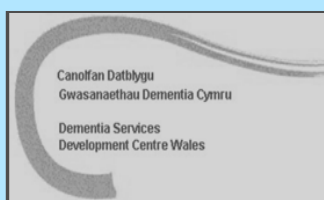


*Volume 22, Number 2, Winter 2016-17*

# SIGNPOST

**Journal of Dementia and Mental Health Care of Older People**



Signpost is the specialist, tri-annual, not for profit journal produced by the Practice Development Unit (MHSOP) of Cardiff and Vale University Health Board in association with Dementia Services Development Centre Wales  
[www.bangor.ac.uk](http://www.bangor.ac.uk)



**Contents:**

**2. EDITORIAL**

**Johannes Grammich**

**4. No laughing matter**

**Alison Wray**

**10. SPECAL– Contented or contested?**

**Alice Gaston**

**14. A USA Dementia perspective**

**Deborah Shouse**

**18. Developing a self-help book for people affected by stroke.**

**Tamsin Miles**

**22. BOOK REVIEWS**

**Madelaine Watkins**

**Dr Christina Maciejewski**

**Gail Lerner-Connaghan**

**26. ABOUT ME**

**Rob McMillan**

**28. DID YOU KNOW?**

**Angharad Jones and Matt Lewis**

**28. NEWS AND WEB**

**Angharad Jones and Matt Lewis**

**30. INFORMATION ABOUT SIGNPOST**

**Signpost is edited by:**

**Angharad Jones and Matthew Lewis  
Assistant Psychologists, Cardiff and Vale  
UHB**

**Cover picture: Designed by Matthew Lewis  
and Angharad Jones**



Welcome to the Winter edition of *Signpost*, which has communication as its main theme. It is easy to see that

communication is pivotal to all our lives. Yes, we use it to achieve practical goals, such as asking for a salt cellar when our soup tastes bland. But communication from others also ultimately shapes how we see ourselves, creating our perceptions of ourselves as human beings in relation to the wider outside world.

As workers in health and social care we are primarily interested in what happens when communication fails. The underlying idea is that once we find out the roots of failing communication we may be in a better position to help our clients and their carers.

Alison Wray investigates in her insightful article ‘No Laughing Matter’ the similarities between humour as intended communication and miscommunication between caregivers and their cared-for person who has dementia; she arrives at a conclusion which is well worth heeding to truly improve the quality of care in our field.

Communication is also at the heart of ‘SPECAL – Contented or contested?’ by Alice Gaston, who explores whether communication strategies developed by psychologist James Oliver fit in with the principle of person-centred care.

Deborah Shouse introduces three inspirational practitioners and their work with people who have dementia in her article ‘The Inside Story of Dementia Care in the United States’;

she also provides useful links, such as websites and blogs, for readers who want to find out more about the different approaches discussed. This article with its emphasis on the USA is strangely timely as the UK prepares to sever her links with mainland Europe, perhaps indicating a turn towards other English-speaking countries instead.

Tamsin Miles reports on the development of a support tool in book and video form for people who have had a stroke in her article 'Developing a Self-Help book for people affected by Stroke'. Her article expands on the method used to create this resource which will communicate to patients how best to cope with the psychological after-effects of the stroke event.

These four articles are followed by a similarly inspirational triad of book reviews. Madeleine Watkins introduces *Mindfulness-Based Interventions for Older Adults: Evidence for Practice* by Carla Martins, a book, which looks at the potential of mindfulness for people over 65. In addition to this contribution, Christina Maciejewski reviews *Person-Centred Dementia Care* by Dawn Brooker and Isabelle Latham, which draws attention to the cultural component in person-centred care, and, finally, Gail Lerner-Connaghan examines *Connecting in the Land of Dementia: Creative Activities to Explore Together* by Deborah Shouse, a book which proposes the creative engagement of the person who has dementia.

These seven contributions are rounded off by the regular 'About Me', in which Rob McMillan reports about DIAL, a new initiative that provides activities for people with dementia which are not primarily medical or care-orientated.

In religion and mythology, things are only truly complete once the number seven is reached, which also makes me think of the Greek goddess Iris, who was a messenger, a communicator between the gods and us hu-

mans. Iris was also the goddess of the rainbow, which suggests how truly iridescent communication is, endlessly fluid and without fixed borders, comparable to the colours of the rainbow, and, no doubt, as this winter edition reaches the interested reader, every article will have, for each one of you, its very own colour and meaning.

*No laughing matter.*



Alison Wray is a Research Professor in Language and Communication at Cardiff University.

Through the discipline of Linguistics, she examines the shape and function of language across contexts, with particular attention to prefabricated multiword sequences (formulaic language).

Her work on dementia communication is founded on curiosity about the incidence of formulaic language in, not only people with dementia, but also those who talk with them. She is principal investigator on a project funded by BRACE Alzheimer's and co-investigator on another project funded by the Wellcome Trust, both examining the potential to identify linguistic patterns that could be used for early dementia diagnosis.

She is a co-investigator on a project at the University of Oslo funded by the Norwegian Research Council, researching the impact of multilingualism on dementia. Alison also sits on the UK's Alzheimer's Society Research Grants panel.

She is currently writing two books (one academic and one for non-academic readers) about how cognitive pressure in dementia affects social interaction.

---

## Humour theory and the role of empathy in dementia interaction

There are many possible reasons why communication can be stressful for people with dementia (PwDs) and their professional and family carers. Clearly, the dementia itself plays a key role: a PwD may struggle to think of words, understand what people say, remember what has been said before, and hold in mind an idea long enough to put it into words. These challenges are frustrating not only for PwDs but also the people they talk to. As a result, carers and family may get annoyed or upset about not being understood, and about being repeatedly asked the same question or told the same anecdote. They may find it emotionally difficult to engage, and start to adopt a negative attitude or become brusque and dismissive, even though that is not how they really want to act. When people are not able to be themselves, it is a recipe for unhappiness, guilt and stress.

The dynamics of failing interaction are complex, but they are not unique to dementia. Therefore, there are potential opportunities for the broader range of life experiences to help us understand what is going on and consider new perspectives. Humour is a case in point. Humour arises in situations not dissimilar from those that create stress in dementia communication: misunderstandings, excessive repetition, mistakes, oversights, and conflicting needs and agendas. A closer look at how humour works gives us some useful insights into the pressures and constraints associated with dementia communication.

### Two types of humour

There are two types of humorous situation that we need to consider. One is exemplified by a comedy sketch. The participants find themselves in a situation of misunderstanding or

conflict that is not funny to them, but is funny to the audience. The other is where the participants themselves find something to laugh about. We need to keep both types in mind, in order to identify the relationship between humour and dementia communication.

### Three criteria for something to be humorous

According to one line of research (Veatch 1998) three important criteria underlie (potentially) humorous situations. Firstly, there must be some sort of clash of expectations – what one sees or hears, versus what one expected. But that on its own is not funny. If I walk into an ice cream parlour and ask for a pair of shoes, that's only weird.

A second criterion must also apply: something about the situation must approximate an alternative normality. There is a Two Ronnies Sketch in which Corbett is a customer in an ice cream parlour. He tries to buy salt and vinegar flavoured ice cream or, failing that, cheese and onion. Here, we see two lines of logic running together: it is appropriate to ask an ice cream salesman about flavours of ice cream. It is weird to ask for flavours that fall outside the expected range. But there is a logic to the aberration, because the requested flavours are normal for crisps. (The sketch ends with Corbett not being able to get ice cream he likes, and asking for some crisps instead: raspberry ripple flavour).

Veatch's third criterion for humour is being able to see both lines of normality simultaneously. In the Two Ronnies sketch, we as the audience can, but the characters cannot, which is why they find it stressful not humorous. But there are many circumstances in which the participants in a situation do laugh about a misunderstanding or other tension, and it is possible because they can see both lines of normality at

once. This is how *double entendres* work, for example.

### Comparing humour to stressful dementia communication

How does humorous interaction compare with mismatches in communication that can arise in the context of dementia? Clashes in understandings about what is going on (Veatch's criterion 1) are common, and they may be coherent positions in themselves (criterion 2). For example, a PwD may say something consistent with believing it's lunch time, whereas the carer knows that it is mid-afternoon. Or, because she has memory problems, a PwD may tell her son in good faith that she's not seen him for ages, even though he visits every day. Neither person inside the situation will find this clash funny (criterion 3). Contrary to the situation with humour, neither will an onlooker. Yet it is not difficult for an onlooker, or indeed the participants themselves, to see both sides of the situation. Even if the PwD can't see her son's point of view, he ought to be able to see hers.

So what exactly is different? Whatever it is, it leaves the atmosphere tense and stressful in the dementia context, whereas in humour laughter clears the tension away. It would be useful to know, because even if laughing is not an appropriate means to remove the tension, perhaps something else would be. The answer may lie in a fourth criterion.

### A fourth criterion and three conditions for humour

McGraw & Warren (2010) propose that humour relies additionally on the situation seeming 'benign'. If this fourth criterion is not met, the tension and stress arising from the conflicts observed in the situation cannot be defused. So this is the obvious place to look. McGraw &

Warren suggest three conditions for a situation to be benign:

- a. The presence of an 'alternative normal' suggesting that the tension is acceptable.
- b. Weak commitment to the violated norm. Psychological distance from the violation.

In the case of the ice cream sketch, the three options for creating a benign situation are easily met. As audience members, we have a clearly defined 'alternative normal' (condition a): we know we are looking at a comedy sketch. So everything we see is contained within a framework of 'this is intended to be funny'. That frees us to look for the humour. In a real life situation, humour is most easily supported when we know someone is trying to be funny. We are able to suspend alternative, potentially more intrusive or offensive, interpretations of the message.

Watching a comedy sketch, we as the audience have a weak commitment to the violated norm (condition b). That is, we know we are looking at fiction. The events are not happening in the real world. Were they to be real, it might be quite disconcerting. In the real world, we will only find a situation funny if the violation really doesn't matter. If person A throws their keys to person B and they fall on the floor, not much is lost and we are likely to laugh. If they fall down the drain, the violated norm (that the keys will safely arrive in the other's hands) has consequences that are too important to laugh away.

Finally, as a comedy show audience we have psychological distance from the situation (condition c), because we are watching, not participating. Were we to be in the situation of one of the characters we might not find it so funny. To find a situation funny when we are inside it, we need not to be deeply affected by the violation. This occurs, for instance, if we

don't take ourselves too seriously.

### Which conditions are lacking in stressful dementia communication?

Previously, we saw that all three of Veatch's criteria for a situation to be humorous were apparently met in stressful dementia communication. In theory, then, misunderstandings in dementia interaction ought to be funny. Can an explanation be found in McGraw & Warren's fourth criterion (the situation must be benign) and the three conditions for achieving it?

Condition (a) is the presence of an 'alternative normal' that makes the tension acceptable.

There is no problem fulfilling this condition in the context of stressful dementia communication. The son only needs to remember that he is talking to a person who has dementia, and that this may sometimes create situations that are unusual. Meanwhile, his mother may well be able to acknowledge that she has memory problems and gets confused at times about what she is supposed to know. An observer, too, will be aware that communication in the context of dementia has its own rules. In sum, condition (a) is met all round. The fact that the situation is not humorous must lie elsewhere.

Condition (b) is a weak commitment to the violated norm. In a stressful interaction, the condition is *not* met because the participants take to heart the clash of expectations. The son is upset when his mother says she's not seen him for ages. The mother is upset that he has not visited, and probably also now because he is upset with her. An observer of the clash is also likely to find some sort of emotional connection with it, such as thinking, 'that would upset me too'.

Condition (c) is psychological distance from the violation and it, also, is *not* met. The son, told



by his mother that he's not visited for ages, is well aware that this situation is happening to him and that he has to deal with it. He finds it hard to distance himself psychologically because her criticism feels like an attack. And an observer may be thinking, 'there but for the grace of God go I' – also a form of psychological closeness to the violation.

So, both for the participants and for an onlooker, it is conditions (b) (weak commitment to the violated norm) and (c) (psychological distance from the violation) that differentiate the clash of expectations in humour from the clash of expectations in stressful dementia communication. In humour, because the conditions are met, we laugh, and that resolves the tension. But in the dementia context, the conditions are not met and the tension remains.

#### *Resolving the tension in another way*

The purpose of comparing humour to stressful dementia communication is to see if we can understand how else the tension might be resolved. Resolution is certainly possible because communication in the dementia context is not equally stressful for everyone. We can therefore look for hints in the successful practices of those who seem not to experience high levels of stress. Person Centred Care (Kitwood 1997) is one recognised approach, and it is deeply embedded in a capacity for empathy. 'Cognitive' or 'controlled empathy' (e.g. Goleman, 2007; Seu & Cameron, 2013) is a "conscious process of trying to know, imagine or understand the perspective of another" (Seu & Cameron 2013, 267). Empathy is a precious and valuable feature of human interaction and at its core is the assumption 'you are like me'. When we see someone as being like ourselves, we know how to anticipate their needs and interpret their behaviour. The more different from them we feel, the harder it is to identify with

them.

Therefore, we would naturally assume that empathy helps reduce the tension in a situation— certainly that must be what a carer or family member of a PwD intends. But there is a paradox here. If humour defuses tension through distancing, how can empathy defuse tension through drawing closer? If the model of humour is right, empathy would not seem to be an obvious way to reduce tension at all.

In my previous research (Wray 2011, 2012, 2013, 2014) I have demonstrated that empathy can indeed create problems in dementia communication. In a nutshell, the more a carer sees the PwD as being like himself, the more he must judge her behaviour in terms of his world. Any rudeness or forgetfulness can only be interpreted as hurtful and deliberate on her part because that is how such behaviour is viewed in his world. Yet he knows this is not fair, because it is the dementia, not her, that causes the problem.

To address this problem, he is tempted to think of her as belonging to a different world, in which the same rules of engagement don't apply. In this way, when she says something hurtful or annoying, he can view it as 'something she does', without reacting in the same way he would if it were someone else talking. To put it another way, he separates out two types of 'normal': normal for his world, versus normal for hers. This approach to his interaction with her gets close to condition (a) for humour (seeing two alternative normals), with a consequent potential reduction of tension. For this reason, it might seem at first to be an appropriate approach to take.

However, another pressure now comes into play. The distance that is made possible by switching off empathy opens up significant

risks. What are the appropriate rules of engagement in this non-normal world? Does one need to be polite, attentive, kind? Carers and family are all too aware how easy it is to become brusque, rough and dismissive, once they no longer have to think about how a person feels and what she needs. Most people who interact with people with dementia, or any other vulnerable group, will have seen others who are in that mindset and will want to avoid it.

The way to do that, is to reunite the two worlds through empathy, thinking 'I won't treat her in a way that I wouldn't want to be treated myself'. But that brings us back to square one. Now, once again, a barbed comment from the person with dementia will hurt, multiple repetitions of a story or question will annoy, just as would be the case with any other interactional partner.

I argue in my previous work that, thus, a double-bind is created for carers and family, a stand-off between these two unpalatable counter-forces (being empathetic and hence vulnerable to hurt and annoyance, versus distancing oneself and rewriting the rules about what is acceptable behaviour). The tension can be highly stressful.

Yet it surely cannot be correct to suggest that empathy is destructive. We know that it is an important feature of effective care. We need a closer look at what empathy can be like. There are two types of cognitive empathy. In *self-based* empathy "we understand another person by 'putting ourselves in their shoes', i.e. by imagining the Self in the Other's world" (Seu & Cameron 2013, 267.). In *other-based* empathy, instead of putting ourselves into the other's world, we manage to understand what it is like for *them* to be in their world. We see their world from their point of view, not ours. The difference can be illustrated as follows.

Imagine a PwD has come to a black doormat and is frightened to cross it because it looks like a hole in the ground. A person whose empathy is self-based is certainly concerned and wishes to help. He puts himself into the position of the PwD and thinks about how he would respond to the mat. If he were in the PwD's shoes, (he believes) he would not be scared. So he says 'there's no need to be scared of a mat'. His empathy entails helping the PwD bridge from her own perspective to another one. But if she cannot do so, his expectations risk causing frustration as he thinks 'why can't you react more like I would in your shoes?'

In contrast, a person exercising other-based empathy considers what it must feel like to be frightened of a mat. He imagines something that would make him that frightened, asking himself, 'what would it take for me to respond as you have?' In this way, he acknowledges the intensity of the PwD's reaction to the mat, and might say, 'yes, that does look a bit scary, so let's walk around it'.

In fact, we see that other-based empathy has more in common with humour, and can release the tension in a situation of conflict (Wray 2016). The situation is benign (criterion 4) because all three conditions are met: There are two alternative normals, the perceiver's and the perceived's (condition a). The perceiver has only a weak commitment to the violated norm because he does not feel emotionally under attack (condition b). And he is psychologically distant from the conflict because he locates his own experience in a separate place from that of the person with whom he is empathising (condition c). Thus, the potential tension of the situation is resolved, not through humour, since that would undermine the core of empathy, but through what we term *good humour*.



Perhaps this account shows why it is not enough for society simply to police the care industry for instances of unkindness (e.g. Abraham 2011; NHS Federation, 2012). For empathy to be sustained we need to pay attention not only to the conditions that create extreme responses to stress but also understand that not all empathetic actions will be equally beneficial. There is a job to do in supporting families and carers to understand the power of other-based empathy, as a way of improving not only the experience of those they care for but also their own well-being.

## Alison Wray

Centre for Language and Communication Research  
 School of English, Communication & Philosophy  
 Cardiff University  
 John Percival Building  
 Colum Drive  
 Cardiff, CF10 3EU  
[wraya@cardiff.ac.uk](mailto:wraya@cardiff.ac.uk)

## References

- Abraham, A. (2011). *Care and compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people*. London: Her Majesty's Stationery Office, [http://www.ombudsman.org.uk/data/assets/pdf\\_file/0016/7216/Care-and-Compassion-PHSO-0114web.pdf](http://www.ombudsman.org.uk/data/assets/pdf_file/0016/7216/Care-and-Compassion-PHSO-0114web.pdf)
- Goleman, D 2007. Three kinds of empathy. <http://www.danielgoleman.info/three-kinds-of-empathy-cognitive-emotional-compassionate/>
- Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.
- McGraw, A.P. & Warren, C. 2010. Benign violations: making immoral behavior funny *Psychological Science* 21 (8): 1141-9.
- NHS Confederation (2012). Delivering Dignity: Securing dignity in care for older people in hospitals and care homes. <http://www.nhsconfed.org/Documents/dignity.pdf>.
- Seu, I.B. & Cameron, L. 2013. Empathic mutual positioning in conflict transformation and reconciliation. *Journal of Peace Psychology*, 19 (3): 266–280.
- Veatch, T.C. (1998). A theory of humor. *Humor: International Journal of Humor Research*, 11, 161–215.
- Wray, A. 2011. Formulaic language as a barrier to effective communication with people with Alzheimer's Disease. *Canadian Modern Languages Review* 67, 4: 429-58
- Wray, A. 2012. Patterns of formulaic language in Alzheimer's disease: implications for quality of life. *Quality in Ageing* 13: 168-75
- Wray, A. 2013. Mislaying compassion: linguistic triggers for inadequate care-giving in Alzheimer's Disease care. In Davis, B. & Guendouzi, J. (eds), *Pragmatics in dementia discourse*. Advances in Pragmatics & Discourse. Cambridge Scholars Publishing, 117-45
- Wray, A. 2014. Formulaic Language and Threat: the challenge of Empathy and Compassion in Alzheimer's Disease Interaction. In Schrauf, R. & Mueller, N. (eds) *Dialogue and Dementia: Cognitive and Communicative Resources for Engagement*. New York: Psychology Press, 263-86

## SPECAL.

Alice Gaston recently completed her undergraduate psychology placement year at The Cardiff Memory Team, which she really enjoyed and learnt a lot. She grew up in the Herefordshire countryside with cats, chickens, ducks and two younger brothers. She is currently unsure what path to take following graduation but plans to take a well-earned year off, gain some more experience and then explore her options!



---

### ***SPECAL – Contented or contested?***

The psychologist and author Oliver James published his book *Contented Dementia* in 2009. It has been a best seller, but has also proved

highly controversial. James discusses the method of care, known as SPECAL (Specialised Early Care for Alzheimer's), which aims to aid the interaction between the person with dementia and anyone they come into contact with. Penny Garner, James' mother-in-law, created SPECAL to help to maintain wellbeing and functioning, post-diagnosis. Family members of people with dementia, paid carers and health and social professionals have found SPECAL useful as a practical guide to employ in a variety of settings. Ultimately, its aim is to be used to overcome the daily problems of conversing with someone with dementia and to understand the difficulties in daily functioning, which may increasingly arise as the disease progresses. Yet, no book is without criticism, and *Contented Dementia* is no exception.

#### What is SPECAL (Specialised Early Care for Alzheimer's)?

Some may wonder what is so controversial about SPECAL. The key "commandments" are as follows:

- Don't ask questions.
- Learn from the person with dementia as the expert of their disease.
- Always agree with everything the person with dementia says, never interrupting them.

James states that someone who has dementia "makes a present of the past", relating present to past situations to process the ambiguous environment around them. As they find it increasingly difficult to store new information and to rely on their short term memory, SPECAL attempts to reduce this pressure and confusing state. This is done by attempting to maintain the connection between the past and the present. Although some may argue that this is confusing the two time periods, James argues that this is in fact a salvation and that the individual

is *protected* from having to store new information. Instead, they are able to live contentedly in the present by using familiar examples from their past. For example – if someone finds themselves in a room full of people, they may become unable to rely on their recently stored information, and instead refer back to the past situation of being in an airport lounge. Within a supportive and non-confrontational social environment, SPECAL aims to prolong contentment and nourish life-long wellbeing.

### What is the view of the Alzheimer’s Society on SPECAL?

As an essential and prolific service of support, the Alzheimer’s Society (2012) acknowledges that SPECAL is popular among carers and reflects “some good practice”, and that it focuses on the feelings and emotions of people with dementia. Despite this, the Alzheimer’s Society have expressed their “serious misgivings” regarding SPECAL. Primarily, they are concerned that the methodology opposes the basic principles of person-centred care and fails to empower people with the condition, a key goal of the *Mental Capacity Act 2005 (England and Wales)*.

### Is SPECAL person-centred care? The disadvantages.

It can be argued that SPECAL disempowers people with dementia. James claims that SPECAL *rejects* allowing the carer to ask the person direct questions - this is because it would require them to “stop and think”. This seems inflexible, and a blatant dismissal of the individual’s autonomy. The motivation of any method of care should surely be to maintain independence and choice as long as possible. This “commandment” of SPECAL therefore seems questionable. Each individual is unique; the lack of direct questions may work for some

people, but not for others, and caring for those with dementia should not rely on a step-by-step, universal guide. Instead, each path of care should follow person-centred principles, but ultimately should be tailored to the needs of each individual.

Another key principle of SPECAL is to “never contradict” the person with dementia. James argues that his response to any uneasy carer afraid of betraying or lying to their relative would be to “grow up and take responsibility”. This could be seen as harsh and insensitive. Surely a carer’s concern regarding lying should not be perceived as immature and shying away from responsibility. Although this may seem inappropriate, the alternative might be to repeatedly highlight the person’s impairment, for example, by saying “you have already asked me that question”. This is likely to cause further frustration and stress. SPECAL attempts to have a protective value; however, the lack of questions could be interpreted as a denial of the person’s capacity of thought. After all, SPECAL is intended for people with *early* Alzheimer’s Disease, where protecting them from their cognitive impairment is likely to be unnecessary before insight is lost. It seems that certain aspects of SPECAL’s methodology are questionable and could be argued to contradict person-centred principles of care. Yet, it is hard to believe that this was deliberate – perhaps James’ choice of language does not accurately convey the intended message.

### The advantages.

One non-controversial aspect of SPECAL is the second commandment: “Learn from the expert”. James describes the essential conditions for achieving lifelong wellbeing for people with dementia, taken from the work of Tom Kitwood from the 1970s. These include *personal worth, agency, social ease and trust and confidence*.

These appear to mirror the basic principles of person-centred care; whether James achieves these in the methodology is open to debate. According to James, the wellbeing of people with dementia becomes threatened as a result of the removal of their agency and authority. With due credit, James offers a method to manage this: SPOTing (SPECAL Observational Tracking), inspired by Dementia Care Mapping (Kitwood, as cited in James, 2008). Interestingly, the connection between SPECAL and person-centred care seems tangible.

#### SPOTing (SPECAL Observational Tracking)

Similar to DCM (Dementia Care Mapping), SPOTing is an observational tool for carers, with the aim of improving the quality of care and overall wellbeing of people with dementia. In both methodologies, the focus is on the “expert” themselves. SPOTing is designed as a simplistic and logical approach to apply in a practical, home setting rather than in a public environment, as with DCM. By using SPOTing, carers are encouraged to create a list of frequent questions asked by their relative or friend with dementia, and to each one a list of possible answers are matched. The carer is then advised to respond with each answer to the frequently asked questions and establish which elicits the most positive or contented response. Carers are reminded to not only focus on the verbal cues, but also the nonverbal positive and negative responses, such as knotted eyebrows, blank expressions or grimacing. Once the most successful answers are identified (those that are rated most highly), the carer is then free to continue using these responses to the questions, whenever the question is asked.

The methodology of SPOTing is comparable to DCM, as James even cites Kitwood’s work as the foundation for his own. So how is it that SPECAL has been perceived to oppose the

principles of person-centred care when these methodologies are seemingly similar? SPOTing is individualised to each person with dementia and it uses his or her satisfaction with the carer’s responses to mould a structured script to surround them. This is implemented to maximise wellbeing within a nourishing and positive social environment (one of the key principles of a person-centred approach to dementia care).

#### The “photograph album” versus the “bookcase” analogy.

As argued by the Alzheimer’s Society, SPECAL challenges the principles of person-centred care. Yet, information presented within Dementia Friends sessions, an initiative launched and championed by the Alzheimer’s Society, shows notable similarities to the principles of SPECAL.

James’ “photograph album” analogy is simplistic to understand and represents how dementia disrupts a person’s memory. Each photograph of our albums represents a memory; the earlier the memory, the closer to the beginning of the album it is. As the disease begins to affect the person’s cognition, the later pages (photographs) become less stable and start to become disrupted. Therefore, they may begin to rely on earlier, more established photographs (memories). It is at this stage that the person may become disorientated and confused. James refers to the facts and the emotions of each photograph as two separate components. Again, when dementia begins to take effect, the factual component of each memory becomes more and more difficult to process and retain. The emotion associated with each memory, however, is likely to remain intact and stored. Again, SPECAL has demonstrated some helpful information for relatives of people living with dementia, which aids the understanding of the effect of the disease on cognition. It may offer reassurance to know that al-

though one aspect of the memory becomes disrupted, another part does not and is likely to be maintained. These fact-free photographs are referred to as “blanks”. Although James offers an accessible metaphor to help carers understand the progress of the disease, connotations of “blank” are far from positive; again, perhaps James’ language does not reflect his intended message.

Despite this, a “bookcase” analogy, very similar to the “photograph album” is used in the Dementia Friends Information sessions. As with SPECAL, the “bookcase” is a representation of categorised memories. Shelves closer to the bottom are more stable, whereas books (memories) on the shelves towards the top of the bookshelf are more likely to be disrupted and uprooted by dementia. Similar to the two components of the photographs, there are two bookshelves belonging to each individual – one with factual memories and the other with emotional memories. As the metaphoric books become less accessible and the inability to store and retain new information becomes more predominant, someone with dementia may begin to rely on the information provided by the lower, sturdier shelves. The commonalities between James’ “photograph album” and the Dementia Friends’ “bookcase analogy” would seem to be significant.

### In summary

To conclude, it is interesting to consider different methods of care for people with dementia because it highlights their commonalities, strengths and priorities. The individual and their unique needs are pivotal to each path of care, and although some methods or exercises may work for some carers or families, they will not work for others. In regards to SPECAL, James provides a practical and usable guide for anyone who may interact with a person with de-

mentia to use as they wish. It is an attempt to support families living with a person with memory problems and although some of the information conveyed is debatable, it deserves some recognition. Despite the criticism surrounding “Contented Dementia”, the simplicity and positive tone of the book and of SPECAL as a method should be acknowledged.

### **Alice Gaston**

Psychology Undergraduate Student

[GastonA@Cardiff.ac.uk](mailto:GastonA@Cardiff.ac.uk)

### **References**

- James, O. (2009). *Contented Dementia*. Vermilion: Ebury Publishing.
- Alzheimer’s Society. (2012). *Specialised Early Care for Alzheimer’s (SPECAL)*. Retrieved 1 August, 2015 from [https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1087](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1087).



**A USA dementia perspective.**



Deborah Shouse is a writer, speaker, editor and dementia advocate.

Deborah's newest

book, *'Connecting in the Land of Dementia: Creative Activities to Explore Together'*, features dozens of experts in the field of creativity and dementia. These innovators share ideas that engage the creative spirit so care partners and people living with dementia can continue to experience meaningful moments of connecting.

Deborah and her partner Ron Zoglin raised more than \$80,000 for Alzheimer's programs by donating all proceeds from her initially self-published book, *Love in the Land of Dementia: Finding Hope in the Caregiver's Journey*, to dementia-based non-profits. Central Recovery Press has since published an updated version of *Love in the Land*. To learn more about Deborah and her work, visit [DementiaJourney.org](http://DementiaJourney.org)

---

## **The Inside Story of Dementia Care in the United States**

Over the past months, I have interviewed several American experts in the field of dementia. I have asked them to describe their approach to dementia care and their vision for their organi-

zation. As you read through this, you'll notice a common advocacy of person-centered care and a distinct focus on meeting the needs of their individual constituents and communities. Here are their thoughts and insights.

## **Redefining Dementia and Focusing on Wellbeing**

### **G. Allen Power, MD,**

Internationally recognized geriatrician, educator, and author Rochester, New York

Website: <http://www.alpower.net>

Blog: [ChangingAging.org](http://ChangingAging.org)

Late every afternoon, Roger paces the corridors, pausing at the locked door, fiddling with the keypad, sometimes even setting off the alarm before he resumes his pacing. Instead of labeling Roger's behavior as "sun downing," Allen Power, MD, teaches practitioners to ask themselves: which vital element of health and happiness is missing from Roger's life? Is it identity, connectedness, security, autonomy, meaning, growth, or joy?

Dr. Power is also the author of two groundbreaking books, *Dementia Beyond Drugs* and *Dementia Beyond Disease: Enhancing Well-Being*.

He advocates for transformational models of care and he defines dementia as, "A shift in the way people experience the world around them."

"I believe that most of people's on-going distress is due to the erosion of one or more aspects of well-being. Imagine these domains of wellbeing as seven glasses being emptied. Start filling the glasses and notice the results."

As Dr. Power trains and consults with memory care communities around the world, he sees meaningful results from this compassionate approach. Suddenly, one person is not constantly calling out. Another is not hitting the aides when they take him to the shower. And another is not setting off the alarm by trying to open the exit door.

“There’s no sure answer,” Dr. Power says. “You need to understand the individual and experiment until you reach the root of the problem. People may be looking for connectedness. They may feel anxious and insecure. They may be bored.”

If someone is repeatedly trying to leave the building, Dr. Power might ask: Are they feeling insecure? Are they feeling lonely and trying to reach someone they love? Are they yearning to connect with an important part of their identity, such as a beloved garden, dog, or pickup truck?

### Working toward an Inclusive Future

Dr. Power uses a strength-based approach to enhance well being. He encourages developing “brain ramps,” cognitive supports that help people move through the day in meaningful ways. “With this positive approach, I can look at a challenging scenario and offer insights,” Dr. Power says.

Dr. Power believes in examining ingrained rituals and routines of institutionalized care, such as scheduling all meals at a certain hour, with an aim of moving to a more individualized and meaningful mode of care.

“We can make activities as mundane as bathing or getting ready for bed more meaningful and relational than we normally do in long-term

care,” he suggests. Dr. Power believes integration into society is a basic civil right.

“There’s a problem with seeing the disease instead of the people,” he says. “Imagine if people diagnosed with cancer, arthritis, or diabetes could only live with others who shared their medical condition.” Dr. Power is contributing to a future where all communities are dementia inclusive and where dementia is just viewed as another way that people see the world.

## **Supporting Each Person’s Pathway Through Dementia**

### **Jed Levine**

CaringKind, New York, New York  
Website: [CaringKind - The Heart of Alzheimer's Caregiving](http://www.caringkindnyc.org/)  
[www.caringkindnyc.org/](http://www.caringkindnyc.org/)

A man sits in the back of the conference room, clutching his wife’s hand. He’s listening intently to a panel of people who are living with early stage dementia and talking about their experiences. When they finish, he says to his wife, “These people are intelligent and I can relate to them.” He starts to let go of the feelings of shame and self-deprecation that have haunted him since he was diagnosed with mild cognitive impairment.

“We’re trying to create a culture where the diagnosis no longer forces people to retreat within or to hide,” says Jed Levine.

CaringKind provides services to those who are living with dementia, their family members, and the paid professionals who care for them. “In our support groups, in our training, and through our help line, we create a sense of community and connection, so people can talk openly about what they’re experiencing,” Levine says.



## Defining the Mission

For years Levine and many of his colleagues were affiliated with the National Alzheimer's Association. But they made a decision to return to their roots as an independent organization in 2015. Their approach features three key components:

Looking beyond the disease and acknowledging the whole person, as well as the emotional and psychological impact of what that person and their caregiver are going through. Developing a culture of creativity, compassion, and a personalized approach to services

Reaching out to diverse communities and targeting services to their needs

Creating a Culture of Compassion and Caring  
Anna is worried that her stepfather is emotionally and financially abusing her mother, who is living with dementia. Her mom is thousands of miles away. Anna wants to go to her and get her into a safe place, but she can barely afford to feed her children. When Anna finally spills her fears to a social worker at CaringKind, she receives guidance, access to special assistance funds, and help with long term planning. "Building relationships and having a direct personal connection has a profound impact on the way we deliver our services," Levine says. "So many families are living on the edge. If people have to give up work to care for a parent with dementia, they can put themselves in real jeopardy."

## Reaching Diverse Cultures

CaringKind is also moving to a more localized approach, with plans to have a social worker in every borough. That means they can connect people who live in Brooklyn or Queens with special services and providers in their neighborhoods.

"Every person has his or her own pathway through dementia," Levine says. "Our goal is that everybody receives the support within the context of their own culture when they need it."

## **Filling Gaps and Changing Healthcare Systems**

### **Debra L. Cherry, PhD**

Executive Vice President  
Alzheimer's Greater Los Angeles  
Los Angeles, California  
[www.alzgia.org](http://www.alzgia.org)

Alejandra worked a full-time job, took care of her two children and also cared for her mother, who had a diagnosis of dementia. Her mother could no longer eat solid food. She desperately needed dentures, which Alejandra could not afford. Her mother was becoming increasingly frail and malnourished and Alejandra did not know where to turn. Fortunately, she approached the Alzheimer's Greater Los Angeles, an independent non-profit organization dedicated to supporting people with dementia and their families. Their Caregiver Emergency Fund helped pay for the dentures. Once she was able to eat regular foods, her mother's health improved.

Alzheimer's Greater Los Angeles has served the family of a President and they've served undocumented immigrant workers. "We tailor our work and offer person-centered care to our ethnically and socioeconomically diverse population," says Debra L. Cherry, PhD. "We also strive to change big healthcare systems so we can increase access for the underserved and improve quality of care."

"We look at the family's culture, language, socio-economic resources, and legal status,"

Dr. Cherry says. “Then our care counselors create care plans and connect them to appropriate resources.” The organization provides 24/7 support in English and Spanish through their helpline and website. A translation service helps with calls in other languages. Their educational programs are far-reaching and offered in a variety of languages and locations. In addition, they have “plain language” pamphlets for those who have literacy challenges or who speak English as a second language.

### Collaborating for more Complete Care

Dr. Cherry and her team have won national awards for building coalitions among community partners in targeted ethnic communities. “During a period of three years, we learn about their community, they learn about dementia and caregiving, and we work together to bring in resources and build services,” Dr. Cherry says.

These coalitions have created legal clinics, started support groups, and founded adult day care centers. “We learn to better serve the community and they learn to better care for people with dementia,” Dr. Cherry says. “The communities then continue the care counseling and support groups on their own.”

Alzheimer’s Greater Los Angeles also steps in to assist groups that need services. They started an LGBTQ community support group and another group for people diagnosed with young onset. They then provided consulting assistance as people in the communities gradually took over. “That work highlights our individualized and collaborative approach,” Dr. Cherry says.

**Changing Systems, One Diagnosis at a Time**  
Dr. Cherry works with large healthcare systems, such as Kaiser Permanente, helping to improve recognition and diagnosis of dementia.

“Only 50% of people with dementia get a diagnosis, and only half of those get the disease documented in their charts,” she says. “Some people are never even told.”

Part of the organization’s focus is keeping people out of hospitals and nursing homes by teaching health care systems to identify family caregivers and evaluate them to assess their stress and needs for services.

In the ideal world, people would be diagnosed in the early stage and given good disease education and support from the beginning to the end of life. Family caregivers would receive respite delivered by reliable, high quality caregivers and other services as needed. This would allow people to stay in their homes and out of hospitals and nursing homes longer. “System change is about educating people and it’s about partnerships with those who can make the change happen,” Dr. Cherry says.

### **Deborah Shouse**

[DementiaJourney.org](http://DementiaJourney.org)

### **References:**

- Kolbaca, Katherine, RN, MSN, PhD, TheComfortLine.com
- Kitwood, Tom, *Dementia Reconsidered: the Person Comes First*, Open University Press, 1997
- Power, G. Allen, MD., *Dementia Beyond Disease: Enhancing Well-Being*, Health Professions Press, 2014
- Power, G. Allen, MD., *Dementia Beyond Drugs: Changing the Culture of Care*, Health Professions Press, 2010

## Stroke.



Tamsin Miles spent her first career working with businesses to facilitate change. Since retraining in Psychology she has worked with people following head injury and across services supporting people with mental and physical health conditions. She has a particular interest in neuropsychology and her current posts include providing psychological support in stroke rehabilitation and weight management services.

---

### Developing a Self-Help Book for people affected by Stroke.

Provisional Book Title:

**Rebuilding Life After Stroke:** A book for people living with stroke

Authors: Prof Reg Morris, Dr Malin Falck, Tamsin Miles, Dr Julie Wilcox, Dr Sam Fisher

Stroke affects around three percent of the population (Welsh Health Survey 2015) at some point in their lifetime. Each year around 7,400 people in Wales will suffer a stroke (Stroke Annual Report 2016). The number of people surviving stroke in Wales is increasing year by year. A focus on therapy services, including Physiotherapists, Occupational Therapists and Speech and Language Therapists, across the Wales means that more people have access to services which can help them regain as much of their previous function as is possible.

While this means that more people are surviving stroke and benefiting from rehabilitation services, there are often residual effects following stroke that therapies cannot eliminate, or compensate for, completely. This leaves around 66,000 people in Wales, living with the consequences of stroke (Stroke Annual Report 2016)

The physical effects of stroke are often the most obvious, such as loss of movement or not being able to see or speak. Stroke can also have very difficult psychological consequences. It can change an individual's sensations, thoughts and feelings and even affect their identity and sense of self. Many people who have had a stroke find that these psychological effects are even more troubling than some of the more obvious physical effects.

Stroke survivors and carers find that these emotional and psychological needs often go unrecognised. The importance of psychological care following stroke is recognised in national guidelines (NICE, 2016; Royal College of Physicians, 2016). Despite this, the availability of psychological services for stroke survivors is limited. Many have reported that they feel 'abandoned' when they have left hospital (Stroke Association 2013). Even the more generic services to support psychological issues after stroke are inadequate (Care Quality Commission, 2011), particularly across many parts of Wales.

Depression and anxiety are two of the most frequently reported psychological conditions following stroke. Figures vary regarding the incidence of these disorders with rates of depression estimated at around 31% (Hackett & Pickles, 2014), and those for anxiety at around 20%

(Campbell Burton et al. 2013). According to NICE (guidelines 2009), when someone is coping with both a long term physical health condition and depression, functional impairment is likely to be greater than if they were suffering from either one individually.

There have not been sufficient studies of a reasonable size to determine the effectiveness of psychological therapies for these issues within a stroke specific population. However, there is good evidence for the effectiveness of a range of therapies within broader populations. One of the therapies which has more recently come to the fore is Acceptance and Commitment Therapy (ACT) (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). As a 'third wave' behavioural therapy, it helps individuals to change the function of psychological events such as sensations, thoughts and feelings. The implication for those coping with stroke is that they can learn to find ways to move back towards a more meaningful life, even with the existence of physical or cognitive deficits. In this way it aims to improve the ability to live life with the consequences of stroke, rather than struggling (counter-productively) to resolve them.

The specific approach of this kind of therapy, is summed up effectively in the following serenity statement and would seem particularly appropriate for those who have survived an acquired brain injury such as a stroke (Kangas & McDonald, 2011):

*Grant me the Serenity  
To accept the things I cannot change,  
The Strength to change the things I can,  
And the Wisdom to know the difference.*

There is good evidence to support the beneficial effect of ACT interventions across mental health disorders (particularly anxiety and depression) and also in a number of chronic physical health settings (Hayes, et al. 2006). A further Meta-Analysis looked at the results of 39 research studies and found that there was significant benefit of using these approaches to reduce symptoms of anxiety across many different mental and physical health conditions (Hofmann, Sawyer, Witt, & Oh, 2010).

Given the continuing pressure on the availability of psychological resources, alternative ways

to deliver psychological support to a wider audience are needed. There is growing evidence for the benefit of self-help material, particularly for anxiety (Gellatly et al, 2007; Hirai & Clum, 2006) and depression ((Anderson et al, 2005; Gellatly et al, 2007). Again, there is limited self-help material on managing psychological difficulties, which is specifically adapted for stroke survivors and their families. Psychologists working within stroke who had seen the benefits of ACT principles with this population, identified the opportunity to develop a new resource.

Following investment from the Welsh Government Stroke Implementation Group towards the end of 2015, a group of Clinical Psychologists based in Cardiff were commissioned to produce a self-help book which specifically targeted this patient group and their families and carers. The aim being to provide a book which would help bridge the gap in available services and provide support for the myriad psychological difficulties which people can experience following stroke, both for the stroke survivor, and the people around them.

### **Method**

A self-help workbook is being co-produced by Clinical Psychologists in collaboration with stroke survivors and family members. Focus groups of survivors and their carers have been involved from the start of the project to scope requirements. The groups helped identify gaps in the available information and the approaches which they felt would most benefit individuals going through a similar experience.

Focus group members reported that initially, they had little knowledge of the psychological consequences of stroke. Individuals also fed back that any opportunity to learn from other stroke survivors and share experiences was valuable as it meant that they no longer felt as isolated in their distress. This supported prior evidence of the value of peer support in facilitating longer term adjustment and coping (Morris & Morris, 2012).

The book includes stroke-specific examples of psychological issues, mood, memory problems, fatigue, identity issues, and feelings of stress, burden and guilt (carers). In order to increase authenticity, these are presented as the indi-



viduals described them and not as psychologists would define them.

The groups let us know the importance of keeping the information accessible to individuals who may be experiencing difficulties affecting their sight or cognitive abilities, such as reading skills or attention. As the book was being developed, feedback was regularly sought from the focus group to ensure that the content was comprehensible as well as interesting and relevant to them. Their input greatly shaped the style and the format of the book itself.

Multiple formats are used to allow a greater number of people to access the resources. This was particularly important for those who may have had cognitive skills such as sight, memory, reading or attention, affected by the stroke. As a result, members of the focus groups were involved more directly in the book production as they kindly agreed to be videoed discussing some of their experiences following stroke. This was an important aspect of the project to facilitate access to a 'virtual peer support group', especially relevant for those who may not be able to attend one locally. The videos provide useful normalisation of psychological consequences of stroke as well as providing tips and strategies which can help people cope.

The book is will be available to individuals with stroke and their relatives who are struggling with psychological difficulties, whether they be emotional and/or cognitive, an audio book form is also being made available for those with visual or reading difficulties.

The book explains some of the many psychological difficulties experienced by people who have experienced a stroke themselves, or those who may be caring for someone who has. Emotional problems are explained and practical tips are provided on how people can move forwards when struggling with these difficulties.

In addition to this, there is a more comprehensive intervention based upon ACT principles. This is intended to be a practical approach which the readers can work through on their own as a self-help book, or with the support of someone else (guided self-help). The aim being to reduce the amount of suffering associated with the changes and difficulties they experience since having the stroke. Feedback has

been positive so far, to the approaches, tools and exercises included within the book.

## **Results**

The book will become available later in 2017 across Wales with a provisional title of "Rebuilding Life After Stroke: A book for people living with stroke". Service users are still engaged in its production right through to final design and layout.

There will be a DVD accompanying the book which includes the videos of stroke survivors and their carers, as well as providing audio based exercises for individuals to listen to.

The aim is for this book to contribute towards the self-management of psychological symptoms of stroke, supporting and promoting self-care and improved psychological well-being and independence. The intent is for its impact to be evaluated separately, following the initial publication.

## **TAMSIN MILES**

Assistant Psychologist  
Cardiff and Vale UHB, and  
North Bristol NHS Trust

[Tamsin.Miles@wales.nhs.uk](mailto:Tamsin.Miles@wales.nhs.uk)

## **References:**

Anderson, L., Lewis, G., Araya, R., Elgie, R., Harrison, G., Proudfoot, J., & Williams, C. (2005). Self-help books for depression: how can practitioners and patients make the right choice?. *Br J Gen Pract*, 55(514), 387-392.

Campbell Burton, C., Murray, J., Holmes, J., Astin, F., Greenwood, D., & Knapp, P. (2013). Frequency of anxiety after stroke: a systematic review and meta-analysis of observational studies. *International Journal of Stroke*, 8(7), 545-559.

Care Quality Commission (2011). Special Review: Supporting life after stroke  
A review of services for people who have had a stroke and their carers. <https://www.cqc.org.uk/sites/default/files/documents/supporting-life-after-stroke-national-report.pdf>

Gellatly, J., Bower, P., Hennessy, S., Richards, D., Gilbody, S., & Lovell, K. (2007). What makes self-help interventions effective in the management of depressive symptoms? Meta-analysis and meta-regression. *Psychological medicine*, 37(09), 1217-1228.

Hackett, M. L., & Pickles, K. (2014). Part I: frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. *International Journal of Stroke*, 9(8), 1017-1025.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour research and therapy*, 44(1), 1-25.

Hirai, M., & Clum, G. A. (2006). A meta-analytic study of self-help interventions for anxiety problems. *Behavior Therapy*, 37(2), 99-111.

Hofmann, S. G., Sawyer, A. T., Witt, A. A., & Oh, D. (2010). The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *Journal of consulting and clinical psychology*, 78(2), 169.

Kangas, M., & McDonald, S. (2011). Is it time to act? The potential of acceptance and commitment therapy for psychological problems following acquired brain injury. *Neuropsychological Rehabilitation*, 21(2), 250-276.

Morris, R., & Morris, P. (2012). Participants' experiences of hospital-based peer support groups for stroke patients and carers. *Disability and rehabilitation*, 34(4), 347-354.

The National Institute for Health and Clinical Excellence Quality Standard for Stroke and Transient Ischaemic Attack (2016). [www.nice.org.uk](http://www.nice.org.uk)

The National Institute for Health and Clinical Excellence Quality Standard for Depression in adults with a chronic physical health problem: recognition and management (2009). [www.nice.org.uk](http://www.nice.org.uk)

Royal College of Physicians (2016). National Clinical Guidelines for Stroke - prepared by the Intercollegiate Stroke Working Party <https://>

[www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-\(1\).aspx](http://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx)

National Health Service Wales (2016). Together for Health: Stroke Annual Report 2016 <http://gov.wales/topics/health/nhswales/plans/plan/?lang=en>

**Mindfulness-Based Interventions for Older Adults: Evidence for Practice.**

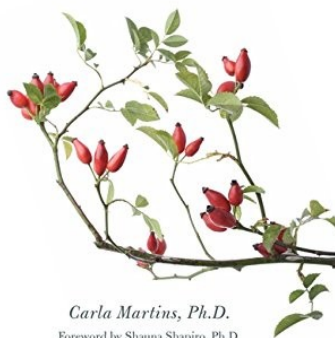
**Author:** Carla Martins with foreword by Shauna Shapiro

**Publisher:** Jessica Kingsley

**ISBN:** 9781849054874

**Price:** £29.99

*Mindfulness-Based*  
INTERVENTIONS  
*for Older Adults*  
EVIDENCE FOR PRACTICE



*Carla Martins, Ph.D.*  
Foreword by Shauna Shapiro, Ph.D.

In this book Carla Martins offers a clear and insightful exploration of her research conducted on the delivery of Mindfulness Based Stress Reduction (MBSR) with older adults. Based on

extensive clinical research Martins explores how MBSR can be applied to intervention with older adults and how this approach has a positive impact on spiritual, physical and emotional well being, attitudes towards death, cognitive performance, physical health.

Mindfulness is often described using the words of John Kabat Zinn , it is " paying attention in a particular way: on purpose, in the present moment and non-judgmentally" (Full Catastrophe Living, 1994) and he often adds " as if your life depended on it". This book highlights the potentially transformative process of mindful aging and gently touches on our relationship to our own death and that of others and possible changes in our sense of meaning in our lives as we age. Martins describes mindfulness and its Buddhist roots and gives a brief account

how meditation can change the structure of the brain (neuroplasticity) and how it may also have a neuro-protective effect in the aging brain.

Shauna Shapiro asks in the foreword ' we are living longer but how might we live better?'. Martins endeavours to answer this question and the first chapter gives a very thorough and engaging account of mindfulness and mindfulness based interventions (MBI) and how they relate to older adults.

Adults over 65 are an often neglected demographic in terms of research and with much of the current research on MBI focusing on 'working age' adults this book is a refreshing find. Although still sparse there is a growing evidence base for the use of MBI for older adults and this book beautifully explores what is potentially an extraordinary therapeutic intervention for older adults. Martins also gives a detailed account of her research methodology and presents both qualitative and quantitative evidence which shows positive outcomes for the participants despite the limitations of this small scale study. Martins writes with an obvious passion and depth of understanding for this subject. She is able to outline the academic and scientific aspects of her research together with accounts of the experiences of the group participants with a reflective and poetic style.

What brought the book to life , for me, were the quotes from the participants following their course of MBSR , quotes from participants about suffering for example include; " when we stop and look with our inner eye we realize that suffering is indeed what helps us learn in this journey." and "What can we do??!! Nothing can change the reality of suffering... it is part of life. Being aware of it and present is a wonderful



way of experiencing it...no rejection...accepting what arises... breathing in and breathing out." (pg 165) and on compassion " I feel more present in the interaction with others, I am careful with what I say to others in order not to hurt them or not to talk impulsively" and "it was learning to respect and accept others, their rhythm...the difference between everyone... I am more tolerant towards others." (pg 167). And on creativity "I feel more creative and dynamic...I returned to my book writing and it was flowing very well." (pg 168).

With our current aging population and our society's attitude to aging often being one of resistance and denial, Martins presents a method which can provide elders with an alternative experience of the aging process. Martins describes that rather than aging being seen as one of negative experience, loss and decline mindfulness offers people a transformative opportunity to develop skills which enable a sense of resting in the aging process with curiosity grace and open heartedness.

Martins explains that the use of mindfulness of older adults can have a profoundly transformative effect increasing meta-cognitive insight, self awareness and a more positive aging experience. Students and academics with an interest in mindfulness research would find this book helpful and it would be a informative addition to any mindfulness practitioners library especially if they deliver MBI to older adults. It would also be beneficial to mindfulness practitioners who wish to explore how they relate to their own experience of aging.

Martins quotes Eleanor Roosevelt "Beautiful young people are accidents of nature, but beautiful old people are works of art" and this book shows that mindfulness could provide a colourful palette in the creation of an alternative way to experience to aging.

## **Madelaine Watkins**

Madelaine is the Deputy Ward Manager of the assessment and Recovery Unit MHSOP in Llandough hospital. She is a mental health nurse working with older adults and I am also a mindfulness practitioner who co-facilitates the Mindfulness for Wellbeing course for Cardiff and Vale staff and for clients through PMHSS.

---

### **Person-Centred Dementia Care 2nd Edition.**

**Author:** Dawn Brooker and Isabelle Latham.

**Publisher:** Jessica Kingsley

**ISBN:** 9781849056663

**Price:** £17.99

This second edition of a book that was first published ten years ago, starts with the concept of Person Centred Care as originally described by Tom Kitwood and then develops this based on re-



search and new understanding. The first half of the book is entitled 'Unpacking Person-Centred Care' and does not shy away from acknowledging that the concept has been widely adopted but that this does not necessarily mean that the lived experience of people living with dementia is at all person centred in many settings. The book adopts the definition of person-centred care used in the VIPS framework and uses the four values so defined as a basis for considering what is necessary for person centred care to work and be effective. I particularly liked the

consideration given to the organisational culture and the recognition that however hard individuals may work to provide person centred care the culture of the organisation must also be considered. The book recognises that organisational culture is made up of complex interactions which influence the decision-making and problem-solving on a day to day basis. My understanding of this was helped by the practical examples used throughout the book and it was refreshing to see examples from hospital and community settings alongside those from residential care. When considering the Social Environment, I also found it really helpful to read the examples taken from the authors' research of the direct contrast between a 'Malignant Social Psychology' approach and one which involves 'Positive Person Work.' The second half of the book focuses on the VIPS Framework Tool which is designed to help providers of health and care services to evaluate their services and assess the relative strengths and weaknesses in providing person-centred care. This is a very useful tool with an easy rating system from which you can derive a baseline measure and then potentially create an action plan for improvement in key areas. There is also a Care Fit for VIPs website that provides different versions of the tool for use in different settings e.g. domiciliary care or hospital environments. The web-site also provides a Plan, Do, Study, Act (PDSA) action planning cycle that can be used as part of an improvement plan.

I would strongly recommend this book as an excellent resource for those working with people living with dementia and wishing to improve their practice. I would also encourage those who are perhaps a little jaded by repeated reference to 'person-centred care' to take a look at this book to rediscover what this really means.

**Dr Christina Maciejewski**

## Retired Consultant Clinical Psychologist

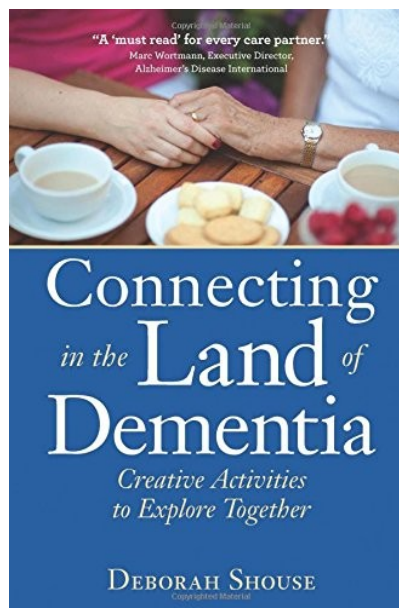
### **Connecting in the Land of Dementia: Creative Activities to Explore Together.**

**Author:** Deborah Shouse

**Publisher:** Central Recovery Press

**ISBN:** 9781942094258

**Price:** £14.99



In her new book, *Connecting in the Land of Dementia, Creative Activities to Explore Together*, Deborah Shouse writes a warm, anecdote-filled guide to “deeply connecting,” as she puts it, with persons living

with dementia. She draws on her own experiences in caregiving of her mother and her partner's two parents during their “dementia journey” and shares, with an empathic heart, the experiences of others, including professionals. Shouse has interviewed dozens of dementia experts, including luminaries from the United Kingdom, the United States, Australia, India and Canada. She gives the reader creative activities to do with the person living with dementia that are simple, use available supplies and are *engaging*.

*Engage* is a key verb for Shouse as she advocates, along with numerous professionals in the dementia treatment field, not entertaining the person with dementia but engaging them mentally and often physically. This means not just having a children's choir come in to serenade the residents of a care facility but specifically choosing music the person enjoyed in ear-

lier days and listening together. Thus the person is actively engaged rather than being a passive listener who is being entertained.

Shouse's language is even creative: rather than "person with dementia," she refers to the caregiver and the person receiving the care as "care partners;" what the care partners are going through is their "dementia journey." Connecting with/engaging the care partner is made clear in the wide array of ideas and practical applications including good descriptions of how to interact. It is a useful guide for the professional while being accessible to family or friend caregivers.

*Connecting in the Land of Dementia* is a workbook, how-to book, an educational guide, a reference and resource list, all while managing to be a fascinating and touching compendium of stories about those living with dementia. Stories, not of victims of a disease, but care partners and the uplifting, rewarding and almost endless possibilities inherent in this approach to caregiving.

Capping off this very useful and readable book of 268 pages, is the reference section: *About the Contributors* describes the sixty-six contributing professionals, their training, roles and accomplishments. *Resources* includes seventy-three books and e-books, eleven CDs, DVDs, and videos, seventeen websites and blogs, thirty-one meaningful creative projects, five resources by people living with dementia and her bibliography of twenty-eight sources.

I highly recommend *Connecting in the Land of Dementia: Creative Activities to Explore Together* for both family and professional care partners, for friends wanting to enhance their visits, for everyone who could be a care partner in the future – really, for all of us so we can share the optimism and hope that this book

has for those affected in our community. It is well-written, factual and educational, yet delightful in the portrayal of all the amazing things that can be done while being a care partner in the dementia journey.

### **Gail Lerner-Connaghan, MS,RN, PMHCNS-BC**

Gail is a nurse and master's level psychologist. Her credentials are Bachelor of Science in Nursing (BSN), Master of Science in Clinical Psychology (MS), Psychiatric-Mental Health Clinical Nurse Specialist, Board Certified (PMHCNS-BC).

---

## About me.

Rob McMillan studied law at Cardiff university and held various related roles before travelling in Africa for a couple of years and deciding on a career change.

He initially started working for Barnardo's supporting teenagers in in-patient care to reintegrate into their local community before carrying out a variety of roles in crisis, housing and mental health support with Gofal.

Rob became interested in supporting people with dementia through a pilot gardening project run by the charity Gofal had which opened his eyes to the positive impact that physical activity and social engagement can have upon people living with dementia. This pilot led Gofal to secure funding for the DIAL project which is where he works today.

## Who are you and what do you do?

My name is Rob McMillan and I am currently the Senior Case Worker of the DIAL project, which is a relatively new project delivered by Gofal and funded by the National Lottery, supporting people with a dementia diagnosis to remain as active as possible.

My role involves managing a small team of employees and volunteers as well as having a small case load of one-to-one community support and group work being delivered in residential and ward settings.

## If it is ever possible, could you describe a typical day?

There really is no such thing! For example, this morning I attended a dementia strategic task-force meeting for Cardiff and the Vale Local

Health Board and this afternoon I am running a craft group in a nursing home. Every day is varied on this project; encompassing direct and indirect contact with our volunteers and beneficiaries.

## What do you most enjoy about your role?

Supporting people with dementia to maximise their life opportunities and see beyond their diagnosis is a hugely rewarding part of my role. I get to meet some amazing people who have incredible life stories and so much life experience and I learn so much from the people I support. Spending time in their company, whilst it can be challenging on occasions, is mostly very rewarding.

**DIAL Project**  
**Cardiff & the Vale of Glamorgan**

**Gofal**  
Thinking Differently

DIAL supports people with dementia, particularly those with early-onset dementia. The project delivers a range of activities including cookery, sports, and therapy to support people living with dementia and their carers in coping with the condition, and there is no charge to access this service.

**How the project can help people with dementia;**

- Improve mental and physical wellbeing
- Support them to access interesting and social based activities to take part in.

**The benefits of DIAL;**

- Increases physical activity
- Builds self esteem and confidence
- Increases social contact and participation in local activities
- Making new memories

Research shows that stimulation and social activities can improve your mental wellbeing

DIAL promotes the wellbeing of people with dementia through inclusion and social activities

## What are the greatest challenges for you and/or your organisation?

Personally, it's managing time as there are just not enough hours in the week to achieve everything I want to help our project. There also



seems to be a lack of services for people with dementia that go beyond meeting their medical and care needs which means we are very much in demand making managing our waiting list a significant challenge.

As a primarily mental health organisation the biggest challenge is raising awareness throughout the organisation which we are aiming to achieve through the Alzheimer's Society 'Dementia Friends' program (all DIAL employees are also 'Dementia Champions').

### **What has your role taught you about working with people with dementia?**

In my role it is important to not focus on the diagnosis but to focus on the person - what their strengths and interests are and what they are able to achieve. I have learnt that, with patience, persistence and thought, individuals with dementia can often access and achieve a lot more than they and others around them realise is possible.

The role constantly reminds me how important it is to treat people as individuals and what may be the right solution/style of support for one person may well not work for someone who is objectively similar. We ensure that all of our support and action plans are person-centred and as inclusive as possible.

Additionally, there has been a tremendous amount of positive progress made in the care, treatment and support of people with dementia, but there is still a distance to travel.

### **Where would you like to go from here? / How would you like to see your role developing in the future?**

We would like to develop a ballroom dancing group for service users and care partners - we have identified a volunteer to lead the group and now just need time and a suitable venue. We passionately believe in maximising the opportunities for all people living with dementia



#### **How the project works;**

- A Caseworker will visit you at home or in hospital to discuss how the project may be able to help you and design a support plan specific to you. This may involve working with the Caseworker, a volunteer, attending groups or a combination of those options depending on what is most suitable for your needs and to find out what type of activities you would like to undertake.
- Your Caseworker or volunteer will visit you at home and support you to access activities or participate in projects you have expressed an interest in.
- We will support you to re-engage with activities you have enjoyed in the past and also to access to activities or hobbies that you have expressed an interest in.

#### **Contact Information**

If you would like to get involved with the DIAL project, or if you would like further information about the project, contact:

Rob McMillan  
DIAL Senior Case Worker

- ☎ 07887 945396
- @ robmcmillan@gofal.org.uk
- www.gofal.org.uk
- @Gofal\_
- f GofalCymru

and also in offering opportunities for people with dementia to have fun and enjoy their lives as much as possible.

We would like to support more care partners and, in particular, establish peer support groups which would run alongside groups for the individuals they care for.

**Did you know?**

### **TALKING WATCHES**



During one of my clinics at The Memory Team here in Cardiff, I met a gentleman living with dementia who had been bought a new watch for Christmas. When I asked him for the day, date and month, he showed me his watch – he pressed a button and the watch informed him, not only of the day and date, but of the time and the year as well.

These 'talking watches' are widely available online and range in price from around £20 to a £100, depending on the watch itself – they all seem to have the same basic technology.

These could be very useful for people finding it difficult to tell the time due to poor vision or mild memory problems.

**News and Web.**

### **NHS Health check.**

Over the last few weeks, the BBC have been discussing the NHS and the challenges its currently facing. A lot of interesting questions and debates were raised from this coverage.... Is the NHS, quite simply, under-funded? Compared to other European countries, it was

claimed that Britain spend a lot less on the NHS and that this cut in spending began with the last Conservative government. Would an influx of spending help ease the difficulties faced by the NHS?

Are challenges, such as the lack of beds for patients due to, or exacerbated by, our aging population and lack of care in the community? We hear all the time about how we continue to live longer, but it is often suggested that we are not ready for this increase in an older population. There have been arguments that money should be spent on increasing the availability of care in communities and that this, in turn, would ease the burden on the wards in the NHS.

Jeremy Hunt, the current Health Secretary, responded to this latest BBC report by saying that current NHS pressures are "unacceptable" and that he is currently working on a "big transformation programme". We shall have to wait and see the details of this programme, and how successful it will be at tackling the many difficulties faced by the NHS and its staff.

### **Beti and David: Lost for Words.**

Beti George is a Welsh broadcaster for television and radio and has been a well-known name and face in Welsh media since the 1980's. Her partner is David Parry-Jones, an iconic broadcaster once dubbed the "voice of Welsh Rugby". He worked as a Welsh sports commentator and writer, presenting on BBC Wales Today and BBC Radio 5.

In 2009 David was diagnosed with Alzheimer's Disease. Filmed over the course of several months, "Betis and David: Lost for Words" is a film detailing their journey living with Alzheimer's, and is a moving record of two people living with Dementia together.

It is available on BBC iplayer until Wednesday the 15th of March 2017: <http://www.bbc.co.uk/programmes/b08fnvq4>

### **Dementia citizens research.**

People with dementia from all over the UK still have time to sign up to Dementia Citizens and be part of research into how favourite music affects people's moods thanks to an app created for Playlist for Life, the Scottish music and dementia charity,

People living with dementia and their carers are invited to sign up now to take part in the Dementia Citizens project, recently launched by innovation foundation Nesta, by visiting:

[www.dementiacitizens.org](http://www.dementiacitizens.org)

The Playlist for Life app uses Spotify to help people living with dementia find and listen to the most meaningful music for them and then organise it to affect their mood. Glasgow Caledonian University (GCU) is researching how this can be used to help improve care for people with dementia.

There is growing evidence that 'personally meaningful music' – the kind that takes you back to a time, person or place whenever you hear it – can be a powerful tool for people living with dementia. Playlist for Life was founded by writer and broadcaster Sally Magnusson in 2013 to bring the power of personal music to everyone with dementia in the UK.

Potential researchers will need an iOS smartphone or tablet (iPhone, iPads, iPod Touch) and will be given a Spotify account that they can keep afterwards, to keep listening to their music even when the experiment is over. Users of the apps during the next three months will help develop the technology and improve the user experience for people affected by dementia. -

The charity intends to develop new features for the app and make it available to the public later in the year.

Founder of Playlist for Life, writer and broadcaster Sally Magnusson said:

**“When I was caring for my mother with dementia, I noticed that music became the only thing keeping her with us. Old Scottish folk songs, hymns, the music of family parties. The music that was part of her life before the illness became a tool to help her live with the illness.**

**“I am delighted that Playlist for Life is now part of ground-breaking research into how this works through the Dementia Citizens platform and hope hundreds of people will sign up to take part so we can all learn more about what it can do.”**

For more information please contact: Sarah Metcalfe, Playlist for Life, 0141 418 7184



## Information about Signpost

### Anyone Can Contribute to Signpost

Including those who are living with mental or physical difficulties, or the care partners of older people with mental health needs in hospital, residential homes and in the community.

### Contributions

All contributions must demonstrate a positive attitude towards this group of people and their care-partners. Contributions can be made in the form

of an article, care study, letter, question, announcement, review or other appropriate proposal.

### Contact Details

Practice Development Unit, MHSOP, Llandough Hospital, Penarth, CF64 2XX.

**Tel:** 02920 715787

**Email:** [Deborah.Hopkin@wales.nhs.uk](mailto:Deborah.Hopkin@wales.nhs.uk)

### Books Available for Review:

We currently have a number of books that require reviewing, if you are interested in providing a review please contact us. Thank you.

- Group and Individual Work with Older People. A practical guide to running successful activity-based programmes.
- People with Dementia, speak out.
- Can I tell you about Parkinson's Disease? A guide for family, friends and carers.
- Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement (Theory and Compassionate Practice)
- Excellence in Dementia Care (2nd) - Research into Practice
- The Forgiveness Project - stories for a vengeful age
- A creative toolkit for communication in Dementia care
- Dancing with Dementia. My Story of Living Positively with Dementia
- Dementia Support for family and friends
- Introduction to the Psychology of Ageing for Non-Specialists
- Mind Clearing. The Key to Mindfulness Mastery.

### Signposts Editorial Panel

**Dr Julie Wilcox** is a Consultant Clinical Psychologist and Joint Head of Specialty for MHSOP, Neuropsychiatry and Clinical Gerontology within the Mental Health Services for Older People in Cardiff and Vale of Glamorgan.

**Annette McLean (Dunne)** is a Clinical Specialist Dietitian in Eating Disorders and the Mental Health Clinical Dietetic Lead for Cardiff and Vale University Health Board

**Chris Sampson** is a Head Occupational Therapist working within Mental Health Services for Older People in Cardiff and the Vale of Glamorgan.

**Paul Bickerstaff** is a Lecturer in Mental Health, Learning Disabilities and Psychosocial Care at the Cardiff School of Nursing and Midwifery Studies.

**Johannes Gramich** is a social worker working within Mental Health Services for Older People in Cardiff.

**Dr Natalie Elliot** is a Senior Specialist Speech and Language Therapist with the Cardiff Memory Team and Mental Health Services for Older People in Cardiff and the Vale of Glamorgan.

**Dr Rachel Brewer** is a Specialty Doctor with the Cardiff Memory Team.

**Matthew Lewis and Angharad Jones** are Assistant Psychologists working within Mental Health Services for Older People in Cardiff and the Vale of Glamorgan.

