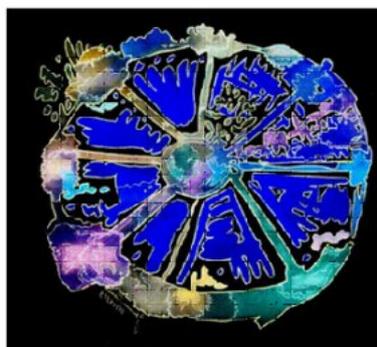
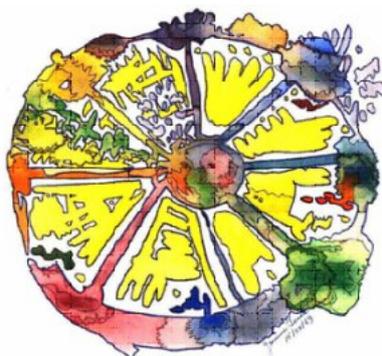


TAD (Thoughts About Dementia) Newsletter



#39: 15th September, 2011

Mistaken identities: the phenomenon of 'Stage 2 Buddies'

Dear Reader

Definitions used in this article:

'Stage 2' is used in reference to the Behavioural Staging of dementia^{1,2}, when people are permanently disoriented in time. Their changed time perception may range from thinking they are a child, to being aware they are old, but not knowing exactly how old.

'Stage 2 Buddies' refers to a friendship between people who are both permanently disoriented in time - who think they are and behave like best mates, companions, spouses or family members. Though they do not know each other, they feel so familiar to each other that they mistake each other's identities for others they have known. It is a case of mutual mistaken identities. They are devoted to each other and content and hence do not try to: leave to go home or to work; call out for their parents; go to their own or others' bedrooms trying to pack; or request the frequent attention of staff. (See previous TAD newsletters on attachment behaviour and attachment figures and re-surfacing past traumas^{3,4}.)

This newsletter is about a particular type of mistaken identity that people with dementia in Behavioural Stage 2 may experience - the phenomenon of 'Stage 2 Buddies'. It makes most sense if we first consider our own mistakes.

Have you ever assumed a new acquaintance was like someone else who had similar characteristics?

It's possible to relate to a new person who reminds us of someone else, as if they were familiar, and to *transfer* onto them, the assumptions and responses we use with the person they remind us of. Others may relate to us on the basis of their experience of another. We may not be aware of this, but if we are, we may not like having expectations, pre-judgements and prejudices imposed on us, rather than becoming known as a unique individual.

Such mistakes in relating can occur from similarities in appearance, tone of voice, age, role, gender, and a variety of other characteristics. This often occurs unconsciously, and can happen to anyone throughout life, and also to people with dementia. (The counselling literature has a name for this, and refers to such mistakes in relating, between counsellors and clients, as *transference* and *counter-transference*.) In courses, I speak about each of us being able to sense the *flavour* of another person. A flavour may be familiar.

Despite individuality - some people have similar flavours

Most of us gradually learn that such mistakes can happen. As we become more aware of them, we can increasingly suspend our presumptions and get to know people as individuals. Yet, despite this awareness we may still experience puzzling, almost instantaneous responses to some people that are difficult to explain. For example, in common language, we speak of negative interactions where someone new just ‘pushes our buttons’ - like a parent, sibling or authority figure may have done. Or, we refer to meeting someone and just ‘clicking’ with them somehow - being comfortable with them though we know almost nothing about them. Evidently, humans are good at picking up on many details rapidly - which influences our desire to be with them and our style of relating. This can happen without our awareness that we are making such rapid assessments, or our ability to explain them to others.

People with dementia

People with dementia make mistakes like ours; they may be compounded by:

- 1) memory difficulties (learning factual details about others is not possible; when a new person is mistaken for someone else, correcting this rarely helps)
- 2) visuo-perceptual difficulties^{5,6,7} (various vision changes occur; they can include difficulty with face and object recognition, and estimating age)
- 3) permanent disorientation in time (to the extent that a person cannot recall who is alive or dead, nor how old they and others are)⁸.

The above difficulties can result in a person with dementia speaking about several generations as if they are present simultaneously - at a variety of ages. Though this does not appear to cause difficulties for the person with dementia, it seems totally illogical and impossible, and can cause problems for carers or caregivers. People in Stage 2 can mistake the identity of others – negatively, neutrally or positively – of caregivers, family carers, residents, managers, professionals, neighbours, and visiting grandchildren.

When people with dementia reside in care homes

In care settings, staff may observe residents making incidental mistakes about people’s identity. Sometimes, permanent strong allegiances and symbolic friendships occur, by accident as it were. They can occur, because as described above, people can mutually feel familiar to each other.

Back to Stage 2 Buddies

I first heard Naomi Feil speak about Stage 2 Buddies, at a course in Canada in 1982. I'd observed Buddies in several care settings where I'd worked, but this had never been named, explained, or celebrated as part of good care. Feil spoke about it, as not just a bonus, but a component of care planning for people in Stage 2, since it contributed to people feeling safe and happy. It was part of her vision of 'bespoke stage-specific, dementia-specific dementia care'.

I'd seen such mistaken friendships tolerated (sometimes in a quiet, embarrassed sort of way), but never really facilitated or written about in care plans. Why? Buddies were not understood and conflicted with the, then, rigid application of 'Reality Orientation' interventions, which aimed to keep people aware of the facts - i.e., this person is not your sister or your spouse, they are so and so; it is inappropriate for you to name and relate to them otherwise.

It was through seeing genuine Stage 2 Buddies being happy, conversant, and thinking that they were at home - oblivious to the limitations of the care setting - that I first realized that people with dementia can really be contented. And also, that much of the behaviour thought to be 'due to the dementia' - was attributable to factors such as fear, anger, loneliness and boredom. That gave me motivation to explore other care options, and is how I first came to try introducing two residents, hoping they might become Buddies. (I've been collecting stories of Stage 2 Buddies ever since.)

Introducing residents hoping they would become Buddies

A lady diagnosed with Alzheimer's dementia, Stage 2, was admitted to a 75 bed long-stay unit. She was anxious, lonely, disoriented, and had few friends or family nearby - she was in need of a new friend. There was another lady in Stage 2, who had lived there for several years, who was also lonely. Her room was in a different wing. Both ladies used wheelchairs, but could not move much independently. Without help, they were unlikely to have met.

Both ladies were asked if they wished to meet someone new to visit with. They did. I took the 'old resident' to meet the 'new resident' and had planned my introduction carefully. That was a waste of time; they were oblivious to it and to me. They beamed at each other, touched hands and started a conversation. It was as if the old resident was visiting a sick friend in the hospital, and it soon moved on to the feeling of best friends re-united. They were not able to remember each other's names or room numbers and would not likely have found each other again without such help, so to encourage this new friendship, they were seated at the same table and in the same lounge.

Listening to their conversations, a newcomer might have been surprised at how ordinary they seemed. People in Stage 2 have difficulty using specific nouns (names) and use simpler substitutes. Since their conversation sounds generic, it is easy to relate and respond to. The number of hours that these ladies engaged with and spoke to each other, and remained alert, was surprising. (My research then

was on the paucity of communication between care-giving staff and residents with dementia. That Buddies could be so good at communicating, despite not comprehending literally, was an eye-opener⁹.)

What are the most usual types of Stage 2 Buddies?

The most usual types of Stage 2 Buddies reported, are residents who think they are siblings, best friends, neighbours or work colleagues, and men and women who think they are spouses or partners.

The most unusual Stage 2 Buddies?

I've seen Stage 2 Buddies who, though from different countries, thought they were school friends. They spoke different languages to each other without any apparent difficulty, presumably responding to gestures and voice intonation.

Residents think they've been reunited after having lost each other

Two residents, both widowed, walked the corridors arm-in-arm morning and afternoon. In between walks they sat on a couch, chatting. They stopped every passer-by telling them the reason for their current happiness. According to them, they used to be married, but somehow had lost each other in life. When they moved into this old people's home they found each other again! They had agreed to hold onto each other tightly never again be parted.

This tale created a conundrum for some staff who realized that these residents, 1) had not know each other, 2) had never been married, and 3) had invented this whole story. Were they really lying? Should they be corrected, separated, tolerated or encouraged? Their devoted and sometimes flirtacious behaviour was seen as cute by some staff, but embarrassing to most.

What may look like, but is not the real Stage 2 Buddies phenomenon

The phenomenon of Stage 2 Buddies occurs uniquely when both people are in Stage 2 (permanently disoriented in time). This is different than friendships where where one person is in Stage 1 (having memory difficulties, but still oriented to time and able to remember the identity of others*), and the other person is in Stage 2. In these instances one person is aware that the other is not familiar to them, though the other person is not.

Sometimes, people in Stage 2 try to form a friendship with people in Stage 1, but often this causes various levels of restriction, intolerance and irritation.

For example, two sisters-in-law were in the same care home; one was in Stage 1, the other in Stage 2. The lady in Stage 2 wanted to cling on to her sister-in-law all day, and now thought her to be her blood-sister. Staff noticed that this clinging was irritating and preventing the lady in Stage 1 from joining in activities and meeting others. Staff separated the ladies, and the lady in Stage 2 became anxious and called out and searched for her sister-in-law endlessly, upsetting all. After several weeks, staff discussed things with the lady in Stage 1. She was aware of her sister-in-law's memory difficulties and was willing to spend afternoons with

her, but mornings with other residents.

In rare instances, the mistaken, persistent and unwelcome attention of someone in Stage 2 towards someone in Stage 1 has resulted in physical abuse of the person in Stage 2.

Misunderstandings about Stage 2 Buddies

Staff and family members who are not familiar with the Buddies phenomenon can misunderstand it, interpreting the new relationship literally, as a deliberate choice. Family members may feel this as a slight to their relationship. The most painful misunderstandings have come from spouses/partners of residents, when they see their loved one with another resident - behaving like their partner. If the real partner does not know that the other resident is being mistaken for them, they may interpret this as deliberate infidelity, ingratitude, or a desire to start a new relationship.

Some staff have helped teach and console family about mistaken Buddy relationships. Often family decide it is better to let their family member continue the Buddy friendship rather than be anxious and lonely. Occasionally though, especially where a past relationship has been strained, understanding and consolation are not possible; a partner experiences the new friendship as a devastating rejection. Some have insisted that staff keep their loved one away from the Buddy, or have even moved them to another care home.

Sometimes, it is staff who don't understand Buddy relationships. In some instances, because of their belief-system, a member of staff has felt that it was their moral duty to only permit what they saw as 'decent, permissible behaviour' between Stage 2 Buddies who thought they were partners. They were separated, 'just in case things got out of hand'.

Do people in Stage 2 ever become a Buddy to someone in Stage 3?

Very occasionally, I've seen a person in Stage 2 become attached to a person in Stage 3 who was immobile and almost incommunicative verbally. Twice, the person in Stage 2, was a former nurse. It was unclear whether they saw person in Stage 3 as a patient or an ill family member. However, they sat with them, massaged their hands, sang and/or spoke comfortingly to them, and seemed to be positively engaged in a helping/caring relationship. In each instance the person in Stage 3 became more animated and verbally responsive (though not always comprehensibly so), with this extra attention.

Do Stage 2 Buddies grieve when their Buddy dies?

Sometimes they do grieve and look for their Buddy, for days to weeks - but not always. Staff often try to comfort them by trying to find a new Buddy for them, soonest, but there's no predicting who someone will 'click' with.

Do Stage 2 Buddies ever have sex?

The answer to this question is anchored in the following assumptions:

. Views of sexuality, and genital and sexual behaviour in old people, are diverse and complex, and related to many factors - including personal beliefs, culture, experience and expectation. Hence, the views of caregiving staff will be diverse.

. It is crucial to determine what Behavioural Stage of dementia people are in, before trying to interpret what appears to be sexual behaviour. (Knowing the stage helps provide information about a person's mis/perception of - their age, where they think they are, and who they think others are.) Some behaviour can be misinterpreted as sexual when it isn't.

For example, night staff found a gentleman in a lady's bedroom in the dark, beside her bed, holding his penis. This was initially documented as a 'sexual incident'. Fortunately, later, other details were recorded. The gentleman was in Stage 2; he usually thought he was still living in his own home. He hadn't touched the lady, nor did she awake. Her room was near to his. The most likely explanation was that he was disoriented and was looking for the toilet.

Sexual behaviour, but not between Stage 2 Buddies

For example, I have seen and heard of instances where male residents in Stage 1, deliberately tried to take advantage of ladies in Stages 2 and even 3, knowing that they were cognitively impaired. They also knew when staff were busy and distracted, and at these times, followed some ladies into the toilet and bedrooms to try to engage in sexual activities with them.

Generic affectionate and flirtatious behaviour, but not Stage 2 Buddies

I'm familiar with examples of ladies in Stages 1 and 2, who were in show business, known to have a flirtatious manner with men throughout their lives. They gave intimate attention to various male residents, staff and visitors, but not just one. They did not form Stage 2 Buddy relationships.

Now, the answer to the question -

Perhaps it has happened, however, in 30 years, I have never seen, or heard of a single example of genuine Stage 2 Buddies who thought they were partners, having intercourse. My impression is that most do not even try, although they may lie in bed together.

Stage 2 Buddies tend to stay close and touch each other. If they think they are spouses/partners, this may include hugging and kissing. Occasionally, some have cuddled up under a throw on the couch - and presumably thinking they were at home, unaware of the presence of others, have placed hands, usually on clothed breast and genital areas. Sometimes a Buddy has awoken in the night and been upset to be alone in bed, and started searching for their spouse. Some have been found, in a nearby bedrooms, cuddled up to a resident who was not their Buddy. One couple lay down together one afternoon, but were disturbed because they were in another resident's room. She was miffed to find them and complained to the manager, who misunderstood what happened. Out of fear of

potential or inappropriate sexual behaviour, some staff have separated genuine stage 2 Buddies, including those who were lying together, fully clothed, only sharing some warmth.

Conversely, some staff are not concerned about the possibility of sexual intimacy at all; they see it as a simple matter of ‘mutually consenting adults.’ [*However, it is not at all obvious to me that people with dementia, in different stages, with different cognitive deficits and levels of awareness, can all be considered to give mutual consent, equally. This is certainly not the case if one of them is in Stage 2 or 3, thinks that they are a young child, living at home with their mother and father, and is frightened by sexual advances, or, where potential advances may cause distressing memories of past abuse to re-surface*^{10,11}.]

The upshot is that Stage 2 Buddy friendships do exist and form, whether facilitated by staff or not. Fundamental questions related to dementia care given in care homes, include - whether staff are taught about Stage 2 Buddy friendships, and, if they will be recognized, accurately described in documentation and care plans, and whether they will be encouraged.

(In a later newsletter, ‘Bees Knees friendships’ will be discussed - where a person in Behavioural Stage 1 trusts, forms a special bond with, and becomes dependent on a particular caregiver - to the exclusion of all others.)

Related ideas for observations and research:

To my knowledge there is no formal research yet on the Stage 2 Buddy phenomenon.

Were you ever taught about ‘Stage 2 Buddies’?

Have you ever heard of ‘Stage 2 Buddies’?

Have you ever tried to help someone find a special friend for a resident?

Have you ever tried to explain mistaken identities and friendships to family members?

Best Regards,
Gemma

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* or in the transition phase between stages 1 and 2

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