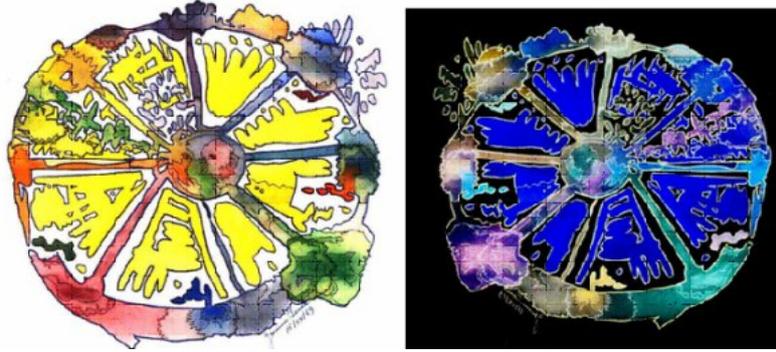


TAD (Thoughts About Dementia) Newsletter



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Re-surfacing traumas not leaving people alone with fears and tears

Dear Reader

People with dementia who are disoriented-in-time (unaware of their age, where they are living, how old they or their family members are, who cannot recall who is alive and deceased), sometimes re-experience past situations as if they were occurring again^{1,2,3,4}. The ‘triggers’ for re-experienced events are not necessarily predictable but have included, physical sensations, the presence of specific objects, darkness, misperceiving cues in the environment, and perhaps most importantly – picking up on an unpleasant and impersonal ‘emotional atmosphere’.

There are a variety of such experiences, but by far the most familiar examples involve elderly residents in care home settings, who think they are young again and are feeling unsafe, who tell staff they ‘want to go home’ to their parents, spouse or other close attachment figure. [When people with dementia are disoriented-in-time and say they want to go home, in the first instance this is understood as their expression of feelings of fear and discomfort, rather than as a literal request to return to a previous actual abode.] Some residents eventually think they are ‘at home’ with their parents, (or at work), and then stop requesting to go there.

Dr. Bère Miesen spent many years studying the progression of changes leading to people with dementia speaking about deceased parents as if they are still alive. (See the previous TAD 34 newsletter, 23 May 2011, Adoption and Attachment). This led him to write about **the importance of not leaving people with dementia who are disoriented-in-time, alone. Also, encouraging caregivers to be visibly present as much as possible so people do not become lost and distressed in their search for finding a ‘safe other person’ to be with.** (See TAD 15 newsletter, 28 June 2010, “Well-being assistant” – host/hostess role

in dementia care settings). This also applies to people with dementia in their own home settings. Family carers sometimes say the person behaves like their ‘shadow’, or a ‘puppy’ who will not leave them alone, even to go to the next room.

One of Miesen’s conclusions was that - people with dementia who cannot ‘find safety’ [feel safe] by staying near people who symbolize ‘safe, significant people from the past’ [attachment figures], only have one remaining way to feel safe. That is to try remember [search for and re-live memories of] feeling/being safe with them.

This implies that people with dementia try to ‘problem-solve’, and actively ‘search for safety and comfort’ - however they do so within the limitations of their damaged cognitive abilities.

To new caregiving staff, such time-dislocated situations can seem bizarre and inappropriate. If staff don’t understand what’s happening to a resident, they may respond literally to the facts, sometimes unhelpfully.

For example, an 87-year-old lady with dementia residing in a nursing home, had been straining on the toilet for about fifteen minutes, without effect. She then suddenly started shouting loudly and repeatedly calling out for help saying, *“please, please, help, someone, help - the baby’s coming”*.

Two young female members of staff were the first to answer the summons, neither of whom had experienced childbirth. They laughed, telling her ‘the facts’:

- . she was 87
- . she wasn’t pregnant
- . she couldn’t be pregnant or have a baby at her age
- . she was ‘just on the toilet having a bowel movement’.

Though they stated the facts, they had missed the feelings and sensations – and had either not noticed that this lady was frightened and uncomfortable, or didn’t know how to respond to this. [Their intervention is an example of the inappropriate use of old-style ‘Reality Orientation’ with a person with dementia who is disoriented-in-time.] The lady seemed to completely ignore their responses, and continued shouting as before.

Eventually, an experienced caregiver arrived, and more helpfully said:

“I’m here to help you. I’ll stay with you. Tell me where it hurts.”

“Down below”, the lady replied.

“In your bottom”?

“Yes”, the lady said.

“Is it a feeling of pressure?”

“Yes, the baby’s coming soon”, the lady said.

“It feels like the pressure of having a baby?”

“Yes”, the lady shouted.

“You’re frightened.”

“Yes, please don’t leave me”, she whispered.

“I won’t leave you. Let’s see what will make you more comfortable”.

The caregiver stayed with her. The lady stopped calling out, but her moaning continued another ten minutes, without any results. The caregiver helped the lady to bed and arranged for someone to examine her. She was severely constipated and required a stool softener and several enemas. Only then did she stop talking about ‘the baby coming’. [Although this lady had children, there was no documentation about whether her deliveries had been long, difficult or otherwise traumatic - but the link between the physical sensation of rectal pressure/discomfort and childbirth is certainly a familiar and plausible one, despite her dislocation-in-time.]

The above situation lasted only a day but occasionally, associations of former turbulence and trauma are recurrent or very persistent - some occur daily for months on end. They are upsetting to everyone around, and usually result in a person being isolated from others, to minimize the distress and disruption to the communal atmosphere.

[To my knowledge, the frequency of such situations has not been researched; neither has the range and order of the care planning interventions used, been suitably documented and analyzed. In my experience, staff are upset that they do not know what to do to help people, do not document it well, and avoid discussing it; they see it as a failure to care well, or to be able to comfort someone, on their part.]

Miesen’s work identified several patterns of distress linked to people being disoriented-in-time: ¹

- a) distress which disappears for the duration that another remains present
- b) distress which disappears during and for some time after a person has been present
- c) (and rarely) distress which is resistant to disappearing, or does not disappear, even in the presence of others.

[Miesen suggests that some people have been so badly hurt in life, and not healed from the pain and sorrow sufficiently, to trust anyone anymore.]

Next, is an example of some intensive, longer-term care planning that staff tried with a lady; it changed her ‘type c’ persistent distress, into ‘type a’. ^{1a}

A lady (I’ll call her Alice), aged 84, had dementia and lived in a nursing home. All day long, she alternately cried and called out for her mother; “Where are you mummy?”, “Please come mummy”, and “Why don’t you come mummy?”

Alice had been doing this virtually all day, every day, for months (since her

transfer from a residential care home) - despite all the best efforts of everyone to engage with her, distract her, comfort her, and try to change her mood. In the morning she had visible tears; but even though they seemed to run out as the day continued, her crying didn't. Various types of medication had been tried, unsuccessfully; since the crying and calling out continued the medication was stopped. Staff were then told that there was nothing that could be done for her, her behaviour was a consequence of 'the dementia'.

Staff could not readily get eye contact with Alice, let alone get her to join in any activities or groups. She was unable answer the caregiving staff or her fellow residents when they enquired about "What was the matter", "Why are you so upset?", and "What can we do to help you?" In spite of the efforts of various residents to comfort her, she did not stop calling out and crying; some mistook her for an frightened child. When nothing they did consoled her, they didn't want to sit near her and asked for her to be quieted ["shut her up"], and removed. Alice's distress quickly spread to all present and made the atmosphere in the room tense. (Staff could not recall Alice ever having had a visitor since being admitted; perhaps her family/contacts were similarly upset, and could not bear the pain of seeing her distressed repeatedly.)

Staff were at their wits end as to what else to try. (Providing full-time, one-to-one care for Alice was not an option for financial staffing reasons.) With no other obvious solution, the decision was made to keep the lounge area pleasant for the other residents. This meant keeping Alice in her bedroom for large portions of the day, so others would not hear her shouting and crying and become agitated too. Not surprisingly, her bedroom was at the end of a corridor, furthest from the lounge.

Then, a new life-history event came to light, one that stimulated further thinking. When Alice was seven years old, her mother had died whilst trying to help the neighbours, whose house was on fire. Alice completed her schooling and seemed to have led a 'normal' life – she married, was a home-maker, had children, grandchildren, hobbies – there was no knowledge of particular ill health or any mental health difficulties in her life. Her dementia had been progressing slowly after being first noticed some years earlier. Whether Alice's grieving for her mother's death was 'incomplete', and who supported her at that time, was not known.

In light of Miesen's work (above), it was considered that perhaps, in seeking 'memories of safety with her mother', Alice had returned to a distant 'crisis memory' – recalling wanting her mother, calling for her, but mother never returning. This possibility, prompted a group of staff members to think about trying to create the 'feeling of a safety' for Alice.

Several caregiving staff were particularly distressed at her behaviour. With new motivation they decided to try and see if giving Alice extra intervals of close one-

to-one contact in her bedroom would help (in addition to the time spent giving her routine personal care and assistance with nourishment). They voluntarily gave up their coffee and lunch breaks, in turn, to be with her. Their goal was to get increased eye contact and reduce the crying and calling out, even for a few minutes. They greeted her, sat close to Alice, looked at her, held her hand/s, and spoke/sang to her. “I’m, I’m here to be with you... I’d like to tell you about....and sing something for you. You probably know this. You can join in if you’d like.”

After several days, when she seemed accustomed to this contact, a caregiver tried putting an arm around her. Alice did not resist. The caregiver started making slow, rocking movements, and humming a lullaby to her; she seemed comforted. Alice stopped crying during some of these intervals. This result was the incentive that staff needed to continue their ‘voluntary’ work with her. Progress continued patiently.

Alice’s improvement also meant that staff could sit in the lounge with her for increasing intervals, (rather than in her bedroom). Within two months Alice had stopped calling out for her mother as much, and, surprisingly, had started to look for ‘her children’. [This was seen as a significant change, because it indicated that she was also remembering her role as a mother – who gave comfort, rather than as a child – in need of comfort].

Alice remained disoriented-in-time, but her crying stopped for the most part, except for occasional episodes. It was now possible for her to sit in the lounge and to be present at various activities there. Although she did not join in, she seemed to be pleased to be present, and observing quietly.

(Note: given that they had been told there was “nothing that could be done for Alice”, some members of staff did not see the purpose giving up their break time, so participating in this intervention was on a voluntary basis at first. The result of this intervention, in this instance, was a positive one. Reference 5 gives another example of reaching someone who was thought to be ‘unreachable’ because of dementia.)

Thinking back over 30 years, I recall half a dozen examples of such ‘extremely distressed residents’ in care homes in Canada, France, the Netherlands and the UK; I still wonder if a similar sort of intervention would have helped them also.

[In discussing such examples with course-participants, a number of them have become concerned about how past traumatic event/s in their own life might ‘re-surface’ in later life, or if they get dementia. They don’t want to think about them now, let alone re-live them over and over again later.

Their question can be rephrased as:

How do we heal from the psychological hurts in life (the consequences of betrayals, disasters, abuses, and accidents), so that they don’t keep hurting?

No one gets through life unscathed, but some people are deeply and multiply hurt. The old advice still applies - in general terms – don't keep it buried inside; speak to a wise, trusted friend. If that isn't sufficient or possible, there are many sources of specialist services available nowadays, including counselling, peer-support and therapy - for specific types of help. This wasn't so for those people who are old, and in our care now.

The key message for trying to bring comfort to someone with dementia, who is frightened (and other people in life), is to let them know: **“You are not alone – I'm staying with you.”** This message can be given in many forms, verbally and non-verbally, and through every sense.

In dementia care, you will often be working to allay 'fear behaviour'. Considering that most 'anger behaviour' has its roots in fear, it is even more important to learn to work well to allay fear. The link between fear and anger will be covered in a future newsletter.

Related ideas for observations and research:

- . How often have you seen people who are disoriented-in-time, seeming to re-experience past, unpleasant or traumatic situations?
- . Was this documented?
- . What kind of care interventions were attempted?
- . Which ones were most and least successful?

Best Regards,
Gemma

P.S. It is this type of work that led Bère Miesen to start recording 'attachment histories' of people with dementia, as part of the information he saw as essential to providing optimal quality dementia care.

References -

- 1 Miesen, BML (1999) Dementia in close-up, Routledge, London.
1a pg 77, example - expanded from the original version I included in the above book
- 2 Miesen BML, Jones GMM (1995) Psychic pain re-surfacing in dementia: from new to past trauma? (C. Rowlings Ed.) Past Trauma in Late Life : European perspectives on Therapeutic work with older people. Jessica Kingsley Pub., London. Pp142-154.
- 3 Jones GMM, van der Eerden-Rebel W, Harding J (2006) Visuoperceptual-cognitive deficits in Alzheimer's disease: adapting a dementia unit. In: vol 4 Care-giving in Dementia (BML Miesen & GMM Jones (Eds). Routledge, London. Pp 3-58
- 4 Jones GMM, Harding J, van der Eerden-Rebel W (2006) Visual phenomena in Alzheimer's disease: distinguishing between hallucinations, illusions, misperceptions and misidentifications. In: vol 4 Care-giving in Dementia (BML Miesen & GMM Jones /Eds). Routledge, London. Pp 59-104.
- 5 Feil N (2002) You-tube clip. <http://www.youtube.com/watch?v=CrZXz10FcVM>

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