Ethical dilemmas faced by carers and people with dementia
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Foreword

Ethical dilemmas often arise as a consequence of having dementia or caring for a person with dementia which are difficult to resolve. Sometimes problems seem insurmountable and it is difficult to decide what to do because it is not clear what is right or wrong, ethically speaking. I am therefore very pleased to present this report on ethical dilemmas faced by carers and people with dementia. It will hopefully help people with dementia and their carers to understand ethical dilemmas, approach them more confidently and feel more at ease with any decisions that might be made.

The report sets the scene by providing background information about dementia, ethics and dilemmas and then presents a series of short stories (vignettes) which describe typical ethical dilemmas based on the literature and the expertise of the working group. The use of short stories describing various ethical dilemmas can be particularly helpful and I hope that readers will be able to relate to the characters described. These are hypothetical situations but the characters seem very real.

Nevertheless, it is natural to want to know what to do or, more specifically, to know how someone with knowledge about ethics might make sense of various ethical dilemmas. The working group adopted a novel and refreshing approach in which they, along with several additional experts in ethics, commented on these hypothetical situations. I hope that this will enable readers to reflect on the important issues and hopefully, with the further guidance on approaching ethical dilemmas in the last part of the report, to be able to apply such reflection to a similar but nevertheless unique situation they might find themselves in one day. Difficult topics are addressed but in a positive manner which emphasises the personhood and dignity of all concerned.

To conclude, as Chairperson of Alzheimer Europe, I would like to express my sincere thanks to Dianne Gove (chair of the working group), the members of the working group Stig Atle Aavik (who has dementia), Ranveig Hoff (his aunt and carer), Chris Gastmans, Julian Hughes, Eila Okkonen, Jan Oyebode and Federico Palermiti, and the additional experts Michael Dunn, Charlotte Emmett, Cees Hertogh, Louisa Jackman, Ian James, Jana Kasparova, Anneli Sarvimäki, Mark Schweda and Guy Widdershoven who donated their time, expertise and enthusiasm to making this a valuable resource for anyone facing or trying to understand ethical dilemmas linked to having dementia or being an informal carer.

Heike von Lützau-Hohlbein
Chairperson of Alzheimer Europe
Preface

Having dementia or living with someone who has dementia often means being confronted with new situations, experiences and challenges. Ideally, people with dementia, as well as their family, friends and carers, will receive appropriate support, be valued and continue to live meaningful lives within their community. However, living with dementia is not always easy. This report is about the ethical dilemmas sometimes faced by people with dementia and their carers. In addressing ethical dilemmas, we are deliberately focusing on some of the more problematic aspects of living with dementia but with the positive aim of trying to make such issues less of a problem.

This publication is mainly written for people with dementia and for those who care for and about them. We hope that it will help you to make sense of some of the difficulties you may encounter and feel better equipped to tackle them. Our aim is to help you to recognise, understand and assess the issues at stake, adopt the best approach for you and the other people involved and hopefully feel at peace with yourself in the knowledge that you did your best. The report might also serve as a workbook for voluntary workers or new employees or perhaps for discussion groups of informal carers facilitated by an expert.

We would have liked to have written a set of clear instructions on how to approach every possible ethical dilemma (i.e. to make categorical statements about what would be the right or wrong thing to do). Unfortunately, we cannot provide solutions to specific ethical dilemmas. There are some pretty typical dilemmas (e.g. surrounding moving into residential care or monitoring someone’s whereabouts without their knowledge), but we cannot make generalizations about people and the situations in which they find themselves. Every person is unique. They have different characters, histories, fears, preferences, beliefs, expectations, living situations and relationships with other people. So the dilemmas and the best ways forward will vary from person to person. The way an ethical dilemma is resolved might not always be the outcome you would ideally have hoped for, but it may be the best outcome possible for the people involved and in the particular circumstances.

Part 1 of this booklet provides background information about ethics and ethical dilemmas.

Part 2 focuses on specific ethical dilemmas. You may have already experienced some of these and, if so, will realise that you are not alone. You may encounter others in the future, but it is extremely unlikely that you will experience them all. Part 2 is divided into seven sub-sections covering the whole course of dementia. In each sub-section, after a brief introduction, we provide one or two short stories reflecting situations and dilemmas often experienced by people with dementia and family members/carers. This is followed by an ethical commentary to help you consider the key ethical issues involved.

Part 3 describes an ethical approach which may be helpful when reflecting on ethical behaviour and attitudes. At the end, we provide general guidance on how to approach ethical dilemmas and ideas about how to avoid some common mental traps in thinking about them.
PART 1

Introduction

Dementia and the challenges it may bring

Dementia is a syndrome or set of symptoms, typically involving loss of memory, mood changes and problems with thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (1). These symptoms tend to develop gradually over a lengthy period of time, as the brain becomes impaired due to damage from the underlying dementia condition (2). Dementia is not a disease per se. There are over a hundred types of dementia and most are caused by or associated with a specific disease, the most common one being Alzheimer’s disease (AD).

Although dementia is a medical condition, it has a social, psychological, emotional and economic impact on people’s lives. Some of the apparent consequences of dementia are not due to biomedical factors alone (e.g. damage to the brain). Rather, they are influenced by the personality and make-up of the person with the condition, as well as the way that other people react towards people with dementia and the way that society is organised (e.g. creating obstacles and failing to recognise or adapt to the needs of people with dementia). With appropriate social and healthcare support from governments and services, and consideration from other members of society, people with dementia can enjoy a relatively good quality of life. Many continue to live in their local communities and play an active role in society for a long time after the onset of dementia.

In the last few decades, people with dementia have spoken and written about their experience of living with dementia. They have shared their painful experiences, their fears and concerns but also their hopes and their desire to get on with life and remain active and valued members of society. There are numerous accounts of the negative impact of caring on people’s lives (often described as caregiver “burden”). However, carers have also described the positive aspects of caring such as the satisfaction they experience from knowing that they are returning the care they received earlier or from protecting the wellbeing, dignity and self-esteem of their loved ones. It is not always a case of people having either a positive or negative experience of living with dementia. Both kinds of experience may co-exist. Some people may nevertheless focus more on either the negative or positive aspects, with others adopting a pragmatic approach and simply trying to get on with life.

Nevertheless, having dementia and living with or caring for a person with dementia almost inevitably involves certain challenges. The gradual loss of various abilities linked to memory, concentration, planning, orientation and abstract thought has an impact on everyday activities and routine tasks. Often, things which were done almost automatically in the past become problematic. In addition, people may find themselves in new situations, confronted with issues they had not previously considered and sometimes faced with difficult decisions. A number of factors affect how well people cope with challenges, such as having different personal resources (psychological, emotional and financial) and coping skills, whether appropriate support is available and different philosophies of life. People with dementia who live alone may face some additional challenges, because they do not have anyone present to support them. Difficulties can arise in all kinds of places such as in people’s homes, the doctor’s surgery, residential care settings, shops and various public places. In addition to those directly faced with a problem or challenge, other people may be involved or affected such as doctors, relatives, friends, neighbours, shopkeepers and health and social care professionals. Difficulties and subsequent challenges can take many forms and affect people in different ways. In this booklet, we are looking at a specific type of difficulty or challenge, namely an ethical dilemma.

1 We are using the term “person with dementia” to refer to people who have or are believed to have dementia (bearing in mind that many people with dementia have not been diagnosed or informed of the diagnosis).

2 We are using the term “carer” to refer to people who provide, organise or coordinate care for a person with dementia on an unpaid/non-professional basis (e.g. out of solidarity, a sense of duty or because of family or friendship ties). However, we understand that not all carers experience their relationship to the person with dementia in terms of care or being a carer.
**Dilemmas and ethical dilemmas**

A dilemma literally means a problem offering two possibilities, neither of which is acceptable. People in modern Western societies may be familiar with the idea of dilemmas (3) because of a tendency to think in either/or terms (i.e. something is good or bad, possible or impossible, a person is happy or sad, agrees or disagrees etc.). However, many “dilemmas” have more than two unacceptable outcomes. So, technically speaking, we should really call them trilemmas and polylemmas but for the sake of simplicity we will stick to the well-known term “dilemma”.

An ethical dilemma is a situation in which moral principles or values are in conflict. This makes it difficult to interpret or decide what would be the right or wrong course of action or attitude to take. In addressing ethical dilemmas, we are deliberately focusing on some of the more problematic aspects of living with dementia but with the aim of enabling readers to address these more positively and with greater confidence. Before looking at ways to deal with ethical dilemmas, it is helpful to reflect on what is meant by ethics and how should we decide what is right and wrong.

**About ethics**

**What is ethics?**

The term “ethics” refers to standards which tell us how we ought to act in various situations and how we ought to live with one another. This is often framed in terms of rights, obligations, duties, benefits to society, fairness or specific virtues (4). The standards of behaviour are based on perceptions of right and wrong or good and bad. Ethics is not just about big societal issues such as immigration, war, abortion or euthanasia which are discussed in the media. Often, everyday matters such as whether it is reasonable to ask for help, how to respect a person’s dignity, how to promote autonomy or what to do if a person repeatedly refuses to get washed also have an ethical dimension. Such everyday matters can be stressful and be persistent and urgent (5) (6). They cannot always be discussed in a detached manner as they hold direct implications for people who matter to us personally. How these issues are approached may have implications for the image we have of ourselves as a good or bad person (e.g. one might ask oneself, “was I fair, was that the decent thing to do, is my attitude to this person justifiable?”).

The right thing to do in response to an ethical dilemma will often be to “treat a person as a person” (7). There have been debates about the minimum criteria necessary to be considered as a person. Some philosophers argue that to be considered a person, someone should have self-awareness, including awareness of their past, be capable of making plans for the future, and be capable of deciding for themselves what they want to do. This has sometimes led to people questioning whether a person with very advanced dementia is still a person. Counter arguments have been put forward which criticise the emphasis on cognitive abilities and failure to give sufficient attention to the social and emotional aspects of being a person (8). The statement that an ethical approach is often about treating a person as a person is based on the premise that a human being who has feelings, even if unable to express them or to exercise autonomy, is a person.

It is important to consider also what ethics is not. According to Velasquez and colleagues, ethics is not simply about doing what feels right or abiding by culturally determined norms and it should not be equated with religion, science or following social conventions (4). Sometimes, it feels uncomfortable to do what is right. On the other hand, a person may have a good feeling about doing something and it may be in keeping with that person’s values but it would be unethical. The fact that a lot of people do something or react in a certain way does not make it right. Whilst many religions strive for ethical behaviour, they do not address all ethical issues and some religious teachings condone behaviour which some people might consider unethical. Laws have
Ethical dilemmas faced by carers and people with dementia

often been used to enforce actions which with hindsight and greater ethical awareness are now considered as wrong. Laws can provide certain limits for behaviour but do not dictate how to act. Moreover, legislation tells us nothing about what constitutes good care. Finally, science may help us understand human behaviour but cannot tell us how people ought to behave.

Theories about what is right and wrong

When trying to decide what is right and wrong, we tend to rely on systems or structures of thought and belief that help us to reflect systematically and critically on human behaviour. Such deliberations are usually based on normative perspectives (shared norms and understandings) of good and bad; we therefore rely on values which are socially defined. However, at the same time we should be able to reflect critically and with compassion about what is right and wrong in a particular situation and draw our own conclusions. This may sometimes lead us to challenge the way that values are defined and interpreted within society.

Philosophers have debated these issues for centuries and have developed a number of ethical standards based on a range of theories. From some of the main theories, the following criteria have been put forward to determine what would be a “good” or the “right” action or approach, namely:

- that which results in the most pleasure and the least pain to those affected (utilitarian approach),
- that which best protects and respects the moral rights of those affected (rights-based approach),
- that which treats everyone equally or if unequally then fairly, based on a standard that is defensible (fairness approach),
- that which is defensible based on outcomes, which would maximise people’s happiness or welfare (consequentialist approach),
- that which contributes towards the good of the community (common good approach),
- that which is consistent with what a virtuous person would do (virtue approach),
- that which is in accordance with our duties as rational individuals living in interdependent societies (deontological approach).

Looking at the above list, you might wonder which would be the best approach to adopt in a particular situation. Apart from the fact that even ethicists might disagree about this, the criteria also raise further questions. Some of these are: what is the most good and the least bad for people, which moral rights should be protected, what makes a person virtuous, when is unequal treatment defensible and does the end always justify the means?

Ethical principles and values

Another approach to determining what is ethical is to consider ethical principles or values. According to the principlist approach, a person can be said to have behaved ethically if they have respected certain principles. A few decades ago a set of four principles was developed by Beauchamp and Childress (9), namely, respect for autonomy, beneficence (i.e. doing good), non-maleficence (i.e. avoiding doing harm) and justice/equity. They were intended to serve as a framework to guide professional medical ethics but have since been applied in a wide range of contexts. There are also other principles and values which are perhaps equally important in other contexts (e.g. in everyday interactions with other people, in relationships with friends and family, in social care, and in residential care settings) such as trustworthiness, honesty, integrity, compassion, well-being, confidentiality and respect for privacy, personhood and dignity.

In addition to the four widely recognised principles of medical ethics, it may therefore be helpful to reflect on a range of concepts. We have set out some of these concepts in Box 1 along with the main principles and values already mentioned.
Moving towards a more holistic approach to ethics
Reliance on principles and values also raises problems. It is still necessary to decide which values and principles should be respected or promoted. What if respecting one value or principle conflicts with respecting another? Are some more important than others? Could it also be argued that we are just picking and choosing in the sense that we do whatever we want and find the moral theory, principle or value that suits us? Moreover, we might ask whether it is right to rely on abstract principles in view of the complexity of human relationships and of people’s lived experience.

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<th>Box 1: Ethical principles, values and related concepts</th>
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The lived experience of dementia

Ethical behaviour in relation to caring for a person with dementia and living with dementia is more than a question of rights and duties. It cannot be merely reduced to a set of abstract principles. It is important to consider in addition the lived experiences of people with dementia and their carers (e.g. in relation to care giving, care receiving, vulnerability and dignity) which are embedded in people’s everyday lives. This approach to ethics, based on the work of Gastmans (11), is described in Part 3, where we also consider the role of conscience (10), followed by some ideas about how to avoid mental traps which may sometimes interfere with our ability to tackle ethical dilemmas. In Boxes 2 and 3 below, we provide a testimonial from a person with dementia and his carer.

Box 2: Stig Atle Aavik – how I currently feel about having dementia

My dementia is progressing nice and slowly. I am able to cook and do other things that people generally do. I have noticed a few changes... not for the better, more of a steady decline. Some days are worse than others, and I think a lot about my diagnosis on days like those.

My family is of great help to me. My son lives close by, my mother a little way off. They involve themselves in my daily life, and my mom supports me even though she is getting old. My family and my girlfriend have become very important to me now that I have dementia and have to depend on professionals.

Medication is also important for me at the moment. I have asked my family doctor to make sure I get the latest medication. The medication I had earlier had a lot of side effects, so I stopped taking it. Medication can help slow down the disease, something I am very concerned about at the moment.

A sound personal economy is also very important to me. It provides me with extra security. I have plans to talk to my children about inheritance soon, and have been in touch with a solicitor. I am getting rid of possessions I do not need any more and collecting things that are important to me.

I tend to be fairly pragmatic. I look at the options and decide what I feel is right. That’s how I am. Everyone is different. At the same time, I appreciate the fact that my having dementia may affect other people and lead to situations where it is difficult for them to determine what is right or wrong and that this could at some point also have an impact on my life. Meanwhile, on the whole, everything is fine. I have my life and I think it is a good life.

Box 3: Ranveig Andrea Hoff – my experience of caring for my nephew, Stig

Stig Atle was diagnosed with Alzheimer’s disease about three or four years ago. It came as a shock to me (and to the whole family of course) and resulted in despair and deep concern.

When the Norwegian Health Association offered Stig the opportunity to represent Norway in the European Working Group of People with Dementia (EWGPWD), he accepted and then asked me if I could support and help him in this work. He means a lot to me, I have known him his whole life, so of course I said yes. The first meetings of the EWGPWD went quite well. Stig was enthusiastic and paid attention. As time has passed, he has been more and more affected by the disease, and it makes me sad and depressed to see how his condition deteriorates.

I struggle to accept this piecemeal loss of Stig, who is physically there, but has difficulties such as remembering dates and understanding the concept of time. We have travelled a lot in connection with the EWGPWD. This has become a bit of a challenge because at times, he disappears from sight but it has fortunately
worked out so far. There are also times when it is difficult for me to remain calm (e.g. when he asks the same thing over and over again). It is not so easy for me to cope when he becomes aggressive, even though I know it is the disease which triggers this aggressiveness and not him.

I feel a kind of helplessness because I know he will never get better. I try to comfort him, to provide closeness and to adjust the pace to Stig’s needs. I hope to keep the good relationship we have always had even under these altered conditions. I was pleased to be involved in this project to explore the ethical dilemmas faced by people with dementia and carers as I know from experience and from other carers that it is sometimes difficult to decide what would be the “right” or ethical way to respond or react in a particular situation.

Finally, the following photo and text are taken from a presentation given by Juha Lehtinen who also has dementia. He stresses that dementia (Alzheimer’s disease in his case) is something that a person has. It may be at the root of many ethical dilemmas experienced by people with dementia and their carers but it is important to see beyond the disease to the person him/herself.

*Photo: Juha Lehtinen, The Memory Association of Lapland in Finland ©*
Ethical dilemmas faced by carers and people with dementia
PART 2

Ethical dilemmas from the first possible signs of dementia onwards

In Part 1, we considered how the experience of dementia can contribute towards situations and changes which are sometimes difficult to manage and may lead to ethical dilemmas. We also explained what we meant by “an ethical dilemma” and gave an overview of some of the main ethical theories, principles and values. Apart from a few brief examples, we have not yet described specific situations, changes or ethical concerns typically experienced by people with dementia and their carers, and how these sometimes constitute ethical dilemmas. This is the focus of Part 2 which is divided into the following seven sections.

1. The period of uncertainty or not knowing (pre-diagnosis),
2. The process of understanding/finding out (diagnosis),
3. The initial period of adaptation (shortly after diagnosis),
4. Living with dementia (getting on with routine life/adapting to challenges),
5. Caring for/receiving care (when increased levels of support are needed),
6. The possible transition into a care home (when continued care at home becomes problematic),
7. Care for a dignified end of life.

Each of the sections covers a different period in the lives of people with dementia and their carers. These periods can also be understood as turning points whereby something happens or there is a realisation that something has changed. This may result in reflection about the need to make further changes, come to a decision or come to terms with what is occurring. The challenges and the processes of adaptation, dealing with losses and reorganising expectations, hopes and plans may be experienced as a crisis or a more gradual awareness. These transitions may occur smoothly and harmoniously, without any great upheaval or emotional disturbance, but can sometimes be problematic. In addition to the practical and emotional issues surrounding many difficult situations, it is sometimes unclear what would be the right or wrong action to take or attitude to have.

In each section, you will find:
1. a brief overview of issues and challenges which typically arise during the period described,
2. a short story (vignette) which brings these together in the context of a specific situation,
3. an ethical commentary on this story explaining the different ethical issues at stake and suggesting possible ways to address them.

We describe these different periods and associated challenges in a linear manner, progressing from the first signs or doubts about dementia to the end of life. However, people are very different. Their experience and the challenges they face might occur at different times, in a different order or in relation to different situations.

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1 These stories are fictional but based on events and situations which many people with dementia and carers have experienced.
1. The period of uncertainty/not knowing (pre-diagnosis)

Background

Noticing differences and difficulties
This section is about the period of uncertainty which often precedes a diagnosis of dementia. It is the time when people start to have concerns about certain difficulties they are experiencing in their everyday lives (e.g. forgetting things, not being able to do simple tasks, losing their way, feeling confused and finding certain professional tasks difficult to accomplish). Sometimes, it is the person who is in the early stages of dementia who has such concerns, but sometimes they lack awareness or are in denial (i.e. are not ready or willing to face the problem). Consequently, it may be relatives, friends, work colleagues or outsiders who notice that they are having difficulties or seem to be acting out of character.

Dealing with difficulties amidst the uncertainty
Most people would be embarrassed about not being able to use the remote control for the television or make a coffee, or about having difficulties driving or forgetting their children’s names. It is therefore understandable that people often try to save face by covering up their difficulties, making light of them or finding coping strategies. At the same time, the constant fear of people noticing their difficulties can be stressful and may result in people with dementia avoiding social contact and withdrawing from some of the activities they used to enjoy. Sometimes friends and relatives help to cover up such problems either intentionally or without actually realising. As difficulties increase, people with dementia may have concerns about needing help, what this implies and how they might be perceived by others.

Fears of making dementia an issue
Some people may suspect that their difficulties are a sign of dementia and start to worry about possible future consequences (e.g. will they lose their jobs, might continuing to work put other people at risk, what about their mortgage or life insurance, will they lose their driving licence and how will they manage without it?). Sometimes, the difficulties experienced are so perplexing that people worry about their mental health (e.g. asking themselves whether they are “going mad”) and about how they will cope, especially if the problems worsen. Such fears may result in some people not wanting to consider that they might have dementia.

Realising that such difficulties are not normal
People who have personal experience of dementia or have heard about typical symptoms of dementia may suspect that this is what they or their loved ones have. However, the early symptoms of dementia are frequently and wrongly attributed to normal ageing. Friends and relatives who spend a lot of time with the person with dementia are ideally placed to notice subtle differences which outsiders might overlook, especially if the person with dementia is trying to hide their difficulties. On the other hand, difficulties often develop very gradually and may sometimes be more noticeable to someone with less contact with the person concerned (e.g. someone who only visits once or twice a year). Carers sometimes notice changes, and normalise or discount them, only realising in retrospect that they suspected something was wrong.

Deciding to consult a doctor
Some people consult a doctor straight away. Others find it difficult to accept that the problems they are experiencing are not “normal” or may be afraid to consider the possibility that they might have dementia. Readiness to consult a doctor may be hindered by:

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4 We are using the term “person with dementia” in this section even though, based on the situations described, it would not yet have been established that the person had dementia.
• lack of awareness,
• denial,
• the perception of dementia as a stigma,
• accompanying fear of devaluation and discrimination,
• a negative experience of dementia,
• exposure to negative portrayals of dementia (e.g. in the media),
• the belief that nothing can be done,
• fear and anxiety of illness and death.

Nowadays, there are several treatments which reduce the symptoms of dementia and different types of support are available which enable people with dementia to remain active within the community for many years with a good quality of life. Nevertheless, doubts, fears, lack of information and negatively biased portrayals of dementia may delay timely diagnosis and lengthen the period of uncertainty.

Ethical issues during this period of uncertainty
The main issues during this period of uncertainty, which might have ethical implications, include the following:

• whether people with dementia should tell other people (e.g. employers, friends, and relatives) about their problems,
• whether relatives and friends should help conceal such problems,
• whether relatives, friends or concerned outsiders should confront people with dementia about their problems,
• whether people with dementia should consult a doctor about their problems,
• whether relatives (e.g. partners or children) should mention the difficulties experienced by the person with dementia to that person’s doctor.

Vignette
Jack started off his working life as a manual labourer on the docks but after several years’ night school, he obtained qualifications in accountancy, was taken on at “Harpers and Jones” and gradually worked his way up to the position of senior accountant. He is now 62 and very popular with his colleagues who appreciate his kindness and sharp wit. He has worked with numbers almost all his life but in the last year has started to have difficulty with some tasks. On two occasions, a colleague has highlighted a mistake which he has attributed to a lack of concentration.

Last week, he walked into someone else’s office and sat down. Everything seemed strange and he was puzzled. His colleague came in and asked him what he was doing at his desk. He joked that he was trying out his seat as he had heard it was more comfortable than his own but he was visibly shaken. On another occasion, he went down to the kitchen to get a coffee but the pot was empty. He came back without one as he couldn’t work out how to make a fresh pot. When asked, he stated that he had changed his mind.

People have started to discuss his behaviour amongst themselves. There have been a few jokes about “senior moments”. His boss has also made the occasional comment. His colleagues are starting to get worried that he will lose his job, which would affect his pension rights. But they don’t want to offend or embarrass him and don’t know how to broach the topic or in fact whether they should. Meanwhile, a few are keeping an eye on him and trying to cover up for some of the difficulties he is obviously experiencing.

Secretly, Jack is terrified that he is losing control and has started to take work home in order to double check. He has always prided himself on his professional achievement and ability with figures and feels that people will lose respect for him if they find out he has dementia. Some might laugh at him, some might not take him seriously any more. Would his friends still want to go for a drink with him, he wonders. He wants to confide in
his wife but something is holding him back. His mother had dementia and he fears that he is also starting to develop it. He doesn't want to imagine his wife becoming his carer.

At home, Jack is forgetting conversations and making mistakes. His wife, Maureen, has suggested he goes to the doctor's to get a check-up but he is reluctant. Last month, when he and his wife went on holiday, although he has always been the one to navigate in the car, he got hopelessly lost. Again she suggested going to the doctor's and again he refused and was quite indignant about the idea he had any undue difficulties. She felt a little hurt by his reaction and interpreted his denial as a lack of trust in her. She is worried about him and doesn't know what to do.

His daughter came round last week and they went to a local football match together. It wasn’t far but they went by car and he drove. He took a few wrong turns and then stopped the car and just stared ahead. He looked devastated. He had no idea where he was. His daughter understood and just looked at him and thought, “Oh Dad, what are we going to do?”

**Ethical commentary by Prof. Jan Oyebode (United Kingdom)**

In this vignette we see some of the ethical dilemmas people may face when someone they know, be it a colleague or a relative, shows possible signs of dementia. A number of Jack’s colleagues have spotted mistakes but when they have drawn them to his attention, he has laughed them off. They are worried enough to be talking with each other about him although they are holding back from raising their concerns with him directly.

Their dilemma seems to arise from a sense that if they talk with him, they may embarrass or offend. In holding back, because they don’t want to dent his self-esteem, they seem to be following the principle of non-maleficence (i.e. avoidance of harm). One might also argue that they are recognising his vulnerability in this situation and by covering up for him and ‘keeping an eye’ on him, they are protecting both his privacy and his dignity. Furthermore, the solidarity they are showing, as part of the same workforce, is a demonstration of inter-dependence. It seems he has been viewed as a good and helpful colleague over the years, and so their protective response is informed by narrative and demonstrates reciprocity for all his kindness. They are showing they are dependable colleagues who can be trusted to support Jack and uphold the value of relationality.

However, not telling Jack may also provoke tension because his colleagues may not be comfortable discussing him behind his back. Although they are showing they can be trusted to cover for him, they are not showing they can be trusted to tell him the truth. Also they may also feel they have a responsibility to uphold workplace standards. In this sense, non-maleficence and respect for privacy on one hand, are coming into conflict with honesty and conscience on the other. Indeed, although their actions may be seen as maintaining trust with Jack, they might be seen in quite a different light by their boss. S/he might view them as untrustworthy for not bringing Jack’s difficulties into the open. However, perhaps they value their protection of Jack’s dignity, more than that of honesty, as long as the mistakes aren’t too bad.

At home, his wife and daughter are also concerned, especially about him losing his way when driving. Their dilemma is connected with how hard to push him to seek help. They may feel they’ll undermine his autonomy and self-respect (dignity) if they insist, especially as his response to their attempts so far have been rebuffed. However at the end of the vignette, we see a type of ‘landmark event’, in which his daughter is present at a point when Jack cannot cover up his problems. Maybe at this point, she has an opportunity to be honest with him about the need to seek help, whilst also showing compassion for his despair. This shows the value of waiting for the right moment in order to preserve trust but also be true to one’s conscience about the need for honesty, and also of being discerning about when outside help is required.
Why is it so hard to admit to oneself and others that something could be wrong? What keeps us from seeking clarification and certainty when we are concerned with an unsettling suspicion? How can we come to the right decision amidst all this confusion and anxiety?

Fearing the diagnosis of a serious disease that can affect one’s whole future life and wellbeing appears completely understandable. Jack must be terrified at the prospect of losing his much-loved wit and admired professional skills, his recollection of people, projects, and stories that define who he is, his sense of orientation and his ability to lead an independent life. Yet, we usually believe that burying one’s head in the sand is no solution and that facing the truth is the right thing to do. After all, learning that nothing is wrong would bring immediate relief. And if there actually were something, knowing for sure would open the possibility of getting active and making decisions. Sure, there still is no curative therapy for dementia. Nevertheless, there would be things to envisage: Existing treatments are more effective at an early stage. Moreover, one could start planning for the future: organise living and care arrangements, make financial provisions or complete an advance healthcare directive. All in all, the knowledge might lead to a new, more conscious perspective on life.

Ultimately, the question of wanting to know or not is a very personal one. The answer depends on your individual disposition, your view on life, and your concrete situation. However, you should not have to make such a grave decision completely on your own. It is vital to be able to confide in your partner, your next of kin or a close friend. They are the ones to accompany and support you. They can offer advice and consolation. Apparently, Jack worries that his environment might start seeing him in a different light: not as the caring husband, but as someone in need of care and a potential nursing case; not as the responsible father, but as a helpless child. He seems to be afraid that people might treat him differently: not take him seriously anymore, second-guess his every decision, act patronizing and overprotective. Maybe he is scared that they might even begin restricting his freedom, hiding his car keys, or not letting him go out on his own, anymore.

Dementia is one of the most abhorred diseases of our days. It is loaded with negative symbolism. The dominant medical perspective focuses on decline and deficit. In consequence, dementia is described in terms of loss of self, identity, and personhood. In a society that praises rational self-determination as its central value, this amounts to a form of social death. Accordingly, the media and the public discourse resound with grim images such as “living death”, or equate affected people with “vegetables” or “zombies”. This malignant imagery not only fuels our horror of the disease itself beyond all reasonable measures; it also causes fear of the reaction of others, of stigma and discrimination, of not being treated as a person, experiencing disrespect, or even being denied fundamental rights. Choosing to avoid or postpone a serious diagnosis is understandable and legitimate. There is a right not to know. However, it is important not to make this decision for the wrong reasons, driven by shame or anxiety, but as the result of a careful, well-informed and balanced deliberation. It is our moral responsibility as relatives, colleagues, professionals, and citizens, to create a situation where this becomes possible.
2. The process of understanding/finding out (diagnosis)

Background

Who wants to pursue a diagnosis?
As explained in the previous section, people with dementia are not always the ones who take the initiative to seek diagnosis as sometimes they are unaware of their difficulties or not ready or willing to find out about the cause. Some may nevertheless feel under pressure from relatives and even doctors to do so.

Often, the diagnostic procedure is initiated by a person’s relatives or doctor. Relatives and friends may be concerned about the safety or wellbeing of the person with dementia or feel that they need support. Doctors may notice possible symptoms of dementia, especially in patients they have known for a long time. However, doctors do not always follow up on this due to a number of factors such as inadequate training and experience, lack of time, insufficient knowledge about medication and support, stigma and difficulties broaching the topic. Relatives and friends may also find it difficult to broach the topic with the person with dementia.

Who should be informed?
Most codes of medical ethics and patients’ rights legislation recognise a person’s right to be told the diagnosis as well as their right to decide not to be informed. On the other hand, under exceptional circumstances, a doctor may withhold a diagnosis from a patient. In practice, carers sometimes ask doctors not to inform the person with dementia of the diagnosis. Other carers may be informed of the diagnosis by the doctor and left with the decision and task of telling the person with dementia themselves.

What is the impact of finding out that you have dementia?
Some people with dementia and carers have reported feeling shocked when told the diagnosis and have not been able to take in all the information given.

“We were diagnosed over two years ago but can still remember those first shattering feelings — shock, disbelief, fear, shame, feeling cut off… and feeling very alone. Your brain feels numb and you can’t take it all in ... But take heart, these first terrible feelings really do pass. We know – we’ve been there.” (Pat, James and Ian from the Scottish Dementia Working Group)

Others have experienced almost a sense of relief at finally knowing what was wrong. A range of reactions is possible such as guilt (e.g. linked to how the person with dementia was treated in the past and for possibly having blamed them for things which with hindsight were not their fault), sadness and grief about what has and may well be lost as a consequence of dementia, and anger. Disclosure of the diagnosis of dementia occurs at a specific time but the impact of the diagnosis is experienced over time as people gradually realise what it means to have dementia and how this affects their life and relationships.

The impact of the diagnosis may also be affected by whether it occurs at a time when it is beneficial to those concerned. For example, a diagnosis might be considered as being too early if it leads to radical changes in someone’s life, severe emotional disturbance and no real “solution”, but timely if it results in access to support, puts an end to confusion and worry and enables people to make decisions about their future lives, relationships and care. What is timely for one person may be premature or too late for another and in keeping with the point about the impact being a process, people may need time to come to terms with the diagnosis.
Ethical dilemmas faced by carers and people with dementia

Ethical issues during this process of understanding/finding out
The main issues during this process of understanding/finding out, which might have ethical implications, include the following:

- whether to refuse to pursue a diagnosis or to be informed of the diagnosis (i.e. the person with dementia),
- whether, and if so when, other people (e.g. relatives and doctors) should initiate the diagnostic procedure on behalf of the person with dementia,
- whether it is right to withhold the diagnosis from the person with dementia and/or to inform other people.

Vignette
Mrs Whitby’s next-door neighbour, John, had dementia and from the first symptoms onwards, he was very open about it. He consulted his doctor, had tests and talked to his family, friends and neighbours about the whole process and the outcome. Later, Mrs Whitby had concerns about a few difficulties she was experiencing and suspected that she might be starting with dementia too. She talked to John’s wife, Elsie, about it but no-one else. Elsie understood her need to confide in someone and respected her desire for privacy.
Mr Whitby had learnt a lot about dementia from John and had noticed subtle signs which prompted him to ask his wife about it. She was not ready to address the issue and denied having any problems. She feared that a diagnosis would change her whole life, practically and in terms of her self-image and relationships.
Mr Whitby had to go to the doctor’s on his own behalf anyway. Whilst there, he took a moment to tell the doctor about his concerns about his wife. As a result, next time Mrs Whitby had to attend the surgery, the doctor asked her about her memory and suggested a referral to the memory assessment service. She was mortified and thought it must be really obvious for him to have asked. Although she didn’t know this was triggered by her husband, he felt guilty and awkward about having gone behind her back. It was several months before a full diagnosis was made during which time Mrs Whitby’s condition had deteriorated somewhat. Nevertheless, she was adamant that she did not want to know the diagnosis although she had not discussed this with her doctor. Her husband, on the other hand, felt that he had a right to know.

Ethical commentary by Prof. Cees Hertogh (the Netherlands)

Living with dementia in a society that sets great store by rational self-sufficiency and that views dementia as a ‘loss of self’ is extremely challenging. In view of these societal prejudices, Mrs Whitby’s fear of how a formal diagnosis of dementia would affect her life and her relations is quite understandable. In addition, she is experiencing signs that further add to her fear and that threaten her sense of self – so to say – from the inside. Also, since dementia is an incurable disease, she might be wondering whether there is any point in getting a medical diagnosis.

From the standard ethical perspective with its emphasis on the principle of autonomy and individual rights, we cannot but respect Mrs Whitby’s attitude. For although people have a right to know and to be informed about their health and medical condition, this right is there in the first place for those seeking medical information and for those who are willing to accept medical assessment. In other words, the right to know does not imply a duty to be informed. Such a duty only arises, when not-knowing and persisting in ‘not willing to know’ might entail serious (health) risks for Mrs Whitby or others/third parties. This might, for example, be the case if the signs Mrs Whitby was experiencing, and/or the signs her husband had noticed, were of such a nature that car driving would be risky. This would face Elsie and Mr Whitby with the obligation to subordinate Mrs Whitby’s right to privacy to her safety and the greater good of the safety of others. In other words, others don’t have a right to intervene in Mrs Whitby’s privacy and to deny her wish not to have a memory assessment, unless respecting this right results in endangering herself or others. In the present situation, however, no such danger exists.
This standard ethical approach to the situation of Mrs Whitby focuses strongly on individual rights and duties but neglects the relational perspective. Conversely, from a care ethics approach, the central question would not be how best to respect the rights of the people involved in the situation. Instead the ethical question would be to know what constitutes good care in view of the fears and worries of both Mrs and Mr Whitby. For dementia, in a way, can be termed ‘a disease for two’, affecting both the person with the diagnosis and her partner, threatening their health and their relationship. Obviously, at this stage, Mrs and Mr Whitby are unable to find common ground to share their thoughts and uncertainties. One way of moving forward – and Mr Whitby could take the initiative here – might be to seek the help of a professional caregiver who could set up a dialogue with the couple, in order to enable them to share their fears and to find a middle way between denial and full diagnostic disclosure.

Ethical commentary by Mr Federico Palermiti (Monaco)

Faced with the onset of his wife’s memory problems, Mr Whitby decided to bring up her health condition with the family doctor, in her absence. While being concerned about these initial symptoms seems entirely understandable, I feel that undertaking the diagnostic procedure without his wife calls for some comment.

Firstly, it is important to take Mr and Mrs Whitby’s friends into account in this case. We could question, for example, whether the fact that their neighbour, John, had dementia had a role to play in Mr Whitby’s decision. Seeing and understanding what it means to live with dementia may have spurred Mr Whitby on to know more and to act swiftly.

We might also question the place and role Mr Whitby seems to want to occupy during this period of doubt. Mr Whitby is rightly very worried by his wife’s early symptoms. He is eager to put an end to this doubt and to know the diagnosis. But faced with his wife’s reticence how can we interpret Mr Whitby’s actions? Is he simply trying to protect her? I am sure this is so. His good intentions cannot be doubted. However, should his desire to protect his wife involve excluding her from these initial decisions?

Regarding Mr Whitby’s desire to find out whether his wife had dementia, perhaps the doctor’s reaction was too rapid and too abrupt, bearing in mind Mr Whitby’s fears about the disease. Did the doctor really need to answer Mr Whitby’s question so quickly? The pre-announcement phase is a step which can take time to be accepted by those concerned.

Finally, Mr Whitby expresses that he felt he had the right to know and to be informed despite his wife’s (very probably short-lived) refusal. But does wanting to know mean one has the right to know?

As I see it, this situation teaches us that two factors coexist (often conflictually) in this process of understanding the first signs of the disease. The first concerns the relationship of trust between all those concerned by this announcement: the patient with his/her partner or children, as well as with healthcare professionals. Even within a couple, this trust can quickly become weakened and disrupted by the fear of this disease. Without wishing to hurt the other person, some misunderstanding can appear. It is then common to find a discrepancy between desired decisions and desirable decisions and this can have consequences on the patient’s future care.

The second fundamental element during this period of doubt is the question of time organisation. Faced with decisions which must be taken, often urgently, several time periods can clash: the period of realisation that something is not right, the period needed to talk about it and to discuss, the period for accepting the consequences of a potential illness and the period in which to make decisions. These various time periods must be considered because they vary greatly depending on the person in question, their experiences, background and perceptions of the illness. Trust and time may conflict; but if they can be carefully negotiated, there is more chance that things will go well for all concerned.
3. The initial period of adaptation (shortly after diagnosis)

**Background**

**Who to tell**

Once diagnosed and provided that they have been informed of the diagnosis, people with dementia, and in many cases their carers are faced with the decision about who to tell. They may feel that certain people should know, either now or later, perhaps because those people will eventually care for them or simply because they have always been open with each other about important issues in life. However, they may have concerns about the implications of doing so (e.g. how will it affect their relationships, how will they be perceived and treated by those who know and how will those who know be emotionally affected etc.).

**Making plans for the future**

As people with dementia and their carers gradually start to come to terms with the diagnosis, many start to think about their future lives and the organisation of care.

“I was shocked. Then I thought about all the plans I’d made for my retirement with my wife. I realised it would no longer be possible. Now, much later, I’m enjoying life with my wife but it’s different and I sometimes feel a bit bitter about it.” (Alzheimer Europe, 2009)

Ideally, when a person is diagnosed with dementia, they should be provided with information about available support and details of organisations which can provide information as well as practical and emotional support. It is important to think early on about what is important to you and to discuss this with your doctor. This is sometimes called “advance care planning”. Box 4 shows some of the issues you might want to consider when planning care.

**Box 4: Planning ahead/things to consider**

- Specific types of care, treatments or tests you would be willing to have if needed or would prefer to avoid if possible.
  - An advance directive (in which you consent to or refuse specific treatment in advance)
  - A statement of values (in which you express your likes and dislikes, values and wishes in relation to care),
- Guardianship measures,
- Proxy decision making (organising for other people to make decisions on your behalf or to be consulted about your care),
- A powers of attorney,
- Taking part in research.

However, some people with dementia are not ready to consider certain issues. They might prefer to focus on the present or to leave future decisions to their partners or healthcare professionals. This might be their way of coping or a reflection of their approach to life. Similarly, some healthcare professionals and carers are reluctant to initiate or take part in discussions about end-of-life issues in the early stages. Although this may be based on good intentions, it can also result in people with dementia missing out on the opportunity to make important decisions about their lives (e.g. about residential care or the wish to live and die at home) at a time when they are still able to do so.

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1 Some of these issues may be governed by national laws, regulations or guidelines (e.g. covering consent, autonomy, restrictions of freedom and guardianship).
Thinking about research

When diagnosed with a serious medical condition, people often want to know what kind of treatment is available and whether there is a cure. There are currently four key medical drugs on the market which treat the symptoms of dementia (principally of Alzheimer’s disease) but there is none which cures any form of dementia. Some people might be interested in taking part in a drug trial, either in the hope that they might benefit from the research or to benefit future generations. However, the aim of a clinical drug trial is to produce generalisable knowledge and not to benefit individual participants. Participation usually involves some degree of risk. Also, some of the participants will not receive the new drug but might be unaware of this possibility.

Research is important to improve existing treatment, to find a cure or way to prevent dementia, and also to test out a whole range of approaches to care and to improve the wellbeing of people with dementia and their carers. As dementia progresses, the capacity (i.e. the legally recognised ability) of people with dementia to consent to research may diminish. The decision to participate in research is therefore sometimes taken by a proxy decision maker. However, people are sometimes hesitant to allow another person, especially one who is considered vulnerable, to take the same risks as they would themselves. It is possible to express such wishes in an advance directive or statement of values even in the absence of precise details about the specific nature of a future research project.

Driving

Being diagnosed with dementia does not necessarily mean that a person has to give up driving immediately although, depending on their condition and the stage of dementia, their doctor might advise them to do so. In some countries, doctors do not have the right to inform the driving authorities that a person is not safe to drive. There is currently no test which doctors can use in the surgery to assess driving ability accurately. In most countries, the onus is on the person with dementia to take the necessary steps to stop driving when they are no longer able to do so safely. In some countries there are specialist assessment centres for driving. Problems arise when the person with dementia does not realise or will not accept (when told by family, friends or their doctor) that they are no longer able to drive safely. Giving up driving can have a considerable impact on independent living, a person’s social life and self-esteem.

Ethical issues during this period shortly after diagnosis

The main issues during this period shortly after diagnosis, which might have ethical implications, include the following:

- whether to inform other people (e.g. relatives, friends, colleagues and employers) about the diagnosis and the impact of doing so,
- whether to take part in advance care planning and if so how,
- whether to leave decisions to others,
- whether to address sensitive issues,
- reasons for, hopes, risks and understanding of participation in research,
- what to do about driving if the person with dementia is becoming unsafe and is reluctant to give up.
Vignette

Hitesh has reacted to the diagnosis quite well, at least within the family. He and his partner, Pam, have explained to the children about dementia. They talk openly about their worries, about things that Hitesh finds difficult and look for solutions together. Hitesh does not want to let his in-laws or members of the local community know. He has gradually reduced his social engagements and work with the church. He relies on his family to respect his wish to keep the matter private. In so doing, their social life is also restricted. Whilst visits are not banned, Pam and the children have stopped inviting friends round. Pam is starting to feel isolated. She regrets not being able to confide in her sister.

People are starting to ask why they are no longer invited round, why he no longer attends social and religious events and why he sometimes acts strangely. Pam is sure that they would understand if they knew and that not telling them may result in them judging Hitesh harshly. She feels dishonest towards people who are genuinely concerned about him. Despite his openness within the close family, Hitesh feels ashamed and wants to protect himself and his family.

In the context of advance care planning, the doctor has suggested that Hitesh should consider writing an advance directive or statement of values. Hitesh is quite enthusiastic about the statement of values but says that he is not dying and does not want to think about end-of-life decisions yet. The doctor has explained that dementia can last many years but that as mental abilities gradually decline it is better to think about important decisions, not just about the end of life, early on. Hitesh doesn’t want to hear anything about it. Pam is worried about being asked to make some decisions for him later and does not want to be in that position.

Hitesh has always been fairly critical of research, sometimes coming out with statements like, “One day they tell you something is good for you and the next day, they tell you the exact opposite! I don’t think they have any idea!” However, he has jumped on the idea of taking part in a clinical drug trial. He says he doesn’t care if there is a risk, he absolutely wants to take part and is even willing to write that in an advance directive. His lack of concern about the details of potential studies and the risks involved lead the doctor to think that he may have unrealistic hopes and not fully understand that he might not even be in the group which receives the experimental drug.

The doctor has told Hitesh that he must let the driving licence authorities know of his diagnosis. He is very reluctant as he doesn’t wish to lose his license. He and Pam argue about it. She tries to persuade him to report it and he says that she is cruel and unsupportive. He says that he is still safe and will give up driving whenever that is no longer the case. Pam doesn’t drive and has always been dependent on Hitesh to get the shopping in but sometimes she gets scared when in the car with him. She thinks a lot about reporting him anonymously but can’t bring herself to do it. Meanwhile, she accompanies him when he goes out driving to try to ensure that he doesn’t have an accident. She has also thought about asking her brother-in-law, who is a mechanic, to disable the car.
Ethical commentary by Prof. Jan Oyebode (United Kingdom)

This vignette outlines several issues on which Pam and Hitesh differ. Hitesh does not want to tell people outside the family that he has dementia, make advance care plans or tell the driving license authorities about his diagnosis, whereas Pam feels telling others and planning ahead is the right way forward. A possible common denominator between these situations could be that Hitesh lacks awareness of his problems. However, a careful reading of the vignette casts this into doubt, since we are told he is open with his immediate family about his dementia. Therefore his attitude seems more likely to be a result of the sense of shame and fear of stigma.

Hitesh is not described as worrying about his decisions but nonetheless he does face an ethical dilemma of whether to ‘come out’ as having dementia. As long as he decides not to let others know, he protects his autonomy and privacy, both of which appear very important to him. However, it could be argued that this decision leads to maleficence (i.e. it causes harm to others) in that it is limiting the social life of his family and making them lie to others. If he declares that he has dementia this may well damage his autonomy – indeed, his GP doesn’t interpret Hitesh’s enthusiasm for taking part in the drug trial as showing desperation for help but seems to assume that Hitesh does not have mental capacity to decide whether to take part. So what is Hitesh to do? Perhaps dementia feels such a threat that he is ignoring his conscience when it tells him that his actions are causing problems for his family. Maybe if he can talk this through with them, he’ll come to give this more weight and the balance will change, especially if he has a strong sense of ‘familism’.

The dilemmas are more obvious for Pam and revolve around whether to tell others about the diagnosis. By covering up for Hitesh, she keeps his confidence, maintains his trust, protects his autonomy, and shows compassion for his position - so not telling has a lot to recommend it. However, by covering up she is not being truthful. If she tells others, the damage to Hitesh’s trust in her could have long-term consequences for their relationship but she has the sense that if she tells his friends they will become more sympathetic to his position, in other words she’ll prevent harm to his reputation.

The consequences are slightly different with regard to telling the driving authorities. If she doesn’t tell, maybe she is not giving enough weight to the potential serious harm if he has an accident. Telling the authorities would recognise this vulnerability, but would still damage trust. This has pushed her to consider going behind his back or deceiving him; but if she did this, she’d be betraying her values around truthfulness and so would damage her sense of her own integrity.

Maybe the answer is neither to tell or not tell, but is for them to find a way of talking more to each other about these issues and think perhaps about facing stigma together for the sake of avoiding harm and lies.
Ethical commentary by Dr Dianne Gove (Luxembourg)

Participation in a clinical drug trial represents a valuable contribution to society but the safety, interests and wellbeing of each research participant are of paramount importance. The concerns that Hitesh’s doctor (and perhaps also his family) has about his possible participation are in keeping with the principles of beneficence and non-maleficence. Such concerns might represent an ethical dilemma if combined with others about respecting his autonomy and promoting his quality of life, ability to cope and hope. Should these concerns influence Hitesh’s possible participation and does he not have the same right as other people to decide for himself and take risks? Well, it depends whether he has the capacity to make a decision about participation in a trial.

Although a person should be considered to have capacity unless proven otherwise, knowledge that a person has dementia should be considered as reasonable grounds for doubt. Researchers are obliged to obtain informed consent (which includes an understanding of the risks involved and the limitations surrounding possible benefit). The aim of a clinical drug trial is to produce generalisable knowledge and not a tailor-made response to an individual’s medical condition. It is not clear what lies behind Hitesh’s sudden enthusiasm for research and whether he is able to make a realistic evaluation of the risks and potential benefits involved.

It is neither feasible nor desirable to try to rule out every possible risk and attempts to do so may jeopardise a person’s quality of life. However, the doctor’s concerns about Hitesh’s wellbeing, safety and autonomy would be justifiable. Continued dialogue between Hitesh and his doctor and family could be beneficial. Hitesh’s hopes and expectations and his threshold for taking personal risk might possibly seem unrealistic. However, he has a right to have hopes and take risks, even to make decisions that others consider unwise, provided that he has the relevant and necessary capacity.

A diagnosis of dementia should not be considered as proof that a person can no longer drive safely. Hitesh feels that he can still drive but Pam’s fear suggests that he perhaps lacks awareness about his driving ability. Perhaps his doctor has already discussed the issue with him. However, there is currently no reliable “off the road” test which can determine with precision a person’s driving ability. Patients sometimes ignore their GP’s advice but GP reporting to the relevant authorities of patients whom they suspect lack such capacity violates the principle of confidentiality. This may affect the level of trust between doctor and patient which would be regrettable but the safety of the general public might be deemed a moral justification for such action.

Meanwhile, Pam is contemplating whether to sacrifice Hitesh’s trust for the sake of his and other people’s safety and even to prevent him from driving by means of deception (also involving his brother). Such measures might be considered as patronising, failing to respect Hitesh’s autonomy and dignity, dishonest and deceitful or on the contrary, as protecting someone who lacks insight into the dangerousness of their behaviour. Either way, there will be implications for their relationship. It might therefore be helpful first to encourage Hitesh to talk about his reasons for wanting to continue driving (e.g. his role within the couple, Pam’s dependence on him to get around, the car as a means to pursue his interests and social contacts), the emotional, psychological and practical impact of giving up driving and to explore ways to address these issues.
4. Living with dementia (getting on with routine life/adapting to challenges)

Background

Life goes on
After the diagnosis and the start of the process of coming to terms with dementia, normal life goes on. People still do whatever they did before diagnosis (e.g. cook, go fishing, do sport, go on holiday and spend time with friends and family). Some are still in paid employment and many will be in relationships and have social roles such as volunteer, committee member, parent, grand-parent, partner and friend. However, having dementia gradually affects the ability to do certain things and may have an impact on relationships. During this period, people with dementia and their carers are increasingly faced with challenges and may need to make changes and accept help from others. This is sometimes described as involving a series of losses. However, people with dementia are increasingly showing that living with dementia can also involve new experiences, learning new skills and making use of new supportive technologies.

The right level of assistance
People with dementia are sometimes unaware that they need help or prefer not to ask. They may have concerns about being perceived as a burden or find it difficult to accept being dependent on other people. Nevertheless, carers may notice areas where they need help and ideally, a formal assessment of needs should be carried out in order to identify any support needed. Carers often have concerns about safety and this can sometimes result in over-protection and a tendency to take over which reduces possibilities for self-expression, autonomy and freedom. It is not always easy to find the right balance. Providing more support than is needed may be demotivating to people with dementia and lead to a premature loss of skills.

Abuse
Abuse can be financial, emotional/psychological, physical or sexual. It can also involve abandonment and intentional or unintentional neglect, and affects both men and women. Some people with dementia, and some people who do not have dementia, are abusive. In some cases, the perpetrators and victims may have a history of abuse, for example in a marital relationship, which has never been successfully addressed.

The abuse of people with dementia can occur in their own homes, in residential care settings and anywhere there is a relationship and expectation of trust. Having dementia and being dependent on other people significantly increases the risk of abuse and can make it more difficult to detect or prove.

Abuse does not always involve malicious intent. People are not always aware that their actions or attitudes are abusive. Sometimes they suspect or know that they are but genuinely feel that they had no alternative (e.g. due to lack of support, difficulties coping and stress). They may in addition fear prosecution should the abuse be uncovered and fear that the person with dementia would be placed in an even worse situation. Outsiders who suspect abuse may also share such concerns. People who are dependent on their abusers may feel helpless to report the abuse but sometimes tolerate it as they are afraid of the consequences (e.g. retaliation, having to go into residential care, shame or fear of the consequences for the perpetrator with whom they have a relationship).

Abuse by people with dementia (e.g. physical and verbal aggression or sexually inappropriate behaviour) is not common but nevertheless possible. Often, such behaviour is attributed to the consequences of brain damage, something that may be true especially for certain types of dementia such as fronto-temporal. However it may also result from frustration, anger and fear, especially if the person finds it hard to communicate their needs to others.
Ethical dilemmas faced by carers and people with dementia

When the truth doesn't seem to help
Memory loss and confusion can be disturbing not only for people with dementia but also for other people. The person with dementia is often unaware that they have forgotten something or that they are confused. Consequently, they try to make sense of their experience with the limited or faulty information they have at their disposal. They may, for example, blame people for moving or hiding things or for not having informed them about something. Explaining that they have forgotten something or put it in the wrong place is not always helpful and can lead to upset and arguments. Sometimes carers play along in an attempt to de-fuse the situation or help the person with dementia to save face.

It is quite common for people with dementia to ask the same question repeatedly and almost immediately forget the answer. Constantly answering the same question can be time-consuming, frustrating and irritating. Also, some questions are difficult to answer. Individual experience may have shown that a truthful response is emotionally disturbing or unhelpful. Carers deal with this in different ways (e.g. ignoring questions, being deliberately ambiguous, withholding information, complaining, writing down responses, providing reassurance whilst avoiding the real question or lying) with varying degrees of success.

Ethical issues during this process of living with dementia
The main issues during this process of living with dementia (getting on with routine life/adapting to changes), which might have ethical implications, include the following:

- determining whether, how much and what kind of support is needed,
- balancing concerns about safety and risks with autonomy (conflicting interests and priorities),
- how to detect and address possible abuse of people with dementia and/or carers,
- how to react in situations where being honest seems pointless, unhelpful and may be emotionally disturbing.

Vignettes

A: My mother has vascular dementia and lives on her own. She manages quite well and hardly ever asks for help. She has always been a very independent person. Her husband (my father) died when she was in her early fifties and she took over the running of the family business. Now she is retired. I visit whenever I can get time off work and find someone to keep an eye on my little boy.

Last week, I found her pill box dispenser down the back of the sofa. She had not taken her tablets for blood pressure and her heart condition for two days but insisted that she had and that the dispenser was in her bedroom. I felt awkward but showed her the dispenser and suggested she must have thought I was referring to her vitamin tablets. She looked embarrassed and sad. Later in the day, as I was doing some cleaning, I came across a burnt tea towel and noticed that the house was not very clean. I asked her about how she was managing with cooking and the housework. She became quite defensive and told me she was perfectly capable of looking after her home and herself.

I got talking to her neighbour who told me that once or twice she had seen my mother leave the house in the middle of the night and had gone out to see what she was doing. She said my mother seemed totally disorientated and unable to find her way back to the house. I am very worried about my mother but she insists she is fine and I cannot go behind her back. I don’t know what to do, to do right.

B: I have got dementia. I was diagnosed three years ago and now live with my son and his family. I am very happy and so grateful to them. I am scared of my granddaughter though. She is a lovely girl but has a problem with drugs. I know I have difficulties with memory and that I lose things but I was absolutely certain that she was stealing money from my bedroom drawer. I alluded to that one day and she pushed me violently and threat-
ened to have me put in a home. One day, her younger sister saw her stealing and told me. I asked her not to tell anyone. I didn’t want to create problems in the family and was afraid that I might actually have to go into care “for my own good”. She agreed but I can see that she worries about me a lot and doesn’t know what to do. Me neither, I am scared and keeping quiet won’t help my granddaughter with her problem.

Ethical commentary by Dr Anneli Sarvimäki (Finland)

Response to the lady with concerns about her mother (vignette A)

You are in a situation where you want to do what is good and right for your mother, but what is good and right in this situation? You are torn between the following aspirations: 1. Caring for your mother’s safety, 2. Not hurting your mother’s feelings and 3. Being honest, not going behind your mother’s back.

The ethical principle “to do no harm” suggests you should consider both your mother’s safety and her feelings. The ethical value “honesty”, on the other hand, suggests you should not go behind her back. But although all these principles and values are good, the problem is that by following one (being honest) you are at risk of jeopardizing another (not hurting her feelings). So try to decide what is most important in this situation. In this situation it seems like the most urgent thing to consider is your mother’s safety. She could be in real danger if she wanders off in the middle of the night. By not taking her medicine she also puts her health at risk.

So the question is how to secure your mother’s safety without hurting her feelings or going behind her back. The important thing then becomes how the possible safety measures are presented to her. Her image of herself as a competent person can be supported by reminding her of all the things she can still manage and supporting her in doing all those things.

Response to the grandmother (vignette B)

You are in a difficult situation where many people’s interests and wellbeing are at stake. Is there a solution that is good and right for everyone or do you have to choose whose wellbeing is most important? You could consider the situation from the viewpoint of:

• your own safety and wellbeing
• your granddaughter’s dishonesty
• your granddaughter’s safety if she goes on stealing and using drugs
• your younger granddaughter’s distress
• family peace.

You realise what is at stake when you write that keeping quiet won’t help your granddaughter with her problems. It will not guarantee your own safety either, since she can apparently become violent and unpredictable. An additional undesirable state in this situation is your younger granddaughter’s worries. So this is not a good situation for at least three people. What is gained in this situation is family peace and the likelihood that you can go on living with your family. But is this worthwhile if you cannot feel safe, your younger granddaughter suffers and the older one continues her self-destructive behaviour?

Would speaking up be the right thing to do considering everyone involved? I gather that speaking up would mean talking to the parents, since the granddaughter is still living at home and they have a responsibility for her. Speaking up would give the parents a chance to help their daughter deal with her problems, which is a good thing.
Making the parents aware of what is going on could make you and your younger granddaughter safer and less worried, which is also a good thing. What harm could come out of speaking up? Family peace might be disturbed at least for a while, but sometimes it is necessary to cause some harm in order to achieve something good. But I understand that the big question for you is whether they would believe you or think that your dementia is becoming worse, causing problems in the family, and make you “go into care”, as you put it. But, as you say, keeping quiet won’t help and you are scared. The younger granddaughter has seen the same as you, so she may want to speak up too. Hopefully, your son and his wife can see the situation for what it is.

Vignette

My Great Auntie Peg lives in a care home. I visit regularly and sometimes find her in a state of anxiety, pacing up and down the room and staring out of the window. She asks, “Is Alfred not back yet?” Alfred is her husband and he died almost thirty years ago. I don’t know what is the best thing to do. When I tell her he died, she breaks down in tears. When I reassure her that he will be there soon, she seems relieved but I feel awful for deceiving her because she trusts me.

Ethical commentary by Dr Ian James (United Kingdom)

This scenario is typical of the vignettes I have explored with my colleagues in recent years via empirical studies with people with dementia, their carers and professional staff. Our findings suggest lies should only be used as a last resort, and only after the truth has been repeatedly trialled and shown to be problematic. When the truth consistently produces distress, the next step is to try to meet the person with dementia’s perceived need. This can be done by attempting to find out why the person wants to see the deceased member of her family (feelings of insecurity, boredom, etc.). If we could identify the reason why Peg wants to see her husband, we may be able to satisfy her need directly. We may also be able to deal with it indirectly by using pictures and videos. A useful technique which uses archive sound and video tracks is called Simulation Presence Therapy.

If such strategies fail then carers can attempt distraction. The distraction techniques usually involve trying to shift the person’s attention on to a different subject or activity. Once Peg’s focus is re-directed she may forget her need to see Alfred. However, if none of the above strategies prove effective, a therapeutic lie should be considered. Therapeutic lies are constructed with the aid of family members, and are care planned so that they are communicated well and consistently. This also ensures that the plans are person-centred, consistent with the person’s history, and able to meet the needs of the individual in a particular situation.

If one chooses to engage in this strategy there is a lot to consider, and our experience is that lies should be avoided as a therapeutic technique unless the liar has been trained to use them in an appropriate and ethical manner. So from this perspective, if we are going to endorse the use of lying with Peg, we need to teach the relative and care home staff to ‘lie as effectively and ethically as possible’.

In conclusion, the use of therapeutic lies is a controversial topic requiring appropriate governance. A therapeutic lie should be seen as one of a range of communication strategies. If a care home, for example, chooses to use such strategies, it will require staff to be trained appropriately. This is a complex area, with differing lies, at various times, being helpful for certain people. The case of Peg is a particularly interesting one, because it involves a lie being told by one family member to another. From our studies we are aware that ‘relative to relative’ lies tend to be judged especially negatively by people with dementia because they undermine the ‘holy grail’ of family trust.
5. Caring for/receiving care (when increased levels of support are needed)

Background

An increased need for care
As dementia progresses, the level of support needed typically increases. This may necessitate more significant changes in daily routines and habits. People with dementia and carers may have concerns about vulnerability, dependence, safety, dignity, self-esteem and how they will cope. The increasing severity of the symptoms and the need for both assistance and understanding may make it more difficult to keep dementia private and result in greater involvement of the wider family, friends and professional carers. This in turn may result in some intrusion into the private lives of those concerned and the need to relinquish control over some aspects of daily life.

Responsibility for care
The partners and adult children of people with dementia are often heavily involved in the provision of care. In some circumstances, such as with young onset dementia, younger children may be heavily involved. Carers have different reasons for providing care (e.g. out of solidarity, love, duty, in return for the care they received as children). There may also be some degree of obligation, especially where outside help is lacking or unaffordable or where people feel under social pressure. In some countries and communities, there are cultural expectations that women should provide care.

A person’s ability or willingness to provide care may change as the needs of the person with dementia change or when caring becomes difficult owing to health concerns or competing personal, family or professional commitments. This can create solidarity and strengthen family or friendship ties but at times, it can lead to conflict and situations in which the wellbeing and rights of some carers are not respected or given due importance.

Safety, monitoring and control
Cognitive difficulties may eventually result in people with dementia putting themselves and others at significant risk (e.g. of fires, traffic accidents, malnutrition and neglect). It can be stressful and tiring for carers to try to keep a constant eye on the person with dementia who in turn may feel controlled, restricted and humiliated.

Round the clock supervision is an almost impossible task but, fortunately, there are numerous devices and systems which can provide memory aids, monitoring, detect and resolve problems or raise an alert. Some of these have been criticised for invading people’s privacy, reducing social contact, leading to social isolation, being stigmatizing and restricting freedom but they can also promote privacy, autonomy, independent living and self-esteem, and contribute towards greater freedom of movement. It is often a matter of how and why they are used, and whether this respects the wishes of the person with dementia (which is linked to the issue of consent).

Sometimes, carers use restraint (e.g. using threats or intimidation, sedating, locking doors or preventing freedom of movement by strapping the person to a bed or chair or using more subtle means such as chairs which are difficult to get up from. Although their intention may be to protect and care for the person with dementia, such solutions can be dangerous and are almost always unethical, abusive and even illegal.
Ethical dilemmas faced by carers and people with dementia

Difficulties experienced by carers in relation to some aspects of care
As dementia progresses, carers may be confronted by situations and care needs which are difficult to manage (e.g. continence problems, the person getting lost, aggressive behaviour) and result in carers feeling physically, emotionally or psychologically overwhelmed. The difficulty might be due to a lack of training, knowledge or resources, or to the task being too intimate or transgressing personal boundaries (linked to gender roles or personal relationships). People with dementia may find it difficult and disturbing to be dependent on relatives and friends for certain types of care and in some cases resist assistance from them. In some situations, difficulties experienced by carers have serious consequences resulting, for example, in the use of restraint, physical abuse or premature entry into residential care.

Impact of caring on carers and on relationships
People with dementia and carers may start to perceive changes in the nature of their relationships. Sometimes, carers view this as a reversal of roles with children and partners feeling that they have taken on the role of parent. People with dementia may feel that they are considered or treated like children. Partners may feel that they have become more of a carer than a partner, spouse or lover, and this may have an impact on their sexual relationship with the person with dementia. Changes within relationships can be difficult for all concerned and may be accompanied by tensions, sadness and in some cases a sense of increasing emotional detachment, which may have an impact on the continued provision of care and the survival of the relationship. However, as suggested in relation to who provides care, dementia can also bring people closer together as they join forces to tackle difficulties and challenges (see also section 6).

Autonomy and consent
The increased need for care tends to be accompanied by difficulties for the person with dementia to take decisions (e.g. to consent to treatment or make decisions about various care options or with regard to everyday life). Carers may need to take decisions on their behalf which would previously have been made by or with the person with dementia. Ideally, they will consult and involve the person with dementia as far as possible in decision making. However, there is risk of carers sometimes taking over and failing to respect the autonomy and hence the dignity of the person with dementia (e.g. owing to time constraints, underestimation of capacity and difficulties communicating). Sometimes, carers know that the person with dementia would object to certain decisions but feel it would be unsafe to respect their decision and that they lack the capacity to make that decision. This can sometimes result in the use of deception (e.g. adding crushed medication to food), which can result in the carers feeling guilty and dishonest. As with advance care planning, certain issues involving deception may be governed by different laws. In addition, the safe use of medication may require advice from a doctor or pharmacist.

Ethical issues linked to caring for/receiving care
The main issues linked to the period when increasing levels of support are needed, which might have ethical implications, include the following:

- the need to manage risk,
- the impact of increased care needs on relationships,
- determining who should provide care,
- the use of restraint and deception,
- the impact of providing care on professional, private and family life,
- decision making when the person with dementia lacks the necessary capacity,
- managing difficult care situations.
**Vignette**

Gary is 70, has Alzheimer’s disease and lives in a city centre flat with his partner, Mike. As time goes by, Gary finds it harder to find his way about and to do the shopping. He sometimes takes a long time to come home, and often comes home without the items he has gone to buy. Gary loses money, has lost the notion of the value of money and sometimes gives huge tips in pubs and at the hairdresser’s. Mike has set up a few standing orders so he doesn’t need to handle money but Gary resents being controlled and feels humiliated. He argues that Mike has no right to restrict his money and make arrangements behind his back as he is not his legal guardian. Mike wants him to carry a mobile phone which he does but he cannot work out how to use it. He puts papers in his pockets with his name and address and has sewn a label in one of his coats. When Gary discovers this, he gets cross saying he is being treated like a child. Mike has heard about a special watch which can track people’s whereabouts and locate them if they get lost. He knows that Gary would accuse him of trying to track him like a criminal. He plans to put it in Gary’s rucksack when he goes out without telling him and thinks that might be justifiable as he is responsible for his safety.

Mike is starting to get tired and irritable. Gary often gets up in the night and this disturbs his sleep. He wants Gary to go to day care and to allow a carer to help him get washed and dressed in the morning so he can have a break but Gary refuses. Mike is quite open about being gay but Gary has always been more discreet. He doesn’t want everyone to know. Gary’s sister, Katie, used to come round in the morning, get Gary out of bed, washed and dressed, and prepare a snack. At that time, Mike had a part-time morning job to help make ends meet. However, Katie’s husband complained that she was not devoting enough time to the family and they had a big argument about it. Now she hardly ever visits and feels guilty about not helping as she gets on well with her brother.

Mike has given up his job and is finding it increasingly difficult to cope. He hates to admit it but does not see Gary in the same way as he did before. He feels more like a parent than a partner and worries that their sexual relationship is starting to be affected.

**Ethical commentary by Prof. Guy Widdershoven (the Netherlands)**

This case shows the dilemmas in which a person who cares for someone with dementia can get caught. A dilemma entails a choice between two alternatives, each having a strong moral appeal. When the person chooses one of the alternatives, the other one cannot be realised, leading to moral costs. The choice cannot be avoided, since not choosing automatically means going for one of the two alternatives.

An example of a dilemma in this case concerns the tracking watch. On the one hand, by putting the tracking watch in Gary’s rucksack, Mike can prevent Gary from getting lost and becoming anxious or getting into danger. On the other hand, if Mike did this secretly, he would be acting behind Gary’s back and compromising Gary’s autonomy and the equality in their relationship. Thus, whatever Mike decides to do, he will not be able to respect important values in his relationship with Gary (as he would either go against the value of respect and equality or against the value of care).

In dealing with moral dilemmas, one should be aware of the intricacy of the problem, and the costs related to one’s choice. It is crucial that the person facing the dilemma is open to the conflict between values, and to the fact that it is impossible to do justice to all relevant values. Thus, Mike should be aware that when planning to put the watch in Gary’s rucksack, he is jeopardising crucial values (autonomy and equality). He should not automatically follow his drive to care for Gary’s safety, but realise that in doing so he will put Gary’s autonomy and the mutuality of their relationship at risk.

In case of a conflict of values in the care for a person with dementia, it is good to share one’s worries and doubts with other people who are involved. Mike might contact Katie, not to try and convince her to take up daily care
again, but to share his concerns and reflect together on his conflict of values. This would also enable her to play a role in the process of finding solutions for Gary, and thus diminish her feelings of guilt. Mike might also try to contact professionals, such as the GP or a community nurse. Other people who know Gary might have a different perspective on the situation, and for instance help Mike to see that he takes his responsibility for Gary’s safety too far. They might also be able to act as an intermediary between Mike and Gary, and explain decisions to Gary more easily, as they are less emotionally involved in the dilemma.

Care for a person with dementia inevitably comes with dilemmas. In a moral dilemma, it is important to be aware of conflicting values and reflect on possible courses of action. Involving other people may help, not because they can solve the issue, but because they can bring in new perspectives and foster the process of deliberation.

Vignette

June and Agnes are in their eighties. They are sisters and now, both widowed, live together. Agnes was diagnosed with dementia five years ago. Last year, Agnes started to have continence problems but was able to manage this herself. Now, she sometimes sits around for hours after having had an “accident” without changing her pad, doesn’t clean round the toilet very well and occasionally leaves soiled pads lying around. Her son came round one day and felt sick with the smell. June has actually got used to the smell and due to poor eyesight can’t see how dirty the bathroom has become but the main problem is that Agnes can be quite violent when June tries to help her. Nobody would believe it. Agnes is such a gentle soul but when June suggests that she might need to change her pad, she becomes indignant and tells her to mind her own business in no uncertain terms. Worse, when June tries to take her arm to lead her to the bathroom, she digs her nails into her arm and has slapped her in the face a few times. June shows the son the nail marks. Agnes refuses to take tablets. She claims “they” are trying to poison her. June therefore crushes several tablets every day and hides them in her meals. The son worries that this might be dangerous or illegal and that technically speaking, as his mother has clearly stated that she does not want to take them, it is wrong. On the other hand, not taking them could seriously damage her health. Agnes’s son was angry with his Aunt June for leaving his mother in such an undignified state and felt that she was neglecting her and not respecting her autonomy. He had also noticed that his Aunt often put a tray across his mother’s armchair which made it impossible for her to get up. She explained that it was the only way to get a moment’s peace and get things done whilst keeping Agnes safe. It was quite obvious that Agnes felt frustrated and cross.

Whilst his mother was having a nap, the son and his Aunt talked about everything. He realised how difficult it had become for his Aunt to care for his mother, both physically and emotionally. The social services have not been very helpful, perhaps as his mother has not been honest about the extent of the problem. He doesn’t feel able to intervene, especially with intimate care, because it is his mother. He doesn’t want his mother to end up in a home and realises that it is unfair to rely on his Aunt, but what else can he do?
People with dementia have the right to make choices about their own lives. Yet problems can arise when those choices conflict with a carer’s perceived duty to keep a person safe. With the best of intentions, some carers can be overprotective and assume those they care for are not capable of making their own choices. This can deny people their human rights.

We should not assume that Agnes cannot make simple decisions about her care without assessing her capacity. Forcing Agnes to take pills or restraining her in a chair without her consent, when she might be capable of making these decisions herself, would be unlawful and a serious affront to Agnes’ dignity and autonomy. Restraint could also physically and mentally harm Agnes and, if used inappropriately (for convenience or without lawful justification), would amount to abuse. Even when Agnes cannot demonstrate capacity to make a choice, her views should always be considered when deciding what is best for her. However, Agnes may not be able to express herself in ways that can be easily understood; so we need to look for clues in her communication. For example, we could see Agnes’ comments about being poisoned as paranoia and a symptom of her dementia. But Agnes may be telling us that the pills are having unpleasant side-effects and make her feel bad. Similarly, Agnes’ violent outbursts around her incontinence could stem from feelings of humiliation and frustration as June intrudes on what Agnes considers to be a personal matter. All this suggests that to do things ethically, we need to listen carefully and communicate well with Agnes, taking into account the ethical standards and laws that apply.

Respecting Agnes’ autonomy also implies being honest and not deceiving her. Hiding crushed pills in Agnes’ food, however well-meaning, detracts from her autonomy and threatens the relationship of trust she has with June. It could also lead to Agnes suffering distress as she experiences side-effects that she can’t explain. Legally, Agnes’ prescribing doctor’s agreement must be sought for this practice. Agnes should have every opportunity to express her views about her care even when the resulting conversations between June and Agnes are likely to be difficult.

In the context of dementia, Agnes finds herself in a system of care where the needs of all parties are relevant. Agnes’ son and her sister have different perceptions of Agnes’ need for personal autonomy: Her son is unhappy about the way in which she is restrained, but June is more concerned that Agnes’ preferences regarding personal hygiene are respected. However, they can both contribute in a meaningful way to Agnes’ care. For example, Agnes’ son may be the best person to access more information and additional support for June.

Ultimately, the different views and limitations of June, Agnes and her son will need to be navigated and carefully negotiated during the decision-making process. Acting ‘ethically’ means trying to find the best route through these different perspectives whilst acknowledging that any outcome may not always be perfect from everyone’s point of view.
6. The possible transition into a care home (when continued care at home becomes problematic)

Background

Moving away from home
At some point, carers may have difficulty continuing to provide care at home and have to consider the possibility of the person with dementia moving into residential care. For people with dementia who live alone, there may come a time when they can no longer live on their own safely or they may need more care than can be provided at home.

In some countries, it is quite common for a person with dementia to be moved directly into residential care after release from a stay in hospital. This may, for example, be linked to additional care needs and perhaps a lack of suitable support. In some cases, this may be seen as an opportunity to make the transition easier. However, carers and people with dementia may sometimes feel that they were not adequately informed or involved in the decision and thus feel frustrated, angry and sad. Carers, even if consulted, may nevertheless sometimes feel guilty about the person with dementia not having been adequately involved in the decision.

The transition into residential care can be difficult as it involves the person with dementia leaving their home, friends and familiar surroundings and in many cases a separation between long-term partners. Nevertheless, it may be seen as necessary owing to carers’ own ill health, care needs or certain behaviours which carers find difficult to manage (e.g. continence problems or frequent night time waking), lack of support, the impact of caring on other members of the family and additional health problems of the person with dementia.

If the wishes of the person with dementia are known (e.g. the issue was discussed or recorded in the context of advance care planning) or they are still able to discuss the matter, this can be helpful; but there is sometimes a discrepancy between their previously expressed wishes and their current needs or wishes. There may also be a discrepancy between promises made by carers (e.g. to provide care at home or to organise residential care when the condition of the person with dementia deteriorates beyond a certain point) and their current wishes. Moreover, problems arise when the person with dementia refuses consent or objects to moving into residential care when this is necessary. In such cases, any move must be in accordance with legislation designed to protect their rights.

Familism
With familism (see Box I), there is an emphasis on the family unit and on the obligation to provide economic, emotional and practical support to close relatives and extended kin. The family may be seen as an extension of the individual, and individual behaviour as a reflection of the whole family. It may therefore be particularly difficult for people who share this core cultural value to consider a relative moving into residential care, irrespective of there being reasons which might otherwise seem wise, justifiable or understandable. Carers may have a strong wish to provide the kind of care and support which they feel is only possible at home, and feel guilty about the person with dementia moving into residential care. They may also have fears about how other people within their community might judge their family.
Confidentiality
Once the person with dementia is living in a residential care facility, relatives and carers who visit may sometimes be consulted by professional carers about care issues, especially as dementia progresses and the ability to communicate deteriorates. This may at times result in personal information being shared with people who do not have a legitimate or legal right to be informed and who may feel awkward about the disclosure of certain details (e.g. linked to sexuality, continence problems and other issues which transgress the boundaries they have with a relative or friend).

Ongoing and new relationships
A move into residential care can affect relationships owing to the physical distances involved but also the difficulty in maintaining the same kind of emotional contact in the light of cognitive deterioration and adapting to a different way of life. New relationships may develop on both sides. However, there may be concerns about people with dementia having capacity to consent to a sexual relationship, mistaking the other person for an existing or past partner or (in residential homes) mistaking their room and bed for another’s.

In some care homes, measures are taken to intervene and residents not given sufficient privacy for emotional or physical contact. This denies them the fundamental human right to engage in an adult relationship. Informal and professional carers may feel justified in taking such actions if they feel that the people concerned lack the capacity to engage in such a relationship, but there may also be value judgements involved, as well as family loyalties, and assumptions that older people should be asexual.

The move into residential care often relieves carers of the necessity to provide care but also takes away the opportunity to show their love and affection for the person with dementia. Care homes have different policies with regard to their involvement and professional carers may appreciate the involvement of families to a greater or lesser extent.

Ethical issues at the time of the possible move into residential care
The main issues at the time when a move into residential care is being considered, which might have ethical implications, include the following:

- when the person with dementia objects to or lacks the capacity to consent to residential care but care at home is no longer possible or feasible,
- when there is a discrepancy between former and current wishes or promises of people with dementia and carers,
- confidentiality and the involvement of carers in decisions affecting the lives of people with dementia,
- when individual needs and wishes are in conflict with family values,
- when people with dementia and their carers make new relationships.

Vignette
Mr Brown is feeling very tired and when he comes down with ‘flu, his GP suggests he needs a break, and says local social services can arrange for his wife to have a week in a care home. She is adamant she doesn’t want to go. Their daughter arranges to take her. She pretends she is just taking her for the day and says she will be back later without telling her she means a week later. She feels guilty but she thinks she had to do this to protect her Dad’s health.
Mrs Brown eventually comes home, feeling quite disorientated and disempowered by her experience. She gets her husband to promise never to let her go again. Their daughter steps in to give higher levels of support. Even-
Ethical dilemmas faced by carers and people with dementia

Ethical commentary by Dr Michael Dunn (United Kingdom)

Disagreement has arisen between Mr Brown and his daughter about the possibility of Mrs Brown going into residential care and about what would be best for Mrs Brown. Such disagreement is not uncommon and family carers must be able to discuss, and make progress in resolving, decisions like this one. It is a long-established ethical principle that people should be allowed to make decisions about their own lives, regardless of diagnosis. However, people with dementia will, over time, lose the ability to make one or more decisions about their care. This looks to be the situation here. Mrs Brown is confused and does not look able to understand or process information about her life at home, or the pros and cons of moving into a care home.

If it is established that Mrs Brown cannot make this decision, then it needs to be made for her in accordance with relevant legal requirements and involving her to the greatest extent possible. Nevertheless, it is not an easy decision to make. The difficulty looks, at first glance, to be an ethical tension between Mrs Brown’s expressed wishes prior to the onset of dementia, and her current expressed desire to stay at home. However, if what she is saying now is borne out of confusion, it might not reflect her own considered judgements about what would be best for her. As such, it does not have the same moral force as it would have if she retained the ability to decide for herself.

Instead, it is Mrs Brown’s current and future well-being that needs to be considered. Mrs Brown gets very distressed by the thought of moving into a care home, and Mr Brown and his daughter are aware that she did not have a pleasant experience in the care home previously. Deciding to uphold Mrs Brown’s previous wishes would mean acting in a way that knowingly causes her distress. Such a step does not look to be one that would make life better for Mrs Brown.

There is no easy answer to whether Mrs Brown’s well-being or her previous wishes should be prioritised. How this balance is struck will depend on the degree of distress that is likely to be imposed on Mrs Brown. It will also depend on the importance of the issue at stake to her. It may also be possible to lessen the harm that is caused to Mrs Brown, if the decision is made to move her to a care home. Deception is one such technique that could be adopted, though there is evidence here that this approach did not succeed in pacifying Mrs Brown previously. Another option might be to prepare Mrs Brown’s bedroom in the care home in such a way that it replicates her bedroom at home. Likewise, if Mr Brown and his daughter accompany Mrs Brown to the care home and spend significant time with her upon her arrival, she might be less confused by a sudden change in her living environment.

The balancing act in situations like this one should also be sensitive to other ethical values that are relevant to the decision. Here, Mr Brown and his daughter envisage difficulties providing care if Mrs Brown remains at home. They may of course want to try but if not, they should not be afraid to recognise that what they want for their own lives can also legitimately be considered. It is not ethically viable simply to exclude the interests of Mr Brown and his daughter as being irrelevant in making decisions like this one.
Vignette

My father has been living in a care home for five years. He and my mother split up 10 years ago but are still officially married and she is his legal guardian. She visits once a month. I don’t think he recognises her and sometimes he doesn’t recognise me which hurts but I understand. He seems to appreciate my visits.

I recently noticed that he often sits with a particular lady and they seem very close. She sometimes puts her hand on his arm and he looks at her lovingly. I didn’t think much about it until one day a nurse asked to talk to me in private. She explained that my father had been “caught in bed” with this lady, that such behaviour could not be tolerated and basically, what was I going to do about it? I was irritated by her tone of voice and attitude. I also felt a bit awkward. So I just laughed and pointed out that they were both adults.

She drew my attention to the fact that he was married and that neither he nor the lady in question had the capacity to consent to a sexual relationship. I didn’t want to go into the details of my parents’ relationship but felt the need to protect my father’s interests. I wondered on what basis she had determined that he or the lady lacked the capacity for a relationship involving sex and what right she had to intervene in such private matters and involve people, like myself, who had no business in knowing such intimate details. I don’t like the way this issue is being handled. I have asked to speak to the manager of the home. I know how I feel about it all but am not sure whether I would be right in arguing that my father and the lady have a moral and legal right to pursue this relationship and should not be prevented by staff from doing so.

Ethical commentary by Prof. Chris Gastmans (Belgium)

Ethical problems relate to the tensions between the responsibilities of people who live and work in a network of relationships. In this case, the ‘relationship web’ consists of the father himself, his beloved lady, his wife and daughter, the nurse, and the management of the nursing home. To do justice to deciding how to respond to the father’s new relationship, it is important to understand the experiences of the father, his family and the nurse because the father’s wellbeing should be considered in the context of this ‘relationship web’. Because of the intimate and emotionally sensitive nature of the father’s behaviour, the relational network has been put under pressure. To reduce the pressure, a solution has to be found that would satisfy all parties. The fact that all concerned could claim certain rights is not a deciding factor. Attention should not be paid to the father’s right to sexual expression, or the possible claim of his family or his caregivers, or indeed the balance between all these rights. In this situation the people involved need to pay attention to their relational bonds. The ethical decision-making process therefore demands great skill from all those involved because each person has a relationship and perspective that brings its own story: ethical decision-making therefore is achieved through dialogue (i.e. discussion) and interpretation (i.e. achieving a shared understanding that makes sense of the different perspectives).

Let us focus on the opinion of the nurse as an example. What does she really want? On what ethical values is her opinion based? It seems that she adheres to the dominant ethical model regarding sexual behaviour in older people in care. According to this model, the principle of respect for autonomy in particular is a dominant factor in assessing the moral permissibility of sexual behaviour. Respect for autonomy tends to be understood in terms of protection of the individual’s right to self-determination, most visibly expressed in the concept of informed consent. Whether or not sexuality is labelled as appropriate mainly depends on the resident’s capability to consent (23). Because dementia is marked by progressive deterioration affecting reasoning capabilities, people with dementia may be seen as falling short of the ideal of the ‘autonomous agent’ on which the principle of informed consent is based. This, in turn, seems to negate their right to sexual engagement. However, as the daughter points out, the capacity of her father to make decisions about his daily life and the expression of his own sexuality might easily be underestimated when focusing solely on the ideal
of human autonomy as expressed in the notion of informed consent. Sexual engagement is based on more than rational decision-making alone (24) (25).

It is a pity that the nurse did not take time to have a proper conversation with the daughter during which they could have explored their viewpoints in order to better understand each other. During their conversation, the daughter could also have asked the nurse why she had confronted her with these intimate details about her father, as the disclosure of a resident’s sexual behaviour to family members may not be as unproblematic as it might seem.

Clinical ethics is mainly seen as an ethics of individual relationships between patients, family members and caregivers. However, a careful reading of the case makes it clear that the father’s intimate relationship cannot be seen as an isolated form of interaction. On the contrary, it is situated in a wider informal and formal care process, which includes his family and the team of caregivers who are also part of a nursing home. A person-centred care approach can only be accomplished within a care home context that supports nurses to deal with ethically sensitive issues such as the sexuality of older people. Supportive interventions that could be offered in this regard are educational interventions on sexuality amongst older people, experience-orientated learning programs, and the development of a formal care home ethics policy on dealing with expressions of intimacy and sexuality by residents with and without dementia (25).
7. Care for a dignified end of life

Background

A dignified end of life is one in which the person with dementia is treated with care and respect as an individual, taking into account their needs and wishes, in the absence of pain.

Regarding access to palliative care services at the end of life

Dementia is considered as a life-limiting condition, even though people may live for many years after the initial diagnosis and receive psycho-social support and treatment for the symptoms. Consequently, it is also considered as a condition for which palliative care should be provided. Such care aims to improve quality of life, reduce suffering of patients and families and address physical, psychosocial and spiritual problems throughout the whole course of dementia (17).

Owing to the origins and development of palliative care being linked to the care of people with cancer in the last stages of life, its appropriateness for people with dementia, even in the last stages of life, is often overlooked. Many people with dementia have no access to palliative care at the end of life. Palliative nursing care and spiritual end-of-life care for people with dementia is largely under-developed. (18) In addition, there have been reports of people with dementia being left in pain and being treated without due respect for their human dignity (19). This can be very distressing for carers and for people with dementia who feel emotional and physical pain despite their cognitive difficulties and may sense the lack of respect for their dignity.

Interpreting and respecting previously expressed wishes

At the end of their lives, many people with dementia have reduced cognitive abilities and have difficulty or are unable to make decisions or express their wishes. Some may have a proxy decision maker and may have discussed their wishes with that person. However, as death tends to be a taboo subject, this is not always the case. Others may have recorded their wishes in an advance directive6. Depending on national legislation, the situation and the decision that needs to be made, previously expressed wishes may be advisory or legally binding.

As a person may have the ability to make a decision about one thing and not another and this may depend on a range of factors (e.g. the time of day, how they are feeling, the complexity of the issue, pain, tiredness and fluctuations in capacity), it must be determined each time whether they are able to make that decision. When the person is unable to do so and has made their wishes known, those wishes still need to be interpreted in the context of the current situation. Difficulties may arise when the wishes are ambiguous, do not clearly reflect the current situation or were made before certain medical advances were made. There may also be conflict when carers disagree with the previously expressed wishes or disagree amongst themselves as to how these should be interpreted. Some people feel that the person with dementia has changed so radically that they are no longer the same person and that, consequently, their previously expressed wishes are no longer relevant.

Deciding on behalf of the person with dementia

Carers and officially appointed proxy decision makers are sometimes asked to make decisions or play a role in decision making about end-of-life care and treatment. Some of these decisions have an impact on the person’s comfort, well-being and dignity, but some may affect the duration or experience of that person’s remaining life (e.g. linked to refusal or withdrawal of tube feeding, hydration and medication). If these processes and the consequences are not fully understood by carers, they may wrongly believe that they have contributed towards the person’s death or suffering.

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6 See sub-section 3 on the initial period of adaptation.
Some carers and proxy decision makers feel overwhelmed by the responsibility and the possible implications of their decisions, wondering what the person would have wanted and whether they made the right decision. They may also have doubts about their decisions in relation to their own values, wishes and spiritual and religious beliefs, as well as those of the person with dementia.

Outside influences in relation to certain decisions about end-of-life care
Decisions made by people with dementia in relation to life-sustaining treatment, either in advance or at the time if they have sufficient capacity, may be influenced by social pressure and negative perceptions of the value of older people and/or people with dementia within society. In other words, some people feel that they should not insist on every effort being made to keep them alive because they are not worth it or are a burden to their families or society. Similarly, carers and other proxy decision makers may be influenced when making similar decisions by portrayals of dementia which emphasise the negative aspects of having dementia and assume that people with dementia have no quality of life. Personally, they may feel differently about it and want every effort to be made to keep them or their loved one alive but feel that insisting on this would be selfish or unreasonable. People are not always aware of such powerful societal influences.

Ethical issues when providing care to ensure a dignified end of life
The main issues linked to the provision of care to ensure and dignified and painless end of life, which might have ethical implications, include the following:

• determining and interpreting wishes where there may be a conflict between what the person with dementia would have wanted and societal influences,
• dealing with possible discrepancies between former and current wishes of people with dementia,
• deciding on behalf of someone with dementia,
• dealing with difficulties accessing palliative care services,
• being involved in decisions about withholding and withdrawing investigations and treatments,
• dealing with the feeling that the person with dementia has changed so radically that they are no longer the same person.

Vignette
Harry has always tried to exercise control over his life and has never shied away from difficult decisions. Shortly after diagnosis seven years ago, he wrote an advance directive in which he recorded his wishes in relation to every possible scenario he could imagine. He was quite an authoritarian person and generally distrustful of people, especially of doctors he didn’t know.
A few days ago, he was admitted to the emergency ward of a hospital following a mild heart attack. The hospital staff know that he has an advance directive in which it is stated that in the event of a heart attack when he has moderate to advanced dementia, he does not want to be resuscitated. If he has another attack and needs to be resuscitated he may therefore die. His wife, Marie, insists that although he is currently unable to communicate, once fully conscious he would tell them that he wants to live. It is so long since he wrote the document and at that time he had a different impression about what it would be like to have dementia. Also, he has changed a lot since he was diagnosed. He is much more trusting, openly affectionate and easy going. He has a grandson who adores him and he is enjoying life.
His son, who has not had much contact with him in recent years, argues that his father currently lacks the capacity to express his wishes and that his previous wishes should be respected to the letter. Marie feels helpless and unsure about who is right. She feels that he is not the same person as the one who wrote the advance directive.
Down the corridor, in another ward, there is a lady with severe dementia called Dawn. When she was younger, Dawn’s mother looked after her own mother who had dementia. She had a manual job with long hours, three children and a husband with alcohol abuse problems. She had no support and was not on good terms with her mother (i.e. with Dawn’s grandmother). She used to frequently say things like, “If I ever get like that, please put me out of my misery” and “please don’t let me ever be a burden to anyone”.

Dawn had a happy marriage, gets on well with her daughter and son and has a network of close friends. Her husband has since died and her son and daughter are being consulted about the possible withdrawal of liquids and food. Dawn has expressed a few times since diagnosis concerns about being a burden to others, do not really reflect her own beliefs but rather those of her mother. Her daughter accepts unquestioningly that a person would not want to be a burden to their relatives and that her mother made her views very clear.

Ethical commentary by Prof. Julian Hughes (United Kingdom)

Harry has changed. It could be said that it’s a dramatic change, from ‘authoritarian’ to ‘affectionate’. But we all change in a variety of ways over the course of our lives and some of these changes are equally dramatic: from the child to the punk rocker to the partner in the law firm and so on. We both are and are not what we once were.

The Law will be different in different countries. But, before proceeding, it is worth noting two general issues. First, when we talk about advance directives we should ask whether the circumstances covered by the directive are actually the circumstances that now obtain. How did Harry imagine ‘moderate to advanced dementia’? There are grounds for thinking that he thought it would be much worse than it is for him. What has changed since he wrote his advance directive and does this have a bearing on how we should interpret it? Secondly, when a person lacks capacity (or competence) and others must, therefore, make decisions for them, these should be based as broadly as possible. Everyone’s views need to be heard and then judgements can be made that are likely to be the best for Harry. And this takes us back to thinking about Harry being the same person. Whether or not we think he is the same person will depend on how broadly we think about what it is to be a person. Some have suggested that a person is someone who can remember. Obviously, this then poses a threat to people with dementia who have memory problems. But there are other aspects to being a person.

As persons we have bodies. We also have families, cultures, histories, moral and religious views, and so forth. We are situated or embedded in these multiple fields, which all contribute to our being the persons that we are. In which case, Harry is the person he is in part because of his history (so we cannot ignore his past wishes). But his body also locates Harry as the man who is before us now. We have good testimony from someone who is very close to him, namely his wife (Marie), that he has changed. Her views need to be given a good deal of weight because of the role that she plays in his narrative or story, which partly defines him as a person. This does not mean that we should ignore the views of his son. But the broad view of the person means that we have to try to keep every aspect of his being this person in view: the concrete circumstances he now finds himself in, his past and present, his beliefs and those of the people who are near to him. It may seem as if we have to act with the wisdom of Solomon; but why should we have presumed that it would be easy to make decisions for other people?
Ethical dilemmas faced by carers and people with dementia

Ethical commentary by Ms Jana Kasparkova (the Czech Republic)

The person with advanced dementia needs increasing levels of nursing care and gradually becomes totally dependent. In the twilight phases of dementia life can be compared to “the flickering of a candle”. We would usually wish people with very advanced dementia to be cared for with understanding, kindness, consideration and sensitivity. People must be pain-free and kept clean; they should have company and enjoy the kindness of human touch. Many relatives and professionals would assume that the person dying with dementia needs to be supported to live well without “undue interference”, especially where this – whether it be unnecessary diagnostic procedures, the provision of food or fluids by artificial means (e.g. tubes or drips), the inappropriate use of catheters or drugs and so forth – might prolong distress without improving the quality of the person’s life. We may assume that it does not make sense to prolong suffering. In other words, we need a palliative approach.

However, judgements about quality of and meaning in life can be largely subjective and, if the judgement is to be made, it should try to respect the view of the person with dementia. Ideally, the person might express his or her wishes in advance and record them in writing (i.e. in an advance directive), as Harry did. However, where there is no advance statement, decisions about whether to provide potentially life-prolonging treatments have to be made by caregivers or by officially appointed representatives. On the one hand, carers recognise the inevitability of death, which often brings about an end to suffering; on the other hand, carers may also feel burdened with guilt and shame for seeming to accelerate the death of a close relative, whether on the basis of an advance directive or on the decisions of carers. Confusing and contradictory feelings are, in such circumstances, entirely normal.

For Dawn’s family the difficult dilemma concerns food and fluids. They are faced by uncertainty over what Dawn had in mind when she talked of not wishing to be a burden. It may help relatives to hear that at the end of life people probably have reduced feelings of hunger and thirst. Liquids can still be used at least to moisten the lips to reduce dryness and to give comfort. The main thing in the case of Dawn’s family must be to try to help them to understand what is happening to Dawn and why, what will help and what will not, what will be a burden to her and what will not. In addition, their own thoughts and feelings need to be acknowledged. In the final phase of life, communication between health professionals and family or other close non-professional carers will be vital. It is by good communication (listening and hearing as well as informing) that the right care and support will be negotiated. This teamwork can help carers to make their final decisions based on the patient’s wishes and in accordance with the person’s life, values, beliefs and conscience.
PART 3

Tackling ethical dilemmas

At the end of Part 1, we mentioned a more holistic, care approach to ethics which takes into consideration the whole person (i.e. their uniqueness, their relationships to others and their dignity and vulnerability) and the unique situation. Now, in Part 3, having explored several potential ethical dilemmas and provided ethical commentaries on them, we look in more detail at this care ethics approach, present a step-by-step guide to tackling ethical dilemmas and finally, provide a few ideas about how to avoid some mental traps and thus maximise our potential to address ethical dilemmas.

A care ethics approach

In the following sub-sections, we describe an ethical approach based on the work of Gastmans (11) and incorporating the role of conscience developed by Hughes and Baldwin (10). The former was mainly developed in the context of formal care but could equally apply to many ethical dilemmas which occur in everyday life. Box 5 highlights the main features of this ethical approach which are then discussed in more detail below.

Box 5: The main features of our ethical approach

- The lived experience
- The interpretive dialogue
- A normative standard reflecting
  - Vulnerability
  - Dignity
  - Interdependency
  - Relationships
- Our informed conscience

The lived experience

Every person is different and every situation is different. Even in situations which seem quite similar, people make sense of them in different ways and have different emotional reactions and concerns. A person’s “lived experience” is the way he or she experiences a particular situation or difficulty and what his or her life is like.

The interpretive dialogue

In order to understand a person’s lived experience, it is necessary to establish an ‘interpretive dialogue’. This involves listening to everybody concerned and trying to understand the perspectives of each in relation to the ethical dilemma. In many cases it is not clear what people want or what is important to them. It might not even be clear in their minds. Some people may seem to be quite ambivalent about some issues. The impact of dementia on the ability to understand and communicate makes this process even more difficult for the person with dementia. For this reason, it is important not to take what a person says unquestioningly at face value but to allow time for discussion, and to consider people’s feelings, their fears, their understanding of the issues at stake and their personal histories, known values and character.

A normative standard reflecting vulnerability, dignity, interdependency and relationships

Behaving ethically and dealing with ethical dilemmas requires some kind of normative standard (i.e. an agreement as to what is good and bad, ethical or unethical). In this respect, ethical principles and values are important as well as a perspective on humankind (i.e. what it means to be human). The principles-based approach to
ethics mentioned earlier, which tends to emphasise respect for autonomy and people as independent agents, may not be readily applied to living with/caring for dementia. Instead, a care ethics approach may apply. This emphasises vulnerability and dignity, as well as people being interdependent and existing in relation to other people. A key question is “how can I treat this person in such a way that I express my respect for him or her?”

**Vulnerability and dignity:** Vulnerability is as an essential part of the human condition and something that is closely linked to a person’s lived experience in that some people, at some stage in their lives, will be more dependent than others. According to Gastmans (11), people with dementia are vulnerable with regard to the psychological, relational, social, moral and spiritual dimensions of their being. This will be the case regardless of whether the person is cognitively aware of vulnerability. This vulnerability may threaten the person’s dignity and lead to dependence on others. The vulnerability of some people has been described as a source for the moral responsibility of others towards them (12), especially in situations where their dignity is threatened and they are not in a position to elicit respectful attitudes or behaviour from fellow human beings (11).

**Interdependency:** Agich (13) suggests that “because we culturally prize independence, it is natural to view dependence as a deficit” (p.103). Dependence has come to be perceived as something negative even though we are all dependent on each other in daily life (e.g. for the food we eat, the cars we drive, clean water and the emotional and practical support we give to each other). Most of us were cared for as children and protected from danger. As adults we may have received maternity care or had accidents or illnesses requiring medical and nursing care. People gradually need more care as dementia progresses but this could be viewed as part of the overall interdependency of everyday life, even if it is sometimes perceived as a burden to families or society. Challenging the emphasis on independence and removing the negative connotations surrounding dependency may contribute towards greater awareness of other issues which are important to people with dementia and carers and relevant to ethical dilemmas.

**Relationships:** Ethics is not just about isolated individuals. A person can, in principle, be considered as an individual autonomous agent. However, the capacity to act autonomously can be lost as a result of dementia. Few of us live in total isolation from other people. As mentioned earlier, people are mutually dependent on each other and connected by relationships. Indeed, the capacity to form relationships and the connections we make with other people are essential aspects of being human and part of our lived experience (10).

“It is crucial to recognise that the life of the person with dementia and their carer will often be very closely entwined, particularly where informal care is being provided by a partner, or by a relative living in the same house. In such circumstances, the interests of the person being cared for and the person providing the care will often be inseparable, and this may have significant implications for how the various needs and interests at stake are balanced and compromises sought.” (Nuffield Council on Bioethics, 2009, p115)

Caring is not necessarily a one way process with one person giving and the other receiving (11). It is something which takes place between different people. People with dementia not only accept care that is offered but often give something back in the form of acknowledgement, gestures or in other aspects of daily life. The reciprocal aspect of care (i.e. giving as well as receiving) may become increasingly difficult for people with dementia and attempts to give may not always be recognised by carers (14) (15). However, carers often understand or assume that people with dementia are unable to do so and do not expect something in return. For many, caring is just one aspect and moment in time of an existing, on-going relationship.

Carers often make sacrifices in order to care for the person with dementia. However, every person has their own intrinsic value and dignity, and is morally justified in protecting their own interests (5). It could therefore be
seen as questionable for someone purposefully and totally to sacrifice their own dignity, health and wellbeing for that of another person (7), however vulnerable the latter may be. We all live in communities with economic, social and political restraints, which in addition to our own personal restraints and interests, impact on what is possible. Longneaux (7) suggests the need for humility to recognise that we are not all-powerful and to accept that we cannot always achieve what we would have hoped for with regard to the people we care about, however much we try.

**Being guided by our informed conscience**

We defined conscience in Box 1 as “our personal, inner judge of what is right and wrong, informed by shared understandings and practices”. The last part of the definition emphasises that it is more than the subjective, inner voice in our heads which tells us whether something is right or wrong. After all, that might be similar to having a “gut feeling” and to a misguided justification of behaviour which is not ethical at all. Hughes and Baldwin (10) suggest that conscience is also objective (i.e. based on a consideration of outside facts and shared values). Consequently, we should really be talking about an “informed conscience”, which is acquired through education, upbringing and openness. When faced with ethical dilemmas, an (informed) conscience can be helpful, not in providing direct solutions, but in guiding us through discussions with others and ourselves. It can help us to determine what the important issues are, and how to interpret and understand people’s lived experience in relation to particular ethical dilemmas.

**A practical step by step approach to everyday ethical dilemmas**

Ethical dilemmas can lead to a lot of thinking, soul-searching and emotional upheaval. We may feel destabilised, find it difficult to decide what to do or how to react. The following steps are based on the care ethics approach described earlier and are intended to provide a structure to help you to address relevant issues with the people concerned.

1. **Establish and maintain an on-going dialogue with everyone involved or concerned about the particular issue.**
   Try to involve everyone who is legitimately concerned or affected by the ethical dilemma in discussions about it. It may seem clear that it is the problem of the person with dementia or the carer. However, the involvement of other people can sometimes be the key to a favourable outcome. On the other hand, depending on the issue and the situation, input from some people is likely to be more relevant and should carry more weight than that from others. It may help to have a neutral person “chair” the discussions such as a friend, relative, social worker or representative from a religious community. This is particularly important where the person with dementia, rather than a carer, is faced with an ethical dilemma as they may have difficulties with memory, communication and organisation. Having a chairperson may help ensure that no one dominates the discussion or acts disrespectfully towards others. It may also encourage quieter people to speak.

2. **Try to understand the issue and seek additional information if needed.**
   Try to identify the key issues related to the ethical dilemma. This might, for example, involve:
   - looking for “the facts” (bearing in mind that people may have different views as to what constitutes the facts),
   - determining what information is lacking and how to obtain it,
   - finding out how different people think and how they feel about the situation (e.g. their concerns, needs, intuitions, worries, hopes and personal interests),
   - reflecting on the dynamics and structure of the situation (e.g. procedures, structures, boundaries and how these fit together),
   - discussing different possible outcomes (3).
Consult relevant sources of information such as the Nuffield Council on Bioethics report; Dementia: ethical issues (5), Alzheimer Europe’s ethics reports on restrictions of freedom and the use of technology (20), and national reports and documents from Alzheimer associations or national ethics committees addressing ethical issues or relating to the problematic situation.

3. **Try to make sense of people’s needs, wishes and concerns (i.e. what is really important to them or bothering them).**

As you listen, try to make sense of people’s views, wishes and concerns. This will involve some degree of interpretation and you may need to dig deeper to explore some issues more fully (whilst respecting people’s right to privacy). It also requires an ethical attitude of “attentiveness” (11) based on empathy, concern about the wellbeing of others, putting yourself in someone else’s shoes and perhaps stepping out of your own personal framework (e.g. of values and beliefs) in order to be more receptive to that of other people. The person leading the discussion should not, however, neglect their own needs, wishes and concerns which are equally important.

Measures should be taken to increase the potential of the person with dementia to participate in the discussions and possible decisions. It should not be presumed that they are unable to participate simply because they have dementia. There are various techniques to aid participation and support decision making (see also Alzheimer Scotland’s guide: *Dementia: Making Decisions* and the work of Baldwin and colleagues produced by the Alzheimer’s Society in England) (21) (22). The dialogue should be on-going, covering both the lead up to possible change or to a decision as well as the period thereafter.

4. **Consider and evaluate the ethical principles and values at stake in relation to the individuals involved (including yourself) and the specific situation.**

Familiarise yourself with some of the key ethical principles and values (see Box 1). Some people consider some principles and values as being more important than others. Our view is that this might vary between people and across different circumstances. It is therefore important to know and understand the people affected by a particular ethical dilemma.

If the person with dementia is unable to express what is important, try to find this out from people who know the individual well. A statement of values can also be very helpful. This is a document which can take any form but generally includes information about what is meaningful and important to someone in life, their likes and dislikes, values, guiding principles and beliefs.

As there may be several people affected by a particular issue, it is possible that people will have different priorities. Therefore, we need to consider the views of all involved. Certain issues, such as vulnerability and dignity, might not immediately occur to people but may threaten their future wellbeing if not addressed. Sometimes there will be “an elephant in the room” and it may take courage to draw attention to an issue that everyone is choosing to ignore.

5. **Reflect together on possible outcomes which might be good or bad for different people concerned, bearing in mind their lived experiences.**

Think about the range of outcomes which might result from different courses of action in relation to the specific people affected (e.g. their personalities, their habits, lifestyle, living arrangement, needs and wishes) rather than in terms of abstract principles. For example, in relation to issues surrounding autonomy and risk, we might ask:

- to what extent Mr X values safety over freedom to get out and visit his friends,
- what kinds of risks Mr X considered acceptable in the past,
- what the likelihood is of certain accidents actually occurring,
- what the potential benefit is to Mr X (i.e. not just the potential risk).
Work towards a resolution of the dilemma together with the relevant people involved and in accordance with your conscience.

“Where there are arguments between people of good conscience, these arguments (so long as they are reasoned and rational) are a way of moving us towards the right answer. It is not that we say we know what this is in any certain way, but we can feel our way towards it through open, tolerant discussion, navigating our way through the messy world of morals.” (Hughes and Baldwin, 2006, p. 29)

6. Take a stance, act accordingly and, bearing in mind that you did your best, try to come to terms with the outcome.

Ethical dilemmas do not all necessitate some kind of action. Sometimes, they involve making sense of where you stand and your feelings about certain situations. However, decisions often need to be taken to do or not do something which might bring about a change in people’s lives. If possible, try to make this a joint decision. It may also help to express how you feel about any decisions you make to the people affected or to someone who is not involved. Try to accept that you did the best you could. If possible, try not to dwell on the other options you might have adopted, and remind yourself you made the best decision you could at the time having given due consideration to all options.

7. Reflect on the resolution of the dilemma and what you have learnt from the experience.

Ethical dilemmas are not about making one-off decisions. It is therefore important to consider situations, any decisions made and subsequent changes over a period of time. The ethical dilemma and attempts to resolve it may have had an impact on the family dynamics and on individual relationships. Similarly, the resolution of the dilemma may have contributed towards a different situation which will gradually unfold and may lead to other issues which will affect people’s lives. It may be helpful to reflect on these issues and their implications and especially with hindsight to learn from the experience, bearing in mind that you did your best.

Looking at obstacles to resolving ethical dilemmas

Adopting a structured, reflective and compassionate approach to tackling ethical dilemmas, involving everyone concerned and focusing on people’s lived experiences should, hopefully, contribute towards resolving ethical dilemmas you may encounter. However, we are sometimes hampered by emotional and psychological issues from the past, as well as by habits and ways of thinking which are no longer appropriate or helpful. With the aim of maximising the potential to tackle ethical dilemmas successfully, we draw attention in this section to a few possible mental traps and highlight the need to be open to other people’s experience in order to increase our understanding of the situation and of possible options. Some of these approaches have been used in the domains of psychotherapy and counselling to help people to become aware of their thought processes and how these might be affecting their behaviour. They have not been specifically applied to ethical dilemmas but may be helpful to some people.

Being weighed down by old baggage

Often, we let ideas, influences and habits from the past affect how we approach current situations. We may have come to accept sayings, values and certain ways of doing things more or less as facts or “reality”. However, our current situation, our relationships and what is important to us and other people at this moment may have changed. It may help to reflect on what we take for granted. We may find that certain long-held values, beliefs and assumptions are not as important as we thought they were. They may turn out to be hindering our ability to tackle a current dilemma.
The need to be realistic
Sometimes, we strive for excellence or the perfect solution when “good enough” would actually be the best option (3). We cannot always do what we would like to do for our loved ones as we are constrained to some extent by social, political and economic factors as well as our own limits. For example, somebody might want to resign from their job in order to care for their parent or partner but doing so might jeopardise their future financial security or the well-being of other members of the family. Another person might want to care for their loved one at home but their own health problems might make this impossible. We are therefore not all-powerful (7). It is sometimes necessary to make compromises, settle for less than “the perfect solution” and try to come to terms with the fact that the end result is not ideal or what we had hoped for.

Expertise traps
Expertise and knowledge may at times block openness to finding the best approach. Someone who approaches the situation with no specific expertise or knowledge may have greater openness, fewer preconceptions and a willingness to consider all possibilities. At the same time, input from people with different kinds of expertise can be helpful. It may therefore be beneficial to bring together relevant people from different backgrounds to discuss the situation and issues at stake and give equal value to the views of people who have no apparent expertise in the domain.

The impulse to take action and solve problems
In recent years, “problem solving approaches” have been criticised, especially in the context of complex, unclear (known as messy) situations (3). In such situations, a problem-structuring approach may be beneficial. This involves taking the time to explore and understand the problem before looking for a solution. It is important to ensure that the problematic situation, which is posing an ethical dilemma, has been fully explored before attempts are made to resolve it.

Either/or thinking
Either/or thinking (see also page 4) often involves an over-simplification of situations. Life is fairly complex and there are often far more options, including opportunities and outcomes, than we imagine. Complexity may contribute towards ethical dilemmas, but it is necessary to reflect on that complexity in order to understand fully the issues at stake. This may sometimes hold the key to a positive outcome.

Mind reading
Sometimes, we presume that we know what people think or how they will react (e.g. “If I asked her …., she would obviously think....” or “if I did that, he would....”). Even if we know someone very well, mind reading deprives the other person of the opportunity to decide for themselves and even to surprise us by their attitudes or actions.

Blame scenarios
Where there has been an unsatisfactory situation or decision (e.g. you are suddenly asked, without preparation, to make a decision about whether or not your loved one goes into a care home) that has led to a dilemma, it can be helpful to ask for a meeting, give feedback, take assertive action or even lodge a complaint. This may help to provoke an apology or bring about positive changes for the future. However, it is not usually helpful to your own well-being to dwell on blaming others for the current dilemma, however justified you may feel in doing so. Blaming serves little purpose in improving the situation and may result in you feeling increasingly bitter, as well as jeopardising relationships. It is more constructive to try and reconcile yourself to the idea that you cannot change the past but can try to influence the present and future circumstances (3).
References

Acknowledgements and details about authors

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Ethical dilemmas faced by carers and people with dementia
This report is about the ethical dilemmas sometimes faced by people with dementia and their carers. In addressing ethical dilemmas, we are deliberately focusing on some of the more problematic aspects of living with dementia but with the positive aim of trying to make such issues less of a problem.

We hope that this report will help people with dementia and their carers to make sense of some of the difficulties they may encounter and feel better equipped to tackle them. The report is divided into three parts. The first provides background information about dementia and ethical dilemmas. The second consists of a series and vignettes and commentaries and the third provides details of an ethical framework and some general guidance on how to approach ethical dilemmas.