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# SIGNPOST

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



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**The articles in the Autumn 2018 edition of  
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**Dr Julie Wilcox**

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 University Health Board.



Hello and welcome to the Summer edition of Signpost and yet again this journal has come up with a great variety of articles exploring health issues in older adults. These range from 'Top tips' in managing family events, to exploring the intimate thoughts of someone coming to terms with a diagnosis of dementia. What always strikes me with the articles produced for this publication is the honesty and sincerity with which individuals explore such difficult and challenging situations.

Luke Tanner's article on the quality of touch in dementia care explores the human need for physical contact and how this can express love, care, security and comfort. He suggests that touch can sustain a sense of personhood and can help meet an individual's emotional needs but he also acknowledges that professional care providers don't always use this simple method of communication in everyday care as effectively as they could, highlighting the barriers and possible misperceptions.

Rachael Litherland provides us with an insight into DEEP – the UK network of Dementia Voices. This project consists of over 100 grassroots groups across the UK, from the

Outer Hebrides to the South of Kent to West Wales, and provides an opportunity for those living with dementia to speak out about their experiences and to change things in their local area. Such projects demonstrate the power of people coming together with a single voice to evoke change.

The next article by Reg Morris introduces the reader to the recent publication of a self-help book for stroke survivors “Rebuilding Your Life After Stroke – Positive Steps to Wellbeing” (the development of which was introduced in an earlier edition of Signpost by Tamsin Miles). I have a vested interest in this as I am one of the authors! Having worked as a Clinical Psychologist for many years in stroke services I am only too aware of the need for psychological treatments in the recovery and rehabilitation of stroke survivors and also acutely aware of the general lack of such resources. This book therefore goes some way to fill this gap. It was structured and written by psychologists and stroke survivors and carers and offers practical advice and exercises that suggest ways to manage psychological distress.

These articles are followed by a new venture for Signpost – the inclusion of a ‘blog’. Wendy Mitchell (who has often contributed to Signpost) reviews ‘waterless soap and shampoo’. This seems a really good way to introduce readers to items that may not be well known but could be of great use and something we hope will continue.

Another departure for Signpost is the introduction of ‘top tips’ for events. Here we have information gathered by occupational therapists from a husband and wife on their recent attendance at a family wedding. The husband, who supports his wife who has dementia, reflects on the event with humour and poignancy but the end result was a successful family occasion that they were able to enjoy together.

There follows two inspirational book reviews both of which involve poetry. Rachel Brewer

introduces ‘*What the Hell Happened to my Brain? Living beyond Dementia*’, which looks at the personal experiences of Kate Swaffer living with young onset dementia. The narrative includes extracts of her poetry, with a theme of language, terminology and communication. The second review looks at John Killick’s ‘*Poetry and Dementia, A Practical Guide*’ which offers readers approaches on how to involve people who have dementia in communication and using such communication as material for poetry. The edition is rounded off by the regular ‘About Me’ which introduces Jenny Pinkerton, the new Clinical Lead Occupational Therapist covering Mental Health Services for Older People, Neuropsychiatry and Low Secure Services in Cardiff and Vale University Health Board.

I think you will agree this edition offers personal reflection and also innovation and development which should enthuse us all to be creative and motivated.

Happy reading.

I would like to thank Debbie Hopkin for her hard work and dedication in bringing this edition together.

**Julie Wilcox**  
**Consultant Clinical Psychologist**  
**Joint Head of Psychology – Older Adults**  
**Cardiff and Vale University Health Board**

## ***Embracing Touch in Dementia Care***



A Person Centred Approach to Touch in Dementia Care. Improving the lived experience of care for people living and working in dementia care settings by enhancing the quality of touch in care.

Physical closeness speaks volumes in every culture. We tend to try and keep the people we love and care for close, remain distant from the people we care little about and push the people we dislike further away! You don't have to be very clever or have all your cognitive faculties intact to understand the kind of messages touch conveys. It is a primitive non-verbal language that all mammals share. This form of communication relies upon the faculty of empathy; an ability to identify with and respond appropriately to the feelings and needs of others. This faculty is absolutely crucial to care-giving as well as humankind. Without it we would be lost and alone. Mammals are social animals because they are born with this seed of empathy. Loving and affectionate touch is the water that helps this seed grow strong. Touch and empathy are so closely bound that many forms of touch are actually experienced as empathy. This is because we first come to know empathy through touch, in the very first days or even moments of our life. Lessons in empathic touch start early, before words begin. Each of these tactile experiences are invaluable lessons in caregiving, enabling intuitive compassionate responses to another person's need for comfort throughout our lives.

Whilst researching my book, *Embracing Touch in Dementia Care*, I observed professional carers with exceptional skills in their use of touch. These carers were not trained in any fancy massage techniques or procedures. They were merely doing what came naturally to them. It was as natural as seeing a father cuddling up on the couch with his child, children playing together, partners consoling each other, a mother soothing her baby, or friends congratulating each other. Upon discussing their use of touch I discovered that they had learnt these skills simply through living their life. Their ability to offer tender loving care largely grew from the tenderness, love and care they had received themselves. Like the faculty of empathy, this loving and comforting touch was simply part of their experience of humanity. This experiential understanding of touch is particularly valuable in dementia care; in promoting the bonds of trust and affection at the beginning of our life, these forms of touch and the kind of relationships they convey can function to secure consent to care at the end of our lives when words can fail and logic and reason falter.

A person centred culture of care empowers carers to trust in their own sense of humanity enough to convey their empathy with touch and to secure consensual caregiving through the loving affectionate relationships such forms of touch convey. In this culture of care, carers are able to sustain people's personhood in and through the language of touch. Using, what I refer to in my book as, "person centred forms of touch" to meet people's emotional needs and enrich the quality of caregiving relationships. These experiences of touch do not take a great deal of time or effort, they are not an "activity" or specialist intervention and they certainly don't require any expensive equipment. They are simply moments in touch. The kind of moments in touch that help us know that we matter and that we belong somewhere. The kind of moments that help us feel safe, secure in the knowledge that we are in touch with people who are willing and able to help us in times of need. Most of us take these moments in touch

for granted, they are so everyday and commonplace that we rarely reflect upon their significance. Take them away however, and we will start feeling more alone, anxious and insecure and are likely to become more withdrawn, aggressive or “needy”.

Given that touch is such a natural and effective way of caring and such a powerful form of communication you would think that professional care providers would cherish this exceptional caregiving tool. Sadly this is not the case in many care settings. Many of the forms of comforting touch described above are often viewed upon with suspicion, doubt and mistrust. Discussions with professional carers about their attitude towards touch often reveal a great deal of uncertainty about what kinds of touch are acceptable in care settings and a lot of concern about how other people (peers, family members, visiting professionals, local authorities etc.) might perceive their touch. In short there is a lot of fear about “getting too close” and a great deal of uncertainty about how close “too close” is. A professional carers use of touch is further affected by lots of other issues ranging from -

- beliefs about “the elderly” and people with dementia,
- staff uniforms and other “us and them” features of care
- a clinical culture of care
- the furniture and layout of a care home lounge
- concerns about infection control
- routine bound systems of care and task orientation
- concerns about how other people (staff, family members, visiting professionals etc) might perceive their touch
- fears of being accused of sexual/physical abuse.

Unless directly addressed, these issues often add up to an extremely confused or touch-averse culture of care. Confident and compassionate care teams cannot exist in these cultures of care because they tend to compel care

staff to detach from the very feelings that arise from their sense of compassion and, in doing so, function to suppress empathy. Care without empathy is not only meaningless but inhumane; it is the kind of care that one might accept from a machine but despair over when it is from a person. Whilst human contact can be intrusive, abusive and exploitative and people with dementia can be more vulnerable to this kind of treatment, there is another greater and far more prevalent risk, and that is the risk of no meaningful contact at all. In protecting people with dementia from invasive or hostile physical contact, care providers can end up depriving them of any meaningful touch altogether. This kind of deprivation is just as harmful as any other form of abuse. When we become overly fearful about carers getting ‘too close’, people with dementia can end up being kept so far away from other people that there is no longer anyone close enough to share their lives with. This is a desperate situation particularly during times of loss, uncertainty and pain.

In these touch averse cultures of care of care, touch can become confined to care tasks and procedures. From the perspective of someone living in care, this task oriented culture of touch means someone’s experience of touch can be limited to being;

*pushed, pulled, buckled, secured, nudged, poked, hauled, carried, rearranged, set, rubbed, adjusted, shoved, clipped, squeezed, budged, heaved, lugged, released, twisted, brushed, repositioned, handled, clamped, raised, bumped, jostled, tugged, humped, swivelled, stood up, hoisted, leaned, caught, rubbed, pressed, yanked, jerked, turned, wiped etc.*

This experience of touch will inevitably shape how they feel about themselves and others. This is particularly the case with the onset of a cognitive impairment; when reliance upon representational and symbolic systems of communication reduces people rely more upon their experiences of touch to make sense of their relationships. Subjecting people living with a dementia to a task oriented culture of touch can result in people feeling more like objects to be

handled or tasks to be done than people to be met. Carer's are therefore more likely to be experienced as having "power over" people with a dementia. When touch establishes a caregiving relationship characterised by domination or control consent to care can end up being secured through conformity and subtle forms of coercion rather than trust and affection. Furthermore a culture of care which alienates carers from their own sense of empathy whilst placing them in positions of power is the very kind of culture in which abuse is more likely to occur.

To see more confident and compassionate carers and less of the malignant cultures of care that undermine the personhood of people living and working in dementia care, we must secure our freedom to express this part of humanity within professional care. Embracing Touch in Dementia Care can help care providers restore trust in touch and identify and remove the obstacles that stop human beings from being human to one another. I urge care providers to use this book to build confident and compassionate care teams that can communicate more effectively in a language that people with dementia are most likely to understand.

**Luke Tanner**

**Author**

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**DEEP**

DEEP stands for the Dementia Engagement and Empowerment Project – the UK network of Dementia Voices. DEEP consists of almost 100 grassroots groups of people with dementia - groups that want to change things in their local area by speaking out about their experiences of living with dementia and taking action. The network connects these groups together so that



they feel more powerful and can act together.

DEEP is:

**a UK wide network** - it connect groups to each other to magnify the views, hopes and intentions of people with dementia. It supports group to share learning and skills and to increase confidence

**independent** - the network belongs to the groups themselves, not to any particular dementia service or organisation

**diverse** - it is made up of groups strongly rooted in their local communities, including some in care homes

**rights based** - it encourages groups to identify and speak out about the issues that are important to *them* (not only to be 'consulted' about issues that are important to *others*)

## About DEEP groups:

The UK DEEP network began with 12 groups in 2012. By the end of 2017 there were 90 groups ranging from the Isle of Lewis in the Outer Hebrides to the South East of Kent. Groups operate in a variety of ways. Some are campaigning groups or awareness-raising and training groups. Some work on consultations and local practice, or policy development. Other groups are working to create dementia-friendly communities, while others get involved in opportunities as they arise. Increasingly we are also seeing Arts and Community based groups such as An Lanntair in the Outer Hebrides, Re-Live Memoria in Cardiff and Feelgood Friday in West Wales.



The size of groups varies. Some are large and some work on a country-wide basis like the Northern Ireland Dementia Action Group. Most, however, are smaller, local groups, varying between 10 and 30 members. Equally groups have started in a pub with two people! Groups are supported and 'housed' by a variety of organisations including the NHS, local authorities and local charities including the Alzheimer's Society, while some groups exist within service settings (e.g. day centres and care homes). Some groups have set themselves up independently, with a constitution and bank account, and some are led by people with dementia. Some groups have paid staff members who provide practical support to the running of the group, as well as volunteer support. Groups also exist without any professional input at all.

'When I listen to that song, This Is Me, it really sort of resonated with me, yes This Is Me, I won't be locked away, and as I say it reminded me of all of us in DEEP, not just DEEP but all the people living with dementia that get up and speak and carry on with their life and be positive.' Dory from DEEP in Deeside

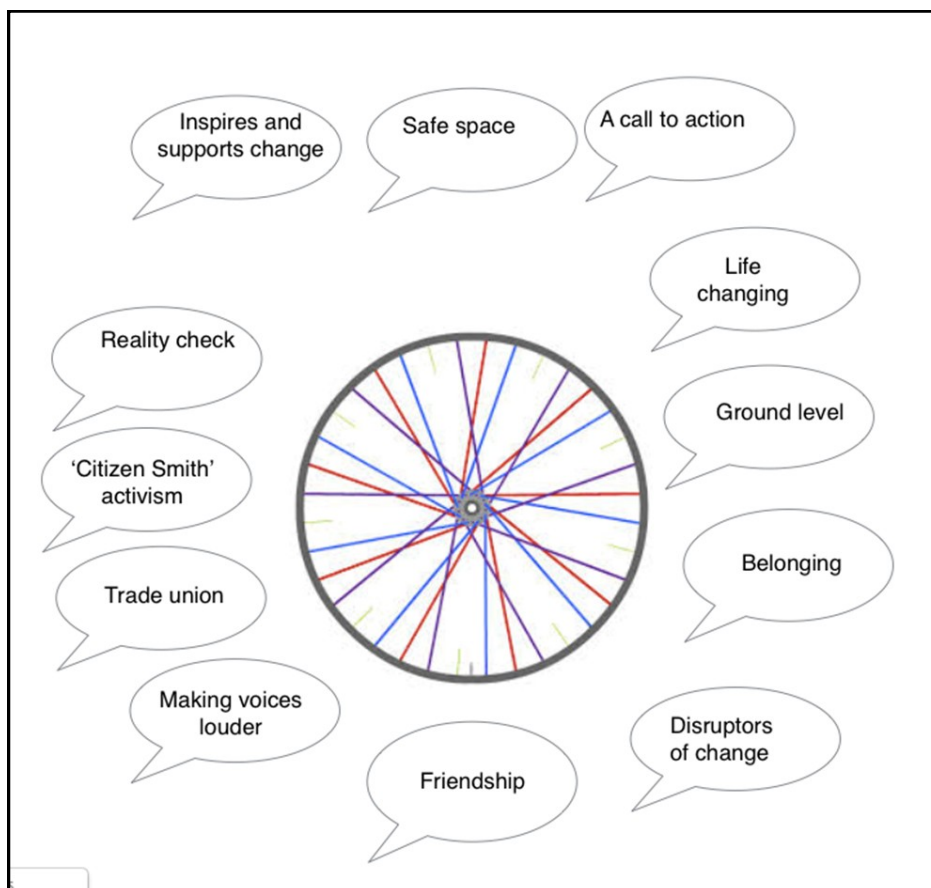
Innovations in Dementia, a national community interest company, supports the DEEP network by:

- Putting groups in touch with each other – to share ideas
- Getting groups involved in national dementia policies
- Collecting examples of different ways that groups work
- Writing monthly updates, to tell groups of each other's work
- Giving out small amounts of funding. This has helped groups to carry out work that they are interested in
- Producing guidance notes to improve the ways that other organisations work with people with dementia.

DEEP has been described as a hub - independent spokes that can work together when needed. A bit like a bicycle wheel. Each spoke is the real experience, the real voices of people with dementia.



We've been asking groups, "what does DEEP mean to you? "  
 These are some of the responses.



DEEP is full of people, their stories, their wishes, and amazing moments of action and social change by working together. For example, MemoryBilia in Kent recently hosted a DEEP meet up. Thirty people with dementia from Kent DEEP groups worked together recently to see what the common issues across Kent are for people with dementia. This is just one of their table discussions:

*What you wish you'd known when first diagnosed with dementia:*

- \* I wish I'd known about the stigma attached to dementia. Some people have a negative attitude towards people with dementia. I wish I'd known that some family and friends might stop contact.
- \* I wish that I'd known about services for people with dementia. More signposting would have been helpful. Peer support groups and the DEEP network are particularly good. A six-monthly newsletter could provide updates on local services.
- \* I wish I'd known that I was not alone. There are peer support groups which help in reducing fear and isolation.
- \* I wish I'd known how my dementia might affect me and others around me. Information needs to be tailored to the person's circumstances.
- \* I wish I'd known how to access health and social care. Sometimes services are not dementia-friendly.
- \* I wish I'd known that dementia does not mean life is ending. There are inspiring and encouraging people in the DEEP network.
- \* I wish I'd known how to talk to others about dementia. It can be difficult to explain dementia and to ask for help.
- \* I wish I'd known that I needed to plan for the future. It is important to talk to family and friends about future plans such as power of attorney.



Three Yorkshire DEEP groups have been using co-production methods to work on action research projects that have been campaigning around the Right to Get Out and About. They are now working with a team of artists as part of A Life More Ordinary project (University of Exeter) to create an activism banner that will be launched in Dementia Action Week, May 2018. These groups are feeling very excited by this work, and have become more confident in thinking about their rights.

Other examples of actions that DEEP groups are taking include:

- \* Scottish alumni group are leading research into what 'self management' looks like for people with dementia
- \* EDUCATE are involved in the Neighbourhoods research project at the University of Manchester as co-investigators
- \* The PACE group in Witney have been giving feedback on the Zipabout travel app, from its first concept to almost completion.
- \* The Laverstock Memory support group have been awarding their own certificates to venues that they have assessed as being truly dementia friendly (using the DEEP audit tools).
- \* Minds and Voices in York are delivering the first post-diagnostic course for and by people with dementia.
- \* Groups in Liverpool worked with the Faculty of Art and Creative Technology (FACT) to write guidelines for meaningful participation in co-production of creative opportunities. BAME groups in Liverpool have built on this project to look at enabling diversity and cultural inclusion.
- \* There are many resources and ideas available about the best ways to involve people with dementia on the DEEP website at [www.dementiavoices.org.uk](http://www.dementiavoices.org.uk) as more information about the DEEP network.
- \* Me, Myself & I in Briton Ferry host an Academy of training for potential carers who have been referred by the job centres.
- \* Increasingly we are seeing groups being set up by people with dementia for people with

dementia for example DEEP in Shropshire, Trailblazers in Oswestry, Halcyon Days and DEEP in Deeside in North Wales and The Memory Jar in South Wales.

"The visit that we had to the Callanish Standing Stones, it was an ancient centre of power and it was stones in a circle and you know what it reminded me of and that's why I found it so important, they said it was an extraordinary testament to the skills and determination of the people who lived here 4000 years ago, now what that reminded me of is the activists that we do and how these stones almost made me think of this, because in a way our extraordinary testaments to our skills and determination and the standing stones you seen them standing together stronger together, and that was what reminded me of what we are doing united we stand, divided we fall and these stones epitomise this for me." Angus from Scottish Alumni

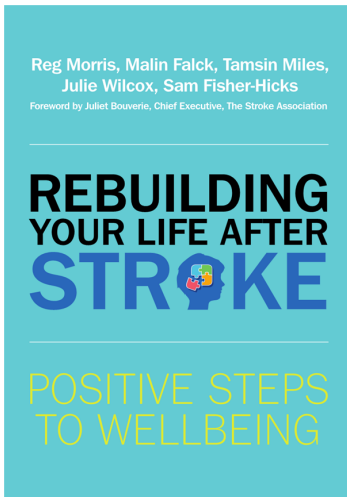
If you would like to know more about DEEP in your area, please contact either:

Paul Thomas – (Co-ordinator for Northern Ireland, Scotland, and Northern England)  
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Rachel Niblock – (Co-ordinator for Wales and Southern England)  
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**Rachael Litherland**  
**Co-founder, Innovations in Dementia**

## Rebuilding Your Life After Stroke: Positive Steps to Wellbeing



The majority of stroke survivors and their carers suffer psychological distress of some kind after a stroke. This can take many forms: anxiety, depression, constant tiredness (fatigue), changes in self-identity or body image, loneliness and isolation, rela-

tionship and marital problems, memory and thinking problems, and many more besides (The Stroke Association, 2013).

depression and anxiety and cognitive problems  
Fatigue, frustration, anger, post-traumatic reactions,  
difficulties with relationships,  
concentration and attention problems,  
impaired space awareness, emotional lability,  
perceptual impairment, dyspraxia, sexual problems  
issues with body-image, identity, self-esteem,  
problems with social integration and  
social participation

These psychological problems are not only distressing for those who experience them, but they can also affect their physical health, recovery and quality of life (Ayerbe et al., 2013; Gillen, Tennen, McKee, & Gernert-Dott, 2001; Godwin, Ostwald, Cron, & Wasserman, 2013). Untreated psychological problems also increase use of health services and drive up the cost of providing care (Appleby, Thompson, & Galea, 2012; van Eeden et al., 2016).

UK guidelines all emphasise the importance of recognising the psychological effects that often occur after stroke and the importance of provid-

ing appropriate psychological care (NICE, 2013; Royal College of Physicians, 2016). However, services to support psychological needs after stroke are often under-resourced and unable to meet needs (Care Quality Commission, 2011). Consequently, psychological needs of stroke survivors and their carers often go unrecognised and untreated; survivors and carers feel 'abandoned' on leaving hospital (Stroke Association, 2013).

Improving the availability of psychological treatments over the longer term in the community is a key aspect of the rehabilitation pathway (NICE, 2016). But in these times of increased need due to the aging population combined reduced resources due to global economic factors, it is important to use the available funding prudently. Many people think of psychological care as involving one to one therapy in one hour long individual session with a therapist. For some people this may be necessary and possible, but there are simply not enough therapists or resources for this to be provided for everybody with psychological distress.

An alternative approach that may help many stroke survivors and carers, without a huge cost, is to offer a book that contains practical advice and exercises that teach how to manage psychological distress. There is evidence that such self-help material can be very effective, particularly for anxiety and depression (Gellatly et al, 2007). However, up until now there has been little self-help material available that deals with psychological problems experienced by stroke survivors and their carers.

NHS Wales (The Stroke Implementation Group) has filled this gap by funding the development of a self-help book for stroke survivors and carers that was published in 2017. We put together a team of psychologist with experience in stroke and stroke survivors and carers to tell us what stroke survivors and carers needed in terms of psychological support and care. Many of those involved participated in interviews about their experiences. These interviews are

available to watch on the internet (YouTube) through a link that is provided with the book.



Some of the writing team

Once we had decided what was needed by the service users and carers, the psychologists set about writing the book. After each stage they sent it to the service users and carers and met with them in groups to discuss if the content and approach was what they needed. After 'going back to the drawing board' several times, the service users and carers agreed that the book did what they needed and the final version of the book began to take shape.

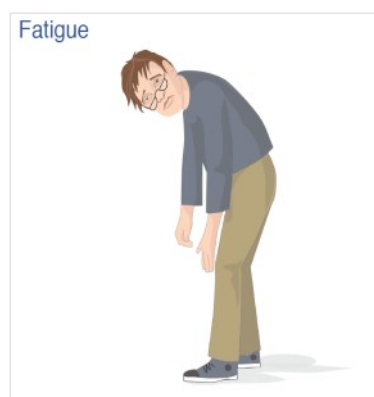
The book has several key features and sections that are designed to be helpful.

- \* The book is spiral bound and designed to be used one-handed.
- \* The book is available in English, Welsh and in an audio-book version for those with impaired vision.
- \* It uses real stories and advice and tips from survivors and carers (some in text boxes in the book, others are video interviews available on the web.)
- \* It contains many pictures, text boxes and

written exercises.

- \* Other exercises are available as recordings and can be downloaded from links on the website for the book.
- \* Part 1 is an introduction and gives advice on how to use the book and find your way through it.
- \* Part 2 deals with the common psychological issues after stroke for survivors AND carers: It has advice on coping both from stroke survivors/carers and psychologists. The psychological advice used evidence-based approaches including cognitive behaviour therapy and neuropsychology.
- \* Part 3 tackles more difficult persistent psychological distress in survivors AND carers using a novel evidence-based approach called 'Acceptance and Commitment Therapy'. This approach encourages people not to rush to tackle psychological problems head on, but instead encourages understanding and acceptance of distress. There are many practical exercises to help with this.
- \* Part 4 is a summary and has material that helps a person to move forward and live a more positive and meaningful life according to their own values and what they see as important to them.

Here is an excerpt from Part 2 of the book that will give you an idea of what is like...



"The worst thing for me was the fatigue... my doctor said I shouldn't have fatigue 'cos I'd only had a minor stroke."

"I just felt like somebody just turns the tap on and saps all the energy from you."

Stroke survivors

And here are some excerpts from Part 3...

In some ways we tend not to live in the real world.  
Instead we live in our minds.



Mind Full, or Mindful?..

Focussing on here and now can allow us to 'turn off' worries and regrets, and tune into the present moment. This is a very important skill in improving our lives.



#### Practice 1: Breathing Space

1. Sit down on a chair or a cushion on the floor, and sit upright with straight back if you can. If not you can choose to lie down.
2. Close your eyes if you feel comfortable with this.
3. Start by simply noticing your body. Notice the sensation of sitting or lying down. Notice the light pressure on your back or bottom.
4. Now, simply notice that you are breathing. Notice the sensations of breathing.
5. Observe how your chest or belly is rising on the in-breath. Notice the belly or chest falling on the out-breath.
6. Keep observing what your belly/chest is doing. Don't try to change or control it.
7. It is most likely that you will be distracted by thoughts. As you notice this gently bring focus back to your breath. Don't give yourself a hard time about it.

#### Practice 3: Leaves on a stream



Here is another exercise that a lot of people find helpful. It is a powerful way to step back from thoughts and feelings, and just let them float away.

This exercise normally takes about 10 minutes. It can help you develop a sense of detachment from your thoughts, so they don't make you feel so worried or sad.

You can do this exercise using these notes. But it may be easier to follow the recorded version available online.

Now take yourself to a quiet place and do the exercise.

#### Detaching from a thought

Try to observe thoughts and feelings as they pass through your mind in a detached way. This helps to prevent you becoming caught up by them and treating them as if they were real events. It will feel less personal.

Here is an example with the thought:

'I might have another stroke'

1. First understand that it is a thought about having another stroke. It is **not a real** message about having another stroke.
2. Step back and observe it. How does it make you feel?
3. Detach yourself by saying 'I'm having a thought that I might have another stroke'. Writing this on a piece of paper can also help.

Up to now we have had some very encouraging feedback about the book:

*"No one told me about the psychological effects (of stroke) but now I know it's normal to have those problems and important to know you're not on your own."*

*"It's really valuable that we have a voice too, as carers and partners."*

*"Hearing from other people, finding out what they have done, how they coped, inspired me."*

We are keen to know how people find using the book so that we can improve it. There are three evaluations of the book in progress; two evaluate the experiences of stroke survivors who use the book and the benefits they gain, and one is looking at how staff experience working with the book.

People can read the book on their own, or they can work through it with a family member or a member of stroke staff. Some stroke services are using it as the basis for stroke groups. Using it with others can be more fun and more productive for some people, especially when it comes to the practical exercises.

The book is available free from stroke services and from The Stroke Association in Wales. In England it has been adopted by the Reading Well Agency book prescription scheme and is available free in most libraries in England. We are hoping that the Welsh book prescription scheme will be able to list it once the scheme has been restructured. It is also available from the publishers Jessica Kingsley or Amazon at a cost of £16.99. All the author royalties go back to NHS Wales.

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### **Biography**

Reg Morris - BA, PhD, DipPsych, C. Psychol, Clinical Psychologist

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I studied psychology at the University of Exeter and was awarded a PhD for research into learning in 1977 and the BPS Diploma in Clinical Psychology in 1986. Since 1996 I have worked in NHS stroke services in Plymouth, Bristol, Bath and Wiltshire, and for The Stroke Association and the Bristol Area Stroke Foundation. I continue to work with both these charities as a trainer, reviewer and participant in service development.

Since 1990 my substantive posts have been in clinical psychology training programmes. In 2008 I moved to become Programme Director for clinical psychology training in south Wales, based at Cardiff University. It has been a privilege to have opportunities for developing training that will support the exciting and unique programme of health-care improvements being planned and implemented by the Welsh Government.

My research interests are in stroke, and most of my research is achieved through supervision of doctoral research projects. I have had funding for research to explore the relationship between the perspectives of service users, carers and staff in NHS stroke services, to set up and evaluate peer support groups and to explore the experiences of staff in third sector stroke services. In 2002 I was a founder member of a UK stroke research network (originally PSYRIS, now OPSYRIS) which facilitates stroke research in psychology. I am an author of the 'Psychological Management of Stroke' textbook published by Wiley International in 2012 and about 20 peer reviewed articles and book chapters, and have co-authored 'Rebuilding Your Life After Stroke' (2017), a self-help book published by Jessica Kingsley Publishers. From 2012-2016 I was co-chair of the UK Group of Trainers in Clinical Psychology and

sat on the Division of Clinical Psychology executive committee. In 2017 I was a founder member of the ACP-UK. I continue to sit on various clinical psychology committees. A list of my publications can be found at:

[http://psych.cf.ac.uk/contactsandpeople/honorary\\_staff/morris.php](http://psych.cf.ac.uk/contactsandpeople/honorary_staff/morris.php)

**Reg Morris**  
**Co-author**

## News

### *Waterless Soap and Shampoo*

I often get contacted by companies asking me to try products in the hope that I'll review on my blog. I usually decline as this isn't the purpose of my blog.

However, a while ago, I was contacted by a company who produce waterless products. The thought intrigued me so much that this time I agreed.

They sent me waterless body soap



And waterless shampoo.



My daughter Sarah, who is a nurse in a hospice said they used the waterless soap, and a shower cap with waterless shampoo, but had never used the liquid shampoo.

I must admit to being very sceptical.....but I was pleasantly surprised at how amazing they were. For the body wash, you simply use the foam and then wipe off with a towel while it's still foamy. The shampoo is in liquid and lathers just like shampoo when you put it on dry hair. While it's still foamy, you use a towel to rub it off.

Sounds impossible but your hair feels like it's just been washed.....most bizarre. It also smells really nice. I washed my hands in the body wash and at first, once I'd towel dried, they felt sticky. But we came to the conclusion that I'd used too much. After a while they felt very soft and clean. Trying it again, but with a smaller amount, it worked perfectly – no sticky residue.

I can think of so many uses for these products. People with dementia in the later stages, often don't like water, so these products would help. But also for children, camping, travelling, and for me, if you're in hospital. I remember hating the thought of using the hospital bathrooms and this would have been perfect.

Also might be really useful for those frequent occasions when I can't work out how to use the shower in hotels.....

I'm sure there's lots of other situations where they'd be ideal.

Obviously, I'd prefer to use water but as an alternative I found them very good. As I say, I don't usually review products, but these seemed worth a mention. I haven't a clue how much they cost, so apologies if they're expensive, but more details can be found at their web site: [www.nilaqua.co.uk](http://www.nilaqua.co.uk)

**Taken from Wendy Mitchell's**  
<https://whichmeamitoday.wordpress.com>



## **News**

### **Weddings and Dementia**

Information gathered by Occupational Therapist's Leah Price and Gail Pickford  
Written by Leah Price

The Alzheimer's Society [2018] identifies the importance of including loved ones with Dementia in special events such as a wedding. It has been suggested using creative ideas such as a wedding themed memory boxes if it has been identified that the event or the location is unable to meet the needs of the individual with dementia and the supporting families.

#### Introduction

Occupational Therapist's Leah Price and Gail Pickford facilitated a discussion with a husband and his wife who have been married for 65 years. He highlighted some potential top tips and forward planning processes that he had to consider when supporting his wife who has dementia to a wedding. These tips may also help, support and enable others who are supporting individuals with Dementia to weddings or other events alike. Mr L agreed that the forward planning of the event to ensure the needs of Mrs L where going to be met was essential and something he would recommend.

#### Family / Carer Support

Mr L explained that the family supported himself and Mrs L during the wedding day. Mr L organised for a familiar paid carer to support his wife for the entire day as part of the Package of Care. Mr L explained that he initially had concerns about the changing facilities for his wife at the event. However, this was not so much of an issue on the day as Mrs L was supported to

attend to her needs before and after the wedding at home within her own environment. Mr L explained that it was a coincidence that the wedding times also fitted in with his wife's daily routine (time of waking up, medication routine, feeding, washing and dressing and many other activities of daily living). Their daughters then ensured that Mrs L was dressed appropriately for the wedding, including her hat being positioned at the correct angle.

### Challenges/Difficulties

Mr L explained that they encountered some difficulties/challenges such as the large hills and car parking situation at the venue as Mrs L mobilises with the use of a wheelchair. Mr L emphasised the value of having assistance from the carer to support himself and Mrs L at this point during the day. Mr L explained that due to the car park being very busy and the event itself, it was difficult to get close enough to the main entrance. Mr L advised that it may be an idea to check this out prior to attending an event or availability of local disabled parking. Mr L explained that the aisle in the church was slightly narrow, and that Mr's L wheelchair was required to fit into the main aisle. Mr L explained that this was not an issue on the day as the wheelchair did not impact on the event itself; however it was a thought that had crossed his mind prior to the event taking place. Also in regards to Mrs L's wheelchair, when the photographs were being taken the environment was very busy for a wheelchair user. However, a family member ensured that she was positioned well within the photographs. Mr L highlighted that another challenge that Mr and Mrs L were faced with towards the end of the event was the lighting during the night time. Mr L explained that the lighting within the car park at the facility did not support the need to transfer Mrs L into the wheelchair accessible vehicle so a torch was needed to enable this. Mr L reinforced how much Mrs L and he enjoyed the event together. Mr L explained that his wife appeared to be smiling and aware of the event and the social contact with other invitees.

### **Reference List**

Alzheimer's Society [2018] Accessed online from <https://www.alzheimers.org.uk/info/20155/give-in-celebration/122/support-us-on-your-wedding-day> accessed on 19th April 2018  
Daughterly Care – *Elders do not have to miss the wedding* [2018] accessed online from <https://daughterlycare.com.au/no-one-has-to-miss-the-wedding> accessed on 19th April 2018



## Book Reviews



### **What the Hell Happened to my Brain? Living beyond Dementia.**

**Author:** Kate Swaffer

**Publisher:** Jessica Kingsley Publishers. 2016

**ISBN:** 978-1-84905-608-3

**Price:** £13.99

Kate Swaffer happens to have one Hell of a brain! Diagnosed with young onset dementia aged 49, she passionately, and fearlessly, shares her personal experience of living beyond dementia. This illuminating insight holds nothing back. She invites us into her world, challenging myths and stigmas associated with dementia. She doesn't shy away from contentious issues. It'll get you talking as it got me thinking.

Her narrative, which is peppered with her poetry, shows the impact of words. The theme of *language, terminology and communication* shines throughout the book:

- \* Positive changes in communication can enlighten our approach. She alludes to the move from the '*pathway to dying*' to the '*pathway to living as well as we can*'. She never shies away from the very real issues of living with a terminal illness, but always advocates living beyond dementia. The phrase '*Living beyond dementia*' sits more comfortably with her than '*Living well with dementia*'. She feels it is more em-

powering to live beyond the diagnosis. This is fuelled by her resilience and positive attitude. Her work as an advocate for people with dementia and ongoing professional activities reflects this. The contents of this book explains ways in which this may be achieved.

- \* She describes her husband as her *Back-Up Brain (BUB)*, rather than her carer. She feels the term BUB is easier for them to live with, inferring equality of power and status along their journey together. The term 'carer' diminishes them both.
- \* She highlights the fact that the language of dementia can be an influential tool. The narrative has to change to empower people with dementia with the ability to live their pre-diagnostic lives. This thread draws me to her thought-provoking example re: challenging behaviours, a loaded phrase. She poses the debatable question '*who's got these 'behaviours'?*' I concur with her cynicism in relation to the term 'Behavioural and Psychological Symptoms of Dementia'. Kate believes this categorisation of 'behaviours' increases the likelihood of continuing stigma and lack of person-centred care being delivered. One example she cites speaks volumes; before her diagnosis she may wander in good weather enjoying the fresh air, but post-diagnosis she is labelled a 'wanderer'. This leads her to explore the reasons for so-called challenging behaviours, and to ask how non-pharmacological and positive psychosocial interventions may enhance the management of such 'issues', rather than popping down the pill route!

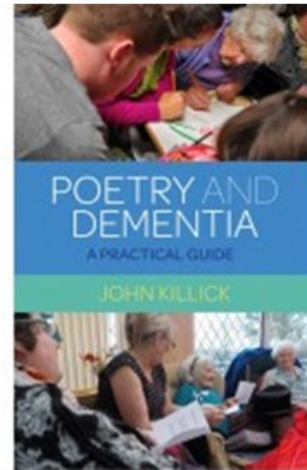
Certain other issues within her powerful prose shine through for me...

- \* She shares the varied and complex emotions she felt post diagnosis. She advocates that '*professional grief support*' be offered as part of the ongoing support and management following a diagnosis of dementia. This is for the person's own emotional journey but also managing others' reactions.

\* She coined and trademarked her term '*Prescribed disengagement*'. She feels people with dementia are doled out negative recommendations after a diagnosis to give up on pre- diagnostic life. She believes the misperception that people cannot live beyond dementia leads them down a road of hopelessness and fear. People adopt the role of sufferer and *learned helplessness*.

She feels strongly that people with dementia must stay engaged with their pre- diagnostic lives. However, she is quite resolute in her view that people with dementia are not safe to drive. I invite you to read about her opinion! Kate shares her emotions and reactions before, during the diagnostic process and post diagnosis honestly with the reader. Her words are genuine and emotive. I haven't read a book quite like it. The bite sized chapters are easy to digest and this book would appeal to a wide audience. It should be a necessity for Health Care workers to read. She holds strong opinions about the need to change attitudes and approaches in order to move forward optimistically. She believes her positive attitude has given her choices, and using such strategies as *Life enhancing aids* e.g. alarm reminders, notes, signs, as well as other invaluable resources, enables her to continue functioning. Kate has obtained several post-graduate qualifications following her diagnosis, and cites a list of committees, publications and projects with which she's involved. She is an international speaker and you can also follow her opinions, and occasional rants, on her blogs and twitter. She is still Kate - the person, however, not the symptoms or label. And she sounds like one Hell of a woman!

**Dr Rachel Brewer**  
**Specialty Doctor with Cardiff Memory Team**  
**Cardiff & Vale University Health Board**



**Poetry and Dementia, A Practical Guide**

**Author:** John Killick

**Publisher:** Jessica Kingsley Publishers 2017

**ISBN:** 9781785921766

**Price:** £16.99

John Killick takes the reader gently through his new practical guide which shows approaches on how to involve people who have dementia in communicating and using such communication as material for poetry. At the beginning, the author gives examples of poetry by well-known mainstream poets, such as Robert Frost, Charles Causley and Gillian Clarke, alongside poems that were transcribed from material derived from people with dementia. The similarities of the use of unfamiliar word combinations and dissociative syntax by such mainstream poets and their occurrence in poems created through work with people who have dementia are striking. Then John discusses how to go about engaging people with dementia in communication within a care home setting ; he shows from his long experience that people who were judged to be hardly able to communicate can open up under the right guidance and speak about their lives and other topics close to their heart. Hereby, their mind less fettered by the rigidity of logic may create memorable metaphors and phrases as usually only poets are able to do (I would love to give some examples but feel that I would be giving too much away); thus, dementia in itself, often seen as a hindrance and burden becomes a

strength. John also introduces examples of actual people and their poetry. He does admit that a poet as a guide is necessary to cast the material derived from communications with the residents into actual poems and does discuss the issues of ownership and consent arising from it in detail. John is clearly someone who has a gift for language and its creative use. But he is very encouraging by saying that many more people have such sensitivity though they may not be aware of it. Therefore, this book can be recommended to everyone who has an interest in involving people with dementia to use words to create poems that can help to increase their often fragile sense of personhood and self-worth.

**Johannes Gramich**  
**Social Worker**  
**Mental Health Services for Older People**  
**Cardiff & Vale University Health Board**

## *About Me*



I am new in post as Clinical Lead Occupational Therapist covering Mental Health Services for Older People , Neuropsychiatry and Low Secure Services in Cardiff and Vale University Health Board.

This a challenging and enjoyable job which I look forward to continue to develop over the coming years. I have left colleagues in medicine and gerontology where I worked for many years and hope to combine knowledge and skills to develop a more integrated occupational therapy service equipped to meet the needs and expectations of a changing NHS in Wales.

I qualified as an Occupational Therapist from Cardiff in 1992 and started work in the mental health team in Gwent Health Authority. Over the subsequent years I found myself working on a basic grade rotation, working in America in various occupational therapy positions, returning and working in the wheelchair service in ALAS, being a founding team member of the Community Respiratory Resource Team (CRRU) and then moving to the Rehabilitation Day Hospital where I was able to support other occupational therapy teams when needed. A very varied and enjoyable career with many different experiences.

I am committed to an occupational therapy team which will continue to provide an excellent service for people with dementia and their carers, and look for opportunities to promote their skills. Recently, the MHSOP band 7 occupational therapists completed a scoping project with WAST, a nurse and physiotherapist to prevent admission to A and E- the occupational therapists integrated approach highlighted issues for mental health service users.

I am pleased to be part of a supportive wider multi disciplinary team in MHSOP which puts its service users at the centre of all care and decision making.

**Jenny Pinkerton**  
**Occupational Therapist**  
**Cardiff & Vale University Health Board**

## 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.

### Contact Details

Practice Development Unit, MHSOP, Llandough Hospital, Llandough, CF64 2XX  
Tel: 029 20715789

### 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, case study, letter, question, announcement, review or other appropriate proposal.

### 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.

- Person-centred Thinking with Older People, Helen Sanderson, Helen Bown and Gill Bailey
- Hidden Camera, Jo Plomin
- Excellent Dementia Care in Hospitals, Jo James, Beth Cotton, Jules Knight, Rita Freyne
- Positive Communication, Robyn Dynes
- People with Dementia, speak out, Lucy Whitman
- Can I tell you about Parkinson's Disease? A guide for family, friends and carers, Alan M Hultquist
- Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement (Theory and Compassionate Practice), Sue Read
- Counselling Older People with Alcohol Problems, Mike Fox and Lesley Wilson
- Telling Tales About Dementia, Lucy Whitman
- The Multi-Sensor Reminiscence Activity Book, Sophie Jopling and Sarah Mousley

### 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 Dietician in Eating Disorders and the Mental Health Clinical Dietetic Lead for Cardiff and Vale University Health Board.

**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.

**Dr Jenny Pinkerton** is Clinical Lead Occupational Therapist covering Mental Health Services for Older People, Neuropsychiatry and Low Secure Services in Cardiff and Vale University Health Board.