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TAD (Thoughts About Dementia) Newsletter

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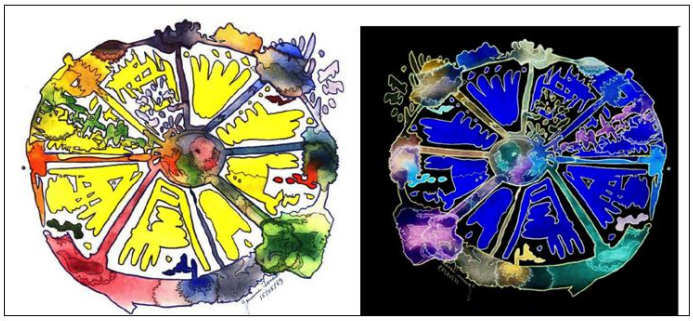


TAD 73 23 Oct., 2021

The 'Ten-plus communication options model' for dementia care
Option 6 - Lie

Related ideas for observations, reflection and research

- Do you have any memories of telling a lie as a child and getting caught out - perhaps even punished for it?
- Is it important to you to tell the truth (as you see it) in *all* things, or do you make exceptions sometimes, to avoid hurting a someone's feelings? (E.g. Your friend asks you if you like their new outfit. You don't like it, but, knowing they saved hard for it and are pleased - you say you think it's nice.)
- Did you ever tell a lie to a person with dementia?
- Were you ever found out? If so, how did you feel?
- Did the person forget this event, or did they lose their trust in you?

Dear Reader,

This TAD, introduces **Communication Option 6,** to **lie**, in the 'Ten-plus communication options model' for dementia care. (See the previous TAD newsletters for details of the models and options one to five [1-6].) **Box 1** gives a brief summary of the model.

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

1	**G**ather information; ask 'good' questions to find out about the person's story
2	**O**rient the person to what's happening, explain 'the facts'
3	**R**eminisce
4	**D**istract, directly and indirectly
5	**A**gree; play along with
6	**L**ie – told to make a person feel better, but a lie none the less
7	**S**ocial response; superficial, safe topics
8	**V**alidate (acknowledge) the person's feelings

9 **I**dle**,** stall for 'thinking' time; remain quiet; repeat last thing person said
10 **C**ombinations of the above options - used consecutively
Plus Humour (with provisos)**, ….. and other options**

Note that '**becoming defensive'** and '**trying to show the person you are right, and they are mistaken'** are NOT options in this model.

Lies work with people with dementia perhaps 99% of the time, at least in the short-term. If they didn't, they wouldn't be told so much. One of the troubles with lying is that using lies can become a lazy short-cut, and even a habit, preventing the use of other communication options. So, why am I going to caution you about lying? There is a risk involved in doing so. And - other communication options may work better than lying, in the long-term, to ease a person's distress.

When evaluating how many of the ten-plus communication options that students use on the communication exercises on my courses, it's reading the 'lies' that intrigues me most. The range and variety of lies doesn't tell me anything about people with dementia but it clearly shows how desperately family carers and caregivers are trying to help.

I tell my students, *"If you haven't taken my course, I can't and won't judge your lies because, with the knowledge and experience you have, you are doing your best. That is beyond criticism. However, once you have completed this course, I will ask you to 'bite your tongue' every time you find yourself lying to a person. Ask yourself if you really needed to lie. Use lying as a last resort communication option, never as a first option. There is always a risk to lying to a person with dementia, and potentially the big risk that they may never trust you again. 'To trust a carer or caregiver' may be the only good thing that is happening in a person's life. Don't risk breaking that trust, if at all possible."*

A separate but related topic is that, at a certain point, people with dementia don't have enough memory ability to be able to hold together detailed 'factual information' about: to whom they told a lie, for what purpose, and in what context. They cannot recall the details of a lie when next they see the person they lied to. This progressive 'inability to lie' coincides with their increasingly 'telling things how they are - in the moment' – i.e. becoming honest and disinhibited.

It seems somewhat paradoxical that as people with dementia progress in their illness they cannot lie anymore, carers and caregivers increasingly lie to them.

What are some examples of lies told to people with dementia?
Here are some examples which may sound familiar. They are usually told when some sort of 'care dilemma' has arisen.

A caregiver has said:

- to a newly diagnosed person with dementia - worried about being a burden - *"You'll never have to go into (day-care, respite-care), or into one of those terrible care homes, you can stay right here at home forever."*
- to a person who is disoriented in time and is refusing to go to bed because she thinks she must prepare a meal for her children returning from school - *"You don't have cook for them, I've already fed them and put them to bed so, you can go to bed now too."*

- to a person who is agitated and wants to leave the care home to 'go home' – "OK. There's a bus coming in two hours; why don't you pack your bag and wait on that chair. I'll call you when it comes."
- to a person who won't join in activities in the care home, because they are afraid they'll miss the visit of their son, who hasn't been in several months. *"He's just phoned to say that he's coming tomorrow afternoon."*
- to a gentleman who thinks his long-since-deceased wife is sick at home. He wants to leave the care home, even though it is dark outside, to go to her – *"I've just phoned your home; the doctor is with her and she's doing fine so you don't need to worry tonight."*
- to a lady attending Day Care sessions. Her family have made arrangements to place her in a care home tomorrow, without telling her. She is to be brought straight from day care to the care home, without seeing her home again. Family have made the staff at the day-care promise not to say anything to the lady. However, she seems to sense that something is wrong and asks various members of staff, "I know something's going on, but no-one will tell me anything - please tell me what's happening?"
  "No, nothing; everything's fine. You must be a bit twitchy or imagining it." *****

About lies and lying – some reference points
Lying is a vast topic and this TAD newsletter will only cover aspects most relevant to caring for people with dementia.

Some people maintain that "A lie, is a lie". They don't think in terms of the size or nature of a lie. No matter how tiny, if it's not the truth it's a lie, and they consider it to be wrong to tell it.

Others, however, think of lies as having size gradations such as 'little' versus 'big' lies. They think of *little lies* as those told to spare a person's feelings - to prevent emotional confrontation, harm, or discomfort in some way. *Big lies* are those told for our own benefit - to avoid punishment, to save face, or to maintain or boost our ego. Although they can't agree on the size of various lies, they think that telling the 'small ones' is permissible.

Defining a lie
For the purpose of the 'Ten-plus Communication model', a lie is defined as 'telling someone something that is known to be un-true'. (Withholding information, in the sense of deliberately not providing specific information, is not considered a lie for our purposes here.)

The following **assumptions about lies and lying** are made for this TAD:
- All lies, regardless of size, told to people with dementia by family carers and caregivers, are told with a good intention – namely to try to spare the person some sort of emotional discomfort. (In that sense they are 'amoral' – beyond the judgement of being good or bad.)
- When a person discovers they have been lied to, they may stop trusting the person who told the lie – temporarily or permanently. This is also true for people with dementia.
- During lucid moments, even people with dementia who are permanently 'disoriented in time' (in Behavioural Stage 2) can sometimes realize that they are being lied to during lucid moments. (**Appendix 1** gives an example of my personal experience with this.)

"Never lie to a person with dementia."
In 1982, while attending a course by Naomi Feil, I heard for the first time, "Never lie to a person with dementia". I was puzzled at Feil's insistence on this. And also surprised at how easy it was *'not to lie'* once you were aware of it. She gave us examples to learn 'how not to lie'.

At the long-stay hospital where I worked, 'officially', we were supposed to use Reality Orientation methods (relating 'the correct facts' consistently) with people in all stages of dementia. with everyone. 'Unofficially' however – we told many lies when 'the facts' seemed too harsh.
(There were no communication models for dementia in the 1980's. For both family carers and professional caregivers, our situation was as mentioned in TAD 67 [1]; 'telling people the facts' and 'lying' were the two most frequently used communication options used.)

Example of adjusting a response - so as not to have to lie

Situation:
An 85-year-old resident who is permanently disoriented in time (Behavioural Stage 2), has been sitting alone in her bedroom all afternoon. An agency-caregiver who has never seen her before, comes to see how she is doing. The lady mistakes the caregiver for her childhood friend.

Lady: "Are you my friend Vera (or Vern), from school?"

*Caregiver (lying with good intent): "No, I'm not Vera, but **I'm your friend**."*

Feil would say this a **double lie;** you're not Vera and you're not a friend. This is an easy lie to avoid. (But only after you're aware of when you lie and consciously don't want to do so.)

Caregiver (choosing consciously **not** to respond with a lie)
*"**No, I'm not your friend Vera, I'm xxx, your helper today, but I'd like to be your friend**. Will you come with me so we can have a chat and get to know each other?*

Note that: other communication options could be used instead of lying.
I'll assume in each case that we are answering "No, I'm not Vera", to the lady's question, before responding with one of the communication options.

Option1: Gather information; ask good questions.
"[No, I'm not Vera]. Were you expecting her? What's she like? Do I remind you of her?"

Option 2: Orient the person to what's happening, explain 'the facts'
"[No, I'm not Vera], I'm xxx, a new agency caregiver and I'll be helping you today."

Option 3: Reminisce
"[No, I'm not Vera.] Please tell me about your friend." (Who, what, where, when, how?)

Option 4: Distract
"[No, I'm not Vera], but we could go for a walk and have a chat together."

Option 5: Agree, play along with
This option is not applicable to this situation. Any attempt at it becomes a lie.

Option 6: Lie
What's the biggest lie I've heard told to this scenario? Telling the lady that you <u>are</u> Vera. *During my years of teaching - asking thousands of course participants how they would respond to this situation - about 3% said they would risk telling this lady that they were Vera. (This is a large lie - trying to impersonate someone you know nothing abou.!)*

Option 7: Social response
"[No, I'm not Vera], but would you come and have a cup of tea with me or go for a little walk?"

Option 8: Validate (the only emotion evident from the description given is that this lady is lonely - so that is the emotion that can be validated directly.)
"[No, I'm not Vera.] You sound lonely. Were you thinking about her, missing her?"

Option 9: Idle, stall for time, remain silent to let the person continue to speak, or repeat the last thing the person said
"[No, I'm not Vera, but you thought I was your friend ….?"

Option 10: Combination of the above options used consecutively
"[No, I'm not Vera.] I'm an agency-caregiver and I'll be looking after you today. Were you expecting Vera today? Can you tell me about her? Would you like to go to the lounge and have a chat with me about her? [Orient; gather information; reminisce.]

Why was Feil so insistent on not lying?
Feil said that if a person with dementia catches you lying to them, you run the ultimate risk that they may never trust you - or anyone else - ever again. This can be serious because people with dementia who may have already become very isolated, need to trust others to help them.

(Clinical dementia psychologist, Bère Miesen, also worried about people with dementia who do not (or cannot) trust anyone ever again, and described several categories of trust, in terms of 'attachment behaviour' [8].)

Feil said that breaking the trust, especially of someone in Behavioural Stage 1, can halt the 'therapeutic cycle of good care and communication'. If you are caught lying and lose someone's trust, you need to start again to try to re-establish trust. This is only a tiny cycle, within a much larger one. Feil argued that this was a waste of time. Don't risk lying, so that you can move on and achieve the real **goals of care** - which are to reduce feelings of fear and loss, so a person can be safe and happy.

At the time, I had never thought of these ongoing associations between trust and the rest of the therapeutic cycle:

- the psychological safety you feel when you have someone you can ALWAYS trust
- the strength that comes from knowing that even if you are frail, this person is strong for you
- renewed self-worth from being accepted – just as you are.

After hearing her say this, I made a schematic and have used it in my teaching ever since. **Diagram 1** shows a small section of the schematic - the loop to re-establish trust. **Diagram 2** shows the whole process.

Diagram 1
GETTING STUCK IN THE MINI-CYCLE OF RE-ESTABLISHING TRUST

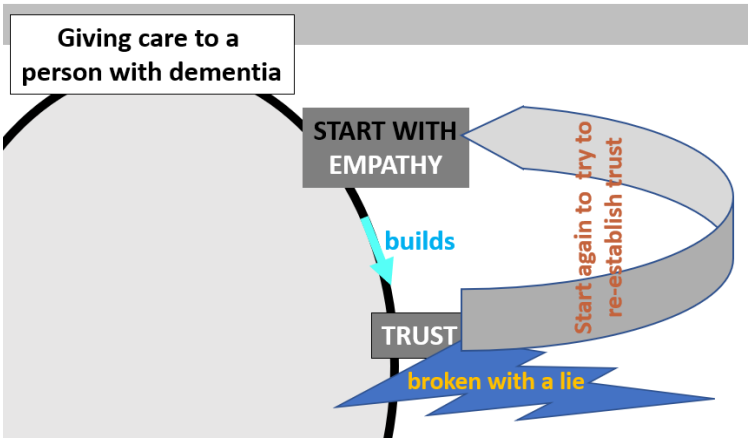
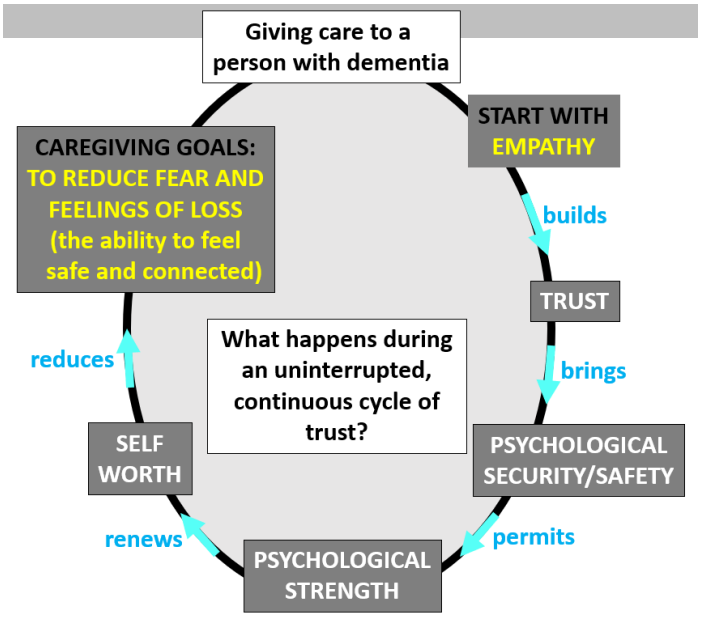


Diagram 2
AVOIDING LYING AND GETTING THROUGH THE LARGER CYCLE



I'm not as strict as Feil was. What's my position on lies? Use lies as a *last resort in your communications, not a first resort* – and use them *only* when you've tried all the other communication options.

The next TAD newsletter will be on communication option 7, 'social response'.

In the meanwhile,
Best regards,

Gemma Jones

Appendix 1 – During a lucid moment a lady catches me lying to her
I'll tell the story in chronological order, which I only figured out after I had lied to a particular lady. This happened during an evening shift in a long-stay hospital. Some bedrooms were multiple occupancy rooms, as was the one that the lady in this example was in.

Most people were in bed, already sleeping when a lady started calling out, loudly, for her long-since deceased husband to come to bed.

Lady: *"Peter, Peter, where are you? What's taking you so long? I've been waiting a long time. When are you coming to bed?"*

Caregiver 1: *runs into the room afraid the lady will rouse others and cause a ruckus. "Sh!!! Peter's been visiting with his brother and is staying at his place tonight. He'll be back tomorrow. You can go to sleep now; you'll see him tomorrow."*

Lady: *"Are you sure?"*

Caregiver 1: *"Yes, that's where he is, so you don't need to worry. Just go to sleep."*

[Caregiver 1 leaves but the lady does not settle. After ten minutes or so she starts calling for Peter again, loudly. Caregiver 2 hears her; she is unaware of what Caregiver 1 has just said to the lady.
Caregiver 2 had been taught to use 'Reality Orientation' (to tell people with dementia the correct facts if they were making mistakes [2]) if they didn't know what was happening.]

Caregiver 2: *"Now I know you're missing Peter, but he's not coming. You remember he died ten years ago. I'm sorry, but he's not coming back. So just settle down now, close your eyes and get some sleep.*

Lady: *"I don't believe you. I would know if he was dead, wouldn't I? I'm his wife. Who do you think you are? You don't know what you're talking about, and you shouldn't say such things. Get out of here right now."*

[Caregiver 2 is upset at this outburst and leaves quickly. The lady is angry, and thanks to the accompanying adrenalin surge, becomes for awake and alert, and starts calling out for Peter again. Caregiver 3 (i.e., me), also trained to use 'Reality Orientation methods', and unaware of what has just happened, enters the room now.]

Caregiver 3 (me)*: "Peter just phoned. He says things were running behind at work and the boss wants them to stay till it's all done. He'll be coming as soon as he can, but don't wait up for him." [I thought this would make her feel safe, so she could go to sleep expecting him. In the morning, she would have forgotten all about it. To my shock, she pointed at me with an accusatory finger and said the following.]*

Lady*: "Just who do you think you're fooling? He's been dead for ten years and he's not coming back."*

I felt like such a fool and a traitor. On going to speak with my colleagues, I heard of their experiences and realized that because we were all using different approaches, we were unknowingly contributing to this lady's disorientation and upset.

Also, the lack of 'apparent logic' to this situation, rattled me. Did this lady know, or not know that her husband was dead? Should I have lied, or oriented her to the facts, or done something else? (Indeed, my encounters with such dilemmas in care settings are the reason I've done the work I have and am writing these TAD newsletters even now.)

What I eventually learned from situations like this one, is that they are not possible to explain convincingly, without some understanding of different types of memory abilities

(e.g. factual, emotional, sensory [7]). Although the lady above might have poor factual memory, her emotional and sensory memory might be fine.
We could use that knowledge to explain that:

- This lady was disoriented in time; she didn't know her age or the current year.
- She *did* know (deep down in emotional memory) that her husband had died but didn't know when that was.
- None of us like to re-visit painful emotional memories and tend to block them. That doesn't mean we've forgotten them [8].
- When this lady was upset, her adrenalin was raised, her alertness was raised, and she heard from Caregiver 2, "he's been dead ten years", she recalled it and and remembered it long enough to relate it to Caregiver 3.

References

***** *This is an example of a 'group lie'. It is beyond the scope of this TAD to discuss this, except to say that caregivers do not have to agree to tell the same lies to the person with dementia that family are telling. (Or vice versa.) It is possible to validate a person's feelings of being upset without conspiring to lie.*

1 Jones, GMM (2021) TAD 67, 17 Mar., The 'Ten-plus communication options model for dementia-care. TAD newsletter. Sent out by TheWideSpectrum.co.uk, pp8
2 Jones, GMM (2021) TAD 68, 18 Apr., The 'Ten-plus communication options model' – Option 1: Gather more information, ask 'good' questions. Sent out by TheWideSpectrum.co.uk, pp10
3 Jones, GMM (2021) TAD 69, 31 May., The 'Ten-plus communication options model' – Option 2: Orienting and explaining the facts. TAD newsletter. Sent out by TheWideSpectrum.co.uk, pp9
4 Jones, GMM (2021) TAD 70, 05 July., The 'Ten-plus communication options model' – Option 3: Reminisce. TAD newsletter. Sent out by TheWideSpectrum.co.uk, pp6.
5 Jones, GMM (2021) TAD 71, 20 Aug., The 'Ten-plus communication options model' – Option 4: Distract. TAD newsletter. Sent out by TheWideSpectrum.co.uk, pp7.
6 Jones, GMM (2021) TAD 72, 24 Aug., The 'Ten-plus communication options model' – Option 5: Agree – play along with. TAD newsletter. Sent out by TheWideSpectrum.co.uk, pp 12.
7 TAD 59: 20 Feb., 2014, Metaphors for cognitive change: attention blackboards and memory Bookcases. TAD newsletter. Sent out by TheWideSpectrum.co.uk, pp14
8 Jones, GMM (2011) TAD 36, 4 July. Re-surfacing traumas: not leaving people with dementia alone with their fears. In: TAD (Thoughts About Dementia) Newsletters, Vol. 1; GMM Jones, 2012. The Wide Spectrum Pubs., Sunninghill, Berks, UK, SL5 7BH. Pp113 – 117.