

Dementia – what is truth?

Exploring the real experience of people living with more severe dementia

A Mental Health Foundation national inquiry

My responses to the questions posed by the Mental Health Foundation in their investigation ‘Dementia – what is truth?’ are set out below. They rely on the reader sharing my understanding of the SPECAL Photograph Album analogy which underpins the SPECAL approach and method, as described in Appendix 1.

1. What do hallucinations, delusions, and confusion mean to people living with dementia? What do they mean to you if you are, for example, a family member or friend, or practitioner?

The person with dementia has not lost their reason, nor their ability to reason, nor their wish to reason. The issue for them, and by implication for the rest of us, is that since the onset of dementia they have been progressively failing to store the facts of what they have been doing in their life only a short time before, whilst storing feelings in the normal way. When they find themselves in need of facts which are permanently unavailable to them, making it almost impossible to make sense of what is happening in their life, they very reasonably make the best match they can with intact information from long ago. This can result in their own interpretation of current activity being vastly out of sync with other people around them. If I, whether as a family member or friend, or practitioner, do not understand the way in which they are compensating for their disability by using a supportive resource which I do not need to use, I am likely to view their statements and behaviour as hallucinatory, delusional and confused.

If, on the other hand, I already understand their disability and their coping mechanism as outlined above, their statements and behaviour will be a signal to me that I need to listen very carefully to them, monitoring any questions they ask me and avoiding interfering with the sense they are managing to make of their situation. I also need to give myself consent to use new counter-intuitive communications skills and techniques. Above all, I must avoid creating in them a feeling that they are wrong and I am right, and that I appear to know more about what they have been doing than they themselves know. They have not lost their reason, are not hallucinatory, delusional or confused: they are using intact information that they already own to replace information that is unavailable to them as a result of their disability. I must avoid tripping them up.

2. Depending upon the answer to the first question, how should others (family and friends, practitioners etc.) respond to help people living with dementia who experience hallucinations, delusions, and confusion? Can people living with dementia be supported to cope positively with these experiences?

The person living with dementia is coping positively and rationally with their experience of having to make sense of the present through accessing the more distant past. They can either be helped or hindered in this way of making sense of their life by the actions and interactions of other people around them. The amount of help we can give them is dependent on our acquisition of new communication skills underpinned by our understanding of how our own memory works and the single change affecting the memory of the person living with dementia.

Dementia – what is truth?

Exploring the real experience of people living with more severe dementia

A Mental Health Foundation national inquiry

It is worth reflecting that the vast majority of occasions when family, friends and practitioners believe the person to be deluded, they are mistaken. As explained above, most of the ‘delusions’ are rational attempts to use intact information to make sense of the fractured present. Where there are genuine auditory or visual hallucinations, they may be triggered by any one of a number of factors: diminishing faculties in terms of eyesight and hearing, side effects of medication, or misinterpretation of their communications by others around them. The person with dementia becomes distressed and begins to experience their thoughts and feelings in sounds and images external to them.

Other questions:

- 3. Are there ways of working with people who have these experiences that go beyond existing approaches and can overcome some of the dilemmas that they create?**

Yes, there are. The Contented Dementia Trust is now in its 25th year of developing, delivering, refining and teaching a particular way of helping people to understand the subjective experience of dementia. This is based on information relayed to us by individuals at all stages of dementia including end stage. In 25 years we have never had a person in end stage dementia at Burford who has lost the ability to talk and communicate with us. Their feedback has dictated the design of the SPECAL methodology which has grown organically out of practice during this time. The major traumas faced by the person living with dementia are created by other people, rather than by the disease. The nature of their pathway through the disability is to a huge extent governed by other people’s understanding and willingness to change in order to remain in sync.

- 4. Are there responses which might advance our understanding of dementia and may even enable a person who still has periods of lucidity to gain some understanding of these experiences?**

There are certainly responses which advance our understanding of dementia: the use of the tools and techniques (Questionless Question, SPECAL Observational Tracking, Verbal Ping Pong) which have been developed to assist the adoption of SPECAL’s Three Golden Rules ensure that we can continuously learn from the person living with dementia, the expert, rather than the other way round.

In terms of lucidity on the part of the person living with dementia, they already have more than enough lucidity into their own plight – it is impossible for anyone not to be aware of the extraordinary fact that they do not know what they have just been doing moments before, information that we all take for granted. There is no need to add to their insight – they have more than enough already. The aim of SPECAL care, which is rooted in person-centredness and is fully individualised, is to ensure that we do not remind them of their disability but instead nurture their own efforts to circumnavigate the difficulties it raises, and thereby restore quality of life. The nature of dementia, as understood by the SPECAL Photograph Album analogy, enables us to work positively with the disability rather than trying to defeat or ignore it, since the person is able to enjoy a repetition of what they are known to enjoy

Dementia – what is truth?
Exploring the real experience of people living with more severe dementia

A Mental Health Foundation national inquiry

without risk of boredom – the feelings are storing and the facts are not, and it is the feelings which matter most to them.

5. What does the latest research and practice on these issues tell us about what works and in what situations?

Latest research findings from University of Iowa¹ (Feinstein J et al 2012) supports the underpinning tenet of the SPECAL Photograph Album understanding of dementia i.e. that feelings are consistently stored in dementia whereas facts are not. Therefore there is a moral imperative to ensure that feelings in the present for the person with dementia are 'OK, acceptable', and provided this basic requirement is met there is a solid platform for everyone to find common ground in achieving negotiation and peaceful outcomes all round. The inference of the Iowa findings is that if feelings are OK life will be OK, and if feelings are not OK the trauma for the person living with dementia and failing to understand the recent cause of the trauma is insupportable and will oblige the person living with dementia to seek ever more extreme forms of communication in order to be heard.

6. What examples can you give involving these situations which were particularly challenging and/or where innovative solutions were used?

A paper published in 1996 'Making a Present of the Past'² provides examples of the ways in which the SPECAL team acquired their practical knowledge, skills and experience of what worked in particularly challenging situations over a continuous six year period at Burford Hospital. The phrase 'Making a Present of the Past' is now a registered trade mark used under licence by the Contented Dementia Trust (formerly SPECAL). The Burford team has an unbroken record in continuing to work together to the present day, constantly developing theory out of practice to create a sustainable model of care delivery from diagnostic cradle to end of life care, embedded in the SPECAL Photograph Album and its Three Golden Rules.

7. What do people living with dementia and carers think about these issues?

People living with dementia

People living with dementia will be protected from being confronted and challenged with these issues if we do not create the confrontation and challenge in the first place. It has been shown consistently and continuously at the SPECAL Centre of Excellence at Burford that people living with dementia are able to continue living as close an approximation as possible to the life they would have led if they had not developed dementia in the first place.

Carers

The view of carers will be governed (a) by the degree of understanding and insight they have into the reasoning behind the activities of the person living with dementia, and (b) how early after diagnosis, if at all, as carers, they were provided with a simple, accessible and highly

¹ <http://www.pnas.org/content/107/17/7674>

² SPECAL, Burford Community Hospital and the Research and Development Department of Psychiatry of Old Age, Oxfordshire Mental Healthcare NHS Trust, Oxford. Garner, P & Godel, M (1996)

Dementia – what is truth?

Exploring the real experience of people living with more severe dementia

A Mental Health Foundation national inquiry

practical explanation of where the activities and issues referred to in this question are coming from. Quotations such as ‘Now at last I understand and have practical tools which make sense and which are already making a huge difference to our life’ are commonplace in the feedback from carers who have understood the SPECAL approach and are using the simple but counter-intuitive skillset needed to implement SPECAL’s Three Golden Rules. This sort of feedback is consistently gathered from family members, friends and professionals in written evaluation of the introductory presentations of the SPECAL Photograph Album.

- 8. What are your views on the ethical and practical issues involved, such as truth telling, distracting, colluding, or creating artificial realities, as responses to people with dementia having these experiences?**

‘Truth telling’

When considering the word ‘truth’ it is important, first, to ask ‘whose truth?’ and to re-frame that question in terms of ‘Whose photograph album, and therefore whose photographs, are we talking about?’ This provides us with an insightful and practical starting point. Our view is that everyone involved in such issues is telling the truth in terms of their own reality, their own photographs, and it is up to those of us without dementia to start out from wherever the person living with dementia is at, and work from there. Those of us without dementia have to give ourselves consent to act in counter-intuitive ways, led by the person living with dementia but at the same time clear in our own mind that we hold the key to negotiating the links between the person’s past and the continuity of acceptable experience for that person in the present, particularly in relation to activities of daily life. We need to have a counter-intuitive approach to risk management strategies, where emotional risk is prioritised, even if only split seconds before the physical risk is managed. If the priority is framed in that way, physical risk will be handled much more effectively and safely (both in physical and emotional terms) than if the priority remains framed in the ‘normal’ way which is one that takes no account of the disability of dementia.

‘Distraction’

I have learned over the past 25 years that the timing of the strategy of ‘distraction’ is crucial. If the person is in a state of trauma, use of distraction may appear to the carer to have ‘worked’ but it will prove futile in terms of resolving the trauma in any practical and sustainable way. Attempting, or even succeeding in temporarily distracting a person living with dementia at a moment when they are rationally matching recent trauma to past trauma and wishing to take action of some sort, is extremely unwise. There is a place for distraction but it is not in the eye of the storm. Distraction should be preceded by careful combination of techniques such as validation, life history and reminiscence to create a therapeutic alliance, and should always be linked in some tangible way to an activity of daily living. Used in this way, distraction can lead to a normalisation of the situation, having acknowledged the issue in a way which takes account of the person’s disability.

Importantly, we reach a position where we are now working positively with the disability: feelings are much more important than facts to the person living with dementia, and the person will now have feelings of contentment entering the album, meaning that any matching

Dementia – what is truth?

Exploring the real experience of people living with more severe dementia

A Mental Health Foundation national inquiry

between present and past will be benign not traumatic. They will now have no reason to seek out old trauma. Their matching has returned to a default position of well-being, which is the norm for us all. Their capacity to engage in a repetition of what gives them pleasure without risk of boredom enables us to recycle strategies again and again. Fully individualised care based on these principles becomes ever simpler and easier for more and more people to deliver as the dementia, using ever fewer resources in an effective and economical way.

'Colluding'

I would reframe this as the creation of a 'we-relationship', a bonding between the person living with dementia and the person they are with at any time. Their companion needs to see themselves as in a 'we-relationship', and to convey this feeling to the person living with dementia; to travel alongside them in the moment and ensure that whichever 'club' the person living with dementia is a member of at that moment, they, as their companion, provide crucial co-membership of that club. From this position of kinship, the carer can work within a context of acceptable experience for them both, negotiating with the rest of the world to achieve an outcome which is acceptable to all concerned whilst taking into account the disability of dementia and compensating for it.

'Creating artificial realities'

In my view the single most important aspect of any intervention or strategy in relation to our interactions and communications with the person living with dementia is authenticity. By definition an 'artificial reality' is not authentic, and the person with dementia has an excellent feelings memory and an extraordinary capacity for picking up feelings from other people. As soon as anything is 'artificial' it will fail the authenticity test and be anathema to the person with dementia. An artificial reality is a contradiction in terms – either it is real or it is artificial. It must be authentic if it is to be ethical, and as carers we have to reframe much of our intuitive actions and reactions to take account of the experience of the person with dementia and learn to 'match' with them.

9. What can be learnt from other fields where similar issues have been encountered?

(a) The field of cancer care is rich in examples. I received much personal guidance from Dame Cicely Saunders who pioneered the modern hospice movement. Back in the early 2000s we discussed a short paper I had prepared on the similarities between palliative cancer care and the management of dementia post diagnosis. She commented on the parallel between the management of physical pain that had driven her early work and the management of emotional pain which epitomises the work of Contented Dementia Trust (formerly SPECAL). She begged me not to 'reinvent the wheel' but to learn from the battles that had been fought, and won, in her own field, where her work had also been seen as counter-intuitive and therefore 'wrong' for a long time by people whose perspective was quite rigidly governed by a medical model of disease management as distinct from a non-medical model of disability management. I learned from Dame Cicely how, in the management of both cancer and dementia, a system of listening to the patient and using

Dementia – what is truth?

Exploring the real experience of people living with more severe dementia

A Mental Health Foundation national inquiry

their words and thoughts to frame a truly individualised approach to their care had the capacity to produce astonishing outcomes: the person had quality of life until they died, and experienced less pain, whether physical or emotional, than their counterpart whose design of care was medically led. The literature of palliative care has much to offer. For example, the interesting recent evidence that couples who reframe the situation of one partner being the patient with prostate cancer and the other the carer, so that they talk in terms of ‘We’ve got prostate cancer in our life’, achieve better outcomes than couples who follow the conventional approach.

- (b) *The Expert Patient Programme. My view is that this programme has relevance provided it can be reframed as the Expert Carer Programme where dementia is concerned, on the basis that the person living with dementia is already expert at managing their own disability, and it is the rest of us who need to study their experience and their coping strategies in order to become expert carers to travel alongside the already expert patient. The knowledge required is counter-intuitive but not rocket science, and is easily understood once the principles of the SPECAL Photograph Album have been grasped.*
- (c) *The Northern Officer Group (NOG) have defined Impairment and Disability in a way which fits with the disability management model of dementia adopted by the Contented Dementia Trust (incorporating the SPECAL methodology): “A disabled person is a person with an impairment who experiences disability. Disability is the result of negative interactions that take place between a person with an impairment and her or his social environment. Impairment is thus part of a negative interaction, but it is not the cause of, nor does it justify, disability.”*

In conclusion:

The overarching question under review by the Mental Health Foundation is ‘Dementia – what is truth?’ Using the language of the SPECAL Photograph Album analogy my answer may be summarised by saying that ‘truth’ in a dementia context is to be found in the ‘photograph album’ of the person living with dementia and in their articulation of what they themselves are using by way of ‘photographs’ at any given moment in order to make sense of their life.

That needs to be the starting point for consideration by anyone considering the various issues raised by this inquiry and wishing to promote a sense of sustainable well-being for the person living with dementia and all others concerned. In my view, after forty years of studying the management of dementia, this is a highly achievable aim.

Penelope Garner