

Ethical dilemmas faced by health and social care professionals providing dementia care in care homes and hospital settings

*A guide for use
in the context of
ongoing professional
care training*





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Foreword



As Chair of Alzheimer Europe, I am pleased to present this publication which provides ethical guidance for health and social care professionals who strive on a daily basis to provide quality dementia care in care homes and hospitals. Often, they are faced with ethically sensitive situations and ethical dilemmas which make this difficult to achieve, particularly when appropriate support and knowledge are lacking. For this reason, Alzheimer Europe set up a working group to produce appropriate guidance and support. This guide is the result of a year's work carried out by this group of experts in ethics and in health and social care provision, a person with dementia and representatives of national Alzheimer associations.

It is clear that despite their wealth of knowledge, experience and expertise, the members of the working group wanted to encourage readers to think for themselves, to work out what would be an ethical approach and to take responsibility for providing ethical care. Some of the commentaries are very down to earth, others slightly more theoretical, but all provide an example of how to reflect ethically. The tone is non-judgemental. It is clear that the experts involved in drafting this booklet have not been sitting in ivory towers. They understand the reality of providing dementia care in these settings and of the ethical challenges involved.

I hope that the managers of care homes and hospitals, which provide care for people with dementia, find it a helpful resource and that the health and social care professionals who benefit from the training are able to relate to the materials and increase their confidence in tackling ethically challenging situations. I am convinced that this

will be a valuable resource to be used within the context of ongoing professional training and hope that it will contribute towards the provision of ethical care but also to the wellbeing of professional carers by empowering them to deal more effectively with ethically challenging situations.

I would therefore like to express my sincere gratitude to the members of the working group who made it possible for Alzheimer Europe to publish this valuable resource: Dianne Gove (Chair of the working group), June Andrews, Lydie Diederich, Chris Gastmans, Jean Georges, Debby Gerritsen, Fabrice Gzil, Agnes Houston, Dana Hradcová, Julian Hughes, Caroline Kilty, Denis Mancini, Alistair Neimeijer, Lucília Nóbrega, Eila Okkonen, Jan Oyeboode and Natalie Rigaux.

Heike von Lützu-Hohlbein
Chair of Alzheimer Europe

1. Introduction

Background and objectives of this publication

This publication has been produced by a group of renowned experts and highly trained professionals in the field of ethics and dementia care, with the collaboration of a person with dementia, representatives of Alzheimer associations and independent feedback from professional health and social care professionals in the United Kingdom, Portugal and Finland. Details of everyone who contributed towards this publication can be found in the acknowledgements section on page 33. The work was carried out in the context of a one-year project organised by Alzheimer Europe and is part of a series of projects linked to the European Dementia Ethics Network, which was set up by Alzheimer Europe in 2008.

The target group of this publication is health and social care professionals of all levels and responsibilities (frequently referred to as “you” in the text) who are faced with an ethical dilemma and concerned about finding an ethical way to deal with it.

Our aim in writing this publication is to provide materials which will:

- enable you to reflect on a range of ethically challenging situations,
- empower you to tackle any you might encounter,
- enable you to reflect on the approach you adopt and
- (if you feel the need) enable you to justify the approach you adopt to yourself and anyone who might ask.

We hope that this publication is thought provoking and will inspire valuable discussion. However, we would like to emphasise that it is intended to be used in the context of ongoing professional care training (e.g. with moderated group discussions, professional guidance and role playing). Ideally, the various information, guidelines, vignettes (short stories), commentaries and activities should be presented in stages (not all at once) and discussion adapted to the level of experience and knowledge of different health and social care professionals.

Promoting ethical care

In some care settings, the philosophy of “person-centred dementia care” has now become a stated norm for many services, even when it is not entirely clear what standard that implies. Within this approach, the focus is on supporting the wellbeing, dignity and autonomy of the whole, unique person rather than on a collection of symptoms or behaviours to be controlled. This implies that care should be suited to the needs and wishes of people with dementia and that their rights, individuality and dignity should be respected, regardless of the extent of cognitive impairment. A person-centred approach therefore benefits people with dementia by respecting their human rights and individuality, and by contributing towards quality of life and wellbeing. However, whilst there is general consensus on the need for a person-centred approach, the actual practice of person-centred care varies considerably. Health and social care professionals sometimes lack the support of their organisation in providing a person-centred approach to dementia care.

Although the wellbeing of the person with dementia must be the central concern when providing care in care homes and hospitals, this must be balanced against other concerns related to the wellbeing and rights of other people such as informal carers (i.e. relatives and friends), co-residents with

and without dementia and professional carers. In everyday practice, it can sometimes be a challenge to achieve this.

As a professional carer of people with dementia in a care home or hospital setting, you may sometimes find yourself in situations in which it is hard to decide what, if anything, would be the right thing to do. It is particularly difficult to make such decisions when each possible option seems to be good for some people but not for others.

In addition, professional carers may hold very different ideas about what is (morally) right or wrong (some may even insist that they know best) and on what basis a certain approach would or would not be ethically justifiable. Such issues are further complicated when acting ethically in the context of professional dementia care is incompatible with respecting established professional and institutional procedures or formal guidelines for care.

The following scenario provides an example of a difficult situation which is quite common in professional care. As you will see, such dilemmas often revolve around values. You want to do the right thing but no one is quite sure what the right thing is and then there is the question “right for whom?”.

Mrs Grey

Mrs Grey, an 87-year-old widow, has moved into a dementia special care unit in a nursing home. The move was arranged because she was neglecting her hygiene and had frequently got lost whilst out walking around her neighbourhood at night. Mrs Grey had become increasingly frustrated with other people, including her children. In her view, they kept interfering with her life and were constantly nagging her about unimportant things. Since her admission to the nursing home, she has increasingly withdrawn from life on the unit and spends most of the day in her room, which is affecting her circadian rhythm and she has started to refuse help with washing.

Initially, nursing staff made an agreement with her that she could wash herself six days a week, and take a shower with the help of nursing staff on the seventh day. It soon became clear that Mrs Grey had a rash on her inner thighs but she hit nursing staff and called them names when they tried to help. This continued for weeks. Hypnotic medication did not calm her and the rash worsened. Finally, the doctor decided that it was necessary to wash her by force. Mrs Grey's family was consulted about this treatment and agreed to it, albeit with some reservations. The treatment involved three members of staff restraining Mrs Grey whilst a fourth washed her. Mrs Grey got very upset. She cried, screamed and tried to break free. Several members of the nursing staff became quite emotional about this situation and could not bring themselves to participate in the washing. Others did not agree with the physician's decision and considered it a threat to Mrs Grey's dignity.

Some potentially challenging situations

– how would you react?

As you were reading through the above scenario, you may have been thinking about how you would have reacted in that or a similar situation. In this section, we would like you to do just that.

Activity 1

Please read the following scenario and then answer the questions at the end in relation to this and to the vignette about Mrs Grey in section one. The idea is not to assess how well you would or would not have done in such a situation. Rather, our aim is for you to gain insight into how you approach such a situation, the issues at stake and the values you consider important or meaningful.

Sisters in a care home

Geraldine and Marjorie are two sisters who share a room in a residential care home. Geraldine was diagnosed with Alzheimer's disease five years ago and Marjorie just six months ago. The two sisters never married and have no children. Geraldine has told staff several times that her sister and a few other people have stolen things that belong to her such as a watch and jewellery. Furthermore, she doesn't seem to recognise her sister, sometimes referring to her as "that bossy woman over there". Marjorie denies the allegations of theft and insists that Geraldine hasn't worn a watch or jewellery for years since she became allergic to nickel. Some of the residents have complained that Geraldine is aggressive and verbally abusive. Some are afraid of her.

Geraldine has asked to have her own room but Marjorie feels protective towards her and remembers the promise she made to their mother that they would always look after each other. She doesn't realise how much money they have in the bank and fears that with two separate rooms their funds would soon run out. Having seen some documentaries about abuse in care homes, she is frightened they would end up "starved and beaten in a horrible home". They do have a niece who lives abroad and visits once a year and she insists that the problem will blow over and that her aunts should remain together. Bob, the manager of the care home, feels that he should at least contact Geraldine's legal guardian as Geraldine has requested this. On the other hand, Marjorie has asked him not to, emphasising that her sister does not have the capacity to make such decisions and that she herself does not want a separate room. The manager is not sure what to do.

To get you thinking, we'd like you to jot down spontaneously/intuitively your initial thoughts about the following questions for each of the vignettes. The questions are not in any specific order.

- What would you do if you were one of the staff in the first vignette or Bob (the manager) in the second vignette?
- Would you have any doubts about your decision? Is there any sense in which it might not have been the right thing to do or that someone might consider it unethical?
- Do you think any of your colleagues would have reacted differently and if so, do you think that they would have been "right"?
- What is this dilemma essentially about?
- Who is affected by the current situation?
- How do you think a person with dementia would be affected by these situations/decisions?
- What are the main difficulties you found in the situations?
- What are the things that you feel of major importance when reflecting ethically about these situations?

If you are working in a group, it might be helpful to discuss your initial thoughts with your colleagues or other group members to see how their reactions to these situations correspond to your own. Please put your responses in a safe place so that you can look at them later once you have gone through this document. You may find that, in the light of what you have learnt, you would react differently or, alternatively, feel reinforced in how you already deal with ethical dilemmas.

2. Caring and coping in ethically challenging situations

Values, principles and theories

Shared norms

When trying to decide what is ethical (i.e. morally good and right), we tend to rely on shared norms and understandings of right and wrong. In other words, we bear in mind values which have been defined by society as a whole, which we have picked up from other people (e.g. from our parents, through our education, through our relationships with others and through our culture). However, we need to be able to reflect critically and with compassion on what is right and wrong in a particular situation. Often, things are not intrinsically right or wrong. For example, we might have learned that stealing is wrong. However, imagine that there is a widower who is unemployed and needs to find food for his four children. Some people might feel that he would be justified in taking two loaves of bread but only paying for one. Such reflection may challenge the way that values are defined and interpreted within society. The end result of such reflection may be to question why something is done in a particular way, to voice concerns or to take some kind of action.

Ethical principles, values and related concepts

To help us weigh up the right way to act, we can also consider general principles such as autonomy (being independent and able to decide what should happen or be done to you), beneficence (doing good), non-maleficence (avoiding harm) and justice or equity (treating people equally and fairly). These were initially developed and used in the context of medical care and treatment as standards to promote honourable behaviour by doctors towards their patients. They have since been applied in a wide range of social contexts. These principles are not based merely on the desire “to be nice to people”, but also on the recognition that people have rights (e.g. to decide for themselves, to be treated fairly and not to be harmed). There are other principles and values which are equally important in both medical and non-medical settings. These include trustworthiness, honesty, integrity, compassion, promoting well-being, confidentiality and respect for privacy, personhood and dignity. At the end of this report, in Appendix 1, you will find a table of definitions.

It is worth noting, in passing, that there has been a good deal of work looking specifically at values and the role that they play in our decision making. This has led to the approach called values-based practice (VBP), but sometimes called values-based medicine (VBM) to make the comparison with evidence-based medicine (EBM) (Fulford, 2004). VBP makes the point that just as facts are important so, too, are values. Values are complementary to facts; and they are everywhere. We must understand the facts – all of them (or as many as possible) – in order to make sensible decisions; but, similarly, we need to understand the values – all of them (or as many as possible) – in order to make ethical (good or right) decisions. This means that the values of all concerned need to be heard: they need to be set out as clearly as possible and considered seriously. VBP is an approach which raises a variety of issues, from theory to practice (see Fulford, Peile and Carroll, 2012, for further information).

Finally, we sometimes try to work out what would be ethical based on ethical theories or approaches. Some of these were developed by philosophers thousands of years ago but they are still highly relevant. Many people reason in this way without necessarily knowing anything about the underlying theories. Examples include:

- the consequentialist approach – doing what is defensible based on outcomes which maximise people’s happiness or welfare; the end more or less justifies the means,
- the deontological approach – acting in accordance with our duties as rational and interdependent individuals living in society; the emphasis is on the character of the act itself rather than on the outcome,
- the rights-based approach – doing what best protects and respects the moral rights of those affected; the more serious the violation of a person’s rights, the more unethical the act,
- the fairness approach – treating everyone equally, or if unequally then fairly, based on a standard that is defensible,
- the common good approach – doing what would contribute towards the good of the community; we are all part of a larger community,

- the virtue approach – acting in a way that is consistent with what a virtuous person would do; the emphasis is on the character of the agent rather than on the nature or consequences of the act itself.

Each of these approaches might be used to understand a situation and to consider the best ways to move forward. Thus, each of the people involved in a given situation might think

and act according to a different approach. We should allow for acceptance and reflection on different points of view. “Ethics in action” (i.e. in daily practice) emphasises practical reasoning, i.e. understanding how to achieve your moral goals, as well as deciding what the moral thing to do should be in the first place. Please see Appendix 2 which includes a short vignette for each of the above-mentioned approaches.

Activity 2

Look at your responses to the vignettes about Mrs Grey and the two sisters. Do your responses seem to connect with any of the principles or approaches mentioned above? If so, which ones? If not, which other factors affected your assessment of the situation and your idea of how to approach it?

General guidelines to facilitate ethical decision making

Taking into account the complexity of the situation

You might still be unclear as to whether your approach would have been ethically defensible or whether a different approach might have been “more ethically grounded”. Making judgements by relying solely on values, principles and theories can be problematic. Such concepts raise numerous questions, such as 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 everyone have the same definition of dignity?

However much we want to do what is ethically good and right for those in our care, there are also many restraints that impact on what is possible. We therefore need to recognise that we are not all-powerful and need 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. Longneaux (2014) calls this the need for humility. Nonetheless, it is usually helpful to tackle ethical dilemmas within an ethical framework and in a systematic manner, taking into account the unique nature of the situation and of everyone involved. This will help ensure that whatever action you take (if indeed action is to be taken), you can defend your decision as being what was right/ethical in that particular situation, at that time and for the people involved, including yourself.

An ethical framework to guide reflection

There are several possible ethical frameworks which might guide your reflection. We have chosen the “dignity-enhancing framework”, developed by Chris Gastmans (2013), combined with Julian Hughes and Clive Baldwin’s (2006) concept of “conscience-guided reflection”. The key elements of this combined approach can be summarised as follows:

- **The lived experience**

Every person is different and every situation is different. A person’s “lived experience” is the way he or she experiences a particular situation or difficulty. Even in situations which seem quite similar, people’s “lived experience” is different: people make sense of similar situations in different ways and have different emotional reactions and concerns. These lived experiences can be considered as the starting point of ethical reflection.

- **The interpretive dialogue**

Often, it is not clear what people want or what is important to them. It might not even be clear in their own minds. Sometimes, people might seem to be quite ambivalent (having mixed feelings or contradictory ideas) about issues which we consider vitally important. A person with dementia who has agreed to move into a care home might, for example, show no interest in the location of the care home even though the choice of location would determine whether or not his/her family and lifelong friends would be able to visit regularly and despite repeatedly saying how much he or she values those people. Dementia has an impact on the ability to understand and communicate which often makes it difficult to determine what is important and meaningful to someone. For this reason, it is important not to take what a person says unquestioningly at face value but to allow time for discussion. We need to consider people’s feelings, their fears, their understanding of the issues at stake and their personal histories, known values and character. In this way, we not only listen to the people involved but also accurately interpret what they mean and what is important to them.

- **The normative framework**

Behaving ethically and dealing with ethically sensitive situations involves reference to some kind of normative standard (i.e. an agreement as to what is good and bad, ethical or unethical). In this respect, ethical principles, values and theories are important. However, as we noted above, pre-suppositions about what is good, bad, ethical and unethical can lead us into traps because normative standards evolve and change over time (they are constantly being defined, redefined and challenged) and also because each situation is unique. Similarly, there is sometimes a tendency to focus on what is wrong or unethical (e.g. undignified care) but equal attention should be paid to reflecting on what is ethical (i.e. taking a positive, proactive approach to respect dignity).

- **Informed conscience**

Hughes describes conscience as “our personal, inner judge of what is right and wrong, informed by shared understandings and practices”. Hughes and Baldwin suggest that conscience is objective (i.e. not just a matter of inner, personal judgement) when it is informed. An “informed conscience” is acquired through education, upbringing and openness. The use of conscience implies an openness to the views of others and a willingness to have our preconceptions challenged. Our informed conscience can be helpful, not only inasmuch as it sometimes provides direct solutions, but also 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 experiences. If our conscience “pricks” us, it implies we need to consider what we are doing afresh, in the light of the lived experience, interpretative dialogue and the normative frameworks within which we live.

Structured approach to tackling ethical dilemmas in daily practice

Action is not always required when faced with a problematic situation. Sometimes, we just need to be clear and able to justify to ourselves and others that what we are already doing or not doing is, from our point of view, ethically defensible. However, when it is unclear what would be right or wrong in a particular situation, it is important to approach that situation in a structured way in order to consider the complexity of it and move ahead. Having already considered abstract concepts such as values, principles and ethical theories/approaches, we now propose a structured approach, consisting of eight components, to help you to reflect on a situation you are facing and to come to a decision. It may be helpful to move through the components in a fairly linear fashion, but to be flexible and move backwards and forwards between them as you gain new insight into the situation and gradually develop your ideas in the context of the specific situation you are addressing.

These components are targeted at health and social care professionals of all levels and responsibilities (e.g. qualified, unqualified, registered, unregistered etc.) who are faced with an ethical dilemma and concerned about finding an ethical way to deal with it. You might work through them alone or you might have the opportunity to work through them with your colleagues (e.g. in the context of a team meeting or together with your manager). Every person working in a nursing home or hospital setting has an ethical responsibility towards the people with dementia in their care. Solutions to ethical dilemmas cannot be achieved solely by objective reasoning but must also come from within and result from dialogue. Consequently, we often address “you” (as an individual and as the reader)

but emphasise the need for dialogue and the need to work together with everyone concerned towards a solution.

Depending on your place in the organisational hierarchy, you might not have the authority or power to take action. Your involvement in such cases would then be more to support those who do by contributing towards a better understanding of the issues at stake and of the ethical implications of various courses of action, if action is needed. You might not have the mandate or the means to change a whole system. However, through your behaviour (acts as well as attitudes), you are able to contribute to the ethical treatment and care of people with dementia.

In Appendix 3, you can find a “checklist for reflecting on ethical dilemmas and ethically challenging situations”. It may be helpful for you to use this form (in a flexible way) to structure your thinking process and ethical deliberation. You could either use this on your own or together with your colleagues. For example, you might find it helpful to use the form to keep a note of your thoughts as you reflect on a particular situation. Alternatively, you might use it as a means to structure and record discussions about such a situation in a team meeting, led by yourself or the person responsible for team meetings in your organisation.

Finally, we understand that sometimes it is necessary to react, and even to take concrete action, immediately, on the spot. In such cases, ethical reflection based on dialogue may have to follow the action but may nevertheless contribute towards understanding why and how the situation arose, whether the solution was/is ethical and whether any further action is needed.

Component 1: The situation

What is the particular situation that is being considered?

Try and write down a clear sentence that sets out what you are focusing on. This helps bring you from a vague notion to a definite issue.

Component 2: The people involved

Who is involved in this situation?

Identify all the people who are directly or indirectly involved in the situation (including those who may have contributed towards its cause and those who may be affected by it) as well as those whom you feel you need to involve.

Component 3: The context

What is the context in which the situation occurs?

Consider the particular situation (e.g. when did the problematic situation start, where is it taking place, how is it evolving?) and identify the institutional and societal context in which the situation occurs. Are there any relevant laws or organisational procedures which should be considered? Are there any institutional ethics policies or professional guidelines which should be taken into consideration?

Component 4: How the situation is experienced

How does the situation seem to be experienced by everyone involved?

This component is about identifying the lived experiences of everyone involved. This should include the person with dementia but also a range of people such as co-residents, other health and social care professionals, the management and informal carers etc. Please think about how the people involved might experience this situation (taking into consideration what you know about them and their lives).

Component 5: The dialogue with everyone concerned

What can I learn from dialogue with the people involved?

Communicate with the people involved and affected by the situation. Listen to what they are telling you, see what they do, try to understand what they mean, what is important to them and whether some have conflicting loyalties or interests. Try to facilitate discussion so that those involved can recognise and express their own needs and interests, and are able to understand other people's perspectives. Measures may need to be taken to maximise the ability of people with dementia to communicate their needs. Ideally, part of this dialogue should also be with other health and social care professionals who are not necessarily directly involved but may be able to offer support and advice. These could be your peers or members of your organisation's ethics committee (if you have one).

Component 6: Key values and principles

What are the key values and principles?

Reflect on the values and principles which you feel are related to the current dilemma and possible outcomes based on your understanding of the people involved, the situation and what you have learned from the dialogue. There are several questions you could ask yourself such as:

- What are the main values and principles (see section 2 and Appendix 1) here (e.g. is this mainly about dignity, autonomy or personhood as so forth)?
- How do these values and principles relate to the different people involved?
- Do they have the same meaning and the same level of importance for everyone (e.g. is trustworthiness the main issue and does it mean the same thing to the doctor as it does to the informal carer or to the person with dementia)?
- Are some more relevant or more important than others in this particular situation and for these people?

Component 7: Realistic option/what to do

What are my realistic options and what am I actually going to do?

For many people, the crux of the matter is “what should I do.... or not do?” Hopefully, the above-mentioned components will have provided you with the information needed to enable you to weigh up the pros and cons (arguments in favour and against) and the risks and benefits of different possible options for the particular people involved and in this particular situation (including organisational and procedural constraints). The dialogue with the people involved and consultation with your peers will hopefully have made it clear to you why some options might be more suitable than others in this particular situation. Consider what you think of different possible solutions based on different arguments. Eventually, you will need to determine which of the different options are actually realistic and achievable. Then, you can try to balance/prioritise them and consider how they relate to your own conscience and moral background.

When you have gone through the various components and feel that you have fully examined the options available, make a decision based on what you personally think and feel is “right”. Act on your decision in the knowledge that you can justify to yourself and other people any decisions made, should you feel the need to do so, and that you can communicate your decision to the people involved.

Component 8: Justification and what can be learned with hindsight

Why did I take that approach and what can I learn with hindsight?

The decision you made might not have suited everyone. You might have hoped for another outcome. However, it is important to remind yourself of the effort you made to understand the issues at stake, the complexities involved and the different, often conflicting needs and interests of the people involved. You made a decision which you felt was the best one for those people in that situation.

As the situation unfolds and evolves over time, you might feel with hindsight that another solution would probably have been better. However, it is not always possible to wait and see. You may be able to learn from your experience of how things developed and take solace in knowing that you did your best with the knowledge, skills and possibilities that were available to you at the time.

3. Vignettes

In this section we present a series of vignettes about ethically challenging situations and dilemmas which are quite common in residential and hospital care settings. These are followed in section 4 by commentaries on how these situations might have been effectively approached.

In the commentaries we will explore different possible approaches to the situations described in the vignettes. In addition, we will try to demonstrate (based on additional information which in a real life situation would have arisen from our ethical reflection and the interpretive dialogue), why a particular approach would or would not have been justifiably ethical (in the authors' opinions).

Activity 3

After you have read each vignette, reflect on, and if in a group discuss with others, different possible scenarios for how the situation might have evolved. Be creative. You can imagine any kind of continuing scenario based on how you imagine the dialogue with the different people involved, their values, the constraints on the situation etc. When you have done this, read the commentary we have provided and again see how this relates to your own thoughts and your discussions within the group.

The vignettes are as follows:

1. Mrs Brown and Mr Green (about relationships and sexuality)
2. Angela and life in the nursing home (about truth telling and personal choice)
3. Joyce and her co-residents (about respecting religious practices and spirituality)
4. Mr Smith and his family (about previously expressed wishes and end-of-life treatment)
5. George and his cat (about the "past" and "present" self)
6. Staff Nurse Pickard (about the use of restraint/coercion)

Vignette 1: Mrs Brown and Mr Green (about relationships and sexuality)

There was an uproar at the nursing home. One of the residents had been found in her bedroom, naked to the waist, snuggling into the arms of a male resident, whispering endearments to him. This was witnessed by a care assistant who had entered the room to deliver some laundry.

The woman, Mrs Brown, was a widow with Alzheimer's-type dementia who'd been there for three months, after some incidents at home where her safety was a problem. She had gone out in the night in her nightclothes and was taken to the emergency room at the hospital because the police thought she would not be safe at home. She had a fall at the hospital so it took a while to discharge her. Her daughter and son persuaded her to go into the care home, though she was very reluctant at first and wanted to go back to her own house. Neither adult-child had power of attorney because they'd left that too late, and the doctor and the lawyer said she did not have capacity to assign it to them now. Mrs Brown was sent for respite to the care home and never left.

The man, Mr Green, was an unmarried former seaman, with a younger brother and sister. The sister had power of attorney. His family said he'd always been a heavy drinker and had "a girl in every port". He was in the home because of alcohol-related brain damage. His dementia was not getting worse with good food and care, but he was incapable of surviving at home. His behaviour was problematic, with some violent incidents when he was looking for alcohol, which is not allowed in the home. On reflection, staff noticed that his behaviour had quietened down since he'd struck up a relationship with Mrs Brown, holding her hand and talking to her in the day room. That was a relief for them after so many incidents, where other residents might have been at risk from his rages. He was seventeen years younger than Mrs Brown and very physically fit.

The manager of the care home had a problem. When he talked to the staff he discovered that Mrs Brown actually seemed to think that Mr Green was her dead husband. The daughter, Betty Brown, knew this, and thought it was sweet that her mother had “the comfort of feeling that she is still with dad.” The son, Bill Brown, was horrified. He said, “It’s like sexual assault. Green is taking advantage of my mother’s emotional vulnerability. And probably physical too! She can’t fight that dirty fiend off her!”

Things got worse when talking to Mr Green’s relatives. His sister Greta Green said she had power of attorney and that she wanted to defend her brother’s right to have a relationship. George Green, his brother, who was very pragmatic, said, “Well, I was fed up with the constant incidents. If it keeps him quiet, I don’t mind. But I don’t want to hear that he’s been raping someone. Get him out of there and put him somewhere else, and be done with it.”

The staff had other issues. Nurse Amy said, “I’m not changing those filthy sheets with what’s on them.” Her colleague, Nurse Betty, added, “Well I think it is disgusting. We should give him drugs to stop that.” Celia, a student nurse, said, “Sex is good”, but suggested Mr Green could be managed by getting in a sexual proxy therapist, or a prostitute. Nurse Daisy was so embarrassed she could not speak at the meeting, left, and applied for another job soon after in a shop. She later reported the care home to the inspectors, and even tried the police who ignored her, thinking that it was nothing to do with them. Each of the staff members agreed with at least one of the four relatives, but there was a complete lack of consensus on what to do.

Vignette 2: Angela and life in the nursing home (about truth telling and personal choice)

Angela, a 72-year-old widow, living with Alzheimer’s disease, believes that she is in this nursing home for some special treatment and will soon return home, although actually this will be a permanent placement. Angela is disorientated in time and often questions how much longer she will have to be there. The staff usually answer that the treatment is almost finished. Often, she experiences difficulties with everyday activities and with staff whispering about those difficulties. Frequently, Angela asks “Do I have Alzheimer’s?” A staff member said, “I don’t know what to answer. It’s difficult to lie, but the truth would distress her.” Angela is always asking staff to give messages to her mother who works in a fish factory in the city. A staff member said, “I tried to tell her that her mother had died, but she started weeping. My answer seemed wrong, but on other occasions, when I’ve told her that her mother was too busy working, she has insisted on going to the fish factory to visit her mother.”

In the facility where Angela is staying, they encourage group activities and organise games, cognitive stimulation, physical exercises and reality orientation activities, but she just says that she wants to rest or relax and watch TV in the lounge area. Sometimes, she talks with her new friend, Louise, a single lady diagnosed with Alzheimer’s 3 years ago. The staff consider it important for Angela to participate in these activities but she says, “I’m tired. I have worked my entire life and now I deserve a rest”. For the staff this is a difficult decision. Allowing her not to take part means that she will sleep during the day and will become agitated at night and won’t rest properly, as has happened a few times already. Therefore, a staff member always takes Angela to activities, pushing her wheelchair, despite her refusal. Angela has actually tried to play cards with the other residents but she couldn’t play properly and was confronted with her difficulties by the other residents. Despite the staff’s insistence on her taking part in activities, Angela isn’t cooperating. A staff member said, “I know it is important for Angela taking part in activities, although she seems very frustrated during these. Should we stop trying and let her sleep during the day?”

Vignette 3: Joyce and her co-residents (about respecting religious practices and spirituality)

Joyce is a single lady and a devout Roman Catholic. She is 74 years old and until recently, she lived with her sister. She was diagnosed with Alzheimer's disease 4 years ago. When she was 15, she was involved in a serious car accident in which her brother was killed. She saw her survival as a gift from God and religion became an important part of her life and indeed of her identity. She taught in a Catholic school for nearly 40 years and became an active member of the Catholic Church (e.g. singing in the choir, reading at church services and being responsible for the altar flowers).

Six months ago, Joyce's sister died and she moved into a nursing home. Joyce and her sister had attended mass together every Sunday since they were children. She repeatedly asked staff in the nursing home if she could go to a nearby church but they could not fit this in with the work routines of the home. Joyce seemed despondent and one day said, "I feel like I am being punished. I want to thank God every day of my life for what I have but I can't. I don't even go to church on Sunday."

As she can't get to church now, Joyce often asks to watch Sunday mass on TV in the lounge. Most of the residents are OK about this even though a few clearly state that they would much rather watch horse racing. Joyce can't hear the TV properly as there is too much noise in the lounge on Sunday due to visits and people talking and playing cards. A practical solution would be to let Joyce watch the TV mass in her own room but unfortunately, both Joyce and the nursing home have very limited resources so it is impossible to get another television.

Jane tried to comfort Joyce by praying with her (even though she is not Catholic herself) during her lunch breaks but Charles, another member of staff, criticised her, saying, "This is unacceptable and unprofessional and you should stop it". Jane responded, "When I'm old, I hope I never end up in a place where you need to beg just to be able to pray. This is about Joyce's personhood, you know! It is an important value to be preserved and Joyce's beliefs and religious practices are intrinsic to that value. We are failing to protect and respect Joyce's moral rights by ignoring her spiritual needs." The manager of the nursing home, Derek, agreed to Jane's request to take Joyce to church once a week and pick her up after the service. Jane found a lady she knew to look after Joyce once there. However, Joyce got confused and started wandering around the aisles, singing hymns at the wrong time, disturbing the other churchgoers and repeatedly asking when she could go home. The lady said she didn't want to look after Joyce at church anymore as she was embarrassed and didn't want to be held responsible if Joyce came to any harm.

So Jane was back to square one. She felt really disappointed. She had tried her best to respect Joyce's personhood and promote her wellbeing in the face of opposition and indifference from other members of staff and things had not worked out as she had planned. She didn't know what to do next.

Vignette 4: Mr Smith and his family (about wishes related to end-of-life treatment)

Mr Smith is 83 years old. Nine years ago he was diagnosed with Alzheimer's disease and since September 2014 he has been attending a day care centre for people with dementia. Initially, he came to the centre twice a week, but now he spends six days out of seven there. He is well integrated and, according to his family, this has had positive effects on the situation at home. In the last few months, Mr Smith has changed a lot and he is now at a severe stage of dementia. He is not able to express himself verbally and because of his growing memory loss he can no longer take any decisions on his own. He is therefore dependent on extensive help to complete daily activities such as eating, drinking and washing.

Mr Smith has been living with his wife for 45 years and the rooms on the ground floor of their house have been converted. Mr Smith's bedroom is now on the ground floor, so that Mrs Smith can take care of him. During the day she is helped by caregivers. Furthermore, their son and their daughter are present and help with administrative and/or financial matters. They also accompany their parents to doctors' appointments and give moral support. Besides dementia, Mr Smith has also been suffering from heart failure for two years now. Two weeks ago they found a lung carcinoma and, according to his doctor, his life expectancy is six months. Undergoing chemotherapy would extend it up to two years. Together with her children, Mrs Smith decides that her husband should neither have chemotherapy nor any other life-lengthening treatments.

The daughter informs the staff of the day care centre about her father's state of health and the family's decision to refuse any life prolonging treatments. She also insists, should her father need help, in case of a heart attack for example, that no first aid measures should be taken and no emergency doctor should be called. The person responsible for the day care centre tells the daughter that she would find it difficult to follow these instructions and to pass them on to the staff, particularly because there is no advance directive specifying Mr Smith's wishes.

Mr Smith's daughter suggests that she could put the family's decision in writing, sign it and also have it signed by her mother and her brother but the management of the day care centre won't agree with it, as they say, that type of document does not have any legal basis. Offering no appropriate help or no help at all to Mr Smith in case of an emergency could be a reason to prosecute staff members. Apart from that, it is also against the professional code of ethics for care staff. The family explains that prior to his disease Mr Smith made clear statements about not wanting any unnecessary or life-prolonging treatments. The daughter insists once more that the family's decision ought to be respected and that after all, they pay a lot of money for her father's care. She then leaves the meeting room.

The day care centre manager discusses the matter with staff members during the following meeting. Feeling insecure about how to react in case of emergency, they express their thoughts: "Should I just watch him die before my eyes?" "I would definitely give him first aid and call an ambulance." "If it is Mr Smith's will not to be given first aid, shouldn't his will be respected?" "I will surely help him, even if there is an advance directive not allowing me to do so!" "Should I just watch him choke in front of me?" "How am I supposed to do it right?"

Vignette 5: George and his cat (about the “past” and “present” self)

The manager of the dementia unit at Green Oaks Hospital recently attended a dementia conference and was impressed by a talk about the use of dolls and robotic animals for people with dementia. A few weeks ago, she brought in a robotic cat which responds to touch and sound. George, who has vascular dementia and is in hospital with a broken hip, took a shine to the cat and spends all day with it on his lap. He talks to it and spends hours stroking it and making it purr. All seemed to be going well until George's son visited and was outraged at seeing his father cuddling and talking to a “kid's toy”. He complained to the staff nurse and demanded that the offending cat be taken away from his father. The son described his father as a reserved, “no-nonsense” man who would have been horrified if he had known that one day he would behave like this. The son felt that his father was being tricked into believing it was a real cat and that staff were failing to respect his dignity. Gloria, the staff nurse, was deeply concerned about this. She had got to know George during the time he had been on the ward and had seen a vast improvement in his mood since the introduction of the cat. He was more cooperative with the physiotherapists responsible for his rehabilitation and had recently started to take part in some of the group activities. The son said that this was irrelevant and that it was important to preserve the dignity of the “real” George, namely the father he had always known, and the values his father had always had. Gloria considered this a reasonable argument but nevertheless felt uneasy about taking the cat away based on her impression of the benefits she felt it currently gave George. At the same time, she realised that once his hip was better and he left the ward, he would have to leave the cat behind and that might cause distress.

Vignette 6: Staff Nurse Pickard (about the use of restraint/coercion)

Staff Nurse Pickard was dreading her day on the care of the elderly ward. In Bay 3, a four-bedded unit, there was a lady, Mrs Patel, who had had a stroke. She was known to have vascular dementia. She kept on trying to pull out a nasogastric tube, so in the multidisciplinary team meeting it had been decided that it was in her best interests for restraints to be used and her hands were tied down with big gloves on. Mrs Patel seemed to hate it and spent the whole day shouting, albeit what she shouted did not make any sense. It was agreed that the restraint of her hands should only be for the shortest possible time. But Staff Nurse Pickard did not agree with the decision because it seemed to be against her human rights. The bay had another lady in it with dementia, who had been a bit of a “wanderer”, but they had found an armchair which she seemed to be comfortable in and which she could not get out of, which made life easier. She didn't complain.

Meanwhile, Mr Abode, from Bay 4, was always coming into Bay 3 and he would start trying to take the gloves off Mrs Patel. When the staff tried to explain to him that he wasn't allowed to undo Mrs Patel's hands, he would get quite agitated and threatening. He'd pushed one of the male nurses yesterday and used foul language. Mr Abode is said to have Alzheimer's disease, which makes it difficult to reason with him. As he was involved in a confrontation overnight, the doctors have added lorazepam and haloperidol to his drugs, if he requires them, for agitation. Some of the staff are glad about this and have decided that the key thing will be to get him to take the drugs early, before he becomes too worked up; because then there is more chance he'll take it by mouth rather than having to be restrained to give him an intramuscular injection. Staff Nurse Pickard feels that it would be sad to have to use force and might be humiliating for him even though, having been a nursing assistant in the dementia ward of the old hospital, he has probably used restraint on his patients in the past. All in all, it looked like it could be a trying shift.

4. Commentaries

This section explores different possible approaches to the situations described in the vignettes in section 3. Each commentary tries to demonstrate (based on additional information which in a real life situation would have arisen from our ethical reflection and the interpretive dialogue), why X, Y or Z approach would or would not have been justifiably ethical (in the authors' opinions).

Some of the commentators have structured their commentary around most or all of the components (with less emphasis on the first two so as to avoid repetition of the vignette), whereas others have focused more on one particular aspect such as values or approaches to show how these can be incorporated into ethical reflection and deliberation.

Commentary on vignette 1, the situation involving Mrs Brown and Mr Green



In this commentary, Prof. Chris Gastmans, from the Catholic University of Leuven, Faculty of Medicine, Centre for Biomedical Ethics and Law (Belgium), focuses on the dignity-enhancing framework described earlier (see page 8). He highlights the need to recognise potential vulnerability whilst enabling reasonable risk and draws attention to stereotypes of older people and their sexuality. Prof. Gastmans emphasises the need for dialogue and interpretation amongst all concerned, combined with a supportive environment for staff faced with ethically sensitive situations, and training for staff on intimacy and sexuality within care homes.

Component 3: The context

Sexuality is an important dimension of human identity. Everyone – young and old – needs love, touch, companionship, and intimacy. In nursing homes, however, the need for intimacy and sexual expression is frequently overlooked by caregivers. It seems to be difficult for care staff to contemplate older people as sexual beings. This results in a perception of residents' sexual expression as a behavioural problem rather than an expression of the need for intimacy and sexual engagement. Nurses involved in the case of Mrs Brown and Mr Green reported confusion, embarrassment, anger, denial, and helplessness when they discovered that Mrs Brown and Mr Green had been kissing, hugging and holding hands. These negative experiences may also be the result of the rather limited knowledge of nursing staff regarding aged sexuality (Mahieu et al. 2011).

Component 4: How the situation is experienced

The case of Mrs Brown and Mr Green clearly illustrates how vulnerability and care are closely intertwined. When confronted with an older and apparently vulnerable resident, caregivers want to respond adequately and appropriately to that person's needs. Caregivers feel emotionally touched, not only as professionals but also as persons. Owing to their strong sense of commitment to vulnerable residents, caregivers experience the provision of care as a moral

duty. Moreover, it is particularly with people with minimal rational capacities and considerable physical vulnerability (like Mrs Brown) that care appears to be the way in which another person can connect to them as a person and treat them as a person. Hence, vulnerability is connected not only with care but also with ethics. Ethics manifests itself "par excellence" in situations where a person's dignity is threatened because his or her vulnerable situation and where he or she is unable to force a respectful attitude from fellow human beings.

However, the vulnerability that is linked to our physical existence not only justifies an ethical appeal for protection, but also for our right to live a reasonable risk. Within the context of aged sexuality, the duty to protect especially relates to the risk of unreasonable harm associated with the sexual behaviour concerned. Staff members at nursing homes often find themselves inclined to take an 'extreme cautionary stance' toward sexual relationships involving partners with dementia.

Cases like Mrs Brown and Mr Green are often perceived as actual or potential abuse and as such might evoke a protective and restrictive reaction from staff. If we want to move in the direction of person-centred care we have to be careful not "to prioritise a non-maleficence approach to care – seeking to ensure that the person with dementia is not harmed and avoiding their exposure to risky situations – over an approach based on beneficence" (Vilar et al. 2014, p. 410) that also takes into account the resident's

well-being, wishes and capacity to assent. This warrants the acceptance of reasonable risk as being an inherent part of human existence and person-centred care. This, however, does not mean – in any way – that I wish to deny or ignore the potential risks and ethical complexity associated with sexual expression in dementia care (Mahieu et al. 2015).

Component 5: The (interpretive) dialogue with everyone concerned

Ethical problems relate to the tensions between the responsibilities of people who live and work in a network of relationships (the “relational web”). In this case, the relational web consists of Mrs Brown and Mr Green, the children of Mrs Brown and the brother and sister of Mr Green, the nurses, and the management of the nursing home. To do justice to deciding how to respond to Mrs Brown and Mr Green’s new relationship, it is important to understand the experiences of Mrs Brown and Mr Green, their relatives, and the nurses because Mrs Brown and Mr Green’s wellbeing should be considered in the context of this relational web. Because of the intimate and emotionally sensitive nature of the residents’ behaviour, the relational network has been put under pressure. To reduce this pressure, a solution has to be found that would, ideally, satisfy all parties. The fact that all concerned could claim certain rights is not a deciding factor. Attention should not be paid solely to the residents’ right to sexual expression or the possible claim of their family or their 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 or perspective that brings its own story. Ethical decision-making is therefore achieved through dialogue (i.e. discussion) and interpretation (i.e. achieving a shared understanding that makes sense of the different perspectives).

Component 6: Key values and principles (stereotypes, ageism and leadership)

Let’s focus on the opinion of the nurses as an example. What do they really want? On what information and ethical values are their opinions based? It seems that most of them adhere to the dominant stereotype regarding sexual

behaviour in older people in care. According to this stereotype, older people are dismissed as being either sexually highly inhibited or on the other hand, out of control and disinhibited. However, one could also imagine them radically changing their opinions if they were to receive and be receptive to recent clinical findings on sexuality, dementia and nursing home care. These studies show that sexuality and intimacy indeed remain important factors of well-being for older people, even in persons with dementia or after having moved to a nursing home.

Component 7: Realistic options/what to do

Taking into account the possibility of incomplete and/or incorrect information on the part of the nurses, I assume that the nurses’ wishes are dynamic (i.e. may change over time) and thus should continually be explored. It is only through the process of joint exploration that the wishes of the nurses gradually become clear.

It would have been helpful if the manager of the nursing home had taken time to have a sensitive conversation with Mrs Brown and Mr Green, their relatives and the nursing staff during which they could have explored their viewpoints in order to better understand each other.

Summary and ways forward

Clinical ethics is mainly seen as an ethics of individual relationships between residents, family members and caregivers. However, a careful reading of the case of Mrs Brown and Mr Green makes clear that their 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 their family and the team of caregivers who are also part of the nursing home. A person-centered care approach can only be accomplished within a nursing 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-oriented learning programmes, and the development of a formal nursing home ethics policy on dealing with expressions of intimacy and sexuality by residents with and without dementia.

Commentary on vignette 2, the situation involving Angela and her life in the nursing home



In this commentary, Julian Hughes, who is a consultant in psychiatry of old age at North Tyneside General Hospital and an honorary professor of philosophy of ageing at the Policy, Ethics and Life Sciences Research Centre at Newcastle University (UK), focuses on values (personal and institutional), particularly with regard to truthfulness and individual choice. He reflects on various possible ethical approaches and in relation to this particular situation emphasises a virtue-based approach and the importance of maintaining relationships and of respecting Angela's values insofar as this is possible.

Component 1: The situation

The situation is not uncommon. Staff have to decide whether or not they should tell the truth and to what extent they should force activities on someone who otherwise seems unwilling to participate.

Component 2: The people involved

The key players in all of this are, of course, Angela, but also the staff, who may think differently about the different situations and may well have different values. But other residents are also involved and, again, they may have different inclinations. One of these residents is Louise and it sounds as if Angela and Louise have struck up a genuine friendship. Finally, we don't know whether there is anyone in the family who might be keen and willing to visit Angela.

Component 3: The context

If we turn to think about the context, it is probably true to say that the general ethos in the nursing home is that it is best to be honest with people. There is a hint of this in the way that staff's attitudes are reported. But, clearly, it also seems to be accepted in the home that small lies, sometimes called "white" lies, are acceptable if they serve a good purpose, for instance, if they help to prevent or settle someone's distress. The other important contextual thing to note is that there seems to be a very strong emphasis in the home on encouraging people to participate in activities. In one sense, this is obviously a good thing. Many homes, in reality, provide very little by way of activity and stimulation, so it is good to hear of a home that is really pushing useful and possibly therapeutic activities in the way that this home is. Nonetheless, the context seems to be that the emphasis placed on the importance of participating is such that the institution has, to some extent at least, lost sight of the possibility that people might not wish to participate and that they should have some choice about this.

Component 4: How the situation is experienced

Poor Angela is likely to be quite confused at times by her position in the home. It sounds as if there are times when she believes she is only there for a short while, but then the short while never ends. It also sounds as if she has some insight and a concern that she might have a form of dementia. But when she seeks clarification, it is not always forthcoming and, instead, the subject is changed. Meanwhile, there are times when she is thinking affectionately of her mother and is then fairly abruptly told that her mother is dead. We can sense what a shock this must be for her. Finally, Angela clearly has things that she is happy to do, such as talk with Louise, as well as things she does not wish to do. And yet, she is forced to do things against her will. Moreover, when she does do them, she sometimes finds that she is criticised by some of the other people that she lives with. All of this will obviously be experienced as unpleasant.

Bearing in mind that the staff may have diverse values, their experience of their working relationships with Angela will also be varied. Some of them may feel quite sure and certain that it is best to tell small lies and it is best to encourage her to participate in activities for her own good. But other members of staff may find that this is a conflict for them. They may be inclined simply not to lie. They may also be inclined to respect Angela's autonomous wishes, and yet they have been told that they need to move her to a lounge to participate in something they know she does not like. They might well feel sad for Angela. But, equally, some of them may feel somewhat annoyed with her because of the difficulties that she causes.

Finally, there may be similar reactions amongst the other residents. Some of them may feel sorry for Angela and recognise that she is confused and distressed at times partly because of the things that the staff make her do. But it would also be excusable (in some sense) for other residents to be irritated by the fact that they have to live with someone who causes problems and disrupts some of the activities, which they enjoy. It is, of course, possible to give a psychodynamic

explanation for some of these reactions. The tendency to feel annoyed may reflect fear: both the fear of something different or unknown and the fear that we too could end up in the situation that Angela now finds herself in.

Component 5: The dialogue with everyone concerned

All of these different experiences of the situation would emerge during the next component in our approach to ethical dilemmas which is to engage people in dialogue. They could then express their feelings, which would reflect their own values, but might also include some acknowledgement of their own fears which are kindled by seeing what happens to Angela.

Component 6: Key values and principles

The two main issues here are to do with being truthful and individual choice. These reflect particular values or principles. We tend, as a society, to place value on honesty and clearly there is a tension around this in Angela's case. We also place value on respecting autonomy, which would entail allowing Angela to make her own decisions about things. But there are other principles or values that tug us in a different direction. Beneficence, for instance, or doing good, might make us feel that we should be encouraging Angela to participate in activities. Non-maleficence, or avoiding harm, might make us feel that small lies are acceptable. It is easy to see how we could use some of the well-known ethical theories to think about these dilemmas.

Consequentialist thinking – for instance, whether we feel this is to do with maximising happiness or maximising welfare – might lead us in the direction of thinking that if small lies make Angela happy and support her wellbeing, then they will be justified. Similarly, if we are sure that participation in activities is good for Angela, then we might feel that welfare is maximised by taking her to participate. This helps to emphasise the importance of facts as well as values. For instance, it would be important to know to what extent these activities – cognitive stimulation, physical exercise and reality orientation – actually do help people with dementia and to understand how they do so. We might then think about whether or not the ways in which these activities help are ways upon which Angela would place value.

But it is not at all clear that these consequentialist arguments win the day. Although there is now talk in the literature about “therapeutic” lying, even if there are instances where lying might be therapeutic, one argument against accepting that lies are good in any sense is that, once deceit is seen as acceptable, it may be difficult to stop

it from becoming pervasive. One lie can lead to another. Being permissive about lying is to encourage an environment of deceit. Indeed, there is a branch of consequentialist thinking which does not look at specific acts (i.e., it does not look at the specific act of telling Angela a lie about her mother) but rather looks at rules (i.e., the general rule that it is allowable to deceive Angela). So consequentialists themselves might argue against lying to Angela.

When we turn to the issue of forcing Angela to engage in activities, however, it is difficult to see how the consequentialists can win the argument. It simply seems to cause a good deal of upset both to Angela and sometimes to other residents when she is forced to take part in things she does not wish to.

We could also talk about duties (as in deontology). But this does not seem to get us much further. We could say the staff have a duty to tell the truth to Angela, but they also have a duty to care for her, which includes not causing her distress when they can avoid it. Similar things might be said about the virtues involved: the virtues of compassion, honesty, integrity, fidelity and bravery are all to the fore in a discussion of the dilemmas that surround Angela's care.

But maybe the really important virtue is the one that is called practical wisdom, but is also sometimes called prudence. This is to do with knowing what we are aiming at, but also knowing how we might achieve it. In our discussions with everyone concerned, Angela, but also different staff members and perhaps (keeping in mind the need for confidentiality) other residents, it might well be that we are fairly clear what we wish to achieve. Most good thinking people will simply wish that Angela could be as settled as possible in a state of wellbeing. It would be malicious if anyone wished for anything different. So the issue in terms of practical wisdom is to figure out how to do this without running rough-shod over other important values. We could say, well she must be taken to the activities. We could say that staff must accept that they should tell her small lies. But both of these options encounter difficulties to do with diverse values because they offend the inclination to respect a person's wishes and to be honest.

Component 7: Realistic options/what to do

So what should we actually do? The practical issue is to decide what else can we do that is not overtly dishonest but which helps to maintain wellbeing for Angela. In connection with lying, it may be that we should simply accept that sometimes it is best to tell the truth whatever the consequences. Thus, for instance, it may be better to tell Angela that she does have Alzheimer's disease. Generally speaking, people are able to deal with this news without

catastrophic reactions. It may, indeed, be quite helpful to her. She may have to have things explained to her a couple of times, but it might then help her to understand why people behave in a particular way. It may even help her to understand why it is that she does not recall that her mother has died and it may therefore facilitate this discussion. It may also make the discussion about her permanent care easier. But if some of this news, for instance about her mother's death, is just too difficult for her to bear, it may yet be that some forms of distraction would be better than simple lies. The conversation about her mother, for instance, could be diverted to talk about how Angela was feeling at the time and whether she was missing the comfort of family. Acknowledging these emotions, akin to validation therapy, might be enough to settle Angela. So the staff might develop care plans that include being honest and, where things are more difficult, exploration of feelings in a way that makes deceit unnecessary.

When we turn to the matter of individual choice, the worry is that if we just leave Angela in her bedroom she will lack stimulation and will deteriorate both physically and mentally. But the only alternative to this is not just that she should be forced into group activities. She already has a friendship with Louise. It might be that a sensible thing would be to encourage this and other potential friendships. It might be that Angela responds much better to one-to-one interaction than to group interactions. Staff might look into the possibility of find someone who would be willing to visit the home in order to provide this sort of one-to-one stimulation for Angela. We should also come back to the issue of the family and whether or not there might be someone, perhaps a niece who does not realise that her aunt is in the home, who could visit more regularly and provide a different sort of stimulation. Staff themselves, of course,

if they are not overworked, could set aside short periods of time for one-to-one engagement with Angela.

Component 8: Justification and review with hindsight

The next step is to consider why we have taken the approach that we have. It has partly been taken on the basis of the acknowledgement of diverse values, which has come from talking with all those involved. We have then sought ways to act which are in accordance with as many of those values as possible. We have recognised that some very important values, such as the value given to honesty, should be given more weight, although the drive to be compassionate makes us not wish to do things which will cause unnecessary distress.

In support of much of what we have done here are some very basic notions such as care, friendship and the importance of relationships. Although we have used the language of ethics (e.g. by talking of theories such as deontology) and have focused on virtue ethics as a way to try to explain what we have chosen to do, the reality – the way it actually feels – is that we have just tried to do the best we can, for instance, to maintain relationships; and we have tried to do this in a way that is friendly to as many people concerned as possible. After all, if we truly care for a person, we shall wish to take them seriously and do the best we can for them.

We shall have to see what we learn with hindsight having adopted these policies in connection with Angela. But one thing we can say more quickly is that we need to recognise differences. Whatever the institutional values are, different staff members are likely to have different thoughts and different values, but meanwhile the values of Angela herself must be respected insofar as this is possible.

Commentary on vignette 3, the situation involving Joyce



In this commentary, Lucília Nóbrega (MA), who is a psychologist and trainer at Alzheimer Portugal in Funchal, Madeira (Portugal), focuses on the importance of personal identity in relation to spirituality and touches on issues related to solidarity and autonomy. Lucília suggests that it may sometimes be beneficial to involve the local community in the dialogue and emphasises the need for a supportive working environment, especially when staff do not agree on the best approach to take. She also emphasises the need to learn and grow from possible setbacks and challenges.

The story of Joyce reminds me of a person with Alzheimer's disease who once said to me "All I was is being stolen from me". Joyce feels that she is losing an important aspect of her life. Religion is an important part of the life of many residents in nursing homes and if we don't meet this need, we aren't caring for the whole person. Here, we explore this particular case using the structured approach to tackling ethical dilemmas in daily practice.

Component 1: The situation.

Joyce recently moved into a nursing home after her sister, with whom she lived, passed away. Since then, Joyce, who has Alzheimer's disease, is struggling to maintain a meaningful aspect of her life, namely her religious practices.

Component 2: The people involved.

Joyce is at the centre of this whole situation but we need to take into account the other residents, staff members and the nursing home manager. It would be important as well to know whether Joyce has other relatives and how far we can involve the local community. Regarding the family, we only know that Joyce's nearest relative was her sister. We don't know if she has other relatives who could be a partner in her care. Other important key partners could be the local communities and volunteers.

Component 3: The context

The institution appears to be open to change in its attempt to respect Joyce's religious needs. The staff members, like Jane, are aware of the importance of maintaining Joyce's personhood and respecting her religious beliefs and the manager has eventually accepted the plan to take Joyce to church. Another contextual factor is the limited resources of Joyce and the nursing home which limit Joyce's possibility to continue practicing her religious faith. The nursing home does not seem to have already established a partnership with community institutions or volunteers but the actions that the nursing home has taken indicate that it may be open to their involvement.

Component 4: How the situation is experienced

Joyce experiences this situation, in her own words, as a punishment. She considers her life as a gift from God and her faith is fulfilled through various religious practices, which are becoming difficult to maintain. Her situation isn't being ignored by staff members or the other residents. Even though they don't have the same interests as Joyce, they respect her spiritual needs and allow her to watch the Sunday Mass in the lounge. Regarding the staff, we have clues in the text, that some staff members, like Jane, feel solidarity with regard to Joyce's situation and feel that the other staff have let Joyce down. It is known that some staff members, such as Charles, don't agree with some of the actions that Jane has taken. Staff should be sensitive and aware of the religious identity of the residents in their care. The nursing home manager, Derek, maybe experiences Joyce's situation as a challenge, and might feel that respecting her personhood and her life story goes over and above certain institutional constraints. Finally, a member of the local community, a churchgoing lady, found Joyce's situation as difficult to handle, maybe feeling initial solidarity and later confusion and fear.

Component 5: The dialogue with everyone concerned

Dialogue with other key players should give us some guidance on how to deal with ethically sensitive situations. Jane, to some extent, provided a good example when she talked to Derek about the possibility of Joyce attending church. This shows how dialogue can be a source of information about potential partners, the values they hold and about which alternatives exist when faced with ethically sensitive situations.

Component 6: Key values and principles

Autonomy, solidarity and personhood are some of the principles and values that are at stake in Joyce's case. Autonomy can be respected through the maintenance of Joyce's activities and practices related to her catholic faith and by ensuring that she has the possibility to express her values. Joyce's autonomy may clash with that of the other residents, as can be seen from what happened in the lounge. Fortunately, Jane isn't passive. She argues that the nursing home has a duty to preserve Joyce's personhood, and thereby, to respect her beliefs and religious practices, by promoting solidarity, personhood and respect for autonomy.

Component 7: Realistic options/what to do

The spiritual needs of residents are overlooked in many nursing homes. Each resident must be respected and valued as an individual and a well-run nursing home must look after the needs of the whole person. We are not considering the whole person if we are unaware of a person's religious identity. Respect for this religious identity is a need that must be met. Therefore, it is important for carers to learn more about residents' religious beliefs. Nursing home managers should ensure that the religious identity of residents is noted on the admission form, along with important dates and practices related to the practice of that religion (or to specific spiritual beliefs).

Clearly, we must always take into account the other residents. Participation in religious activities should not interfere with their activities and rights. Should one individual's wish take priority over that of other people? Joyce has the right to enjoy her Sunday mass and the other residents have the right to enjoy their Sunday activities. In this case, can we forget that Joyce is vulnerable? No, and

we mustn't. There are many constraints but it is essential to enable Joyce to continue with this meaningful activity. Moreover, there are many ways to address Joyce and other residents' needs and sometimes we need to adapt activities, show willing and be creative. Many church communities do volunteer work and, as stated earlier, it should be important to the nursing home to be open to the local community. Members from these communities with knowledge about dementia could accompany Joyce to church, be with her and take part in some meaningful activities. If praying with Joyce contributes towards her wellbeing and respects her personhood and her right to express her autonomy, we might consider it a good thing. It would be important to know if there are other residents with similar interests and past activities as Joyce so that activities could be developed in keeping with a meaningful theme such as praying or celebrations. Besides the local communities, an important step would be to find out if Joyce has any relatives who might be interested in doing some activities with her. With good support, a person who lives with dementia can achieve wellbeing throughout the course of their disease. With appropriate support, not only from Jane, Joyce could continue to practice her religion and continue to be a whole person.

Component 8: Justification and what can be learned with hindsight

We must take into account that religion is an essential part of many of our residents, giving a purpose and a meaning in life, and that it can improve their psychological wellbeing. One of the things that people most fear in nursing homes is the loss of their personhood and this is Joyce's fear. Many practical answers exist to Joyce's case, but whatever the answer may be, it should give her the opportunity to engage in lifelong meaningful activities. Jane's actions, with hindsight, must be ethically valued as she promoted Joyce's values, a key duty of care workers, even if the final result wasn't what Jane had hoped for. Many of us have felt, like Jane, discouraged. However, we should view negative outcomes as challenges in that they give us an opportunity to grow and learn. This learning should motivate and enable us to continue to work on addressing the ethically challenging situation, and to reflect on what could have been or be done differently, whilst always trying to engage the key partners involved.

Commentary on vignette 4, the situation involving Mr Smith and his family



In this commentary, June Andrews, who is Professor in Dementia Services at the University of Stirling (UK), focuses on the relationship between law and professional carers' ethical duties. She explores the options for carers in situations where they are expected to obey orders which are contrary to their ethical principles. Prof. Andrews also highlights the need for clarity from employers as to what is expected from staff, and for everyone to take responsibility for themselves in relation to future end-of-life decisions.

Component 1: The situation

An old man with dementia and cancer is near death and everyone wants to do their best for him.

Component 2: The people involved

A family seems to want to fulfil the wishes of their father, and a care centre manager wants to do the right thing within her powers. Her care workers want to maintain their own integrity. And the father can't now say what he wants. As a society with ethical standards operating within a legal system, we are all involved.

Component 3: The context

This context involves law and professional guidelines. The care centre manager states that she cannot legally withhold

treatment. That is not allowed unless there was an advance directive. She implies that if only there was an advance directive she could do what the family wants, because it would be proof that Mr Smith wanted it. If she is right, this is the end of the matter in respect of Mr Smith and his family. They left it too late.

No third party can make you do something illegal, even your employer, or a paying customer. You need to know the status of advance directives in your own country so you can be sure of your ground in these matters. Care companies need to have an organisational policy, to avoid problematic situations which occur too late, when there is no time to discuss and explain. Perhaps the rule is not so hard and fast as the manager says but she has to do what she believes is right until someone proves to her that she is wrong about the law. The time to do that would have been when writing

the organisational policy or when Mr Smith started coming to the centre.

Here is a second context issue. Your employer can make you do something that is legal. It is not unknown for staff working in health and social care to be asked to do things that they feel are against their conscience and to mount a legal challenge. Recently two midwives in Scotland went to court to appeal against an employment requirement that they should comply with processes leading to abortion. They lost that case. If you take a job, you have to do what the employer requires, as long as it is within the law, and abortion is within the law in Scotland. In Mr Smith's day centre, at this time, staff demonstrated to their manager in so many words that they would not just let someone die even if told to do so. They are out of control and an employer has an ethical and legal duty to manage their staff. It is easy to see why this is vital in care work.

Component 4: How the situation is experienced

Everyone is different. Let's look first at the manager and care staff. Let's assume that the care staff feel that even if there was a legal document protecting the action of withholding treatment they could not do it. This is a training and employment issue for the manager. Like the Scottish midwives, if they don't like it they have to do other work. They might as citizens try to change the law but employees have to do what they are told if it is legal and foreseeable. Disobedience as an employee could only ever work once. Then you'd be dismissed for breach of contract. If a member of my team tells me in advance they won't do what I might reasonably ask of them, and are adamant about that, they have to leave at once because that is already a breach of contract.

Component 5: The dialogue with everyone involved

From the point of view of the family, and everyone else including Mr Smith, language is very important here. One might argue that stopping a person from choking is "first aid", like removing a bit of food from the back of the throat, and that an advance directive is usually about "medical treatment" like inserting an intravenous line. One might argue that it is natural to die of disease, but not from an accident. These staff members do not distinguish between an accident that they should always prevent and a process of dying that they may have to facilitate. An advance directive from Mr Smith would be unlikely to request that he should be allowed to fall out of windows or wander into the traffic, or choke himself with the wrong food, but it

might say, "Don't treat". "Keeping me safe" and "treating me" are two different issues for most people. The time to have discussed this is now past.

What about the writers of professional codes? The professional code of ethics of the care staff must be open to inspection. It cannot require them to defy the law. It is a guide on how to do what is right but cannot cover every complex eventuality. However, the dignified end to life is an issue that affects every single human being, and as such the code of conduct needs to have been clearer about whether it holds out punitive measures for getting it wrong.

Component 6: Key values and principles

Well, everyone wants to prevent Mr Smith suffering. However, talking about the advance directive gets no one anywhere if the law is clear and Mr Smith failed to take action in time. The ethical challenge to care staff, about whether you become a collaborator when your employer is asking you to obey orders that are contrary to your ethical principles – this is the complex issue here. Problems occur when unanticipated issues arise. However, this sort of issue is very common in our work with people with dementia, so we all need to think ahead. Failure to do so is a sort of negligence, which gives rise to suffering for everyone concerned.

Component 7: Realistic options/what to do

What is everyone going to do? The family must learn for the future, for themselves and future generations. The employer must be clear with staff about what is expected, so that staff can be clear for themselves and with clients from day one. The professional organisations must have a listening ear to discover if they should give clearer guidance or even lobby the government to change the law on these issues if the law causes unnecessary suffering. Society must realise that this is going to be an increasing issue if we all continue to age successfully.

Component 8: Justification and what can be learned with hindsight

What can we learn with hindsight? We must all as individuals take responsibility for ourselves in order to try to avoid the muddles that will continue to arise for those of us who would not, or could not, address these issues for ourselves in time, before cognitive impairment set in. We need to do this to help and support those who are going to help and support our old frail future selves.

Commentary on vignette 5, the situation involving George and his cat



In this commentary, Dr Fabrice Gzil, who is research programme manager at the Fondation Médéric Alzheimer in Paris (France) and coordinator of Social Sciences for Dementia, a pluridisciplinary research network for ageing citizens with cognitive disabilities, focuses on the ethical implications of using robotic animals in the context of dementia care. He explores different views of personhood, particularly in relation to the concept of the “past” and “present” self. He also refers to different ethical approaches and values surrounding honesty, dignity, wellbeing and personal choice.

Component 3: The context

The situation presented in the above vignette might become more and more frequent in the future. Having animals visiting people in hospitals or in nursing homes has been shown to decrease levels of agitation and increase social behaviour. However, real animals can be unpredictable, can transmit disease and may provoke allergies. Thus, various robotic animals have been developed to offer the benefits of animal-assisted therapy in environments in which real animals could not be easily accommodated. For example, cat robots exist which purr and meow like any normal cat, but they do not make any mess and their detachable fur can be washed.

Component 4: How the situation is experienced

Gloria analyses the situation through a “consequentialist” approach. She is focused on George’s wellbeing and tries to follow the principles of beneficence. She has seen an improvement in George’s mood since the cat was introduced to him, and she thinks it might also be beneficial to George’s physical wellbeing. Robotic animals are sometimes criticised because they might replace human relationships. Yet, it doesn’t appear to be the case here, since George recently started to engage in some group activities, which was not the case before. Thus, not taking the cat away might be the best option to promote George’s current wellbeing and future functional autonomy.

Gloria’s point of view could be supported by some studies from the literature (Misselhorn et al., 2013), providing some evidence that interacting with robotic animals might reduce stress and anxiety, provide pleasure and peace of mind, give a sense of nurturing and an opportunity for attachments, and result in improved health. However, for some authors, those studies rely on casual observations and should be confirmed by more evidence-based studies. What’s more, Gloria feels that the robotic cat is beneficial to George, but other factors might explain the improvement in George’s mood. Similarly, Gloria believes that leaving the cat behind when he leaves the ward might cause distress

to George, but one could also argue that as soon as he is back home, George might forget the robotic cat and possibly enjoy interacting with real cats and dogs. Some studies indicate that people are fascinated by robotic animals for a short period and that there is a loss of interest after a few weeks or months.

George’s son – let’s call him Mark – analyses the situation from a “deontological” or rights-based perspective. From his point of view, it is not George’s immediate wellbeing which should guide decisions. Rather, what should be promoted and respected above all is George’s dignity. Mark doesn’t deny that the cat might have some benefits, but he considers that the robotic cat is an offense to George’s dignity, because it is both deceptive and infantilising (amounts to treating him like a child). Mark feels that his father is being tricked into believing the cat is something with which he could have a true relationship. And Mark is appalled at seeing his father playing with what he considers to be a “kid’s toy”.

Mark’s point of view could also be supported by literature on this matter. Some authors consider that using a robotic animal involves a combined risk of humiliation, loss of dignity and deception. Although robotic animals can create positive effects, like “therapeutic dolls”, they are based on the idea that people with dementia are going through a second childhood (Cayton, 2006). This notion is dispiriting and encourages a deficit-based approach to care. However, for other authors, it is not clear that the benefits of robotic companions depend on deceiving people about their true nature and it is not necessarily the case that interacting with robotic pets means treating people like children. People with dementia might develop pleasure from acting as if the robot could understand them, without thinking that it is actually capable of perception and feelings. This argument is especially relevant in George’s case, since unlike other robots, the robotic cat responds to touch and sound but cannot show simulated emotions such as surprise, happiness and anger. It cannot respond to its name, it doesn’t have the ability to detect human social gestures and does not respond with human-like social cues. Thus, it is possible

that George enjoys interacting with the robotic cat, whilst being fully aware of its mechanical nature (similar to the use of Tamagotchi² in adults with no cognitive disabilities).

Component 5: The dialogue with everyone concerned

Little or no information is provided in the vignette about any attempts to talk to the people concerned, not even to George, about how they feel about the situation, their values and what is important to them. I will come back to this later.

Component 6: Key values and principles

Mark and Gloria disagree because Mark has a “deontological” (or dignity-focused) approach whereas Gloria has a “consequentialist” (or well-being focused) approach. Whilst both of them are deeply concerned by the value of singularity or personhood, i.e. by what makes George unique and determines who he is and his individual interests, they radically disagree when it comes to putting this important value into practice. Thinking about personhood, Gloria focuses on George’s current needs and future capabilities. What matters for her is that George experiences the least discomfort and distress possible and that he recovers the use of his hip. For Mark, in order to honour George’s personhood, one should not only consider George’s current situation and immediate interests (i.e. things that now cause him comfort or distress) but also and primarily George’s past values and critical interests (i.e. what George has always considered a dignified life and what he consequently would have regarded as an undignified life). For Mark, it is of crucial importance to consider the narrative, i.e. what has made George who he is and what is meaningful to him based on his past character. The “real George”, Mark argues, would certainly have considered that for an adult, enjoying playing with a robotic cat and believing it to be a real animal, is contradictory with a dignified life. He would have regarded the pleasure of that play as ridiculous and childish.

So what is the main ethical dilemma about in this specific case? Well, it is very difficult to argue that Mark’s or Gloria’s point of view about personhood is the right one. Both

opinions have been defended by outstanding moral philosophers reflecting on dementia care. Gloria, like Rebecca Dresser (1986), focuses on George’s present self, whilst Mark, like Ronald Dworkin (1986), focuses on George’s past self. Mark refers to the father he had always known, but Gloria had got to know George during the time he had been on the ward and she has some knowledge about how things are experienced by people with dementia. In other words, the question here is not “who knows George best?”. The question is an ethical one, namely “which George is it morally important to consider – the past one or the present one?”. It is quite impossible to answer this question. One cannot disregard George’s past self and former convictions when caring for his present self. Similarly, one cannot disregard George’s present self, his current wellbeing and his actual needs because of the values he held before having dementia (Gzil, 2009).

Nonetheless, there appears to be a limitation in Mark’s argument. In claiming that the “real George” is the one that existed before he had dementia, Mark implicitly introduces the value of autonomy or self-determination. He argues that the past competent George should have authority over the present George who has dementia and that because the George he used to know would have been horrified if he had known that one day he would act in that way, the care staff should take the robotic cat away. This argument is not correct because Mark speculates about what his father would have wanted. It seems that George never explicitly stated what he would or would not want should he have dementia. If George had written an advance directive, stipulating that he didn’t want care staff to use robotic animals with him, Mark’s claim about autonomy would perhaps be more convincing. But in the absence of expressed wishes from George himself concerning this specific topic, one can hardly determine what George would have wanted.

This doesn’t mean that Mark is wrong when claiming that the past character of his father should be taken into account or that Gloria should disregard Mark’s concerns. Moreover, we should note here that it might be easier for care staff than for relatives to consider the person with dementia “here and now”. Care staff know about dementia and are dedicated to the person in their care, but family members, who have known the person for a long time, and might miss the person they knew before, might not easily accept that their loved one has changed and now has very different needs

2 A small electronic toy with a screen, programmed to behave as if it were a pet

and capabilities. Thus, even if Mark is not right in claiming that the “real” George is the George that existed before he had dementia, Gloria should nevertheless listen to what Mark says about it being important to respect George’s dignity. This might be a way for him to express his sadness about the changes he has observed in his father, who no longer resembles the father he used to know.

Component 7: Realistic options/what to do

The lack of dialogue with everyone concerned makes the dilemma quite difficult. First, we know very little about the context: How do other patients in the dementia unit, their family members, and the care staff consider George’s behaviour towards the robotic cat? Poorly trained care workers or “unsuspecting” relatives and friends might make fun of someone interacting with a robotic cat, or they might see the robotic cat as demeaning, patronising and inappropriate. Second, we also know very little about George’s family: Does he have a wife, other children or grandchildren? What do they think about the robotic cat? Did George appoint one of them as a proxy? Last but not least, we know very little about how the situation is experienced by the central character of this story, i.e. George himself. Is he aware that the cat is actually a robot? Does he care about it? What would he say, if asked to comment on his interest for the cat? Did he ever have a cat? Does he like cats? More importantly, does he only have “immediate interests”, i.e. things that make him comfortable or distressed or does he still also have “critical interests”, i.e. things that make him happy or unhappy? What are George’s current values? What does he really care about? (Jaworska, 1999) Given all these uncertainties, it seems that Gloria should proceed with humility and not feel that she has any special importance that makes her better than anyone else to make a good decision. Since it doesn’t appear that Mark has been designated as proxy by his father, he should proceed with the same humility.

It might be worth considering here that George is not in a nursing home but in a hospital. If the problem had occurred in a nursing home, the ethical dilemma would have been slightly different: the decision would possibly have had consequences for a much longer period of time; the use of a real animal, instead of a robotic animal, could possibly

have been a matter of debate; and the rationale for using animal therapy would possibly have been different. Here, we know that George will stay in the hospital ward for at most a few weeks. Then he will go back home or in a nursing home and he will have to leave the cat behind. This could be an argument that Gloria – or rather the manager of the dementia unit who brought the cat on to the ward – may use, since the “interpretative dialogue” would be worthwhile pursuing. The care staff could try to explain to Mark that providing George with a robotic cat doesn’t mean that they consider him like a child, or like a person who can only enjoy very basic pleasures and can be easily deceived. They could make it clear that they are not transferring their social caring responsibilities for George to a robot, that they are deeply concerned about George’s rehabilitation and that they know that George values his functional autonomy, but that they have also noticed that because of his cognitive disabilities, he is very uncomfortable at the hospital and doesn’t spontaneously engage in the rehabilitation process. In other words, the care staff could make it clear that the robotic cat is only one but a key element in a more global caring strategy intended to maximise the chances that George can walk again and live independently at home, since it is one thing that he appears to strongly care about. However, if Mark is the only relative visiting George, or if he has been appointed as a proxy, and he insists on the cat being taken away, then – given the still limited scientific evidence supporting the use of robotic animals in dementia care – it is difficult to see how the care staff could proceed against his will.

Component 8: Justification and what can be learned with hindsight

The analysis of this case shows that the use of robotic animals in dementia care can, in some very specific circumstances, be beneficial to people with dementia, but that there are outstanding ethical issues attached to it. In order to improve the lives of people with dementia, robotic technology should be introduced with foresight and careful guidelines (Sharkey and Sharkey, 2012). It is of crucial importance that, before introducing robotic animals, care staff have an in-depth discussion with people with dementia and their relatives, and are prepared to tackle the ethical dilemmas associated with the use of those technologies.

Commentary on vignette 6, the situation involving Staff Nurse Pickard on the elderly ward



In this commentary, Dr Alistair Niemeijer, who is assistant professor in care ethics and lectures at the University of Humanistic Studies in Utrecht (Netherlands), focuses on the conflict between the ethical principles of “duty of care” and (respect for) autonomy. He argues in favour of a move towards a new definition of autonomy and of the need to challenge standard conceptions of risk.

As Nurse Pickard unfortunately knows all too well, shifts where one has to constantly make tough decisions can be incredibly trying for a caregiver, particularly when it comes to something as fundamental as limiting or overriding the autonomy of the person you are caring for. The freedom to decide where to go or what to do is a central moral principle (and indeed human right). Many of the moral dilemmas that are raised in dementia care are often issues that draw attention to the conflict between the ethical principles of duty of care and (respect for) autonomy. Autonomy is often described as (personal) control, freedom of choice and/or movement and ‘self-rule’ of the person with dementia. Duty of care can be interpreted in terms of the ethical principles of beneficence and non-maleficence (e.g. by providing more safety or by protecting people with dementia from harm).

In this example, several forms of restraint might be distinguished, though some are more subtle (a comfortable armchair from which a person can’t get out) than others (fixating a person’s hand or administering medication which affect behaviour). In other words, safeguarding people by restricting them in one way or another could be perceived as an intrusion on the autonomy (and consequently freedom) of the person with dementia.

The whole notion of autonomy is, however, not very straightforward in the case of people with dementia, since autonomy is commonly linked with rational agency and/or decisional capabilities. It is often maintained that people with dementia have a diminished capacity to make decisions, so how appropriate is the basic notion of an ‘autonomous person’ with regard to the actual living situation of care-dependent people, i.e. vulnerable people such as people with dementia? In order to answer this question, it might be helpful to try and move towards a different concept of autonomy, one which is not simply based on self-determination (*negative freedom*), but on the remaining capabilities (*positive freedom*) of the care recipient and his/her actual experience of freedom.

Nevertheless, upholding patient or client safety, which is often defined as “freedom from accidental harm” (Kohn, Corrigan and Donaldson, 1999), is generally considered by care professionals as an integral part of their professional care activity. It is also manifested by an array of safety and quality measures within each care setting, aimed at both protection from and prevention of future harm recurring (Mitchell, 2008). These can include different forms of restraint, which although often viewed as a “necessary evil”, are ultimately aimed at improving safety and quality of care.

With regard to the case of Mrs Patel, there appears to be a contradictory aspect with regard to the aims of using this form of restraint, at least from an institutional point of view, as it is generally conceived as something which is in her *interest*, because it protects her from (self-inflicted) harm. However it might be argued that restraining could be more harmful to Mrs Patel. To date, there is little empirical evidence that restraint actually *does* increase safety. In fact, most research points to numerous negative physical and psychological outcomes associated with its use, and in some cases using restraint can actually lead to more unsafe situations (including more falls). Nevertheless, restrictive measures seem to be primarily inspired by the desire to minimise risk.

Accordingly, the rationale for the manner in which the restraints were used by Nurse Pickard seemed, at least in part, to be based on a certain (sometimes very explicit) fear amongst the medical staff of incidents that might (re)occur. This fear can result in an aversion to risk-taking combined with unwillingness to use (softer) alternatives to physical or pharmacological restraint. Nursing and medical staff seemed to anticipate a ‘catastrophe’ (Beck, 2006). The (un)predictability of the behaviour of different individuals with dementia appears to play an important role here, and seems to reinforce the feeling among nursing and support staff that a catastrophic outcome is indeed realistic and consequently, that physical restraint is warranted.

For example, in my own research I have seen several nurses who tried to be accommodating to people with dementia who “wandered” by increasing their area of movement. However, once the person was perceived to be at risk, which would be compounded by those people who did get lost, distressed or bothered other people, staff would revert back to the previous physically restrictive measures to minimise risk – even though these measures also involve risks (cf. Niemeijer et al., 2014).

Of course the reluctance to take risks and keep someone out of harm’s way by nursing staff is perfectly understandable, also given the fact that the need to protect the care recipient’s safety at all costs appears not only to be an institutional need, but one that is borne out of external (societal) pressures at all levels. What then needs to be changed so that increasing autonomy can be considered as an attainable value instead of as something which might have potentially ‘catastrophic’ outcomes?

By challenging standard conceptions of risk and safety, values can come to the surface that have been so deeply rooted as to have been invisible and which might have proved an impediment to any change. For example, in opposition to the ‘total institutionalisation’ of people with intellectual disabilities in the 1970s, the term ‘dignity of risk’ was coined by Robert Perske to challenge professionals going too far in their effort to protect and keep vulnerable people safe (Perske, 1972). Reflecting on the potential benefit of experiencing day-to-day risk, Perske pointed to the need of vulnerable people to be able to take chances, which requires adopting new skills. Every endeavour is accompanied by an element

of risk and that every opportunity for growth carries with it the potential for failure. When people with dementia are denied any dignity of risk, they are being denied the opportunity to learn and recover (Parsons, 2008). Respecting the dignity of risk does however not preclude staff intervention to preserve or enhance autonomy, rather, it emphasises a person’s potential to learn and the possibility to make wrong decisions, which not only involves the person with dementia, but also those that care for him or her.

Therefore, encouraging, supporting and embedding normative learning processes of care professionals institutionally is important when organising good care for people with dementia. Instead of being left alone in learning to know their experiences with difficult issues such as restraint and determining decisions upon them, both staff and care recipients should be supported in this process of becoming aware of their decisions and searching for what matters. Whatever the environment, wandering or other ‘risky behaviour’ should ideally not be viewed as an expression of a disease that needs to be treated or secured and controlled, but as a form of communication, which, despite our limited understanding of the phenomenon, is interpreted and responded to in terms of what is driving the behaviour (O’Neill, 2013).

By fundamentally (re)drawing on a care vision of safety, whereby care for vulnerable people is considered as a “practice of risk” instead of a “practice of protection” (Lopez et al., 2010), allowing for, responding to and learning from indeterminacy, including “risky” behaviour, this might provide a starting point in offsetting and opening up the prevailing discourse of safety in dementia care.

5. Conclusion

We hope that you have found this publication helpful and enjoyed working through the different vignettes, perhaps also sharing your thoughts and feelings about them with your colleagues and peers.

We have emphasised throughout the importance of taking into account the lived experiences of people involved in dementia care practices, of interpretive dialogue, of respecting the values and wishes of the person with dementia, insofar as this is possible, and of taking personal responsibility for addressing situations and issues which are ethically sensitive and thus threaten the provision of person-centred care to people with dementia. This does not mean resolving single-handedly every ethically sensitive situation or dilemma you encounter but rather reflecting on ethical issues linked to the provision of dementia care in

nursing home and hospital settings, addressing issues that are within your power to address, seeking the involvement of others when this is not the case, challenging unethical care practices and sharing the insight you have gained with others. Moreover, ethical reflection is a central part of providing good dementia care and should be promoted through ongoing professional training.

In the introduction to this publication, we described our aim as being to provide materials which would enable you to reflect on a range of ethically challenging situations, empower you to tackle any ethical dilemma you might encounter and enable you to reflect on the approach you adopt and, if you feel the need, to justify that approach to yourself anyone who might ask.

ACTIVITY 4

As a last activity, we would like you to go back to the two vignettes in the introduction (the one about Mrs Grey and the one about the two sisters) and have a look at the notes you made (for Activity 1). In the light of what you have read, your reflection and your possible interaction with others, consider what your responses might be now... perhaps a little different, perhaps not. In any case, we hope you will now:

- find it easier to reflect on ethically challenging situations and ethical dilemmas,
- feel empowered to tackle situations/dilemmas similar to those described in this publication,
- feel able to reflect on different ethical approaches to tackling such dilemmas and
- feel able to justify your approach to yourself and (if you see fit) to others.

6. Building an ethical infrastructure – a message to organisations

Caring for people with dementia in an ethical manner is not an option but a fundamental component of good care. This document was developed to provide guidance and training for health and social care professionals in nursing homes and hospitals faced with ethically sensitive situations and dilemmas in their work with people with dementia. However, as mentioned in the introduction, achieving ethical care and learning how to deal with such situations takes place in a particular working environment, which is affected by a range of factors such as staffing levels, skills and training, collaboration with colleagues, the hierarchical structure, budgets, laws and organisational procedures.

Despite these constraints, which determine to some extent the range of options available to individuals and teams, we emphasise the need for each health and social care professional to accept personal responsibility for ethical care and

to address ethical dilemmas and challenging situations when encountered. To achieve this, they must be able to count on the support of their organisation. Ethical care must be a priority for those responsible for running the care homes and hospitals in which they provide care for people with dementia.

Some of the factors mentioned above (e.g. time, cost, high staff turnover etc.) may result in some organisations being reluctant or unwilling to address certain care practices and situations which may be ethically challenging for their staff and for people with dementia in their care and/or to provide an appropriate and supportive atmosphere for the provision of ethical care. However, failure to address such issues may lead to an escalation of a challenging situation and have a negative impact on the physical and mental wellbeing of staff, people with dementia and informal carers.

It is essential that those responsible for the organisation/provision (rather than the direct/person-to-person delivery) of dementia care build an organisational ethical infrastructure (i.e. a general context/environment allowing ethical analysis and empowering professionals who have to tackle ethical dilemmas with skills and opportunities to share their thoughts).

The following suggestions may be helpful in this respect:

- Build up a practice of moral deliberation/reflection.
- Integrate this into your organisation's vision and objectives.
- Involve people with dementia and informal carers in your ethical infrastructure.
- Consider teaming up with other organisations and sharing ethical expertise (e.g. an ethics advisor or ethics board) if yours currently lacks the necessary means.
- Work on capacity building in ethics (e.g. training in ethics and in ethical reflection).
- Provide staff with the necessary time and support to discuss ethically sensitive situations.
- Create an environment in which staff will feel safe to reflect on situations.
- Involve and value staff of all levels, not just those in higher positions, in your ethics committee.
- Consider ethics in all work undertaken and in all reports.

7. References/reading list

- Baldwin C, Hope T, Hughes J, Jacoby R and Ziebland S (2005). *Making difficult decisions: the experience of caring for someone with dementia*. Alzheimer's Society.
- Beck U (2006). Living in the world risk society. A Hobhouse Memorial Public Lecture given on Wednesday 15 February 2006 at the London School of Economics. *Economy and Society*, 32: 329–345.
- Cayton H (2006). From childhood to childhood? Autonomy and dependence through the ages of life. In Julian C. Hughes, Stephen J. Louw, Steven R. Sabat (Eds) *Dementia: mind, meaning, and the person*, Oxford, UK: Oxford University Press, 277–286.
- Dresser R (1986). Life, death, and incompetent patients: conceptual infirmities and hidden values in the law. *Arizona Law Review*, 28, 3: 373–405.
- Dworkin R (1986). Autonomy and the demented self. *Milbank Quarterly* 64 (suppl. 2): 4–16.
- Fulford KWM (2004). Facts/values: ten principles of values-based medicine. In: Radden J (Ed.) *The Philosophy of Psychiatry: A Companion*. New York: Oxford University Press, 205–234.
- Fulford KWM, Peile E and Carroll H (2012). *Essential Values-Based Practice*. Cambridge: Cambridge University Press.
- Gzil F (2009). *La maladie d'Alzheimer: problèmes philosophiques*. Paris, Presses Universitaires de France.
- Gastmans C (2013). Dignity-enhancing nursing care: A foundational ethical framework. *Nursing Ethics*, 2, 42: 142–9.
- Hughes JC and Baldwin C (2006). *Ethical issues in dementia care*. Jessica Kingsley Publishers.
- Jaworska A (1999). Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philosophy and Public Affairs*, 28, 2: 105–138.
- Kohn LT, Corrigan JM, Donaldson MS (Edit.) (1999). *To err is human: building a safer health system*. Washington, DC: National Academy Press, Institute of Medicine.
- Longneaux JM (2014). L'éthique à la recherche bien-être, l'engagement de chacun. *Speech at the colloque "Maladie d'Alzheimer: L'éthique à la recherche du bien-être"*. Huy, Belgium, 24 April 2014.
- López D, Callén B, Tirado F and Domènech M (2010). How to become a Guardian Angel. Providing safety in a Home Telecare Service. In: Annemarie Mol, Ingunn Moser, Jeannette Pols (eds.). *Care in practice. On tinkering in clinics, homes and farms*, 71–90.
- Mahieu L, Van elssen K & Gastmans C (2011) Nurses' perceptions of sexuality in institutionalized elderly: a literature review. *International Journal of Nursing Studies*, 48, 9: 1140–1154.
- Mahieu L and Gastmans C (2012). Sexuality in institutionalized elderly persons: a systematic review of argument-based ethics literature. *International Psychogeriatrics*, 24: 346–357.
- Mahieu L, Anckaert L and Gastmans C (2014). Eternal sunshine of the spotless mind? An anthropological-ethical framework for sexuality in dementia care. *Medicine, Health Care and Philosophy*, 17: 377–387.
- Mahieu L, Anckaert L & Gastmans C (2015). Intimacy and sexuality in institutionalized dementia care: clinical-ethical considerations. *Health Care Analysis* (in press).
- Misselhorn C, Pompe U & Stapleton M (2013). Ethical Considerations Regarding the Use of Social Robots in the Fourth Age. *GeroPsych*, 26, 2: 121–133.
- Mitchell P (2008). Defining patient safety and quality care. In: RG Hughes (Ed.), *Patient safety and quality: An evidence-based handbook for nurses* (Vol. 1; pp 1–1–1–6). Rockville, MD: Agency for Healthcare Research and Quality (AHRQ).
- Niemeijer AR, Depla MFI, Frederiks BJM, Francke AL & Hertogh CPM (2014). The use of surveillance technology in residential facilities for people with dementia or intellectual disabilities: A study among nurses and support staff. Exploring the benefits and drawbacks. *American Journal of Nursing*, 114, 2: 28–37.
- Parsons C (2008). The dignity of risk: challenges in moving on. *Australian Nursing Journal*, 15: 28–29.
- Perske R (1972). The dignity of risk. In: W. Wolfensberger (ed.), *Normalization: The principle of normalization in human services* (pp. 194–200). Toronto: National Institute on Mental Retardation.
- O'Neill DJ (2013). Should patients with dementia who wander be electronically tagged? No. *British Medical Journal*, 346: 3606.
- Sharkey A and Sharkey N (2012). Granny and the robots: Ethical issues in robot care for the elderly. *Ethics and Information Technology*, 14, 1: 27–40.
- Villar F, Celdran M, Faba J & Serrat R (2014) Staff attitudes towards sexual relationships among institutionalized people with dementia: does an extreme cautionary stance predominate? *International Psychogeriatrics*, 26, 3: 403–412.

8. Acknowledgements

Alzheimer Europe would like to express its sincere thanks to the members of the ethics working group who donated their time, energy and expertise to make it possible to produce this publication. Please find below, in alphabetic order, details about their respective backgrounds and a photo of each person. This was a very dynamic working group and this publication is the result of a great deal of reflection and discussion between all members of the group.

Professor June Andrews FRCN is Director of the Dementia Services Development Centre at the University of Stirling. She is a Fellow of the Royal College of Nursing and has received a Lifetime Achievement Award from the Chief Nursing Officers of the UK. She has also been recognised with the prestigious Robert Tiffany International Award and the Founders Award of the British American Project. She headed the Royal College of Nursing in Scotland, and directed the Centre for Change and Innovation within the Scottish Government in addition to her career in the NHS. She advises health departments and service providers around the world and is author of *Dementia; the One-Stop Guide*.



Lydie Diederich (MA) joined the Alzheimer Association of Luxembourg (ALA) in 2000 after having obtained her diploma as a graduated educator in Liege. From 2000 to 2005, she was in charge of a day-care centre for people with dementia. In 2005, she obtained a Masters in Gerontology from the University of Luxembourg. From 2005 to 2007, she prepared and coordinated the opening of the specialised nursing home “Beim Goldknapp” in Erpeldange where, since its opening in 2007, she has been the Director. Then, in 2010, she became a member of the board of directors of ALA.



Chris Gastmans, PhD, is Full Professor of Medical Ethics at the Catholic University of Leuven, Faculty of Medicine, Centre for Biomedical Ethics and Law, Belgium. His dissertation for his doctoral degree in theology was a critical study of the historical, anthropological and moral theological foundations of nursing ethics, conceptualised as an ethics of care. He teaches and carries out research in the field of end-of-life ethics, elderly care ethics, nursing ethics and empirical ethics. He is Past President of the European Association of Centres for Medical Ethics (EACME).



Debby Gerritsen, PhD, is Leader of the Mental Health Research Programme at the Department of Primary and Community Care of the Radboud University Medical Center in Nijmegen, the Netherlands. Her research regards frail elderly people with and without dementia receiving long-term care. She focuses on their quality of life, mental health and the measurement of patient outcomes in long-term care. The topic of her PhD thesis was QoL and its measurement in nursing homes, which has resulted in several international peer-reviewed publications. She is a member of Interdem, a pan-European research group on detection and timely INTERvention in DEMentia.



Jean Georges has been the Executive Director of Alzheimer Europe since 1996. Prior to this, he worked as a journalist and as a parliamentary assistant to members of the Luxembourg and European Parliament. He was responsible for setting up the European Dementia Ethics Network in 2008 and has since contributed towards several ethics projects in that context.



Dianne Gove, PhD, is Director for Projects at Alzheimer Europe. She is also Chair of Alzheimer Europe's Ethics Working Group. Her background is in psychology, education and psychotherapy (analytical Gestalt therapy). In 2013, she was awarded a PhD from the University of Bradford for her research into general practitioners' perceptions of dementia and how these relate to stigma. She has directed several projects (e.g. focusing on legal rights, assistive technology, palliative care, advance directives, social support and continence care).



Fabrice Gzil, PhD, is Research Programme Manager at Fondation Médéric Alzheimer in Paris, France. He is also the coordinator of Social Sciences for Dementia, a pluridisciplinary research network for ageing citizens with cognitive disabilities. His PhD thesis entitled "La maladie d'Alzheimer: Problèmes philosophiques" was about the early history of dementia, the epistemology of animal models of Alzheimer's disease and the ethics of dementia care. His current work aims to promote within society a culture of dementia focused on human rights and dignity.



Agnes Houston was diagnosed with early onset Alzheimer's dementia in 2006 at the age of 57. She is an active member of the Scottish Dementia Working Group. In 2012, she was elected Vice Chair of the European Working Group of People With Dementia and is also a board member of the newly formed Dementia Alliance International. She has campaigned for best practice and improving the lives of people with dementia, especially regarding sensory issues and dementia in Scotland and received a lifetime achievement award by Alzheimer Scotland in 2013. In 2015, she was awarded an MBE.



Dana Hradcová is a Managing Director at the Centre of Expertise in Longevity and Long-term Care at Faculty of Humanities at Charles University in Prague. Her dissertation in applied ethics was an ethnographical study of relations in which care is shaped in nursing homes for people with dementia in the Czech Republic. She works as a consultant for the Czech Alzheimer Society and carries out research in the field of long-term care for people with dementia and people with learning disabilities.



Julian Hughes is a Consultant in Psychiatry of Old Age at North Tyneside General Hospital and an honorary professor of philosophy of ageing at the Policy, Ethics and Life Sciences (PEALS) Research Centre at Newcastle University, UK. His research and writing are mainly about philosophical and ethical issues in connection with ageing and dementia. He has a particular interest in palliative care in dementia. His clinical work focuses both on care homes and on behaviour that people find challenging. He is currently deputy chair of the Nuffield Council on Bioethics.



Caroline Kilty, PhD, is a Module Leader on a course entitled "Contemporary Perspectives in Dementia across the Continuum of Care", on a post grad Gerontology programme at University College Cork (Ireland). Caroline has worked at the Alzheimer Society of Ireland for 8 years, as Nurse Manager. Caroline completed her PhD in the area of early onset dementia, and works as a post-doctoral researcher at UCC.



Denis Mancini (MA) has been working for the Alzheimer Association of Luxembourg (ALA) since 1996. He was in charge of a day-care centre for people with dementia for ten years and coordinated six day-care centres for two years. Then, in 2010, he became the Director of Outpatient Services of ALA where he is currently responsible for the conceptualization and implementation of quality care. Initially trained as an educator, in 2015 he obtained a Masters in Gerontology from the University of Luxembourg with a focus on dementia and coaching.



Alistair Niemeijer (PhD) studied philosophy at VU University in Amsterdam and Applied Ethics at Utrecht University. He conducted his PhD research at the department of Elderly Care Medicine at VU University Medical Center. Currently, he works as an assistant professor in care ethics at the University of Humanistic Studies in Utrecht and as a postdoc researcher at the department of Social Medicine at VU University Medical Center, where he coordinates a qualitative research project on reducing restraints in residential care.



Lucília Nóbrega, who has a Master's degree in Health Psychology from the Psychology and Science Education Faculty of University of Porto, collaborates with Alzheimer's Portugal (Delegation of Madeira), promoting several activities with people living with dementia, in groups and individually, and with caregivers, training and support groups. She also collaborates with some nursing homes, promoting several activities with older people and providing training to care workers and professionals.



Eila Okkonen, PhD, has worked as a professional nurse in various Finnish hospitals and has been a Senior Lecturer at a nursing college, a Project Manager at the University of Applied Sciences and the Head of a centre for education. She is currently Executive Director and Editor-in-Chief at Muistiliitto. She has a Masters in Health Care and Teaching from the University of Helsinki, where she also obtained her PhD for her research into psychosocial risk factors, coping styles and subjective health of patients. She is also a member of The National Advisory Board on Social Welfare and Health Care Ethics.



Jan Oyeboode, PhD, is Professor of Dementia Care at the Bradford Dementia Group, University of Bradford and is an honorary clinical psychologist in Birmingham and Solihull Mental Health Foundation Trust. She has a longstanding interest in caregiving, including running carers' groups, and writing about and researching caregiving. Her research has included studies of the morale and training needs of staff looking after people with advanced dementia in hospital wards; and she also has an interest in end of life and bereavement research.



Natalie Rigaux (PhD) is Professor of Sociology at the University of Namur (Belgium). She has focused for many years on dementia: first, providing an epistemological critique of the medical discourse on dementia, then through an observation of professional practices in a specialised nursing home and now conducting an ethnographical observation of the life of people with dementia living at home with the help of their family and professionals. Her main perspective is that of moral and political sociology.



The vignettes (short stories/cases) and commentaries were written by the following members of the working group and further developed through discussion between all members of this group. Our aim, in involving experts in ethics, dementia, professional dementia care and living with dementia in this process, was to help ensure that the vignettes reflect realistic situations and that the commentaries are informative and meaningful to readers.

Title of short story/case	Author of short story	Author of commentary
Mrs Grey	Debby Gerritsen	
The two sisters	Dianne Gove	
Mrs Brown and Mr Green	June Andrews	Chris Gastmans
Angela and life in the nursing home	Lucília Nóbrega	Julian Hughes
Joyce and her co-residents	Lucília Nóbrega	Lucília Nóbrega
Mr Smith and his family	Lydie Diederich and Denis Mancini	June Andrews
George and his cat	Dianne Gove	Fabrice Gzil
Staff Nurse Pickard	Julian Hughes	Alistair Neimeijer

Appendix 2 was written by Julian Hughes and Lucília Nóbrega.

Alzheimer Europe would also like to express its sincere gratitude to the health and social care professionals who provided independent reviews in the form of detailed feedback on the penultimate draft of this document. This contributed towards the validation of the group's work and also consisted of constructive advice concerning several issues which we subsequently amended. The independent review included (in alphabetic order):

- Aileen Beatty, from the United Kingdom, was formerly Lead Clinician of the Behaviour Support

Service for people with dementia in North Tyneside and now works for the Care Quality Commission.

- Patrícia Castro, from Portugal, is a social worker at the Alzheimer Association's Delegation of Madeira.
- Deolinda Fernandes, from Portugal, is a nurse who works in a nursing home.
- Gonçalo Fernandes, from Portugal, is a psychologist at the Alzheimer Association's Delegation of Madeira.
- Roland Mbe Ngang, Geronom, from Finland, works at the Uudenmaan Seniorikodit Oy (Nursing Home for Seniors), Villa Lauriina in Espoo.

Appendix 1 – Ethical principles, values and related concepts

Autonomy	Traditionally described as the condition or quality of being independent and being able to decide what should happen or be done to you. However, it is increasingly recognised that people exist in the context of relationships, engage in give and take, and are interdependent. Relations, institutional conditions, legislation and dementia therefore affect the exercise of individual autonomy.
Beneficence	All forms of action intended to benefit or promote the good of other people.
Compassion	Deep awareness of the suffering of others coupled with the wish to relieve it.
Conscience	Our personal, inner judge of what is right and wrong, based on shared understandings and practices.
Confidentiality	Keeping information we have learned in confidence secure and private; not divulging it to other people without permission.
Discernment	Having sensitive insight and being able to make judgements and decisions without being unduly influenced by personal attachments and external influences.
Familism	The subordination of personal interests and prerogatives (e.g. specific and personal rights and privileges) to the values and demands of the family.
Historicity/ Narrative	The person’s life story, what has made them who they are; what is meaningful to them based on their past.
Integrity	Strict adherence to a set of consistent moral values and principles; acting in accordance with one’s core beliefs.
Humility	Not feeling that you have any special importance that makes you better than anyone else.
Justice/equity	Treating people equally and fairly.
Non-maleficence	Not doing what might be harmful or hurt somebody.
Privacy	Freedom from unauthorised intrusion or observation.
Singularity/ Personhood	What makes a person unique and determines who they are and their individual interests.
Relationality	The importance of trusting relationships. The way we experience ourselves in relation to others.
Truthfulness/ fidelity	Telling the truth/being true.
Trustworthiness	The state of deserving confidence.
Virtue	An inner disposition which enables a person to live well or flourish as a human being.
Vulnerability	Being in need of special care and protection especially in situations where one’s rights and needs might not be respected.

Appendix 2 – Short examples to describe ethical theories

Each of the following vignettes/short stories reflects a different ethical theory or approach to an ethically challenging situation. We have based them on different people and different situations to those already described in the publication so that you can reflect on a broader range of situations and potential ethical dilemmas.

Consequentialist approach

Mary has been a resident in the nursing home for four years and she now has severe dementia. For some years she has been plagued by urinary tract infections and it has been difficult more recently to find antibiotics which work because the bugs have built up resistance. She has now had two quite bad chest infections. On both occasions she has been taken into hospital from the nursing home. On both occasions it has not been possible for staff to do anything therapeutic for her because of her marked agitation. She gradually improves back in the nursing home, but she has now developed a further chest infection and seems to be very ill. There is a worry that she might die, but she is not accepting medicines by mouth and she remains agitated. A decision has to be made about whether or not she should be taken into hospital. The staff involved discuss amongst themselves and with the family the consequences of the different options and decide that nothing would be achieved by a further hospital admission that could not be achieved in the care home with familiar staff in familiar surroundings. It seems quite likely that her wellbeing or welfare will be maximised by her staying in the nursing home, rather than being admitted to hospital again, so this seems to be the right thing to do.

Deontological approach

Mrs Martin is known always to have been a very proud lady who was careful with her appearance. She now has severe dementia. Her personal hygiene has been deteriorating. She eats her food in a very messy way, which leaves stains down the front of her blouse. She is also sometimes incontinent of urine and occasionally of faeces. She refuses to wear pads of any sort. She hates any form of personal intervention. She becomes very agitated and physically aggressive when staff try to bath her or to change her clothes. They have, therefore, adopted a policy of tolerating her poor personal hygiene. However, there comes a point at which her smell and appearance are upsetting for other people. Moreover, her family can confirm that she herself would never have wished to be seen in such a state. The care home, therefore, work out a care plan underpinned by their perception of their duty of care. They recognise that they have a duty to respect Mrs Martin's autonomy, but they are concerned about her dignity and the risk of infections if her personal hygiene is not attended to at some point. So, on the basis of duty, they agree amongst themselves and with the family that they will intervene and provide personal care when there is faecal or urinary incontinence. They will also change her clothes at least once daily and make sure that she has had a bath at least once a week. Part of the reasoning is that the staff feel that they would wish to be treated this way themselves and, therefore, they feel they have a duty to treat Mrs Martin in a similar fashion.

The rights-based approach

Albert loved to walk around the nursing home garden and get some exercise, but owing to his balance problems he needed a walking stick. He tended to forget this and last week he fell and broke his arm. He said he was trying to catch a cat that he thought he had seen. Some staff in the care home felt that Albert should now not be allowed out into the garden on his own but this meant that Albert would sometimes become upset because there were not enough staff to take him out when he wanted to go. He said that he understood that he might fall over but he said he would be more careful. Although some staff were not convinced by this and thought it would be unsafe, the majority view was that Albert had a right to take risks and a right to do what he wished to do, given that this was not harmful to anyone else and given that it was important for his quality of life. Therefore, it was agreed that he should be allowed to go into the garden, but that staff would always make sure that when he did so he had his stick with him and he would be reminded that he needed to keep his stick on him the whole time he was out. The staff were able to make this into a sort of joke with him. But the important thing was that he was not restricted or deprived of his liberty and, despite the risks, his right to self-determination, at least to this extent, was upheld.

The fairness approach

The Oak Tree Nursing Home organises weekly tours for residents and tries to give everyone who has some degree of mobility the opportunity to go out in the rented bus. They usually go down to the seaside, which is close by, for an ice cream. Sometimes, however, the number of staff available to help with these trips is very limited. In that case, they can only take one or two of the residents. They usually tend to take the more mobile residents on these occasions. For the sake of fairness, however, the senior carer keeps a register of who goes on the trips and tries to make sure that the outings are distributed evenly amongst the residents. Some residents require extra staff, but the aim is that all residents should get out, insofar as is possible, an equal number of times.

The common good approach

Elizabeth is a smoker and when she was admitted to the nursing home she couldn't break this old habit. It was forbidden for her to smoke in her bedroom and, because of the health risks posed by "passive" smoking, she was also not allowed to smoke in the lounge. The staff understood, however, that Elizabeth felt better when she could smoke as she had always done in the past. So provisions were made for a protected area to be constructed in the garden just outside the door of the care home where Elizabeth could go to smoke. In this way, she was not restricted in what she could do, but the common good of all was kept in view. It could be said that this was an inconvenience for Elizabeth, but the staff made sure that the shelter in the garden was well protected from poor weather and they always made sure that someone was free to go with Elizabeth when she went for a cigarette so that she was not lonely. The key principle, however, was that the good of the overall community was maintained in an amicable fashion.

The virtue approach

Lately, Simon had been talking about his parents and saying that they were waiting for him to visit them. He would insist on the need to leave the nursing home to return home. Staff felt that it was wrong to lie to him and wanted to be honest with him, but they knew that Simon really believed his parents were alive and they felt that telling him the truth would be very distressing. Therefore, when Simon talked about his parents as if they were alive, the staff would tactfully divert his attention to other current issues in his life and avoid having to tell him directly that his parents were dead. In this way, they were trying to avoid telling him an outright lie, which would have been dishonest, but at the same time they were showing the virtues of compassion, fidelity and practical wisdom.

Appendix 3 – Checklist for reflecting on ethical dilemmas and ethically challenging situations

1. The situation in a nutshell. Please write a brief sentence summarising the situation as you see it.

2. Who is involved in/affected by the current dilemma?

Who might be involved/affected?

Who (if anyone) caused the situation?

What is your relationship (role) vis-à-vis the main people involved?

How are you affected by the situation?

What responsibility do you carry for resolving the current dilemma?

Who else needs to be involved to resolve the situation?

3. What is the context in which the situation occurs?

Where is the dilemma occurring?

day care centre

residential care home

hospital/clinic

other: _____

When did the dilemma start or become apparent?

Are there constraints/guidelines to consider?

budgetary

organisational

professional guidelines

a law/legal directive

ethics policy

other: _____

4. How do you think the situation is experienced by everyone involved?

5. About the dialogue with everyone involved

What have you learnt from talking to the people involved?

In addition to the dialogue with the people involved, who else have you consulted?

colleagues hierarchical superior ethics committee other: _____

6. Which principles, values and related concepts seem to be at stake?

- acting with compassion
- acting with integrity (in accordance with your own beliefs)
- avoiding what might be harmful or hurt the people involved/affected
- balancing and respecting the family versus the personal interests of those involved/affected
- being able to exercise discernment (sensitive insight)
- being truthful and trustworthy
- exercising humility
- promoting the good and wellbeing of the people involved/affected
- respecting confidentiality, privacy and/or dignity (circle relevant responses)
- respecting the right for people to make decisions about their lives/what should happen to them
- respecting the uniqueness of everyone concerned
- taking into consideration potential vulnerability, dependency and/or power relations
- treating people fairly and equally
- understanding the life stories of the people involved/affected
- other: _____

7. Taking possible action or reacting

What are your main/realistic options?


What do you think the major argument against your decision might be?

How would you refute this argument?

How do you feel about your decision?

8. (LATER) What did you learn with hindsight?



The background of the page is a solid green color with several large, white, five-pointed stars scattered across it. The stars are of varying sizes and orientations, creating a decorative pattern.

This publication is about the kinds of ethically challenging situations and ethical dilemmas faced by health and social professionals of all levels who provide care for people with dementia in care homes and hospital settings. It contains short stories based on typical situations which professional carers might encounter, along with exercises and appendices to encourage and facilitate ethical reflection, structured guidance on how to tackle ethically challenging situations and commentaries from experts in the field of ethics as well as professional care.

The publication should ideally be used in the context of professional care training (e.g. with moderated group discussions, professional guidance and role playing) and adapted to the different levels of education and experience of the readers. It doesn't provide ready-made answers but hopefully, in the context of ongoing professional training, it will contribute towards empowering and motivating health and social care professionals to provide ethical care, and tackling ethically challenging situations with more confidence, thereby contributing to the wellbeing of their clients, colleagues and themselves.