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The articles in the Spring 2017 edition of Signpost have been edited by:

Paul Bickerstaff, Lecturer in Mental Health, Learning Disabilities and Psychosocial Care, Cardiff School of Nursing and Midwifery Studies.

Cover picture: designed by **Debbie Hopkin**



Hello everyone, and welcome to the Spring 2017 edition of Signpost. As usual there is an interesting variety of articles looking mental health issues in older adults from a range of different perspectives. What does stand out for me is that in all the articles there is a sense of positivity and hope. Despite the challenges that people who are living with dementia, or have experienced a stroke, face there is an overwhelmingly positive 'can do' attitude. With a lot of thought, perseverance, and creativity peoples' quality of life can be improved.

Deborah Shouse reminds us of the importance of knowing the person and using this information in a meaningful way so that care is focused on the individual. It is reassuring to know that the drive towards person centred care is as strong across the pond as it is over here.

Wendy Mitchell's article is a very honest and inspiring account of living with dementia. It has an encouraging message about how to meet the challenges dementia poses and overcoming them with practical solutions. It also shows how embracing new technology and ways of social networking can be utilised to great effect.

Lastly Alison Shone highlights the importance of inspiring a sense of hope, purpose, and belonging in people who may, without this support, become despondent and disillusioned with life. The feelings of accomplishment and companionship that a choir brings should not be underestimated.

In conclusion, what I like about all these articles is their message of hope. Whether you are someone experiencing the conditions discussed in these articles, are a carer, or a healthcare professional you can take away a sense of optimism.

P. Bickstaffe

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.

Deborah returns to this edition of Signpost with
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 organization. As you 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.

Providing Comfort and Connections

Tena Alonzo

Director of Education & Research, Beatitudes Campus, Phoenix, Arizona

Website: www.beatitudescampus.org

Mildred was asked to leave her second memory care community. At first glance, she looked like a sweet elderly lady, sitting quietly in her wheelchair with her perfectly coiffed hair and her delicate white crocheted sweater. Her Bible was always by her side and her family and friends knew her as a loving, caring woman. But when the staff tried to assist her with dressing or bathing, Mildred might scratch, bite, or hit them. Her desperate son called Tena Alonzo. Beatitudes Campus, a senior living community of 750 residents, engages in research and training and welcomes people with dementia-related behaviors.

"Within minutes of her coming into our community, her issue became clear," says Alonzo. "She had a frozen shoulder and though she'd been on psychotropic drugs, she wasn't being treated for pain. She was protecting herself by keeping people away from that tender shoulder."

In studying the available research, Alonzo had learned that pain is often undertreated for people living with dementia. Her team addressed the pain and purchased adaptive clothing so the staff wouldn't need to disturb her sore

shoulder.

“As Mildred became physically and emotionally comfortable, she stopped rejecting our efforts to care for her,” says Alonzo.

“You gave me my mother back,” Mildred’s son told Alonzo. “The mother I’ve always known who would not hurt a fly.”

Modeling Evidence-Based Care

“Eighteen years ago, we decided we wanted to better serve people living with dementia,” Alonzo says.

Beatitudes Camus leaders knew that perhaps fifty percent of people age 85 and older were impacted with difficulty in thinking and needed help living successfully.

Alonzo and her team were drawn to Tom Kitwood’s seminal book, *Dementia Reconsidered: The Person Comes First*. They used Kitwood’s tenets, focusing on individuality, trying to understand what made each person unique. They investigated the connection between communication and behavior, asking: “How can we figure out why someone is behaving a certain way? How can we meet them where they are and address their needs?”

They also incorporated the Comfort Theory, developed by Katherine Kolbaca PhD, RN.

“When people are treated as individuals and made comfortable, they don’t demonstrate dementia-related behavior,” Alonzo says.

For example, during sun downing times, if people’s pain was managed and if they were well rested, not hungry, and engaged in something meaningful, they were less likely to call out or try to leave.

Trying, then Trying Again to Keep Individuals Connected

Arthur was a master gardener. He had dementia, limited mobility, and reduced sight. Alonzo and the team asked the family, “What parts of master gardening can we add to his life now?”

“Soil and seeds,” they said.

Putting his hands into the earth was meaningful for Arthur. But if that hadn’t worked, they would have continued brainstorming. Perhaps his gardening gloves were important? Holding a trowel? The music he listened to while planting? The cup of tea afterwards?

“We find what makes sense to the person,” Alonzo says. “It’s easy to tell when you’ve gotten it right.”

Promoting Comfort

“The part of our brain that tells us when we’re comfortable functions throughout life, even with dementia” Alonzo says. “Most of the time, the emotional brain, which you can reach through the senses, is also intact. How a person feels is more important than they how think and you can transcend the fact that your thinking is impaired.”

Through their practical applied research, they are beginning to benchmark excellent dementia care, demonstrating that individualized care is cost effective and has good outcomes.

“In the perfect world, each person will have the quality of life that we all long for and that only a sense of comfort can bring,” Alonzo says.

Creating a Dementia Friendly Community from the Inside Out

Lisa Gwyther, MSW LCSW

Director of the Duke Alzheimer's Family Support Program
Durham, NC
Duke Family Support.org

The café at the Nasher Museum is buzzing. One large table of friends seems to be having an especially good time.

"Where else can 76-year-olds have 55 new friends?" says a care partner whose husband is living with dementia. "As difficult as this disease is, we have met so many incredible people through the support group."

Making new friends, having new experiences, creating a new sense of community and connection—these are some of the benefits of the Duke Alzheimer's Family Support Program's Early Stage Memory Loss groups.

"Our focus is on building a dementia friendly community from the inside out" says Lisa Gwyther, MSW LCSW.

The Duke Family Support Program has served North Carolina since 1980. It offers a variety of state and regional support services and is the state's gateway for people with questions about memory disorders or family care.

Destigmatizing Dementia

In 2012, Duke's Family Support Program started Memory Makers, an 8-week early stage memory loss education and support group for people with early stage dementia and their care partners. Memory Makers is the portal into the

Alpha community, an ongoing social network of care partners, family members, and people living with dementia. Duke social workers orchestrate a dynamic variety of community-based outings, including enjoying monthly museum programs, attending baseball games together, going to local cinemas, and participating in educational programs. At one regular monthly Saturday luncheon at a local deli, the Alpha group was laughing so heartily that the wait staff and other customers peeked in, curious about who was having such a great time. They saw 40 diverse people of varying ages truly appreciating each other's company.

"Because we look just like any other group of friends, when we go out into the community we are helping to de-stigmatize and de-medicalize dementia," says Gwyther.

Their focus is on developing programs that simultaneously address the needs of the person living with dementia and the family. They give presentations to community groups, educating as they go.

"We're trying to build a convoy community to see families through living with cognitive disability when friends may drop off," Gwyther says. "Alphas remain Alphas. We have a number of widowed care partners who still participate because they feel so deeply connected and they have so much to offer to this caring community."

Advocating for Culture Change

Douglas Pace

Director - Alzheimer's & Dementia Care, Alzheimer's Association
Washington, D.C.
www.alz.org

For decades, Ralph worked the afternoon shift, arriving at work by 3:00 p.m., returning home by 11:30, staying up for several hours, reading, talking to his wife, watching television before turning in and sleeping until 9:00 a.m. So when he went into a memory care community, he did not respond well to being woken up at 6:30 for a 7:30 meal. He did not appreciate being served a hearty breakfast before he'd even had his first cup of coffee.

"In the ideal world, before someone comes into a community, you have a conversation and get a life history so you know and understand them," says Douglas Pace. "If someone is used to taking a bath at dawn or a shower every evening, then you coordinate those preferences into their care."

Throughout his years in the long-term care industry, Pace has been an advocate of individualized care for people living with dementia.

"But the provider community has been slow to adopt this concept," he says. "It's easy to talk about 'culture change' but implementing these ideas requires a complete system overhaul."

The improvements include giving front-line staff, such as Certified Nursing Assistants and housekeepers, adequate dementia education, including them in care planning, and allowing them to have a voice in decision-making. That way, the person with dementia comes first.

Making Meaningful Care Decisions

Memory care units are the fastest growing segment of Assisted Living.

Pace advocates with provider associations and healthcare groups and he works with CMS (Centers for Medicare & Medicaid Services) on how care is delivered. He also collaborates with the Home Care Association of America.

"Organizations need to be dedicated to quality improvement," Pace believes. "Care communities can share their stories through outcome-based data, which might include improved pain management, reduced falls, or fewer hospitalizations."

Increasingly, people are looking for exemplary care for loved ones.

"The baby boomers are starting to come through the system," Pace says. "They are seeking programs, services, and communities that will make this stage of their life meaningful."

Connecting at Home through Meaningful Activities

Dan Kuhn, LCSW

Vice President of Education at All Trust Home Care, Hinsdale, Illinois
www.alltruthorhomecare.com

"What is your opinion of this painting?" Maria asks. Beside her, 85-year-old Ethel sits mutely, staring at the paper.

Ethel was an amateur artist, but had abandoned painting as her dementia progressed. Maria is an amateur artist working as a home-

health aide, there to assist Ethel with bathing, meal preparation, and quality of life.

She's painting with Ethel to see if she can inspire Ethel's dormant inner artist.

"We want our staff to explore connecting with clients through creativity, imagination, and fun," says Dan Kuhn, whose organization specializes in the care of people with dementia. Kuhn, an award-winning speaker, author, and dementia advocate, believes that meaningful activities are a vital part of home health care.

As he and his intake team get to know their clients, they match staff and elders who share similar interests. He encourages his care team to experiment until they find a way to connect with each client.

Maria is patient. She enjoys sitting with Ethel while she paints. Several days into the project, she asks Ethel's opinion and Ethel picks up a sketching pencil and adds her touch to the page. Soon, Ethel is contributing to the artwork.

Ethel's family is thrilled.

"Mom hasn't spoken in months or showed any interest in anything," her son says. "Painting allows her to express herself."

Exploring Interests and Building Relationships

Creating relationships and having permission to form close bonds is satisfying for All Trust's care team, clients, and families.

"We all seek connection," Kuhn says.

Often dementia is cast as a disease, disability, and death sentence. Kuhn's grandfather lived with dementia and he understands the joys and challenges of the journey.

"There is loss, changes and sadness," he says.

"But care partners can reframe the experience, grow from it, and connect with loved ones in ways that would have not been possible without dementia."

He envisions a world where people living with dementia are actively engaged in meaningful arts and activities throughout their lives, so there are possibilities for joy everyday.

Deborah Shouse

DementiaJourney.org

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Learning New Skills with Dementia and the Advantages They Bring



On the 31st July 2014 I was given the devastating diagnosis of Young Onset Dementia. I was 58, otherwise healthy and working full time in the NHS. Although it was truly shocking to hear such news, it was also, bizarrely, a relief.

A diagnosis of dementia was a bummer of a diagnosis but at least it was an explanation and I could now move on.

People often ask me 'what's it like'? Well every day is different. You have good days and bad. Most of my days at present are fair to middling but on bad days, it's like a fog descends on the brain and confusion reigns.

During these days I have to work really hard at remembering the day of the week. This feeling I can liken to the process of untangling a necklace. If you're feeling calm, you sit there patiently and untangle the knots one by one which allows you to work out the reality of the day. But on bad days, it's like when you're feeling impatient with the necklace – the more you try and untangle the more knotted it becomes. On these occasions it's hard to make sense of the world around you.

My way of dealing with these moments is to tell

myself it's not me, it's the disease. And the fog will clear eventually. So I'll just sit quietly and wait.

Despite how my life has changed over the past year, I try my best to remain a very positive person. For me a diagnosis means adapting. You can still live positively if you accept that changes need to be made to compensate for the bits of your brain no longer working as they did and continue to adapt as the disease throws up more challenges to solve. I have a monthly calendar that keeps me in order for the future; a weekly calendar on my fridge that tells me what I'm doing each day and alarms going off all day telling me it's time to do things like take medication. For every challenge that dementia throws at me, I try desperately to find a solution or an alternative way. I almost see it as a game and this helps stop depression setting in as happens so often.

I write a daily blog called, *whichmeamitoday* which acts as my memory for all the things I've done. This was the first new skill I learnt soon after diagnosis. My blog has been read all over the world – for me it's simply my memory but it's very humbling to think that others choose to read it. I can type words quicker than I can think and speak them, so when I type it's as though dementia has never entered my world. This was the first new skill I learnt soon after diagnosis.

I was a very private person pre dementia but I was so shocked at the lack of awareness and knowledge of dementia that I'm now prepared to shout from the rooftops at every possible chance that comes my way.....my blog allows me to reach people around the world.

It came about soon after I was diagnosed. I expressed the wish to my daughter one day to record my thoughts and feelings electronically.

Gemma suggested I write a blog. Well her first challenge was to explain the meaning and workings of 'a blog'!

Gemma started me off by creating my web page and writing me instructions and that was where www.whichmeamitoday.wordpress.com was born. It enables me to educate, inform and ramble as well as providing me with a reliable memory of all that I've done, felt and thought.

After that I had the confidence to venture into social media, none of which I'd used before. The world of Twitter was my first challenge as I soon realised that here I could 'meet' people who I wouldn't come across in person. Professors, researchers, people working in the field of dementia, all available to me at the touch of a button.

It has been a wonderful way to influence others and, bizarrely, has been an avenue to gain access to speak at conferences and events all over the country. It's also been a way that the media have contacted me.

Living alone, as I do, it also means I'm never lonely, as I have access to 'virtual friends' whatever time loneliness strikes.

I also now have a Facebook page; I'm less confident in this area, but it's still another new venture.

I suppose my biggest single newly found skill is one of 'adapting'. I often say that a diagnosis of dementia is all about adapting and if you can accept this, it makes living with the diagnosis easier.

Many people are frightened of dementia and back away from it which is very sad. A diagnosis has and will throw many people into a state of deep depression because so little emotional support is offered post diagnosis. Post diagnosis-

tic support is something of a postcode lottery: it is brilliant in a few areas and non-existent in others. I soon found out I lived in a very poor postcode.

We all had a life before dementia – we all had talents pre dementia and many of those talents don't disappear overnight. Our brain is only partly damaged. I can type as though dementia never entered my life simply because that bit of my brain hasn't broken. I can type words quicker than I can think to speak them. I could never speak all these words today if I didn't have them written down. Or maybe I could say all the words but they'd be in the wrong order.

Learning to adapt can help keep some of those talents alive, maybe in a different format, but still using our brains to adapt to a new way of living. Continuing to use our brain is the one thing that helps us to continue for as long as possible.

I recently had to move from what I thought was my forever home in York to a quieter village near Beverley. I used to live near the centre of York and it was very busy and very noisy. I don't know if you're aware but dementia isn't just about memory – so many of our other senses can be affected as well. One of the first to be affected with me was my hearing. In York, the only way emergency vehicles could get through the city is to have their sirens blaring and that physically hurt my ears, so it was vital I moved somewhere quieter. I used to run every other day but I had to give that up as my legs and brain refused to talk to one another so I'd fall over. I had to give up driving. I couldn't turn right as my brain couldn't react quick enough and make decisions quick enough to enable me to make right hand turns. So dementia really isn't just about memory.....

I hadn't appreciated how hard it would be to get

use to a new house when I moved with a new lay out. I have a tiny kitchen but when I moved in it had two doors which confused the hell out of me as I couldn't remember where the doors led to so I would spend ages walking round in circles – my solution was to remove the doors – I can now see exactly where each exit leads without getting confused. I don't see the kitchen cupboards or wardrobes in my bedroom – they just blend into the walls so I just forget there's stuff behind the doors. Many people said I should have see-through cupboards, but not only are these expensive, they are also chaotic to look at because you either have to keep them mega tidy – which was never going to happen – or you can see lots of stuff. My solution was to take a photograph of the contents of the cupboards and wardrobes and stick them on the doors – the photos attract my attention and remind me that they have things inside. Simple yet effective solutions.

I'm not downplaying the enormous struggles we have on a daily basis but what I am saying is there are often solutions that can help and make life easier and calmer.

Which brings me nicely onto the importance of talking – if you don't talk about how you feel and the problems you're having while you're still able to, how can you ensure what happens later, when you can't communicate, is what you want?

You may think it odd for me to describe talking as a new skill, but in this age of rushing about and online computers, we often forget the simple things in life and talking is one of those skills many of us have forgotten how to do.

That's why, soon after the diagnosis and once I'd got my head around how I felt, me and my daughters sat down and wrote my lasting power of attorney – together.

Yes, of course it was difficult, but then it would be strange if we hadn't found it difficult. What it did highlight was the chaos and disagreements that may have ensued if we hadn't talked. My daughters each had their own opinion on what I may or may not have wanted. Imagine the sadness and emotional distress this would have caused if we hadn't TALKED. Imagine the upset and disagreement if we hadn't TALKED..... imagine the falling out if we hadn't TALKED.....imagine the distance it may have put between them if we hadn't TALKED.....imagine the sadness I would have caused in my death that I couldn't put right if we hadn't TALKED.

So now my daughters know my wishes. They know they won't have to make those difficult emotional decisions because those decisions have been made. It's done and dusted and filed away.

It's important for everyone to talk about end of life wishes as dying is the one thing we all have in commonand it would be foolish to leave it to different minded people to decide how you wanted to be treated when you can no longer influence the outcome.....

I also completed my Do Not Resuscitate form with my GP – these are all very difficult conversations to have but once you've had them you can draw a line under it and start getting on with your life.

Public speaking has been another new venture. Frightening at first, I soon realised that people's expectation of what someone with dementia can say is so small that anything I say is a surprise. So now I'm never phased by speaking in public. It allows me to tell it as it is and hopefully inspire others to do the same.

The one piece of advice I'd give to someone

newly diagnosed is, don't be afraid. Fear can bring out the panic and panic does us no good at all. Instead, see it as a challenge, a challenge to live life differently, to embrace the here and now. What does it matter if we forget someone's name? Or get words muddled? In the grand scheme of things it's a relatively minor blunder.

People often ask me if I'm afraid of the future. My simple response is, why be afraid of something over which I have no control. I don't think of the future for that very reason. Instead I enjoy and live in the moment. That way, I won't waste any precious time worrying about something that I can't change.

Wendy Mitchell

www.whichmeamitoday.wordpress.com

Strike a Chord



It was in June 2014 that Wales' first stroke choir 'Strike a Chord' was born, meeting at the White Hut community centre in Cwmbran on Thursday at 12.30pm.

Arts funding organisation, Head4Arts and the Stroke Association collaborated in starting a choir to help stroke survivors with their rehabilitation. The aims of the choir was to improve confidence, quality of life after stroke, increase participation, increase confidence in communication and to form friendships.

I had a call from Head4Arts in October 2014 to say that my name had come up and would I be interested in leading the weekly sessions starting as soon as possible.

If this opportunity had arisen any time in the previous seven years I would have had to decline as my time was occupied in teaching music and looking after my two children. However my youngest, Oskar, had just started full time school and my days were much more flexible, so I agreed.

I felt a little apprehensive as I had trained at the Royal Academy Of Music and the Royal Welsh College Of Music And Drama, predominately as a singer with some piano skills and as a teacher, not as a music therapist. I had no experience of any kind in health care ; I'm very much a performer.

I rang my friend Joy Gravestock, who is a music therapist in Nottinghamshire, and spoke to her for an hour and twenty minutes about what to expect, possible difficulties, what not to do and how to approach it. She finished our conversation by saying, "Ali you're perfect for this."

My first session was fairly nerve wracking. As with any new job there were pre match, first day at school nerves. I'm a performer. I've spent much of my professional life working in and with choirs of different styles and numbers and this was just another one. There were just a handful of stroke survivors present and I let them lead me. I had a few songs that I knew they'd done before and I have a wealth of vocal and breathing exercises from which to draw. The Stroke survivors were tentative at first, there wasn't much eye contact and most of them were very quiet.

There were only five or six singers for the first few weeks and I let them get comfortable with me by letting them set the pace and letting them choose the songs they sang. I could tell that the potential was huge and exciting as this was such a new idea in Wales and gradually word got around and more people started to join. The numbers began to grow and by March 2015 we regularly had 16 singers attending each session. They were enjoying singing and they were beginning to notice a change in themselves. I was getting comments like, "I like being part of the group, a chance to chat with other people" and "my voice has improved and

the tone of my voice is improving" and "my voice has got louder".

On 4th June 2015 we were invited to perform at the All Wales Staff meeting in Tongwynlais. In all my professional days I have never witnessed a standing ovation to last as long as it did. The 47 members of the Stroke Association staff, which were in attendance, were utterly moved by our performance and what the choir meant for the survivors and their life after stroke.

The Arts Council for Wales funded the project for another year and Persimmon Community Champions donated £1,000 to the choir. The choir was flourishing. The emotional response to the choir is astounding. Our reputation began to grow and we were being asked to perform in various venues in the area. This provided a massive boost to the confidence of the stroke survivors and what started as a sing along group was now a disciplined choir.

We held a sell out Christmas Concert in December 2015 which allowed the friends and families of the survivors to hear the progress they had made. Some members of the choir sang solo's for the first time, which is an astonishing achievement in so short a time. We raised £1,342 that night and the emotional response was palpable, many tears of joy were shed.



Then came the Epic Awards. In December the Stroke Association and Head4Arts submitted an application to the voluntary arts' Epic

Awards, as we fitted the bill with perfection. The Epic Awards celebrate voluntary arts groups throughout the whole of the UK and the Republic of Ireland, so a big deal really.

In February 2016 we found out we had been shortlisted for the People's Choice Award. This was an online public vote. Oh my, we all got to work as the closing date was on the 23rd March. I spent day and night contacting not only everyone I knew but everyone I didn't know, a mammoth task. I appeared on BBC Radio Wales with Roy Noble and we were featured on S4C's Heno. Everyone embraced our **cause** and it was a two horse race between us and the 'Dublin Ukulele Collective'. The awards ceremony was held in Cardiff so we couldn't let this one slip to the Dubliners, it needed to go to a Welsh group. I travelled to many Welsh choir rehearsals to plead with their choristers to vote and we were always at the top until Dublin went on Ireland's biggest TV show, the equivalent would have been us going on Ant and Dec and singing with Take That! Their votes soared and they took the lead. My phone packed up as it couldn't handle the pressure of all the calls trying to get through.

After I'd revived it, while visiting a choir in Maesteg, it appeared we'd gone ahead again, but only just. We featured in numerous newspapers in print and online. Notably the Western Mail and Wales Online. This choir is so likeable and worthy that our lead was not to be overtaken. In the dying minutes of the vote, the Ukulele group got hundreds of votes and were seriously catching us. I was having a screaming text conversation with my friend, urging her to keep fighting as she had been a member of the National Youth Choir and the BBC National Chorus of Wales. Her contacts are infinite but she'd done all she could for us.

I stood in my kitchen with my trusty phone and awaited the result. Still furiously texting and tweeting, shamelessly, in an attempt to win this for our most precious choir.



We did it! Briefly, time stood still. We had over 3,000 votes. We won. Fair play to the Dublin Ukulele Collective, what a battle. Never have I felt such overwhelming pride.

This remarkable choir is more than a choir. They teach me every week to be a better person. They are the most inspirational, dignified group of people with whom I have the great pleasure to working with. The Award led to stroke survivor Ness Morley and me travelling to Salford to appear on BBC One breakfast news. This was one of the finest experiences of my life. If I'd known our chaperone from the Epic Awards was paying for the breakfast though, mine would have been considerably larger. Next time.

Ness was articulate, sensible and inspiring as always, as she told the nation how much the choir means to her. She said that having been a music lover all her life, one of the saddest effects of having a stroke was that she had lost the ability to whistle. However, after we had worked together and after rehearsals on breathing and breath placement exercises she could now whistle once more. That's what this choir does. It gives stroke survivors a small part of their lives back. This devastating condition

robs you of your choice. It robs you of your ability to speak, to run, to understand. Strike a Chord Cymru gives you a sense of belonging. To be part of something wonderful and to whistle again.

"I love working with all the choir members and the Stroke Association. It's such an honour to be a part of this project. Singing is so healing and makes us feel happy. Everyone goes away from the sessions smiling after an hour of fun!"

To find out more about the choir please contact Lucy Thomas on 02920 524400 or email info.cymru@stroke.org.uk.

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Alison Shone
Musical Director
Strike a Chord

Book Reviews

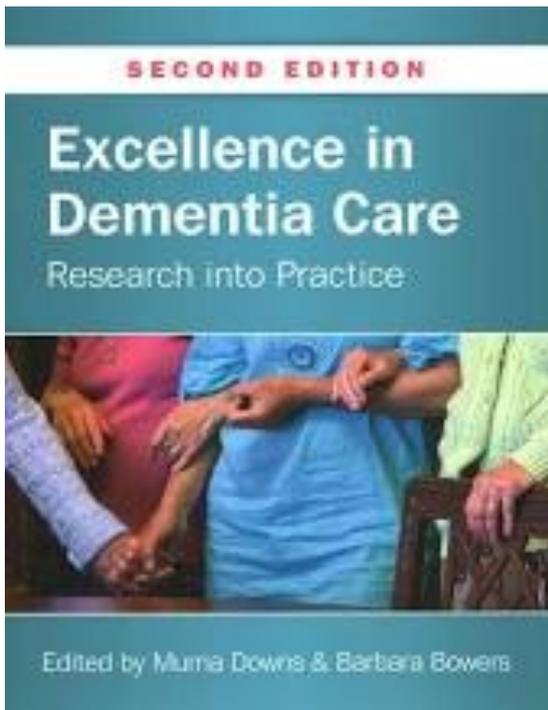
Excellence in Dementia Care: Research into Practice, 2nd Edition

Authors: Murna Downs, Barbara Bowers

Publisher: McGraw-Hill Education (UK)

ISBN: 9780335245338

Price: £37.09



Excellence in Dementia Care: Research into Practice is an excellent textbook for informing those working in the field of dementia about research based best practice and innovations in this area. This is not done in a vacuum but in a cultural and political context. What particularly stands out about this book is that the person with dementia is at the centre and their engagement in developments in policies and services is vital for these to be effective.

The textbook aims “to provide a contemporary and comprehensive overview of research” the goal being to “achieve excellence in dementia care”. With this goal in mind contributors to the book are from a range of disciplines and different countries. Also of importance are the ex-

periences and perspectives of people with dementia and their carers which form part of the contribution.

Excellence in Dementia Care: Research into Practice is divided into five parts. I have to admit that before reading the book I had thought that some of the parts would be more valuable in my role as a clinician than other parts but this has not been the case. It has been helpful and challenging to read about the progress that has been made in the knowledge and approach to dementia but challenging in realizing the work that still needs to be done to change the way people with dementia are viewed and engaged in service development. This is perhaps why some of the research referred to is sometimes contradictory and inconclusive.

As mentioned the book is divided into five parts, below follows a taster of the chapters/ topics relating to dementia care research that form part of this goldmine of a book-
-“The Context of Dementia Care”; covering such topics as “Dementia-friendly communities and Ethics in Dementia Care” (Cathy Henwood and Murna Downs).

-“Conceptualizing Dementia Care”; “A bio-psycho-social approach to dementia”(Steven R. Sabat) stands out with its focus on seeing the person with dementia as more than the effects of the brain damage. The chapter discusses how the psychological and social domains need to be considered too e.g. in how they might impact the way a person with dementia is able to interact with the environment and on his/her ultimately quality of life.

-“Best Practice Dementia Care for the Person”; this includes important areas of research such

as “Understanding and enhancing the relationship between people with dementia and their family carers” (Carol J. Whitlach) . Here the importance of the partnership between the person with dementia, their carers e.g. family and health care professionals is discussed. The partnership is seen as being vital for outcomes which are positive for both the person with dementia and the carer. So the term “care partners” is used to describe the important contribution from the different “partners”.

- “Care Pathways”; chapters include “Whole Person Assessment and Care Planning” (Benjamin Mast), “Acute Care of people with dementia in the general hospital” (Michael L. Malone) as well as chapters on transitions in care, specialist housing and care homes.

-“ Making Sustainable Change Happen in Dementia Care”. In this section Rachael Litherland and Andrea Capstick in “Involving people with dementia in service development and evaluation” warn against the tendency of believing that people with dementia have the same experience- “uniformity of experience”- and describe different ways of truly engaging the person with dementia in the way a need in service is identified and developed. Barbara Bowers’ “A trained and supportive workforce” is also invaluable e.g. if looking at developing a training programme for paid care staff.

The above description is just a taster of the many thought provoking chapters. I found that because I work in the field of learning disabilities the chapters often had a double force particularly when describing stigma, assumptions and labelling that the person sometimes encounters. I described *Excellence in Dementia Care: Research into Practice* earlier as a gold mine (a cliché I know but true). The reader gets to one layer and has the need to dig deeper to discover more e.g. about a particular

intervention, model or approach which has been used with success. Such as example is the SHARE programme: Support, Health, Activities, Resources and Education described by Carol J. Whitlach in her article. This occurred when reading most of the articles. Initially I saw this as a negative and that the authors should have provided more information but on reflection this is the nature of such a textbook and it has the positive effect of encouraging the reader to investigate the subject matter further to see how valid it is and whether it can be applied to his/her own practice. In this respect the textbook is excellent in the number of references following the chapters. There is also the section called Further Information which directs the reader to different organisations and reports related to the chapter’s topic.

The different chapters/articles have a similar helpful format. At the beginning there are the learning objectives and towards the end there is a section entitled debates and controversies in the field followed by the conclusion. There are exercises within the chapter encouraging the reader to assimilate what has just been read and to apply the information. Some of the chapters also have helpful case examples. I think the text exercises would lend themselves to small group learning and the resulting discussions could be used to develop practice which is clearly based on research. There are sometimes similar themes in the chapters which cross over the five parts of this textbook. This is to be expected where the aim is to place the person with dementia at the centre . The feeling of unity in the book in spite of different contributors is further assisted by the authors sometimes referring to the different chapters to develop or emphasise a point. The introduction makes reference to the modular structure of the book and informs the reader that the chapters can be read sequentially or in isolation. I found some of the chapters harder to assimilate than

others possibly because of the content matter but also because of the different styles of writing and also whether the author was based in another country and so referring to different models of provision. However it is also useful to be aware what different governments, organisations are doing in “dealing” with the different aspects of dementia.

To recap I would recommend this book to those working with people with dementia whether it be clinically or in developing services and policies. As the introduction states the book would also be of interest to people with dementia, their family and advocates. It definitely encourages the practitioner to think of his/her own practice and provides the tools to further develop interventions which are research based and person centred.

Denise Harris
Occupational Therapist

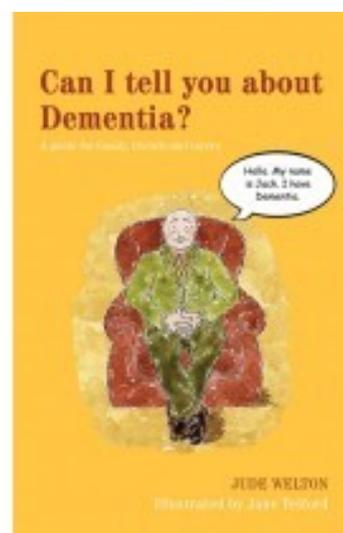
Can I tell you about dementia?

Author: Jude Welton

Publisher: Jessica Kingsley

ISBN: 9781849052979

Price: £8.99



Agreeing to review this book was serendipitous. I was looking for something to give my 17 year old nephew something to read about dementia as he was about to take his first trip to visit his granddad in a care home whose dementia had rapidly progressed. For anyone who is closely involved with someone who has dementia, the journey is unique and challenging.

‘Can I tell you about dementia?’ is written from the perspective of the person with dementia (were they able to explain everything that is happening to them). His name is Jack. This re-enforced the ‘this is me’ approach that can be very helpful when interacting with someone with the illness. The book was very informative in that Jack explored all aspects of the illness and tried to explain effects dementia can have on people not just cognitively but emotionally and psychologically. He gave lots of examples of how behaviour can change as someone’s abilities deteriorate. He also gave many useful tips on how to help someone with dementia and understand how they are feeling. I particularly found the section about activities very well

written as so often people of a certain age with dementia are expected to like Vera Lynn!

However in trying to show the broad spectrum of the effect of dementia I felt the book was very ambitious and jumped continually from the very mildest situation to the worst scenario. I also found some statements challenging. For example 'I don't feel guilt or shame' is supposition. It is impossible to know this. Equally 'losing my memory means I can't make decisions or judgements or think of consequences' is not necessarily true. Many people can be encouraged to make small decisions about what they would like to do and how they would like to be cared for, even in the very final stages of the illness.

From my nephew's perspective, he felt that an explanation of the physical deterioration that happens – weight loss, being ill kempt, even managing cutlery was missing as he found this quite significant when he visited his grandad.

This is a useful book for a brief overview of the effects of dementia but possibly, not the only one someone should read if trying to understand the illness.

Caroline O'Haire

Assistant Director, Frailty Division

About Me



Christine Sampson trained as an Occupational Therapist (OT) at St Loyes School of Occupational Therapy, Exeter, 1970 – 1973. Christine started working for Cardiff and Vale University Health Board (UHB) in February 1974 in adult mental health. In 1980 she returned from a career break of eight years to neurological rehabilitation, moved to substance misuse then on to mental health services for older people and retired at the beginning of May 2017.

Introduction of who you are and what you do.

My name is Christine Sampson and until very recently I was the Head OT/Clinical Lead OT for Mental Health Services Older People, Neuropsychiatry and Forensic Services. Over the last eight years my role has been to manage and provide clinical leadership to three sub teams of Occupational Therapy Mental Health Service. During this time I developed an interest that grew into a passion for initially working with and then improving services for people living with dementia and their carers. Working with the Cardiff and Vale Dementia Champions Network I developed a simple 'At a Glance' Guide to Supporting and Enabling People Living with Dementia. My rationale being to distil an abundance of complex information into accessible form and that, if nothing else if everyone followed these basic guidelines the World would be a better place for people living with dementia.

Dementia is Everybody's Business

'At a Glance' Guide to Supporting and Enabling People Living with Dementia

Improving Confidence ♦ Investing Time to Save Time ♦ Preserving Dignity and Respect

Improving Wellbeing for People Living with Dementia

- ♦ Avoid confrontation and challenge
- ♦ Smile
- ♦ Create calm and quietness
- ♦ Gain eye contact
- ♦ Speak clearly in an uplifting tone
- ♦ Use simple sentences.... avoid 'and', 'but', 'or', etc
- ♦ Ask one question at a time
- ♦ Give one instruction or prompt at a time
- ♦ Give single short pieces of information at a time
- ♦ Wait for a response, take your time and give time
- ♦ Listen for significant words
- ♦ Use simple written communication or pictures
- ♦ Use gesture to communicate e.g. thumbs up
- ♦ Limit cause for embarrassment
- ♦ Support individual choice
- ♦ Use demonstration and repetition
- ♦ Observe and respond to body language e.g. signs of pain, pleasure
- ♦ Do things together, side by side, hand over hand
- ♦ Place objects within the person's sight and reach
- ♦ Empathise and show compassion : through words, facial expression or gesture
- ♦ Collaborate and talk with the person and carers

♦ Think about - Glasses : Teeth : Hearing Aid : Shoes

GIG NHS Cardiff and Vale University Health Board
Butterfly Scheme endorses this guide

Available at:- <http://www.cardiffandvaleuhb.wales.nhs.uk/dementia-at-a-glance>



About Me

Reflecting on your career as an Occupational Therapist what changes have you seen over the years?

There have been so many changes over the past 47 years too many to mention and too many people to credit. 1990s saw the implementation NHS and Community Care Act with the on going expansion of locally based community based services; thankfully paternalistic models are being modified with person/patient centred care gradually becoming core to the ethos of service provision and evidenced based practice and outcomes based treatment the drivers of service delivery.

Mental health services have transitioned from social psychiatry through the medical model and on towards psychological and psychosocial based treatment. The stigma associated with mental health conditions prevails but is slowly reducing. Dementia is receiving greater recognition as a treatable though not yet curable condition rather than an infirmity to be shamed and concealed. People are living longer and the line between adult and older age becoming blurred. Third sector and service users are partners and stakeholders in planning and designing services. We are moving closer to integrated health and social care services. Locally, we have relocated from the run down and oppressive Victorian asylum buildings of Whitchurch Hospital to the bright and airy new buildings at Hafan y Coed and MHSOP Unit Llandough Hospital. Email is becoming the primary mode of communication, electronic patient records are replacing hard copy records and transformational leadership is the growing mode of operation.

I have experienced the growth in professional confidence and role identity of Occupa-

tional Therapy supporting and empowering people to adapt to the challenges of physical and mental health conditions. Adopting evidenced based practice frameworks for practice and service analysis. Embracing the concepts of occupational justice and inclusion to enable independence or supported independence in self-care, productive and leisure occupations. Keeping our heads and person centred practice at the heart of everything we do and utilising the tools of health economics to support practice. One of the delights has been to be in the company of the bright, smart and enthusiastic fresh generation of occupational therapists borne of this professional confidence.

Describe a typical day?

There has been no such day as a typical day. My days have been peppered with a range of professional and multi-disciplinary management and strategy meetings, multi-agency meetings, supervision, managing HR issues, report writing, service improvement and project leadership to name but some and of course the incessant email activity.

My favourite type of day would have been to catch up with my OT Clinical Lead colleague to review the day ahead followed by a lively and interactive supervision session with one of my team leaders or specialist staff, an MDT service improvement planning meeting and a Dementia Champions Network meeting, advocates and 'agitators' for improvements in dementia awareness, treatment and support across the patch.

What do you most enjoy about your role? / What do you most enjoy about your work?

The most enjoyable aspect of my role has been staff supervision. As time has gone on there

has been less opportunity to practice clinically: staff supervision is the next best thing supporting staff to become the best that they can be and to practice in the best way that they are able to. I have been very fortunate to work with fantastic staff who are committed to the continuous process of developing their practice working towards excellence. Over the past year I have had the pleasure of leading a service improvement project to increase meaningful activity for patients on our dementia assessment wards. It has been a joy to work with the three new Occupational Therapy Technicians who we recruited and to witness the growth of their passion and skill in working with people living with dementia and their carers.

One of the most creative, dynamic and joyous multidisciplinary forums that I have worked with has been the MHSOP and Neuropsychiatry Psychological Therapies Management Committee working together to develop in-service and external provider training promoting psychological and psychosocial therapy and psychologically minded services for both older people experiencing mental health conditions and /or dementia.

In summary the aspect that I have enjoyed most about my work is productive dialogue that brings about positive action and service improvement.

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

It goes without saying that the greatest challenges to the NHS are and will continue to be to deliver high quality truly person centred services in the face of financial and Political uncertainty. The ever increasing costs and possibilities as a result of advances in medical knowledge, medicines and technology challenge health providers to remain true to the original purpose of the NHS to provide health services

to the young, the old and the vulnerable.

Dementia and services for people living with dementia and their carers now receive greater attention and innovations across health and social care, third sector and community than ever before. However there remains much work to do to change attitudes and beliefs towards people living with dementia among service providers and health and social care workers before people living with dementia and their carers can be confident that they will be treated and regarded with dignity and respect in accordance with equality and human rights

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

Some of the most rewarding experiences of my career have been in sharing a joke, a laugh, a smile, a song, a story, a conversation, finding a solution to a problem or being in a moment with people living with dementia. It took a while to learn the art of communication or to learn to speak dementia (see 'At a Glance' Guide). I have learned that to work well with people living with dementia requires a high level of commitment and a high level of skill, creativity, flexibility, a sense of humour and an interest in the person and their life experiences. It requires a willingness to 'listen' to words, behaviour, emotion and nuance. And even more importantly to work well with people living with dementia and their carers requires willingness to listen to and engage with carers, give the person time, to regard and treat the person and carer with dignity and respect, to be kind, generous hearted and non judgmental.

Where would you like to go from here? /

How would you like to see your role developing in the future?

I have already handed the baton over. But on my wish list I would like to see families, friends, neighbours, communities, everyone learning to

speak dementia. I would like to see community and primary services strengthened to enable people to remain in their own homes in familiar environments for as long as to do so serves them well. I would like to see community services extended to hospital at home services to prevent hospital admission, reduce length of stay and minimise disruption and transitions in continuity of living. I would like to see improvements in the quality of dementia care across the range of health care, social care, home care, residential and nursing home care settings. I would like to see parity in the commissioning of services to ensure greater representation of Allied Health Professionals and psychologists in multidisciplinary teams to ensure that people have access to the right treatment, at the right time, in the right place by the right person. I would like to see more primary care services enhanced with the addition of occupational therapists able to provide a range of early and preventative interventions. I would like to see more community networks supporting older people whose mental health and wellbeing has been affected by loss, grief, loneliness, isolation, physical illness, exclusion and ageism. I would like to see an increase in co-productive community initiatives to promote and empower healthy lifestyle choices, physical and mental wellbeing.

As for me.....at the moment I am learning to enjoy everything that there is to do in life other than work.

Christine Sampson
Retired Head of Occupational Therapy

Did you know?

One device that can be helpful for people with dementia is motion sensor lighting. This can help people with Dementia to remain independent in their own home whilst also staying safe. For a lot of family members of individuals with dementia they may worry about falls if their relative gets out of bed at night and tries to walk in a dark room. One way of preventing this issue would be to install motion sensor lighting which will automatically switch on the lights when movement is detected.

There are several types of these available including lamps which switch on when you wave at them and motion sensor pads for under a carpet, which trigger the light to be switched on for a set length of time. These are available from home stores such as B&Q or you can also buy such gadgets from Amazon starting from £10. This can be a great investment for piece of mind and to save an individual with Dementia the distress of having to look for the light switch. It is however important to check when buying these products how long the light stays on for, as with some of such sensors the light is only activated for 1 minute would not be much use if somebody had got up to go

to the toilet in the middle of the night as the light will have switched itself off before their return.



Another useful gadget for a person living with dementia is a medication reminder. This again will help allow them to remain independent for as long as possible whilst still taking care of their health needs. This product will send prompt such as an alarm for the individual to take the right pills at the right time of day. You can get a variety of different medication reminders online at Amazon or a number of other retailers and may be able to pick one up in your local pharmacy. The picture below shows an example of one.



News and Web

Identity and Dementia

Traditionally Dementia has always been associated with the loss of individuality and personality, however, more recently this view has been challenged. Researchers such as Tom Kitwood have argued against this idea. He argued that 'personhood' is entrenched in social relationships. Further research by Pia Kontos explored how even people with severe dementia can still use gestures and actions to enact their identity. Furthermore, material items and everyday objects can be key in helping people with Dementia to retain their identity and keep their sense of personhood. Buse and Twigg (2015) studied the use of clothes as a

means of exploring the life stories of people with dementia, using sensory and material properties to stimulate memories. This research highlighted the importance of keeping personal items such as clothing and their potential as tools for reminiscence and enactment of memories. Their research highlighted how clothes continue to be significant for the identities of people with dementia even in the later stages. It is therefore important for families and careworkers of people with dementia to understand the importance that clothing can have on identity and be sensitive to this when the person with dementia is no longer able to choose their own clothing. It is important to remember that even items of clothing that now have little practical purpose may be important for memories and reminiscence and may be used as tactile cues for reminiscence. Although individuals may not be able to express their identity in the same way, people with dementia often still have a strong sense of clothes which are not 'them' in terms of style, colour, texture etc. For example, a man may be somebody who has always worn a jacket and tie or a lady may love to wear pink. Things like this are still important to consider for a person with dementia and may help to maintain their sense of personhood and wellbeing.

Buse, CE and Twigg, J (2015) Clothing, embodied identity and dementia: maintaining the self through dress. *Age, Culture, Humanities* (2), 2373-5481.

Kitwood T., Bredin K. (1992) Towards a theory of dementia care: Personhood and well-being. *Aging and Society*, 269-287.

Kontos, P. (2004) Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Aging Society*, 829-849.

Healthy Lifestyle and Dementia

The Welsh Government and public health Wales are encouraging people to follow 6

simple steps to reduce their risk of developing dementia. The steps are:

1. be active (physically and socially)
2. Check their health regularly
3. Try new things
4. Say no to smoking
5. Only drink alcohol within the guidelines
6. Watch your weight

Although the most prominent risk factor for developing dementia is age, there is growing research that having a healthy lifestyle can also have a huge impact on your risk of developing cognitive impairments. It's interesting to know that diet can have a large impact on brain function.

An interesting study that I read recently specifically looked at the consumption of Marmite and its impact on brain function. Their findings really highlighted to me the importance of healthy eating. Scientists at the University of York conducted a study which found there is a potential link between eating Marmite and brain activity. The research looked at people in their 20s and the effect of consuming one teaspoon of marmite everyday on the brain's response to visual stimuli. They compared those individuals with a control group who consumed peanut butter. Using electroencephalography (EEG) to record electrical activity in the brain they found those that consumed Marmite had about a 30% reduction in their brain's response. This suggests diet may have a large impact on brain activity. This study does not look at memory specifically and instead tested response to visual stimuli but it does emphasize the significant impact that diet can have on your brain. The research was also conducted on participants in their 20s so it is not possible to make generalizations as to whether eating Marmite could affect your risk of developing dementia. It does however demonstrate that certain aspects of your diet may have a substantial impact on the function of nerve cells in the brain. Eating healthily is therefore an important component of reducing the risk of

developing dementia and keeping your brain working at its best.

Smith, A. K., Wade, A. R. P., Penkman, K. E. H., & Baker, D. H. (2017). *Dietary modulation of cortical excitation and inhibition. Journal of Psychopharmacology, 31(5), 632-637.*



Forget Me Not Café and Support group

Did you know there is a local Cardiff support group for people with memory problems and their carers? This group offers various activities to get involved in including: puzzles, games, books and music, arts and crafts, “a stroll down memory lane” and sing-a-longs. It also offers a cup of tea and a piece of cake whilst having the opportunity to mix with other individuals who are experiencing similar difficulties. The group runs every Tuesday from 2-4pm at St Edward’s Schoolroom (Junction of Blenheim Rd / Westville Road, CF23 5DE). It’s a great opportunity for people with memory problems and their carers to get out in the community and meet new people. The group is also open to people recovering from a stroke or people who feel isolated and vulnerable and offers a friendly and welcoming environment. It is free of charge but a nominal donation of £1 is requested for the refreshments.

For further details, contact Kathie on 02920 495769 or kath@mayer.uk.net.

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.

partners. Contributions can be made in the form of an article, care study, letter, question, announcement, review or other appropriate proposal.

Contributions

All contributions must demonstrate a positive attitude towards this group of people and their care-

Contact Details

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Tel: 02920 715789

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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.

- Mind Clearing: The Key to Mindfulness Mastery, Alice Whieldon
- Dementia: Support for Family and Friends, Dave Pulsford and Rachel Thompson
- Telling Tales about Dementia: Experiences of Caring, Lucy Whitman
- Losing Clive to Younger Onset Dementia: One Family's Story, Helen eaumont
- Can I tell you about Parkinson's Disease, Alan M Hultquist
- People with Dementia Speak Out, Lucy Whitman
- Counselling Older People with Alcohol Problems, Mike Fox and Lesley Wilson
- Spirituality and Personhood in Dementia, Albert Jewell
- Life Story Work with People with Dementia, Polly Kaiser and Ruth Eley

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.