

Truth Telling and Dementia: A personal guide

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Truth telling is a virtue, we learn from the start of our lives. To tell the truth is taught as black and white; the lie or the truth. In reality there are some shades and some shades of virtue in the grey parts.

This guide springs from a talk I did for Engaging Dementia and while it is academically informed it is more of a personal reflection on my own caring journey. I hope it will help another carer and person with dementia.

The preface to this is that, when you are challenged by a situation as a family carer, the feeling is one of being 'out of control'. So what I am stressing here is that it is important to acknowledge that feeling out of control, while being confronted by a loved one on an issue such as the loss of parents or a spouse, is a very difficult place to be.

Indeed, it can lead us to look for control by finding a consistent response; to always lie or always to tell the truth and to find the virtue of that in the act itself – either the kindness of protecting the person from potential upset or the rightness of telling the person the truth.

Step 1 when I see anxiety start to bubble up I check the time. I know from professional experience that high anxiety will not last forever so I always time the episodes and now I find I have the very useful bit of information – it usually lasts 2 hours or less. When you are in the eye of the storm it is tempting to feel this will never pass or that it is always like this. This is a very small thing but somehow knowing at the outset before I get caught up in it is a little bit of gold dust for me.

Step 2 The second thing I offer you is a word – a little word and in the midst of feeling 'oh no not again' 'why me' 'how can I help her' I don't have to think – I just reach for a word and the word is 'Sorry'.

I can tell you that when you are feeling persecuted it's hard to know what to say– let's be honest, no one more than your family can push your buttons and no one has infinite power to maintain their cool in these situations. Although I know that Mum knows who I am and loves me (somewhere in there) when she vows she never had a daughter – it really hurts. I can intellectualise this but it doesn't change the feeling and not acknowledging the feeling (to myself) I suspect might be the worst thing I could do.

I have a strong belief in the need for emotional presence – by this I mean being open to the emotion that Mum is feeling and that I am feeling because not acknowledging the hurt means you push it down but it doesn't go away. And if I do that – I become grumpy and riled. But knowing it means I can deal with that later and not act out on that hurt now which will almost certainly mean an escalation of the distress for both of us.

So back to 'sorry' – you are not taking ownership or blame when you say sorry – you are just saying – it's hard – I know – I hear you and I wish, for you, that it wasn't. So you aren't saying sorry for your own behaviour – you are saying I'm sorry you are having a hard day today, I'm sorry you are so upset or frustrated or angry and sometimes that is enough. If not enough it's hard to see, when said genuinely, how it would be a point of escalation.

So Mum is angry or frustrated or stressed and she is saying that we have to let her parents know where she is and that I know their number why won't I just ring them....

This takes us into the territory of whether to lie or how else to respond. So again – I offer you a coping strategy I have used to feel more in control...

Step 3 This is to know there is a finite number of ways I can respond; Just 4 in my experience...

A. Truth telling / reorientation – Oh Mum I know you miss Nanny and Grandad but they aren't with us anymore. They lived very long lives and we cared for them the best we could until the end of their life. If they were alive now they would hate you to be worrying about them

B. Validation– It sounds like you are very worried about upsetting your parents – Do they worry about you a lot?

C. Fiblet – Nanny and Grandad are not worrying about you I know they're fine.

D. Lie – Your Mum and Dad are well – they are in the shop and I'm sure they're very busy.

So from now on I just have a choice between 4 options – any of them might be helpful or unhelpful in a given moment but my job is to work out – what does she need from me now. This somehow takes me out of the messiness of the situation and into a more problem solving arena. Again for me, feeling like there isn't an infinite number of possible responses helps me to feel in control of the situation. It also stops me from simply responding in a knee jerk way to my own stress. Even in the strongest relationships there are patterns and dynamics which the type distress many people with dementia experience can challenge.

Option A used to work really well in the early days with dementia but even now this can work really well and take away a lot of frustration at times. I know very quickly to stop with option A if there is a sense that she is totally impervious to anything I am saying; not able to take it in – maybe I just finish the sentence about Nanny passing away and she says 'that's nice but do you mind if I ring her now'.

But there are times when I say the same thing and she says 'well I think I knew that really, thank you for telling me because people don't always you know. It is sad but then I don't have to worry about them'. I say, 'No we've done all that'. She says 'Did we have a funeral'... Then I can tell her about the funeral and it is always a source of comfort – if we can get there.

Option B might go like this:

Mum: I'm in a terrible mess I can't remember where I parked the car when I got here.

Me: You've lost your car. Oh my goodness what can we do. Or What is it like? Can you tell me anything about it? Have you ever misplaced your car before? How did that turn out?

I know by the answers to these questions where she is at. The more negative the answers, the more I might be inclined towards option C. If she calls me out for making a fuss and not answering the question it can be hard to stay in this place. One thing I've found useful here is repeating back the last thing she says – not so much paraphrasing which takes more thought power than I might have – but for instance:

Mum: I'm in a terrible mess I can't remember where I parked the car when I got here.

Me: You can't remember where you parked the car?

Mum: Well it wasn't my car I borrowed it.

Me: you borrowed it?

Mum: yes – a nice lady...

So this can be a good way of treading water – like sorry – it won't inflame the situation, it might not really sort it out but remember this won't last forever. This stage is about exploring how she feels without getting caught up in the facts of what she is saying.

There is so much written about the lie in dementia – often it is called a 'therapeutic lie' that is a term I reject – well it might be therapeutic but maybe for the person making the lie.

I have less problem with what I call the fiblet – it's a sort of lie by omission. I'm not going to say – I am your daughter, or, You don't even have a driving licence anymore, we can use the ambiguity of who I am or how she got here, as long as I have a sense I am someone she is happy to be with. I have to say I struggle hugely with option D. It feels like the ultimate lack of respect, to pretend, when she is so distressed. There are times when she is very lucid and we talk about how I should respond when she is so upset and what she said to me was 'please don't ever lie to me, it feels like you are the one signpost in the mist and if you stop telling me the truth where will I be – completely lost.'

However, in those moments where nothing is going in – if I tell the truth she isn't hearing the truth – if I say Nanny died 11 years ago – she hears – she just died – and that isn't any reason for me to feel virtuous that I told the truth because she heard a lie. In addition, she may say – 'you are lying, I spoke to her yesterday' then she doesn't trust me and both her and myself are very much worse off. For me, to decide that I have a response to Mum which is to lie or be 100% truthful in all situations where she is confused is the ultimate in controlling her rather than increasing my own sense of control. So for me it's a 4 step dance and I choose the step each moment and that gives me a feeling of being in control.

Professor Irving wrote this personal guide as part of her participation in an Engaging Dementia webinar on 16th June, 2020. The webinar was entitled "Resilience for people with dementia and carers: Addressing the challenges of the "new normal". A full recording of the webinar is available on www.engagingdementia.ie