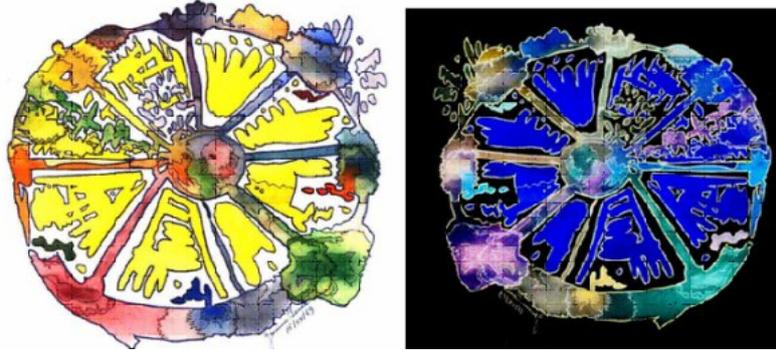


## TAD (Thoughts About Dementia) Newsletter



### #25: 6th January, 2011 Changes in time perception

Dear Reader

Time perception (TP) is a fitting topic to start the New Year with. “Where did 2010 go”? Or perhaps, “didn’t last year drag on”? Do you remember how, as a child, to wait one day until your birthday could seem endless, whereas now, a day can appear to ‘fly by’? Do you ever remember discovering that you seemed to have ‘lost time’, because you had no recall of an event (whether that was from being somewhat inebriated, or perhaps from day-dreaming)? If the perception of the passing of time can seem so subjective, paradoxical and elusive to us as children and adults<sup>1</sup>, what can happen to it in old age<sup>2</sup>, and in dementing illnesses<sup>3</sup>? Surprisingly little formal research has been conducted into this yet. Why?

TP is complex. Like memory, it is often mistakenly assumed to be a ‘single ability’. TP is dependent on the accurate working of many conscious and unconscious abilities, including attention, learning, updating of information in short and long term memory stores, and sensory perception. It involves ‘time’, ‘timing’, the learning and coordination of ‘timing mechanisms’, and the constant updating and maintenance of a variety of ‘internal representations of time’<sup>4</sup>. We seem to have several ways of perceiving time, which work in isolation and together, and some sort of ‘internal time-keeper’, as well as ways of using information about time from clocks and calendars. For example:

- . cyclical-time: for repeating cycles like days, months (moons) and seasons
- . chronological-time or calendar-clock-time: for events that follow one after another without a repeating pattern
- . ‘time in tenses’: for past, present and the expectation of future time

It is difficult for us to conceive of how people function if they have damage to one or more types of TP ability, i.e. how they would perceive their ‘present reality’.

We can only have some awareness of what is happening currently if we can ‘perceive’ in ‘present-time’. There are plenty of ways of avoiding living in present time (reality) and living in other times and states. In working with people with dementia, you may have noticed, that particular sensations and emotions, re-experienced through memory, re-connect them to past memories of similar sensation or feeling<sup>5</sup>, (sometimes, traumatically so). As well, learned behavioural responses to the ‘meaning and value of time’ to an individual, can result in a range of behaviours - from obsessive punctuality, to lackadaisical relaxation.

Perhaps there are other forms of TP, which we have no terms for yet, because they are difficult to isolate from our overall sense of awareness. We can make estimates about ‘how much time is elapsing’, as an event occurs, but these are not always very accurate - even in healthy people. Interestingly, we can recall events and time periods, in retrospect - but curiously, we do not seem to have a specific memory facility for remembering the ‘length of time’ that an event took to happen.

Changes in TP can occur in many illnesses: It is inevitable in dementing illnesses, as various brain areas related

to specific cognitive abilities become damaged. Researchers are looking for distinct types and patterns of change in different types of dementia, also, for initial 'small changes' in TP, which are difficult to detect. TP changes are usually first noticed when a person starts having obvious difficulty knowing the date, week or month. For example, attempts to help people to 'stay oriented to time', with calendars, reminders, and diaries can help some people with dementia, but not everyone. Also, there comes a point where these cues and prompts may no longer be helpful, and only make a person feel badly that they cannot make use of them. So what else can be done?

Is it helpful for carers and caregivers to observe and document changes in TP?

Yes. TP changes are useful to observe and record to assist diagnosis, and for understanding how a person is 'perceiving their world', to understand their resulting behaviour, and how best to help them. Changes in TP can bring a variety of dilemmas.

Consider for example, how you might behave if you thought:

- . you were a child again, at home, with punitive versus nurturing parents around
- . you were at boarding school and missing home
- . you were expecting your own children to arrive home after school, but it is now dark outside and you cannot find them anywhere
- . you thought that you were at work with your colleagues, and it was a busy day
- . you could not recall marrying for the second time, and expect to find your first spouse in bed with you, but instead find someone else there.

Reflecting on these examples illustrates that having difficulties in TP inevitably also involves having difficulties with accurate perception of location or place. (And even more so when people have visuo-perceptual difficulties.) Some of the resulting mistakes may evoke pleasant or unpleasant memories or emotions. In dementia care settings, the latter are of most concern.

What is the largest change or gap in TP you've had? (Have you ever been day-dreaming or travelling, and not recalled the time between one event or place and another? Have you ever awoken from a vivid dream and found it difficult re-orient and re-connect with your life? How long did it take? How did you problem-solve that? What could have happened if you could not have?)

What's the largest change in TP that you've seen in a person with dementia? It can range from being unaware of several seconds, minutes or hours, days, weeks, months, years - to a loss of awareness of more than 85 years. Puzzlingly, some people with dementia do not even seem to be able to perceive or use 'cues' about whether it is day or night from looking outside, or work out what season it is from cues like trees without leaves, or there being snow on the ground.

How specific damage and patterns of progression can cause such marked changes to TP, is not yet understood. What has been observed however is that in Alzheimer's disease, TP typically changes slowly, progressively and irreversibly. In other illnesses and conditions, such as with infections, high fever, large strokes, head injury, and reactions to drugs/medication, it can happen very suddenly and dramatically, and may or may not be reversible. Some people with vascular dementia have shown unusual patterns of change in TP and even recovery<sup>6</sup>. For others, there can be unexpected partial abilities, for example, a lady knowing that it was her birthday on a particular day, but not knowing the year, or whether they are middle-aged or old<sup>7</sup>.

A familiar example

A caregiver recently said that she found it difficult to figure out what was the best thing (most helpful), to say to some residents who were 'very disoriented in time', and distressed as a consequence. (Not all residents were.) Part of her dilemma came from not having received any formal teaching about dementia or communication options, so she was left to follow her own intuitions. However, these were not always the same as those of her colleagues, which added to her conundrum about whether she was saying the 'right' or 'best' thing. She knew there was no single formula that worked in all situations.

Her biggest concern was for a 95-year-old female resident, who had been diagnosed (non-specifically) with 'dementia', five years earlier. This lady repeatedly asked members of staff, throughout the day, every day, about:

- . where her mother was
- . whether they knew her mother
- . when her mother would be back.

This lady's mother had died over 30 years earlier. How could she forget that? The caregiver could not recall when exactly this behaviour had started; she guessed it had been happening over the past two years, with increasing frequency.

The caregiver had tried a variety of ways of responding to this lady, with different results:

- . when she oriented the lady to 'the facts', by reminding her that 'mother was dead', the lady usually disagreed vehemently and became bewildered, distressed, anxious, sad and/or angry
- . if she ignored the lady's queries about mother, the lady continued searching for, and asked other residents and staff, about mother. After some while, when she could not find her mother, she would also become anxious, desperate and/or angry
- . if she lied to this lady, (e.g. telling her that her mother was fine – just gone out shopping for a while and would be back later), she would often settle. Very occasionally though, this lady did realize that her mother was dead, though only briefly, and was angry at being lied to.

How was this brief awareness possible? One explanation for such 'lucid moments' is that 'deep down', the lady does still know her mother died. (It is not a recent memory, and it will likely have been stored in 'factual memory', and 'emotional memory' and perhaps even in some types of 'sensory memory'. Given that in most dementing illnesses, access to factual memory is most damaged, whereas access to emotional memory storage is least damaged, it would be expected that this lady would know 'at some level' that mother was dead, though she would not likely recall the factual details anymore, such as: the day or date, how many years ago.)

So... if this lady knows 'deep down' that her mother is dead, why does she ask about and search for her mother? There are several ideas about why this could be so. First, is that all humans have a tendency to 'avoid thinking about their painful memories', at times. Second, is that when people cannot 'find safety' in their present environment, they often search for 'memories of safe times' in order to try to feel better. Hence, this lady's frequent mention of and searching for her mother, may be a direct signal that she is often frightened.

The caregiver wondered if there were other communication options that she didn't know about?

There were several that she used, but didn't have a name for.

- . asking about mother and reminiscing about home-life
- . naming and acknowledging (validating) the lady's current feelings and memories about her mother – whether they were sadness at missing her, or contentment at the thought of her being present
- . distracting the lady from asking about and looking for mother, before this behaviour started, by engaging her and including her in familiar activities (household-type tasks) which she liked to do. The lady then seemed to assume that she was 'at home' and mother was somewhere, nearby.

What has previous research shown?

In Alzheimer's disease, changes in TP often go hand-in-hand with spatial disorientation, visuo-perceptual difficulties and misperceptions. Home-like (and sometimes work-like) cues that are highly visible, can help a person to 'feel like they are in a familiar environment, rather than 'feeling lost'<sup>8</sup>.

From his research, specifically about people with dementia who thought their long-deceased parents were still alive, Miesen identified various levels of TP change<sup>9</sup>.

- . unusual and temporary (e.g. as with people who are ill from infections, fever, or are not tolerating medication well)
- . occasional – only at certain times of the day e.g. when people are tired, hungry, or over-stimulated. Sometimes people are able to realize and correct their mistakes.
- . occasional mistakes, but occurring more frequently, and throughout the day. People eventually do not notice or correct their mistakes any more. When they are in the presence of caregivers (who can function as symbols of parents /attachment figures) they do not ask about their parents so often, or at all. However, they do so when they are left alone and/or feel frightened and lost.

. permanent – where people constantly disoriented in time, but reassured by the presence of others. (There are reports of rare individuals, who even find it difficult to settle down and feel safe, even with caregivers<sup>10</sup>.)

Interestingly, ‘brief, lucid moments of awareness’ have been reported even in people with permanent TP.

Feil<sup>11</sup> was the first to challenge the ‘Reality Orientation approach’ (repeatedly telling people the ‘facts about the present-time’ and ‘correcting their mistakes’, in the hope they would re-learn and remember them again), being applied to everyone with dementia, in all stages of the illness.

She encouraged caregivers to ‘forget the facts and work with the feelings’ when people were no longer able to learn and retain facts about present time. Her work led her to distinguish between at least two factors involved in being able to be ‘oriented to present time [reality] accurately’: ‘the desire to be oriented’, and ‘the ability to be oriented to reality’. If the circumstances in a person’s present reality are unpleasant and unchangeable, there is reduced motivation to be present in and ‘participate in reality’. If a person has brain damage, such that they cannot update and remember new information, and are upset by it, it is unhelpful to ‘force the facts’.

Feil was adamant about avoiding lying to people with dementia. She conceded that lies often *can* work to calm-down people with dementia (if they didn’t work so well, they wouldn’t be told so often). However, although only remotely probable, she was concerned about the loss of trust that could occur if/when a person with dementia found they were being lied to. She argued that, especially for people in ‘behavioural stage 1 – Malorientation’, who sometimes only trust only one carer or caregiver, a loss of trust could represent losing the only good contact they had. Although people can learn to trust again, it can take time. Feil sees this as a delay to achieving the overall goal of ‘helping to reduce a person’s feelings of fear and loss’. (My own position on lying is not quite as strong as that of Feil. My research into communication between caregiving staff and residents with dementia, found that lying was very frequent - often a first resort and sometimes almost-only resort. If all other options have been tried and failed and you don’t know what else to do, and it is necessary to comfort a person, use a lie only as a ‘last resort’.)

New research?

A group of us have been studying changes in time perception in people with different types of dementia, for some years now<sup>12, 13</sup>. Aside from explaining some of the different patterns of TP change, we are further developing the ‘Changes In Time Perception Over Time (CITPOT) tool’ to document TP changes over time. It is hoped some form of it could become part of the assessment and care dossier of every person with dementia. In the future, dementia caregivers will have opportunities to use a variety of communication and care interventions, as more details about the type and rate of TP change are better understood.

#### **Related ideas for observations and research:**

- . Have you noticed different patterns of change in TP in people with dementia that you work with?
- . Have you noticed any lucid moments of awareness, for example, where a person who is normally disoriented in time, is suddenly/briefly aware that they are ‘old’, even though they don’t know exactly how old.
- . Are you encouraged to document your observations and communication and interventions for people with dementia who are disoriented in time?

Best Regards,  
Gemma

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