

# Related ideas for observations, reflection and research When a person with dementia asks you something, such as for help to leave the care home to go home, or, whether you've seen their [long-deceased] parent - what do say? E.g. How often do you tell people 'the facts' (e.g. that the care home *is* their home now, or, try to convince them (using rational logic) that they are old now, live in a home for older people, and that it's unlikely that their parent is still alive?) E.g. Do you ever lie (e.g. pretend the person can leave later, or, pretend that their parent is alive), or try to *distract* them from the topic of parents)? Were you ever formally taught about when to stop using (correcting, or working with) 'facts' and switch to another option (like reminiscing, relating to emotions, distraction...)? If not, how do/did you decide *when* to do switch from one option to another? Have you ever heard anyone say something like, "people in Behavioural Stage 2 cannot learn new facts, so switch to working with people's

- Stage 2 cannot learn new facts, so switch to working with people's feelings (or the emotional content of information) instead?
- Do you distinguish between 'factual information' versus 'emotional? information, i.e. 'the emotional flavour of an event or happening?

Dear Reader,

In TAD newsletter 67, the '**Ten-plus Communication Options Model**' was introduced. TAD 68 discussed **Option 1** of the ten-plus options. **Option 2** is discussed here, and the remaining options will be covered in future TADs. To brush up on the model, see **Box 1** for a quick summary. (If you are new to the TAD newsletters, previous TADs are archived on TheWideSpectrum.co.uk website.) **Communication Option 2** is 'orienting a person to what's happening (current events), explaining the facts (about present reality)'. This option involves relating, explaining, cueing, repeating and reinforcing 'the facts' related to present time and/or the event or story the person with dementia is telling you. To do this implies *you* know 'the facts'. [Note: the way the term 'reality' is used here refers to our experience of reality; this is not necessarily the reality experienced by the person with dementia].

Box 1 Summary listing of the 'Ten plus communication options model' (Jones, 1985)

G	1	Gather information; ask 'good' questions to find out the person's story			
0	2	Orient the person to what's happening, explain 'the facts'			
R	3	Reminisce; through prompts, questions, triggers			
D	4	Distract, directly and indirectly			
Α	5	Agree; play along with			
L	6	Lie – told to make a person feel better, but a lie none the less			
S	7	Social response; superficial, safe topics			
V	8	Validate (acknowledge) the person's feelings			
I	9	Idle, stall for 'thinking' time; remain quiet; repeat last thing person said			
С	10	Combinations of the above options - used consecutively			
Η	Plus Humour, and other options				
Not	e that	"becoming defensive' and 'trying to show the person you are right and they			
are mistaken' are NOT options in this model.					
With more detailed knowledge about these communication options <sup>1-4</sup> , the 'Behavioural					
Staging Model' <sup>5–10</sup> , and the 'Attention Blackboards' and 'Memory Bookcases Models' <sup>11</sup>					
<sup>13</sup> , you'll notice that some options make better starting points than others, in given					
situ	situations. (TADs referenced here, are archived on www. <u>TheWideSpectrum.co.uk</u> .)				

# 'Facts' versus 'the emotional flavour of things'

Distinguishing between these is essential for using this option.

*Facts* are (accurate) pieces of information that answer questions like – 'who', 'what', 'where', 'when', and 'how'. (TAD 68 goes into these in detail.)

*The emotional flavour of things*, has to do with *emotional responses to* people, events and objects – whether they are liked or disliked, or evoke emotions (such as happiness, sadness, fear, or anger.)

Some examples of questions that ask about factual versus emotional information are compared in **Box 2**.

Asking about facts	Asking about the emotional flavour (and less-detailed responses)
What did you have for breakfast?	How was your breakfast? Did you enjoy it?
Who came to visit you this week?	You had some visits this week. How did they go? Did you enjoy being with them again?
When did you receive this notice? (Why haven't you opened it?)	I haven't seen this notice before. It looks recent. Shall we open it together and check that everything is OK?

Box 2 Sample questions about facts versus the emotional flavour of things

What's is the day and date today? (Do you know when your next dentist appointment is?)	It's Friday again today. Only a week till your dentist appointment. Does it seem a long time since the last one? Are you OK about seeing the dentist?
What is your address?	Can you tell me about where you live - what it's like?
Do you know where you are; what and where this place is?	Where do you think this place feels like? Does it remind you of being somewhere (on holiday, at Sue's, at work, at home)?
What have you done today?	How has today been for you? Have you been comfortable?
What did Henry have to say for himself?	Did Henry (seem/ look/ feel) OK to you? Was he in a chatty mood today?

# Four types of orientation'

The four types of orientation/awareness usually referred to are shown in **Box 3**. (There are certainly more types, and more nuanced versions of the four, but that is beyond the scope of this TAD.)

# **Box 3 Four types of orientation** (awareness; ability to participate in present time/reality)

These types relate to a person's **ability to be oriented to**:

- **1 Person/s** to know who you are, and the people you are connected to; and to know the name and relationship or role of those around you
- 2 Place to know where you are right now... (and, to know why you are there, is implied)
- **3 Time** to know aspects of time, such as, the hour, part of day, date, year and season and the time of one's life (child, adolescent, adult, middle aged, young-old, middle-old, or old-old)
- 4 **Context or situation** to understand what is happening (the occasion and emotional atmosphere (e.g. a celebration, dirge, meeting, collective ritual, activity), and one's place or role in this in relation to others present

Changes in '*time perception*' are the ones that are most noticeable when a person has dementia. A person in **Behavioural Stage 1** can usually be helped to be oriented, (at least for an hour or so at a time), by the careful use of calendars, clocks, blackboards, memos, reminders, prompts and cues. For a person in **Behavioural Stage 2**, such assistance may help only for some minutes before they ask again - or become distracted.

# When facts aren't correct, find out what Behavioural Stage a person is in (to know about their time perception ability)

If you don't know what stage a person is in, and the person says something that obviously isn't correct (or doesn't seem correct), the best starting point is to review 'some relevant facts'. See if the person can connect with them. (Do they know the time and date; where they are; the names and roles of people present; what is happening.)

If a person *can* understand and retain facts they are told, even with difficulty, (e.g., with the use of reminders and cues), using **Option 2**, as described in this newsletter, is a good starting point. If they *cannot* do so, it's usually unhelpful to repeat the facts. It can make a person feel fearful, angry, argumentative or defensive. It can feel being corrected or patronized – worst of all, it can make them mistrustful of you and affect your relationship.

[In the language of Memory Bookcases Model, we would say the following:

Once a person's 'factual memory bookcase has collapsed', and they no longer have a 'top shelf on which to place new factual memories' according to time, they are 'permanently disoriented in time'. Hence, there is little point in either:

- . telling them new facts, or expecting a person to remember them
- . correcting incorrect statements and expecting a person to remember the corrections.]

#### When to orient a person to 'reality' and when not?

Participating in 'reality' accurately, (i.e. being aware of and oriented to what is happening now), is the highest potential of our conscious human awareness. Help to facilitate this whenever possible. This usually involves explaining 'the facts' and the context about a situation or story to a person with dementia.

However, when it isn't possible (temporarily, or at all) for a person to remember the things that have happened in the 'immediate to recent past' (minutes, hours, days, months), try using another communication option. Avoid 'forcing the facts' or 'pushing reality' on anyone with dementia who *cannot*, or *does not want*, to take them in. This is shown in the example of the father and daughter, below.

[**Note about avoiding reality**: At times, even 'normal' healthy adults find [their perceived] reality 'too painful' or unpleasant to wish to be actively present in it. There are many reasons for and ways of avoiding reality - for not being able to, or, not wishing to participate in 'present reality'. And this is true for people with dementia, too – in addition to their cognitive difficulties, which make it increasingly difficult for them to remain 'oriented to present time'.

An important example of this comes from Miesen's work <sup>13, 14</sup>. His research has shown that people with dementia who cannot secure the presence of 'attachment figures' to feel safe in the present moment, may return to 'memories of past attachment figures' to find comfort in present time. (That may be their only option for feeling safe in the present moment.) However, once an attachment figure has been secured and the person feels safe again, they may stop speaking about or seeking past-time attachment figures – at least until the next time they feel unsafe <sup>15, 16</sup>. ]

#### Uncertain when to stop orienting, correcting, or supplying new facts?

'Orienting' a person is essentially 'correcting' them when they say something that is incorrect - according to our reference point/s. It involves providing them with information in the form of 'facts'. This implies that 'you know something they don't know' - and often, that they're 'not as smart as you'. This can make them feel bad and can put you in a position of oppressive power compared to them - even though it's not deliberate - so be careful when correcting people.

Given that people in Behavioural Stage 2, and onwards, cannot learn new facts, (although they can learn new emotional information), this is usually the time to stop trying to orient a person. Stop - when you notice someone resisting what you are saying, unless it is urgent that you keep trying to orient them, even briefly.

As people with an Alzheimer-type dementia (or progressive vascular dementia) continue through the stages of their illness, their answers will likely change in a similar way to what is shown in the examples in **Box 3**. (This pattern may not apply to other types of dementia.)

# Box 3 Example of a gentleman with increasing difficulties staying oriented to time

**Situation:** Mr Y, 85, lives at home, alone. He was widowed in Oct. 2015; Jane's death, affected him greatly. His only child, Vi, lives nearby; she phones daily and visits several times a week. She noted these changes in her Dad's ability to be orientated to time.

Date	Communication interactions over time
July 2016 Pre-stage 1	During a visit at 6:00 pm [This is the first time Mr. Y makes a slip-up by referring to his wife as still alive, but he catches and acknowledges the mistake. The daughter doesn't dwell on it.]
Bookcase Micro-wobble stage	Dad: "I wonder when your Mum will be back. It's nearly time for dinner." Vi: Pauses - looks at her Dad closely, then asks, "Do you remember about Mum - when she had cancer?"
Also called 'Mild Cognitive Impairment'	<ul> <li>Dad: Embarrassed "Oh, yes. I just forgot there for a moment. How could I forget?"</li> <li>Vi: "It's easy to forget the things we wish hadn't happened You're getting hungry. That's why you're thinking about Mum."</li> <li>Dad: "I am and I am." []</li> </ul>
Sept. 2017 The start of Behavioural Stage 1	During a phone call at 8:00 pm [This time Mr. Y makes a slip-up by referring to his wife as still alive; it takes longer to for Vi to remind him his wife had died. She tries to do this in small steps.]
(usually only identified in retrospect)	Dad: "I don't know where your Mum has gone. She's been gone for ages. Did she tell you where she was going?" Vi: "Do you remember Mum had cancer?" Dad: "Of course I do."
	<ul> <li>Vi: "Do you remember she had surgery and chemotherapy treatments for several years?"</li> <li>Dad: "Yes, but was it that long?"</li> </ul>
	<ul> <li>Vi: "Yes, several years, and then she passed away in the summer."</li> <li>Dad: "When was that?"</li> <li>Vi: "That was just over a year ago now".</li> <li>Dadi "U sen" to the the sum over a ".</li> </ul>
	Dad: "It can't be that long, are you sure?" Vi: "Yes Dad; it's been over a year now. How long does it feel to you?" Dad: "I guess I just got muddled up there for a minute. It doesn't seem that long ago." Vi: "Maybe it's because you had a little snooze and were dreaming of her." Dad: "Yes, that'll be it." []
Note: Both	above mistakes were made in the evening when Mr. Y was getting tired.
Jan. 2018	During a visit at 11:00 am [This time Mr. Y needs more orientation points, but he does eventually remember.]
Still in Behavioural Stage 1	<ul> <li>Dad: "I can't find your mother anywhere. I don't know where she's got to. She didn't say anything about going out. Do you know where she's gone?"</li> <li>Vi: "Dad, do you remember that Mum was so ill, that she had cancer?"</li> <li>Dad: "Yes. But that was sorted out."</li> </ul>
	<ul> <li>Vi: "Do you remember that she went to the hospital for surgery?"</li> <li>Dad: "No"</li> <li>Vi: "And she came home and had chemotherapy after that?"</li> <li>Dad: "I'm not sure."</li> </ul>
	Vi: "Remember we put the bed in the living room for her?" Dad: "Yes. Right there – in the corner."
	<ul> <li>Vi: "And then, she went into the hospice and passed away there."</li> <li>Dad: "Yes, yes It doesn't seem real, even now."</li> <li>Vi: "No, it doesn't seem real."</li> </ul>
	Dad: "Yes, she passed away; I almost forgot! I guess I'm trying to forget all that."

July 2018	During a visit at 2:00 pm
In	[Mr Y is able to be oriented, but with even more difficulty on this occasion.]
Transition	
Stage 1 - 2	Dad: "I can't find Jane anywhere!"
	Vi: "Do you remember she was ill Dad?"
	Dad: "No."
	Vi: "Do you remember she had cancer?"
	Dad: "Cancer?"
	Vi: "Yes, cancer."
	Dad: "Impossible. She's never been ill a day since I've known her."
	Vi: "Well, she did have cancer, and was very ill from it."
	Dad: "I don't think so. I don't recall any cancer."
	Vi: "Well - she did have cancer. Do you remember we visited her in hospital?"
	Dad: "No, I don't remember any hospital."
	Vi: "When she came home, we moved her bed into the living room, and you
	and I looked after her until she went into the hospice. Do you remember that?"
	Dad: "Oh yes and then she passed away. I almost forgot."
	Vi: "That's right. She passed away peacefully. That's almost three years ago now."
	Dad: "Three years ago, you say, is that so?"
	Vi: "Yes, Dad. It's been almost three years now, and you were missing her"
	Dad: "Yes."
	Vi: "Do you want to look at some photos, or go for a walk with me?" []
Dec. 2019	
Dec. 2019	The daughter has arrived to visit after her Dad became distressed during a phone call
	[Mr Y is finding it increasingly difficult to make phone calls. Several times now, he has
	become upset during a call, and she has gone over to settle him. ' Home help' is now
Behavioural	coming in twice daily to assist him.]
Stage 2	Dad: "Have you seen Jane? I can't find her. I've looked everywhere."
	<i>Vi:</i> "No Dad. Do you remember she was ill?"
	Dad: "III?"
	Vi: "Yes, she had cancer."
	<i>Dad: "</i> Nobody told me that."
	<i>Vi: "</i> Well, she had cancer Dad - and she was very ill."
	<i>Dad:</i> "If she had cancer, don't you think I'd know about it, being her husband and
	all?"
	<i>Vi:</i> "You may have forgotten that she did."
	<i>Dad: "</i> You may have forgotten how much I know about her."
	<i>Vi:</i> "I know you are the expert about her Dad."
	Dad: "And don't you forget it." []
3 Jan. 2020	Phone call at 8:00pm
(pre-Covid)	[Obvious disorientation is shown by Mr Y. His daughter makes no attempt at orienting
Further along	him on the basis of her recent experience; she listens to him and then tries to distract
in	him.]
Determinant	
Behavioural. Stage 2	Dad: "I don't know where your Mum is. I've been looking for her everywhere."
Staye 2	Vi: "You were missing her?"
	Dad: "Yes."
	<i>Vi: "</i> What did you want to say to her Dad?"
1	Dad: "I want to know where she's been. It's getting late, it's dark!"
1	<i>Vi: "</i> Were you thinking about dinner?"
1	Dad: "Yes – and I want to know what's been going on."
	Vi: "What were you hoping to eat?"
	Dad: "Well, I was hoping for a pie."
	Vi: "Which is your favourite."
	Dad: "Any of them, but maybe the fish pie."
	Vi: "What about the deserts? Any favourites there?
	Dad: "Any sponge cake at all – long as there's jam in it. []

## The time-course and mistakes about time will vary somewhat between people

Example 3 illustrates the type of *changes* that people typically experience if they become disoriented in time, *gradually*. It is impossible to predict the time-course exactly, and there are some important exceptions. In acute delirium (resulting from things like infections or metabolic/alcohol/drug toxicity) extreme disorientation can occur *rapidly*, within hours. People who have strokes in particular brain locations, may have difficulty with time perception, but not with other aspects of cognitive functioning.)

## Three questions to ask yourself if in doubt about 'using facts'

These questions can help you decide whether to orient someone (tell them facts) or not:

- 1. Is the topic (or presenting issue) **important enough** to warrant correcting? (*If not, don't.*)
- 2. Is giving the person 'additional facts' **likely to 'overload their attention blackboard'** and make it more difficult for them to function after you leave? (*lf so, don't.*)
- 3. If this the first time this person has made this mistake, (i.e. not picking up on the facts), **is this perhaps evidence that the dementia is progressing**? Are they moving from Behavioural Stage 1 to the transition phase between Stages 1 and 2, or into Stage 2? (*If so, it may be helpful to try to orient the person, and document and date the changes.*) This could help get an accurate diagnosis and determine the speed of progression.

[In the language of the Memory Bookcases Model; is this evidence that the 'wobble' in the Factual Memory Bookcase getting larger?]

In summary, help to orient people with dementia if they can be, or want to be. **Box 4** summarizes points related to using Option 2 of the Ten-plus Communication Model.

# Box 4 Summary points about trying to orient people using 'the facts'

- If a person *can* be oriented, help them to do so in every way possible. (This applies to people in Behavioural Stage 1, in transition between Stages 1 and 2, and to people having 'lucid moments of awareness'. A person will briefly appear to be one stage higher than they usually are.)
- 2. If a person specifically requests to be oriented help them with this. However, if they are 'permanently disoriented in time' (i.e. in Behavioural Stage 2), they will be unable to retain the information you give them for very long, so you may need to repeat it if they ask again. That is – unless the information has a strong emotional component. In that case – people may remember the emotional part of the information, and be unclear about the facts.
- 3. If a person cannot be oriented, remain oriented, or resists being oriented, it is unhelpful to force our perception of 'the facts' (reality) on them. It can be unkind, even cruel sometimes to do this, for example, if the person if re-living past trauma <sup>14-17</sup>.
- 4. Working with the emotional flavour information is likely to make and keep a person calm and communicative. This approach may help them to: • enjoy a conversation
  - · be distracted to a pleasant topic, reminiscence, or activity
  - $\cdot$  be able to settle well to a meal, solitary activity, visit, or a good sleep
  - $\cdot$  or even perhaps, to have a lucid moment.

The knowledge from each option will help you use the other communication options better. For example, elements of using Option 1 well - such as 'asking good questions' - are also used to try to orient a person. Likewise, as the next TAD newsletter covers, using **Option 3** ('Reminiscing - through prompts, questions or triggers'), will benefit from your knowledge about the previous two options.

Till then, Best regards,

Gemma Jones

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