse in every GP practice. Findlay McQuarrie, in answering Question 6 of this consultation on when a diagnosis of dementia should be delivered, also noted that “my GP failed to recognise early symptoms when his attention was first drawn to them. This suggests [that] GPs need special training, or at least one GP in a group practice specialising in the field of dementia.” Similarly, Margaret Barbour told us that “we need nurses in GP practices to help to guide [us] down this very convoluted path.”

A separate idea for more support from the NHS was introduced by Lukas Kalinke: “perhaps the NHS should introduce a service so that if family/friends notice a change in behaviour they phone a helpline.”

Section five: the needs of carers

25. 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 view that conflicts “cannot be resolved, only mitigated” (Angela Melamed) was one that appeared in a few responses to this question. The Ethics Department of the BMA similarly noted that “the kinds of tensions that are likely to develop between carers and people with dementia are unlikely to be amenable to off-the-shelf solutions. The questions talk about resolving dilemmas in these circumstances, but it is much more likely to be a question of managing the conflicts and tensions as they arise rather than bringing them to resolution.”

A different view was offered by Barbara Pinton, who told us that “sometimes you just have to bite the bullet, and tip the scales in favour of the carer, remembering that if the carer goes down, the whole ship goes down with them.”

A similar view was offered by Professor David A. Jones: “While maintaining an adequate quality of care (however this is delivered), the needs of voluntary carers such as relatives should have relative priority over the needs of the person with dementia, both because this is necessary for the

sustainability of care, and because the carer is a person too and has significant needs.”

In addressing the specific question of *how* conflicts can be resolved, however, mediation was a common theme offered by respondents. Several respondents, for example, raised the idea of independent advocates to resolve disputes. This was a view raised by Professor Bob Woods: “There is a role for much greater involvement of advocates in dementia care. As the dementia progresses, there is a risk that the best interests of the person with dementia are seen as less important than those of the carer, and advocacy would have an important role in ensuring the perspective of the person with dementia continues to be heard.” Mrs Penny Hibberd, an Admiral Nurse and lecturer from Canterbury Christchurch University similarly felt that an advocate could be used, working alongside an Admiral Nurse. The Field Lane Foundation also picked up on this idea, proposing “a dementia mediation service to be set up, staffed by people with expert knowledge in the field.”

A different idea, offered in the context of more effective administration, was raised by the AAC Research Unit at the University of Stirling: “A record of what was discussed and decisions made should be kept for referral and should be reviewed on a regular basis to check if views or circumstances have changed.”

- 26. 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? (Short version question: How can professionals (such as doctors and social workers) help if a carer’s own needs are very different from the needs of the person for whom they care?)**

The role of health and social care professionals in resolving conflicts of interest

A large range of opinions were offered in answer to the first part of this question. Barbara Hall felt that professionals should have a role that *supplemented* that of the person’s family: “Social care professionals need to be very tactful when suggesting different strategies for dealing with a dementia case. It is never right to ride rough-shod over the family and not consult them about things which are important.” An anonymous respondent, describing themselves as a family carer, wrote that care professionals “should listen to and absorb a person’s ethical principles over a period of time, enabling them to act and react within the known boundaries of their beliefs.”

However, other respondents envisaged a more proactive role for social care professionals:

"A social worker should be allowed to help choose and arrange care at a suitable nursing home, rather than being limited to providing a supposed 'listening ear' by regular visits."
Anonymous consultation respondent

"...there are occasions when carers have motivations of their own which may lead to pressure, coercion, abuse or neglect and to a decision about future care needs being made which is contrary to the older person's best interests. Professionals need to be aware of this and it is important not to simply accede to any request from a carer to 'keep the peace' and avoid complaint."
British Geriatrics Society

Other points made in response to this part of the question referred to similar mediation procedures as outlined in Question 25 above.

Ethical dilemmas

Relatively few responses directly addressed the issue of where ethical dilemmas could occur for professionals. One response that did was offered by Professor June Andrews, Director of the Dementia Services Development Centre at the University of Stirling:

- "Should I tell the family that this care setting/programme is substandard, or reassure them that it is good as the best I can offer?"
- Should I allow this person with dementia privately to have a sexual relationship, or should I tell the family to allow them to decide to forbid it?
- Should I respond to this carer's view that they are being abused by the patient, or is the patient my only responsibility?
- Should I respond to an apparent abuse of the patient by the carer, or do I remain silent, as the alternative institution is probably unpleasant and not what the patient would have wanted?
- Should I respond assertively to this medical emergency in a person with dementia simply because the family demand it?

27. 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?

Several respondents referred to the circumstance where the health or wellbeing of one person may be compromised by their partner. For example, Mrs Penny Hibberd, a lecturer and Admiral Nurse from Canterbury Christchurch University, felt that such a circumstance would include “in cases of abuse or continued concern for the safety of one or more people in the household.” Similarly, Annie Foster felt that circumstances would include “cases of abuse or dangerous neglect.”

In a joint response from the Christian Council on Ageing and Faith in Elderly People, Leeds the well-being of the couple was addressed from another perspective: “Often the prospect of separation in advanced age, for example after 60 years of marriage, is hard to contemplate and might well hasten the demise of both parties as well as adversely affect[ing] their well-being.” Jean Burnard offered an illustration of this point:

“A husband and wife in my family both ended up with dementia, the wife in her 90s, the husband in his 80s. They had been together for over 60 years, living in a very small flat. They both ended up in different residential homes. They died soon after. The daughter was told the reason [for this] was that her father needed different medical treatment. This, to me, was not a judgment in the best interests of the couple.”

A related practical point was raised by CARE, which told us that “in situations where just one spouse/partner is in a care home, the other partner must be easily able to access the home for visiting. Therefore the location of the care home must be taken into consideration.”

However, Susan M. C. Gibbons highlighted some of the difficulties inherent in considering the interests of a couple jointly, commenting that a leading criticism of the idea of ‘relational autonomy’ is “the obvious danger of swinging the pendulum too far towards over-emphasising interrelationships, thereby overlooking or insufficiently valuing the importance that people attach to their private ‘self’ and self-determination.” This contrasted with a view offered by a number of respondents that it is *not* helpful to see people with dementia and their partner as two distinct entities.

A different point was offered by Mrs Lesley Perrins: “It depends on the relationship. Not all people want or should remain together when one of them has dementia – for others it will be devastating to separate.”

28. 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? (*Short version question: Is it too difficult for family members to get the information they need? Or are professionals such as doctors or social workers too willing to share confidential information about the person with dementia?*)

Too much, or too little information?

Views were split for the first section of this question. However, far more respondents took the view that too little information was imparted, rather than too much.

Many of the responses to the first part of the question cited their own experiences. For example:

"We were not allowed to see the report to the social work funding panel."

Mrs Kathryn L. Johnston

"We get virtually no information unless we press for it. Even then it is provided reluctantly."

Colin Isaacs

"I had no difficulty in getting information about the medical condition of my wife from her GP and, later, from a psychiatrist. Both were cooperative without breaching confidentiality. But, in so far as general information about the condition, how to care for her, or where I could obtain help, such information was not forthcoming."

Findlay McQuarrie

"I was stunned that my doctor would not speak about my concerns ... I felt frightened about my husband's changes in behaviour."

Agnes Charnley

"I don't know enough about his other medical problems. How on earth am I supposed to make proper, decisions regarding his future?"

Mrs Debra Catton

This selection of views is indicative of most of the responses we received to this question, echoing significant levels of frustration among respondents.

Conversely, very few respondents felt that too much information was imparted, although an example of such a response was offered by Associate Professor Robert Jones, who took the view that “decreasing respect for confidentiality seems to be pushing the balance towards too much information being given. The professional should make proper professional[ly] balanced best interests judgments here.” Another similar view was taken by an anonymous respondent to the consultation: “Past history and views of [the] patient need to be taken into account. Provision of all information can result in inappropriate disclosure of medical history.”

A greater number of respondents stopped short of taking the view that too much information is given, instead stating that there was no cause for complaint about the amount of information they received:

“Sometimes it is difficult to gauge how much information is needed in any given situation. I have found in my experience that enough information has been supplied to make sensible decisions.”

Barbara Hall

“In my rather narrow range of experience (i.e. speaking to patients and families who wish to make a brain donation for research), lack of information has rarely been a problem. The carer or carers have invariably been involved together with the patient in key discussions.”

Professor Seth Love

“Often the information is adequately shared, as [a] family member has to attend appointments – as the affected person cannot organise care themselves.”

H. A. Carsley

“We have no experience of any problems but our contact with anybody about my mother is minimal.”

Anonymous consultation respondent

“As a carer for my husband I have not found it difficult to get information.”

Anonymous consultation respondent

"I think that the amount of information is about right in my experience."

Anonymous consultation respondent

Respondents also commented on the way information is sometimes given, and in particular how the person with dementia may be excluded from the process. Such views included:

"Family carers are frequently given information as an alternative to that information being given to the person with dementia."

Claire Biernacki

"I did hate it when Social Services asked to speak to me in another room. This made my mother suspicious that things were going on from which she was excluded and I thought that it showed a lack of respect."

Mrs Linda Tolson

How should a professional caregiver decide how much information to share with families?

A significant number of respondents, primarily family carers, opted for a blanket approach to information sharing, namely that *all* information about the person with dementia's condition should be shared with their family carers. Daphne Sharp, for example, told us that "all information should be shared with the family carers. This person is still their loved one and as such they should be given every single bit of information necessary."

However, other respondents thought that how professional caregivers chose how much information to share with family members depended upon a number of factors:

The sensitivity of the information

Several respondents felt that the nature and sensitivity of the information was an important factor in deciding how much to impart. Such a view was taken by the Ethics Department of the BMA: "Care is required about requests for disclosure of particularly sensitive information from the patient's record, about which relatives may be curious, but which is not relevant to providing care. If families are involved in the provision of care, however, relevant information needs to be shared with them."

Dr Ian M. Jessiman, for example, felt that "unless there is a matter which has come to [the] notice of the professional caregiver under terms of strict secrecy, I would consider it fair to give the family carers any information that would otherwise have been given to the patient."

Best interests

Some respondents chose to adopt the maxim that withholding information should only be done in order to protect the best interests of the person with dementia. Examples of such a view, which was prevalent in responses to this part of the question, include:

“Information should be divulged if it is in the interest of patient care.”

Royal College of General Practitioners

“The right to withhold information should always and only be based on best interests and not for the sake of the organisation.”

European Care Group

“I believe we all have a right to privacy, but where that right inhibits appropriate care, the GP should have the right to override it.”

Hazel Simpson

The relationship between person with dementia and their carer

Several respondents referred to the status of the relationship between the person with dementia and their carer. A summary of this view was offered in a response from the Royal College of Physicians: “The amount of information shared should be proportionate to the relationship with the demented individual – by which we mean the social and not the genetic relationship.”

The distinction between the type of relationship that exists between a person with dementia and their carers was also a point raised by Hazel Simpson, who brought attention to potential difficulties children may have to overcome in obtaining information about their parent’s health:

“I think it’s easier when a spouse is concerned. It would be more difficult for a son or daughter to get information about a parent, and perhaps a parent would be reluctant to allow offspring to talk about him.”

Linked with such points was an observation made by an anonymous respondent who noted that “a professional caregiver should be able to pick up from the family carers whether it would be less distressing to withhold some details or whether to give all the facts away anyway. I’d say, as a rule of thumb, if the family carers are not asking questions it is because they’d rather not know the answers.”

What has previously been discussed with the person with dementia

A small number of respondents felt that professional caregivers should refer to meetings and discussions that have taken place with the person with dementia in order to ascertain how much information should be imparted to family members. Such an approach focuses on the preferences of the person with dementia themselves, an example of which was offered in a joint response from the UK Psychiatric Pharmacy Group and The College of Mental Health Pharmacists: "This issue of confidentiality should be discussed, initially with the person with dementia on their own and, if they agree, then their carer should be able to attend the consultation and/or be given information as appropriate, but with the understanding that the decision can be reversed."

Section six: research

- 29. What should research into dementia be trying to achieve? On what basis should funding be allocated? (Short version question the same as full version)**

What dementia should be trying to achieve

A number of suggestions were made for what research into dementia should be trying to achieve, from which several categories can be gleaned:

Research into dementia care

Responses received which took the view that research should focus on dementia care included:

"Whilst I accept that research into dementia and its causes needs to continue, there should be a balance between what is spent on that and what needs to be spent on treating and caring for thousands who have it."

Anonymous consultation respondent

"...research should focus on what makes the person with the illness feel ok about themselves and make sure [that] their life is as easy as possible."

Anonymous consultation respondent

"Research into dementia should be trying to find ways to help people live 'better lives with dementia' rather than over-focusing on the pursuit of a biological 'cure.'"

Dr John Kelly

A few respondents also suggested that research should be trying to achieve further advances in assistive technology. One example was provided by Mrs Rachel Bucknall of One Creative Environments Ltd., who stated that “much more work needs to be done on technological aids which could help this and other groups of patients.”

A related point was raised by the Older People and Disability Team from the Social Care and Learning Department at Bracknell Council, who told us that “research into how other countries are managing to take care of those with dementia to see if there are approaches we can try.”

Research to improve the earliness and accuracy of diagnosis

Several respondents felt that diagnosis should receive more attention from the research community. Barbara Hall, for example, told us that research should concentrate “detecting it [dementia] at an early stage.” This view was supported by a response from the UK Age Research Forum, which drew attention to biomarkers: “Research should include the development of biomarkers for the identification of people at risk as well as for early, differential diagnosis.”

Better understanding of the science of the disease itself

A number of respondents, primarily with an academic or research interest, felt that a better understanding of the science of dementia should be the aim of research. A reason for this call for a better understanding was clarified by the Academy of Medical Sciences: “Despite identification that amyloid, tau, presenilins and ApoE4 all have important roles, the precise mechanisms of neurodegeneration also remain to be elucidated.” Similarly, the Wellcome Trust stated that “the aim of dementia research should be to improve understanding across the full research spectrum from the basic biological process, through treatment discovery and development, to delivery of health services and dementia management support resources for people with dementia and their carers.”

Other points made to support this argument included that offered by a joint response from the Medical Research Council and the Economic and Social Research Council, which called for “a better understanding of the way the brain works and what goes wrong in cases of dementia, and an understanding of its causes – genetic and environmental – and interactions between different causes.”

An extended answer calling for better understanding of science was provided by Professor R. J. Mayer:

“Research has been driven by the original neuropathological findings in Alzheimer’s disease and Parkinson’s disease ... Pathological features include intraneuronal neurofibrillary tangles or Lewy bodies and extra-neuronal amyloid plaques. Much research and pharmaceutical investigation focuses on understanding how these ‘hallmark’ features of dementing illness occur and how they can be prevented. However, the main feature of all of chronic neurodegenerative disease is extensive regional neuronal atrophy: neuronal cell death. It is only when the mechanisms by which neurones die are known that novel therapeutic targets will be identified. Considerable new investment is necessary to understand neuronal death and prevent it.”

Better understanding of risk factors

Several respondents called for research to obtain a better understanding of the risk factors involved in the development of dementia. Examples include:

“Long-term cohort studies, to include a range of ethnic groups, will generate further advances in preventing dementia through an enhanced understanding of the influence of risk factors earlier in life, such as hypertension, diet and lifestyle.”

Academy of Medical Sciences

“It seems sensible to focus the limited NHS resources available for research into dementia on following up possible links between cognitive decline and physical aspects of bodily health.”

John Shore

“More research into activities and their effect on the general health and well being of dementia sufferers would be beneficial.”

Older People and Disability Team, Social Care and Learning Department, Bracknell Council

The basis of funding allocation

Most respondents who directly addressed the issue of the basis on which funding should be allocated had an interest in academia and/or research, or were connected with a charity or voluntary body concerned with dementia.

In its response to this part of the consultation, the Wellcome Trust felt “the primary criteria for research funding to be the importance of the research question, and scientific excellence.” The Medical Research Council and the

Economic and Social Research Council also felt that, the scientific merit of the research proposal should take precedence in allocating funding for research.

In addition to its comment regarding the importance of the research question, and its support of scientific excellence, the Wellcome Trust also drew attention to the global nature of the prevalence of dementia:

“It is important that funders consider the potential outcomes of dementia research on a global scale. Only ten per cent of the population-based dementia research has been directed towards approximately 66 per cent of people with dementia, who live in developing parts of the world.”

The principle of linking research funding to the number of people diagnosed with the particular condition was raised by a number of respondents who chose to address this question. For example, Professor David A. Jones felt that “funding should reflect the number of people with the condition and the impact on the lives of those people and their carers, while balancing it with other research needs.” Joseph Loftus similarly noted that “state-funded medical research should be funded on a per capita basis, i.e. the numbers of those suffering from a condition.”

- 30. 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? (Short version question: What is your view on involving people in research if they cannot decide for themselves? Under what circumstances, if any, should such research be allowed? What safeguards would you choose and why?)**

Views on involving people in research if they lack capacity to give consent

Several approaches were offered in response to this part of the question, and these can be broadly divided into three groups: first, that it is discriminatory to prevent people with dementia taking part in research; second, that people with dementia can make meaningful contributions to research; third, a cautious view in relation to involving people with dementia in research. These will be addressed in turn.

1. It is discriminatory to bar people with dementia from taking part in research

Several respondents felt that barring people with dementia from taking part in research, perhaps due to incapacity, was discriminatory. One such view was offered by the UK Age Research Forum which stated that the “exclusion

of potential volunteers due to frailty, age or impaired capacity may severely limit the progress that can be made in research, and can restrict the ability to validate new treatments in the target population. Further to this, their exclusion can be considered discrimination against older people and those who have a mental or neurological disease.” This was a view which was adopted by a significant number of other consultation respondents, including the Alzheimer’s Research Trust, which stated that: “Avoiding research on participants who lack capacity through dementia is prejudicial to the elderly and to the mentally and neurologically unwell and is in our view unethical.” The Ethics Department of the BMA similarly commented that “while there is no ‘right’ to be included in research, we would not wish to see entire populations – especially those who already risk marginalisation within society – being excluded.”

2. People with dementia can make meaningful contributions to research

A number of respondents felt that the value of involving people with dementia in research should be noted. For example, Claire Biernacki told us that “people who lack capacity must be involved in research; otherwise our ability to answer questions about their needs and circumstances are compromised. Lack of capacity to assent to being involved in research doesn’t preclude the person’s potential to be able to contribute meaningfully in a project.” Similarly, H. A. Carsley told us that “[my mother] would be quite cross to think that she could not take part [in research], because she could no longer consent herself.”

3. Caution should be practised in involving people with dementia in research

Some respondents felt concerned about the idea of involving a person in research if it simply wasn’t possible to find out what their views were, or would have been: for example, one family carer who wished to remain anonymous, told us: “If [the person with dementia’s] views are totally unknown, they should not be made to partake in any research.”

Barbara Pointon, on the other hand, highlighted the difficulties involved where past views may no longer seem applicable:

“While he still had capacity, my husband consented to take part in lots of research based at our local teaching hospital. But he actually became traumatised by over-testing (which tended to emphasise what he couldn’t do and undermined his confidence further) and a behavioural psychologist recommended he should stop.”

Under what grounds, if any, should such research be permitted?

If there is good reason to believe that the person would have consented if they had capacity

Several respondents alluded to taking a substituted judgment approach to research participation. For example, Dr Ian M. Jessiman endorses “research where there are sound grounds for believing that they would have been willing or happy to consent had they been asked.”

Several respondents took the view that an example of a ‘good reason’ was written evidence given by the person that they wished to be involved in the research when they were capacitous, and had been fully informed of the nature and process of the research. For example, Rebecca Taylor felt that “if a patient has left explicit wishes to be involved in research ... they should be allowed to take part.” Similarly, another anonymous respondent felt that it was not right to involve people with dementia in research “unless a directive has been produced allowing research to be carried out.”

The possible role of a proxy decision-maker was highlighted by some with the Falkirk branch of Alzheimer Scotland, for example, suggesting that research could be allowed after careful consideration and where “they had appointed a person such as a spouse, son or daughter to make that decision for them”. Others, such as John Shore stated: “I do not trust the situations where someone else acts as a proxy or decides to involve the patient in research trials on the basis of what *they* think the patient would have wanted to do.”

If the person with dementia is consulted

Professor Gordon Wilcock argued that “people with dementia, sometimes even quite moderately severe dementia, often have an idea as to whether or not they wish to participate in research, and it is very important that they are consulted, as well as those who are their carers or attorney.”

If the person with dementia is not harmed by the research

Several respondents were concerned with the well-being of the person with dementia in their role as ‘research participant.’ For example, one anonymous respondent stated that “as long as we are not submitting the person to physical harm and protect their psychological health as best as is reasonable and is monitored we must undertake research.” Jim Ellis commented that “if the research involves observation only, I see no problem.”

A related point was raised in the course of a dementia consultation event where a view was adopted that people with dementia should only be subjected to dementia-related research.

What safeguards should be used?

Some of the responses to this part of the question have already been addressed in the discussion of the circumstances where research should be permitted above. Other points included:

- Discussing research participation at an early opportunity

Several respondents were in favour of research being discussed at the time of diagnosis. For example, one anonymous respondent felt that research should be discussed at the time of diagnosis. A similar view which focused on addressing the issue in advance was offered by Professor June Andrews, Director of the Dementia Services Development Centre at the University of Stirling, who stated that "safeguards would be less of a problem if we all signed advance directives allowing ourselves to be involved in research if capacity ever is lost."

- Using proxy decision makers

A handful of respondents felt that proxy decision makers could be used in order to ensure that research using people with dementia is carried out appropriately. For example, a joint response from the Medical Research Council and the Economic and Social Research Council took the view that "where participation in research is involved, if *either* the welfare attorney *and/or* the practitioner responsible for the patient's care consider that the patient should not participate, then that should be the decision.

On a related point, one respondent also highlighted that at present a welfare attorney in England and Wales does not have specific power to give or withhold consent to research.

- Using checklists as safeguards

In its response to this consultation, the Wellcome Trust drew up four conditions which should be met in order to enrol adults incapable of providing consent to research in a programme, namely:

- a. the participation of such adults is necessary to answer the research question
- b. the participants' interests are safeguarded or promoted
- c. discussions have been carried out with an appropriate legal authority responsible for the care of a mentally incapacitated adult
- d. the research complies with relevant laws."

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

Does the law and requirements for independent ethical review prevent research?

Most respondents felt that research could be slowed and hindered rather than unequivocally 'prevented' by the law and independent ethical review.

Perhaps unsurprisingly, a number of academic respondents drew attention to 'cumbersome' elements of the ethical review process. For example, one anonymous respondent stated: "in the last few years the increase in 'form filling' and 'red tape' has been notable ... This has resulted in either the slowing of progress or the putting off of researchers to develop new models." The Academy of Medical Sciences expressed a similar view:

"The Academy cautions against the complexity of ethical review, which may, in principle, discourage researchers from undertaking studies in the field. In light of the extent of paperwork required and the need to monitor progress with Primary Care Trust research and development offices, we consider that a more manageable system could be encouraged."

Also addressing the ethical review process, the Alzheimer's Research Trust stated that it "appears [to be] geared towards trials and we are aware of a view in our research community that there is scope for some streamlining for research that involves little or no risk of harm to participants." This view was supported by the Ethox Centre: "Governance standards and conditions that are applied to research involving people with dementia need not be so rigid for *non-interventional* research such as qualitative research into quality of life and relationships."

Another view expressed on this point was in relation to the retention of human tissue samples:

"Investigators in many countries outside the UK are able to keep research samples beyond the term of a single research grant, for ongoing work on a topic for which consent has already been given. In the UK it is necessary to seek permission to keep the tissue already used for research, if consent has not been given for secondary uses."

The Wellcome Trust

However, some felt reassured by the measures currently in place. For example, a response from Spiritual Care for Older People (SCOP) in the Diocese of Oxford, noted that "several researchers ... have been frustrated by what appeared to be 'silly' rules, but rather this than a free for all."

Could any changes in the regulatory framework be ethically justified?

There were few responses that specifically addressed possible changes in the regulatory framework for research. However, the comments that did address this point include:

“It is the disparity between the outcomes of different research ethics committees when a research study is presented that most offends. There may also be a lack of knowledge in many of these committees about qualitative research and its value in this area, and their own understanding of assessing capacity in a person with dementia.”

UK Psychiatric Pharmacy Group and The College of Mental Health Practitioners

“[There is a] contradiction between having a common UK standard for Clinical Trials and differing language for non-clinical trials.”

Associate Professor Robert Jones

“[A] variable interpretation of what may be ‘negligible risk’ and how it should be handled could impede timely and effective progress of reasonable research. The case should be considered for a central ethical authority, either to consider projects centrally (UK-wide) or to ensure authoritative guidelines and interpretation, in order to avoid such local idiosyncrasies.”

Associate Professor Robert Jones

“It would be better if the law made it clear that the patient’s attorney had to be consulted and, if within his authority, could refuse consent.”

Anonymous consultation respondent

These comments therefore primarily dealt with what were perceived to be disparities in regulatory frameworks as they currently stand.

Section seven: other issues

32. Are there any other ethical issues relating to dementia that we should consider? (Short version question the same as full version)

A wide range of other issues for the Working Party to consider were raised in answer to this question, including:

- **The effect of social transformation:** specifically the effect the lowering birth rate will have on future carers of people with dementia.

- **Abuse within the family:** concerns were raised about the anger and frustration that can arise where a family member is caring for a person with dementia. Dr C. A. Trotter, for example, in answering Question 12 on radical changes in mood or behaviour of this consultation, stated that there was “little acknowledgment that carers are frequently abused both verbally and physically by patients in the later stages of dementia.”
- **Volunteers and safeguards:** Dr Hazel McHaffie felt that the issue of minimum safeguards for care home volunteers should be considered. Dr McHaffie asked: “What minimum safeguards should exist to protect persons with dementia where unpaid helpers are involved? How much confidential information should such persons be given? How much training in dementia care should be required?”
- **The ethical acceptability of administering covert medication.**
- **Financing care:** a small number of respondents asked for this issue to be addressed. For example, H. A. Carsley asked “is it ethical to withhold treatment because it is expensive? Is it ethical to tell families that [the] affected person can have help with personal care, but they are low priority, there is no carer available – don’t we have a duty to provide [personal care]? Is it ethical to make affected persons pay for care once provided, when, if they are ill, that is an NHS role?” Age Concern Leeds raised a similar point about the prioritisation of care: “how much of a priority does society make this [dementia care]?”
- **Deciding when to stop providing medication for a person with dementia.**
- **Assisted suicide and euthanasia:** a handful of respondents felt that the Working Party should consider this issue. Peter Hindle, for example, felt that “to avoid this issue in the case of a terminal illness is unacceptable.”
- **Sexual relationships:** several respondents raised the issue of sexual relationships in the context of a diagnosis of dementia, with some focusing on issues of consent, and others on respecting the autonomy of the person with dementia in continuing or beginning a sexual relationship.
- **The use of developing knowledge about genetic risk factors:** the Academy of Medical Sciences drew attention to this ethical issue, stating that “one further ethical consideration arises from our increased knowledge regarding risk genes for dementia, combined with growing access to full genetic profiles and proposed susceptibilities.”