



## Deliberative workshop on dementia

A report prepared for the Nuffield Council on Bioethics

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# 1. Executive summary

## Introduction

The Nuffield Council on Bioethics commissioned Opinion Leader to undertake a one day workshop with some members of the public on the ethical questions concerning the care of people with dementia.

The workshop took place on 5<sup>th</sup> August 2008 and fifty-four people attended on the day, recruited to a representative sample of the UK population.

## Main findings

### *Initial perceptions*

- Most people had a broad awareness, particularly of the symptoms of dementia.
- However, they had little knowledge of the causes or of an exact definition.
- There was some spontaneous and immediate perception of the impact on those around people with dementia and a general sense of little support for carers.
- Sources of information were reported as predominantly second or third hand; from celebrity examples such as Terry Pratchett, the media or hearing of friends' experiences.
- The main areas of confusion were around causes, definition and prognosis.
- Participants felt that to a certain extent dementia is a hidden illness – with little physical presence in everyday life until you have direct experience of it – and some psychological barriers to thinking or talking about it too much.

### *Ethical considerations*

- Initially participants frequently established opposing positions e.g. ideal versus practical.
- However, opinions fluctuated as discussions developed and compromises were sought between the two.
- Participants were keen to find a 'middle path' where possible.

### **Freedom of action versus prevention from harm:**

- Participants began by establishing what was unacceptable; anything that involved forcing the person physically to do something they did not want to, and so causing distress.
- They then began seeking compromises; namely options that would have the least impact on the person with dementia by allowing them to still *feel* free, whilst allowing the carer to reassure themselves by monitoring movements.
- Many of these compromises involved the use of technology or additional support from social services, but electronic tagging remained controversial for many, causing division of opinion.

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- In summary, the desire to protect freedoms was a priority but the middle path was to maximise practical changes that avoid taking away independence as far as possible

#### Decision-making:

- Participants really struggled to come to any consensus on life-sustaining treatment and who and how decisions are made, with many taking opposing positions.
- In summary no middle path was possible between respecting the person's past wishes (e.g. to die without life-sustaining treatment) and considerations of the present situation.
- Discussions pointed to the importance of clear advance decisions to help avoid ambiguity and excessive burden of responsibility on the family in the future

#### Conflicts of interest:

- Participants took more of an objective approach to addressing conflicts of interest than in other dilemmas, in terms of considering the practical and financial impacts on the family / carer.
- Many emphasised the importance of balancing the quality of life of the carers against that of the person with dementia, and considering how many people are affected.
- External support, e.g. from social services, was seen by some to be crucial to balancing these needs to avoid the burden being wholly carried by the family/carer.
- However, some participants from certain cultural groups felt their background taught them that the family should take all the responsibility for care and protect their relative's wishes.

#### *Impact*

- Knowledge about dementia increased greatly (with those saying they knew a fair amount or a lot increasing from eight to 41) as well as about the specifics of dementia and its definition.
- Some confusion remained about causes and treatments, with participants particularly concerned about diagnosis (of relatives or themselves).
- There was little change in how participants felt about the ethical issues raised by dementia at the beginning of the day compared to their feelings at the end of the day.

## Conclusions

Understanding increased significantly throughout discussion and deliberation about dementia care, especially of the complexities of the situations involved – the participants found that there were no easy answers. Overall participants emphasised the importance of the following:

- Patient-centred care
- Case-by-case and continuous assessment
- Protecting dignity
- Considering quality of life (for all involved)

This consultation supports a flexible approach to dementia care, with a strong focus on the individual.

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## 2. Introduction

### Background

The Nuffield Council on Bioethics was established in 1991 with the remit of examining ethical issues raised by new developments in biology and medicine. It is an independent body, jointly funded by the Nuffield Foundation, The Medical Research Council and the Wellcome Trust.

In November 2007, the Council set up a Working Party on dementia to explore the ethical and social issues surrounding dementia. The group will publish a report in summer 2009 to include recommendations for future policy and practice and is considering the following issues:

- How decisions are made for or with people with dementia;
- How dementia care is provided and standards of current care;
- The use of advance directives or 'living wills';
- The acceptability of restricting freedom of movement or deception in the interests of the patient e.g. locking doors, disguising medication in food;
- Experimental treatments;
- Balancing the interests of the individual and their carer e.g. in situations where the carer can no longer cope;
- The implications of changes in behaviour for the individual and those around them.

According to the Council's standard practice, the Working Party is holding a public consultation. As part of this, the Working Party published a consultation document and is inviting views from mid May to mid August 2008 but it is also looking to expand its consultation activities in order to reach a wider public audience. The Working Party commissioned Opinion Leader to conduct a workshop with fifty members of the public to capture this wider audience, who do not necessarily have any connection with dementia and who would be less likely respond to the consultation.

### Objectives

The objectives of the research were to:

- Obtain the views of a number of informed members of the public in order to strengthen the evidence base underpinning the Working Party's conclusions.
- Enhance the openness with which the Council is seen to operate (and hence increase public trust in the Council's conclusions)
- Add weight to the final report by demonstrating that the Council has sought the widest possible evidence base and by requiring the Working Party to justify conclusions which are seen as running counter to popular or received opinion.
- Help fulfil the duty set out in the Council's Terms of Reference to anticipate concerns among the 'public'.

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While it was not the primary aim of the research to raise general public awareness about the ethical or social issues surrounding dementia, this was potentially a secondary effect.

The key questions considered at the workshop were:

- What top of mind views and concerns do the participants hold about dementia?
  - What drives these views?
  - Are there any key stigmas/ myths/ misinformation?
- What are the participants' views on the key ethical dilemmas concerning dementia?
  - Freedom of action and restraint in the interests of safety
  - Making decisions (and in particular, what are the participants' views of advance directives; balancing past and present wishes; and, life sustaining treatment)
  - Conflicts of interest (in particular, the impact of care needs on those who need to meet them)
- On balance, how do the participants perceive dementia after exposure to information and time to discuss the issues?

## Methodology

Dementia is a sensitive topic area about which many members of the general public will have little immediate insight. Furthermore, the ethical and human rights issues raised by the considerations of caring for people with dementia are complex and in many cases there are no easy answers. Traditional research would only tell the Working Party what people think given how little they know. Therefore, a deliberative approach was chosen in order to enable people to develop an informed viewpoint and give greater credence to the overall conclusions of the final report as a result.

A deliberative approach provides the opportunity to present people with new evidence and information as the day progresses. A variety of deliberative techniques enable the participant to understand and scrutinise information and start to understand some of the trade-offs that have to be considered in dementia care.

The workshop lasted for a whole day to allow sufficient time for participants to receive information and have discussions about the issues (see appendix for agenda and materials). The day was a mix of presentations from the front and round table discussions. Participants sat at tables of 11 managed by a facilitator taking 'real-time' notes on a laptop.

Participants were given a variety of stimulus throughout the day, designed to help them think from the perspective of a person with dementia, as well as from the perspective of the carer and family of the person. Presentations included Josh Appignanesi's [Ex Memoria](#)<sup>1</sup>, a short film showing life in a care

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<sup>1</sup> A prize-winning short film filmed from the perspective of an older person with dementia, developed with the Bradford Dementia Group and supported by the Wellcome Trust.

home from the point of view of a person with dementia, as well as presentations on some of the dilemmas faced in dementia care. Slides from these presentations are included in the appendix. At the tables participants were given a variety of fictional scenarios created to show some of the difficult dilemmas faced by those caring for people with dementia, as well as supporting handouts with information from the presentations.

Participants also filled in a questionnaire to capture both their uninformed awareness of dementia at the start of day, and again at the end of day, to see how their responses changed over the course of the day.

## Sample

Fifty-four people attended the workshop on the day. These participants were recruited as a representative sample of the UK population. The number of people from an ethnic minority group was increased above the small number that would be representative according to census data, in order to ensure that their voices were heard.

People who had direct experience of dementia, such as having a parent with dementia or being the primary carer for a person with dementia were, as far as possible, screened out as it was felt that these people's views were already being captured by the main consultation. It also enabled all participants to start from the same point, preventing those with more experience of dementia from dominating the discussion. However this did not exclude people who had jobs working in care or participants who may have had a more distant family member (e.g. a grandparent) with dementia.

See below for the specific demographics of those attending on the day:

<i>Demographic</i>	<i>54 participants</i>
<i>Gender</i>	
Male	25
Female	29
<i>Age</i>	
18 – 29	14
30 – 44	14
45 – 59	12
60+	14
<i>Socio-economic group</i>	
AB	8
C1C2	29
DE	17

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<i>Ethnicity</i>	
White	41
Black African	3
Black Caribbean	2
Pakistani	4
Bangladeshi	2
Other asian	2

### 3. Initial perceptions of dementia

#### Awareness levels

The first discussion of the day was around participants' top of mind perceptions and understanding of dementia. Participants had a familiarity with dementia, but did not have a detailed knowledge of it.

Most people had heard of dementia and had some level of awareness about its symptoms and effects but did not know about its causes or exact definition. They were also aware that dementia may have an affect on the lives of friends and relatives of people with it. However, there were a small number of, usually younger people, who had very low awareness of dementia, saying only "It's new to me". They may have heard the word but did not know what it referred to. Older participants tended to have a higher level of awareness of dementia and related issues compared to younger participants. They were more likely to have seen dementia first hand in relatives or to have friends who had parents with dementia.

Initial discussions of dementia tended to be centred on symptoms rather than causes. Most participants were aware that dementia affects the mind, and leads to diminished mental abilities in those that have it. The most common symptoms mentioned were becoming confused and losing memory. Some also identified subtleties in symptoms that others were not aware of, for instance some mentioned that dementia primarily affects the short term memory and that long term memory may remain.

*"It's confusion and memory loss that happens to older people"*

*"You forget what you did five minutes ago"*

There also seems to be a general perception that these symptoms are degenerative and that the condition tends to get worse gradually over time. There was also a predominant belief that the progress of the condition is irreversible, and that people who have it do not get better.

*"There's no improvement, it's a downhill process"*

Participants were generally aware that dementia is more common among older people. This awareness could lead to them being concerned about elderly relatives, or even for themselves in the future.

*"With my mum it is something you are constantly looking for. Always looking at how sharp she is but I have to talk to her friends about it as they see her more than me and will notice the changes."*

*"It never really crossed my mind until I got into my late 40s. It's one of those things you think you can be blissfully unaware of."*

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While participants generally associated dementia with being a disease of old age, a few people showed an understanding that it can be found in middle-aged people as well.

Some mentioned behavioural changes in people that develop dementia. They talked about people with dementia displaying unusual and erratic behaviour such as dressing inappropriately, leaving the house and forgetting where they live, etc. There was also some perception that dementia can bring about personality changes in the person who has it. Participants thought that people with dementia may become more aggressive and behave in ways they may not have in the past such as swearing in public.

*"It leads to changes in personality, and mood swings. My nan was a really nice person, but she just started to snap. This was before we knew that she had dementia."*

Some talked about people with dementia regressing to a childlike state, where they are unable to do anything for themselves, and they observed that this places a high burden of responsibility on people who care for people with dementia. They thought that gradually losing your mental abilities must be extremely frustrating for people.

*"I knew someone who cared for someone with dementia and it really upset them that they did not know who they were anymore."*

Some participants expressed a view that there was little support available for those with dementia:

*"There's not much help available; people either have to live at home with family or in a care home, there's no other solutions."*

Although they showed empathy with people who have dementia, participants also talked about the emotional effect that having a close relative with dementia would have. They thought that watching someone close to you go through behavioural and personality changes, and to lose their mental capacity, must be very difficult.

This empathy seemed to lead to some spontaneous awareness that there are ethical dilemmas around caring for people with dementia (although the participants did not term it so), and that families may sometimes be faced with hard decisions to make on behalf of people with dementia such as whether they should live in their own home or be put into a care home.

*"I had uncle with it, so I was surrounded by all the moral issues around it."*

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*"If it happens to people in their 40s and 50s it's not necessarily an old person's disease. I am quite shocked it affects younger people."*

## Areas of confusion / myths

While participants tended to have a reasonable understanding of the symptoms and effects of dementia they were much less sure about what dementia is: its cause, treatment and prognosis.

### *A 'hidden illness'?*

Some participants reflected on the reasons for their confusion and lack of knowledge of dementia. Some participants raised the fact that dementia has little visual presence in everyday life; as they expressed it, you do not bump into people with dementia often in the street. To this extent, dementia is physically hidden from members of society who do not have any personal experience of it.

Furthermore, some people considered the possibility that there are some psychological barriers to thinking about or discussing dementia. Although the participants at the workshop had little difficulty discussing the topic once raised in this setting, some felt that dementia is not often discussed in day-to-day life. It was suggested that dementia is something that people do not want to think about, especially with regards to themselves being affected by it. Some participants also mentioned feeling uncomfortable around people with dementia because of some of the behaviours they can display, and that people may avoid people with dementia.

*"It's not a topic of conversation, it's a bit taboo. Something you put to the back of your mind."*

### *Definition*

Many were also surprised to learn that dementia is not a single disease, prompting recognition that it could be much more complex.

There was a lot of confusion about what dementia actually is, and participants tended to mix it up with the diseases that cause it. Alzheimer's disease was often mentioned alongside dementia; however they were not sure of the difference between the two, and questioned whether the two terms were synonymous.

*"I have a sister in law with dementia, but I don't know if it is Alzheimer's or dementia."*

### *Cause*

Overall, participants had very little knowledge of the causes of dementia, knowing only that it was related to problems with the brain.

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*"Something about brain cells being lost. Don't know really."*

Many participants became concerned about how dementia is diagnosed, and how exactly they would tell if a relative had it. Some expressed a desire to know more about the *"hereditary aspects of dementia"* and others felt that lifestyle *"might increase the likelihood of getting it"*.

### *Prevalence and cost*

When it came to the facts and figures about dementia, participants were particularly surprised at the prevalence of the illness and its cost. This was something that participants generally had no awareness of before.

*"The money is staggering – the amount of money shows just how many people have it."*

For some people this prompted a desire for more money to be invested in research in an attempt to slow the pace of people developing dementia. Others worried *"about the money running out"*, especially as the elderly population increases.

### *Prognosis*

Participants were also unsure what treatments are available for dementia, and whether it is something that someone can recover from. Where people had a point of view on the prognosis for a person with dementia, they tended to think that dementia is incurable and that once someone has it their condition will worsen. However, some mentioned hearing about treatments which can slow or halt the progress of dementia, although this was mentioned in very vague terms.

*"There are ways of slowing it down, making it easier. Is there a drug that can slow it down?"*

Many participants were shocked to learn both that a person may die from dementia, and the number of deaths attributed to dementia. There was some level of intrigue as to the actual cause of death and whether it was a subsidiary illness such as pneumonia.

## Sources of knowledge

Participants' knowledge of dementia came predominantly second or third hand from friends and the media (this is to be expected as these participants were recruited on the basis of not having a parent with dementia, and never having cared for someone with dementia). However several people had limited first hand experience of dementia through more distant relatives such as grandparents, and these participants had significantly more insight into the particular issues raised by caring for someone with dementia.

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### *Indirect experience via friends/relatives' experience*

Some had experience of seeing relatives such as grandparents lose mental capacity through dementia, and therefore had first hand experience of the symptoms and their gradual onset. However, they had not been directly involved with the care of these relatives, and so did not know much more than people who had no first hand experience of dementia

*"My gran forgot to eat and go to the toilet."*

Some participants had second hand experience of dementia through talking to friends and family who had cared for people with dementia. This could give them a powerful insight into the effects of dementia on the person who has it, and people close to them.

*"A colleague at work had a mother with it."*

### *Media and celebrities*

The most common source of information reported was popular media. People mentioned real life stories of celebrities who have had dementia, or who have had family members with dementia e.g. Terry Pratchett in newspaper articles, and television documentaries covering issues around dementia. Television drama also appears to be a key source of information of what it is like to have dementia, and what it is like to be close to someone with dementia. Characters with dementia have appeared in soap operas such as *Eastenders* and *Coronation Street*, and has been featured in films such as *Iris*.

*"I have seen it in the press recently and watched a documentary on television about dementia."*

*"I see it in Coronation Street, Mike Baldwin had it. You saw his family break down, its has formed my understanding of dementia."*

These predominantly second or third hand, and in the case of the media, visual information sources would help to explain the participants' awareness of dementia that is based predominantly around the symptoms and how it impacts on life, rather than displaying any more detailed knowledge of what it is and why people develop it.

## In Summary

- Top of mind awareness of dementia was high, with few people having not heard of it at all, but knowledge and understanding was low
- Initially participants associated dementia with symptoms such as confusion and memory loss, and as a condition affecting mainly older people

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- Participants displayed a high level of empathy with people with dementia because of the symptoms they suffer, and people close to them because of the emotional distress of seeing a loved one lose their mental capacity
- Confusion exists around the definition of dementia and its causes, treatments and prognosis
- Current knowledge of dementia is based on the experiences of friends and relatives, media stories, and television and film dramas
- People feel dementia is a taboo topic in society, and something they want to put to the back of their minds

## 4. Ethical dilemmas

Before beginning to consider some of the ethical dilemmas involved in detail, the film, *Ex Memoria*, was shown and discussed as an introduction to the potentially difficult questions that might arise in caring for people with dementia. There was also a short presentation given in plenary to introduce the idea of 'ethics' (accompanied by a handout, provided in the appendix). The three main areas of ethical debate participants were asked to consider were:

- Freedom of action versus protection from harm
- Decision making; how to balance past and current wishes, life-sustaining treatment and the role of advance directives
- Conflicts of interests between the person with dementia and the carer(s)

Participants addressed these three question areas on their tables in sequence, in some cases splitting into smaller groups to role-play or consider the situation from different perspectives.

It was apparent quite early on in discussions that participants adopted one of two possible contrasting standpoints. In terms of safety versus risk for example, participants were either concerned to honour the person with dementia's wishes or more concerned with managing their safety. There were some participants who were more inclined to the 'ideal' or 'principle' of maintaining the person with dementia's wishes and others more conscious of the practical or 'real' perspective in each case.

In the ideal or philosophical standpoint the person's wishes would be maintained no matter what, whether their wish was to go to the toilet alone, be free to walk at will or to be allowed to die in the case of life-sustaining treatments. There were some participants who felt very strongly that this should always be the case.

From the practical or realistic standpoint, other perspectives and considerations impacted, such as the need to minimise risk in the interests of the person; society's safety; and the family's wishes in preserving their loved one's life for as long as possible.

The complexities of the dilemmas in question meant that as discussions developed the majority of people began to feel that there were no straightforward right or wrong answers. For many therefore, the process of debating the ethical dilemmas involved in caring for a person with dementia led to people moving from one standpoint to the other during discussion.

However, in each dilemma discussed, participants seemed to go through the following thought process:

- Start with the ideal – maintaining the person's wishes
- Consider all needs and perspectives at each stage of the illness

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- Minimise any issues that can occur and take account of practicalities as far as possible

In the following sections we consider the three dilemmas in more detail.

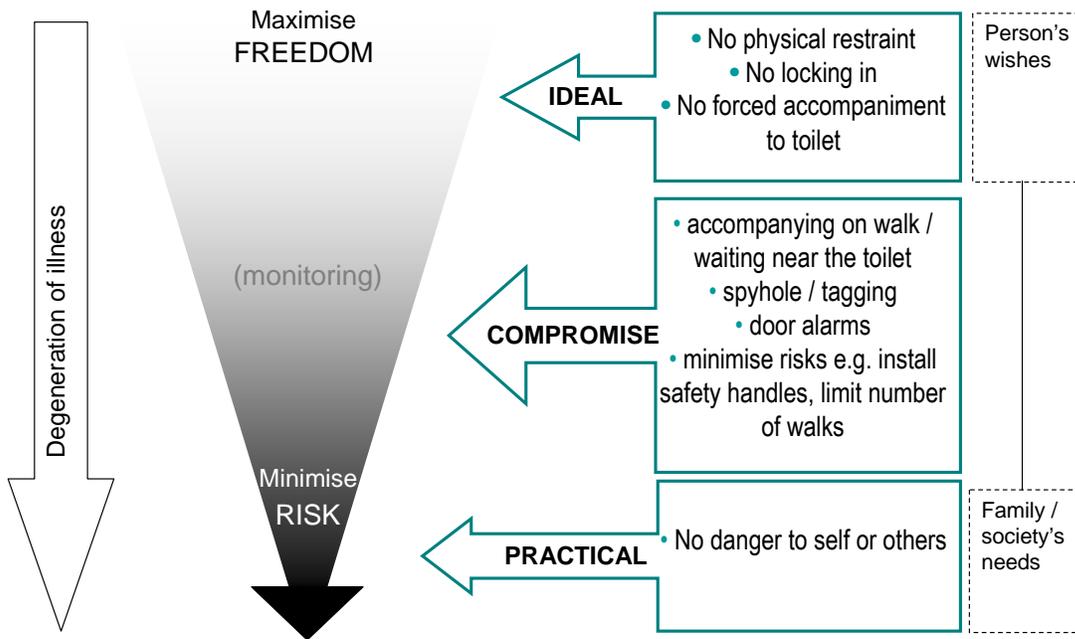
## 4.1 Freedom of action versus protection from harm

Participants were shown two scenarios designed to illustrate two of the possible considerations in the balance of freedom and risk; one on how far to restrain freedom of movement, and the second on the acceptability or otherwise of forced accompaniment to the toilet. These scenarios are included in the appendix but a brief description of each follows:

- Scenario One introduced a married couple, in which the husband who has dementia likes to take walks and the wife, whilst not wanting to go against his wishes, is worried about his safety.
- Scenario Two introduced an elderly mother with dementia who did not want to be accompanied to the toilet but had recently taken a fall, and a daughter concerned to take steps to ensure her safety.

The participants' first instinct in balancing protection of basic freedom and protection from harm was to find the middle ground; an action that would preserve at least the appearance or feeling of freedom whilst allowing family members to assure themselves of the person's safety. Participants' discussion therefore drew the parameters of what was unacceptable, and then began to explore what was acceptable or where compromises might be found. The participants' main focus in this discussion was weighted more to the person with dementia's perspective than that of the carer.

Figure 1: Balancing freedom of action and protection from harm



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## Key areas of discussion

### *Restraint*

Participants were clear that the person with dementia should not be restrained, either physically or by being locked in if it was their desire to go out. A small number thought that there might be certain circumstances when it may be necessary to lock doors, such as at night time and others also felt it would be acceptable to restrain someone if they were being violent either against themselves or others. However, it was felt that restraining or stopping the person with dementia from doing what they wanted to do would be wrong in principle and would also likely result in some significant distress.

### *Forced accompaniment to the toilet*

Equally, people felt very strongly that if the person with dementia expressed distress at being accompanied to the toilet, their desire for privacy should be respected and their dignity maintained as a priority, and that they should not be accompanied.

*“Going to the toilet is a very private thing; you don’t want to share it.”*

*“If they have the state of mind to object, they should be allowed to go in alone.”*

### *Making no attempt to prevent harm (either to the person with dementia or to others)*

Most people did recognise that safety was a concern, both for the person with dementia who could fall and hurt themselves and for society at large, who could be affected, for example, in traffic accidents if a person with dementia wanders in the street. It was therefore unacceptable for most people to make no attempt to limit the risks involved. Furthermore, it was felt that the distress felt by the person with dementia at having their freedom restricted would have to be balanced with the distress felt by family members who may be concerned about their safety.

Beyond these relatively clear absolutes, however, and in order to find some middle path between them, most of those consulted were inclined to make compromises. Overall, the compromises made involved allowing the person to still *feel free*, whilst putting measures in place that would either minimise the risk or allow for the risk to be monitored and any issues swiftly dealt with. In many cases, this involved employing technology to maintain a physical distance or sense of freedom whilst allowing the carer to know where the person was or what they were doing.

In order of acceptability:

### *Accompanying on walks or following / waiting outside the toilet*

The easiest and most immediate solution for many was for the carer to use their discreet presence to enable the person with dementia to maintain their freedom whilst also being on hand to protect them. In

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the scenario of someone wanting to go for walks, this might involve either going with them or, if they wished to be alone, to walk at a discreet distance. However, participants were conscious that this could be extremely time-consuming for the carer, and in fact there might not be sufficient family or neighbours on hand to enable them to go out at all times. In the scenario of the person wanting to go to the toilet alone, many suggested that the carer wait outside the toilet, making their presence known to the person inside to reassure them they were there to help in case of need.

### *Minimising the risks*

For the scenario of a person wishing to maintain their privacy in the bathroom, as well as waiting outside, it was felt that the logical process would be to do a thorough risk assessment and to make changes to minimise any risks that became apparent. Suggestions included installing handrails next to the toilet, non-slip flooring, panic buttons and either removing locks or using locks that could be opened from the outside. For the scenario of maximising freedom of movement, the options were felt to be more intrusive and included limiting the number of walks, moving to a safer area or using an ID bracelet or similar to allow for identification of the person in case of their getting lost and distressed. For those aligned with the safe or practical standpoint, the last option of an ID bracelet was not acceptable as it would not avoid the person getting distressed. For those most concerned with the ideal or ideological standpoint, the first option of limiting the number of walks was not acceptable as it would involve an overt limitation of the person's freedom.

### *Using technology to monitor actions*

For many, technology presented new options for maintaining the appearance of freedom at the same time as providing the carer with the reassurance of the person with dementia's safety (or at least the knowledge that if they were not safe the carer would know and be able to take action). In the case of freedom of movement, people mentioned door alarms and tagging, and in the case of accompanied toilet trips, the idea of spyholes was mooted. In each of these options, opinion was divided in terms of how ethical they were; whilst some saw them as enabling greater freedom, others felt that they constituted a surreptitious removal of freedom. Tagging caused particular discomfort for some, with many feeling it removed the dignity it was designed to protect:

*"At least this finds a way for him not to be locked in the house and allows him to go outside."*

*"Having a person accompanying him is different to a tag; you tag a dog or a criminal."*

*"It seems logical, but it makes my skin crawl."*

## Guiding considerations

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It was strongly felt that all decisions about restricting freedoms should be taken on a case-by-case basis according to each individual's circumstance at each particular stage of their illness. Considerations were:

- How severe is the dementia? How much do they understand? Is it possible to explain your actions to them?
- How risky is the situation in the first place? E.g. what area do they live in? How much harm have they actually done / come to already?
- How much can the carer / carers cope and how much support do they have?
- What are the financial implications of any required changes / technology?
- How discreet is the intrusion into the person's freedom?

## In summary

The participants' primary perspective, in addressing the ethical dilemma of freedom of action versus protection from harm as a whole was, as a priority, to preserve the person with dementia's freedom. It was felt to be extremely important to treat the person as an individual, to consult them at all times and to reassess their needs and risks continuously. During this process, however, people were prepared to accept compromises; to make small and incremental changes to minimise risk as the person's symptoms worsened and the risk to themselves and others increased.

Overall the consensus was to maximise the changes that can be made without taking away independence for as long as possible. Beyond this, it would be necessary to make compromises on both sides:

*"We have to accept some risk."*

*"You're going to have to limit them a bit, and not always be safe."*

## 4.2 Decision-making and the role of advance directives

To introduce this topic, participants were given a presentation by Professor Tony Hope, Chair of the Dementia Working Party and Professor of Medical Ethics at the University of Oxford, on the details involved in making decisions about the care and treatment of people with dementia, particularly regarding life-sustaining treatments, the role of welfare attorneys and living wills. The slides from this presentation are included in the appendix.

Participants were then asked to consider a scenario (Scenario Three, based on the case of Tina, also included in the appendix) where someone with dementia had expressed wishes stating that if in the future she could not make decisions for herself, she would not want medical treatment which would prolong her life. In this scenario, the person in question was living with severe dementia, although apparently quite contentedly, and developed lung cancer. Participants were asked to consider the

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situation from different perspectives, from the person with dementia's perspective and from the family's, to consider whether Tina should be given life-sustaining treatment. They were also asked to consider how past wishes and the present situation should be balanced.

### *Key areas of discussion*

In contrast to the discussions on freedom and restraint, there were no apparent compromises to be found and so the participants' consensus was that there was no middle path to take in this situation. Similarly to the previous dilemma however, most people again began with a desire to adhere to the principle of maintaining the person's wishes, but quickly began to vacillate about whether this was truly in their best interests now. A few people felt strongly that life should be preserved at all costs and many still felt this when considering the situation as if the person were their own relative. Although there was much disagreement, the process of weighing up the issue did produce a number of clear themes, as set out below.

#### *Quality of life*

Central to discussions about decision-making, the person with dementia's quality of life was seen by participants to be at the heart of the matter and the basis upon which any decision about preserving life should be made. However, quality of life in itself did not always provide a clear-cut guiding line. Many felt that a definition of quality of life is in itself subjective and puzzled over how it is defined and who defines it, when such importance (life and death) is placed upon it. Questions the participants raised were:

- How to judge whether the person's quality of life was sufficient to justify overruling their previous wishes to die
- Whether their quality of life would actually be improved by the outcome or potentially worsened by painful and long series of treatment.
- Who has the right to make this decision?

*"It's not the quality of life you expect, but it is quality of life to them. They do enjoy some bits."*

*"I can't judge your quality of life – it's all someone's point of view."*

#### *Who makes the decision?*

For some, this should categorically be the person with dementia themselves, i.e. adhering to their past judgment of what their quality of life would be and that it would not be desirable. It was also asserted that attempts should be made to consult the person at all stages, rather than assuming they have no contribution.

#### **Opinion Leader**

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*"Whether she's happy or not, it's not your decision."*

However, some people felt that quality of life cannot be predicted in advance, and that the only people who can truly judge this are those with the capability to review on the basis of the present circumstances, namely the family. Some felt that this was too much pressure to put on the family, and were worried about how objective they might be (emotionally and in terms of inheritance). These people felt that it would be important to bring in a medical perspective, asking health professionals what they judged their quality of life to be.

*"The moment you sit down with the family and ask them, it becomes their responsibility."*

*"There's an element of guilt if you keep them alive – why are you doing that? For her or for yourselves?"*

#### *The role of advance directives*

Based on the above considerations, the participants emphasised the importance of making very clear and considered advance directives whilst the person with dementia was still capable. The use of advanced directives was generally perceived to be a positive step as it was felt to reduce the degree of decision-making for relatives and medical staff.

*"The benefit of living wills is removing the responsibility."*

*"It would have ensured that the family did not have to make a decision."*

Advance directives were also seen to have another benefit in terms of formalising the decision and indicating that at least a certain degree of consideration had gone into making it. This reassured those who had concerns that potentially the person was in an emotional or flippant mood when vocalising their wishes and that if it had been written down it would have considerably more weight.

Some still preferred to allow for the flexibility of their family making the decision to account for differences or changes in the present circumstances and to enable them to make a mutual decision. A suggestion was to have a clause in the directive in order to override it if the person had 'quality of life'. However, others felt that this would undermine the value of the directive and simply re-open the previous debate about definitions. These participants felt that the true value of a written directive was to make it incontrovertible so that there was no option of a decision (and therefore emotional pressure) for the family. This would also help to mitigate any potential conflicts between different points of view. In order to make this possible, the participants felt that it was crucial to make the stipulations in the advance directive as clear cut and specific as possible.

#### **Opinion Leader**

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### *Guiding considerations*

Considerations that the participants felt were crucial to decision-making about life-sustaining treatments were:

- How did the person make their decision?
  - Did they really mean and feel it? How certain were they? Was it recorded and how?
- How severe is the dementia?
  - Can the person be consulted at all? Have you tried?
  - What is their quality of life? Who has been consulted?
- What is the nature of the secondary illness? What will any treatment achieve?
- How can the family's perspective be taken into account? Should it be taken into account at all?

### *In summary*

In order to help achieve some perspective on such a difficult and abstract issue, people attempted to make multiple comparisons with more everyday or familiar situations in order to ground their decisions. This ranged from thinking about other advance choices that people make, such as whether they would prefer to be buried or cremated or stipulations made by Jehovah's Witnesses:

*"If your mum said 'I want to be buried' you wouldn't say 'oh she didn't mean that'"*

*"It's like the Jehovah's Witnesses- they've made that decision, you can't go against it"*

When considering the question from an abstract perspective, the participants were more inclined to decide that the person's past wishes were paramount. However, when applying the decision to a personal situation, i.e. imagining the person was their relative, the decision was, for many people, reversed. Overall, it remained a split between those who could be sure that they would respect the wishes of a loved one and let them die, and those who declared that, even if they knew it might not be right, they would still fight for their relative's life. However, all pointed to the importance of as much conversation with the person with dementia as possible on diagnosis, resulting in a set of specific instructions to aid any future decisions. There was a sense that whilst this situation will never be truly black and white, there were certain legal precautions that would remove at least some of the grey area.

## 4.3 Conflicts of interest

In the final discussion, participants were asked to consider situations where there is a conflict between the interests of the person with dementia and their family or carer. Participants were split into two groups to consider two different potential scenarios:

- In Scenario four, the Jardine family face the difficult choice of putting the grandmother of the family (Pat's mother), into a home which she expressly does not want to do, or of Pat caring for her herself somehow, with the consequent impacts on the family.

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- Scenario five depicts an elderly couple where the husband has dementia and is becoming progressively more infirm. His wife and primary carer has herself fallen and needs an operation.

Participants were asked how they would balance the wishes of the person with dementia with the needs of their carers, and when decisions should be taken about the family as a whole.

### *Key areas of discussion*

The participants found these two situations and the questions they posed immediately more tangible, as they were situations they could imagine encountering in their own lives. As a result of this, there was less of a focus in the discussion on conflicts of interest on the person with dementia and more empathy for the needs of the carer and family. Practical and financial considerations also dominated, as people were able to draw out and weigh up how such a situation would affect them in day-to-day life. Overall, participants were able to be considerably more objective and less emotional when weighing up the relative needs of the patient and carer than in the previous dilemmas.

### *Considering the impact on the carer*

The majority of people consulted felt that it was a question of balancing the quality of life of the person with dementia and that of any carers or family involved. The number of people affected was seen to play a role, expressed in relation to the Jardine family example as *“four lives against one”*. Whilst participants were conscious of the wishes of the patient and keen not to add any unnecessary stress to her situation, they were most concerned about the strain that a duty of care would put on the family. Some participants suggested that in fact it would be in nobody’s best interests for the family to be put under such pressure that the care they gave their relative was no longer compassionate:

*“Ultimately the family unit is the most important because if they break up due to the burden of care, then they can’t support the person with dementia anyway. This means that if they are not happy to have the person there it would be better to have her supported in her own home or in a care home.”*

### *Choosing the best care for the patient*

Some people thought that the person with dementia would be better off receiving professional care within a residential care home in any case. Others felt that in an ideal situation it would be best for the carer to be a family member, as they will be more attentive naturally than a rushed health professional with other patients to care for but that this was not always possible:

*“There’s nothing as good as her own daughter looking after her but you have to compromise.”*

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For many, the compromise was to maintain the person with dementia in their own home for as long as possible, or to supplement care with the help of social services. External support, including financial help was seen to be crucial to this situation by many and there was some confusion about how much would be available:

*“Couldn’t she just stay in her home and have a 24-hour carer?”*

### *The impact of cultural differences*

There were exceptions to this focus on considering the needs of the carer and on limiting the impact on their lives. Cultural differences in particular had an impact on perspectives about responsibilities and duties of care for some ethnic minority participants, although not all. Some Muslim participants and a participant of Caribbean origin, reflected that their cultural background had taught them to always adhere to a strict duty of care towards older relatives and for the family to come together to take responsibility for their relative’s care. Rather than seeing the care of their relative as a burden which raises questions as to whether to seek external help in order to ease this burden, some participants felt there was no question at all:

*“Without question you would take them into your home – if you have parents you are blessed, you have everything.”*

*“They’re our parents, it’s our duty. When they get older they act as we did when we were younger so now we should take on that role.”*

*“When my father was ill the family all took turns in looking after him and my brother gave up his job.”*

### *Treating people as individuals*

First and foremost, participants were clear that with couples where one has dementia and the other is an ageing carer with a physical health problem, and have very different or opposing needs, as in Scenario five, pragmatically they should be treated individually. In the scenario given, this would involve the person with dementia going into a home at least while his wife and carer had the operation she needed.

*“It is best for the person with dementia: ultimately he needs specialist care and Clarissa is unable to look after him – it’s more for the benefit of his carer [that he goes into a home] but ultimately for both of them because he needs care she cannot provide.”*

Some suggested that, beyond the operation and recovery period, it might be possible to persuade both parties that it was in their best interests for the person with dementia to remain within a care-setting as his dementia becomes more severe.

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Participants also sought practical alternatives to separation that might still enable them to be treated individually. One suggestion was to have specialist support provided in-home and another to find a home that would accommodate double rooms and provide for both of their specialist needs in one place. However, participants recognised that both of these ideal scenarios would probably be either extremely costly or unavailable as services that are currently offered.

*"In an ideal world they can stay in their home and have specialist carers, but I live in a real world."*

### *Treating people as couples or family units*

Many felt that although it might be medically right to treat the individuals involved separately, it might not enhance or sustain their quality of life if they wanted to remain together.

*"If I was Clarissa I'd want to spend the next three years with my husband than the next six years by myself."*

*"They should not be split up, absolutely not"*

Others felt that, addressing them as a couple, for example by putting them both in a home when the carer did not really need that level of care, would be contravening the carer's needs.

*"She probably doesn't need to be in a care home – so would you put someone in who doesn't need care in a care home?"*

In this situation participants could find no easy answers. However, if the couple in this situation expressed different wishes about where they wanted to live, participants felt that the difficult decision would have to be made to separate them. This was felt to hold the potential to have some negative impacts on the couple's wellbeing, beyond any medical considerations and so should be avoided at all costs:

*"I think they would deteriorate quickly if they were separated."*

Participants were clear that in any instance the couple would need support from social services and from the wider family.

### *Guiding considerations*

- Are there any family members to help and to take a role? If not, social services need to take responsibility.
- How severe is the dementia? Can both parties be consulted?

Opinion Leader

- What do the individuals want? Can their wishes be accommodated?
- What are the potential costs involved and are they sufficient to fulfil their wishes?

### *In summary*

Many felt that the compromise would be to address the immediate individual needs in the short-term, and how they can be accommodated without making difficult decisions, and then to re-assess the couple/ family's situation afterwards:

*"The carer needs time out to have the operation and recover, but they wouldn't want to be split up permanently."*

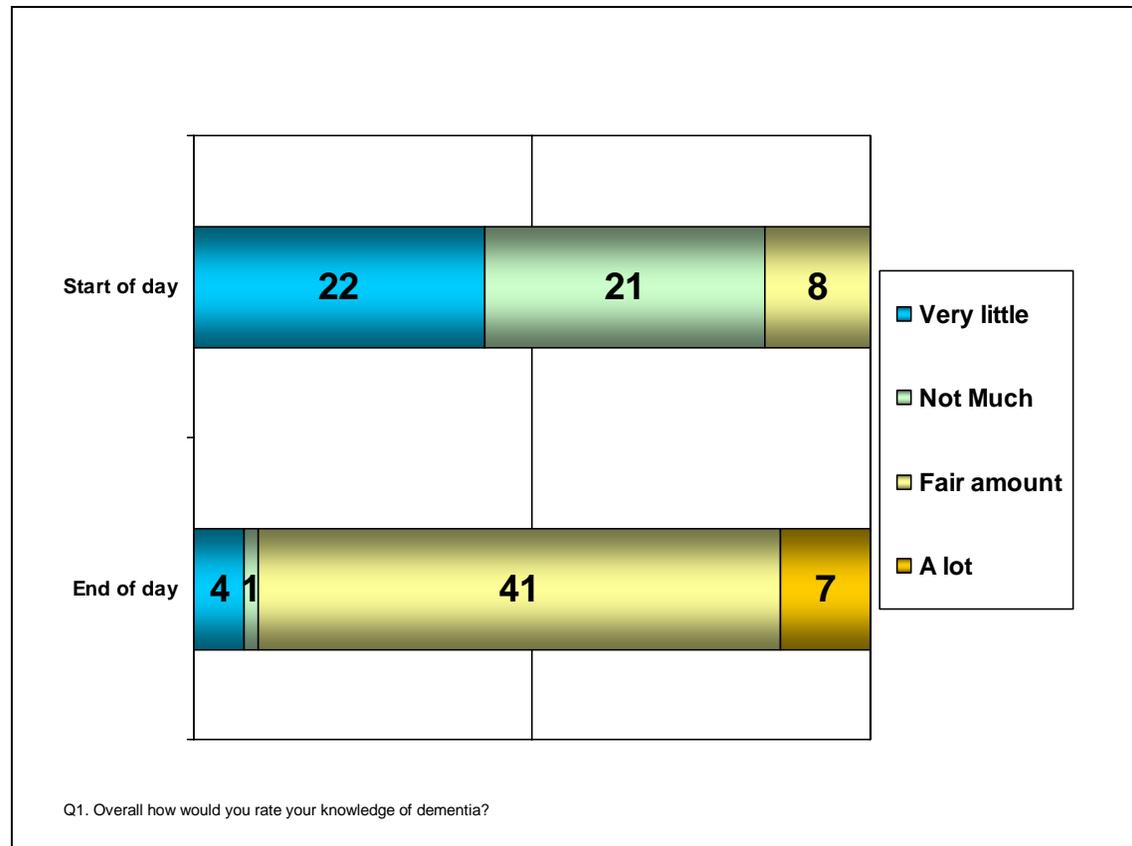
*"So they put them into a home whilst she has the operation in the hope that discussion can follow on."*

As far as possible, small changes and external support should be delivered, ideally from the family but also from social services, to enable couples to remain together and to reduce the impact on carers i.e. to return / stay in their home, move into double-occupancy accommodation, or to be offered a sheltered home. Support might involve changes to the house to make it easier to move around in and safer environment; telephone support could be installed in case of need or perhaps a warden could be employed to watch over the person with dementia.

## 5. The impact of information and deliberation

The deliberative process, providing people with information and space to debate, causes changes in participants' levels of knowledge and can affect their attitudes throughout the day. Respondents were asked to complete identical questionnaires at the beginning and end of the day to try to capture any changes that took place.

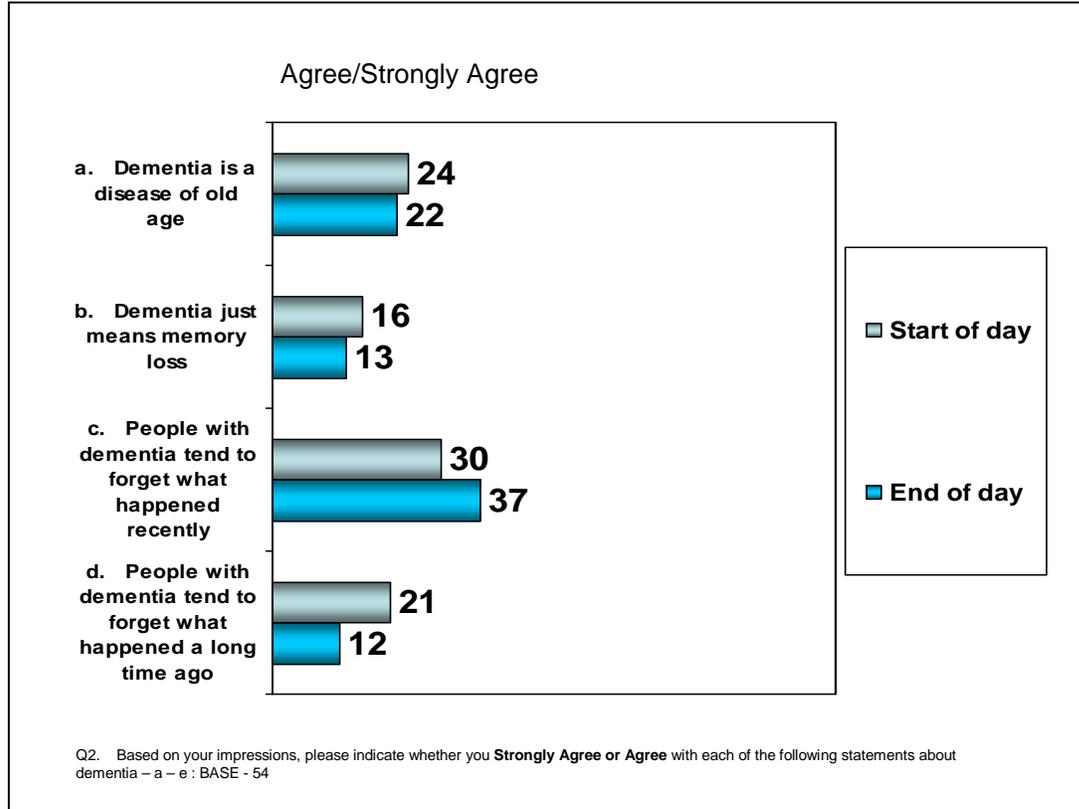
### *Perceived knowledge of dementia*

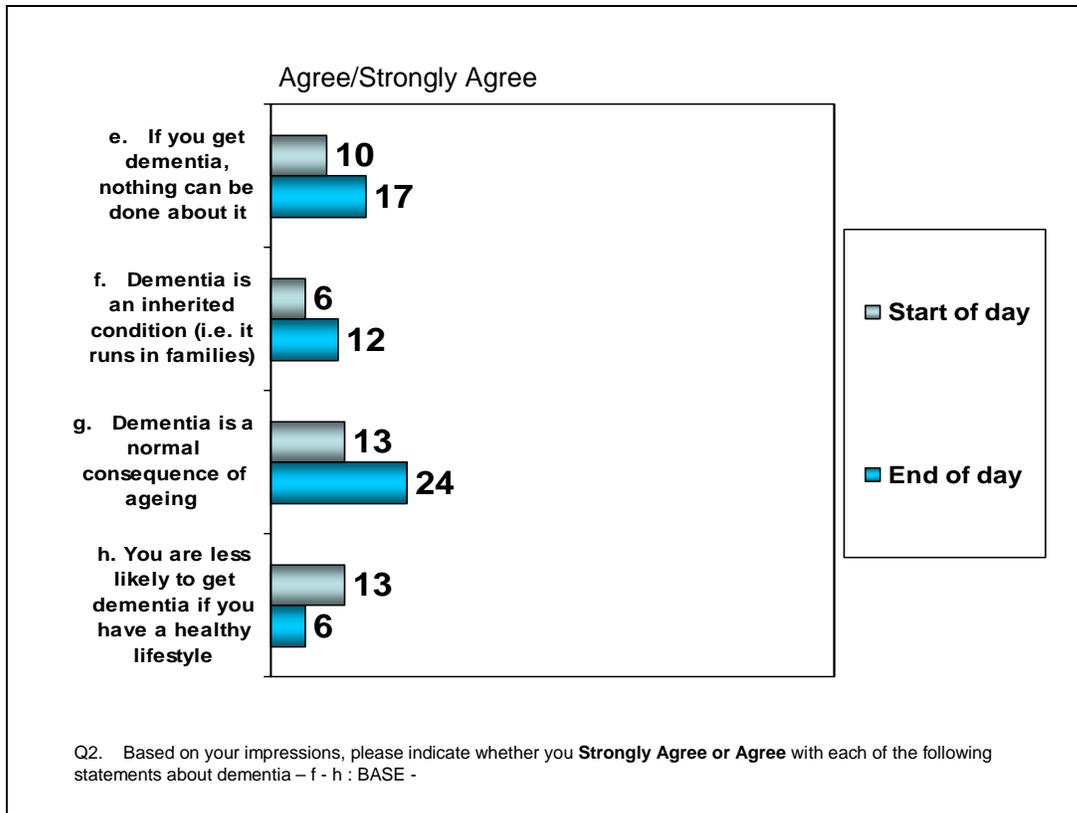


Participants felt their knowledge of dementia improved greatly, with the number of participants saying they knew a fair amount or a lot about dementia increasing from eight before the event to 41 at the end. This is also borne out by their responses to specific questions about dementia. People became more aware of what dementia is, namely a complex set of symptoms as opposed to a single condition, and that it can vary from person to person. Because of this they felt it was important that decisions are made on a case-by-case basis depending on the particular set of circumstances, and that they should be reviewed as circumstances change over time. They became more aware of the scale of issues surrounding dementia, and how an ageing population will make these issues surrounding dementia more prevalent in the future.

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## Agreement with statements about dementia

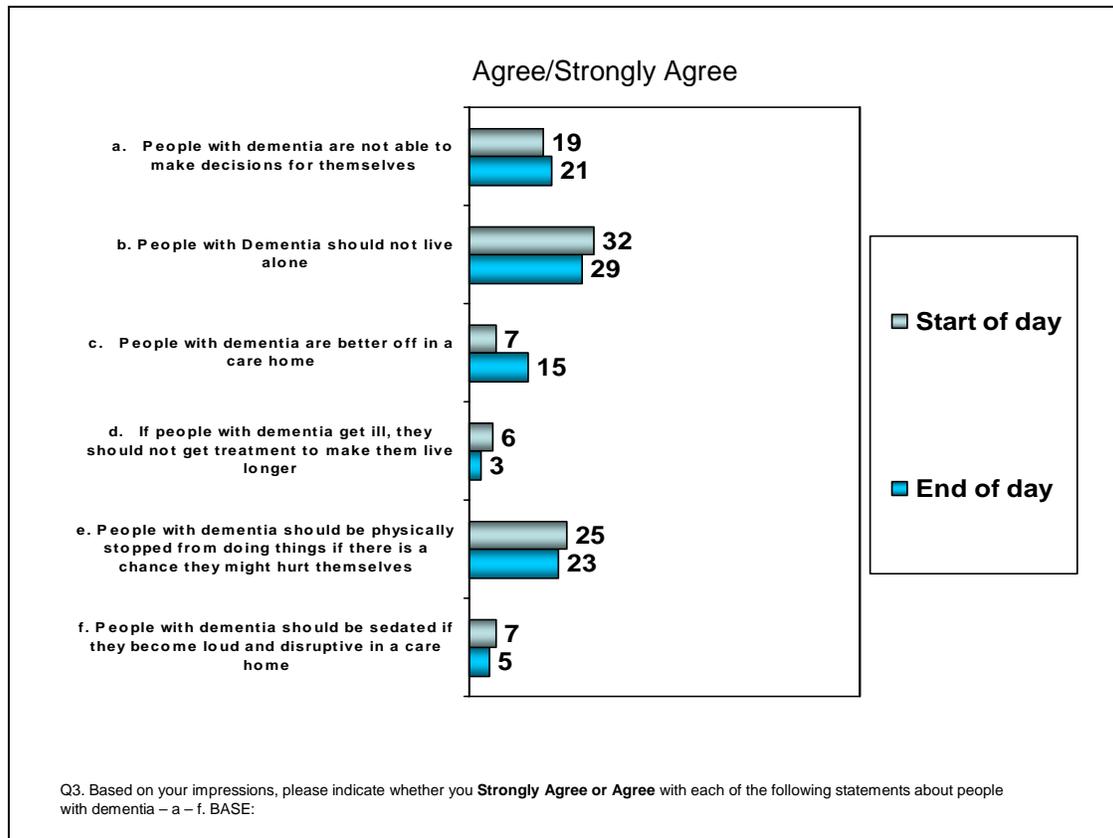




However, areas of confusion remained in terms of the causes of dementia, and potential treatments and prognosis for people with dementia. This confusion led to some concern about how people are diagnosed with dementia. At the end of the day participants still had questions remaining about what would happen to them if they had dementia, for example how healthcare professionals would diagnose them and what their future prospects would be once they had it.

As opposed to questions of fact on dementia on the start and end of day questionnaires, the answers to which altered somewhat through the course of the day, responses to questions on ethical issues around dementia showed little change. For those consulted, better knowledge of dementia as a disease does not seem to have shifted opinion on how they thought people with dementia should be cared for. Ethical judgments on dementia seem to be based more on 'gut reaction' than on information.

## Agreement with statements about people with dementia.



## 6. Conclusions

Participants began the day with a fairly high awareness of dementia and its general symptoms, and some sense of the impact it might have on carers, but little knowledge or understanding of the full implications of care. Dementia is not something that people encounter in day-to-day life, unless they have direct experience via a relative and it is not something that participants reported to have thought about before. Considering dementia in more detail led participants to reflect on their own families and their own future, particularly about diagnosis and prognosis if they were affected in the future. Participants also became particularly mindful of the potential implications of an ageing population in terms of increasing care needs for greater numbers of people with dementia.

The participants were very keen to engage in the complexities of the dilemmas around the care of people with dementia, however they found there were no easy answers and could come to no overall consensus about the three dilemmas presented to them. There were some distinctive features in the approach the participants took to debating the issues around caring for people with dementia:

- The participants took a very person-centred approach to addressing the care needs of the person with dementia:
  - maintaining the individuality of the person as paramount;
  - consulting and involving them as far as possible;
  - dealing with each person differently, on a 'case-by-case' basis.
- They also emphasised the need to take account of the stage or severity of the dementia at every point, but especially when making decisions about their care.
- Many participants felt very strongly that the dignity of the person with dementia should be safeguarded at all stages.
- Quality of life was raised as a guiding principle for many. However, as this was found to be important both when considering the needs of the person with dementia and for those caring for them it also raised some difficult questions.

Interestingly, whilst people's understanding of dementia increased significantly over the course of the deliberation and the information enabled individuals to fully discuss the ethical issues, there was little change in people's ethical standpoints after debating them in some detail.

Therefore, whilst it may be desirable to raise understanding amongst the general public about the implications of caring for people with dementia (especially as more of us are required to care for ageing relatives) it may be that views on how best to do so will continue to follow each individual's own moral compass. Consultation with the public would therefore support recognition of the fact that there are no right or wrong answers in dementia care and that each situation should be considered on a case-by-case basis.

### Opinion Leader

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## 7. Appendix

### Agenda

## Nuffield Council for Bioethics: Deliberative workshop on dementia

Tuesday 5th August 2008, Thinktank, Birmingham

#### Key research questions/ objectives

- What top of mind views and concerns do the participants hold about dementia?
  - What drives these views?
  - Are there any key stigmas/ myths/ misinformation?
- What are the participants' view on the key ethical dilemmas concerning dementia?
  - Freedom of action and restraint in the interests of safety
  - Making decisions (and in particular, what is the participants' view of advance directives; balancing past and present wishes; and, life sustaining treatment)
  - Conflicts of interest (in particular, the impact of care needs on those who need to meet them)
- On balance, how do the participants perceive dementia after exposure to information and time to discuss the issues?

Time	Item	Stimulus required
9.30 - 10.00	Arrival and registration Complete pre debate questionnaire Complete filming and permission sheet (can explain just for internal use at Nuffield, not for broadcast)	<ul style="list-style-type: none"> <li>● Pre debate questionnaire</li> <li>● Filming permission sheet</li> </ul>
10.00 - 10.15	Welcome and introduction <ul style="list-style-type: none"> <li>● Purpose of the research, agenda and ground rules, role of Nuffield Council and Working Party, etc</li> <li>● OL and Nuffield to speak</li> </ul>	<ul style="list-style-type: none"> <li>● Copy of ground rules for each table</li> <li>● Handout outlining Nuffield and Opinion Leader and the purpose of the research</li> </ul>
10.15 - 11.00 45 mins	Initial warm up (5 mins) <ul style="list-style-type: none"> <li>● <b>Collect in filming permission sheets – query if any mind and flag up using green card if do</b></li> <li>● <b>Collect in pre-debate questionnaires</b></li> </ul>	

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	<ul style="list-style-type: none"> <li>• Each participant to introduce themselves and tell the table something about themselves</li> <li>• Each participant asked to share with the table what comes to mind when they think of 'dementia'</li> </ul> <p>Perceptions of dementia (15 mins)</p> <ul style="list-style-type: none"> <li>• What does dementia mean to you? <ul style="list-style-type: none"> <li>○ Probe for who it affects and it what ways</li> <li>○ Familiarity with symptoms</li> </ul> </li> <li>• Do you know anyone with dementia? <ul style="list-style-type: none"> <li>○ Probe for experience of dementia (through knowing others)</li> </ul> </li> <li>• How knowledgeable would you say you were about dementia? <ul style="list-style-type: none"> <li>○ What makes you say that?</li> </ul> </li> <li>• How do you know what you know? Where did you get your information/ views from?</li> <li>• Is dementia something that you have ever thought about before? <ul style="list-style-type: none"> <li>○ Probe for whether anyone on the table is concerned about dementia at all, why and in what ways.</li> </ul> </li> </ul>	
	<p>Imagining what having dementia / caring for someone with dementia would be like (25 mins)</p> <ul style="list-style-type: none"> <li>• What do you imagine it might be like to have dementia [instruction: don't spend a long time on this as we will return to it later]</li> <li>• How able do you think people with dementia are to take part in everyday life?</li> </ul> <p>instruction: ask someone on the table to roughly flip chart thoughts on the following:</p> <ul style="list-style-type: none"> <li>• How do you think dementia might affect the day to day lives of: <ul style="list-style-type: none"> <li>○ People with dementia?</li> <li>○ Those who live with/ are close to people with dementia?</li> </ul> </li> </ul>	

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	<ul style="list-style-type: none"> <li>• What kinds of care and support to you imagine that someone with dementia might need?</li> </ul> <p>[instruction: Brainstorm this and keep as a resource for later session]</p>	
11.00 – 11.25 25 mins	<p>Briefing on dementia</p> <ul style="list-style-type: none"> <li>• Pub quiz led from the front to provide key facts and figures including <ul style="list-style-type: none"> <li>○ Demographic changes/ incidence of dementia</li> <li>○ Prevalence of dementia</li> <li>○ What causes it</li> <li>○ Etc</li> <li>○ Impact on carers</li> <li>○ The correct definition of dementia</li> </ul> </li> </ul> <p>Give nominated lead person the answer sheet to fill in</p> <p>Lead facilitator will inform participants of how the quiz will work (tables work together to decide on their answers as a group, record their answers as they go) then answers will be delivered from the front, tables work out their scores, report back in plenary and a winner is revealed (prize will be distributed!)</p>	<ul style="list-style-type: none"> <li>• Printed presentation slides to supplement quiz just for facilitators' reference</li> <li>• Participant answer sheet</li> </ul>
11.25 – 11.40 15 mins	<p>Reactions to information</p> <ul style="list-style-type: none"> <li>• Did you learn anything?</li> <li>• Were there any surprises? <ul style="list-style-type: none"> <li>○ What were they?</li> </ul> </li> <li>• Did anything contradict what you thought you knew? (could refer back to brainstorm of earlier discussion)</li> </ul>	<ul style="list-style-type: none"> <li>• Reference sheet on key facts, figures and ethical questions</li> </ul>
11.40 – 11.55 15 mins	<p>Understanding the issues</p> <p>Show film <i>In Memoria</i></p> <ul style="list-style-type: none"> <li>• Providing insight into experience of person, carers, family</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>
11.55- 12.30 35 mins	<p>Starting to debate the issues</p> <ul style="list-style-type: none"> <li>• What are your initial reactions to the film?</li> <li>• What difficult questions does the film raise for you?</li> <li>• Does it raise any ethical questions? [instruction: handout and read out reference sheet]</li> </ul>	<ul style="list-style-type: none"> <li>• Reference sheet on what an ethical question is</li> </ul>

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	<ul style="list-style-type: none"> <li>• Can you think of a situation where it is right to not tell the truth to someone which dementia?</li> <li>• How do you think the risks of someone having dementia should be managed? <ul style="list-style-type: none"> <li>○ Probe for whether participants perceive that carers are too cautious or not cautious enough</li> </ul> </li> <li>• Can you think of a situation when it is right to restrain someone which dementia? <ul style="list-style-type: none"> <li>○ For example, when they might cause harm to themselves</li> </ul> </li> <li>• To what extent do you think people with dementia should make decisions for themselves? <ul style="list-style-type: none"> <li>○ Are there any circumstances when it is right to make decisions for the person?</li> </ul> </li> </ul>	
12.30-1.15 45 mins	LUNCH	
1.15-1.20	<p>Welcome back and into to afternoon</p> <ul style="list-style-type: none"> <li>• The key ethical questions/ dilemmas</li> </ul>	
1.20 – 1.35pm 15 mins	<p>Balancing freedom and risks</p> <p><b>Give out scenario 1: David and Margaret</b></p> <ul style="list-style-type: none"> <li>• Table facilitator to read through scenario 1 : wanting to go outside and take a bus journey unaided and alone</li> <li>• Table to discuss as one (15 mins)</li> <li>• What are the implications of this? <ul style="list-style-type: none"> <li>○ Who for?</li> </ul> </li> <li>• What do you think should be done in this situation? <ul style="list-style-type: none"> <li>○ Probe around perceived acceptability of physically restraining as compared to electronic tagging</li> <li>○ Whose interests would this serve?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Scenario 1</li> </ul>
1.35 – 1.55 pm 20 mins	<p><b>Give out scenario 2: Phyllis and Sandra</b></p> <ul style="list-style-type: none"> <li>• Table facilitator to give scenario 2: falling in the bathroom whilst using the toilet/ should the person be accompanied to the toilet in the future</li> <li>• Table to split into 3 smaller groups (10 mins)</li> <li>• Each group to look at the scenario from the perspective of one of the following:</li> </ul>	<ul style="list-style-type: none"> <li>• Scenario 2</li> </ul>

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	<ul style="list-style-type: none"> <li>○ Someone who might have dementia in the future</li> <li>○ A care worker</li> <li>○ A family member (suggest this could be wife, or son)</li> <li>● Each group to feedback to the table and discuss as one group (10 mins)</li> <li>● What were the key differences between the different perspectives?</li> </ul> <p>Table facilitator to try to enable group to come to consensus on the question (should the person be accompanied to the loo).</p>	
1.55 – 2pm	<p>Groups to prepare feedback (5 mins)</p> <ul style="list-style-type: none"> <li>● 1 point about Scenario 1 (implications and consensus)</li> <li>● 1 point about Scenario 2 (e.g. differences between perspectives and any consensus)</li> <li>● Consensus overall on how freedoms and risks should be balanced and how this was arrived at (if it was)</li> </ul>	Flipcharts
2.00 – 2.15  15 mins	<p>Table feedback</p> <ul style="list-style-type: none"> <li>● Participant from each table to feedback to room the top points from the 2 discussions and the consensus view of the table, if this was arrived at</li> </ul>	<ul style="list-style-type: none"> <li>● Flipcharts and roving mic</li> </ul>
2.15 – 2.25  10 mins	<p>Briefing</p> <ul style="list-style-type: none"> <li>● Short presentation covering: <ul style="list-style-type: none"> <li>○ Life sustaining treatment</li> <li>○ Advance directives</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● Presentation by Prof Tony Hope</li> <li>● Reference sheet to be given at table</li> </ul>
2.25 – 3.05  40 mins	<p>Decision making</p> <p><b>Give out scenario 3: Tina</b></p> <ul style="list-style-type: none"> <li>● Table facilitator to read out 'Tina' scenario</li> <li>● Table forms two smaller groups <ul style="list-style-type: none"> <li>○ One is Tina</li> <li>○ One is Tina's daughter</li> </ul> </li> <li>● Each group to discuss: <ul style="list-style-type: none"> <li>○ What should happen if Tina becomes physically ill?</li> <li>○ What, if any, role could advance directives play</li> </ul> </li> <li>● Each group to report back to the table</li> <li>● Table to discuss each perspective and see if a consensus can be arrived at <ul style="list-style-type: none"> <li>○ If not, detail why not</li> </ul> </li> </ul>	<p>Scenario 3</p> <p>Refer back to Life sustaining presentation reference sheet as necessary</p>

### Opinion Leader

3.05 3.15	BREAK (Grab a coffee/tea, some fruit and return to tables)	Music maestro!
3.15 – 3.40  25 mins	<p>Conflicts of interest</p> <ul style="list-style-type: none"> <li>Table facilitator to introduce final scenarios (5 mins) <b>Give out Scenario 4: the Jardine Family and Scenario 5: Clarissa and Terry</b></li> <li>Table forms two smaller groups (10 mins) <ul style="list-style-type: none"> <li>One group looks at decisions taken in residential care (Scenario 4)</li> <li>Other group looks at decisions taken by someone's wife who is the primary carer and living at home (Scenario 5)</li> </ul> </li> <li>Each group to: <ul style="list-style-type: none"> <li>Explore the carer's perspective and what's best for them</li> <li>Explore what's best for the person with dementia and the health professional's role</li> <li>What the role of health/ social care professional should be and why</li> </ul> </li> <li>Each group to feedback to table (10 mins)</li> </ul>	Scenarios 4 and 5
3.40 – 3.45	<p>Groups to prepare feedback (5 mins)</p> <ul style="list-style-type: none"> <li>How did the group decide how to balance the wishes of the person with dementia with those of the carer (Can refer to Scenario 4 and Scenario 5 or other examples discussed to illustrate)</li> <li>What the role of health and social care professionals should be</li> </ul>	Flipcharts
15.45 – 16.00	<p>Table feedback</p> <p>Participant from each table to feedback to feed back on the role of health and social care professionals should be and the balancing of the person with dementia's wishes against those of the carer.</p>	<ul style="list-style-type: none"> <li>Flipcharts and roving mic</li> </ul>
16.00	<p>Thanks and close</p> <ul style="list-style-type: none"> <li>Thanks and next steps from Nuffield and Opinion Leader</li> <li>Hand over to table facilitators for final admin, FILLING IN POST-WORKSHOP QUESTIONNAIRE and payment</li> </ul>	<ul style="list-style-type: none"> <li>Post workshop questionnaire</li> <li>Evaluation questionnaire</li> <li>Incentive signing sheet</li> </ul>

### Opinion Leader

		• Incentives
16.15	CLOSE	

# Life sustaining treatment and advance directives

## Issues around medical treatment of people with dementia

Some key issues:

- How capable is the patient of giving consent?
- How should previous wishes be taken into account?
- How can others judge the patient's quality of life?
- How should disagreements be resolved?
- How much value on extending life?

## Life sustaining treatment

- When is it right not to give a life sustaining treatment?
  - If a person has capacity, they have the right to refuse medical treatment
  - When no capacity, family, friends and doctors have to make decisions in the patient's 'best interests'

## Best interests

- Things to consider when making decisions in a patient's 'best interests'
  - Patient's wishes and feelings before they had dementia
  - Beliefs and values e.g. religious beliefs
  - Weigh previous beliefs and wishes against current state of mind

## Advance directives

- Advance directives state how a person wants to be treated if they lose capacity in future
  - A refusal of treatment must be honoured if it refers to the specific situation
  - Some fear that people may not be able to fully imagine how they will feel if they develop dementia



## Nuffield Council on Bioethics

### Ground rules for event 5<sup>th</sup> August 2008

- Mobiles off!
- Make time for everyone to have their say
- Express your views and listen to the views of others
- Be sensitive to the views of others
- Respect the opinions of others – not everyone will think the same thing
- There are no right or wrong answers
  - Today is an opportunity for you to say what you think and feel
- Take a break when you need one
  - But not more than two people to be away from the table at the same time



## Who are the Nuffield Council on Bioethics and Opinion Leader

### Who are the Nuffield Council on Bioethics?

- An independent organisation which tries to identify, look at and report on issues brought up by improvements in science and medicine

### Why are they interested in dementia?

- The increase in cases of dementia, an improving understanding of the condition, and new care and treatments have left unanswered questions about how people with dementia should be treated
- The Nuffield Council on Bioethics have formed a group to look at, and gather opinion on these issues
- As well as this event the Nuffield Council on Bioethics will also be talking to people with dementia, people who care for people with dementia, and a range of professionals who treat or care for people with dementia
- This will mean they can advise on what the right things to do are when it comes to caring for and treating people with dementia

### Who are Opinion Leader

- An independent research agency
- Asked by the Nuffield Council on Bioethics to gather, and report on, public opinion on issues around dementia

#### Opinion Leader

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## What will happen with the information gathered today?

- Along with the other parts of the consultation, the opinions gathered today will feed in to the final report by the Nuffield Council on Bioethics. This will give recommendations on how they think the care of people with dementia should be managed in the future

## Any questions?

- If you have any questions about this workshop and what will happen to the results, please contact:

Becky Seale

Opinion Leader

4<sup>th</sup> Floor Holborn Gate

26 Southampton Buildings

London

WC2A 1AH

020 7861 3090

[bseale@opinionleader.co.uk](mailto:bseale@opinionleader.co.uk)

- If taking part today has raised questions for you about care and support or dementia please contact:

The Alzheimer's Society Dementia Hotline

0845 300 0336

## Pub quiz answer sheet

*Please circle or tick your table's chosen answer*

1. What is dementia?
  - A. A chemical compound with a pungent smell
  - B. A South American country
  - C. The loss of mental abilities
  - D. A genus of flowering plants
  
2. How many people in the UK have dementia?
  - A. 100,000
  - B. 300,000
  - C. 700,000
  - D. 1.1million
  
3. How many more people will have dementia by 2025?
  - A. 50,000
  - B. 100,000
  - C. 200,000
  - D. 300,000
  
4. What proportion of people over 80 years old have dementia?
  - A. 1 in 3
  - B. 1 in 5
  - C. 1 in 8
  - D. 1 in 12
  
5. Who is more likely to have dementia, men or women?
  - A. Men
  - B. Women
  - C. Both equally likely

6. True or false: Dementia is just caused by getting old?
- A. True
  - B. False
7. How many deaths each year can be attributed directly to dementia?
- A. 0
  - B. 10,000
  - C. 60,000
  - D. 150,000
8. What percentage of people in care homes have dementia?
- A. 39%
  - B. 48%
  - C. 64%
  - D. 75%
9. What percentage of people with dementia live in the community as opposed to a care home?
- A. 25%
  - B. 35%
  - C. 50%
  - D. 65%
10. What is the total cost of dementia to the UK every year?
- A. £3 billion
  - B. £7 billion
  - C. £12 billion
  - D. £17 billion
11. The families of people with dementia save the UK money by caring for them so they don't have to go into care homes. How do they save the UK every year?
- A. £700 million
  - B. £1.9 billion
  - C. £4.3billion
  - D. £6 billion
12. How much more is the cost to the UK of caring for people with dementia likely to be in next 20 years compared to today?
- A. The same amount
  - B. 1 ½ times as much
  - C. Twice as much
  - D. Three times as much

#### Opinion Leader

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## Facts and figures on dementia

### What is dementia?

- Dementia is the loss (usually gradual) of mental abilities such as thinking, remembering, and reasoning
- It is not a single disease, but a group of symptoms that go along with some diseases or conditions that affect the brain

### How many people have it, and how many will have it in the future?

- 700,000 people have dementia in the UK
  - This means 1 out of every 120 people in the UK have dementia
  - 11,500 of these people belong to an ethnic minority
  - 2/3 of these people are women
  - Globally there are 18 million people with dementia
- Dementia is not caused by getting old, but older people are more likely to have it
  - For every 5 years older a person gets after 65, they become twice as likely to suffer from dementia
  - 1 in 5 people who are over 80 years old have dementia
- People are living longer than they used to, and are expected to live longer in the future
  - On average men live to about 80, and women to about 83, by 2045 these are expected to increase by about 4 years to 84 for men and 87 for women
  - In the future a greater percentage of the population will be over 65 – today 16% of the population are over 65, in 30 years time 25% will be
- Because of this there is expected to be more people with dementia in the future – by 2025 are expected to be 300,000 more people with dementia than today

### What causes dementia, and what are its end results?

- Dementia has many causes. However, over half (55%) of cases of dementia are caused by Alzheimer's disease

- About 60,000 deaths a year are caused by dementia. This is about 10% of deaths of men over 65, and about 15% of deaths of women over 65
- If the start of dementia could be delayed by 5 years, the number of deaths caused by it would probably halve to about 30,000 per year

## How are people with dementia cared for, and how much does it cost?

- About 65% of people with dementia live in the community, rather than in care homes
- 64% of people in care homes have dementia
- The total cost of dementia to the UK, including money people with dementia and their carers receive in benefits, the cost of care in care homes, and the money lost in tax by people taking time out of work to care for people with dementia is about £17 billion
- Families of people with dementia save the UK £6 billion every year by caring for people with dementia in the community
- In 20 years time costs of care for people with dementia are likely to be 3 times higher than today

## What are ethical questions?

- Ethical or moral questions ask how right or wrong something is
- Although we might not realise it, we all face ethical questions every day
  - Is it right to take a holiday abroad when it could contribute to global warming?
  - I think one of my friends is claiming incapacity benefit when they are able to work, should I report them?
  - A credit card company refunds you twice by mistake, is it right to keep the extra money?
- When it comes to answering ethical questions we may need to weight up lots of different things
  - The values or principles we think are important (e.g. it is wrong to lie)
  - The possible consequences of the decisions we are making

## What is an ethical dilemma?

- An ethical dilemma is where doing the right thing might also mean doing the wrong thing.
- It is where there is no clear cut right and wrong answer and the moral 'codes' or principles that we generally keep, can't give us an obvious solution.

## Life sustaining treatment and advance directives

### Life sustaining treatment

- Life sustaining treatment is any treatment that would extend the life of a patient, and without which they may die
- If a person is able to make their own decisions, then they have the right to refuse medical treatment
- However, when people are not able to make their own decisions, such as some people with dementia, the decision falls to family, friends and professionals to make it for them in their 'best interests'

### Best interests

- Current law states that family, friends and doctors have a responsibility to act in a patient's 'best interests'
- The law includes a checklist of things to consider when making decisions on treatment
  - These include the patients wishes and feelings before they had dementia, and beliefs and values they had which may influence the decision e.g. religious beliefs
- Family, friends and doctors may have to weigh previous beliefs and wishes against the patient's current state of mind
- However, the law does not define 'best interests' precisely, and does not spell out exactly who should take the decision to give or withhold treatment

### Welfare attorneys

- People can choose a 'welfare attorney' who will make decisions for them if are not able to make their own at some point in the future. This is usually a close relative
  - The welfare attorney must act in the person's best interests
  - The person can set limits on the power the attorney has. These powers can include refusing life sustaining treatment
- However, welfare attorneys and doctors may disagree on what is in the patient's best interest
- Doctors are advised to seek second opinions on treatment if they disagree with the welfare attorney's decision

- Conflicts may eventually go to court – however, the law does not state whose opinion should be considered most important

## Advance directives

- Some people make advance directives, also known as 'living wills', which say how they want to be treated if they lose their mental capacity
  - For instance, they may say that if they are not able to recognise, or have a conversation with close relatives, then they would not wish to be given life sustaining treatment
  - The law says that a refusal of treatment must be honoured if it refers to the specific situation
  - However, some people fear that these may lead to decisions being made which are not in the person's best interests.
  - Others think that people are not able to fully imagine how they will feel if they develop dementia and predict the kinds of decisions they would make in that situation

## MEET DAVID AND MARGARET

- David is 74 years old and has had dementia for 4 years
- David has always been very active and independent, and enjoys going for walks or going shopping by himself
- A few times in recent months David has become confused while on trips to the town centre
- He has returned home very late several times, and once his wife Margaret had to search for him, finding him in a confused and distressed state
- Margaret is worried about David going out by himself, and is considering stopping him leaving the house on his own



## Issues to consider

- How much should David's enjoyment of his trips be taken into account?
- How much should Margaret's concern for his safety be taken into account?
- To what extent should Margaret be able to restrict David's freedom
  - Not at all?
  - Electronic tagging to monitor his movements?
  - Door alarms so she can tell when he leaves?
  - Locking him in the house?
  - Physically stopping him leaving?
- Does it make a difference if David fights against efforts to stop him going out?

## MEET PHYLLIS AND SANDRA

- Phyllis is 79 years old and has had dementia for 3 years
- She lives with her daughter Sandra and her family
- Phyllis is becoming more confused, and is less able to do things for herself
- Phyllis recently had a fall while in the bathroom in the family home and fractured her wrist
- Sandra is worried about letting Phyllis go to the toilet by herself and thinks she should be accompanied
- However, when Sandra has gone into the bathroom with her, Phyllis has become very upset



## Issues to consider

- How much should we consider the distress caused to Phyllis in this situation?
- How much should we consider the potential injuries she might suffer if not helped to the toilet?
- How much should we consider Sandra's concern for her mother in this situation?
- To what extent should she be assisted
  - Not at all?
  - Taken to the toilet?
  - Helped onto the toilet?
- How could taking her to the toilet be managed in a care home e.g. should she be taken every few hours whether she appears to need the toilet or not?

### Opinion Leader

## MEET TINA

- Tina is 67 years old. She's had Alzheimer's disease for 8 years and now has severe dementia
- When first diagnosed with Alzheimer's disease, Tina told her family that she would not value life with dementia
- She said that in the future, if she could not make decisions for herself, she would not want medical treatment which would prolong her life
- Now, Tina appears very contented in her care home, reading random pages from a detective story, drawing the same picture over and over, and eating her favourite food
- Tina has been diagnosed with early stage lung cancer which will eventually kill her, but which is treatable
- Doctors have asked her family whether they want Tina to receive medical treatment for the lung cancer



## Issues to consider

- How much should Tina's previous wishes be considered in making this decision?
- How much should her current behaviour and apparent state of mind be considered in making this decision?
- What role do her family have?
  - Honouring her previous wishes?
  - Protecting her health?
- Would it make any difference if she had made a 'living will'?

### Opinion Leader

## The Jardine family

- Pat and Bill have been married for 20 years and are both in their fifties. They have two boys, aged 13 and 15
- Pat's mother, Jean, has Alzheimer's
- After Pat realised that her mother was sometimes forgetting to eat, wash and change underwear, Pat is always at Jean's house, helping her with general day to day life. More worryingly, Bill went around one day to find that something had been forgotten about in the oven for several hours and the front door was locked from the inside
- Jean has always said "don't put me in a care home". She is content with her life and, apart from Dementia, is in good health for her age
- Pat and Bill feel that the only options are for Jean to move in with them or for Jean to go into care. They might need to build an extension and Pat would need to give up her job to be at home
- Pat's teenage boys don't want an older person in the house
- Pat and Bill are worried about the financial implications of Jean's care and the impact this will have on their life and future plans. Bill feels that Jean's care has been forced upon them



## Issues to consider

- How should Jean's wishes be taken into account?
- What about the wishes of the Jardine family?
- Is there any way that both of their needs and wishes could be met?
- What should the role of health and social services be in this situation?

## MEET CLARISSA AND TERRY

- Clarissa and Terry are both in their 70s
- Clarissa has been caring for Terry for the last 5 years
- Terry's health has never been as good as Clarissa's as his lungs were damaged through TB when he was a young man
- As he has got older, he has found it increasingly difficult to move around and do things as he easily gets out of breath
- In the last year, Terry has also been suffering from dementia, following a stroke
- Clarissa was providing full time care to Terry but has recently had a fall and needed a hip and knee replacement
- An older lady herself, she is increasingly struggling to look after Terry and has found the last year really difficult, as Terry's dementia means he needs even more support
- Social services have been around and believe that the couple are not coping in their current situation



## Issues to consider

- Is it important that their needs are considered individually or together as a couple?
- If they both need different types of specialist care, is it right that they should live in separate care homes?
- What if one or both of them refuse to go into a care home?
- What should health and social services do in this situation?
- How should Terry's wishes be taken into account, given his dementia?
- Should Terry be able to stay living at home, even if Clarissa doesn't want to be his full time carer?

### Opinion Leader

## Pre and post questionnaire and results

### Nuffield Council on Bioethics, Dementia Consultation Start of day questionnaire

We would like to get an initial impression of how much you think you know about Dementia and issues related to dementia. Please answer the questions below as best you can based on the impressions you have of Dementia.

Q1. Overall, how would you rate your level of knowledge of Dementia?

I know very little about Dementia	I do not know much about dement	I know a fair amount about dementia	I know a lot about dementia
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q2. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree** with each of the following statements about dementia (by placing a tick in the relevant box)

PLEASE TICK ONE BOX ON EACH LINE	Strongly Agree	Agree	Neither agree or Disagree	Disagree	Strongly Disagree
a. Dementia is a disease of old age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Dementia just means memory loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. People with dementia tend to forget what happened recently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. People with dementia tend to forget what happened a long time ago	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. If you get dementia, nothing can be done about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Dementia is an inherited condition (i.e. it runs in families)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### Opinion Leader

g. Dementia is a normal consequence of aging

h. You are less likely to get dementia if you have a healthy lifestyle

Q3. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about people with dementia (by placing a tick in the relevant box)

PLEASE TICK ONE BOX ON EACH LINE	Strongly Agree	Agree	Neither agree or Disagree	Disagree	Strongly Disagree
a. People with dementia are not able to make decisions for themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. People with Dementia should not live alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. People with dementia are better off in a care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. If people with dementia get ill, they should not get treatment to make them live longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. People with dementia should be physically stopped from doing things if there is a chance they might hurt themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. People with dementia should be sedated if they become loud and disruptive in a care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Nuffield Council on Bioethics, Dementia Consultation

### End of day questionnaire

Q1. Overall, how would you rate your level of knowledge of Dementia?

I know very little about Dementia	I do not know much about dement	I know a fair amount about dementia	I know a lot about dementia
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q2. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about dementia (by placing a tick in the relevant box)

PLEASE TICK ONE BOX ON EACH LINE	Strongly Agree	Agree	Neither agree or Disagree	Disagree	Strongly Disagree
a. Dementia is a disease of old age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Dementia just means memory loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. People with dementia tend to forget what happened recently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. People with dementia tend to forget what happened a long time ago	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. If you get dementia, nothing can be done about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Dementia is an inherited condition (i.e. it runs in families)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Dementia is a normal consequence of aging	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### Opinion Leader

h. You are less likely to get dementia if you have a healthy lifestyle

Q3. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about people with dementia (by placing a tick in the relevant box)

PLEASE TICK ONE BOX ON EACH LINE	Strongly Agree	Agree	Neither agree or Disagree	Disagree	Strongly Disagree
a. People with dementia are not able to make decisions for themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. People with Dementia should not live alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. People with dementia are better off in a care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. If people with dementia get ill, they should not get treatment to make them live longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. People with dementia should be physically stopped from doing things if there is a chance they might hurt themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. People with dementia should be sedated if they become loud and disruptive in a care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q4. Have any of your opinions changed throughout the day? If so, what was it that made you change your opinion?

Opinion Leader

## Evaluation questionnaire and overview of results

Nuffield Council on Bioethics: Dementia, Tuesday August 5<sup>th</sup> 2008

### End of Day Survey

We would like your help to evaluate today's event and would be grateful if you could help us by completing this survey so that we can find out your views.

Q1. Based on your experience, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements (by placing a tick in the relevant box)

PLEASE TICK ONE BOX ON EACH LINE	Strongly Agree	Agree	Neither agree or Disagree	Disagree	Strongly Disagree	Don't know
a. I enjoyed taking part in the event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. There was not enough time to fully discuss the issues properly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. The event was well organised and structured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. The information that was given to me was fair and balanced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. The event was run in an unbiased way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I think events like this are a good way of consulting people about policies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Working with the mix of people at my table was useful for discussion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I have learned a lot from today's event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

a) Q2. How would you describe the event you have just taken part in? Please tick all that apply

b) Interesting  e) Boring

#### Opinion Leader

- |              |                          |                |                          |
|--------------|--------------------------|----------------|--------------------------|
| c) Enjoyable | <input type="checkbox"/> | f) Confusing   | <input type="checkbox"/> |
| d) Easy      | <input type="checkbox"/> | g) Informative | <input type="checkbox"/> |
| e) Important | <input type="checkbox"/> | h) Hard work   | <input type="checkbox"/> |

Q3. Do you have any additional comments?

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Q4. The Nuffield Council on Bioethics or Opinion Leader may wish to re-contact you at a later date to ask for further feedback or information about your views and this event. Are you happy for us to re-contact you?

Yes

No

Name: \_\_\_\_\_

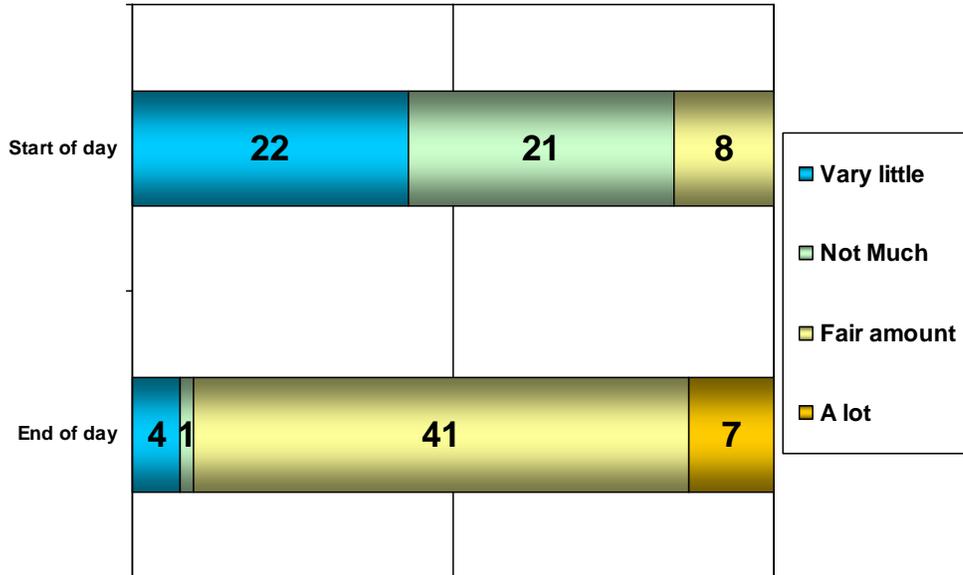
Address: \_\_\_\_\_  
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Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

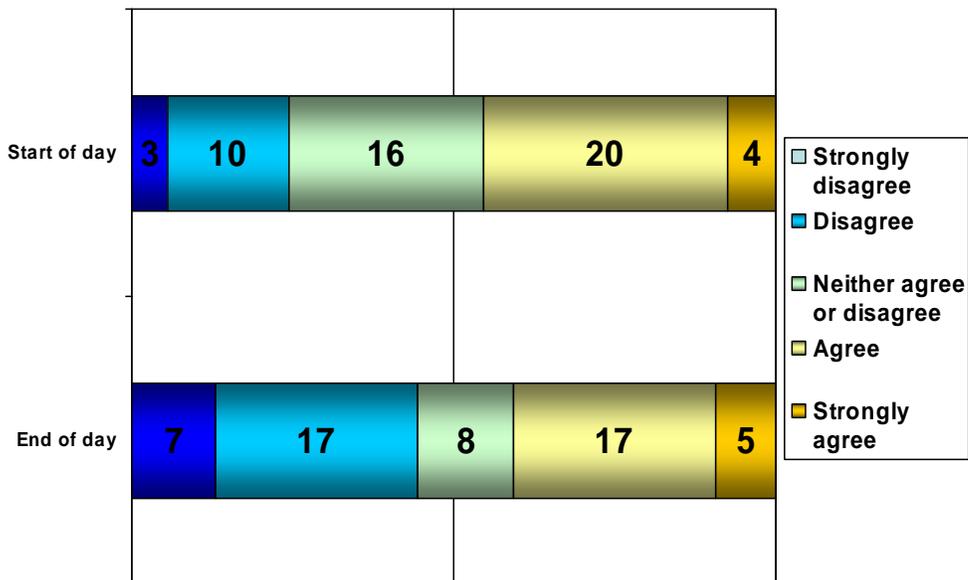
**Please hand this back to your table facilitator**

Overall how would you rate your knowledge of dementia?



Q1. Overall how would you rate your knowledge of dementia?

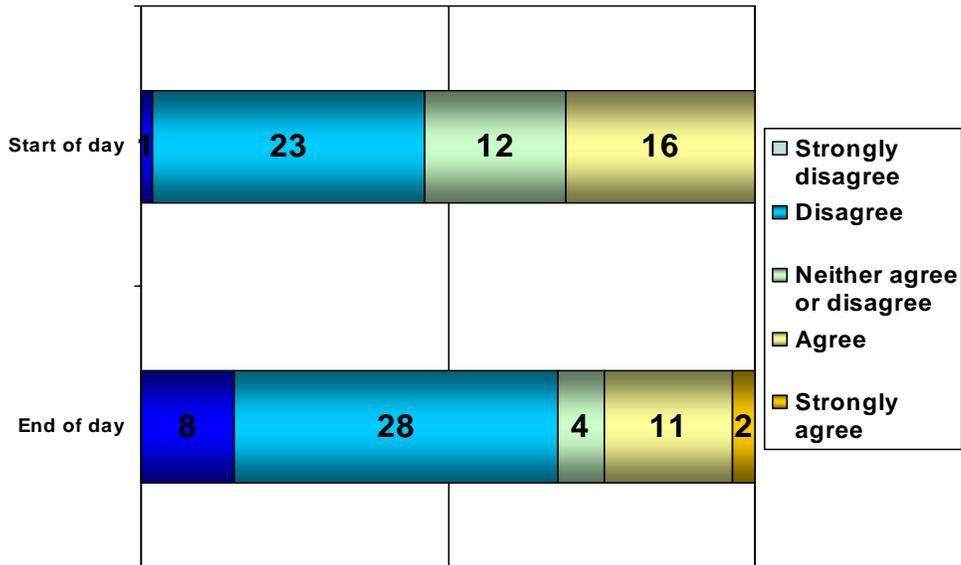
Dementia is a disease of old age



Q2. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about dementia – a. Dementia is a disease of old age. Base: Start of day – 53. End of day – 54.

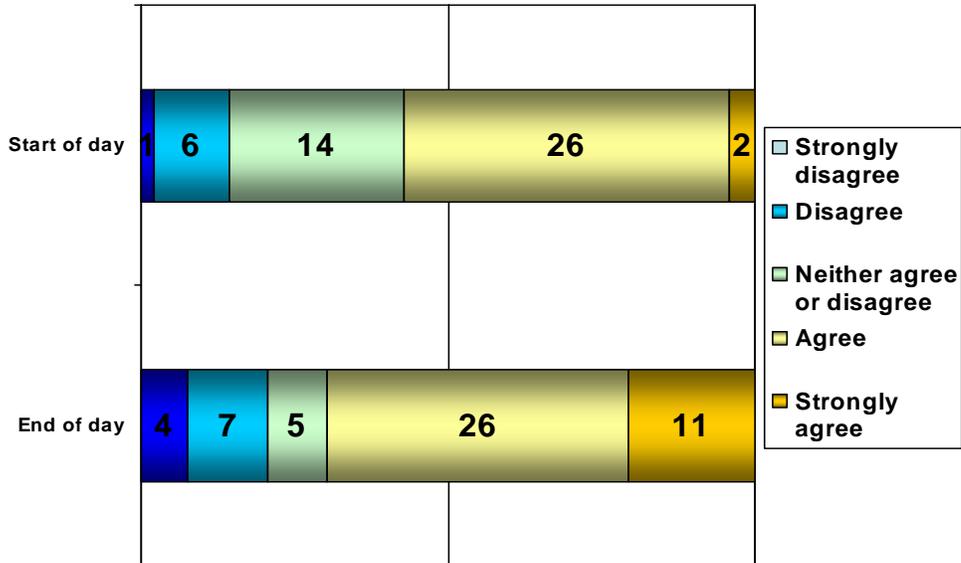
Opinion Leader

Dementia just means memory loss



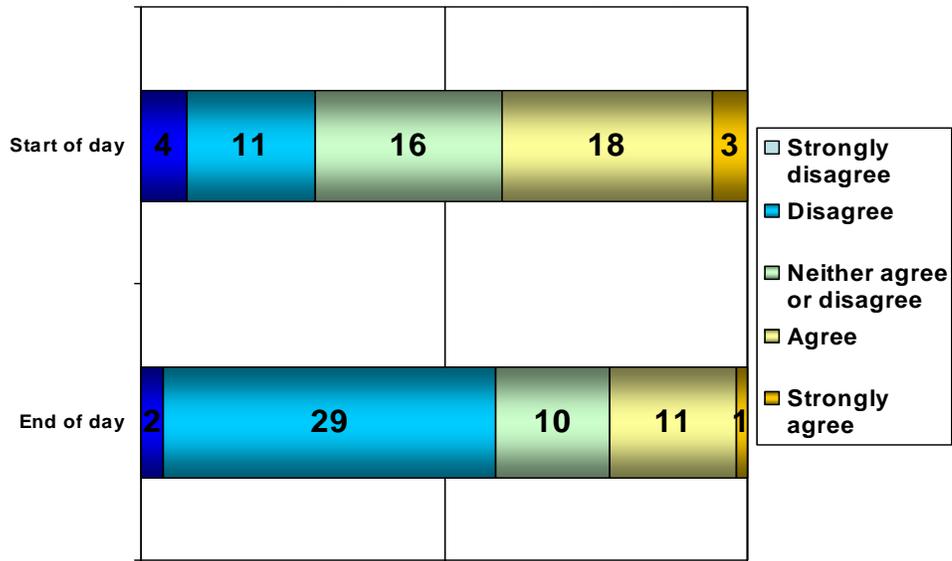
Q2. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements about dementia – b. Dementia just means memory loss. BASE: Start of day – 52. End of day – 53

People with dementia tend to forget what happened recently



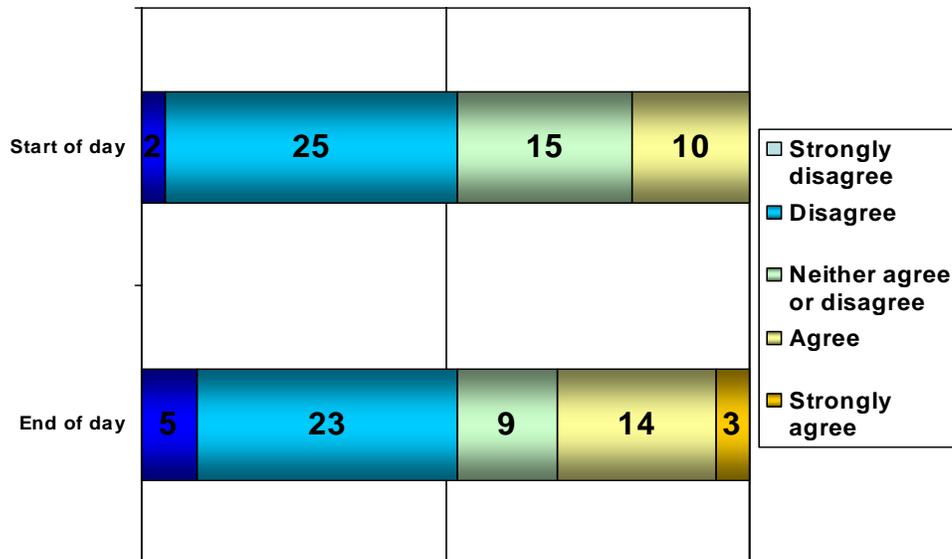
Q2. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements about dementia – c. People with dementia tend to forget what happened recently. BASE: Start of day – 52. End of day – 53

People with dementia tend to forget what happened a long time ago



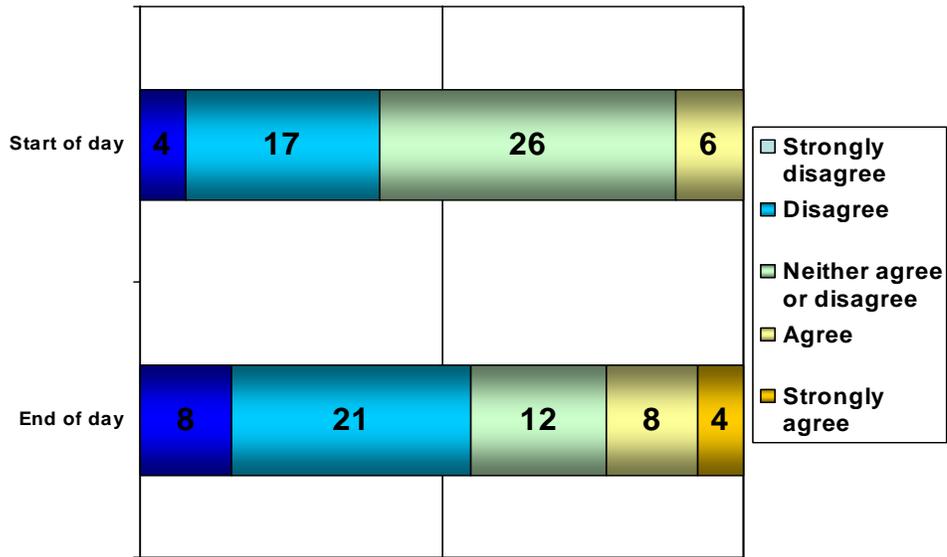
Q2. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements about dementia – d. People with dementia tend to forget what happened a long time ago. BASE: Start of day – 52. End of day - 53

If you get dementia, nothing can be done about it



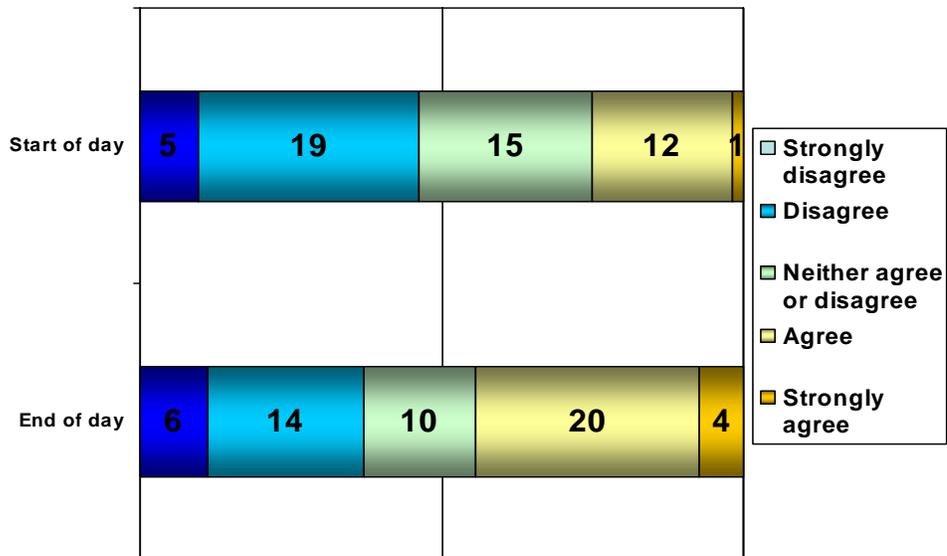
Q2. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements about dementia – e. If you get dementia, nothing can be done about it. BASE: Start of day – 52. End of day - 54

Dementia is an inherited condition (i.e. it runs in families)



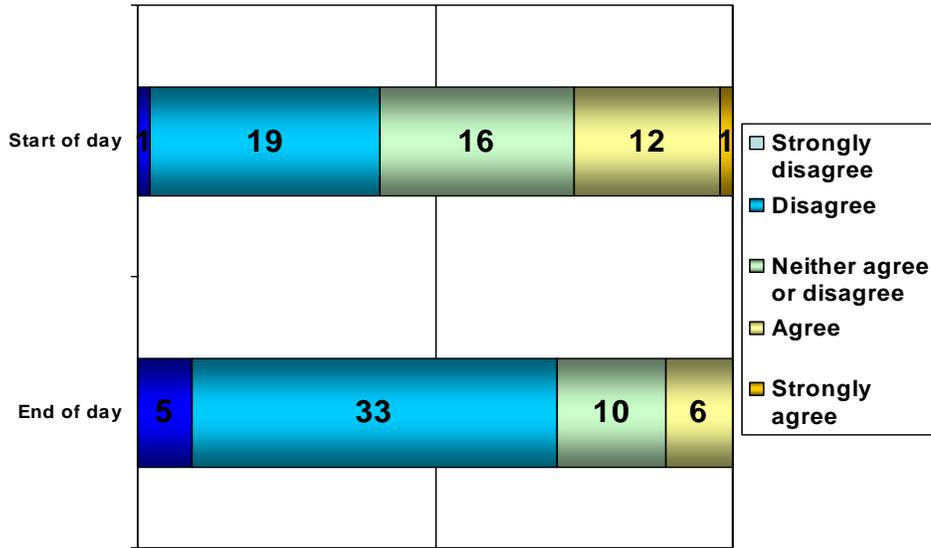
Q2. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements about dementia – f. Dementia is an inherited condition (i.e. it runs in families). BASE: 53

Dementia is a normal consequence of aging



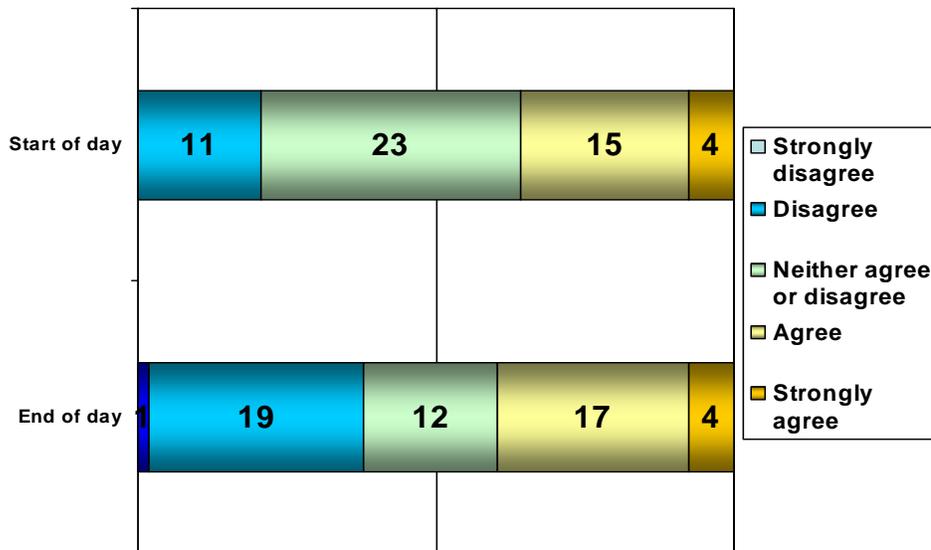
Q2. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements about dementia – g. Dementia is a normal consequence of aging. BASE: Start of day - 52. End of day - 54

You are less likely to get dementia if you have a healthy lifestyle



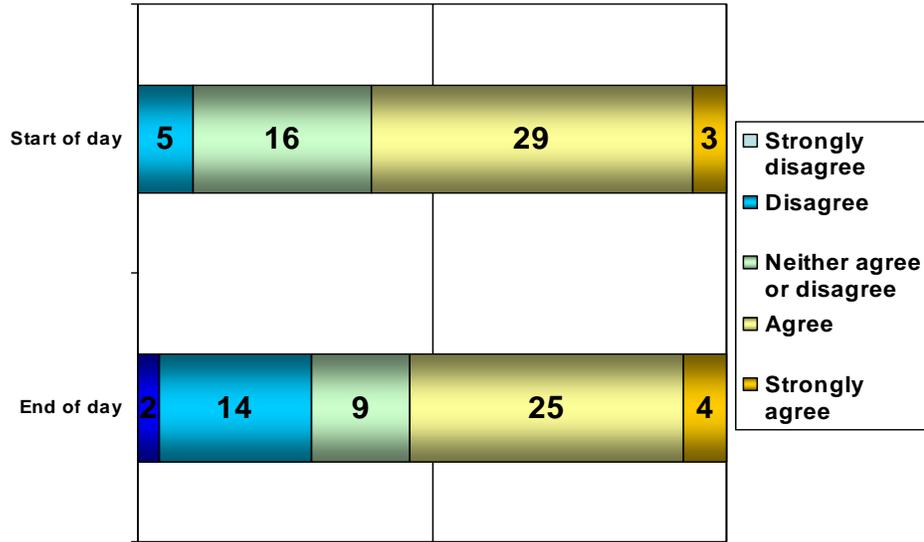
Q2. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements about dementia – h. You are less likely to get dementia if you have a healthy lifestyle. BASE: start of day – 49. End of day - 54

People with dementia are not able to make decisions for themselves



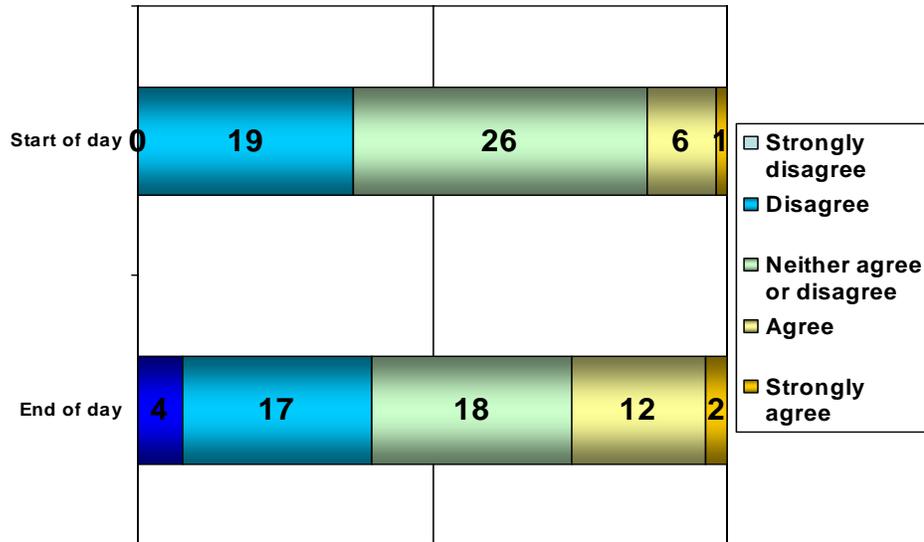
Q3. Based on your impressions, please indicate whether you **Strongly Agree, Agree, Disagree, Strongly Disagree** or **Neither Agree or Disagree** with each of the following statements about people with dementia - a. People with dementia are not able to make decisions for themselves. BASE: 53

People with Dementia should not live alone



Q3. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about people with dementia -b. People with Dementia should not live alone. BASE: Start of day - 53. End of day - 54

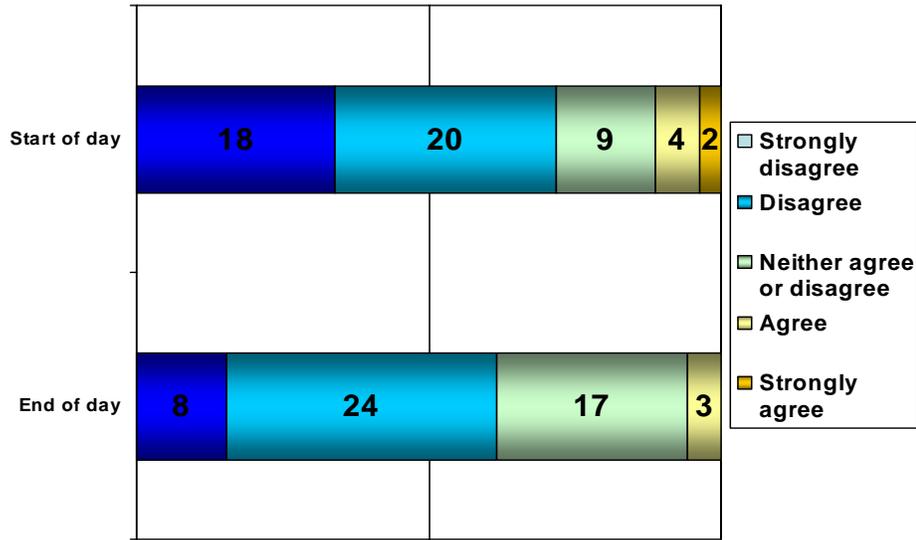
People with dementia are better off in a care home



Q3. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about people with dementia -c. People with dementia are better off in a care home. BASE: Start of day - 52. End of day - 53.

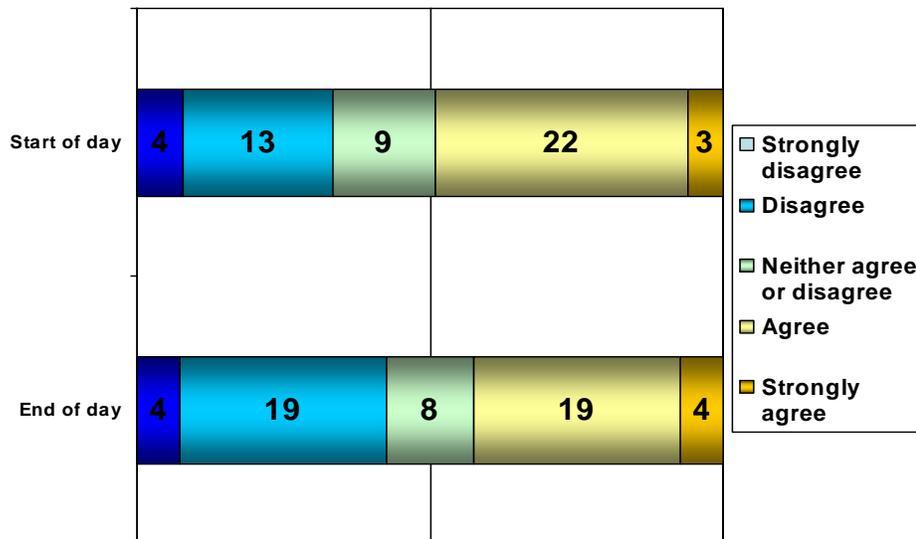
Opinion Leader

If people with dementia get ill, they should not get treatment to make them live longer



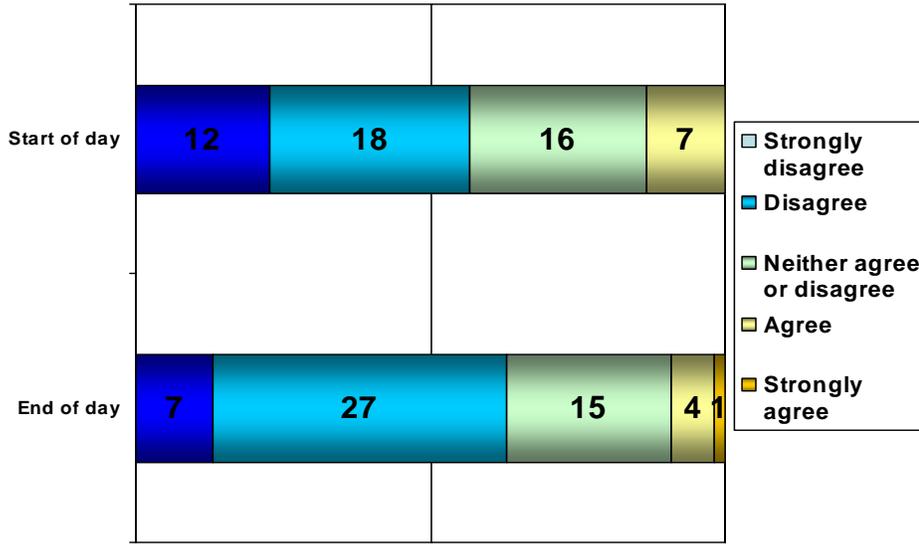
Q3. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about people with dementia – d. If people with dementia get ill, they should not get treatment to make them live longer. BASE: Start of day – 53. End of day - 52

People with dementia should be physically stopped from doing things if there is a chance they might hurt themselves



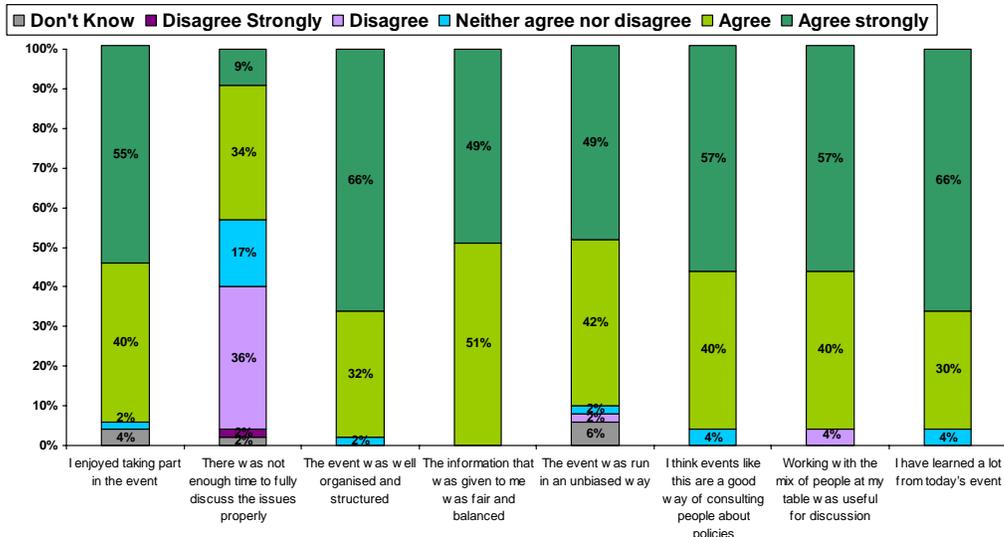
Q3. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about people with dementia – e. People with dementia should be physically stopped from doing things if there is a chance they might hurt themselves. BASE: Start of day – 51. End of day – 54.

People with dementia should be sedated if they become loud and disruptive in a care home



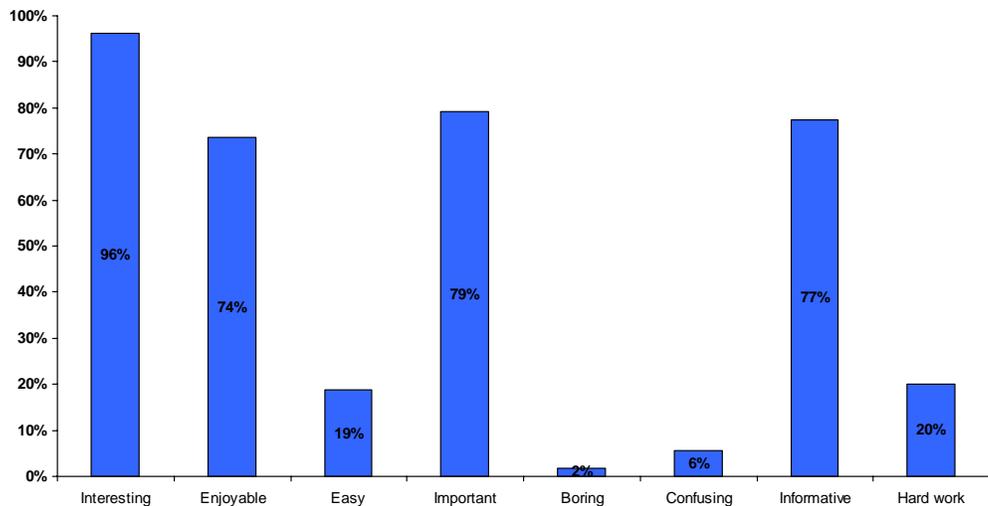
Q3. Based on your impressions, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements about people with dementia – f. People with dementia should be sedated if they become loud and disruptive in a care home. BASE: Start of day – 53. End of day – 54.

## Agreement with statements about events



Base: All Participants responding to end of day questionnaire (53)

## Words selected to describe event



Base: All Participants responding to end of day questionnaire (53)

### Opinion Leader