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Cover picture: Artwork by Joseph Simon Murray, Elizabeth Alison and Adam McGee-Abe, displayed in Mental Health Services for Older People, Llandough Hospital.

Editorial



Welcome to this edition of the Signpost Journal of Dementia and Mental Health Care of Older

People. My name is Kim Sweet and I am a mental health nurse within the Mental Health Services for Older People and Neuropsychiatry Directorate of Cardiff and Vale University Health Board. I have a long association with Signpost however it is the first time I been the guest editorial editor.

Today I listened to Health Secretary Jeremy Hunt announce new dementia care plans which he said will make the UK a world leader in fighting the illness. Faster diagnosis, more funding for research and greater help from businesses to support sufferers are the ambitions with NHS England set to invest £90 million in a bid to diagnose two-thirds of people with dementia by March next year and leading British businesses have signed up to the cause with more than 190,000 staff at various retail and banking establishments being trained to become “dementia friends” in order to offer support and sign posting. It is gratifying to hear such positive news when the focus is upon the clinical and human nature of dementia and not upon the ‘burden’ of epidemiological,

demographic and financial implications that are so often emphasised.

Such are my thoughts when I read this Signpost journal with its focus upon new developments and the innovations being made to progress care and treatment options for people with dementia and their carers in order to improve quality of life. In this edition Gillian Drummond informs us of a very successful Singing for the Brain Project which has been in existence for over two years. As one of those who has been fortunate enough to attend a 'Forget-Me-Not Chorus' performance in Cardiff I can only endorse the uplifting and joyous effects experienced. An activity analysis report of a therapeutic group offered by Solace, the Carers Support Service, which aims to provide a skill and social maintenance programme for people with dementia and ongoing social and support opportunities for carers, describes the positive impact this can have for people with dementia and their carers. Joseph Simon Murray, Elizabeth Alison and Adam McGee-Abe go on to present the art therapy practices they utilised in order to complete a three-dimensional, tactile wall artwork entitled 'Spring' that is to be unveiled in the new Mental Health Service for Older People Unit at University Hospital Llandough in June 2013 and Paul Bickerstaffe discusses why the process of selection and training of student nurses is so important in promoting dignified and compassionate care. In his article Damian Utton describes his rationale for the design of Brookside Extra Care Village in order to create

a dementia friendly residential environment that offers safety and security without compromising freedom and quality of life within the local community. Finally, Clive Ballard and Zunera Khan and propose that the Private sector, NHS and university organizations need to come together to develop an infra-structure that can improve the diagnosis of dementia and that will optimise treatments to improve the lives of people with dementia living in care homes.

What an action packed exciting edition, I hope you enjoy it as much as I have.

Kim Sweet

Advanced Nurse Practitioner

**The views expressed in this journal are not necessarily those of the editorial staff or Cardiff and Vale University Health Board
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Hearts and Voices – A Singing for the Brain project in an acute mental health dementia in-patient setting



Gillian Drummond is the Dementia Quality lead for Greater Manchester West Mental Health NHS Foundation Trust (GMW).

Since qualifying as a Registered Mental Nurse in 1987, she has worked in a range of both functional and dementia older peoples services across both GMW and Pennine Care NHS Foundation Trust. In addition to this she has worked as a Practice Development Nurse and Practice Educator completing a Post Graduate Certificate in Education (Practice Educator) in June 2006.

Dementia and the care setting

Dementia is one of the biggest challenges we face today. It is estimated that 670,000 people in England are living with dementia and twenty-one million people in our country know a close friend or family member with the disease (Department of Health, 2012). The term dementia is used to describe a group of symptoms characterised by the progressive

decline in cognition, this most commonly affecting the individual's memory, intellect, social skills and the ability to learn. It is also evident that dementia can often have a significant impact on the quality of life for those living with the diagnosis and their carers (Cooke et al, 2010, Downs and Bowers, 2010).

Living Well with Dementia: a National Strategy for England (Department of Health, 2009) aims to ensure that all people with dementia and their carers are supported to live well with dementia. However with this often complex illness, the loss of conversational skills is relatively common as the illness progresses, and this can then lead to a loss of confidence, withdrawal, low mood and increased challenging behaviour (Alzheimer's Society, 2010), all of which are often precursors to admission to a mental health hospital setting. Killick and Allen (2001) indicate that assumptions cannot be made that the aforementioned symptoms and behaviours described are wholly attributable to the illness but may in part be due to the deprivation of opportunities for real and meaningful communication and increased isolation.

Woodlands Hospital provides in-patient assessment and treatment for individuals with moderate to severe dementia with complex presentation who live in the Salford area of Greater Manchester. The unit is part of a large mental health trust, Greater Manchester West Mental Health NHS Foundation Trust (GMW). GMW provides district mental health services

in Bolton, Salford and Trafford, and also provides substance misuse services in Salford, Cumbria, Wigan and Leigh, Blackburn with Darwen and Central Lancashire.

Music and dementia

Increasingly, there has been a focus on the value of using arts as a mode of therapy to help with communication and social interaction across all areas of mental health (Skingley and Vella-Burrows, 2010). Wall and Duffy (2010), provide a review of the effects of music therapy for older people with dementia advocating that 'music therapy' has a specific role in improving the quality of life and experiences of those living with the disease.

Music is often the source of reflection and pleasure in the absence of any disease or ill-health condition. Singing is an activity which can bring people closer together, it is integral to our everyday life and the source of inspiration (remember how the world felt on hearing Susan Boyle for the first time), jubilation (consider the raucous sound of football fans when their own team are winning), entertainment (who of you are secretly addicted to the *X- Factor*, *Last Choir Standing* and *The Voice*) and memories (never forgotten lyrics from the songs from our school and teenage years).

It is not unusual for the person with dementia to have lost the skills of communication but retain the ability to sing and remember lyrics from familiar songs. Memory may fail in many ways, but often a melody will be retained as a

means to weave memories into a fabric of reality and touch uninjured parts of the brain, enhancing communication and leading to a more social life (Sorrell et al, 2008).

In dementia care, interventions which incorporate the use of music can be a simple and low cost alternative to traditional, more restrictive methods for management of agitated behaviour such as medication and physical restraint (Witzke et al, 2008).

Music has been shown to create positive caring environments in which people with dementia can experience a rich pattern of cognitive and emotional reactions, in turn leading to periods of lucidity, recall and reminiscence (Alzheimer's Society, 2010).

Why singing for the brain?

In the winter of 2009, the author encountered two BBC programmes – part of their *Wonderland* series – about how singing was 'unlocking' the brains for people with dementia. These documentary films, featuring an 'Alzheimer's Choir', were in essence about love, time and the phenomenal ability of music to engage people with dementia and their carers. These moving accounts had a profound effect on the author and instilled a passion to bring 'The Singing for the Brain' concept to Woodlands.

Singing for the Brain is an established phenomenon that is simple but effective in dementia care. Pioneered by the West Berkshire branch of the Alzheimer's Society in 2003, the initial project has since been

successfully replicated across many parts of the UK (Alzheimer's Society, 2010).

Singing for the Brain has both physical and mental benefits. It exercises all the muscles involved in communication, helps improve breathing, combats depression and reduces stress. It stimulates the brain and challenges those taking part by introducing unfamiliar material, simple part-singing, singing in rounds and singing from memory.

Groups are friendly and informal with the social aspect being every bit as important as the health and wellbeing element. People have the chance to meet with others in similar circumstances and to offer one another support through difficult times. Perhaps most importantly of all, by helping people to focus on what they can do, rather than what they can't, Singing for the Brain boosts confidence and gives people a much needed lift.

As with the 'choir' featured on the BBC programme, these groups are often community based and discussions with the local Alzheimer's Society has confirmed that never before has a project been facilitated within a mental health inpatient unit – this was therefore a pioneering project for the Trust and also the Alzheimer's Society.

The Dragons' Den

After an initial meeting with the Alzheimer's Society, it was evident that funding would need to be secured to develop the vision of having a collaborative group within Woodlands. The

source of the first 12 months of funding was established through the 'GMW Dragon's Den'.

The GMW Dragon's Den was launched by the Trust in 2011, with the aim of encouraging clinical staff with innovative ideas and a passion to improve the patient experience, to apply to enter the 'den' and face the panel of 'dragons' to sell their idea and win the 'cash' to implement their proposal.

The Dragons were better known as the Trust Chair and Chief Executive and a range of our Trust Executive and Non-executive Directors, and projects presented were required to support the priorities indicated in the Trust Quality Account (GMW, 2011). The singing for the brain project in particular, spanned a number of the priorities within the Quality Account:

- Improving clinical outcomes through the delivery of recovery focused services
- Improving carer engagement and involvement
- Enhancing the quality of life for people with dementia

The Project Plan

From the outset, the project adopted a collaborative approach with our partners at the Alzheimer's Society. A steering group was developed including staff from both of the organisations together with a number of carers and volunteers.

The project was expertly driven by the GMW's innovative 'Open Doors Project' and guided strongly by the expertise of the Alzheimer's Society by building on their success in delivering Singing for the Brain projects nationally.

The Open Doors Project (Howorth et al, 2011;2012) is a service that aims to literally and metaphorically open doors for people with dementia and their carers. It is a service embedded in the NHS but coordinated by a person living with dementia that has been actively recruited and is employed by the Trust. GMW is proud to be the first NHS Trust in England to employ an individual with a diagnosis of dementia in this manner.

The Open Doors Project is one element of the innovative Reach Beyond Service that aims to engage older people, carers, staff and citizens of Salford in working together to develop user/carer and public participation in service development.

The remit of the steering group was to oversee the implementation of the project in line with the philosophy and Service Specification of the Singing for the Brain brand (Alzheimer's Society, 2010). A large part of this work was the recruitment of the Singing for the Brain Group Leader, and ensuring that the appointed individual had the high levels of skills, knowledge and competency both in relation to the use of music, interpersonal and leadership skills. Sensitivity to dementia was a key component but as part of the project the

appointed leader was provided with dementia training in line with the Service Specification.

The Launch of the Singing for the Brain Project

The project was launched on 5th December 2011 and since this time the sessions have been held on a weekly basis. Each session lasts for two hours and includes a relaxed welcome with refreshments and time for interaction and socialisation at the end of the group.

There is the use of a 'greeting song' to welcome everyone by name and promote a sense of inclusion and participation and a 'goodbye song' to end each session and wish each other well until the next session. Each session incorporates some tried and tested vocal warm-ups and breathing exercises that aim to strengthen the voice, ease tension and increase lung capacity.

The Singing for the Brain Leader will have prepared the song list, which will have an identified theme. Popular themes have been weather-related songs, colours, love and romance and animals. Topics have also emerged based on the seasonal time of the year with the emphasis promoting orientation in relation to time and person. Well-known songs are used to evoke verbal and emotional responses and it is key that staff who know the patient are part of the session to support anyone who may become upset or distressed.

Therefore each session consist of a range of patients, staff, volunteers and carers/relatives, and the sessions are held in the main dayroom space of the ward to promote participation both directly and indirectly (Box 1, below, shows the levels of participation for the specific groups).

wellbeing – which is the very essence of the recovery model. Singing emphasises what the person with dementia can do rather than what they can no longer do and as such underpins the concept of recovery.

Since commencing the project on 5th December 2011 there have been 59 sessions.

Total number of Patient with dementia	Patients visitors	Hospital staff	Alzheimer Society Staff	Visiting staff	Volunteers	Total number of participants
436	117	145	63	15	122	898

Box 1: Levels of Participation

Impact on patients and their carers/relatives

From an anecdotal perspective, the Singing for the Brain Project has provided an uplifting and joyous afternoon for those who participate. It has brought the ward community together as it is one of the few activities that includes the majority of the patient population irrespective of level of impairment and psychiatric symptomology. The group has enabled the more introverted and withdrawn patients to ‘come out of their shell’ and had a positive effect on the patients’ mood and motivation.

Recovery Focused Care is always a difficult concept with an illness such as dementia that is progressive and as such viewed as a palliative condition. This project reaches out to those who are at the most acute phase of their illness and engages them and their relatives in an activity that improves their mood and overall

It has long been recognised by the service that visiting someone with advanced dementia and complex behaviour whilst they are in hospital can be difficult for carers and relatives. Imagine a visit where the person cannot remember even the events of a few moments ago, are unable to communicate their feelings and recognise the environment and also may not recognise you as a close family member. How distressing must it be to know that once you leave, your family member will not remember your presence and the content of your visit – what do you talk about and how can we as a service ensure that meaningful visiting times are preserved and enabled to take place?

The Singing for the Brain Project has enabled the service to aspire to promoting a ‘good visit’ by delivering the Singing for the Brain sessions in conjunction with visiting times and encouraging the patient and their family/friends to participate in the activity together.

There have been numerous occasions where the memories triggered by the singing have led to couples having a dance. The sessions have therefore provided the vehicle for couples to recapture some intimacy and just witnessing the sheer delight on the face of both the person living with dementia and their spouse or partner as they embrace and take the floor, has been both poignant and delightful experience.

It is very often an enjoyable experience for all those involved and the sessions offer an opportunity for both the person with dementia and their relatives to come together with others in similar circumstances and provide a mode for interaction that is essential for those who are touched by dementia.

Ever conscious of the need to consider outcome-focused measures within care and the importance of ensuring that when using music as an intervention continued assessment of the effects is considered (Witzke et al, 2008), the service has recently commenced a more formal approach to considering the patient and carer/relative experience of the group, and has begun to work collaboratively with the local university to evaluate the effects of the project in relation to engagement and effect.

Impact on volunteers

Volunteering is an important expression of citizenship and fundamental to democracy (Volunteering UK). Within both GMW and The Alzheimer's Society, volunteers are considered

a crucial element of service provision, adding richness to the patient journey and are greatly welcomed and valued. The continued success of the project has been without doubt due to the commitment and enthusiasm of the volunteers that have been involved in the project.

The volunteers have been sourced from both the Alzheimer's Society and GMW (through the Open Doors Service). The volunteers that have been involved in the project (many of which have personal experience of supporting a close family member with dementia) report feeling a positive sense of wellbeing when they have been to the group, and this is underpinned by a feeling that they have made a real difference to the patient experience; and personally helped to improve the quality of life for the patients they have supported within the session.

Impact on staff

There is evidence to support the view that nursing staff recognise the benefits and have a positive attitude in relation to the use of music with people with dementia (Sung et al, 2011).

There are precious few activities that promote the participation of all the available team of staff with the patients for a sustained period of time. From a therapeutic relationship perspective, Sorrell et al (2008) were keen to emphasise that singing together can be a way of connecting, serving as an alternative means of communication and social interaction.

An important point to recognise is that as with younger generations, all older adults will not be equally affected by the same kind of music so the presence of staff who know the patient is imperative to the forward planning and implementation of the sessions.

Our staff have also been key in recognising any escalation of emotion and irritability and managing any resulting agitation in a sensitive and calming manner.



Planning for the future

The Singing for the Brain project has now become firmly embedded within the care and treatment at Woodlands Hospital, the steering group continues to meet and review the project and as already highlighted, there are plans in place to formally review the project.

It is with much excitement that the project has recently been awarded a further three years funding through our partners at the Alzheimer's Society and Zurich Insurance.

A return visit to the Dragon's Den in late 2012 has secured funding for 12 months to develop a similar project within our service at Trafford.

The author wishes to sincerely acknowledge the support from the following people in relation to the Singing for the Brain Project:

- *Clare Morel and Tanah Stevens – Singing for the Brain leaders.*
- *Paula Hewitt, Anne Grout and Lisa Day from the Alzheimer's Society and their volunteers.*
- *Hesmita Patel, Karen Barnes and Marie Donaldson – Staff on Moss Ward Woodlands (GMW).*
- *Cathy Riley and Trisha Day from The Open Doors Project (GMW), and their volunteers.*

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Brilliant Sanity and Dementia...

Brilliant Sanity and Dementia



Luke is a freelance therapist in dementia care homes based in

London and a trainer/consultant for Dementia Care Matters. As a dementia care therapist Luke draws upon his training in massage and body psychotherapy to offer a range of psycho-social approaches to provide a person centered therapy for people experiencing a dementia. In 2011 Luke collaborated with Dementia Care Matters, mental health nurses and massage therapists in order to explore the role of touch from an ethical, theoretical and clinical perspective. The result of this collaboration and hundreds of hours of therapeutic touch and massage work in

residential dementia care settings was a training process that maximized the potential benefits of touch in dementia care. Luke joined Dementia Care Matters as a trainer and consultant in 2013 in order to facilitate this training and develop therapeutic cultures of care that achieve sustainable improvements in the quality of life for people living with a dementia.

Professional carers experience so many pressures; the restraints of time, resources, paperwork; the tasks of physical and emotional care and interpreting the distinct ways in which each person expresses them. Clearly being a competent carer is an exceptionally challenging job. "Being competent" however, places another pressure on the carer, to appear to always know what you are doing! A competent carer must be less muddled, confused and caught up in making mistakes than the person they care for. In this article I want to focus on this latter pressure, the pressure of "being professional".

We often learn far more from our mistakes than the times when we get it all right.

These experiences are often wonderful opportunities to learn from the very people we care for. Because being a "competent" carer can imply that we should know better than the person we care for this pressure can inhibit how much we learn from someone with a dementia. How can we learn from someone if we are led to believe that we are less confused, saner or somehow better than that

person?

In many ways our ability to truly help someone is limited if we believe that we are better than the person we seek to help. Person-centred care relies upon our ability to be present for someone without prejudice and predetermined agendas so that our actions are guided by what that person feels rather than what we think is best for them. In dementia care this often means being present to someone in pain and distress. In order to do this we need to be able to be with our own pain and distress. If we are uncomfortable with these experiences our actions are likely to be motivated as much by our own need to avoid pain, distress and confusion than empathising with the other (empathy requires us to experience something of what the other person feels in order to understand what they need). If, however, we try to control someone's feelings, thoughts or behaviours our caring can be experienced as a form of control and we can become a nuisance instead of a help.

In her book "How to be a Help Instead of a Nuisance" psychotherapist Karen Wegela suggests helping is less about changing what is wrong with a person than focusing upon what is right. In person-centred psychology we call this focusing upon someone's inherent health. The focus on the problem or pathology undermines a central force in person-centred therapy, someone's "*tendency to actualize himself, to become his potentialities...to express and activate all the*

capacities of the organism." (Rogers:1961). Karen Wegela refers to this inherent health as "Brilliant Sanity" and states that focusing upon what is wrong or the problems with people tends to cover up a person's brilliant sanity. If someone is encouraged to feel that they are considered to be a mere problem then they are unlikely to be able to perceive their brilliant sanity and therefore lose touch with their own self-esteem.

When someone has a diagnosis of dementia they do not lose this inherent health, or brilliant sanity; in my experience it is often expressed with startling clarity. Part of the tragedy of dementia care is that so often we are unavailable to the brilliant sanity of those we care for: for example, when the running of a care home becomes more important than the people living in it or if we believe we are saner or better than those we care for. If, in contrast, we recognise the capacity for brilliant sanity in others with a dementia as much as in ourselves then we can be available to the wisdom, clarity and compassion they have to offer us. As a result care work can become deeply fulfilling for both parties involved. Caring can become a mutual and reciprocal process. The moments when the brilliant sanity of those I care for shines through are the moments which most sustain me in my work as a therapist. I would like to share some of these moments and how they have helped me get a little closer to the core of what it means to be a human being.

Many of us have ways of remembering in everyday life that are usually forms of conscious recall: for example, the moments I am recalling in this article. Someone with a dementia teaches us, however, that this is only one kind of memory and that there is another more fundamental form of memory which shapes all of our lives; our emotional memory. Emotional memory is ordinarily a less conscious form of memory that functions as the background to our conscious experience. Emotional memory fosters our sense of self, place and each other while our recalled memories allow us to perceive things more explicitly in terms of particular events and identities located in time and space. An experience of a dementia undermines this latter capacity for voluntary and conscious recall and moves emotional memory to the fore. This means present circumstances can trigger past experiences that can be

re-experienced vividly as powerful emotions in the present. As we know these emotional memories are not always good ones, often what is experienced is what has been fearful and painful in the past. Many people with a dementia that I spend time with re-experience past experiences of being neglected, wronged, abused or misjudged with profound clarity, expressing them directly in their feelings, words and behaviors. They remind me that all those difficult times in our past are never simply "gone and forgotten" or "left behind" since we carry that pain within us throughout our lives. The task in life therefore is not simply to overcome, forget or repress painful feelings,

but to learn to live with them. People with a dementia, who experience and express their emotional memories with startling clarity, can remind us that our emotional memory is at the core of who we are. They are telling us, so to speak, more about who we really are.

During such times of distress many people with a dementia call out for their mother, father, or a partner. I believe that this is not out of confusion, but out of wisdom. It is based upon the understanding that our suffering is made easier when it is shared with someone who loves us. Living with our pain is made easier if we don't try to do it alone. Somehow when in a loving relationship our pain becomes more bearable. I have found, therefore, that simply being with someone as they experience some pain and distress is the best thing I can do to alleviate their hardship. I have also found that during such times a person with a dementia will welcome me with an open heart and that I don't need a lifetime of shared history to experience their friendship, intimacy or affection. Is this confusion or is this just a disregard for the many conditions that society teaches us to place upon the giving and receiving of love. Children are born into this world loving unconditionally and learn as they grow up to place more and more conditions upon this love. The experience of dementia undoes this conditioning and means that someone's heart is often more open to others, less preoccupied with who we are, what we do or what we have acquired.

This is why experiences of love can be just as much part of the experience of dementia as experiences of pain and loss. This, however, largely depends upon us; if we, as carers, are able to accept the person with a dementia as they are and be in a relationship with them then we can ensure that love is as much a part of the experience of dementia as pain and loss. In fact carers are in a privileged position to do just this. We are not, like many relatives, suffering from the sense of loss of who that person used to be, ; therefore, we are able to accept more freely who that person is now, with their experience of dementia. We can also learn from people with a dementia how to do this; we can learn to place fewer conditions upon the giving and receiving of love. Experiences of love, however, are not without pain; love hurts. This is something I have also learnt from being with people who have a dementia. Towards the end of their life the biggest regrets that people have shared with me is not what job they did or didn't have, or how much wealth they acquired, but rather how well they have loved. Many people share their regrets about not sharing their love more, not appreciating, betraying or abusing someone's love. Some people re-experience these past acts with such vividness that it causes them pain. If we listen and feel into these experiences we can learn a deep truth about relationships; when we hurt others we love we are always in some way hurting ourselves too. We may well awaken to this truth in the very last years, months, weeks

or days of our life. I have been lucky enough to spend time with a man who was able to re-experience all the love that he felt in his life, not with regret, but with great appreciation. He felt so much love for those in his life that I could see that it actually pained him. He was so thankful to be able to tell someone before he dies just how much love he has felt in his lifetime and how thankful he is to have felt this love. With tears streaming down his face, he was thankful that someone was there to witness his love. He even asked me to tell my friends of this love and how dear it was to him. This was a man who, experiencing a lot of confusion, often spoke “nonsense”, yet was able to express himself without reserve and with such clarity and compassion. Through him I have begun to learn how intertwined love and pain really are; if we open ourselves up to love we are always opening ourselves up to pain. Many people with a dementia I have spent time with are able to experience both pain and love without setting these experiences against each other, i.e. setting them up to be mutually exclusive. Furthermore I have found that even in times of great hardship people do not necessarily lose their compassion or kindness for others. I was fortunate enough to learn this through being with a very confused and very distressed lady, to whom I silently comforted with gentle touch. I was accustomed to having very confused and “nonsensical” conversations with her, but having offered her some comfort she poured out her heart with startling clarity. She spoke of the depth of her pain and loneliness. How desperately she missed her

loved ones and how painful it was to be alone at night with no one to hold her. Yet despite her pain and her desperation, she also thanked me for my kindness and told me that she did not want to take anything away from me. This kindness moved me to tears. So often, when I am overwhelmed by my own pain or problems, I become too self-absorbed to consider the well-being of another. Whilst this lady was unburdening herself and requesting my support and love, she also made it clear she did not want to take anything from me. She did not want me to lose anything in order for her own benefit and wellbeing well-being. Furthermore, whilst expressing how much she needed what I was able to offer her she said that she knows that I can only help her “a little bit”. This lady with severe cognitive impairment, whilst experiencing her pain so deeply was able to offer such wisdom and compassion. Something that I find when suffering myself so difficult to do even with all my cognitive abilities intact! I wanted to share these experiences in order to remind myself and others who care for people with a dementia that we ought not to presume to know better than or be saner than the people we care for. To remind us that caring is a mutual process, which can be enriching to both carer and cared for if we can accept our common humanity; we are equal in our capacity to be confused, fearful of uncertainty and to feel pain as well as our capacity for love, wisdom, clarity and compassion. I hope that this article is not received as a prompt to be an even more competent and professional

carer but as a suggestion to be as human as humanly possible so that we are enriched rather than depleted by our work.

Luke Tanner

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Barriers to Evidence Based Treatment for People with Dementia in Care Homes



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He has published widely in the areas of dementia with Lewy bodies, vascular dementia, behavioural and psychological symptoms in dementia (BPSD), and on clinical trials in people with dementia. He is perhaps best known for his work identifying the harmful effects of antipsychotic drugs in people with

dementia. His current ongoing research includes studies focusing upon non-pharmacological and pharmacological treatment of psychiatric and behavioural symptoms in people with dementia, Parkinson's disease dementia, Down's syndrome dementia and the management of pain in people with dementia.

There are more than 700,000 people in the UK with dementia. Of the 250,000 of these individuals living in care homes less than half receive a diagnosis of dementia, with many individuals in care home settings not receiving optimal pharmacological or non-pharmacological treatment. One of the key treatment issues has been the overuse of antipsychotic medications for the management of behavioural and psychiatric symptoms in people with dementia living in care homes. Although good progress has been made with significant reductions in antipsychotic prescribing over the last 5 years, further reductions are needed. As the evidence supporting the value of person centred training interventions for care home staff and specific psychological and social therapies continues to grow, it is becoming increasingly important to ensure that these treatment options are available and essential that multidisciplinary teams with the right skills work together to ensure best evidence based treatment and care for people with dementia living in care homes.

Dementia has a vast impact on health and social care services. There are around 700,000

people in the UK with a form of dementia; about 250,000 of whom live in care homes (Alzheimer's Society, 2007). While care homes meet the environmental and physical health needs. People with dementia may have complex needs and may frequently experience additional mental health problems, disabilities, physical illnesses and social needs. In order to promote well-being and improve mental health of people with dementia, it is vital to ensure the best management of cognition, function and key non-cognitive symptoms. People with dementia often experience [behavioural and psychological symptoms of dementia](#) (BPSD) such as hallucinations (seeing or hearing things), delusions (believing things that aren't true), anxiety, agitation and aggressive behaviour. Approximately, 90% of people with dementia may experience these symptoms at some point (Ballard et al., 2009a), and they are especially common in people living in care home settings (Margallo-Lana et al., 2001). These symptoms may cause difficulties not only for the person and their carers, but also in relation to their clinical management.

Under diagnosis and access to the right treatment is an important issue in providing the best management of well being and improving quality of life for the people living in care homes. Epidemiological studies have indicated that more than 60 % of people living in residential and nursing homes in the UK have a form of dementia (Matthews et al., 2002). These figures are now a decade out of date and there have been no subsequent

systematic studies, although clinical opinion suggests that the proportion of individuals with dementia continues to grow. The National Audit Office (NAO) (2007) reflected that less than 28 % of people in care homes are in places registered for people with dementia. This suggests that even at a conservative estimate there are more than 150, 000 people living in care homes, who may have undiagnosed dementia and will prevent access to the right treatment, support and benefits for many people with dementia living in these settings. Further action and research is therefore urgently needed to address these key issues. One of the key challenges is the continuation of national support for reducing antipsychotic prescribing.

Antipsychotics in people with dementia

People with dementia have frequently been prescribed [antipsychotic drugs](#) as a first line of treatment for behavioural symptoms. Antipsychotic drugs have been around for a long time, but until recently there was no evidence of reduced prescribing despite increasing evidence of harms associated with long-term prescriptions. As a result of clinical and political imperatives, there have however been significant reductions in antipsychotic prescribing over the last 5 years, with an estimated decline in the use of antipsychotic medication for people with dementia of 51.8 % between 2008 and 2011 (Health and Social Care information Centre (HSCIC), 2012).

The widespread use these drugs for people with dementia has been questioned for some time (Ballard and Howard, 2006) owing to only modest effect and accumulating evidence that the risks associated with antipsychotic medication outweigh any possible benefits (Ballard and Howard, 2006). Clinical research indicates only limited benefits for the treatment of aggression and psychosis in people with Alzheimer's disease (AD), with statistically significant but small benefits (standardized effect size 0.2) for short periods of treatment up to 12 weeks. There are however significant safety risks associated with treatment including an increased risk of stroke, other cerebrovascular problems and death. There are an estimated 1800 excess deaths and 1620 cerebrovascular accidents per year as a result of the prescription of antipsychotics for people with dementia (Banerjee, 2009). This finding is further supported by the Dementia Antipsychotic Withdrawal Trial (DART –AD) which reported that after 24 months, 71 % of the people with AD in care homes taking placebo (dummy) treatment remained alive compared to 46% of those continued to take antipsychotic medication (Ballard et al., 2009b)

A commonly used atypical antipsychotic drug called quetiapine has not shown to be effective for treating symptoms such as psychosis, agitation or aggression in people with dementia and is associated with accelerated cognitive decline (Ballard et al., 2005). Some antipsychotic drugs such as risperidone, aripiprazole and olanzapine do provide small

but significant benefit over a short period of time of 6 – 12 weeks of treatment. Risperidone is the only antipsychotic with a specific license to treat severe aggression for people with dementia for a maximum treatment period of six weeks. Most best practice guidelines, including the NICE SCIE dementia guidelines (NICE/SCIE, 2007), suggest that treatment with antipsychotic medication should be prescribed carefully with a regular review and maximum treatment period of 12 weeks.

Historically, there have been few evidence based approaches for management of behavioural and psychological symptoms. There is now growing evidence in favour of personalized psychosocial interventions, such as social interaction, enjoyable activities and reminiscence for the management of key BPSD such as agitation and depression (Fossey et al., 2006). There is also evidence that person centred training interventions for care home staff can improve practice and enable the safe withdrawal of antipsychotics for people with dementia without worsening of BPSD (Fossey et al., 2006), however there is extremely limited availability and implementation of interventions shown to confer benefit in randomized controlled clinical trials (Fossey et al., 2013).

Psychological Treatment to Improve Cognition

An emerging evidence base indicates that different approaches to cognitive training and cognitive stimulation confer modest but

significant benefits for people with AD. The best evidence based non-pharmacological intervention is for Cognitive Stimulation Therapy (Spector et al., 2003). The limited number of individuals trained to deliver these interventions adds a further challenge in promoting evidence based care for people in care home settings.

Pharmacological Treatments: Acetylcholinesterase Inhibitors (AChEIs) and Memantine

There are 2 classes of licensed pharmacological therapy for people with Alzheimer's disease, Acetyl cholinesterase inhibitors (AChEIs) and memantine. Three AChEIs (donepezil, rivastigmine and galantamine) are licensed for the treatment of people with mild to moderate AD and memantine is licensed for the treatment of people with moderate-severe AD. The AChEI rivastigmine is also licensed for the treatment of people with Parkinson's disease dementia. Symptomatic benefits of AChEIs drugs have been reported in more than 30 randomized controlled clinical trials (RCTs), which demonstrate a significant improvement in cognition in addition to stabilisation of everyday function for people with mild moderate AD taking AChEI medication for six months. (Loy and Schneider, 2006); (Birks and Harvey, 2006); (Birks et al., 2009). People on treatment improved on average by about 10 per cent on standardised cognitive assessments, which is the equivalent of six months of expected decline in cognitive function, whilst the level of

performance remained above the baseline for nine to twelve months for majority of people. In 6 further RCTs, memantine has been shown to stabilise cognition and function (McShane et al., 2006). One of the RCTs examining the benefits of memantine on cognition and function in with people in moderate to severe dementia, a 28 week placebo controlled trial, undertook a more detailed evaluation of items from a standardized assessment of activities of daily living assessment. Of note, the study demonstrated a positive effect of memantine on specific elements of functional ability such as ability to stand up, move, dress, eat, take in fluids and use the toilet, with significantly less decline on these specific functions in people taking memantine compared to those receiving placebo over 28 weeks. These aspects of functioning are of particular relevance for retained function, maintaining a degree of independence and quality of life for people with more severe dementia living in care homes. (Doody et al., 2004)

There has been a considerable discussion about whether the symptomatic improvements conferred by anti-dementia drugs have a meaningful impact on person's quality of life in the absence of a formal quality of life measures in the majority of clinical trials. A large survey conducted by the Alzheimer's Society which included more than 2,000 carers of people with Alzheimer's disease taking anti-dementia drugs highlighted a number of benefits in areas relevant to quality of life such

as social functioning and confidence (Ballard et al., 2007). The survey also suggested that the majority of people taking anti dementia drugs felt that the treatments did provide them meaningful improvements. A further RCT of the AChEI galantamine used goal attainment scaling as the primary outcome and demonstrated significant benefits on key goals that were specified by the study participants themselves (Rockwood et al., 2006).

The National Institute for Health and Clinical Excellence (NICE) guidance now recommends that AChEIs are now available as part of NHS care for people with mild-to-moderate AD. NICE guidance also recommends memantine for people with moderate AD, who cannot take AChEIs, as well as for people with severe AD (NICE, 2011). However, only 10% of people with dementia receive AChEI or memantine medication; this figure has remained the same since 2008 (HSCIC, 2012), and this figure is very substantially lower for people with AD living in care homes. This might be the case as a result of an imprecise assumption that people in care homes shouldn't be prescribed memantine or cholinesterase inhibitors, although this is not stated either in the license indication or the NICE guidance and there is good evidence that these individuals will benefit from therapy. The failure to prescribe these treatments is depriving individuals with AD in care home settings from beneficial pharmacological treatments which are licensed and recommended by NICE.

Conclusion

In the UK alone, approximately less than half of people with dementia living in care homes obtain a proper diagnosis. Antipsychotic prescriptions are reducing, but are still over utilized for the treatment of BPSD for people with dementia living in care settings. Conversely, only a small minority of care homes receive appropriate access to evidence based person centred care training. Private sector, NHS and university organizations need to come together to develop and infra-structure that can improve the diagnosis of dementia and to optimize pharmacological and non-pharmacological treatments to improve the lives of people with dementia living in care homes.

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Wesley Church Activity Analysis Solace



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Advisor (DCA).

As one of six DCA's employed by the UHB, she job shares with a qualified nurse working within Solace and the Memory Team. Solace provides carers looking after an older person affected by a mental health condition a point of contact for information, education and support. The Memory Team based at Llandough Hospital is a multi-professional team that specialise in the assessment, diagnosis and treatment of people experiencing problems with memory.

Within both teams her role is developing towards providing support to carers looking after an older person with a diagnosis of dementia. This includes education about the illness, the importance of looking after themselves, information about local organisations and practical and emotional support. Through her work she hopes to support carers and people with dementia to

live well and receive the right help at the right time, enabling them to continue to live fulfilled lives.

Aim and Purpose

The aim of this activity analysis is to assist with the overall evaluation of an activity based therapeutic group offered to people with dementia and their family carers as part of a weekly maintenance programme. The maintenance sessions are offered following completion of an evidence based 7 week cognitive stimulation therapy (CST) programme titled 'Making A Difference' which the person with dementia may attend, whilst their family carers are invited to attend a carers support and information forum that runs alongside the CST programme. Group CST programmes for people with dementia are considered to have a positive impact on memory and communication skills through the use of familiar every day activities and have been shown to significantly improve quality of life for a person with dementia (Alzheimer's Society 2013).

Current NICE guidelines recommend that people with mild to moderate dementia have the opportunity to participate in structured CST programmes in group settings (NHS 2011). Furthermore NICE guidelines also recommend that the needs of the carers should be assessed and the opportunity for carers to access support and education should be offered (NHS 2011).

Activity analysis is a method of deconstructing an activity into basic components to understand the value and meaning a person associates with an activity and the performance skills required to carry out that activity. As a method that is traditionally used in the field of occupational therapy, Foster and Pratt (2002) explain that synthesis of the findings enables links to be established between the needs of the individual with the demands and potential of the activity, allowing for adaptations to be made to facilitate optimum levels of performance based on individual need.

Here, an observational approach has been used as a starting point in evaluating the use of a weekly activity based group which aims to provide a skill and social maintenance programme for people with dementia and ongoing social and support opportunities for carers. The outcomes of the observations have been presented under specific headings based on areas of skills observed. Recommendations to support further evaluation of this group will be provided later.

Scene Setting

The maintenance sessions held at the Wesley Church in Canton, Cardiff offers a range of arts & craft based activities for people with dementia and family carers. These range from a variety of small, quick to complete activities to longer term projects that people can work towards completing over a period of time within group sessions and outside the group at home.

The sessions are held at the same time, in the same venue and facilitated by the same staff and volunteers each week where possible, aiming to create a sense of familiarity and routine, considered to be important to empower a person with dementia.

Activities: Wide range available from quick to complete tasks to longer term group projects.

Environment: Wesley Church, Cowbridge Road East, Canton Cardiff. The group has access to two rooms as well as access to kitchen facilities.

Access: Recommended via side entrance to church on Nottingham Street, where there is ramp access available. Separate male and female toilets available near to the function room used for groups. Standard height toilets, available, no rails. No disabled toilet in this area of church.

Day: Every Wednesday

Time: 1pm – 3pm

Duration: 2 hours

Group size: Currently approx 4 couples

Group mix: Male and Female. People with dementia and carers

Staff: 1 Cardiff and Vale UHN employee and 2 volunteers (1 with a strong interest in art and empowering others)

Materials and equipment: Wide range of art and craft based materials available, i.e. crayons, felt tip pens, paints, pencils, assorted paper, wool, assorted needles, assorted beads, wood model making kits. Sustainable items bought where able.

Cost: Venue hire and costs of materials. Partially provided by Solace budget, fundraising and grant applications sourced by Solace staff.

Refreshments: Hot drinks and biscuits, these are provided by Solace and group members.

Travel: Group members are encouraged to make own arrangements.

Performance skills

It is easy to assume that adults with dementia will inevitably lose everyday skills and become dependent on others. Even people unaffected by a health condition will lose skills if they are not practiced. It is widely considered important for people with dementia to remain as active as possible and continue carrying out as many of their previous activities as independently as possible, in order to retain their skills (Alzheimer's Society, 2013) For all human-being doing things for ourselves can enhance our physical, social and emotional well-being, through the preservation of dignity, confidence and self-esteem.

The various arts and crafts activities used require an individual to utilise a range of performance skills. Providing the opportunity to practise these skills in a meaningful way a

person with dementia may be able to maintain these skills over a longer period of time with the potential to develop new skills. In addition, the carers may also benefit from skill acquisition and maintenance, along with the opportunity to increase social contact.

Bead Work.

During the observation of individuals engaging in bead work to produce decorative snow flakes, participants were noted to require precise use of fine motor skills to allow them to grip and accurately thread small beads onto fine pre-shaped wire.

Delicate pincher grips were used in order to pick up the selected bead, accurate vision to locate the hole for threading, and the use of fine hand motor skills and eye co-ordination to successfully thread the bead onto the wire. Participants were observed at times to reach across the table, utilising gross motor skills and postural control in order to retrieve an item to continue with the task in hand. The activity is completed at a table from a seated position, using a chair without arms requiring the use of sufficient trunk and posture control to maintain an adequate working posture and level of comfort.

Colouring pre-drawn age appropriate sketches

Participants engaging in this activity were observed to have access to a range of coloured pencils of varying widths, successfully supporting varying abilities of fine motor and

grip skills. The ability to manipulate a colouring pencil within boundaries set by the drawing requires a person to adjust their technique at certain points i.e. change directions, use larger strokes over larger area's and small motor movements to colour smaller detailed area's of a picture. Individuals were given the choice to choose to draw their own pictures from memory, copy existing pictures or colour pre-drawn sketches. Offering this range of choice supports the person to engage in the activity at a level compatible with their skills, whilst also offering the option to increase or decrease the level of task demand on an individual basis.

As above, the activity is completed at a table from a seated position, using chairs without arms requiring the use of sufficient trunk and posture control to maintain a safe sitting position and adjust position accordingly to support an adequate working posture and maintain of comfort.

Key skills: hand and eye co-ordination, gross and fine motor skills, range of movement, posture control and mobility.

Cognitive Skills

Both beadwork and colouring pre-drawn sketches require participants to use a wide range of cognitive skills.

Dementia is commonly associated with memory loss; however the disease can affect many cognitive functions. As in all areas of skill, in order to maintain cognitive skills the opportunity to 'do' is essential and Reynolds

(2009) suggests that art therapy may help patients regain some function because it actively engages both hemispheres of the brain.

One participant with dementia who was previously a professional decorator, but who had not engaged in any similar activity for many years was observed to work methodically and precisely, measuring a pre-drawn sketch which he had chosen to copy by free hand. As a professional decorator it is highly likely he would have used measurements and calculation to ensure an accurate end result. The use of free hand sketching appeared to have allowed him to not only regain a use for previously mastered skills, but also the potential to develop new skills and interest through sketching.

All participants were observed to engage in decision making related to their chosen activity i.e. select required materials and choose colours, allowing them to successfully plan and sequence the activity. Some participants were able to make decisions independently, whilst others required minimal support to facilitate successful decision making i.e. limiting range of choice available. For those with dementia, having the opportunity to engage with the decision making process may not only contribute to a sense of empowerment but may also help to encourage pre-existing memory of knowledge and understanding to be drawn upon i.e. choosing blue to colour the sky.

For all members of the group significant levels of sustained attention and concentration were observed throughout the duration of the session, significant as people with dementia often have difficulty with concentration and attention (Reynolds, 2009). The use of arts and crafts appears to naturally create an environment that is supportive of needs often associated with people with dementia, i.e. quite ? quiet, limited distractions, use of familiar activity etc, leading to a suggested positive impact on attention and concentration. A noticeable difference between the attention and concentration skills of participants with dementia and carers was the carer's ability to use divided attention. This was demonstrated by the carer's ability to continue to produce bead work whilst talking amongst themselves, in comparison with the person with dementia either working quietly and focusing all their attention on the task in hand or temporarily stopping the task in order to engage in conversation.

Key skills: attention, concentration, comprehension, planning, sequencing, decision making, judgement, perception, object recognition, memory recall

Psycho-Social Wellbeing:

Arts and crafts used therapeutically are frequently acknowledged for its potential to improve a person's physical, mental, and emotional well-being (Art Therapy 2013). A study by Fiona Kelly (2007) found that the use of creative sessions with people with dementia

on a long term ward provided an opportunity for sustained positive interactions, a noted rise in participant well-being and facilitation of self-expression.

The use of art and craft activities as a group activity was observed to encourage socialisation and the practise of social and communications skills on a number of levels.

Relationships developed within the group were observed to foster supportive and positive social interaction between all members, with no segregation between those with dementia, the carers or staff/volunteer. The group has provided opportunities for new relationships to be formed and social interactions were noted to range from general 'chit chat', sharing task based knowledge, peer support, praise and encouragement of achievements. Decision making and equipment selection was also observed to provide the opportunity for meaningful social engagement. Throughout the observation period members were observed to use social skills on a 1:1 basis and also as part of a wider group interaction.

At times social interactions were also observed to facilitate a person taking on a specific role within the group, i.e. teacher and learner. In one instance a gentleman with dementia was observed to be sharing his work and methods with another carer and encouraging him to try the same techniques.

Including carers within the same group, was observed to serve a positive purpose by creating the opportunity for discreet carer's education. By facilitating the opportunity for family carers and the person with dementia to attend therapeutic groups as a couple, carers are exposed to witnessing the wide ranging positive outcomes of 'doing with' rather than 'doing for' a person with dementia can bring, an observation reinforced within the group by the 100% participation level. Staff skills to adapt an activity where needed in the presence of family carers, provides the potential for carers to learn such skills in a non threatening practical way and may encourage them to look for ways to adapt activities in other area's of life, creating greater opportunity for their relative to maintain skills and wellbeing through participation in everyday tasks.

Furthermore, attending as a couple may lead to the strengthening of relationship identity as either husband or wife or mother and daughter for example, rather than the potential to view relationships as person with dementia and their carer, allowing them to have a sense of normality.

The general atmosphere during the sessions observed felt calm and relaxed, creating a non pressured environment, through the focus on ability rather than disability. Individuals were observed to have a clear sense of pride on completion of work, demonstrated through actively inviting the group to view work and accepting compliments. One group member with dementia, who was observed being

presented with a piece of their work which had been framed by Solace staff, could be overheard discussing plans on where to display it at home.

Key Skills: 1:1 and group interaction skills, verbal and non verbal communication skills, develop new social relationships; maintain individual identity and couple identity, role rehearsal, activity adaptation skills, empowerment.

Conclusion

It is widely accepted that the use of activities that are meaningful and provide stimulation for a person with dementia and the ability to practise and use remaining skills will give greater opportunity for skills to be retained for longer.

Whilst this observation has presented performance skills, cognitive skills and psycho-social wellbeing areas separately it is important to acknowledge that a positive impact in one area is likely to lead to a positive impact in another, i.e. successfully performing a task is likely to have a positive impact on a person's psychological wellbeing and self esteem. Performing activities within a group setting encourages people to engage not only with the task but also with each other, leading to improvement or maintenance of social and/or communication skills.

Limitations and Recommendations

Observational analysis can only report on what was observed during the period of time the observation was carried out and cannot make any assumptions related to service user experience. Also it will not provide insight into potential carry over effects that may occur outside of the sessions. From completing the observational analysis, themes can be identified for further evaluation. The consideration of using service user focus groups or interviews for example will provide insight into the subjective views of participants to further enhance the evaluation of the use of arts and crafts based maintenance session for people with dementia and their carers. If planning to use focus groups or interviews to further explore themes presented by this observational account, a prepared copy of themes may be given to focus group/interview participants to act as a prompt to capture relevant data for evaluation; however caution must be given to avoid leading questions.

Suggested themes from observation for further exploration:

- Re-use of skills and new skill acquisition
- Continuation of engagement with activities outside of the group
- Impact on family relationships
- Impact on social skills
- Impact on wellbeing of person with dementia

- Impact on carer wellbeing
- Outcomes of attending regular weekly sessions on a person's sense of structure/routine.

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Tactile Art for Mental Health Services at University Hospital Llandough



As three graduates of Cardiff School Art & Design (CSAD) who have been commissioned by The Gwanwyn Arts Festival from Age Cymru and Cardiff and Vale University Health Board, we are working towards a pioneering art therapy project to treat mental illness. After creating an initial piece, we have completed a further three-dimensional, tactile wall artwork that is to be installed in the new Mental Health Service for Older People unit (MHSOP) at University Hospital Llandough (UHL) in the autumn of 2013.

Back in May 2012 Philip Thomas, Gwanwyn Festival Coordinator at Age Cymru, came to Cardiff School of Art & Design to give an introductory talk about funding for a Tactile Art installation that could be used by carers and professionals to soothe and interact with patients in our local community.

During the commission we wished to address and promote creative collaborative solutions to assist in improving people's well-being. The theme of these artworks has been inspired by the four seasons, with the intent of depicting each season in a multi-sensory technique.

Statistics

There is a growing concern with the number of those with dementia and the need for increased awareness. In the United Kingdom there are about 800,000 people with dementia, with this number set to double in the next 40 years to 1,700,000. Furthermore, it is reported that delaying the onset of dementia by 5 years would reduce deaths directly attributable to dementia by 30,000 a year (Alzheimer's Society, 2013). Statistics like these cemented our desire to get involved, knowing that we could directly contribute to enhancing the quality of life for dementia patients.

With on-going efforts to revitalise the treatment and perception of dementia, new facilities are providing more stimulating environments through the use of innovative and varied art therapy forms. This is enabling carers and staff to assess and stimulate patients with different levels of need simultaneously and with more ease.

Assessment

When assessing the severity of dementia there are certain initial things to look for and ways families and professionals can research and

review developments in dementia care. There are five key areas for assessment, consisting of tactile difficulties, changes in visual perception and reminiscence ability, degradation of cognitive skills and changing attention span.

Once assessments have been completed people with dementia are often categorised as:

Mild – Moderate – Severe

In severe cases the patient shows serious damage to their perceptual ability.

Through understanding these categories we realised our artwork had to be open to interpretation, in order to be multi-purposeful, ranging from visual to tactile to cognitive engagement.

Treatment aims

Initial aims in treatment are to relieve the symptoms resulting from dementia, by soothing, relieving anxiety and encouraging interaction. These are all through direct and indirect stimulation, all of which promote patients' cognitive abilities.

Cognitive stimulation can occur through activities and challenges, such as interactive puzzles, abacuses, mazes and sliding picture puzzles. These interactive challenges could not only provide stimulation but also encourage focus from the patient. One branch of treatment method is through artistic endeavours that target the still healthy areas of

the brain and find new paths to recollection and conversing information.

Benefits that improve the quality of life through creative engagement are:

- reduced depression and anxiety
- reduced agitation
- increased concentration, orientation, fine motor skills
- increased mobility
- improved attention span
- greater social interaction
- improved self-esteem

All of which we would hope to achieve post-interaction with our artwork.

Art therapy

There are varying forms of art therapy, helping participants improve their creative expression and “re-find” their voice. Art workshops prove very beneficial through initiating group activity and reducing feelings of isolation, through sessions such as memory quilting, painting and art gallery guided tours.

To fully comprehend this in an effective manner we wanted to find a source where this could be analysed consistently. An interesting study discussed and visualised the changes in professional artists' practice throughout all stages of dementia. It showed the changing artists' technique and composition from

geometric and realism to extreme abstraction in form and colour. (Musella & Fasanaro. Visual Art in Alzheimer Disease: A tool for therapy, research or both?) From this we decided not to limit our design to one art style.

Recognitive movement and tactile therapy

Two methods used in art therapy to trigger memories are recognitive movement and tactile memory. Recognitive movement is the recall of a memory through a movement, whereas tactile memory is the recall of memory through the touch of an object. For example recognitive movement is associated with a repetitive activity such as sewing or kneading dough, whereas tactile memory is associated with the feel of objects, such as a tree bark texture can link to a memory of a tree swing.

Recognitive movement can influence the viewer to interact with a material in an instinctive active movement, both physically and visually. These physical activities can vary from plucking, squeezing, pinching, stroking, pushing, twisting or opening and closing an object. Recognitive movement can also influence visual movements, from following a pattern of light and moving objects, to simply the flow of the design and material, like that of wood grain. Specific contours can gently guide the eye and the hand to experience things in a certain order, enticing the viewer to physically interact with a material.

Through incorporating ideas of both recognitive movement and tactile memory into our design,

we could increase the possibility of memory recall through a plethora of materials.

Reminiscence

Another idea used in art therapy is to encourage reminiscence. Some actions are so well remembered that they become second nature, with memory of habitual shapes, environments, movements and functions. Interaction through memory such as switches, typewriters, handles or buttons can often require a form of muscle memory. Not only can reminiscence therapy occur through reminiscence rooms, but there are many modern day objects that can be familiar too. Many people retain objects that hold personal sentiment, from family heirlooms to childhood toys which while treasured, can also induce powerful memories.

Reminiscence rooms

We wanted to increase every chance of recognitive stimulation, whether through a certain texture or a familiar pattern. This resulted in us looking back to 1950's and 1960's wallpaper patterns for inspiration, and through this we discovered that environment installations such as reminiscence rooms are increasingly used to calm patients in care homes and hospital settings. This technique is especially effective for those with dementia as short term memory is lost early but long term memory stays relatively intact for a considerable length of time.

These reminiscence rooms trigger long term memory by 'transporting' people back to earlier times. Stirring fond memories and helping with recollection, getting patients physically and mentally active, interacting with familiar objects from the past and coming up with solutions for tasks and puzzles, can be stimulating and rewarding.

Current mental health projects

We also saw great interest and success in what was currently available, such as multisensory therapy, which can reduce anxiety and promote engagement and interaction, and activity classes, which encourage expressions of feelings and opinions, reminiscence and physical contact with materials and objects.

Through our initial research into products that aid mental health, we discovered that there was a continuous use of bright colours, pliable silicone and gel based products. The products that we found most intriguing were those that integrated opposing characteristics through materials, such as combining textures that are coarse and smooth or cold and warm. This could also be done through light and dark colours. By integrating opposing characteristics into our tactile art pieces, we aimed to increase the range of stimulation, without compromising the material quality and its effectiveness.

Various special need objects and toys that took our interest seemed more targeted for a younger age group, whilst we intended to

appeal to all age categories. We were therefore keen to explore how combining elements of fine art, applied arts and decorative arts could benefit all categories and ages within one session; such as with children enjoying the pictorial qualities and tactile nature of artwork first, while other individuals could try to analyse and critique the work in relation to their own experiences and preferences.

Verbal and cognitive engagement with patients proves an ongoing obstacle, and with this degenerative condition making interaction for families, friends and carers ever more a challenge, we strongly believe the use of art can be of great benefit. Our goal is to motivate and enable individuals into relaying expressive and informative communication to family and carers.

'Art can be the bridge for communication'

By merging current objects and products into a visual and tactile artwork we aimed to provide people with dementia new opportunities and avenues to communicate self-expression and converse with loved ones. Art can assist self-expression when verbal skills and memory start deteriorating, as it allows for non-verbal expression of emotions. It can also encourage family and community engagement, providing a new source of excitement, hope, happiness and reconnection through creative pursuits. In some cases, it has been seen that the artistic process proved more effective than being in a

social group conversing, and helped to decrease depression levels.

Help Carers

A key project goal was to provide activities and ways for professionals to interact with their patients. Carers can use verbal instructions with hand motions that 'zoom in' to encourage individuals to observe specific areas of the art piece in a fun and non-confrontational manner. This activity will encourage personalised experiences of the artwork, initiated and guided by the carer, allowing them to use the piece as a gauge of the individuals' day-to-day wellbeing.

Concept

With all this gathered information we wanted to cognitively stimulate the patients through artwork that is open-to-interpretation. The most rewarding element of the design stage is collaborating with other artists, adjoining ideas and designs to create diverse elements that complement each other. Our concepts were pooled together from various forms of art therapy, including architecture, furniture, music, nature, abstraction and symbolism.

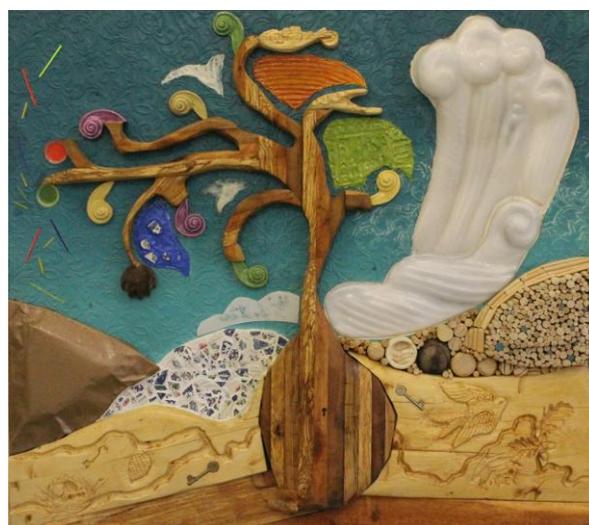
Aim

"To engage the local community is fundamental, particularly with the sourcing of materials and positively highlighting the ever-evolving nature of art with therapy."

Design

The piece was designed to be personalised for the community by sourcing local imagery, with the benefit of helping recollective memory for patients.

We incorporated certain health and safety considerations into the design of our "Prototype", such as avoiding absorbent materials, using rounded edges and ensuring hard wearing materials which allowed for physical interaction.



We also selected the image of a tree for the main focus in our "Prototype" due to its association with nature and the cycle of life. Just as a tree changes through the many seasons of its life, so do people. The cycle of life of a tree is not perceived as negative and our own natural experiences of aging and change need not be either. It is for these reasons we considered a tree naturally relevant to our art work.

Evaluation Criteria

In order to achieve our goal we set up criteria to analyse each material and feature of the piece, making it full of vibrancy but not overwhelming. We had to consider the varying cognitive, social and physical abilities that each individual would have when interacting with our art. By using multiple elements with opposing characteristics we could encourage a response from all patients, no matter the stage of dementia they may be at. Thus we outlined our design strategy with contrasting elements such as:

Cold	→	Warm
Rough	→	Smooth
Light	→	Dark
Soft	→	Hard
Absorbent	→	Reflective
2D	→	3D

Prototype Conclusion

Upon completion we took the piece to Llandough Hospital for feedback. Patients and staff individually highlighted which features had the most impact for them, ranging from the recollection of distant memories to engaging and interlinking different elements on the piece, such as a key with a key-hole. With this feedback we came away more informed and developed ideas for the commissioned piece “Spring”.

‘Spring’

After presenting our finished “Prototype” and receiving the commission to produce a tactile art piece for University Llandough Hospital, we considered which of the “The Four Seasons” we should base our art work on. We decided that Spring would be the most appropriate season as not only is the Gwanwyn Festival celebrated in Spring but we could also reflect iconic ideas of Spring, through depicting new life in blossoming flora to bright and cheerful colours.



Concept and Design

Alongside the central theme of nature and seasons, we continued to apply the research gained from the “Prototype”, in regards to design inspirations and materials and processes explored, alongside new approaches. Quilting with PVC fabric and button tufting were two new elements, with another implementing art deco design inspired brass sun rays. As well as depicting nature, there are human traces to be found throughout the design, elements such as a tree swing.

This piece will also be lighter and more durable than the “Prototype” having been constructed with a fibreglass structure.

Throughout this commission we have kept an updated online record of processes via our blog on the Gwanwyn Festival’s website. <http://gwanwyn.org.uk/> .

The Way Forward

Through careful research this project has offered a unique perspective in art therapy, by utilising the creativity of skilled artists and implementing it within existing therapy practices and ward environments. The final outcome of this combination means that a personalised therapeutic artwork can be produced that can directly relate to an individual and group audience. We believe that projects like this are the way forward in creating new bridges of communication and hope that our “Spring” unveiling in Llandough Hospital created a seed of growth for further projects to come.

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Dementia-friendly design: Brookside Extra Care Village



Damian Utton is a chartered architect and a Partner at Pozzoni, an architectural practice working

across the UK from bases in Manchester and London (www.pozzoni.co.uk). Damian has spent most of his career working in the older people sector and leads a team creating innovative designs within cost and programme constraints. Damian is also the author of “Designing Homes for People with Dementia” and is a regular speaker at national and international conferences on all aspects of designing for older people.

Introduction

This case study is an overview of **Brookside Extra Care Village**: How the dementia-friendly design has responded to local need, demand and site constraints to create a community resource will be highlighted and how the scheme is currently working.

Brookside Village is an extra care development of 111 apartments and community facilities located at Ormskirk, Lancashire and is the

result of a partnership between Councils, NHS Central Lancashire and links with Age UK, Alzheimer's Society and University of the Third age.

Design work began in 2007, and the first residents moved in to their new home during April 2012



Dementia Design Principles

Because dementia affects everyone in different ways there are no set guidelines for dementia design.

However there is a consensus as to the principles of good dementia design, including to:

- compensate for disability
- maximise independence
- enhance self-esteem and confidence
- demonstrate care for staff
- should be orientating and understandable
- reinforce personal identity

- welcome relatives and the local community
- allow control of stimuli

(Marshall et al 1998)

This translates into specific design features such as:

- Small, familiar, domestic and homely in style
- Scope for everyday activities
- Discreet monitoring for safety
- Different rooms for different uses
- Age-appropriate furniture, fixtures and fittings
- Safe outdoor spaces
- Bedrooms large enough for personal possessions
- Good signage and multiple cues where possible
- Using objects for orientation
- Good visual access
- Controlled stimuli, especially noise

(Utton 2006)

Brookside has incorporated these principles and features as far as possible in the design.

Design Brief

The over-riding concept for Brookside was to add support to the housing, lifestyle, health

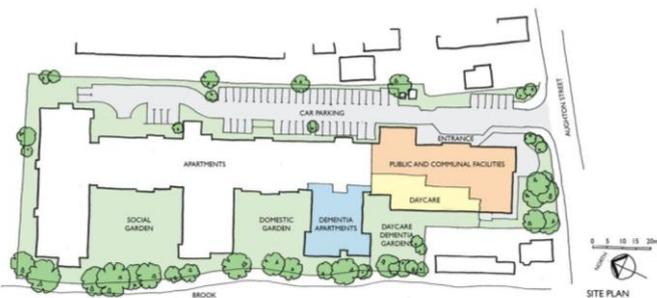
and social care needs of the older people in the Ormskirk area, creating a built environment that offers safety and security without compromising freedom and quality of life

To achieve this, the apartments required:

- Design for independent living and creating a home for life, with a proportion of apartments, with their own communal lounge, kitchen and garden specifically for people with low-level dementia
- Day care centre for people with dementia from Brookside and the wider community
- Public access to the community facilities, creating a community hub providing information and access to advice and support, health and well being activities and specialised health and social services

Layout

The building layout is organised to have all the public uses at the street frontage end of the site with progressive privacy to the private apartments and a mix of larger social spaces and smaller intimate personal spaces



There are three garden areas created (social, domestic and dementia) to maximise afternoon

sun to the gardens and views to the activity of the school and the school playing fields.

The day care facilities and the cluster of dementia apartments are linked via the dementia garden and discreet security ensures the safety of the people with dementia.

The building layout would be linear, however the length of the corridors has been reduced in scale by creating incidental spaces of sitting areas, recessed doorways, and creating 'events'. To avoid any dead-ends there are lounges or alcoves at ends of all circulation spaces – creating a destination. Residents are being encouraged to personalise the recessed 'front porch' by their apartment doors and 'street-scaping' the kitchen windows so that they face onto the corridors.

Community Facilities

In order to make Brookside a vibrant community, there are a range of community facilities for residents and that are also open to the public. These include:

- Bistro café
- Community Room which
- Library
- IT suite

There is also a range of community facilities that are accessible for residents only and these include:

- Exercise studio

- Music studio
- Hair salon
- Lounges: each with a different theme

Brookside is also a base for several local organisations providing care and support services within Brookside and to the wider community. These are:

- Your Housing Group (housing provider)
- HICA home care (care provider)
- NHS Older Adult mental health and memory assessment teams from Lancashire Care foundation NHS Trust
- Age UK
- Alzheimer's Society
- Visiting medical professionals from the local community health trust – Southport & Ormskirk NHS Trust

There is 24 hour waking cover on site at Brookside with a minimum of two staff: one housing and one care.

Secure doors with fob access with clear signage and design layout ensure that the general public do not access the resident only areas.

Apartments

There are a total of 111 extra care apartments, one and two bedrooms, which have to comply with certain standards, as well as the

mandatory planning consent, associated conditions and current Building Regulations.

Additional features to the apartments include:

- The kitchen open to the living areas for ease of access;
- Kitchens have windows to corridors with blinds so residents can choose whether they wish to have full privacy or allow views to the activity outside;
- Mobility scooters can be parked either in the apartment hall or in the corridor recess, or front porch, by each apartment front door.
- Ceilings strong enough for a future ceiling track hoist to be fitted
- Wet room shower-rooms for ease of access and with doors from the bedroom and hall.
- Low window sills allow for views out to the garden when sitting down or lying in bed
- Ground floor apartments have their own 'balcony' in the form of a slightly raised terrace with guarding and handrail. This allows the resident their own personal outdoor space without compromising security.

On-site day-care facilities

- The day-care facilities are self-contained with access from the main entrance, and are staffed so residents

cannot accidentally walk off; they would have to pass the day-care office, through a secure door, and past reception. The facilities are locked out of day-care hours so residents from the dementia apartments cannot access the facilities or a route through.

Garden areas

The concept was to create three garden areas: social, domestic, dementia gardens for the residents plus a Bistro garden for public.

There is full access to the three garden areas for the various user groups with the intention of daily year-round use.

There is scope for organised activities such as a gardening club with a greenhouse, shed and raised planting beds provided as well as the everyday, but equally important activities such as hanging out the washing or sweeping the path.

The dementia garden creates passive stimulation from the colour and smell of plants and also provides therapeutic activities with a greenhouse, shed and raised planters. There is the opportunity for exercise with looped paths and seating areas and points of interest and landmarks for way finding.

The social and domestic gardens are well used, especially with visiting children who have the space to play, which in itself is an enjoyable activity for residents to watch.

Dementia-friendly Apartments

The original design brief required a cluster of 15 apartments to ground, first and second floors specifically for people with dementia.

This cluster was to have their own community lounge and assessment kitchen with access to the dementia garden. Other specific design details include: each front door of a different design and memory boxes to help people identify their own door, glazed kitchen cupboards to easily identify the contents, safety cut off devices for water, gas and electricity, separate hot and cold taps with cross heads as mixer taps can cause confusion.

However, the housing market crash of 2008 forced a rethink of the proposed mix of tenure within the development and ultimately, the decision to move ahead with a specific cluster of apartments for people with dementia was decided against and the decision to integrate appropriate delivery of dementia care across the whole site was taken.

This was an acknowledgement that *admission at an earlier or moderate part of the disease journey would be advantageous* for people to become integrated within the whole scheme, though individual circumstances such as on-going carer. However there is still the potential to utilise this specifically designed space on the ground floor as a longer term design option, should it be felt useful to have an element of the scheme designed for more significant dementia need. This would allow in

the future for a planned approach to internal movement within the scheme to offer a longer term support option that would allow for people to remain within Brookside if needs changed significantly.

The rooms that were designated to be the dementia lounge and rehabilitation kitchen became a themed lounge, similar to the other themed lounges throughout Brookside.

Dementia Design

The building has included dementia design principles throughout. The people with dementia who are now living across Brookside may benefit from:

Colour and contrast for orientation throughout

- Assistive technology to help residents to maintain their independence
- Pull cord payphone and pendants and the staff have direct phones
- Automatic opening doors with a fob access
- *Just Checking* – this is a monitoring system of movement within apartments using wireless movement sensors. This can give assurance to relatives and staff that people are following routines that work for them, such as appropriately using the bathroom and kitchen at relevant points of the day, as well as highlight patterns that may be concerning such as repeated short term

use of parts of their accommodation or leaving doors open and unlocked.

- *Memaxi* – This is a touch screen calendar and video link display and acts as a cue to help people remember dates and times

The development of longer stay Rehabilitation units

Following the decision to integrate dementia care across the scheme, the local PCT and County Council made the decision to commission seven longer stay rehabilitation flats as short-term tenancies. The flats are supported by the domiciliary provision on site as well as a multi-disciplinary health team including both physical and mental health care professionals from Lancashire care Foundation NHS Trust and Southport & Ormskirk NHS Trust. These flats have focussed on supporting the needs of individuals who require either a longer term rehabilitation input, for example following a stroke or acquired brain injury or who may be looking at an enhanced care need such as long term residential support, perhaps as a result of an exacerbation of dementia or functional mental health need or where this is a physical rehabilitation need alongside a co-morbid mental health condition or dementia.

An ability to test whether a housing with care option could meet the needs of an individual or couple was a significant element of the thinking around the development of these short-term tenancies and this has already proved to be the case. It has also made it possible to offer a

rehabilitation option to a couple rather than just to an individual, in other words, the need for rehabilitation has not resulted in the need to split people up.

Finance

There are 40 apartments for sale. When a resident moves on they will receive the cost of the apartment back from Your Housing Group who would then remarket and resell the individual apartment. As a Registered Social Landlord, any surplus from this is ploughed back into the organisation for the benefit of the residents. The remaining apartments are social rent and a service charge applies to all residents.

Potential residents must be registered with West Lancashire Borough Council for an assessment of their housing needs. If the assessment identifies additional care needs then a Fair Access to Care assessment through Lancashire County Council is undertaken. If positive then when a vacancy occurs, a panel will allocate the property, depending on an individual's care and housing needs.

Current state of play – what's working well

The first residents moved into Brookside during April 2012. As of summer 2013, there were 132 residents, aged between 53-82 years of age.

There are seven apartments designated as rehabilitation apartments, some are for people with dementia, and others are occupied by

people with other conditions e.g. stroke. The Lancashire Care Trust Older Adult Mental Health and Southport and Ormskirk Trust rehabilitation teams of the NHS work collaboratively and closely with the residents requiring rehabilitation. There have been four individuals and one couple who have come to Brookside for rehabilitation between April 2012 and January 2013 and this number is likely to increase as time goes on. One couple initially came for rehabilitation but have made the positive decision to continue living at Brookside, so the ability of this provision to open up possible solutions for people is clear.

Residents, managers and staff have commented that residents feel safe and secure, have likened it to a hotel or cruise ship, the contemporary feel is much liked as it is not seen as a care facility by residents and public. Large windows and high levels of day lighting also contribute to a light, airy and spaciousness feeling.

Bistro staff has commented that they have noticed that the residents with dementia have improved in their attitude, appearance, mobility, and are more outgoing since moving in to Brookside.

The community facilities are very successful at Brookside. There are several factors contributing to this such as the location close to the town centre, on a busy road frontage with 'kerb appeal' and passing footfall plus the Managers hard work to build links with the local community.

The general public have access to the bistro and typically the bistro is busy mid-morning, lunchtime, and dinner time. Many residents come down mid-morning when mothers and toddlers are in the bistro.



The Manager and staff have forged strong links with the adjacent school. For example, there is a joint knitting club for residents and the pupils, residents attend school plays and listen to the school choir, the school art class has a competition to create a poster advertising the day-care facilities.

The hair salon is designed to create a high street feel and is very much a social area.

There is a plan to use the gardens for a Tai Chi session which will involve the adjoin school and local tai-chi classes on national tai-chi day.

The Scheme Manager says the public and community involvement creates natural life and activity. This helps her as she doesn't have to constantly create 'artificial' activities. Staff have also commented that having the public in the development 'keeps residents young'.

The lounge areas at the end of the corridors are used for activities and each is themed with corridor displays.

The themes are games, crafts,



relaxation, garden room, TV room and travel room.

The exercise room has classes in tai chi, yoga and dancing which are very popular and have a wide appeal. The music room is also very popular for both group and individual activity. There are several residents who play musical instruments and they often give recitals to other residents.

The shared facilities such as the exercise, music and activity room are jointly commissioned by the local NHS and Social Services department and are utilised by both direct NHS and commissioned services to provide a range of in-reach services to Brookside, as well as offering public clinics and services, further adding to the public footfall to the scheme – services already operating at Brookside include NHS direct provision such as the Falls clinic, Stroke rehabilitation, Psychology support and Speech and Language therapy. Wider commissioned services such as a Community choir, a Singing for the Brain group, Nail cutting services and Dementia Advisors also utilise the shared spaces to deliver support to the West

Lancashire population, but a number of these supports are also used and enjoyed by people living within the scheme.

Residents have the choice of parking mobility scooters either in the hallway of their apartments or in the corridor recess by their front door (front porch). Corridors are wide enough to let two scooters pass each other although by allowing mobility scooters throughout the scheme there will be a long-term maintenance issue with wear and tear.

The apartment kitchen windows facing onto the corridor are popular with residents. There is the opportunity to personalise these windows and residents have the choice to open the blinds to these windows to see life and activity, and not feel alone in the building, or close the blinds for privacy.

A gardening club will be starting when a grant fund becomes available. The intention is for residents to have ownership of garden areas and the school will get involved with gardening as well as volunteers in the community.

Conclusions

The design of Brookside is flexible and adaptable to changes now and in the future, and so the project team were able to respond to changes whilst construction works were on site.

The inclusive dementia friendly design throughout the scheme has given the flexibility for residents to make their own choices where they wish to live throughout the scheme.

Creating 'events' at the end of corridors to avoid dead-ends, creating incidental spaces and cues help residents to orientate themselves throughout the building.



Allowing people with relatively moderate or low-level dementia into the scheme from when they first move in creates the opportunity for them to become more integrated with the community. Anecdotal evidence from elsewhere suggests that neighbouring residents are more likely to help look after their neighbour with dementia if that persons dementia has developed whilst they have been living there.

There is also debate in the sector about the suitability of extra care apartments for people with a more significant dementia need. The flexibility of the design allows for the creation of spaces for people with a higher dementia need should this be required in the future. A resident may have to move within Brookside, but not have to leave the community.

The building location is an important key for creating links with the surrounding community.

The building design can provide the space and opportunities for activities and connections with the wider community but the commitment and hard work from the Scheme Manager and staff is essential to creating a successful scheme that integrates with the wider community. The Bistro is also proving to be a community hub , and the public access to Brookside brings life, activity and stimulation for the residents and anecdotal evidence from the staff at Brookside suggests that this has a very positive effect on people with dementia.

The Brookside scheme has also been founded on a broad shared vision between a range of partner agencies, who all continue to be active in developing the resource. This includes the NHS Primary Care Trust and the emerging Clinical Commissioning Group, the local County Council, the local Borough Council, NHS Provider services, a wide range of VCFS agencies and the Housing provider. Leadership, a shared vision and on-going commitment to a collaborative partnership approach are critical to the delivery of an integrated model. Brookside has also benefited from a shared investment across agencies to deliver the width of provision outlined in this paper.

The building design and operation are integral to each other and to the success of the scheme. The design can provide the space but the commitment of the manager and staff is required to create the purposeful activity and use for these spaces.

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‘There must be a much greater focus on the massive contribution that older people make to society’



Sarah Rochira took up post as the Older People's Commissioner for Wales following over 25 years working in the public and third sectors in Wales.

During her career she has worked within a wide range of NHS organisations across Wales, with specific responsibilities for the quality of clinical services, health improvement, equality and diversity. Sarah has worked extensively with and for older people. She was director of RNIB Cymru from 2008-12 and has also been an active campaigner for changes to UK and Welsh Government policy and priorities.

Prior to becoming Commissioner, Sarah chaired Age Alliance Wales, an alliance of 20 voluntary organisations committed to working together to improve the lives of older people.

As Older People's Commissioner, Sarah works to ensure that older people have a voice that is heard, that they have choice and control, that

they don't feel isolated or discriminated against and that they receive the support and services they need to lead lives that have value, meaning and purpose.

Who are you and what do you do?

My name is Sarah Rochira and I am the Older People's Commissioner for Wales. I am an independent voice and champion for older people, standing up and speaking out on their behalf. I work to ensure that those who are vulnerable or at risk are kept safe and ensure that all older people in Wales have a voice that is heard, have choice and control, don't feel isolated or discriminated against and that they receive the services and support they need.

My work is driven by what older people say matters most to them and their voices are at the heart of all I do. I want Wales to be a good place to grow older – not just for some, but for everyone.

Can you describe a typical day?

One of the best things about my job as Commissioner is that no two days are alike. One day I could be in rural Wales, for example, speaking with a dementia support group as part of my Engagement Roadshow, while on another I could be meeting with politicians and government officials to drive changes in policy on behalf of older people, or meeting with individuals and their families to provide support in particularly serious cases.

What do you most enjoy about your role?

For me, the best part of my role is meeting and speaking with older people across Wales; last year my team and I met with over 8,000 older people at a wide range of events. Older people have such a wealth of knowledge and experience so it's just so important to engage with them, to learn from them and for their voices to drive my work as Commissioner. I feel privileged when older people share their experiences with me and have heard some amazing stories, as well as some incredibly poignant and touching ones.

What are the greatest challenges in your role?

In many ways, Wales has led the way in action to improve the lives of older people, such as its Strategy for Older People and creating the role of Older People's Commissioner, the first of its kind in the world. However, there is still a huge amount to do to ensure that people can get the help and support that they need wherever they live in Wales, to end the postcode lottery.

Similarly, the current economic climate and restricted budgets across our public services mean that many of the public services that older people rely upon, such as community facilities and public transport, are under threat. A key challenge is making sure that older people, who often rely on these services and the opportunities and support they provide, are not disproportionately affected and that their needs are fully considered when decisions are made.

What changes for older people have you noticed since starting your role?

It has been encouraging recently to see a shift in focus towards wellbeing and quality of life, a more holistic approach in the way that policy makers and service providers think about the support provided to older people. This is just so important as older people rarely talk about services or systems, they talk about quality of life instead, about wanting to live lives that have value, meaning and purpose. It is vital, however, that public services work with and listen to older people even more when they design, develop and deliver services so that the right information, advice, help and support is available, vital to help older people to live independent and fulfilled lives.

There have also been a number of key improvements to health services in Wales regarding dignity, introduced following my 'Dignified Care?' Review, which has been a positive step forward. Dignity is now a Tier-One priority across the NHS in Wales, for example, and dignity spot checks are now carried out by Healthcare Inspectorate Wales. There are also a wide range of other actions and initiatives underway to improve patient care and the patient experience, although there is still more work to be done to make sure the NHS in Wales gets it right for everyone as any failure can have devastating consequences.

It is also positive to have seen dementia being discussed much more often and more openly

than ever before in recent years. Alongside initiatives to improve diagnosis rates and create dementia supportive communities, we all need to talk more about dementia, to break down the stigma around the condition and challenge misconceptions so that people no longer need to struggle in silence. We must also harness the community spirit that defines us as a nation to ensure that people living with dementia can get all of the help and support that they need to have the best quality of life possible.

What further changes would you like to see?

We are all living longer, healthier lives and this is something that should be celebrated. However, despite a much greater awareness of the issues faced by older people, which are now highlighted across the media much more regularly, age discrimination and the language used about older people is still a significant problem that must be addressed.

Many of the older people I have spoken with have told me that they feel discriminated against, that they find it difficult to access services and support because of their age. Alongside this, we often hear older people described as a 'burden', hear about the 'silver tsunami' or the 'demographic time-bomb'. Using this kind of language about any other group would, quite simply, be unacceptable, but many commentators are still perfectly happy to use pejorative language when describing older people and perpetuate

stereotypes around frailty and dependency, which reinforce negative views about older people, underpinning much of the discrimination they face.

There must be a much greater focus on the massive contribution that older people make to society through volunteering, providing care and support to family members and paying taxes, which is valued at over £1bn a year after accounting for costs relating to pensions, welfare and health. This contribution is expected to increase dramatically as the number of older people continues to grow in the years ahead.

If we fail to recognise and value the contribution made by older people, if we fail to challenge falsely held assumptions about growing older, then older people will continue to be discriminated against, which often results in their rights not being upheld and subsequently poor treatment.

This is why, as Commissioner, I am launching a large-scale campaign to challenge age discrimination in Wales. Alongside using older people's voice to raise awareness about the types of discrimination faced by older people, the campaign will also include training and toolkits for service providers, practical resources to help to change attitudes and ensure that there is an improved understanding about who older people are and what they need, often only a little bit of help, to have the best quality of life.

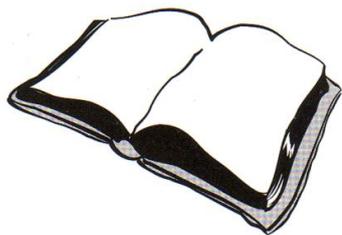
Where would you like to go from here?

Wales, like the rest of the UK, faces difficult challenges in the years ahead and reductions in funding for public services are already having an impact upon older people. However, I also believe that this is a period of opportunity. The challenges we face must drive us to be smarter in the design and delivery of public services, to work with the energy and creativity of older people and, working together, refocus our work to ensure that we deliver the changes that older people have told me that they want and need to see.

Delivering this change will not be easy. It will require all of us to be at our best, to think and behave differently and to be brave and bold. But we must be ambitious, each of us must play our part, not just for older people today, but also for the younger generations who will follow.

Book Reviews

'Can I tell you about dementia?' A guide for families, friends and carers.

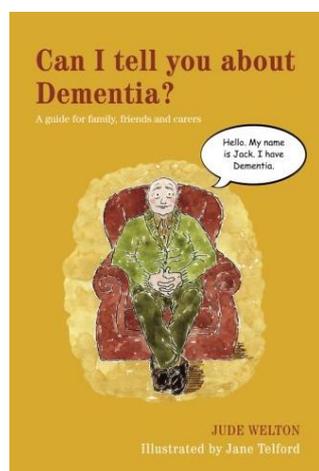


Authors: Jude Welton

Publisher: Jessica Kingsley Publishers

ISBN: 978-1849052979

Price: £7.99



Current projections indicate that by 2021 48,000 people in Wales will be diagnosed with dementia (source – Dementia UK Report 2007 / Alzheimer's Society). Across the

developed world increasing life expectancy is linked to projections of increasing numbers of people diagnosed with dementia. In a fiscally challenged era politicians focus upon the related rising economic costs of dementia care. But importantly there is now also a growing public and professional appreciation of the daily human cost and challenge of living with dementia for both individuals and those seeking to support them.

For too long marginalised in a youth centric culture as a shadowy inevitability of old age, dementia is now attracting regular media

attention. Popular and academic texts are increasingly focused upon not only the medical treatment of dementia, but upon how we understand the actual human experience of living with dementia and the implications for a progressive person-centred approach to dementia care. Dementia is coming in from its historic place on the margins.

The literature in this field has traditionally been dominated by a highly medicalised discourse. The growing awareness of the need to engage with people's real lived experience of dementia has seen a broadening out of the literature on offer, and in this book review I would like to recommend the title **'Can I tell you about dementia' ? A guide for family, friends and carers, by Jude Welton (published by Jessica Kingsley : 2013)** as an excellent and accessible attempt to understand the inner experience of someone living with dementia.

Through the course of just 48 pages this slim book covers a surprisingly wide territory. Very often texts in this field through their very length and use of technical language appear forbidding for non-specialist readers. This book through its brevity and aversion to jargon should appeal to a wide readership. The quality of the content also reinforces the old adage that very often 'less is more'.

Introducing Jack

The narrator of the book is Jack. Jack is 80 years old. He lives with his wife and he has Alzheimer's disease. Across the course of the book's 14 brief chapters Jack takes the reader on a personally narrated journey through his experience of living with dementia. He guides us through the changing course of his illness, from the earliest days of his initial signs and symptoms to the later stages of his illness.

In her introduction the author Jude Welton asks the reader to 'suspend disbelief and listen to the words that someone with dementia might tell you if they could'. Through the literary device of enabling Jack, despite his progressive cognitive decline, to retain a clear coherent articulacy the reader is privileged with what we might call an insider's view of the illness. Jack is able to reflect upon his experience of dementia and articulate his thoughts and feelings. Aspects of his illness which traditional medicalised readings of dementia have tended to understand as meaningless manifestations of cognitive dysfunction, are instead through Jack's commentary made meaningful. As Jude Welton outlines in her introductory remarks, she hopes 'that Jack's words will help to show how behaviours that might seem puzzling and bizarre make sense if we appreciate what it really means to lose your memory, and lose your ability to think clearly, to reason and communicate'.

Jack explains to the reader how the gradual loss of his short term memory sees him increasingly call upon memories of his past to make sense of his present. In Jack's own words, 'I used to cycle to the shop to collect groceries for Mum and Dad. Past things like this don't always feel like a memory. They feel like now'.

Jack's inability to recall individual moments and make them connect essentially collapses time. The past populates his present. As Jack explains, 'sometimes people think I'm talking rubbish if I say "I'm late for work", or "turn those lights out! There's a bombing raid on the way!" That might seem nonsense, but it's not nonsense to me. Sometimes a memory seems to surface in my brain from long ago, and it feels as if it's happening now'.

The intention of the book is to reveal to the reader how seemingly meaningless behaviours may well have meaning for the person with dementia. With this insight in place the argument is clearly made that it is how others then relate to the person with dementia and seek engagement with their inner experience which has the biggest impact upon quality of life. Or as Jack explains, 'if people contradict what I'm saying, I don't like it. It makes me confused and distressed'. At its heart the book seeks to promote understanding for the reader of the changed world view which someone with dementia experiences, with the hope that this understanding builds a bridge to empathy and a more person centred and sensitive approach

to engaging with and caring for someone with the illness.

Jacks concluding remarks are particularly powerful when he explains how as his illness progresses he loses the capacity for speech and communication through language. The connection with others is retained purely through emotion. Jack observes that, 'once facts have gone from my memory, it's feelings that remain....your body language, your tone of voice and the expression on your face all have a powerful impact on the way I feel....smile please'.

These concluding remarks powerfully reinforce the argument made in the book's introductory pages that at heart, 'it is the way we relate to and behave towards the person with dementia which has by far the biggest impact on their quality of life'. It's all about the relationship.

Mark Jones

Dementia Care Advisor, Young Onset Dementia Service, Cardiff & Vale University Health Board

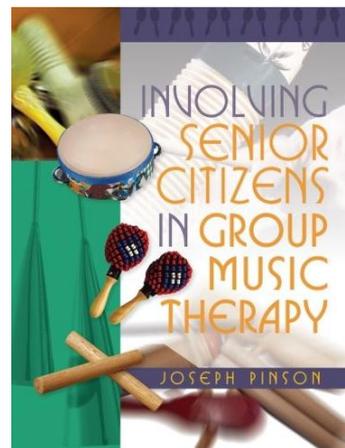
Involving Senior Citizens in Group Music Therapy

Authors: Joseph Pinson

Publisher: Jessica Kingsley Publishers

ISBN: 978-1849058964

Price: £17.99



Involving Senior Citizens in Group Music Therapy is a manual which gives detailed guidance on how to best engage with 'senior citizens' in care homes. It also

suggests how the reader might actually write the lyrics and music. Pinson comes across as a very enthusiastic and experienced teacher who clearly knows what he is talking about and who is eager to pass on advice. He uses a conversational style, quoting amusing anecdotes from his own experience at times, which makes light reading of most of this book

He also gives examples of actual songs in the appendix. All these songs are very accessible and the author has included less complicated versions of most, acknowledging different levels of ability. The songs themselves are engaging, rhythmically and melodically varied but also simple and it is easy to see that they

would appeal to older people, indeed, to most people who like music. The lyrics too are tailored to the experiences of older people, giving their reality and concerns a voice, and this quite literally so. In introducing the songs, the author emphasizes the importance of simplicity and repetition.

However, Pinson takes the principle of repetition too far when he also applies it to this book (which is not written for his clients) by repeating in his conclusions, often verbatim, what he has already said in each chapter. While the author has the tendency to be repetitive and very carefully explains his therapy approaches in every detail, he takes it for granted that the reader knows what 'parachuting' entails in the therapeutic context and only gives a very scanty explanation of what the 'Iso-Principle' means even though, as Pinson tells us, this principle lies at the very heart of music therapy.

As the word 'senior citizens' in the title suggests, this is a book written for an American readership, which becomes apparent not only in many Americanisms but also in the choice of songs. The almost exclusively American song examples are not unproblematic since they are supposed to tap into a shared memory - I doubt whether a song like the 'Crawdad song' would achieve this aim with senior citizens in Britain as they might neither know what a 'crawdad' is nor recognise the tune.

However, the songs are there as examples only and music therapist could use this book as inspiration for their own song choices.

Johannes Gramich

Social Worker, Mental Health Services for Older People, Cardiff & Vale University Health Board

In this section we review new products and ideas which may be of relevance to people with dementia or those working and caring for them. Please note that we not specifically endorse any product and aim to provide neutral information.

Alzheimer's Society One Button Radio



The Alzheimer's Society's online shop features a number of products designed to

make life easier for people with dementia. The one button radio achieves this by removing the need for station selection, volume control and various other functions which can cause confusion when operating. Instead, options are pre-programmed and automatically activated by the touch of one button. The contrasting colours ensure the button is easy to see and simple to use.

The radio can be mains or battery operated. It currently costs £85.00.

<http://shop.alzheimers.org.uk/product/one-button-radio>

Study examines quick and simple 'dementia test'.



The test, known as the Self-Administered Gerocognitive Examination (SAGE), assesses a variety of mental functions and can be done using only pen and paper. The idea behind the SAGE score is to help provide a doctor with further information as to whether further tests are required.

The study assessed whether community-based screening for over-50s was feasible. They found that a large number of individuals in the community could be assessed using the SAGE. Although an interesting idea, it is important to be aware that the SAGE is not designed to diagnose Alzheimer's disease or other forms of dementia.

<http://www.nhs.uk/news/2014/01January/Page/Home-test-has-potential-to-spot-mental-decline-early.aspx>

Vitamin E is 'beneficial' in dementia suggests a study in The Journal of the American Medical Association (JAMA). The study had 613 participants with mild to moderate Alzheimer's disease take part. Participants were split into one of four conditions:

- A daily dose of vitamin E
- A dementia drug treatment known as memantine

- A combination of both vitamin E and memantine
- A placebo

Over an average space of two years, the participants ability to carry out everyday tasks, such as washing dishes or dressing themselves was measured and the changes over time were investigated. They found that participants receiving a daily dose of vitamin E had slower functional decline, with the annual rate of decline reduced by 19%. It was also found that participants in this group needed less help from carers.

However, the Alzheimer's society said that the dosage was very high and might not be especially safe.

<http://www.bbc.co.uk/news/health-25552768>

A 'Dementia Action Alliance' is being formed by the community in Buckhurst Hill. The aim of the group is to bring together different services, such as the police and council, that will be able to provide a better service overall for those suffering with Dementia. The hope is that this will encourage members of the community to set up action groups, provide patients with more knowledge and give these patients a sense of belonging in the community.



http://www.guardian-series.co.uk/news/efnews/10944566.Community_to_become_more_dementia_friendly/

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: Rosalind.Cooper@wales.nhs.uk or Emma.Williams33@wales.nhs.uk

Books Available for Review:

The Essential Guide to Life after Bereavement, Judy Carole Kauffmann and Mary Jordan, 2013.

End of Life Car, Nigel Hartley, 2014.

Dance and Movement Sessions for Older People, Delia Silvester and Susan Frampton, 2014.

Signposts Editorial Panel

Dr Simon O'Donovan is Clinical Director for Mental Health Services for Older People in Cardiff and the Vale of Glamorgan and leads the Younger Onset Dementia Service.

Dr Christina Maciejewski is a Consultant Clinical Psychologist working within Mental Health Services for Older People in Cardiff and the Vale of Glamorgan.

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.

Kim Sweet is an Advanced Nurse Practitioner working within Mental Health Services for Older People in Cardiff and the Vale of Glamorgan.

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.

Rosalind Cooper and Emma-Marie Williams are Assistant Psychologists working within Mental Health Services for Older People in Cardiff and the Vale of Glamorgan.