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TAD (Thoughts About Dementia) Newsletter

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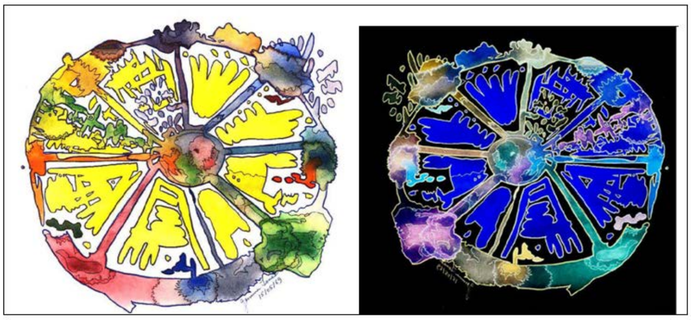


TAD 63 19 April, 2020

The ACCORDION method for solving dilemmas in dementia care: example of a person getting lost outside repeatedly

Related ideas for observations, reflection and research

. Have you ever come across a 'care-giving dilemma' in which you struggled to make a choice, because you didn't know how to:
    - achieve the 'very best possible outcome' for the person with dementia?
    - balance the various and competing needs of the person with dementia?
    - balance the needs of the others involved in the dilemma/situation?

. Did you ever read about, or take a course in 'problem-solving care dilemmas' or 'ethics in caregiving'? If you've been reading about this subject, you may have noticed that finding *general references to* dilemmas and interventions is easier than finding *detailed* descriptions of just how a particular intervention was chosen to solve a specific situation. (That's why some 'worked examples' are provided here, and in subsequent TADs.)

. How are care dilemmas solved at your workplace? Is there a system used for doing this? Do you document how you did this?

. Did anyone ever teach you how to write down 'the thinking process' that you/they went through, in order to come to try to find a choice of intervention/solution for a difficult situation?

. Do you think that a course in 'solving care-giving dilemmas' was, or would have been helpful to you in your involvement with or planning care for a person with dementia?

. Have you ever chosen to do something to help someone by following your own conscience, whilst knowing that other people would likely have made a different choice? Did you think about how you would justify your choice if you had to write it out?

Dear Reader,

This TAD 63 newsletter is a long one - it describes: a way of working through and documenting dilemmas in dementia care; illustrates this with a detailed example: and provides copies of blank templates for you to try using it. (The next few TAD newsletters will give other examples of working through dilemmas in dementia care.)

In this TAD you will encounter three sets of numbers to correspond to:

- **9 steps in the method,** to describe each letter in the word/mnemonic 'ACCORDION',
- **4 core principles**, which all medical dilemmas and dementia-care dilemmas, are based upon
- **8 values**, which have been selected to discuss dilemmas arising specifically in dementia care

This material is like a crash-course. It's designed to be practical, thorough, and of immediate use to readers, even without having had any 'formal' experience of solving and documenting care dilemmas (sometimes called ethical problem-solving).

Although I originally developed this ACCORDION method for caregiving staff in a nursing / residential home, (who did not have any formal education in dilemma solving *), it can also be used by family/friend carers, and others who are involved in the care of a person with dementia.

To help make this TAD more readable, two *links* have been added to direct you to additional pages of text about 'assumptions', 'terminology', and some ' blank templates' of the ACCORDION Method for you to use for your own work.

Can you describe to others how you solve dilemmas?
Everyone solves problems – somehow – in one way or another. We often follow our own 'thinking process', privately, in our head. The trouble with this is that, if asked to, it can be difficult for us to explain or write down, just what our thinking was and what vocabulary/terms and concepts we were using.

So, the main advantage of using some type of 'method' to help solve care dilemmas is that it can be discussed and written down in a consistent, comparable way.

Introduction to the 'Accordion Method' for solving dilemmas in dementia

The word '**ACCORDION**' is used here as a mnemonic, to help readers recall and work through **all** the steps involved in this method.

The 'ACCORDION Method' **is only one way** of working through and recording the 'thinking process' that goes into choosing a solution or intervention for a care dilemma. There are other methods [e.g. 20, 21. 24. 26]. But inevitably, any 'dilemma-solving method' (ethical problem-solving method) that you use, or have heard of, uses words like '**principles**' and '**values**'. Regardless of which method you (learn to) use, the number of steps may differ but essence is the same:

- a dilemma is described
- principles, values and interests are considered
- various related examples and options are weighed up
- a care intervention is eventually chosen, documented evaluated, and re-evaluated.

Choosing one principle or value** over another can be a painstaking and painful process – hence the word *dilemma*. What can also make this choice difficult is that colleagues, and/or others involved (stakeholders), may select or prioritize things differently than you do.

If there are other methods, what's the advantage of using the ACCORDION method?
It is useful for people who have not had formal teaching about solving care dilemmas. Since caregiving professionals have a legal 'duty of care' and have to make decisions for, and act on behalf of people with dementia, they may need to show evidence of how a specific decision was made in someone's best interests. (Demonstrating a *desire* to do one's best for another may not be sufficient.)

The advantage lies in its **thoroughness and (relative) simplicity**. Individuals and teams can use it and there are **prompts to provide facts and details** while following the 9 steps, so that essential information and questions can be considered. Although working through the steps in this ACCORDION method may seem long and effortful at first, compared to thinking it through in your head (and it is), like all things, it gets easier with experience. (Later, you'll take short cuts.)

About dilemmas and solving dilemmas
Dilemmas come in all sizes and shapes; they may occur daily or infrequently. There are many situations for which there is no obvious 'easy', 'best' or 'right' outcome, and yet, family carers and professional caregivers *do* need to make decisions and respond to them – sometimes rapidly. Differences of opinion (conflicts) are inevitable since people have different values, experience and viewpoints. Some situations are exceptionally difficult to re/solve; they are complex, involving many values, people, and conflicting interests. This is why solving dilemmas is done on an individual basis.

We all solve dilemmas - some quickly and automatically, some slowly and agonizingly. It can be difficult to explain to others 'just what our thinking was' to come to our final choice of actions. Trying to solve dilemmas can make us feel inadequate and powerless because, although we want 'to do the best thing possible', it isn't obvious what that is, and/or, others may not agree with the way we see things. When we have learnt a given method for thinking through dilemmas, it can help us to describe the rationale we used to make a particular decision, and to explain to others how we saw that one option (care intervention) seemed a better starting place than another one.

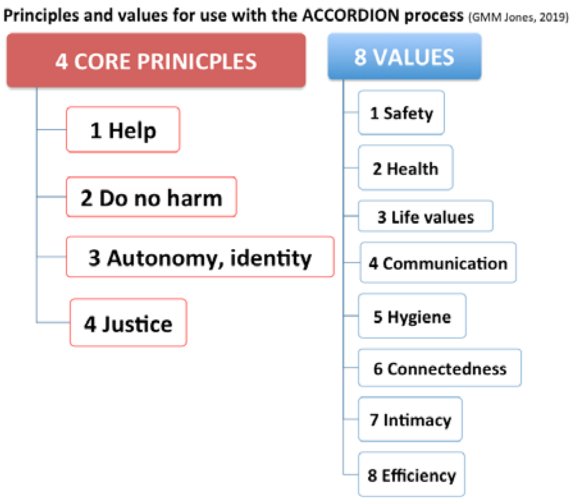
A care dilemma is about a conflict that arises from trying to choose between different *principles* and ***values*** (see below), **people and priorities**. The conflict comes from finding several things worthy of striving to achieve, though **they cannot all be fulfilled** or honoured – and not simultaneously; the 'best outcome that can be imagined' may not be achievable.

Solving care dilemmas is about deciding which **principles** and/or **values** apply most to a given individual, situation, and context - and then weighing the various possible solutions or interven-tions against each other, before making a final choice. There are no pre-set solutions that work for all situations. I repeat, **solving care dilemmas is always bespoke and personal** to achieve the best solution for each person involved in a given situation.

The 'principles' and 'values' listed in **Box 1**, below, form the basis for discussions about ALL care dilemmas, even if other words are used to describe them. (They are explained later in more detail.)

The next thing to appreciate is that **'principles' are considered more important than 'values'**.

Box 1 Summary of concepts to use for solving dementia care dilemmas



So, with that as a starting point, we can also consider which people involved in a care dilemma, these principles and values apply to. **Tool 1**, below, can help you remember who is involved, and in what way, during your thinking and discussions. This tool has been marked with 'x' to show the points that will be considered in the example to follow. **Note:** not every category will be relevant.

Tool 1: to assist in the discussion of a dilemma
A table for indicating the principles, values, and people involved

	Person with dementia	Spouse partner	Other family, friends	Caregiving (paid) staff	Services, organisa-tions involved	Others: attendees, residents in care settings	Others …
4 CORE PRINCIPLES							
1 Help	x	x	x		x		neighbours x
2 Do no harm	x						
3 Autonomy/ identity/privacy	x	x					
4 Justice							
8 VALUES							
1 Safety	x						
2 Health	x	x					
3 Life values	x	x					
4 Communication	x	x					
5 Hygiene							
6 Connectedness	x						
7 Appropriate intimacy							
8 Efficiency					x		

The list in **Table 1** provides more information about beliefs, core principles, values, and legislation that pertains to solving care dilemmas. If you are a professional caregiver, the **examples of dilemmas** given for each of the 8 values, will likely be very familiar to you.

Table 1- Key details about beliefs, core principles, values, and legislation

	Description	Comments
Beliefs and assump-tions **embedded in this documentation**	**About 'personhood' and quality of life** . As individual humans **we all have equal dignity** (inherent moral worth), whether that is affirmed (acknowledged, respected and protected) by others or not. People retain their dignity and worth, even when they have dementia.	. "A person with dementia is the 'same' person, despite changes in mood and behaviour" (20) . " A person with dementia is of equal value to a person without dementia". (20) . With 'good care' and support, people with dementia can have a good quality of life in all stages of the dementia (illness/condition). . **'Quality of life'** is dependent on both the **principles** and **values** listed.
4 Core principles **All affect quality of life**	These are also sometimes referred to as **moral principles** (1)	Core principles: **these are the most essential for solving dilemmas** and **they take priority over the '8 values'** (below, in blue).
	1 Help, heal, benefit (beneficence) - to optimize health/wellbeing without bringing people to harm	Q Is the intervention helpful for everyone involved in this dilemma and implementing the intervention?
	2 Do no harm (non-maleficence) - do not do anything to minimize or jeopardize the well-being of the person	Q Will any person/s be harmed by the intervention?
	3 Respecting, supporting autonomy, well being and identity This refers to the right of an individual to behave and make choices freely - without interference from others, or without infringing on this right for others. **Autonomy includes** the right to **privacy.** Trying to maintain the autonomy of a person with dementia can cause various dilemmas. E.g. Which autonomy needs to be respected – **'past autonomy'** or **'present autonomy'**? **In most situations, 'present autonomy wishes'** (and evidence of choices made in the present), **weigh more heavily than 'past autonomy choices'**. This is especially so if the decision is of **crucial** versus **marginal** importance (24). - ***Crucial importance***: moral/religious/spiritual convictions, or previous lifestyle choices of long duration, meaningful to life) - ***Marginal importance***: things which increase pleasure or pleasantness momentarily or briefly	Q Does the intervention foster/maximize free choice? Q Is consent or 'informed consent' needed? Q Are privacy and personal data respected? Q Is the person 'competent' with regard to the dilemma or issue at hand: . do they have a DEPRIVATION OF LIBERTY SAFEGUARDS (**DoLS**) in place? (to change to a Protection of Liberty Safeguards (**PLS**) since new 2019 legislation) . If not, is DoLS (or PLS) assessment needed? . Is an advocate needed? Q Is the person with dementia is permanently disoriented in time? place,? person, ? or situational context ? Q Are they frightened, How do we respect the person's perception of their identity (and their roles and responsibilities), in the present moment?
	4 Justice, fairness The wish of the person is respected as much as possible, whilst the needs and wishes of others are also considered. This may involve considerations of solidarity and reciprocity.	Q Is anyone (of all the stakeholders) endangered, put at risk, stigmatized or discriminated against as a result of the proposed intervention?

8 Values for caregiving	**These 8 values have been chosen to assist with solving dilemmas in dementia care** **They, like the 4 principles, also affect quality of life**	**Note: In other fields, different values may be chosen -** E.g. in entertainment, high-security work, public health nursing, banking, retail business, disaster relief planning, counselling
Value 1	**Safety** – **physical, perceptual, emotional**	**Examples of dilemmas involving this value** . difficulty **driving**, **cooking**, using gas fire, being alone in the house . the **safety, cleanliness, tidiness** of the living environment . a person does not appear to notice that their presence and friendly advances cause another resident to become aggressive . a person **does not recognize danger** (e.g. estimating traffic speed) . a person becomes **frightened every time a particular person visits alone** (e.g. their eldest son) visits alone, and remains upset for hours afterwards . a person appears to be **terrified whenever they see a particular resident**; staff don't know whether to leave them in the same lounge or separate them . a person **often gets lost when they go out** and causes major upset and searches; they refuse to use a GPS (tracking) device
Value 2	**Health** – **physical and emotional wellbeing**	**Examples of dilemmas involving this value** . **the use of sensory and prosthetic aids** (e.g. glasses, hearing aids, dentures, limbs); are they useful, cumbersome, or unhelpful for a person with dementia at a particular stage? . to what extent should **mobility and exercise** be encouraged (pushed?) when person is resistant, in pain, and does not seem to have a good quality of life, and thinks it cannot be improved? . a person doesn't remember how often they have fallen, or, the advice or appliances they've been given to reduce falls and does not follow/use it . a person enjoys unhealthy eating, drinking, smoking, and use of drugs though it damages their health e.g. a person with dementia with high blood pressure is using increasing amounts of salt; a person who is diabetic, using too much sugar, but in the short-term, get sensory pleasure from this . due to unhealthy lifestyle choices, the care of one person is very considerable; sometimes goes at the expense of other/s living with them
Value 3	**Respect for life values** - **culture** - **expression of diversity** - **philosophy of life**	**Examples of dilemmas involving these values** **involve significant changes in previous habits or wishes –** . a person who was formerly vegetarian, out of religious values, now enjoys and wants to eat meat in the care home; their family are very upset . an Advance Care Plan says to withhold antibiotics for pneumonia; the person did not believe they could have quality of life with dementia. Now, they enjoy life in the care home, engage happily with residents, daily events, and seem to wish to live. Should their Advance Care Plan be nullified, and antibiotics be given when they have pneumonia, even though they are no longer 'have the mental capacity' (competency) to update their Advance Directive? . a person believes that life should be saved and extended as long as possible by whatever medical means, but their view is contrary to current medical treatment guidelines. . a person is from a culture with no concept of dementia as a 'medical illness'; it is thought of as normal aging - a 'second childhood'. Should medical and care-giving staff use the term 'dementia' in the way 'Western Society' uses it with this person and their family, or use their concepts and language?
Value 4	**Communication and honesty**	**Examples of dilemmas involving these values**

	- options, opportunities for, and adjustments to	. about the diagnosis of dementia – to tell or not to tell the person, when and how to tell this, and with whom present . about lying: for example the carer's need for the person to go for respite care, or into a care home (bringing the person with dementia to care home, pretending it is a temporary visit or holiday and that they will return home eventually) . hiding (much needed) medication in food (covert administration) . about the death of family members/friends; attending the funeral . withholding information - such as family deaths . correcting the communications of the person because the facts are not accurate - even though it upsets the person and makes them close down . agreeing with (going along with) what the person says, even though you know it is not true
Value 5	**Hygiene** – **acceptable standards to promote:** - **health** - **safety** - **a sense of well-being**	**Examples of dilemmas involving this value** . neglect of former levels of self care and refusal of assistance for washing, brushing teeth, grooming, shaving, changing clothes . uncleanliness and messiness of the living environment makes it harder for the person to function and be safe . One has a 'duty of care' to look after the person - at what point can pressure or force be used to help them, and to what extent? . carers and caregivers feeling guilty about not being able to look after the person the way they would like to, and feeling the judgment of others for their apparent 'lack of care'
Value 6	**Connectedness and inclusion** - **to/ with - family, social network,** - **community** - **those in the living setting – to the extent possible**	**Examples of dilemmas involving these values** . family of the person with dementia are embarrassed to take their loved one out of the house because of his 'inappropriate, disinhibited behaviour' . a person with dementia is disruptive when in the lounge with other residents, but is unaware of this, and enjoys being there . a person seeks places of quiet, to be away from the noisy lounge, so much so that they appear to be becoming reclusive . a person is upset when family visitors leave to go home, without taking them; their visits are decreasing because of this . a person's abilities are deteriorating and they can no longer participate in the 'card and games group' as before; no one wants to be their partner anymore
Value 7	**Appropriate intimacy** **– physical and emotional closeness in socializing, care, and sexual behaviour**	**Examples of dilemmas involving this value** . a lady with dementia, now living in a care home, does not recognize her husband anymore; she is upset when he enters her bedroom and wants to give her a kiss and a hug and spend private time with her there. . a male resident with dementia makes lewd comments to the caregiver who helps to bath him, and has started to grope her; she is now wary and afraid of working with him . a daughter visits her father in a care home. He mistakes her for his wife and wants to become intimate with her. She is upset and does not know how to continue visiting him. . a lady with dementia is flirtatious with other male residents who do not have dementia; this brings her into confrontational situations which she is does not seem able to evaluate or control . a person with early stage dementia wishes to be intimate with another resident, and is aware that this person is not his partner. This upsets their legal partner. . a caregiver is upset; her own values do not allow her to facilitate what she sees as 'infidelity' between residents, even though they are not fully aware of what they are doing . a gentleman in a care home wishes to have private, intimate time with his wife when she visits but there is inadequate accommodation for this . a gentleman wishes to be intimate with another resident; he mistakes her for his partner. His wife is upset by this.

Value 8	**Efficiency** **When there is more 'need' than 'resources' available - there is a duty to use resources, and time, timeliness, and timing, in an efficient and equitable way.** [21]	**Examples of dilemmas involving this value** . Deciding how to offer activities for residents in advanced stages of dementia, and those who are bed-bound, (for whom not much formal stimulation is available), as well as offering activities for the other residents
Legislation pertaining to dementia care	**The legislation listed opposite pertains to the UK.** (Many dilemmas that occur dementia care, require a systematic reflection on responsibilities, as well as knowing the law, since the juridical notion of autonomy and competency does not yet fully take into account a range of, and fluctuations in awareness and abilities. [25])	**Legislation to be aware of** . Care Act, 2014 . Equality and Human Rights Act, 2010; Human Rights Act, 1998 . Health and Social Care Act, 2008, (Regulated Activities) Regulations 2014 . Health and Safety at work Act, 1974 . Mental Capacity Act, 2005 Section 3; known as 'Treatment Order' includes: - **Deprivation of Liberty Safeguards** (DoLS) DoLS will change to **'Protection Liberty Safeguards'** following new 2019 legislation. https://www.natsip.org.uk/mental-capacity-act/3660-the-mental-capacity-amendment-act-2019 - (Deprivation of Liberty Safeguards) and the - **Restrictive Intervention** (RI) **guidelines** . Mental Health Act, 2007 . Management of Health and safety at work Regulations, 1999 . Manual Handling Operations, 1992 **Also:** . The Code of conduct of your own profession . The code of conduct or care philosophy of your work establishment and/or employer E.g. In-house policies for employees Equality and Diversity policy

See Appendices 1 & 2, at the end of this document for additional information about assumptions, terms, and templates.

Now, let's consider a real example.

Example of using the ACCORDION Method to solve a care dilemma:

How to help a gentleman who repeatedly gets lost when taking walks alone?

What follows, shows all the 9 steps in the ACCORDION Method. (Not all dilemmas will require this much documentation; it's been done here to illustrate all the details of the process.) The things discussed are shown in italics.

1 A assimilate the issue: name and describe the presenting issue/ care dilemma

What is happening - **in a nutshell** - in your own words? (The description of the presenting issue, will be expressed more formally in part 4, 'organize your description of the dilemma'.

A gentleman is getting lost more frequently when he takes walks alone in his neighbourhood. He had to stop driving his car because of unsafe driving and getting lost, so his walks are important to him. The police have had to search for him several times the past months.

His wife, sole and primary carer, is worried and tired as a result of his unpredictable disappearances. He seems unaware of the anxiety he causes his wife and neighbours, who also helped search for him; he denies getting lost. The carer support worker has been trying to help find a solution.

2 C collect the facts – all those relevant to this care dilemma

Consider factual details about the person with dementia – with questions about the type of dementia, and their awareness and acceptance of the diagnosis

. What is known about the person who the dilemma revolves around?
He is 82 - a former deliveryman, who has always been active. He does not use, and does not want to learn to use a mobile phone – he's says it is 'nonsense to carry a phone around near home'.

. Is it known what type of dementia were he was diagnosed with? (Or was a generic term like 'mild to moderate dementia' or, 'moderately severe dementia' used?)
'Probable' Alzheimer's dementia was diagnosed.

. When was dementia diagnosed?
The diagnosis was made 2 years ago, though he'd been struggling about 2 years prior to that.

. By whom? (A GP, geriatrician, old-age psychiatrist, neurologist, at a memory clinic, or other?)
Diagnosis was made by the family doctor/GP

. Was the person (gentleman) told their diagnosis?
Yes, and as well, they were sent a letter with the diagnosis stated on it.

. Were family member/s or someone from their support network with them?
Yes – the wife and eldest son were present at the time of diagnosis.

. Did/do they discuss the diagnosis?
No it isn't discussed. The gentleman doesn't want to talk about it with his family; they don't want to upset him.

. Did the person with dementia ever seem to accept the diagnosis?
At the time of, and for a while thereafter, he seemed to accept it. Since then he is denying it.

. Does the person with dementia understand what a diagnosis of dementia means?
Yes, he knows what dementia is. His friend had it. That is why he and his wife are fearful, and try to deny his difficulties.

. What words or term/s does the person with dementia use to refer to their 'thinking difficulties'?
He says he just has troubles associated with 'normal old age'.

. What Behavioural stage (or split-staging profile) can the person be described as being in?
He fits the characteristics of someone in 'Behavioural Stage 1' – 'Mal-orientation'. He is frightened of having dementia, worried about others noticing his mistakes, and about what they would think of him if he 'was crazy'.

. Is this person on a Deprivation of Liberty Safeguards (DoLS) or (PLS)? (When?)
No. This is not applicable, yet.

. Is this situation likely to continue without intervention?
It is not known if this gentleman will continue to get lost, and more frequently, but this would be a realistic expectation, given what is known about increasing visuo-spatial disorientation as Alzheimer's Disease progresses.

Details of what is happening – questions such as:
. What (has) happened?
He likes to get out most days, usually for an hour or two. Recently, this gentleman has been getting lost while going out walking in the neighbourhood where he has lived the past 40 years. The police have picked him up already several times, after his wife reported him missing - when he was out for more than 5 hours and she could not find him.

. **How serious** was it?

The first time he was lost, someone called the police to say they were speaking with a gentleman who was upset and asking for directions in the ***park****. The next time the police found him cold and sitting alone on the* ***grass beside a busy road****. Most recently, staff in a* ***supermarket*** *reported to the police that they noticed a gentleman was still seated on one the chairs by the front door as they were closing - he did not know how to get home. When one of the staff offered to drive him home, he became distressed and refused the offer of help. The longest search took six hours, during which time the neighbours were out by car and on foot looking for him, too. Each time he was brought home he was distressed and disoriented.*

. **Where?**

The gentleman is getting lost on long walks about 2 to 3 miles from his home.

. **When** did it start? When it is happening? **How often**? For **what duration**?

He got lost driving his car a few times. He has been out on walks, longer than usual, several times the past months but found his way back eventually. He has been lost three times in the past six weeks, which required the police to look for him.

. **Who** (all) is involved, and/or, who is affected?

(Person with dementia, family/friend carers, children, neighbours, the professionals related to care assessment and provision, volunteers, staff in care facilities, residents in care facilities, public services, e.g. police, fire department, ambulance)

- *The gentleman is involved, as well as his wife, children, neighbours, and police.*
- *The wife is becoming anxious that it will happen again.*
- *The children are worried for their parents.*
- *Most neighbours are elderly themselves, many are frail and may not be able to help search in future.*

. **Who (all) knows** what is happening?

The extended family and most of the neighbours have been told what's happening, so they can be aware of his struggles.

. **What has been tried so far**, by way of helping of offering an alternative or distraction?

The wife has tried to go out walking with him several times, but he sometimes does not seem to like this – he says that she walks too slowly and that this is HIS time away from home.

. **Is the person aware**, even briefly or intermittently, of what they are doing, and how others are affected by what is happening?

It's hard to say whether he has forgotten it, or whether he was so upset that he doesn't want to talk about it. He does mention that he misses driving. It seemed he was briefly aware of being lost, and very embarrassed when the police brought him home, but he appeared to have forgotten by the next day. He didn't speak about it again, and when it was mentioned he denied he was ever lost. Maybe this was bravado? He also does not seem recall (or wish to admit) that his wife and neighbours were worried and looking for him.

. **What are the risks** of this situation continuing?

- *That he will be lost longer - overnight, or further away from home, and come to serious harm*
- *That the neighbours will report the wife to social services for neglecting her duty of care for him*
- *That the wife's anxiety and stress will affect her health and ability to care for him adversely*
- *That the police will find repeated and/or prolonged searches to be a drain on their resources*

. **Are there any benefits** to this this situation continuing?

That this gentleman has the feeling of independence to come and go as he likes, like normal.

3 C consider other questions: legal questions, and those related to 'core principles', 'values', relevant 'interests', and 'resources' (For more details, see the information above and also the links above.)

LEGAL CONSIDERATIONS

Are there things related to this situation that the law prohibits or requires?
Yes. If restraint is to be considered, there are legal issues about its use.

4 CORE PRINCIPLES

1 **Help, heal, benefit** to optimize health/wellbeing
- *that is the goal of the care intervention*

2 **Do no harm**
- *no one wants to negatively affects this gentleman well-being by restricting his walking*

3 **Autonomy/freedom** – respect for a person's wishes and identity
- *his having the autonomy/freedom to leave the house whenever he wants to go for a walk is very important to him, especially since he cannot drive anymore*

4 **Justice / fairness** – consider others
- *if seems that if this happened once or so, as an accident, it is understandable. If it is starting to happen more often, then the rights of others need to be considered.*
- *the right of his wife 'not to be anxious, stressed, tired' from hours of searching (and neighbours)*
- *the right/requirement of police and emergency services to allocate resources equitably to citizens*

8 VALUES FOR CARE-GIVING

1 **Safety** – physical, sensory-perceptual and emotional
- *He is affected physically and emotionally: getting lost, disoriented and distressed, tired and cold (and possibly injured)*

2 **Health,** wellbeing, quality of life
- *Walking is healthy for him; getting lost, being cold and upset is not good*

3 **Respect** for life values
- Before he had dementia, this gentleman was very considerate, conscientious, and would not have wanted to be a bother to anyone, or to frighten his wife

4 **Communication** and honesty
- *It is not known yet how much he knows, but is denying - about getting lost, and likewise about his diagnosis. Hopefully if he trusts people in future, he will be able to speak about this honestly.*

5 **Hygiene**
- *Not applicable*

6 **Connectedness and inclusion**
- *He wants to be/feel a part of his neighbourhood and part of the community*
- *It is not known what other activities he used to do, or still does, outside of home*

7 **Appropriate intimacy**
- *Those who approach and help this gentleman when his is lost, need to be careful when entering his 'personal space', e.g. when touching him to comfort him (or help him to his feet), to prevent him from possibly becoming defensive*

8 **Efficiency and timing**
- *Searching for someone use people's time, energy, and money. Police services to search may be compromising resources for other serious crime events happening at the same time.*

RELEVANT INTERESTS

Apply relevant principles and values to each aspect of the dilemma being considered.
Note: one value may clash wish another value.
Note: one value or interest may take precedence over another at a particular time.

. **Whose needs and interests** need to be considered and/or balanced?
(E.g. primary carer, extended family, neighbours, friends, staff, other residents, professionals, others)?
- *most obvious are the needs of the gentleman and his wife*

. **What are the conflicts of interest (in terms of principles or values)?**
(involving others, organisations, services, policies/procedures, precedents)
- *the husband's autonomy need (to walk freely) conflicts with his wife's need to maintain her health (minimizing stress and anxiety)*
- *there is a conflict of interest between the various needs of the gentleman: between his autonomy/ freedom and his needs for safety and connectedness to his neighbours and environment*

. **Is there any other knowledge needed** to solve this dilemma?
- *it would be good to know if this gentleman actually does remember getting lost, even though he seems unable to remember shortly after the incident. If he does know, it would be easier to talk to him about finding ways to help him continue to go on walks.*

. **Any other issues requiring consideration?** (E.g. time of day, staffing…)
- *all three times that this gentleman got lost, were in the late afternoon*
- *he has never yet become lost when he has gone out in the morning*

. **What are the "ideal possible outcomes**" that can be imagined?
- *that this gentleman can continue to go out for walks in his neighbourhood, as often as he does now, or as often as he wishes to, as independently as possible*

. **What are the "less, or least-ideal possible outcomes**" that can be imagined?
- *if walking is restricted, his physical and emotional (mood, self confidence) health may be affected*
- *his connections to the neighbourhood/ community would be reduced – and hence, his overall well-being might be reduced*
- *if he continues to get lost, and neighbours and police or other emergency services are called upon to search for him too often, he may need to be admitted to a care home with a secure unit*

RESOURCES - What intervention/s are possible - given the available resources?
E.g. time, timeliness, and timing of the interventions required; the overall resources of those involved in caregiving, such as their:

. **proximity to support**
- *close to neighbours; their children lives an hour's drive away*

. **physical and emotional health**
- *both husband and wife have reasonable health for their age; however the wife has some arthritis which limits her walking ability*

. **financial resources** - to assist with proposed intervention
- *unknown; but wife says they have a 'nest egg' for emergencies*

. **access to knowledge and to a support system**
- *wife is aware of the local Alzheimer's support services though she has not yet attended*

. **availability and the sustainability of the various types of resources required**
- *the children are aware of their Dad's diagnosis, and are able to visit on weekends*
- *the husband has a retired friend, an old work colleague who lives 25 miles away and still drives*
- *this couple are friendly with several couples in the neighbourhood*

4 O <u>organise your description of the dilemma</u> in terms of which core principles, values, and interests that need to be addressed

Consider all those that apply, and consider which interests are the most urgent.
A married gentleman, diagnosed with Alzheimer's disease two years ago, has become lost three times in the past six weeks while taking his customary walk in the neighbourhood. This has resulted in the police

and neighbours having to search for him for several hours. He was very distressed each time the police found him, but he did not seem to remember what happened by the next day. His wife is very anxious that he will get lost more often and possibly come to harm.

The re-worded dilemma:
- *Since this gentleman is getting lost more frequently, his need 'to walk freely' conflicts with both his own needs 'to be safe and healthy', and with his wife's need 'to maintain her health and the ability to care for him'.*
- *His need to walk freely, but getting lost, is causing worry and upset to his wife, children and the neighbours.*
- *The husband's episodes of 'getting lost' are expected to continue (and likely happen more often).*
- *Finding him has required several hours of police searching, and is utilizing limited time and resources.*

5 R <u>reflect</u> and <u>discuss the situation with others to gather ideas for interventions</u>

Consider similar examples, and generate all possible, relevant options.

. Think of how would you wish to be treated in similar circumstances?
I would like people to speak with me about their concern for me, and offer to try some solutions so that I could still go for walks, somehow, with guidance, maybe accompanied.

. Is it known how this person would want to have been treated in these circumstances, given their prior belief-system, or, what they said previously about such issues, before they had dementia?
Since this gentleman is described as 'considerate and conscientious', it is likely he would have wished not to be a burden. He was also worried about his friend who had dementia, especially when he became disoriented and didn't recall the concern he caused others.

. Is it known what this person would choose right now?
No, no one has talked to him about it yet.

Are there any comparable examples anyone knows of?
No.

If there are no comparable examples, consider those that are most similar to the situation being considered, involving similar conflicts of values.
- *someone had a good experience with using a **GPS tracking device** with a grandparent with dementia*
- *someone had a bad experience with using a GPS tacking device; the person was angry and threw it away (waste of money and it caused mistrust in family carers)*
- *someone knew of a wife who had **installed locks on all the doors**, so that her husband could not leave without her knowledge – especially at night-time*
- *suggestion: give the gentleman an **identification bracelet**, so anyone who finds him knows what his difficulties are, and how to call his home*
- *suggestion: to install a **door alarm** , so that his wife would know when he was leaving the house, and would be able to accompany or follow him*
- *suggestion: give him a **personal pendant alarm**, so he could use it if he felt he was in trouble*
- *another lady whose husband got lost when out for walks, accepted **a companion for walks and outings** although he refused to let his wife accompany him*

6 D decide on the best intervention/s after comparing options:

weigh and balance the current situation against the examples.
In order to act in this gentleman's best interests right now, it was decided that the door locks and identification bracelet were too much to start with. Instead of the ID bracelet, it was decided to put small, laminated labels in the pockets of this gentleman's cardigan or coat, with his name, address and phone number on it.

Document details of the intervention/s chosen (also referred to as writing the ACTION PLAN)
This may include such things as those below:

. **What is the intervention/s?**
This gentleman will go for accompanied walks five times weekly; three times with a paid companion, and twice, on weekends, with family/friends.
- *involve him: ask him if he likes to do a set route each day, or if he would like to do different ones*
- *his wife will try walking with him, as possible - her health permitting - and his tolerance of her presence*

Organise additional aids:
- *have a door alarm installed, so the wife knows when he has gone out*
- *let him choose, and use a GPS tracking device; research those that looks most like a watch, to minimize his self consciousness about wearing one*
- *find a paid companion to accompany the gentleman for walks, 3 afternoons a week*
- *set up a roster of family/friends/neighbours who can go on walks on the 2 weekend days*
- *get a large whiteboard and write a reminder each day of who is accompanying him on the walk and at what time (E.g. Short clear message: Walk with George today; 2:00 in afternoon)*
- *have small, laminated labels made with the gentleman's name, address and phone number on it. His wife will put them in his pockets, as needed.*

. **When will it start?**
Each part will start as soon as possible.

. **Where will this be documented?**
The carer support worker will document this.

. **Who (staff, family, friends, neighbours, professionals) is to be told?**
The gentleman's wife wants to tell everyone possible, so they can help keep their eyes open for him.

. **Who is involved in carrying it out?**
Mostly his wife, but also those 'befriending walking companions' who are helping this gentleman.

. **How often is it to happen?**
Five walks a week will be scheduled - and an additional one if the wife is able to go on a short walk with her husband.

. **What else needs doing/arranging for it?**
Decide when the carer support worker will speak with the gentleman alone, and his wife alone, and with them together about the details of this plan.

7 I **implementing the intervention**

Decision: *to start several the interventions this week; and the accompanied walks, as soon as 'walking companions' can be located.*
If necessary:
- *if the four or five 'planned' walks are not enough, try for one walk a day*
- *If he cannot make use of the reminders on the blackboard, and leaves the house before the companion arrives, use the GPS to monitor him*

8 O **on-going evaluation: evaluate, adjust and adapt - as required**

- *as per the requirements of this situation or the services involved*

9 N **note new changes (CARE PLAN REVIEW)**

- *Watch for any signs of fatigue in this gentleman; may need to supplement his outings by taking him out on car or bus journeys in future*
- *Consider whether he needs to follow a fixed route, with a mid-way refreshment break to help keep him comfortable and oriented.*

- *Watch out for signs of him starting to fight against these interventions*

Formal end to this example

Some of you will want to know 'the ending' to this example, but I can only give you a partial one. (The purpose of this TAD was to go through the ACCORDION method, not to give a full trajectory of his story.)

This gentleman was happy walking with others, but not with his wife, who could not keep up with him. That meant that he was only able to take a walk 5 days a week. Things went well for a month, and then, one morning, he left the house, alone, and got lost. There was another police search for him, with much upset for all involved. Thereafter, his family and friends and befriender/walking companions, decided to arrange for him to have a walk in the mornings, in the hope of tiring him out a bit, so he wouldn't want to go out in the afternoons. His wife was going to try to get him to choose and wear some sort of GPS (location / tracking device), after consulting with the Alzheimer's Society for advice about which types were most highly recommended. [You can anticipate that a variety of other options would be tried and evaluated, even after this one.]

So – that's how the ACCORDION method works. More examples are covered in the next TAD newsletters. I hope this way of working will be of use to you, especially in these times of Covid-19, with the extra ethical dilemmas that confinement, additional fear and uncertainty, and the loss of normal routine may pose.

Best regards; keep safe,
Gemma Jones
P.S. My colleague, Dr. William van der Eerden, will be using the ACCORDION method when discussing ethic and dilemma-solving with the medical students this year.

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* **This "ACCORDION model**" for solving dilemmas in dementia care has developed over the past decades of working with people with dementia and their family carers, professionals involved in caregiving, internationally. It also comes from: teaching and speaking to family carers and caregiving professionals about the dilemmas they face; twenty years of being with people at the Alzheimer Cafes; from being a member of the workgroup for the Nuffield Council on Bioethics (that wrote the 2009 report "Dementia: ethical issues"); from being a family carer, and from reading about this subject (see references).

** The **values** chosen for use this document are the ones that I think are most useful for solving dilemmas in dementia care. There are many different values; each field will use those most suitable to its focus.

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Appendix 1

There are three items here

A assumptions
B the range of cognitive abilities that can be affected in dementia
C 'words and terms' used in this TAD

A Assumptions behind this TAD

That the readers:

. are familiar with terms used at their work (such as: Deprivation of Liberty Safeguards, or Protection of Liberty Safeguards, duty of care, safe-guarding, restrictive interventions), and where the work policies and related guidelines are kept.

. are familiar with the four-stage '**Behavioural Staging model of Alzheimer-type dementia',** when '**Split Staging'** is used, and how to record the progression of dementia (6, 8)

. are **familiar with assessing different types of fear behaviour;** how to help people feel safe by selecting from a range of communication options (such as those in the Ten Plus option model); activity intervention strategies; and understanding their role as possible 'attachment figures' for people with dementia who are showing fear (attachment-seeking) behaviour. (8)

. have had some basic teaching and first-hand familiarity with **the range of cognitive, sensory-perceptual and behaviour changes that can occur** in different types of dementia (see Box below). That they are aware that Alzheimer's disease is increasingly being understood as a visuo-cognitive illness (that is - as a seeing/perceiving-thinking illness).

This understanding provides scope for thinking about a range of new **care interventions** (including sensory-perceptual and emotional ones), which can assist in solving dilemmas in dementia care.

B The range of cognitive abilities that can be impaired by dementia

The various types of cognitive (thinking) abilities that can be affected by dementia, and those referred to in the example given in this TAD, and future TADs, include those abilities that are needed to:

- learn, to put into memory, and be able to recall three categories of things/events
  . memory for factual details - **factual memory**
  . memory for the emotional flavour of people, things, events - **emotional memory**
  . memory for sensations (or sensory percepts) associated with people, things and events, as they are associated with the six various senses - **sensory memory**
  [vision, hearing, touch, smell, taste, kinesthesis (balance, rhythm and movement)]
- pay attention
- think logically (rational logic, emotional logic, and sensory logic systems)
- order and sequence information and objects
- use language: comprehend and speak (express)
- plan (make choices)
- solve problems / think symbolically and abstractly
- calculate
- make mental maps and schematics of places, things, processes
- read and express emotions accurately in oneself and others
- be oriented (or not) to the four axes of awareness:
  1 – recognizing the **persons** who you know well, and those around you
  2 - to **place**: where you are (what country, place, building you are in)
  3 – (chronological) **time**:
    … what part of the day it is
    … the date, date, year, and season are
    … what part of your life you are in (childhood, adolescence, midlife, old age)
  4 – the **context**: what is the occasion, purpose and/or mood of events happening now

C Terms used in this document (in alphabetical order)

Adult Safeguarding (Six Principles of from the Care Act)

1 Empowerment. People are supported and encouraged to make their own decisions and informed consent.
2 Prevention. It is better to take action before harm occurs. ...
3 Proportionality. The least intrusive response appropriate to the risk presented.
4 Protection. Support and representation for those in greatest need
5 Partnership. Services offer local solutions through working closely with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse.
6 Accountability. Accountability and transparency in safeguarding.

Advance decisions (also called 'advance directives' or 'living wills')
People who are able to make decisions for themselves, may write 'advance decisions' to say what kind of treatment they want, or don't want, if they are no longer able to decide for themselves. Advance decisions to refuse treatment are legally binding as long as they have been properly made. (Some people see advance decisions as a way of exercising their autonomy and life values. Others are concerned because they assume we cannot know what our quality of life in the future will be like, and our advance decision may not be of help in our later circumstances.)

Best interests
When a person with dementia is no longer able to make decisions for themselves, another person who they have chosen (or who has been appointed), and is known legally as 'welfare attorney (WA)', can make decisions for them. The WA acts in 'the best interests' of the person with dementia

Capacity
People, also people with dementia, have the legal right to decide what to do with their lives (such as - where to live, what medical treatment to accept, what to do with their money). If a person's dementia progresses, the law says that people can make their own decisions until it is shown that they no long have the capacity to do so. When decisions are made for a person with dementia they must be in their 'best interests'.

'Capacity to consent' to decisions is **time-specific and issue-specific.**
It means that the person with dementia has been assessed as being able understand
. what the issue is
. what the options are - and be able to remember them
. understand what are the consequences of a given decision are
. and, able to communicate by whatever means, their choice (15)

Carer - refers to a family, friend /other person who provides unpaid care to a person with dementia

Caregiver - refers to people who are paid to provide care for a person with dementia

. Deprivation of Liberty Safeguards (DoLS)
(They part of Mental Capacity Act, but they don't apply if someone is being detained under the Mental Health Act, 2005, for England and Wales.)
Deprivation of Liberty Safeguards (DoLS)are intended to ensure that people who need to be looked after in care homes and hospitals having continuous supervision, but lack the mental capacity to consent to being there and are not free to leave, and are looked after in a way that does not inappropriately restrict their freedom. (16)

Duty of Care - refers to a legal obligation to:
. always act in the best interest of individuals and others
. 'not to act' or to 'fail to act' in a way that results in harm
. act within your competence and not take on anything you do not believe you can safely do (20)

Ethics and morals
. both refer to doing the right thing and some people use these words interchangeably,

though there can be differences in the way most people use these words.

. in this document these words will be used with the following distinction

- ***morals*** are the values you choose to live by for yourself, from within your own sense of integrity; they are often influenced by your personal, spiritual and/or formal religious beliefs
- ***ethics*** deals with the standards, rules, or codes of conduct for particular purposes (such as those policies required to be observed at the workplace, or by legislation)
- ***ethical decision making*** focuses on how to determine right from wrong (or, how to choose the best outcome), by weighing the pros and cons of an issue, or the competing values and interest of an issue

Quality of life is difficult to define but has to do with a person's senses of the goodness or value of their life, connections, activities and surroundings. It is a highly subjective judgment, which can be based on any, some or all the (core) principles and (moral) values (identified herein) being acknowledge, respected and affirmed.

In dementia care, **12 components** have been identified with quality of life by Droes et al (5), namely: affect; self-worth/self-image; attachments; social contact; pleasure experiencing activities; a feeling for the aesthetics of the living environment; physical and mental health; secure financial situation; self-determination (autonomy) and freedom; personal spirituality; safety and privacy, having purpose and meaning. When we judge the quality of life of another person we must be aware that we are usually using both our own values and criteria to judge this, or those that someone else has objectively determined, neither of which may accurately represent what the person with dementia, or their family/friend carer experiences.

Restraint, as defined in 'Management of Health and Safety at Work Regulations', 1999, HMSO, UK, (15). **is:**
"The use or threat or use of force to make people do things they are resisting, or, restricting their freedom of movement whether they are resisting or not." Any restraint used must be a proportionate response (the least restrictive possible) to the likelihood of the person or others suffering harm. Any restraint/restrictions must only be used if they are in a person's best interests.

Restrictive intervention (RI) is defined as ' an intervention that restricts an individual's movement, liberty and/or freedom to act independently.' (RI) practice is in place constantly, as part of the environmental safety aspect of care. RI courses, (teaching materials such as those available from the Social Care Institute for Excellence (SCIE)), emphasize different types and degrees of restriction. Some RI courses may distinguish between '**reactive strategies'** and '**restrictive techniques'**. Once such example, shows a hierarchy of interventions, as shown in the Box, here.

Reactive strategies:

. Good communication
    - Talk to the person calmly; find out what is the matter from their point of view

. De-escalation techniques include:
    - Wait (for the person to become calmer)
    - Wait for family to assist or be present
    - Revisit (the situation)

. Restraint reduction strategies (the '**least restrictive practice'** approaches described in the Mental
Capacity Act, 2005, after a '**best interest judgment**' has been made).

Restrictive techniques:

. physical
. chemical
. mechanical
. seclusion

Six Safeguarding Principles from the Care Act, 2014, are required to be followed:
1 empowerment
2 prevention
3 partnership
4 protection
5 proportionality
6 accountability.

Well-being refers to moment-to-moment contentment and also objective factors such as a person's level of mental ability. (Definition from 17)

Work related violence or aggression:
'any incident in which a member of staff is verbally abused, threatened or assaulted by a resident or member of the public during the course of their work'. (Definition from 9)

Appendix 2

There are 4 items here

1 a tool to help discussion of a caregiving dilemma

2 a mnemonic for the ACCORDION method

3 a template for the ACCORDION method (questions and issues)

4 a (brief) blank template of the ACCORDION method

----

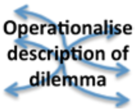
1 Tool to assist in the discussion of a dilemma: a table of principles, values, and the people involved

Some people find it helpful to think through the dilemma by using this table to considering each principle, value and person involved (stakeholder), individually.

	Person with dementia	Spouse partner	Other family or friends	Caregiving (paid) staff	Services and Organisa-tions involved	Other people , attendees, or residents in care settings	Others …
4 CORE PRINCIPLES							
1 Help							
2 Do no harm							
3 Autonomy/ identity/privacy							
4 Justice							
8 VALUES							
1 Safety							
2 Health							
3 Life values							
4 Communication							
5 Hygiene							
6 Connectedness							
7 Appropriate intimacy							
8 Efficiency							

2 'The ACCORDION Method' Mnemonic to help solve caregiving dilemmas

	The "ACCORDION method"
Assimilate the dilemma	**1 A assimilate the issue: name and describe the presenting issue/ care dilemma** - What is happening - in a nutshell, in your own words?
Collect all facts	**2 C collect the facts – all those possibly relevant to this care dilemma** **Details about the person with dementia – for example:** **The type of dementia, their awareness and acceptance of their diagnosis** . What is known about the person who the dilemma revolves around? . Is it known what type of dementia were they diagnosed with ? (Or was a generic term like 'mild to moderate dementia' or, 'moderately severe dementia' used? . When was dementia diagnosed? . By whom? (GP, specialist geriatrician, old-age psychiatrist, neurologist, trainee doctor at a memory clinic, or other?) . Was the person told their diagnosis? . Were family member/s or someone from their support network with them? . Did/do they discuss the diagnosis? . Did they accept the diagnosis? . Does the person with dementia understand what the diagnosis of dementia means? . What words/terms do they use to refer to their 'thinking difficulties'? . What Behavioural stage (or split-staging profile) can the person be described as being in? . Are they on a Deprivation of Liberty Safeguards (DoLS)? (When?) **Details of what is happening – such as:** . What (has) happened? Where? . When did it start? . Who (all) is involved, and/or, who is affected? (Person with dementia, family/friend carers, children, neighbours, professionals related to care assessment and provision, volunteers, staff in care facilities, residents in care facilities . Who (all) knows what is happening? . When it is happening? . How often? For what duration? . What has been tried so far, by way of helping of offering a alternative or distraction? . Is the person aware, even briefly or intermittently, of what they are doing, and how others are affected by what is happening? . What are the risks of this situation continuing? . Are there any benefits to this this situation continuing?
Consider questions ??????	**3 C consider other questions: legal, core principles, values, interests, resources** **Consider:** **LEGAL CONSIDERATIONS** - Are there things related to this situation, which the law prohibits or requires? **CORE PRINCIPLES** 1 Help, heal, benefit to optimize health/wellbeing 2 Do no harm 3 Autonomy/freedom – respect for a person's wishes and identity 4 Justice / fairness – consider others **VALUES** 1 Safety – physical, sensory-perceptual and emotional 2 Health, wellbeing, quality of life 3 Respect for life values 4 Communication and honesty 5 Hygiene 6 Connectedness and inclusion 7 Appropriate intimacy 8 Efficiency and timing **RELEVANT INTERESTS** Apply relevant principles and values to each aspect of the dilemma. Note: one value may clash with another value. Note: one value or interest may take precedence over another at a particular time.

	- **Who else's needs and interests** need to be considered and/or balanced (E.g. primary carer, extended family, neighbours, friends, staff, other residents, professionals, others)? - **What are the conflicts of interests or values?** (involving others, organisations, services, policies/procedures, precedents) - **Is there any other knowledge needed** to solve this dilemma? - **Any other issues** requiring consideration? (E.g. time of day, staffing…) - **What are the "ideal possible outcomes"** that can be imagined? - **What are the "less or least-ideal possible outcomes"** that can be imagined? **RESOURCES** - What intervention/s are possible - given the available resources? (E.g. time, timeliness, and timing of the interventions required; the overall resources of those involved in caregiving, i.e. their: . proximity . physical and emotional health . financial means . access to knowledge and a support system . availability and the sustainability of the various types of required resources
	**4 O organise your description of the dilemma in terms of which core principles, values, and interests need to be addressed** Consider all those that apply, and: . the best interests of those involved . conflicts of interest . most urgent interests **Reword the dilemma:**
	**5 R reflect** and **discuss the situation with others to gather ideas for interventions**. Consider similar examples, and generate all possible, relevant options. . Think how would you wish to be treated in similar circumstances? . Is it known how this person would want to have been treated in these circumstances, given their prior belief-system, or, what they had said previously about such issues - before they had dementia? . Is it known what this person would choose right now? If there are no comparable examples, consider those that are most similar to the situation being considered, involving similar conflicts of values.
	**6 D decide on the best intervention after comparing options: (ACTION PLAN)** weigh and balance the current situation against the examples. **Document details** of the intervention chosen (ACTION PLAN) including such things as: - What is the intervention/s? - Where will this be documented? - Who (staff, family, professionals) is to be told? - Who is involved in carrying it out? - How often is it to happen? - What else needs doing/arranging for it to happen? - How and when will it be evaluated?
	**7 I implementing the intervention**
	**8 O on-going evaluation: evaluate, adjust and adapt - as required**
	**9 N note new changes (CARE PLAN REVIEW)**

3 TEMPLATE for the ACCORDION process (as above, but without the box and lines)

1 A assimilate the issue: name and describe the presenting issue/ care dilemma

What is happening - in a nutshell, in your own words? (This is expressed more formally, later.)

2 C collect the facts – those relevant to this care dilemma

Details about the person with dementia – for example questions such as:
The type of dementia, their awareness and acceptance of their diagnosis

. What is known about the person who the dilemma revolves around?
. Is it known what type of dementia were they diagnosed with?
(Or was a generic term like 'mild to moderate dementia' or, 'moderately severe dementia' used?)
. When was dementia diagnosed?
. By whom? (GP, geriatrician, old-age psychiatrist, neurologist, at a memory clinic, or other?)
. Was the person told their diagnosis?
. Were family or someone from their support network with them?
. Did/do they discuss the diagnosis?
. Did the person with dementia accept the diagnosis?
. Does the person with dementia understand what a diagnosis of dementia means?
. What words/terms do they use to refer to their 'thinking difficulties'?
. What Behavioural stage (or split-staging profile) can the person be described as being in?
. Is this person on a Deprivation of Liberty Safeguards (DoLS)? When?
. Is this situation likely to continue without intervention?

Details of what is happening – questions such as:

. What (has) happened?
. Where?
. When did it start? When it is happening? How often? For what duration?
. Who (all) is involved, and/or, who is affected? (Person with dementia, family/friend carers, children, neighbours, professionals related to care assessment and provision, volunteers, staff in care facilities, residents in care facilities)
. Who (all) knows what is happening?
. What has been tried so far, by way of helping of offering an alternative or distraction?
Is the person aware, even briefly or intermittently, of what they are doing, and how others are affected by what is happening?
. What are the risks of this situation continuing?
. Are there any benefits to this this situation continuing?

3 C consider other questions: legal, core principles, values, interests, resources

LEGAL CONSIDERATIONS

- Are there things related to this situation that the law prohibits or requires?

CORE PRINCIPLES

1 Help, heal, benefit to optimize health/wellbeing
2 Do no harm
3 Autonomy/freedom – respect for a person's wishes and identity
4 justice / fairness – consider others

VALUES

1 Safety – physical, sensory-perceptual and emotional
2 Health, wellbeing, quality of life
3 Respect for life values
4 Communication and honesty
5 Hygiene
6 Connectedness and inclusion
7 Appropriate intimacy
8 Efficiency and timing

RELEVANT INTERESTS
Apply relevant principles and values to each aspect of the dilemma being considered.
Note: one value may clash with another value.
Note: one value or interest may take precedence over another at a particular time.

. **Whose needs and interests** need to be considered and/or balanced?
(E.g. primary carer, family, neighbours, friends, staff, other residents, professionals, others)
. **What are the conflicts of interest (in terms of principles or values)?**
(involving others, organisations, services, policies/procedures, precedents)
. **Is there any other knowledge needed** to solve this dilemma?
. **Any other issues** requiring consideration? (E.g. time of day, staffing…)
. **What are the "ideal possible outcomes**" that can be imagined?
. **What are the "less or least-ideal possible outcomes**" that can be imagined?

RESOURCES - What intervention/s are possible - given the available resources?
E.g. time, timeliness, and timing of the interventions required; the overall resources of those involved in caregiving, such as their:
. proximity
. physical and emotional health
. financial means - to assist with proposed intervention
. access to knowledge and to a support system
. availability and the sustainability of the various types of required resources

4 O organise your description of the dilemma in terms of which core principles, values, and interests need to be addressed
Consider all those that apply. Also consider which interests are the most urgent.
Reword the dilemma:

5 R reflect and **discuss the situation with others to gather ideas for interventions.**
Consider similar examples, and generate all possible, relevant options.
. Think how would you wish to be treated in similar circumstances?
. Is it known how this person would want to have been treated in these circumstances, given their prior belief-system, or, what they said previously about such issues, before they had dementia?
. Is it known what this person would choose right now?

If there are no comparable examples, consider those that are most similar to the situation being considered, involving similar conflicts of values.

6 D decide on the best intervention/s after comparing options:
weigh and balance the current situation against the examples.

Document details of the intervention chosen. (WRITE THE ACTION PLAN)
This may include such things as:
. What is the intervention/s?
. When will it start?
. Where will this be documented?
. Who (staff, family, friends, neighbours, professionals) is to be told?
. Who is involved in carrying it out?
. How often is it to happen?
. What else needs doing/arranging for it?

7 I implementing the intervention

8 O on-going evaluation: evaluate, adjust and adapt - as required

9 N note new changes (CARE PLAN REVIEW)

4 – A brief template for the ACCORDION method

1  	**A** assimilate the dilemma - describe in a nutshell
2  	**C** collect the facts (all that are relevant)
3  	**C** consider questions about - legal principles, values, interests, resources
4  	**O** organise a fuller description of the dilemma
5  	**R** reflect and compare similar examples; generate various options for the intervention/s
6  	**D** decide on best intervention/s; document details of the decision and implementation
7  	**I** implement intervention/s
8  	**O** ongoing evaluation of intervention/s
9  	**N** note new changes and options for next meeting