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SIGNPOST

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Signpost is edited by:

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

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Sally Knocker, Dementia Care Matters
www.dementiacarematters.com



What a better way to kick start 2016 than by embracing the eclectic mix of articles this edition of Signpost has for you to savour! Although it is a diverse array of articles, a common thread weaves throughout: the vital

importance - ***'feelings that matter most'***.

Karen Hayes draws us into the creative world of drama and theatre, which enables the person with dementia to have a voice, most importantly, ***a voice that is heard***. She reassuringly emphasises that any interpretation during the exercises is valid; nothing is deemed right or wrong. Communication in all forms is the key to connecting with the individual, and tapping into their personal experience. I urge you to read Karen's description of Phyllis's poignant experience which is so very vivid and real.

This clearly links with Philly Hare's focus on the empowerment and inclusion of people with dementia. It is heartening to read of the blossoming progress and the shift towards ***'the voices of people with dementia being centre stage'***. This brings support and hope. Refreshingly, the 3 ½ year programme showed that it ***is*** possible to engage effectively those at very different/all stages of dementia.

Sally Knocker opens the door for us to the ever growing Butterfly households, and shines light on the positive experiences people with demen-

tia have in such care homes, a marked improvement since 2013. In this brave article we see a dynamic shift in approach, ***where the focus is on 'being with' people, rather than 'doing for'***. I think this reflects a more equal, balanced relationship, based on respect and dignity. It is encouraging that the stark feedback in 2013 led to a positive change in the care culture, therapeutic atmosphere and breaking down the 'them and us' mentality. As the owner of Fairfield puts it; ***'feelings matter most'***. I applaud their willingness to implement change, and the staff, carers and people living in the home have all benefitted. Details are given on how care homes can achieve the **Butterfly Service Status** (page 21).

Similar sentiments are echoed by Luke Tanner. He describes how emotional intelligence can help vulnerable people with dementia with traumatic stress levels. He invites us to understand the heightened negative emotions and biochemical changes underlying stress. *I'm sure it will resonate with many readers, whoever we are!...* We learn of normal 'self-regulation' and coping mechanisms, *but what happens if you have dementia?* Please read Luke's insightful words on how to meet their attachment needs and the 'Being a Star' training. This echoes the continuing belief ***'that feelings matter most in dementia care'***.

Dr Christina Maciejewski has been an invaluable asset to this journal for many years, and of course in her work in Cardiff since she gained her clinical psychology post there 18 years ago. Throughout nearly 2 decades, she has been instrumental in bringing about changes for people with Young Onset Dementia and their carers'. Her description of the sparse provision for such people with complex needs years ago, has vastly changed. She provides a revealing insight into the now blossoming, multidisciplinary team approach for people with Young onset De-

mentia and their families. She has helped develop a growing, appropriately tailored service to meet their individual challenges, aided along the journey, by the Alzheimer's Society and funding from the Welsh Government following the National Dementia Vision in 2011. There are still challenges ahead, as in all areas of dementia care, but Christina aims to audit the work of the Young Onset Dementia Multidisciplinary Team approach – **so keep tuned into Signpost where the outcomes may be shared....!**

Join me in 'getting to know' Dr Carolein Lamers and her expertise in her field, and dip into the variety of books that have been very well reviewed. Angharad and Matthew keep us up to date with current news on relevant topics we can all learn more about.

As always, the individuals with dementia have the most powerful and revealing voices. The best way to end my editorial is to urge you to read what they have shared throughout this edition. Phyllis's poignant pointers, Peter's powerful prose and the farmers at Fairfield's warm hospitality!

'It is how you make people feel. This is what is important' : this is true for each and every one of us; whoever we are.

Dr Rachel Brewer

Specialty Doctor

Cardiff Memory Team

Cardiff and Vale UHB

Theatricality, a training tool....



Karen has published two anthologies of dementia specific poetry *Only Just Orchid* and *The edges of Everywhere*.

She was a dementia consultant for Collective Encounters Theatre in Liverpool and Poet in Residence for

Sensory Trust's environment and dementia project in Cornwall.

She has recently finished working on *Inner Skin*, an installation with women at risk of dementia within the Chinese Community in Bristol with visual artist Barbara Disney. She was librettist and stage director for WNO's dementia-based devised opera film *I Had an Angel*.

In 2013, she was commissioned by Mindsong to write a dementia-based community opera *The Bargee's Wife* and song cycle *I can hear you waiting* for the 3 Choirs Festival. She is currently working on a dementia-specific project focusing on Shakespeare's King Lear.

Theatricality as a training tool for working with people who have Dementia.

I am very often asked what I consider to be the rule for working with people with dementia. To be honest I don't really have any hard and fast rules as I find that flexibility on a person to person basis is the approach that works best for me. However, as a guiding principle I tend to suggest a working method which I was taught as a young performer developing improvisational skills. That

principle was Accept and Build which, in a stage performance context means, accept whatever creative offer is made and work with it.

Imagine a rehearsal room in which there are two performers, without script or direction to guide them and with neither props nor scenery, groping blindly to establish recognizable order. Their task in this empty room is to create a world which is both believable and immersive and in which each can develop an understanding of their own identity and their relationship to each other as it exists in that moment. It is a task which demands trust, imagination and courage. It is also a partnership and thus requires complicity. Both partners must agree, on the floor and usually in the presence of watchers, that this world in which they are collaborative co-creators, has the capacity to offer an infinite potential for surprise and will yield its secrets most willingly if they can explore it together. One actor grasps the arm of the other and points to a folded jumper on the floor, slowly bending to pick it up. "This baby's heavy", she says mournfully. The second actor's response at this point is crucial. If she were to say "That is not a baby, it's just your cardigan", then the illusion would evaporate; the creative impulse is frustrated and the story is closed down. In a theatre context the audience lose interest in the discredited scenario and wait for the next offer. In some cases they may even leave the auditorium, feeling that the business of stagecraft is rather cheap and based on a tawdry make-believe. If, on the other hand the second actor were to accept and build on the offer he might have said, "she must be", or "shall I take her for a bit?", "Is she yours?" or even just "Aaahh, she's gorgeous". This would have enabled the creative impulse, redolent in that original premise, to flow and, in that moment of acceptance, actors and audience would have taken the first step in the crafting and reception of a scenario. The empathy which allows the second actor to accept the offer enables the scene to grow and means that the characters can relate to each other. Complicity has been established.

When I first met Phyllis it was exactly this dramatic offer which was made. She was making a slow, careful journey along the corridors and through the public rooms of the residential wing of the care home she lived in, her shoulder rubbing along the paintwork as she listed slightly to the left. In her arms she carried an untidy bundle of clothes which she plucked and petted occasionally. She and I made a few circuits together and that was the moment she confided to me how heavy the baby was. It did not appear to have a name but Phyllis was adamant about its needs and her responsibilities toward it. The nursing staff addressed her with a sort of affectionate derision, "She's still dragging that baby around" they said, "she must smell a bit by now Phil". In the stage scenario this might have been a legitimate enough return and could have prompted any number of dramatic responses. However, Phyllis wasn't an actor, this was not a made up scenario but rather a genuine and present experience and the loss of confidence in her, when others doubted its validity, was immediate. She clammed up and instead of her former flow of description and feelings she was reduced to an inarticulate and resentful tirade delivered under her breath, a succession of suspicious glares at each staff member she encountered and a weeping refusal to give any of the bundle of clothes in her arms back to their rightful owner.

When I work with care staff, artists, volunteers or anyone else wanting to spend time with people with dementia I very often use particular drama games and exercises. The intention is to offer each participant a practical insight into what it is like to feel off-balance, conspicuous, unsure of the rightness of one's own perceptions. These semi-improvisational experiences demonstrate the precarious nature of self-confidence and how easy it is to be made to feel foolish or fearful, particularly in front of others. I try to adapt the experience as we go and to explain the process and its aims, after all most people (even actors) do not respond well to pressured spontaneity. It seems to me however, that by taking the participant out

of the rules of a good-care / bad-care equation and allowing them to experience some of the stress which any staged improvisational situation can foster, they may also gain an insight into the world which a person with dementia might inhabit; what it is like to be put on the spot and how upsetting it can be to find your understanding of the world at odds with other peoples, and how fiercely you might fight to protect what you understand as the truth in the teeth of other peoples' denial.

This is the short poem which I put together using Phyllis' own words as we walked the circuit of the unit.

You Take the Baby.

She's a handful, this baby,
She has no name,
She's not mine.

There's only the last bit to go
And my back is bloody,
Oh it has been poor
For such a long time.

Look, I cannot dress her,
I have to go round and round,
It is only forty or fifty miles.
I have been walking
For nearly twenty years.
My back it breaks,
But I am looking for someone,
To see if they've moved.
I think I've been here before
But that is life.

I've got to get back.
You take the baby,
I cannot disturb her.
Don't listen,
I want to go home.

I have a favorite game which I very often use to 'train' participants who want to work amongst

people living with dementia. Again this is a game which I was introduced to as a young actor and is memorable because of its utter simplicity. Two people stand slightly closer than is comfortable, facing each other and their instruction is to make and maintain eye contact while moving silently around the room. The game works best when there is a clearly defined central performance space and when the rest of the group is spread around the edges of the space as onlookers. Of course it is that very theatricality which gives the activity its frightening aspect. There are actors and there are watchers and something is going to happen but neither group knows what that something is or what form it will take and there are almost no instructions. Move around the room and do not break eye contact. Occasionally, as the game runner I will throw in an instruction or at least a suggestion, usually encouraging the pair to experiment with the distance between them, their respective speeds, stillness, height difference or perspective but still the instruction remains the same, keep moving but do not look away. I usually let the scenario run for a few minutes until I can see that the performers are either out of steam or beginning to coast. I encourage them to bring their encounter to a natural end by mutual agreement but with no overt signal. They just have to feel that it is over. Applause and feedback are the performers' natural element and I lead that applause, making it clear to the watchers that this is what is expected. I ask questions of the performing pair, along the lines of how did it feel, what did you think was happening? There is a reason for this as both their experience as protagonists and the audience reaction are an important part of the process. The two people in the spotlight have been on an adventure together, complicit in each others experience but not necessarily agreed upon what that experience was. They need to be congratulated on their courage and for their journey to be acknowledged, and to agree that the intensity that each had experienced in those few uncertain moments had been shared by the other. The audience are asked similar questions and for similar reasons. Most

feel that they have witnessed something rather marvelous but feel shy of admitting what they thought they saw or how they interpreted it. Again, it needs to be acknowledged that the audience work hard to interpret the spectacle and yet they cannot be certain that they experienced the same thing or whether they interpreted it correctly. My role is to reassure and to feedback. Any interpretation is justified, nothing is wrong or right, most reactions to the performance are overlapping and the critiques mirror each other. The audience feels justified in its interpretation and performers feel they did a good job. Everybody communicated and parallel individual interpretations are all valid.

I don't want to labour the point but it is clear that every time this game is played out in front of me. That there is a metaphorical, as well as, an actual experience to be talked about here. A person with dementia, when asked to communicate verbally, often feels wrong-footed and becomes hesitant or tongue-tied. In a similar way, most people feel at the very least self conscious when asked to perform a non-verbal or physical exercise. We are word reliant and feel embarrassed about our instinctive physicality on show, feel that we are being judged and are found wanting, we feel that our human self is so exposed, with all its vulnerabilities on the outside and no opportunity to hide behind a pre-learned routine. This is improvisation at its most basic and it is also a demonstration of what it is like to be adrift, with no markers or guidance, dependent on somebody else and in the full glare of the spotlight. As an actor I often experienced, before a show was due to open, anxious dreams where I was naked, or had turned up to the wrong gig and now had to go on stage not knowing any of the lines, or in the wrong costume, or even with a musical instrument which I had never played before. It is a profoundly terrifying dream. That feeling, replicated in the expressions on the faces of the two performers in the room in this game as they try and understand that there really is no other instruction than the one they thought they heard, is the same

expression which I often see on the face of the person with dementia when asked for an opinion or to name something, or to choose what they would like to eat from the array of choices in front of them. The two performers generally report that the experience of being in such close and permanent eye contact with each other feels very intense although not, oddly enough, uncomfortable. They report how intimate it feels to be so observed and held by the gaze of a partner, how trusted and trusting they need to be, how quickly they adapted to each new movement or gesture. How fluid they felt physically. This sense of fluidity and trust is, in actors' terms, a complicity which allows the performance world to float above the ordinary world and to be unquestioningly accepted by performers and audience alike.

For the watchers, ranged around the walls there is often a similar feeling of dismay around how each one should be interpreting what is happening, whether what they thought they saw was right or somehow an embarrassing aberration from the truth which will only expose their own lack of empathy and understanding. Again my job is to reassure. There is no right or wrong because there was no instruction and thus nothing to be accomplished other than two people moving around a room whilst looking each other in the eye. I always rather enjoy this moment when, like a conjuror opening all the trick drawers and pockets to prove that they're empty, I repeat that the stories that they thought they read into those spontaneous movements and gestures are real because that is what they saw and that other peoples' observations, though different, are no less real. There can be multiple truths occurring simultaneously and all of them equally valid. Mostly the stories that the audience tell are to do with the emerging stage relationship and the way that power or control seems to stretch and shrink between them. One person moving forward while the other moves backward seems to indicate that one is pushing or pulling while the other is following or beckoning. Who is the stronger? Who started it? We start to imagine a relationship, a

scenario, a meaning. We create stories and they flow and merge into each other. The point is that communication is fluid and physical gesture is eloquent and eye contact is compelling. All three qualities are present in our everyday communications but, mirroring the added potency which occurs in a theatrical setting and with the intensity of the non-verbal element added to the mix, our everyday encounters with people with dementia also depend on an awareness of those qualities being uppermost in our minds. We must be open and create the conditions for complicity and for flowing communication on physical, gestural and every other plain. In other words we must forget ourselves and our rightness or wrongness and be engaged in and enjoy being part of the performance.

There are many other games which I play with participants to demonstrate not only how it might feel to be asked to do things you feel that you cannot do or to be put on the spot, but also to emphasize the metaphor of performance as a key to understanding how to navigate through the pitfalls of communication and how to access a kind of empathy when engaging with somebody with dementia.

The final link in this chain of connections is that of the poet as performer. When I share my methods and process relating to poetry created with people with dementia I try to be clear that one of the key things to focus on is yourself as a conduit, a mouthpiece, if you like. You are the one who is likely to be reading these pieces aloud, not only to the author themselves but very often to family members and carers, and even to wider audiences and possibly from a stage with lights and microphones and all the other paraphernalia of performance. Each poet has their own way of performing these poems and I feel strongly that the poet's own voice is authentic in whichever way it presents itself. However, there is another element to the performance of dementia-specific poetry and that is that it cannot forget either its originator or its own humanity.

When I first stepped out to read some of the pieces that I had put together as part of my very first poetry residency, I was often told that the ones audience members liked best were the really mad ones. Often pieces were judged to be poorer because they weren't mad enough. This reaction conjured visions of Sunday visits to Bedlam and I concentrated more and more on the reality and intimacy of the speaker's delivery rather than the outlandishness of vocabulary. Subsequently I was also told once or twice that a particular poem had worked because the listener could hear that person's real voice and picture their expression through the delivery. I think that this is quite a crucial aspect of this work. I, as the poet, know the speaker personally; I was with them when they said these words, I remember clearly what the room looked like, what chairs we were sitting in, how they inflected their speech, what the rhythms and phrasing were like, how their breathing was controlled, what emphasis came where.

I am not suggesting that I as poet should try to impersonate the speaker or to produce a character study in the way that an actor might. However I know that when I read a particular person's words I am most definitely involved in an act of heightened communication and that these lines have a theatrical resonance to them which need to be reflected in the delivery and that the authenticity of the reception of the poem by each member of the audience depends on my ability to focus on the original speaker and to allow them to communicate through my performance of their words.

I wouldn't presume to offer an acting lesson, or expect a poet to deliver an acting performance. However, the basic principles of communication and trust which the previous exercises are designed to demonstrate also apply here.

An audience will be moved by the truthfulness implicit in my invitation to share an experience. Thus, when I choose what poems to read, I try to

put together a program which, like a theatrical performance, will challenge the obvious assumptions about dementia; that offers changes of speed and dynamic, that provides a range of truthful experiences and reflects as many individual voices as possible and that offers the audience a relationship with the owners of those voices.

People often say to me that you should make a play out of all those different characters. What they mean, I think, is that they hadn't realised until they were introduced to a whole range of voices during a reading, that every person with dementia is an individual with a life and a history and with perfections and imperfections, with hopes and despairs and, most important of all, with an original, singular voice. My role, as the poet in this performance context, is to let that voice be heard.

Karen Hayes



Philly Hare is a Programme Manager at Joseph Rowntree Foundation. She is currently overseeing the final year of JRF's *Dementia without Walls* programme. Through 2016 she will be on secondment with Innovations in

Dementia.

Philly's particular interests are the empowerment and inclusion of people with dementia, and the application of research evidence to practice.

Philly has a first degree in English and Philosophy (Exeter University) and an MSc in Applied Social Studies (Oxford University). As a qualified social worker, Philly has experience within the NHS, Local Authorities and the voluntary sector in many areas of adult social care. In the 1990s, she managed the Scarborough/Ryedale Kings Fund Carers Project and later set up the Princess Royal Trust Carers Resource. She spent five years as Senior Researcher with the independent consultancy, Acton Shapiro, prior to joining JRF in April 2006.

She is currently an Exchange Fellow at the University of Edinburgh, an Advisor to the Life Changes Trust, and a member of the Prime Minister's Challenge Champions Group for Dementia-friendly Communities.

Dementia without Walls:

My reflections on a programme with people with dementia at its heart

Deciding on a focus

JRF's major programme of work 'Dementia without Walls' officially started in June 2012 – following a year or so of scoping, talking, round tables, visits, reading and thinking. During that period we worked hard to identify areas in the field to which JRF – as a relatively small funder – could bring real practical added value. In line with our aspirations for a society which has adjusted well to ageing, we wanted to be part of a wider movement that makes the UK a good place for those of us with dementia to live, and live well. We wanted to help ensure that people living with dementia are *more understood, more heard, more included, more connected and more supported* – with and by each other, their local communities and society as a whole. We wanted this programme to be about investing in action, learning and empowerment (regionally and nationally), and also about 'being the change we want to see in the world'. It was agreed that the core questions we wanted to explore, through action and research, were:

- How does **society** as a whole need to change to support the growing numbers, diversity and aspirations of people affected by dementia?
- How can our **local communities** change to be better places for people with dementia to live well?
- How can **our own organisation** be part of this societal shift, and part of making York a dementia-friendly city?
- How can people with dementia better **connect with and support** each other, so their experiences can shape policy, practice and attitudes?

The proposed programme related directly to our operational activities, offering a great opportunity for joint work across JRF and JRHT (our housing trust). A growing proportion of JRHT's residents (in care homes, extra care schemes, sheltered housing, adult services and our general housing stock) are and will be affected by dementia, bringing challenges for them and their families, as well as for our staff. Many staff will also be affected by dementia in their personal lives.

In terms of both focus and timeliness, the programme also fitted absolutely with the strategic goals of national strategies across the UK on dementia, national and regional alliances for action on dementia, the Prime Minister's Challenge and the Alzheimer's Society (leading on the PM challenge).

Over the subsequent 3 ½ years of the programme, we have forged many creative partnerships, commissioned numerous projects, published reports and papers, produced films, and worked hard to engage meaningfully with people with dementia. There are still more publications to come out, but with only a few months left, this feels like a good time for me as Programme Manager to take stock! So what have we learnt and what have we achieved?

Taking stock: the DEEP network

For me the key thing without a doubt has been the central importance of involving people with dementia – not in a tokenistic, consultative way, but right at the heart of the programme, in full collaboration.

One of our major achievements has been the establishment and growth of DEEP. A scoping study in 2011 had mapped the groups and projects involving people with dementia across the UK and explored what they needed to support the further development of their work. Twelve groups (and four time-limited projects) across

the UK were identified. They agreed that they would like opportunities to network and connect together, share ideas and sometimes work collectively on national dementia issues. Out of this the DEEP network was born - managed by Innovations in Dementia in partnership with the Mental Health Foundation, and funded by JRF and Comic Relief. At the time of writing (late 2015) there are over 60 involvement groups that are part of the DEEP network, translating as at least 1000 voices of people with dementia. DEEP provides the network and essential support:

- Building connections between groups, mapping interests and skills
- Brokering national opportunities for people with dementia to be involved and influential
- Collating and developing good practice about involvement groups or involvement approaches
- Being a central repository of the work, ideas and solutions of groups and keeping groups updated about each others work
- Funding local groups and initiatives who have ideas about increasing the involvement of people with dementia
- Setting expectations about how others will engage with and involve people with dementia effectively and supportively

People with dementia are gathering strength in numbers by making connections through DEEP. Through engagement and empowerment, shared working, a range of involvement opportunities, and organisations and professionals who are willing to shift the balance of power, the voices of people with dementia are beginning to take centre stage, alongside those of their carers. The mechanisms and momentum are now in place for a strong user movement of people with dementia.

Taking stock: JRF/JRHT

In our internal work to become a dementia friendly organisation, involving people with dementia and others directly affected by dementia in the process of change has been key. People with dementia and carers have been actively involved in several projects across JRF & JRHT including:

- Advising JRF's York Committee on its community grant giving to dementia focussed projects;
- Involvement in writing the brief for, and in the selection and training of, a film production company commissioned by JRF to make a series of films about life with dementia;
- Providing their perspectives on how to improve the Folk Hall during a refurbishment programme;
- Visiting the Homestead Park to give their views;
- Auditing the Pavilion, JRF's meeting facilities in York.

Involving people with a range of needs and abilities has helped show it is possible to engage those at different stages of dementia, so long as consideration is given to how they can best contribute and what support mechanisms need to be in place (e.g. physically walking round the Folk Hall as well as asking questions). These have also provided more informal opportunities for staff to mix with people with dementia, which have served to increase awareness and challenge attitudes. The value of involving people with dementia as a means of changing people's attitudes and shifting organisational culture should not be underestimated.

As shown in our independent evaluation, JRF's approach to involvement of people with dementia has been seen as valuable by external stakeholders, and feedback from people with

dementia and their carers who have been involved in the work has also been very positive:

"I'm so grateful for that [involvement with JRF] ...allowing you guys to get some real, real insight into what it's all about...for real people... because that is important. ...it's helped an awful lot. You giving me the opportunity to give you what I know about it and how it feels...it takes me back to that stage when I was in work...and was useful. "

(Peter Jones, person living with dementia)

Taking stock: involvement in the wider programme

In the wider programme, people with dementia have been involved in all sorts of ways – not only as 'research subjects' but also as co-researchers, writers, co-chairs or members of advisory groups, bloggers, advisors, storytellers, media spokespeople, presenters at events, film stars, and activists. Women who have dementia have been central in our project 'Dementia: through women's eyes' and in <http://www.dementiawomen.org.uk/>. People with dementia have helped to tease out the issues relating to disability rights and dementia and to truth and meaning in dementia. They have co-written accessible reports and resources, and have commented at every stage on the involvement of people with dementia. And they have made important links with other people with dementia from all around the world.

In the dementia friendly communities we have supported in York, Bradford and elsewhere, we have learnt that the active, meaningful engagement of people with dementia and their families is fundamental and must be encouraged, resourced and nurtured. JRF's support for DEEP has been a significant driver in enabling people with dementia not only to speak out, but to shape and redefine what they mean by DFCs.

Those who have done so have played an important role in encouraging others to be open about their dementia - a significant step in widening awareness. Both York *Minds & Voices* and Bradford *FIT (Face it Together)* are part of the DEEP network, and they have come together to work on a DEEP guide on involvement in DFCs. The role and focus of both groups is likely to evolve alongside that of the DEEP network, whose members are starting to find a common discourse based on rights. In Bradford, FIT has already been involved in a range of activities, including feeding back on signage and accessibility following a trip to a Country Park near Bingley; advising on St. Luke's Hospital refurbishment; planning the Westfield Shopping Centre; and interviewing for Bradford Community Trust and DAA posts. In York a 'core group' of individuals is involved in many ways in the York Programme; evaluating bids for funding; auditing physical spaces; making or reviewing films; giving media interviews; writing blogs; speaking at conferences and events; participating in further research, such as the work on Women and Dementia led by Innovations in Dementia and the University of York; reflecting on progress and considering gaps which might be filled with new work. Some have achieved national influence. Wendy Mitchell's blog 'Which Me am I Today?' is well-known and she has recently appeared on the BBC 2's Victoria Derbyshire programme. The short JRF film of Peter and Avril Jones in Haxby has been nationally and internationally applauded, as has the film and blog about young Annie and her nana Liz.

Reflections

There are of course acknowledged challenges in involving a range of people so that key players are not too heavily relied on or seen as the 'usual suspects'. It has not been easy to make wider connections with people with dementia,

especially those who live alone or are from different ethnic or sexuality groups. It remains a challenge to engage people in actual projects and activities. Small newly funded projects find it hard to go 'cold' into the community, needing time to establish relationships and connect into existing networks and individuals. More consistent use of 'social prescribing' by health staff could do much to encourage involvement in these projects.

Nevertheless the progress made in and through the programme- with the help of all our programme partners – has been, I believe, significant. We have tried very hard to practice what we preach and to hear the voice of people with dementia loud and clear in all our work. Although our programme is coming to an end, we are delighted that funding for DEEP has been secured for at least the next four years, that we have a bespoke new website and that many of the projects we have supported will continue.

Please visit www.dementiawithoutwalls.org.uk to find all our reports and other programme outputs.

Philly Hare

Policy and Research Manager: 'Dementia without Walls'

Joseph Rowntree Foundation

Follow me on Twitter @philly_hare

Joseph Rowntree Foundation (JRF) works for

social change in the UK by researching the root causes of social problems and developing solutions. Joseph Rowntree Housing Trust (JRHT) provides housing, care homes, retirement and supported housing. Together they use evidence and practical experience of developing housing and care services to influence policy, practice and public debate. The two organisations jointly employ around 770 staff.

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- https://www.youtube.com/watch?v=Ab9eKFb_tD8
- Funding by JRF, Comic Relief and Life Changes Trust
- www.dementiawithoutwalls.org.uk



Sally Knocker has worked in the field of dementia care for thirty years with a specialist interest in activity and occupation. She has been a lead tutor on Dementia Care Matters University Recognised one-year course 'Person Centred Dementia Care' in Cardiff and has project managed Butterfly Projects in Wales, England and Ireland.

Sally believes passionately that in an ideal world people *working* in a care home will be sitting down **more** and people *living with a dementia* will be sitting down **less**. Sally is the author of the latest in the Dementia Care Matters series, published with Hawker Publications, 'Loving, the Essence of Being a Butterfly in Dementia Care.'

The Fairfield Family

"It's first class – second to none. When I was down, they were there for me. They are there for everybody. That IS care."

Brenda, living at Fairfield

From the moment you walk through the door at Fairfield Nursing Home in Drimoleague in the West of Ireland, you can feel the love of a real home. There is a genuine sense of people living and working in the home sharing the day and that what matters most is that **everybody**

has moments throughout the day when they feel special.



It was an absolute pleasure and privilege to watch an amazing team creating magic

for people and demonstrating all the best elements of the Dementia Care Matters Butterfly Household model in action when I visited in March this year.

In this article we will share what are the key ingredients of success, which Fairfield Nursing Home has put into practice and made a reality in the last two years. There are a number of homes throughout Wales which have also been on a similar journey to join the growing group of Butterfly Households, as well as new projects starting in Australia and Canada.

Background to Fairfield Nursing Home

Fairfield Nursing Home is a home for 49 people. Fairfield Nursing home completed a 12 month culture change "Butterfly Project" with Dementia Care Matters in January 2014 and achieved our Butterfly Home award with a 'Level 2' outcome in February 2014 which was a significant achievement.

A year later, after another day-long observation, they went one step further to gain the highest 'Level 1' outcome. They are only the second home in Ireland to achieve this and currently only 5% of homes in the United Kingdom have reached this level.

On the day of the observation, the consultant carrying out the audit spent the whole day (5 ½

hours) in the lounges looking in detail at the lived experience of people living at Fairfield and at the quality of interactions. On this day in March, the majority of people in the communal areas were receiving positive social care or positive personal care experiences for a re-



markable 77% of the time. This represents a huge shift from their original observation in January 2013 when only 28% of the time was in positive experiences. The

frightening reality in the majority of the observational audits which Dementia Care Matters conducts in the UK and Ireland is that 70% of the day is usually spent in what we describe as 'neutral care', where people are bored and sleepy and tasks are being carried out with little or no social interaction.

The Dementia Care Matters approach

Dementia Care Matters works in partnership with a care home during the culture change process with an initial observational baseline audit as the starting point followed by monthly consultancy visits, 8 one-day training workshops for the team and 6 leadership development days. In all our work, there is a central focus on more 'BEING with' and less 'DOING for' people and this requires a huge shift in approach for many care homes where both nurses and carers are used to being very task focused.

What was life like at Fairfield before the culture change process began?

In January 2013 the observational audit carried out by Dementia Care Matters revealed a very common picture which we see in the majority of homes in the United Kingdom and Ireland; 'the lived experience of residents observed on the day was characterised by high levels of boredom, lethargy and some isolation. Incidences of "controlling care" were recorded as high with a culture of staff talking over people living here i.e. talking about them rather than to them or including them and also staff talking repeatedly about task, breaks and what they will be doing next.'

The Dementia Care Matters auditor noted that whilst it was evident that staff members were very warm and caring to people living in the home, there were some dominant features in the care culture:

- A strong predominant nursing culture of care. The home looks and feels like a hospital rather than a home.
- Staff are observed to be very task orientated almost passing people by as if they were superfluous to the tasks.
- Long periods of 'neutral' care exist – high levels of boredom, lethargy, and staring into space.
- People are engaged with by staff members who have a role of Activity Co-ordinator whilst other staff fade into the background and do not demonstrate that they even notice people who are left for long periods.
- Some attempts have been made to introduce rummage boxes and visual murals in corridors but this is largely 'wallpaper' and not part of the staffs repertoire in occupying people.
- All staff are dressed in uniform emphasising 'us and them' rather than recreating a home

-like atmosphere.

- The lounge is empty in atmosphere and comprises of people sitting around the edge disconnected from being involved in 'living' in the lounge.

(From Dementia Care Matters qualitative observational audit report January 2013)

It can be very hard for the team to take on board this kind of feedback:

"I remember the hostility from quite a few staff to the Butterfly Project especially when I shared the headlines from the audit with staff. People felt that they were being unfairly criticised and



were defensive about facing the truth. It just felt like a massive job at the start, so much boredom, staff stressed and everyone stuck at what to do. The

genuine interest of Sean as the owner was crucial. He was always there pushing things along. I remember times when some of the nurses and care staff became tearful as the sheer scale of it all hit them and the frustrations they were having in bringing people along."

Daren Felgate, Consultant with Dementia Care Matters

The 'secrets' of success in transforming the culture of care at Fairfield

- Creating small 'matched' households full of love and friendship
- Breaking down 'us and them' between

people living and working in the home

- Inspired leadership from nurses and House Leaders
- Valuing life stories and identity
- Developing an engaging, cosy and vibrant environment
- A whole team and whole day approach to activity and occupation

Creating small 'matched' households

When we first visited Fairfield in 2013, there was a real mix of people living together including some without a dementia who were quite independent, those in the moderate stages of dementia who were still very physically active and often seeking out things to do and those in the later experiences of dementia who were also quite physically frail needing nursing care. It has been the experience of Dementia Care Matters that this 'mix' is unhelpful at many levels – it is hard to create an environment that is meaningful for people with such different needs and team members have to adapt their ap-



proach and use completely different skills from moment to moment. People who are

very frail and much quieter often receive less focused attention and those who are more 'able' can be quite unsettled by a person who is calling out or may not understand a person in the later stages of dementia cuddling a doll which they may perceive as childish.

The Fairfield team have worked very hard to develop three distinct houses; Deelish, Dro-musta and Rockmount. The three houses all have an appropriate feel, meeting the needs of

people at different points in their journey and there is outstanding consistency across the whole team in terms of demonstrating the importance of connecting with people. Developing separate households can be a difficult process particularly in terms of explaining the benefits to families who might be concerned if they perceive their relative is being labelled in some way or may be spending the day in a different



lounge. However, the key to success is creating a sense that each house is special in its own way and that happy households bring out the best in everyone. Creating

three teams led by a House Leader means that care staff are able to develop a particularly close relationship with a smaller group of people and also with their colleagues rather than working across the whole home.

Lynda, House Leader of Rockmount, the household for people who don't have a dementia or are in the early experiences, describes 'a wonderful buzz and feel. People living here are busy with chores; the smell of baking will fill the air, the joy of gardening, daily sing songs, laughter and lots of TLC. Rockmount has come to life and it is a pleasure to come to work. Our family show and give so much pleasure in return. People have started living life again to the full and have a real sense of belonging.'

The group living approach makes sense to the people living and working here and is providing a specialist approach for people which is appro-

priate to their experience of dementia and their personality and life experiences. There is laughter, fun and a genuine sense of family together with people living here involved in the everyday life of the home. It is clear that the staff enjoy coming to work and the relaxed 'go with the flow' feel to the day appears natural and comfortable for everyone involved.

As Eileen, the House Leader of Deelish House, the household for people who are in the middle 'stage' of dementia experiencing different realities, says:

'The change is incredible, a complete transformation. No longer are people led by a fixed and regimented timetable, people are living 'their' day 'their' way. We now feel a real sense of family and a deeper understanding of the people we spend our days with. Deelish house has become a relaxed, homely environment full of shared moments and emotional contentment.'

Breaking down 'them and us' divide

One of the first and critical components of change is breaking down the 'them' and 'us' culture between people living and working in a care home. Many care home environments appear to reinforce it as a place of work, rather than a house resembling a family like atmosphere.

It is surprisingly controversial when we ask people to no longer wear uniforms and stop using large trolleys. People working in a care home are quick to point out that some people like staff in uniforms as they can identify them easily. Whilst it is of course possible to be kind and caring in a uniform, it still fundamentally separates people and prevents organisations creating a 'family home' like atmosphere. The other key element of staff wearing their own clothes and accessories at work is that sud-

denly they become individuals and people living with a dementia will often notice the colours and varieties of people's appearance which helps create conversations and connections. The Fairfield team embraced this change after some initial adjustment and it was very quickly evident that they understood the importance of sharing themselves throughout the day.

Inspired leadership from nurses and house leaders

Fairfield has a very motivated and passionate leadership team who grasp what dementia care should look, sound and feel like and who have formed/recruited a very genuine, positive caring staff team who have no evidence of 'controlling care' or staff who appear to be 'in charge' and following a particular regime or routine.

Watching the two lead nurse managers and house leaders at work was particularly inspiring during the observations. They truly led by example, rolling their sleeves up in a totally genuine way, spending time sitting and chatting to people, walking with a man who was constantly on the go; demonstrating to their team that they are there alongside them and not locked away in an office. Whilst they were directing their team throughout the day, it was clear that they have created a sense in team members that anyone can be a 'leader' to initiate an activity or create a moment with an individual.

Claire, the manager, and Mary, the nursing director, describe what it was like for them; *'For the 12 months during the butterfly programme, we dreamed of what our home could become. And during this period we saw people come to life, it was truly amazing. Our home became a bright, airy, colourful lively place to work and live. There were days when we thought that 'it just was not possible;' change is not easy at the best of times! The whole experience has lifted our spirits and motivated us more than words*

could possibly describe. We all feel that this is the future of Fairfield now; there is no going back to a 'task' run day. We are so proud of the staff's commitment to improving the quality of peoples' lives at Fairfield.'

Valuing life stories and identity

There are a group of men living in Fairfield who are farmers and it was heartening to see these men still looking the part in their jackets and with caps on as if they were just about to head out to the fields. During my visit a number of these men, some with quite advanced dementia, recognised me as a visitor to the home and greeted me with quiet gentlemanly warmth asking me if I would like a cup of tea and checking I was doing alright.

This is a significant sign that people living at Fairfield really feel that they are 'at home' and have sufficient wellbeing themselves to want to **look after me**; a refreshing reversal when so often people in care homes are always *receiving* care not giving it!

There is a real sense throughout the home that people's backgrounds are known about and cherished. Individual life story summary profiles have been put on people's doors and fuller life story books and memory boxes are read from and looked at during the day. Team members also frequently share stories and photographs from their own families, for example, Mary, the nurse showed a picture of her young daughter in her Irish dancing costume which prompted some lovely banter "She's better looking than her mother!"

Developing an engaging, cosy and vibrant environment

Another key aspect of culture change is creating an environment that is stimulating for peo-

ple living with a dementia. This requires us to look at things in a different way - a tidy lounge may look neat to people visiting but provides no opportunities or invitations for people to be busy. A book which is open on a table is more likely to be read and two piles of towels, one



folded and the other lying in a mess, will be an obvious call for action to a person living with a dementia to encourage them to finish the job. Staff may be tempted to tidy things if they are not aware of the new approach and so it needs constant reinforcing with the whole team including the housekeepers.

In Fairfield, there is a great range of pictures, objects and colourful items to stimulate interest including sporting memorabilia linked to some of the men's interests, farming images, and kitchenettes invite those who are still able to make themselves a drink, do some washing up etc. In Dromusta, the lounge for people in the later experiences of dementia, there is some specialist equipment such as projector with lights and a bubble tube, but some simple bird feeders outside the windows also provide many joyful moments when various birds are spotted feeding.

Vicky and Catherine, House Leaders on Dromusta explain; *'People are getting the attention and affection they deserve. This is no longer just a job where people are cared for. Our residents are like an extension of our family, staff strive to give love and attention and be in the moment with people. It might be the touch of a*

hand, a whisper of a song or the smell of flowers. This is what brings a smile to peoples' faces and makes it all worthwhile.'

A whole day and whole team approach to occupation and activity

It was great to see that attention to people's individual lives and identities is evident in the choice of things to do with people, rather than just generalised 'activities'. It is also very clear that the whole team see themselves as activity workers and Lynda, the House Leader who was originally the Activities Coordinator in the home did remark on the benefits of this shift.

There was a remarkable range of opportunities for occupation and activity for individuals and groups throughout the day including:

- Baking cakes
- Hair being done (curlers etc.)
- Foot spa and hand massages
- Knitting
- Life stories being shared
- Hats being decorated for Cheltenham
- Chat about the Wales-Ireland Rugby match
- A fashion parade round the home
- Horse names being put up and for the Sweepstake
- Watching the races
- Brass polishing
- Sweeping floors
- Man blowing bubbles
- Washing up
- Walks to visit other houses and out in the garden
- Folding napkins, sorting cutlery
- Newspapers being read
- Singing
- Ball throwing
- A meditation group run by a woman living in the home
- A visit to the Mobile library to choose books

- A few card games which included a visiting husband joining a group of men in the home
- Man (who is a farmer) sorting and fiddling with wool ropes
- Toy farm animals in front of another farmer who is in the later experiences of dementia
- Man lying with feet up listening to own (heavy metal!) music with headsets
- Team sharing stories and photos from home
- Watching birds outside the window
- LOTS OF CHAT – the Irish banter was second to none!

All of these experiences and events were woven into the fabric of the daily life of the home without any sense that they were 'activities' in the formal sense of many activity programmes in some care homes.

The team made the most of a topical event like the Cheltenham races, building up expectation throughout the day, talking about a local jockey who had won the day before, preparing supporter banners, decorating hats, doing a fashion parade round the houses and watching the race itself! This was a really clever way of making the day feel a bit different and special and including a wide range of people in different ways.

Conclusion

This article sets out to share in a simple way some of the key elements of transforming a very hospital-like nursing home environment into a real 'home from home' experience. It must be emphasised it is no mean feat to achieve this. It takes total dedication and determination from the leadership team as well as financial investment from the owner.

This is driven by the belief that older people living in a care home deserve the very best. When watching a day in the life of people living and working at Fairfield, it becomes evident

how rich are the rewards of a whole team who 'gets it' and that it really is possible to find a new 'family' in a care home when all the right ingredients come together.

In all the homes which go on this journey with Dementia Care Matters, it is noteworthy that the starting point is often one owner or one manager with the vision and the bravery to really 'go for it'. Sean Collins who is the owner of Fairfield is one of those owners who took that courageous step and describes very movingly in his own words what that process was like;

'This culture change has been an incredible journey for all the staff and for myself personally. It has absorbed us both physically and emotionally. There were many times over the first year of the transition when we thought we would not make it. We had people in many different stages of dementia with complex conditions and needs. How could we transform their lives? You can't half do emotional care, you can't half make people feel like they matter. We had to accept the truth and accept the reality that what we were doing was not the best way and that there must be another way. We needed to change our attitudes, we needed to accept that even though our residents were well looked after physically and that their clinical needs were met, they spent most of their time bored. Our system and culture revolved around getting tasks completed. Our system rewarded task completion. For example mealtimes were a task to be completed, a schedule based around staff rather than residents. Now mealtimes are a social event enjoyable and relaxing.

We now understand and value what makes people feel alive, we now understand that people must feel like they matter, they must have a purpose. We understand that it is how we make

people feel is what is crucial. It is what we must do everyday. Each and every person in Fairfield has responded incredibly to this challenge.

They have given of themselves emotionally. Staff now share personal stories and this resonates with our residents. They have connected with our residents, there is no longer a 'them and us'- it's a family. Our culture, our ethos, our way of living a full life is about recognizing that 'feelings matter most'. People are in our nursing home to continue living.

Dr David Sheard and his team over 12 months of training has changed us all. They have shown us a better way. They have shown us that by our behaviour with people living in the home, and by concentrating on making people feel better, we can ensure that our residents continue to live full and meaningful lives. We have watched people come alive.

For me personally David Sheard changed my attitude to growing old and changed my belief system. He showed me another way. He made me face the truth, he enlightened me to change our culture within Fairfield. He showed me another way, a way based around people's feelings. Moments in Fairfield now are guided by the realization that, 'It is not what you say, It is not what you do, It is how you make people feel. This is what is important.'

Thank you Sean. We couldn't say it any better than that.

Sally Knocker
Consultant Trainer,
Dementia Care Matters

How the 'Butterfly' care homes get their wings

Care homes hoping to achieve the Butterfly Service status undertake a one- year project that will typically include:

- An initial qualitative observational audit and detailed report
- A launch and management strategy day to scope the year's work
- Twelve days consultancy – one day per month
- A nurse and/or house leader modelling project - six days
- A workshop training programme for 15 participants
- An unannounced Kitemark audit

Elements of the whole programme can also be selected depending on the needs of the organisation. For more information about Dementia Care Matters, visit www.dementiacarematters.com or telephone 01273 242335.

Further Reading

- Knocker, S (2015) Loving the Essence of Being a Butterfly in Dementia Care, Hawker Publications
- Knocker, S (2014) Achieving culture change in dementia care homes: is training the answer?, *The Modern Registered Manager*, Vol 2(1) Jan/Feb 2014.
- Sheard, D M (2013) Implementing person centred theories in dementia care: exploring the Butterfly approach, *The Modern Registered Manager*, Vol 1 (3) May/June 2013.
- Sheard, D M, (2013) Steering culture change matters in dementia care home – Commissioning briefing booklet, Dementia Care Matters. Brighton.
- Sheard, DM, (2012/2013) Mattering : in a dementia care home, Part 1 and Part 2; Dementia Care Matters: Brighton.



Luke is a trainer and consultant for Dementia Care Matters. Luke specialises in training in touch, feeling based communication, attach-

ment and later stage dementia care within Dementia Care Matters Being a Star training and one year University recognised courses. Luke also provides consultancy in culture change processes to care providers across the UK and Ireland in Dementia Care Matters "Butterfly Household" Approach.

Reducing Traumatic Stress.

Understanding attachment and a feeling based approach to dementia care

For 20 years Dementia Care Matters has emphasised that feelings matter most in dementia care. This principle remains at the core of our whole model of care. To some people this principle can sound more like a fluffy sentiment than a philosophical stance. However it is based upon a belief in the central role feelings play in human life. We take feelings so seriously that we evaluate how carers do dementia care, (serving lunch, giving medication, assisting in personal care etc) in terms of how it makes someone feel. Consequentially we believe that emotional intelligence is the key competency in dementia care. This is not simply because we are particularly emotional and sen-

timental people but because people with a dementia are extremely vulnerable to traumatic levels of stress if their feelings are not taken into account. It is universally recognised that a dementia undermines memory, logic and reasoning ("higher" cognitive processes). However a dementia also functions to undermine the "primitive" processes that regulates someones feelings and emotions. Psychologists refer to these processes as "*affect regulation*" and "*self regulation*" as the process by which an individual influences their felt states. In this article, I explain why an impaired capacity to self regulate makes people with a dementia vulnerable to traumatic levels of stress and describe the ways a feelings based approach compensates for this disability.

Understanding Stress and the Role of Affect Regulation

'Stress' is a word used so often in our society that it may have begun to lose some of its impact. People refer to all manner of stresses; the stress of an exam, of moving house, of public talking. When referring to the stresses of life we often talk more about what 'stresses us' out than we do about how we experience and respond to it. However we can learn more about stress if we focus less on the external events and more on the felt states and coping strategies that shape our experience of stress. Consider for a moment a time in your life when you felt stressed. How did you know you were stressed, what do you tend to do when stressed? You may have felt hot, sweaty, noticed that your heart rate increases, your breathing becomes shallower your mind races. Such sensations may have alerted you to your levels of stress. You may have also noticed that you tend to rush around, have difficulties focusing your attention, become irritable, short tempered or aggressive. These behaviours also alert you to your own level of stress. You may

have found yourself being more 'emotional' when stressed, anxious, upset, tearful, fearful, or enraged. These heightened negative emotions may have also helped you to realise that you are stressed. Perhaps, under the sway of these feelings and behaviours, you lost your own self-awareness and only realised how stressed you were when someone else pointed out your behaviour. You may have become visibly agitated, aggressive, withdrawn, emotional, and anxious. In this case you depended upon someone close to you and brave enough to help you recognise your own feelings and needs. Reflecting upon this experience of stress helps us recognise that specific sensations, feelings, behaviours and emotions enable us to identify when we are experiencing a level of stress that is beyond comfortable. Psychologists refer to stress as '*arousal*', and acute level of stress that is beyond tolerable is referred to as '*hyper-arousal*'. In states of hyper-arousal we are likely to experience escalated negative emotions such as fear, panic, anger or anxiety. These heightened emotions increasingly determine our behaviour and even our perception of reality.

The sensations, feelings, emotions and behaviours we experience during times of stress are the result of a multitude of biochemical and physiological changes that function to prepare us for 'fight or flight' responses to a perceived threat. This response is so basic to our survival that it is largely coordinated by the sub cortical or "lower" areas of the brain, such as the brain stem, limbic system and hypothalamus. Perceiving a potential threat the hypothalamus activates the pituitary adrenal glands to engage the *sympathetic nervous system* (a branch of the Autonomic Nervous System) to super-charge the body and mind in preparation for vigorous action, (fight or flight). The biochemical changes that underlie this process create a dispersed response that influences our entire

body-and-mind, alert us to a perceived threat and prepare us to take some form of action. Whilst these basic changes are involuntary and unconscious, the coping strategies we consciously employ to resolve the situation rely upon the "higher" cortical systems of the cerebral cortex. These systems enable us to inhibit some of the aforementioned impulsive behaviours and coordinate our attention, emotion, behaviours and cognition with our conscious intentions and actions. They enable us to organise our actions as well as reason and reflect upon them. Effective responses to stress rely upon the optimum functioning of upper and lower neural systems and the effective interaction between them.

The more differentiated and adaptable our coping mechanisms the more developed our capacity to self regulate. We need not avoid stressful situations for fear of being overwhelmed nor fear that our responses to stress might make a bad situation worse. Normally effective responses to stress involve the body and mind lapsing into rest and relaxation once the threat has past. A complementary branch of the autonomic nervous system, the *para-sympathetic nervous system*, helps to restore us to this resting state by inhibiting sympathetic activity. In healthy functioning the activation of the parasympathetic nervous system follows sympathetic activity to enable us to cope with the stresses and challenges of life without being overwhelmed. Some coping strategies might be more effective than others and depending upon our repertoire of coping mechanisms we are likely to have different strategies for different situations. For example not all acts of self regulation involve reducing stress, sometimes it involves seeking it out and even thriving from it; after all, most people find it uncomfortable to be unoccupied for long periods of time. During such a time you may have noticed that you felt restless, lost in thought, prone to day

dream, lethargic and sleepy. You might have found yourself fidgeting, wandering about, distracted or unmotivated. You may have felt bored, frustrated, flat, sad or low. Sustained periods without sufficient stimulation may have resulted in feelings of depression, low self-worth, even shame. Once again specific sensations, feelings, behaviours and emotions help us to recognise when our internal levels of arousal have fallen beyond what is comfortable to us. 'Hypo-arousal' refers to a state when levels of arousal are chronically low. Having fallen below our threshold of comfort we are normally motivated to take some kind of restorative action. Coping strategies generally involve some kind of work, leisure or domestic activity, anything that keeps us active, occupied and in some way stimulated.

All of the various strategies we might habitually or consciously employ to self regulate, in one way or another, help keep our levels of stress at a comfortable optimum level (see fig.1).

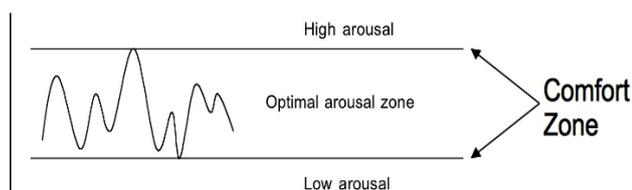


Fig.1

By staying in our comfort zone we avoid difficult feelings and escalated negative emotions. When we are within this comfort zone we tend to feel most relaxed, safe and secure. Our capacity to *self-regulate* therefore provides us with our basic sense of security and well-being. This means that we tend to feel most at home in our comfort zones. Our sense of belonging is often tied to those places within which we enjoy most readily this experience of feeling at home in ourselves. "Homely" environments afford us the opportunities for both comfort/relaxation

and occupation/stimulation that we need to self regulate.

Coping with Stress and the Experience of Dementia

Consider your own response to stress and the degree to which this may be compromised with the onset of a cognitive impairment. A milder cognitive impairment would undermine your ability to effectively employ coping mechanisms, i.e. planning a course of action, adapt it to novel/changing situations and reflecting upon its efficacy. A moderate level of dementia may undermine the cortical functions critical to inhibiting your more impulsive behavioural responses to stress. A more severe cognitive impairment may undermine your ability to identify and interpret your own feelings and needs (insight) and effectively communicate them to others. In the later stages of a dementia, there are very few resources available to either interpret or express affective states. Having a cognitive impairment, however, does not undermine your actual ability to feel the stress or negative emotions. The cognitive impairment associated with a dementia therefore actually impairs someone's capacity to self-regulate. People with a dementia struggle to adopt and adapt new coping strategies to novel situations; they are often reliant on strategies acquired earlier in life that are not fit for present purposes (see fig.2). Sometimes people experiencing uncomfortably low levels of arousal seek out places, activities or people that were a source of stimulation in the past such as their children, school or work. Alternatively someone experiencing higher levels of stress may seek out parental or attachment figures that were a source of comfort in early life.

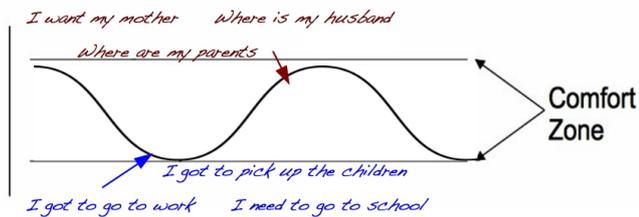


Fig.2

In the latter case psychologists call these “attachment behaviours”, because they are the more primitive coping strategies that we acquire in our early childhood. During these early years the primary means of regulating levels of stress was through interactions with caregivers who offered comfort during times of distress. Infants do not come with ready-made coping strategies that enable them to deal with stress independently of their caregivers. They are however equipped with basic behavioural responses that function to alert a care giver to their distress. Affect regulation in infancy therefore happens in and through care giving interactions that respond to such behaviours. These early experiences of attachment are internalised, (imprinted upon the limbic system) to become attachment styles. These attachment styles are often unconscious patterns of behaviour that are most active during times of stress. Many of the anti-social, aggressive, agitated and repetitive behaviours listed amongst the behavioural and psychological symptoms are identical to the behaviours outlined in the extensive literature on insecure attachment styles (Ainsworth, 1979). For many people with a dementia these impulsive behavioural responses to stress are the only ones available to them. Unfortunately many of these behaviours often alienate carers and relatives because they can be difficult, confusing, shocking and upsetting particularly when observed in adults. However the fact remains that many people with a dementia are just as dependent upon attachment figures for interactive regulation as they were in their infancy and childhood. Consequently if at-

tachment needs are not met in and through care giving interactions people with a dementia are vulnerable to heightened negative emotion and traumatic levels of stress (see fig 3).



Fig.3

Identifying Symptoms of Traumatic Stress

When stress is prolonged and or acute the very mechanisms that are supposed to enable people to cope with the challenges of life can be potentially debilitating. Prolonged stress sustains sympathetic activation suspending the body and mind in a state of readiness for a fight or flight responses. This primes the limbic system to become more sensitive to mild or novel stressors. This means that people are likely to react more strongly to subsequent stressors that are milder in nature. Sustained levels of high stress therefore reduce the threshold of arousal that is tolerable thus functioning to narrow our comfort zone (see fig.4).

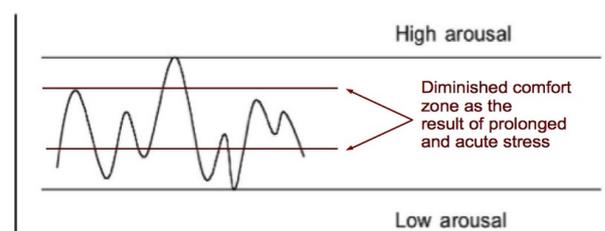


Fig.4

Sustained exposure to acute stress have profound behavioural and psychological implications; irritability, anxiety, aggression, withdrawal, paranoia, delusions, obsessive compulsive behaviours, psychosis, post- traumatic stress and even self harm have all been linked to pro-

longed exposure to this biochemical state (Cozolino, 2002). Furthermore because this state forges a neural highway to the fear circuitry of the brain it limits the participation of cortical regions crucial for memory, reality testing, language and the integration of sensations, emotion, cognition and behaviour (Cozolino, 2002). Experiences of hypo-arousal or hyper-arousal therefore limit someone's capacity to store information, learn, reflect, and develop new coping strategies for novel situations and to make use of these abilities in relationships. The bio-chemicals released in the case of acute stress can inhibit hippocampal functioning to the extent that sensations, emotions, behaviours, images and meaning become dissociated. This means that sensory, motor and emotional aspects of past-traumatic experiences can actually intrude upon the present resulting in traumatic flashbacks. A last resort coping strategy to traumatic levels of stress is dissociation. Dissociation can be characterised as a (hyper??)hypo-aroused state that deals with heightened arousal and emotions by not feeling them. Overwhelmed by stress the body and mind shuts down, numbed by high levels of the biochemical endorphins. Physiologically, endorphins are released when we are injured or stressed. Endorphins act similarly to morphine and reduce the amount of pain we experience when we are hurt. In high levels they have an analgesic effect, dulling emotions, dampening down experience to produce an altered state.

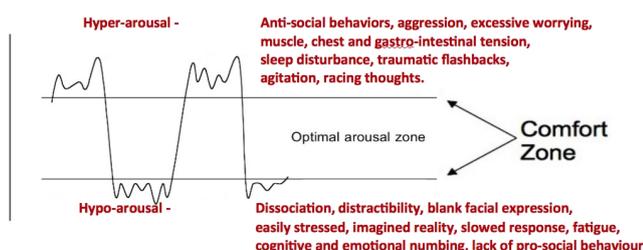


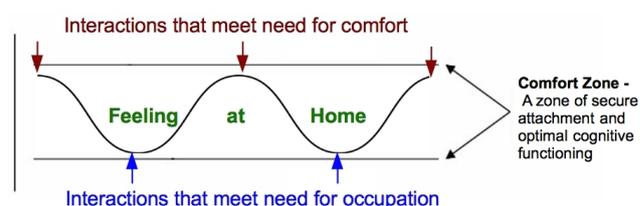
Fig.5

The symptoms of traumatic stress are as diverse as they are profound (See fig.5). These

symptoms are also strikingly similar to many of the most distressing behavioural and psychological symptoms of a dementia. Like symptoms of trauma they arise from physiological states of hyper or hypo-arousal. These behavioural and psychological symptoms therefore indicate a profound need for interactive regulation. They are not an inevitable feature of cognitive impairment but rather a consequence of a care provider's failure to meet someone's basic attachment needs. More often than not they are the result of leaving people with a profound need for interactive regulation isolated and unoccupied for long periods of time throughout the day. This makes someone with a dementia extremely vulnerable to traumatic stress and more reliant on the very behaviours that care givers find most distressing and disruptive.

Enabling Feeling Based Carers

Contemporary attachment theory suggests that to meet attachment needs caregivers must provide adequate experiences of "interactive affect regulation" (Stern: 2000, Schore:2012). Interactive regulation refers to care giving interactions directed towards someone's affective states. Experiences of comforting and stimulating interactions/activities matched to an individual's changing affective state help someone remain in their comfort zone (see fig.6).



These interactions need to be spontaneous responses to individual signals of distress rather than scheduled interventions or activities at set times of the day. These interactions also need to be matched to an individual's level of a dementia. Someone experiencing the earlier

stages of a dementia may be comforted in and through a meaningful conversation or stimulated through participation in a domestic activity such as laying the table or doing the laundry. In contrast someone experiencing the late stages of a dementia may be comforted by gentle touch and physical closeness and stimulated by enlivening sounds such as birdsong or uplifting music i.e. a more sensory intervention. Someone experiencing more moderate stages of a dementia may require a degree of “emotional coaching”. Simply asking someone with moderate stages of a dementia “what’s the matter?” is not enough since they may not have sufficient insight to know what the matter is. In such cases someone’s basic behaviours need to not only be acknowledged, but also elaborated into specific feelings, needs and actions. This helps someone not only become aware of their feelings and needs but also understand them. In identifying and naming a range of feelings someone feeling “bad” may be able to differentiate this basic state into a range of feelings like “irritation”, “disappointment”, “anger”, “annoyance” or “hurt”. This feeling based language is an important element of effective interactive regulation (Gerhard: 2008). Care givers can also help someone to identify their feelings and needs non-verbally by mirroring their facial expressions. This provides an opportunity for someone to see how they feel because it is written on the carer’s face. Exaggerated mirroring of words and gestures can therefore help someone to discover how they feel themselves. Without this “emotional lending a hand” the person is totally lost in a sea of difficult feelings they can neither avoid nor make sense of. In each case an emotionally attuned interaction fosters a sense of togetherness on the basis of a mutual recognition of someone’s feelings, “I know that you know how I feel”. This feeling of being understood is profoundly comforting, in meeting our basic attachment needs. Experiences of feeling understood are profoundly

comforting - in basic attachment needs it functions to reduce stress levels (Stern: 2000). This kind of understanding is not a rational categorical understanding but rather an empathic understanding which shows that we know what “IT” feels like. It has nothing to do with knowing, naming or identifying a symptom of dementia. It is an empathic understanding conveyed by the experience of someone’s touch, the look in their eyes, the tone of their voice, the pace of their speech and look on their face. There is immediacy to this bodily form of communication, that is to say, we feel rather than interpret the message it conveys. It hits us in a similar way a lively song may excite us and a slow song may calm us down.

Creating Feeling Based Organisations

Staff need emotional support to do emotional work. Emotionally intelligent feeling based carers can only flourish within emotionally intelligent, feeling based, organisations. Feeling based interactions rely upon someone’s capacity to feel, reflect upon and cope with difficult feelings and emotions, their own and others. This kind of capacity is often referred to as emotional intelligence. Carers must learn to feel comfortable and at home with a range of emotions to do this emotional work. Imagine a care giver that cannot cope with the feelings of anger that are triggered by the “difficult” attachment behaviour of someone in their care. The difficult feelings that the person triggers in them overwhelms their capacity to attune to the other. They may be compelled to avoid this person or suppress their behaviour rather than engage with them. Furthermore if someone struggles to identify, name and reflect on their own feelings and emotional needs they will struggle to identify, name and reflect upon someone else. In such cases care givers are likely to rely on terms, such as “attention seeker”, “wanderer”, “aggressive”, that reduce all behav-

hours to pathological labels or symptoms of a dementia, both of which obscure the underlying feelings and needs. Feeling based organisations develop person centred practice by both recognising and nurturing staff's emotional intelligence (Sheard: 2009). This is why dementia care matters begins every Being a Star training programme with an opportunity for staff to reflect upon their own feelings and needs, and consider the key ingredients to their own emotional well being (Sheard:2008). Feeling based care also requires a relaxed, go with the flow culture of care that subordinates care tasks and routines to people's changing emotional needs. Task oriented interactions that overlook people's affective states and focus exclusively on physical care needs fail to meet attachment needs. Attachment needs are not met in care giving interactions directed exclusively on someone's basic physical needs unless they have this essential feeling based component. Feeling based cultures of care therefore recognise every care giving interaction as a therapeutic intervention that provides an essential opportunity for interactive regulation. In helping to regulate levels of arousal and affect regular experiences of emotionally attuned relationships reduce people with a dementia's reliance on more primitive and often distressing coping mechanism.

Developing Feeling Based Environments

Feeling based environments provide people with a dementia adequate opportunities to self regulate in and through their interactions with their environment. Engagement in activities and occupation tends to be higher when those activities are self-initiated. This means shifting the focus from scheduled large group activities to brief and regular interactions that are spontaneous responses to individual changing needs. Filling a dementia care setting up with stuff enables people to occupy themselves independ-

ently of caregivers. Clutter often compensates for the disability because people with a dementia can lack the capacity to seek out the means to occupy themselves. Tidy care homes with objects and items out of reach, in boxes on shelves deny people the opportunity to occupy themselves when they need it most. To safely and effectively achieve this level of independent well being care providers need to create care giving environments matched specifically to people's functional capacities and emotional needs. For example:

A small scale living environment for people experiencing the earlier stages of a dementia provides easy access to functional household items and facilities. These environments enable plenty of opportunity for independent domestic activities, household tasks and partnerships in daily living activities.

A small scale living environment for people experiencing a moderate level of dementia (or different reality) needs to be full of visual cues that prompt people to engage in self initiated activities. An environment full of stuff to rummage through and plenty of "half done" domestic tasks (an unsorted basket of laundry to sort, pile of ironing to fold etc) set up around the room all invite opportunities for self regulation.

A care giving environment matched to the needs of people experiencing the late stage of a dementia includes easy access to comfort objects and other items that provide opportunities for sensory stimulating and sensory soothing experiences throughout the day. Care givers working in a specialist later stage of dementia draw upon these environmental features to create a sensory journey; balancing times of sensory stimulation with sensory soothing to help people feel at home in themselves.

In compensating for an impaired capacity to

self regulate, matching the environment with someone's stage of a dementia provides the maximum chance for someone with a dementia to remain in their comfort zone. In these enriched environments all a person needs to do to self regulate is have the freedom to follow their feelings. It matters less whether the activity makes logical sense or is completed and more how it makes that person feel inside. The items, activities and features of the environment are, however, always more meaningful when they are related to an individual's identity and previous life experiences. Matching the features of the environment to both someone's stage of a dementia and individual life history therefore enhances the quality of interactions.

Feeling at Home in your Comfort Zone

The loss of a capacity to self regulate is a very significant disability that has profound emotional, psychological, behavioural and cognitive implications. In a culture that tends to value thinking over and above feeling we tend to emphasise how a dementia undermines, "higher cognitive processes" and ignore how it undermines the "primitive" processes that regulates feelings and emotions. Furthermore in a culture that tends to separate mind and body, thoughts and feelings, cognition and affect, it is easy to overlook how connected these two processes are. To adequately compensate for this disability care providers need to:

- Believe that feelings matter most in dementia care
- Recruit feeling based carers
- Recognise that the quality of EVERY care giving interaction matters
- Nurture staff's emotional capacities
- Create a relaxed 'go with the flow' culture of care
- Develop enriched and "matched" care giving environments

This feeling based approach enables people to relax into the experience of a cognitive impairment, feel at home in their comfort zone and, in doing so, also optimises people's cognitive functioning.

Luke Tanner
Consultant Trainer,
Dementia Care Matters

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Christina is the clinical psychologist with the Younger Onset Dementia Service of Cardiff and Vale University Health board.

She was previously Head of Specialty for the clinical psychology service to older people and also held an honorary position with the Dementia Services Development Centre -Wales

this appointment was the catalyst for the beginnings of the development of a service as the post holder was told that she had one designated session per week to develop services for younger people with dementia. I remember being enthused by the steering group who met to discuss the need for a service for younger people with dementia and pleased that the group included a carer. That carer described to the rest of the group his experience of trying to obtain a diagnosis and support for his wife and the difficulties he encountered, particularly as he was in full-time work at the time.

FOCUS groups for carers

Development of a Younger Onset Dementia Service: Some Personal Reflections How it all Began...

Eighteen years ago I had just gained a clinical psychology post working with the Practice Development Unit in Cardiff. I remember that one of the first tasks I was asked to lead on was the development of a service for younger people with dementia. The Practice Development Unit had been in operation for some years, having been first established to lead on new developments for older people with mental health needs in the Trust. By the time I came to work in the Unit there had been significant development of multidisciplinary, multi-agency teams and although the work of the unit continued to have a focus on service development there was also a strong teaching and training focus to ensure that practice was also innovative and good standards of care were maintained.

At about the same time as my appointment a new consultant psychiatrist was appointed to the mental health services for older people and

One of my first tasks was to work with other members of the steering group to convene two focus groups for carers of younger people living with dementia. At the time we were able to identify about 20 carers, although population estimates suggested that there were approximately 100 younger people living with dementia in the area. The focus groups identified concerns which are now well recognised as common for younger people. The carers described delays in reaching a diagnosis and concerns about the lack of pre-and post-diagnostic counselling. Individuals also spoke about feelings of isolation at various stages of their contact with services. In addition to the initial feeling of isolation when they were unsure what was wrong with their partner they also described feeling as though there was no support for them after the diagnosis and feeling left to cope alone. A number of carers talked about their relief that they had finally met other carers who were facing a similar situation. Based on the groups the steering group identified a number of key areas. It was decided that a care pathway

needed to be developed which included ongoing support for the person with dementia and their family. The need for age appropriate day-care and continuing care was also acknowledged. It was felt that the existing dementia services could develop the expertise to work with younger people with dementia and that this was preferential to developing a totally separate service. However, it was also recognised that there were many additional issues for younger people and their families and that there was a need for specialist support e.g. in the areas of employment and benefits. With this in mind the steering group supported the Alzheimer's Society to submit lottery bids initially for a development worker and subsequently for a support worker. Thus the work began. By 1999 I was writing in Signpost 'Progress has been slow and frustrating at times as we are faced by the difficulties of trying to make changes without any additional resources,' Little did I realise at the time just how much longer it would take to develop the service.

A Report for the Dementia Services Development Centre-Wales

Four years later in 2003 the Dementia Services Development Centre-Wales (DSDC) were commissioned by Welsh Government to prepare a series of papers based on a Service Mapping project identifying the scope of dementia services across Wales. The task of describing the services for younger people with dementia fell to me. It was a relatively easy report to write in that I was able to identify a paucity of services for the estimated 893 younger people living with dementia in Wales at this time (based on the work of Harvey et. al. 1998). While there were two examples of dedicated day care services both were small and in North Wales. The survey identified 21 residential/nursing care beds (0.3% of the total) available specifically for

younger people distributed across 8 homes. Over the previous year 61 younger people had been cared for in 29 homes. Thus at this time the majority of younger people needing care were placed in care homes alongside older people. Only one hospital ward was identified which offered respite care for younger people with dementia on a continuing healthcare ward for older people. Difficulties were identified with patient mix and this provision was subsequently closed. The mapping project found no examples of consultant psychiatrists with special responsibility for younger people with dementia. (By this time the post in Cardiff was vacant.) The report also identified that there were no dedicated teams or community psychiatric nurses for younger people with dementia in Wales.

The Next Eight Years

Looking back now I find it hard to clearly remember my work to develop services over the next eight years. I am told that I 'valiantly' continued to chair the steering group and I know that I wrote various versions of a business case which were submitted to the Trust/Health Board in its different identities over these years.

These were always received positively with a recognition of the need for the service but no commitment of funding was possible. The development work continued mainly due to the support of National Lottery funding for a part-time support worker post with the Alzheimer's Society. When this funding finally ran out in 2010 under pressure from service users the Health Board agreed to fund the post. This was the next small step in the development of our service.

2011. Welsh Government Support

In 2011 following the National Dementia Vision for Wales the Welsh Government announced

£0.5 million of recurrent funding for the development of services for younger people with dementia across Wales. Although at first this sounds like a significant investment when it was divided between each of the health boards across Wales the funding only supported the development of a full-time dementia care advisor post and one full time and one part-time support worker posts. The one clear advantage we had from the previous research and development work over the preceding years was a clarity of vision as to what our service priorities were. These were to provide some practical support to allow younger people to continue to enjoy their home life and interests. Around the same time the Health Board supported developments by funding a part-time consultant psychiatrist post and a part-time nursing post. A rather big step – a definite service!

The Multidisciplinary Team

In 2013 (a mere 16 years after this story began) it was identified that there were a number of younger people with continuing healthcare needs who had been placed in relatively high cost external placements in order to meet their support needs. A multi-disciplinary group began work on examining the feasibility of bringing these people back to a designated local in-patient unit close to their families. It was also identified that this could potentially release funding which in addition to making a saving for the Health Board could also fund a small multi-disciplinary team. I guess that is commonly what is known as a 'win-win' situation. By the following year after individual assessments and comprehensive care planning a number of younger people with continuing healthcare needs and behaviour that challenges had been repatriated to a small extended assessment unit in Barry Hospital in the Vale of Glamorgan. The funding released meant that the following

part-time posts were created; occupational therapist, physiotherapist, speech and language therapist, dietician, therapy technician, community psychiatric nurse and clinical psychologist. Finally, seeing the opportunity for a new service I was determined to apply for the psychology post with this new team.



2015 – Going forward

As I write this the year is coming to an end and I have been working with the younger onset dementia service in Cardiff and the Vale for over a year. The team is currently supporting over 120 younger people living with dementia and their families. As I reflect back on the early development work one feature that particularly strikes me is the change that has occurred over these years in awareness of the voice of the person living with dementia. In 1997 we organised a focus group for 'carers' and I remember our concern when one gentleman brought his wife along with him as we had not made any provision for 'sufferers' and were alarmed at what she might hear the other carers speaking about. We were not expecting her to contribute to the discussions. The service that has now developed very much focuses on the person living with dementia and alongside them their partners and supporters. While groups are held for both partners and adult children there are also post-diagnostic groups, friendship groups and cognitive stimulation groups for the younger people living with dementia and also joint activities such as a monthly walking group.

I find it hard to imagine that we would initiate any new developments now without first canvassing the views of the people living with dementia themselves. I have personally gained much from helping facilitate a post-diagnostic support group for people living with a dementia. This group has taught me much about the benefits individuals can gain from mutual understanding and support and has given me an insight into what it actually means to be living with a dementia. I have also helped facilitate a group for adult children which has given me an appreciation of the effect of dementia on the whole family and the caring roles that some children take on alongside their studies, early careers and own young family lives.

Having previously worked in older people's services I have been challenged and intrigued by the differing presentations of dementia in a younger population. In addition to researching the rarer forms of dementia and their symptom profiles I also find myself regularly seeking to understand the marked perceptual difficulties that some of the younger people I work with experience and trying to offer suggestions for compensation strategies and environmental adjustments. The range of presentations encountered has also demonstrated for me the necessity of having a full multi-disciplinary team to support younger people. Next year I am hoping to audit the work of the team to examine the patterns of multidisciplinary team involvement. Currently anecdotal evidence suggests that for many individuals the co-ordinated input of two or three multidisciplinary colleagues is required at any one time. For some people and their families input from every professional in the team is needed at some point during the years that they live with a dementia.

The last year has also allowed me to reflect on the achievements of the service and the potential for further development. While the service

is well received and has achieved much in the last four years there are still many challenges. One key area that continues to challenge me is how to provide post-diagnostic support to those people who choose not to participate in a group format. The team continues to be challenged in helping younger people to access the kind of practical reliable support at home that they want and need. We have had some success with personal assistants but continue to find it difficult to maintain younger people who live alone and rely on care agency support. We are fortunate in being able to access Ty Hapus (an independent charity affiliated to the Alzheimer's Society) for dedicated day care. The Assessment and Recovery Unit and acute in-patient wards at Llandough Hospital provide assessment and treatment on a day and in-patient basis. Although there has been some development of dedicated care home provision in Wales over the last ten years this is still an area of need locally with younger people often being cared for in homes designed for an older cohort. We have developed two small units for younger people with continuing healthcare needs who have challenging behaviour. The nursing, medical and therapy team are continuing to work together to further develop these units. We continue to explore the challenges of adapting a relatively small environment to the needs of an active younger group of people and creating a stimulating yet safe environment. To date we have not been able to identify a similar NHS provision with which to benchmark and share experiences.

Final Reflections

Eighteen years ago I began what was initially a piece of strategic development work. Over the years I was made aware of the consequences of the dearth of dedicated services and the isolation and lack of support that younger people and their families experienced. Now I am start-

ing to realise what can be achieved by a specialist multidisciplinary team that works cohesively and has a core philosophy of seeing the individual person rather than their diagnostic label.



On a daily basis I am learning much from the courage, compassion and humour shown by the younger people living with dementia and I feel privileged to have been given the opportunity to walk alongside them.

Christina Maciejewski
Consultant Clinical Psychologist
Younger Onset Dementia Service
Cardiff and Vale UHB.

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About me...



Carolien works as a clinical psychologist for Betsi Cadwaladr University Health Board with people diagnosed with dementia

on Anglesey and as a clinical lecturer/ admissions tutor at the North Wales Clinical Psychology Programme, Bangor University

Who are you and what do you do?

I am from the Netherlands, where I trained at the Radboud University in Nijmegen as a social gerontologist. My first post in the Netherlands involved working with a sociologist and GP on a project to support informal caregivers of people with dementia. I also worked as a trainer and provided organisational consultancy to care homes. So, from very early on in my career, I have been interested in the impact of the local and wider social environment on older people's wellbeing. I moved to the UK in 1990, when it was really easy to 'walk' into a job. However, I had to re-train in order to practise as a Clinical Psychologist.

I initially worked in older people clinical psychology services in Sheffield, with people who had mental health challenges or organic difficulties, in the community, care homes and hospital wards. In 2002, I moved to Bangor to take up a three-day post at the North Wales Clinical Psychology programme at Bangor University. The remainder of my time is spent working within the older adult clinical psychology service in Betsi Cadwaladr University Health

Board, North Wales.

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

I always squeeze too much into a clinical day. Like most of my colleagues, I find there is too much work to be done in the time available. My clinical days are very varied, from doing home visits across Anglesey, to supporting people who are adjusting to growing older and its associated physical, psychological and social challenges. I view the social networks around people as crucial when trying to address these challenges, so I regularly work with family and friends, as well as professional care providers.

I also believe in people supporting each other, so I was very excited to introduce a carers support group called 'Caring and Coping with Loss in Dementia' to North Wales, which I helped develop when I was working in Sheffield. You will often find me in meetings, where we plan services and ways to support staff in carrying out their work. Again, I engage with colleagues across the mental and physical health services, as well as local authorities and third sector. I am excited to be involved in exploring ways to make our communities more age and dementia friendly as part of the Aging Well in Wales initiative, and I often get frustrated about how there is sometimes too much talking and not enough doing! I believe that we should always scrutinise, and never underestimate the importance of the way we view and talk about older people as this shapes both our communication (written and spoken) and our behaviour towards the older generation.

I also supervise trainees during their first year clinical placements and with their research assignments, hopefully helping to enthuse them about the wide range of options where (clinical) psychology thinking can be helpful.

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

The part of my role that gives me energy is when, as a team, we identify a problem or challenge and begin to explore possible solutions. This could be addressing an individual's difficulties or surmounting systems or organisational barriers when either working with a client or with staff members. Between all of us, we are able generate ideas, share skills, competencies and resources that might begin to address the challenge faced. Also if we all 'own' the solution, we are more likely to commit to implementing it and seeing it through.

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

Like for many of us working in the NHS, there is more work to be done with fewer resources and staff. This means we need to work collaboratively and pool resources. While staff on the shop floor are willing to be creative and try out new ways of working, it is often the structures, rules and regulations that restrict us providing the optimum support and care for somebody. The fact that we do not all have a similar hymn sheets makes us sing out of tune. I find working towards a shared vision and related strategic plan helps all systems converge and collaborate. Sometimes there is too much rivalry between disciplines and services. At the end of the day, if it was our relative or us who needed care and support, we would want the best we can get and not be told that it can not be done because of some regulation. This negates the whole emphasis on person and relationship centred care.

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

People with dementia work with us, they invite and challenge us to ensure we continue to see the person. Having had the privilege and pleasure to meet groups of people who received a diagnosis of dementia and to talk with them about their experiences, the ideas and images they share reveal a very understandable view of the world. I am always struck that the social relationships are so important for people when they have been diagnosed with dementia. They are concerned in the same way as people without a diagnosis about being loved and being lovable, whilst being concerned about those people that they in turn care about and love.

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

The closer I get in age to the people I am working with, the more challenging it can become. People's fears, losses and worries become more familiar from a personal perspective, rather than being read in a text book or heard from others. However, this also gives me a different perspective, and I think that the people I work with can somehow tell. I grow in my competencies and understanding by experiencing similar issues to the people I work with. This experience also connects me again with my first love: social gerontology. I am curious how people manage the hurdles put in front of them, reconnecting again with 'normal' psychology. I believe the only way of understanding when things go awry for people is to know how things usually develop. Every person is unique and perhaps even more so at an older age.

**Dr Carolein Lamers
Clinical Psychologist**

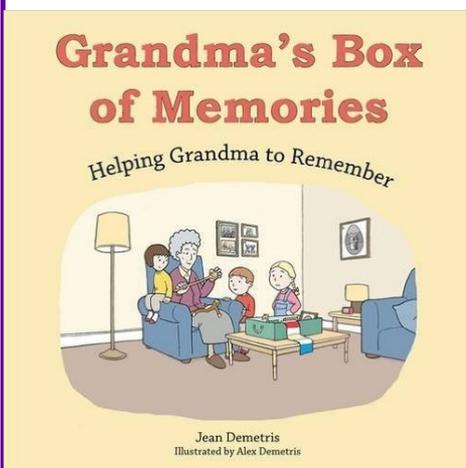
Grandma's Box of Memories: Helping Grandma to Remember

by: Jean Demetris

Publisher: Jessica Kingsley Publishers,
June, 2014 (32 pages)

ISBN: 978 1 84905 517 8

Price: £10.99



Ever wondered how you might explain dementia to a young child? *Grandma's Box of Memories: Helping Grandma to Remember* is a child's book

designed to do just that. This story is aimed at 4 to 7 years olds, with lovely illustrations to help families explain dementia to children in a gentle and thoughtful style. The book is designed to promote discussions within families about how children can help relatives living with dementia.

The book starts by introducing Alice and all the fun she has with her grandparents. However, she starts noticing her Grandma often becoming confused and forgetful. This book is a good introduction to how dementia can be explained to young children, although I wonder whether the author missed an opportunity to normalise and validate emotions children may feel when their relative no longer remembers their birthday or appears very distressed.

Alice and her family decide to make a memory box to help remind Grandma of the happy times

she spent with them. The idea of a memory box is really nice; it can help children feel engaged in the care for their relative. It can also promote families to contemplate and discuss positive memories, therefore helping the family to focus on their relative's identity and personality beyond their dementia diagnosis. This book does a really good job in describing the memory box and giving useful examples of items that could go in it, in line with reminiscence and life story therapies. The items Alice puts in the memory box will engage Grandma's senses of touch, sight, smell and hearing and derive from memories across her life span. Through providing concrete examples this can encourage children to think about what they could put in their own memory boxes. The author also gently guides the adults on when and how memory boxes can be useful.

Towards the end of the story, Alice gives the box to Grandma and the story describes how the memories can help Grandma when she is confused or upset. Phrases such as: 'Grandma might remember the smell [of the lavender]' are used, which implicitly suggests the memory box might not always help Grandma. I wonder if this message would have been more helpful if expressed explicitly, as young children could take it personally if their memory box does not help their relative all of the time.

Overall, this book offers a useful resource to talk to young children about dementia, which can pave the way for family discussions whilst remembering the person behind the dementia diagnosis and all the happy times spent with them. The colours and illustrations within this book are fantastic and will engross children's imaginations. The author is commended for

addressing this sensitive, yet essential, topic. *Grandma's box of memories* is highly recommended for anyone wondering how to explain dementia to young children and support them to feel included in the care of their relative.

Sarah Harris

Trainee Clinical Psychologist
South Wales Doctoral Programme in Clinical Psychology



**How We Think About Dementia
Personhood, Rights, Ethics, the Arts
and What They Mean for Care**

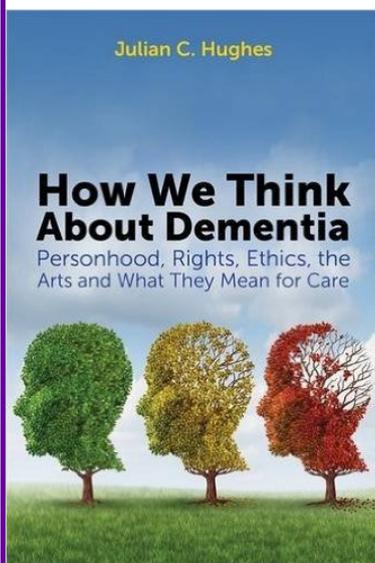
by: **Julian C Hughes**

Publisher: Jessica Kingsley Publishers,

July, 2014 (248 pages)

ISBN:978 1 84905 477 5

Price: £19.99 (paperback) £18.99 (Kindle)



“How We Think About Dementia” provides a series of thought provoking essays on what it means to have dementia, how it affects our identity as a person, and how people’s rights and identities should best be cared for. This book particularly examines

the concept of personhood and uses philosophical perspectives to challenge the view that

dementia takes away an individual’s identity and personhood.

Hughes takes exception to the perspective that we, as people, are defined by our cognitive abilities. Instead, a person is defined as: having a physical presence; being minded (i.e. the ability to engage mentally with the objects, environments and people around us); and having the ability to participate in the world, particularly in reference to our own narrative and context. This is presented as the Situated Embedded Agent (SEA) view of personhood.

The point Hughes makes is a powerful one, although diseases such as dementia can destroy our potential to interact meaningfully as we once could, these are only a part of our identity. Declarative memory is not viewed as being critical to personhood. Memory exists within our whole body as is demonstrated in enduring procedural recall, in learned gestures and mannerisms as well as in the narrative of our own lives and the lives of those around us.

The book focuses in particular, on severe dementia and its care and treatment in the final years, with a need to view this time in its appropriate whole life context. Interactions and engagement with the world can still hold significance for the individual and suggestions are made as to how best enable these through more individualised and person centred care approaches.

A number of chapters are devoted to capacity issues, particularly in cases where explicit wishes are hard to ascertain. The importance of the broader life context, implicit gestures and tacit knowledge of the wishes of dementia sufferers by the care team is raised. Hughes proposes plans for individualised treatment based upon this knowledge, with understanding garnered through building relationships with care

teams over time. He recognises that this requires exceptional skills but does not make reference to issues of staff continuity within care environments that this also raises. This highlights additional challenges in providing ideal care to dementia sufferers within the constraints of today's pressurised care industry.

Professor Hughes is a consultant in Old Age Psychiatry within Northumbria's NHS foundation and is also an Honorary Professor of the Philosophy of Ageing at Newcastle University.

"How We Think About Dementia" is targeted towards clinicians and care teams supporting dementia sufferers. It provides interesting perspectives on individualised care, which may enable fresh thinking about care plans, activities and making the most of patient-carer interactions. The references to philosophical perspectives may be surplus to the requirements of many readers however, on the whole, this is a readable and engaging book, which can gently challenge thoughts and beliefs.

Tamsin Miles

Assistant Psychologist
Health Psychology
North Bristol NHS Trust



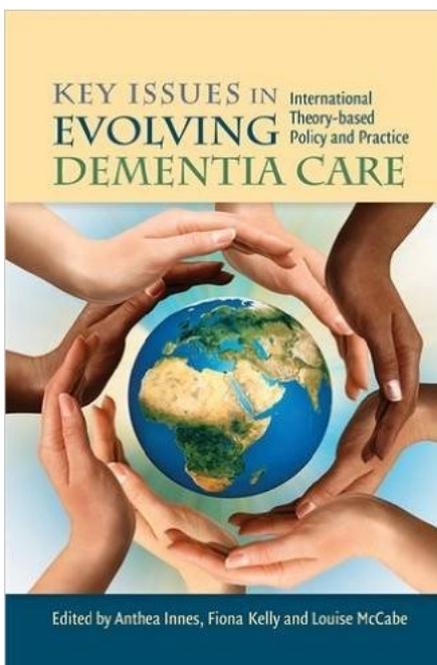
Key Issues in Evolving Dementia Care. International Theory-based Policy and Practice.

by: Anthea Innes, Fiona Kelly and Louise McCabe

Published by: Jessica Kingsley Publishers, April, 2012 (264 pages)

ISBN: 978-1-84905-242-9

Price: £24.99 (Paperback), £23.99 (Kindle)



Dementia has been generating a lot of interest globally especially in the last two decades. This is largely because the number of people with Dementia is rapidly growing all around the world and in the developed

countries, Dementia care costs more than Cancer, heart disease and stroke combined. In spite of the huge resources directed towards Dementia care, there are still horrifying stories of poor care and non-uniformity in care standards nationally and internationally.

This book aims to explore the varied theories, policies and practicalities associated with Dementia and Dementia Care at present and provide useful observations for the future. This book is unique in that it encapsulates the theories and concepts of academics and professionals from different backgrounds such as mental health professionals, geriatricians, gerontologists, epidemiologists, health policy consultants, nurse practitioners to name a few. The contributors are from across the globe, giving the book a truly international flavour. Identifying challenges and barriers to change is cru-

cial for instituting change and this book offers examples in policy and practice where these have been explored and addressed effectively.

The book has been divided into sections which are clearly defined and the titles of each section are self-explanatory. The first part looks in detail at the key ideas and issues that underpin policy and practice. It explores the impact of Dementia in social and economic terms. The practical impact of the different theoretical perspectives is examined through case studies. Part two of the book looks at policy development through case studies from England, France, Scotland and Malta. The challenges faced during the development of strategies are also discussed in detail.

The last part of the book integrates the various theories and policies and looks at the different innovative approaches to Dementia Care adopted around the world. Once again, case studies from the UK, India, Australia and the USA are used effectively. In this part, there are chapters dedicated to Memory clinics, post diagnostic services, innovative dementia training, gaps in dementia care and how these are bridged. The end of the book, appropriately titled – Conclusion- highlights the key issues and themes that are pertinent to better understanding of Dementia, dementia care and policy making in this area.

The aim of the book is to provide a holistic, multidisciplinary and global view to Key Issues in Evolving Dementia Care and in my opinion this has been achieved. The book is packed with facts, figures and theories and can be quite overwhelming if an attempt is made to read it cover to cover. It is best digested and assimilated in small doses and the organisation of the book into clearly defined sections enables the reader to focus on a section at a time. Inclusion of case studies and examples makes

it an interesting read. It is suitable for anyone interested in Dementia and care of people diagnosed with Dementia.

Dr Sugandha Kumar

Higher trainee, Old Age Psychiatry
Cardiff and Vale UHB





Person Centred Dementia Care, National Course: Cardiff 2016

David Sheard is returning in 2016 to personally facilitate this course alongside Peter Priednieks, Director of Learning and Sally Knocker, Consultant Trainer

One Year Course – Merging Person-Centred Care and Culture Change

“An Emotional Journey” ©

“This course has been the best training that I have ever done in my 26 years of working with older people.”

Participants can link the learning from this programme to new qualifications that form part of the Qualifications and Credit Framework (QCF). Evidence of how this course is mapped to the QCF Awards will be provided.

On completion, participants may use the work undertaken to gain 30 credits at Level 6 at the University of Surrey through Accreditation of Prior Learning, this may be transferable to other Universities.

Venue: Cardiff

March 2016 – February 2017

1 day per month - Full course dates at www.dementiacarematters.com

£825 + VAT for one place

Includes – a copy of *Achieving real outcomes in dementia care homes*, a copy of *Inspiring: leadership matters in dementia care* & *Resources Membership* for 1 year providing access to Dementia Care Matters large directory of resources.

“David’s beliefs, values, boundless energy and passion have driven changes that too many were only a dream. His herculean effort has revolutionised the culture of care nationally and internationally.”

(Judging panel 16th National Care Awards 2014)

Care Personality of the Year 2014



Peter is the most experienced member of Dementia Care Matters working alongside David since the first Butterfly Care Home began in 1995 – Peter is known for his expert training skills with a calm and reflective style.



Sally has worked in dementia care almost all her working life and has gained a national reputation for her energy and fun approach to training with expertise in meaningful activity.



Key Features

This course gets to the essence of Feelings Matter Most and the Butterfly Approach.

A flexible practice-based learning opportunity.

- Designed for Directors, Managers, Nurses, and Senior Care Workers working with people living with a dementia who wish to positively focus their work.
- Focused on achieving skills and culture change in care homes.
- Addresses the complex and challenging issues within the field of dementia care.
- Twelve days attended workshops across the year.
- Three optional assignments offering 30 University credits at Level 6.
- Invaluable 600 page participant online manual.

Benefits:

- Spend time with Dementia Care Matters learning why dementia care matters so much emotionally and practically to him.
- Learn from David after his 35 years what really works in transforming dementia care.
- Hear directly from the course facilitators what the very best in dementia care over the last 20 years looks, sounds and feels like and what it takes to achieve this.
- Experience the training: really benefitting from the balance between David's direct, emotional and passionate style with Peter's reflective, thoughtful and very caring approach and Sally's fun loving energy.
- Return to work after these sessions fired up and inspired with the emotional drive to really know how to change things.

12 workshops over 12 months

This course is focused on achieving skills and culture change in care homes. Participants from other services are welcome and they will need to be able to transfer the course manual into their own work role.

Content:

- Key steps in achieving culture change in dementia care homes.
- The essence of the Butterfly Household™ Model of Dementia Care.
- The method of qualitative observations of peoples' lived experience and quality of interactions.
- Ways for staff to adopt the Butterfly Care Home approach and knowing how to be a Butterfly.
- Training on emotional intelligence as the primary competency in dementia care.
- Attached leadership skills in dementia care.
- The 'Look ' Checklist to improve the environment.
- The Model of Care - 'The Inspiring 50 Point Action Checklist. '
- The real meaning behind and how to reach people's emotions and expressions of 'behaviour. '
- The language of a person living with a dementia and how to develop your feeling based communication skills.
- Skilled approaches in safeguarding balanced with a human rights approach to sexuality, intimacy, relationships and assessing consent.
- Specialist approaches in later stage dementia care.

For booking forms and further information please book online or contact:

**Dementia Care Matters
St George's House
34-36 St George's Road
Brighton
Tel. 01273 242335**

Email: info@dementiacarematters.com.

www.dementiacarematters.com

**For information about an in-house course specific to your organisation please contact our Brighton office:
Tel. 01273 242335**

Dementia Care Matters works with the School of Health & Social Care, University of Surrey

Did you know...

**Key Safe to allow emergency access:
£21.99**

An important part of any home safety plan is to allow access in an emergency. This is a great value key safe that stores an access key for use by neighbours, friends or the emergency services.



Avoid a forced entry and help those that will help you with this essential safety aid.

Helpful as a complement to a monitoring system for those living alone. When an alarm is received the problem often faced is accessing your home to assist. The Defender Security Key Safe attaches to any wall or flat surface with 4 bolts and accommodates a multitude of keys, including bigger keys such as car keys.

[Link to device](#)

Xcellent Global 4 in 1 Indoor Wireless Key Finder Keys Caller Locator Pet Finder Alarm Kit M-HG053

£17.99

The key finder: serves 4 people at the same time and covers a range of up to 30 meters. It would be also helpful to find the naughty pets in the house.

Transmitter also has handy built-in LED Flash-

light, which would be more helpful in darkness.

Set consists of one remote control (transmitter) and 4 receivers (blue, green, red and purple) which can be controlled independently



Small and lightweight: receivers weigh only about 8 grams and easily fit on any key ring (receiver's length just about 5cm)

Requires 4 CR2032 button cell batteries (included) and 2 AAA-batteries (not included)

[Link to device](#)

People working long hours are more likely to have a stroke, according to analysis of more than half a million people.

The data, published in the Lancet medical journal, showed the chance of a stroke increased when people were working beyond the traditional 9am to 5pm. The study showed that people who worked a 48 hour week increased their risk of stroke by 10% and people working up to 54 hours increased their risk by 27%. When working over 55 hours a week, a person increases their risk of suffering a stroke to 33% compared to somebody doing a 35-40 hour week.

Dr Mika Kivimaki, from University College London, said that in the 35-40 hour group there were fewer than five strokes per 1,000 employees per decade. This increases to six strokes per 1,000 employees per decade for those working 55 hours or more a week.

Dr Kivimaki admitted researchers were still at the "early stages" of understanding what was going on. However, it has been suggested that working longer hours can incur more stress and can have a negative impact on a person's lifestyle e.g. not having enough time to exercise or prepare healthy meals at home, and thus be a marker of poor health.

The Stroke Association's Dr Shamim Quadir has said "We advise that you have regular blood pressure checks, if you're at all concerned about your stroke risk you should make an appointment with your GP or health professional."

Dr Tim Chico, a consultant cardiologist based at the University of Sheffield, said: "Most of us could reduce the amount of time we spend sitting down, increase our physical activity and improve our diet while working and this might be more important the more time we spend at work."

Combining a pre-school nursery and Care Home.

The Providence Mount St. Vincent Care home (known as The Mount) in Seattle is the home of around 400 older adults. It is also the location of a pre-school nursery for children between 16 weeks and 3 years old.

The 'Intergenerational Learning Centre' hit headlines recently after an American filmmaker Evan Briggs produced a short video called 'Present Perfect' which follows The Mount residents and children whilst they interact together at The Mount.

The Mount's website writes "The Intergenerational Learning Center (ILC) is an award-winning child care program....Five days a week, the children and residents come together in a variety of planned activities such as music, dancing, art, lunch, storytelling or just visiting. These activities result in mutual benefits for both generations. This enhances the opportunities for children and people of all ages to have frequent interaction and is an integral part of the Mount's intergenerational community."

The Mount believes that integrating both generations has mutual benefits for both. It offers the chance for children to learn more about the natural process of aging, and it gives them the

opportunity to meet new people and become part of a large extended family. According to The Mount, it also provides the children with the opportunity “to give and receive unconditional and unbounded love and attention”.

The older residents then have the opportunity to frequently interact with the children, through physical play or activities and “laugh and enjoy the spirit and joy that children bring to the home environment”. Many residents have a “renewed sense of self-worth” and have the opportunity to share their knowledge and be role models for the younger generation.

You can watch Evan Briggs’ video ‘Present Perfect’ here: [View link here](#)

Alzheimer’s Society offers funding for further study.

The Alzheimer’s Society ‘Clinician and health-care professionals training fellowship’ is an award for practicing professionals working in dementia health and care services to help financially aid study towards a higher research degree (usually a PhD) and develop a dual career that combines research and practice.

Please see the following link on applying for the fellowship award of up to £225,000:

[View link here](#)

Conferences and events coming up this year.

- **Scottish Caring and Dementia Congress**
20th April, Murrayfield Stadium, Edinburgh.
- **National Care Homes Congress**
May, location TBC.
- **Conference with Dementia Care Matters**
June, University of Surrey, Guildford.
- **Young Dementia Conference**
September, location TBC.
- **Alzheimer’s Disease & Dementia**
29th September - 1st of October, London.
- **Care Conference for Wales**
October, Cardiff City Stadium.
- **National Dementia Awards**
3rd November, The Brighton Centre.
- **National Care Awards**
25th November, The Hilton London Metropolitan.

Information about Signpost

Anyone Can Contribute to Signpost

Including those who care for older people with mental health needs in hospital, residential homes and in the community.

Contributions

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

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

Contact Details

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

Tel: 02920 715787

Email: Amanda.Furnish@wales.nhs.uk

Books Available for Review:

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

- Group and Individual Work with Older People. A practical guide to running successful activity-based programmes.
- Dad's not all there any more
- People with Dementia, speak out
- Person-centred dementia care 2nd Ed
- Can I tell you about Parkinson's disease? A guide for family, friends and carers
- Playfulness and Dementia – A Practical Guide
- Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement (Theory and Compassionate Practice)
- Excellence in Dementia Care (2nd) - Research into Practice
- The Forgiveness Project - stories for a vengeful age

Signposts Editorial Panel

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

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

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

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

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

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

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

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

