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NHS WALES GIG CYMRU

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Cover picture: Image kindly provided by Alive!

Editorial

I felt very honoured when I was asked to join the steering group of 'Signpost' last year. 'Signpost' has always been around me since I started working in Cardiff eight years ago. It used to lie on the round kitchen table as a paper copy; now it's on the electronic screen. It has always been welcome for information on the most recent developments in the field and for offering different points of view. As a social worker I feel that I am representing this group, who work along nurses, occupational therapists, psychologists and doctors.

Reading through the summer edition, I find that the concurrent theme is the 'person-centredness' of care. As is always the case with ideals, we cannot expect that it will ever be fully achieved, but will remain a beacon to strive for. While all the articles agree on this, all of them offer different perspectives on how we can get nearer this goal.

Jackie Pool, who started as an occupational therapist, tells us in 'About Me' that she has dedicated her life to working with the public to change attitudes to help to bring about person-

centred care. Brendan Mc Cormack, seeking inspiration in philosophy and Far-Eastern thought, suggests in his contribution, *Dementia Reconsidered: Does the Person Come First?*, that our whole culture needs to change in order to provide person-centred dementia care. Tim Lloyd-Yeates shows how modern i-Pad technology can enable our clients to have meaningful stimulation, tailored to their needs. June Andrews shows in another thought-provoking article how environmental factors, such as the decrease of light in care settings, can have very negative effects on our client group.

As the days are beginning to close in again, I hope that this new edition will provide you with 'illuminating' reading for the summer and beyond.

Johannes Gramich

Social Worker

Mental Health Services for Older People

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Dementia Reconsidered: Does the Person Come First?

Prior to his current position Brendan McCormack was Director of the Institute of Nursing and Health Research and Head of the Person-centred Practice Research Centre at the University of Ulster. His internationally recognised work in person-centred practice development and research has resulted in successful long-term collaborations in Ireland, the UK, Norway, The Netherlands, Canada, Australia and South Africa. His writing and research work focuses on person-centered practice, gerontological nursing and practice development and he serves on a number of editorial boards, policy committees and development groups in these areas. He has a particular focus on the use of arts and creativity in healthcare research and development. Brendan has more than 150 peer-reviewed publications as well as 8 books published. He is the Editor of the "International Journal of Older People Nursing". Brendan is a Fellow and Board member of The European Academy of Nursing Science. In 2011 he was awarded the status of 'Senior Distinguished Research Fellow' by the University of Ulster, in recognition of his research achievements.

Introduction

"After a century and more of research into dementia, mainly within the standard paradigm, we have heard just about all that might be cause for dismay. As we now reframe the whole field, and give much greater weight to personal and interpersonal considerations, most of what follows will be news. We will discover much more about how to enable people who have dementia to fare well, without having to wait for magic bullets or technical fixes. And if we make the venture of genuine and open engagement, we will learn a great deal about ourselves" (Kitwood, 1997).

Tom Kitwood wrote his seminal work, *Dementia Reconsidered: The Person Comes First* in 1997. Since then, much has changed in the world of dementia care and our ways of being with people living with a dementia have in many respects been transformed. It is rare these days to read any commentary, opinion, research, development, innovation or education programme on dementia without reference being made to the work of Kitwood. However, the extent to which the work of Kitwood has been adopted, other than some key principles, is an important issue to consider. In this paper, I address this issue and argue for a person-centred approach to dementia care that embraces Kitwood's central

concept of 'love' and that can be shaped through a focus on human flourishing.

The Dementia Challenge

Contemporary practice in dementia care espouses the values and principles of person-centredness. The original person-centred focus of person-centredness emerged through the work of Kitwood (1997) and has since then been developed and extended by others (Røsvik et al 2011; Dewing 2008; Brooker 2004). This work has had a transformational impact on the lives of people living with a dementia and those who care for them. Significant advances have been made in the deinstitutionalisation of dementia care and a focus on normalisation is the accepted world-view. Significant changes in the development of high quality dementia care services include – the use of person-centred models, frameworks, tools and processes in the organisation of dementia services; improvements in approaches to maximising functional independence (such as continence promotion; falls prevention; restraint reduction, pain management, reduced use of anti-psychotic drugs, nutritional care); improvements in acute hospital care; recognition of the need for specialist palliative and end-of life care; and the more extensive use of positive interventions that are focused on hearing the voice of the person with dementia and planning care that is consistent with their biography.

Whilst this list of innovations and improvements is to be celebrated, the reality is that there is still a long way to go if we are to truly embrace a person-centred philosophy. Continued challenges include – the continued dominance of a (bio) medical model underpinned by a paternalistic philosophy of care; a dominant focus on safety and risk-avoidance; not enough attention paid to the person's need for social engagement and community participation; the existence of regulatory standards that reinforce control, risk-aversion and safety, despite espoused philosophies of person-centredness; and the under-valuing of dementia-specific skills among care workers.

However, whilst there will always be challenges to be addressed, we should celebrate the success so far and the fact that most people living with a dementia have a much better quality of life than their predecessors.

Person-centredness

"Mutual confirmation is the most important aspect of human growth. An I-thou relationship involves real knowledge of another, and requires openness, participation and empathy" (Buber, 1958)

This quote from the work of Martin Buber highlights the importance of equality in relationships. Buber's philosophy represents a fundamental premise of person-centredness and one that has shaped the thinking of Kitwood and others (refs). Buber's position is

predicated on humanistic values of respect for others irrespective of differences. So in an institutionalised non-person-centred approach to caring for the person with a dementia the dominant stance is that of 'I-it', that is the person with a dementia is not treated as an equal but instead is treated as a 'thing' that can be treated and manipulated according to our needs as cognitively intact and powerful people (as care workers). Ongoing reporting of scandals in dementia care as reported in the media are examples of this approach continuing to exist. In contrast, an 'I-Thou' relationship is predicated on principles of equality, respect for persons and care for the other as a valued human-being irrespective of them having a dementia. Kitwood suggested that a person with a dementia (like every other person) has a need for 6 psychological needs to be me on a daily basis - **Attachment** (we need to feel attached to another person or to a group); **Love** – Everybody needs to be loved and accepted and to love); **Comfort** (we need a variety of comforts in our lives as well as to feel comfortable with ourselves and others); **Identity** (for others to know *who I am* or *who I was);* **Inclusion** (we need to feel a part of something); **Occupation** (to have something meaningful to do). For many practitioners of person-centred dementia care, then paying attention to these psychological needs equates to respecting the person's personhood, i.e. recognizing the other as a person in an I: Thou relationship. But whilst this stance goes some way towards respecting another person for who they are, Kitwood argued that at the heart of personhood is 'love for another'. Kitwood's idea of love in dementia care, whilst presented as one of these 6 psychological needs, is indeed given much more importance and significance in his writings than this. The need for the person with a dementia to experience love as a person is critical to the other psychological needs being met.

Flourishing Persons

Fundamentally, operationalizing Buber's person-centred values and Kitwood's ideas about love for another person is about helping all persons to flourish as human beings. Human flourishing occurs when we bound and frame naturally co-existing energies, when we embrace the known and yet to be known, when we embody contrasts and when we achieve stillness and harmony. When we flourish we give and receive loving kindness (Titchen & McCormack, in press). The Buddhist ideal of persons living in the moment, in the here and now and embracing the energies of life appear to offer an exciting (yet challenging) way of thinking about person-centredness with people who are living with a dementia. In 2012 I had the privilege of spending a week in Dzgogchen Beare – a Buddhist retreat centre in the far South-West of Ireland http://www.dzogchenbeara.org where, with a friend and colleague we explored the concept of 'human flourishing' through meditation, creativity and writing. During this 7-day retreat, it became clear to me that much of the complexity of person-centredness that is debated and challenged in the literature can be

simplified through connecting with our deeper selves in stillness. The Buddhist teachings that are practiced at Dzgogchen Beare focus on 'loving kindness' meditation. Loving kindness meditation is based on the belief that we all have the potential to love fully and unconditionally – a belief that is central to Kitwood's understanding of personhood. In Buddhist teaching, meditation that focuses on love cultivates loving kindness through which we can develop an increasingly deep, pervasive and unconditional love that completely transcends our normal limitations. The starting point of this is to learn to love ourselves and then extend this feeling out into all our relationships and to all persons. The lens of loving kindness enables an understanding of person-centredness that is inclusive of all persons – a position upon which I have argued is essential to the development of person-centred practices and cultures, i.e. that if we expect people with a dementia to be treated as persons then all those engaged with them as 'care partners' need to also experience those same values. In this regard we define person-centredness as:

"Person-centeredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development". (McCormack & McCance 2010)

Healthful relationships are those that are growthful, nurturing, challenging, supportive, caring and most of all, loving. It is as important for care workers to experience such qualities in their relationships with colleagues and managers as it is for the person with dementia. Indeed, if we are to truly transform dementia care practices, then there is a need for profound change in the 'being' of care workers, the culture of care services and the relationships between the person living with a dementia and care partners (Senge et al 2005). It is of little surprise then that in health and social care services there is an increased emphasis on practices such as 'mindfulness' (Carroll 2007) as a means of helping care partners to create stillness, become alert to self and others and develop increased awareness of the reality of things (being present). However as yet, the practice has not been used to any significant extent with people with a dementia, but some examples are beginning to emerge (cf http://www.carehome.co.uk/news/article.cfm/id/1561161/using-mindfulness-to-improve-life-for-people-with-dementia).

Enabling all Persons to Flourish

If we are to advocate the importance of love and connection in dementia care, then it surely is important to consider how all persons are to be helped to flourish. Whilst developments such as the use of mindfulness are to be

welcomed, the challenges associated with normalizing such practices in everyday caring encounters are great – such as the need to train all staff in these practices, assessment processes required and the rebalancing of existing work to make room for these ways of engaging with the person with a dementia. However, thinking that we can create more loving relationships through such practices as mindfulness may be an example of applying a single change of practice to a deeper issue of the need to change the culture of practice. Consistent with the Buddhist teachings on loving kindness, McCormack & Titchen (in press) have developed an understanding of human flourishing that is inclusive of all persons. The framework has seven characteristics that need to be developed/put in place in order for all persons to flourish.

Bounding and framing

The condition of 'bounding and framing' refers to the need for care settings to be clear about what needs to be done to create a setting that promotes loving kindness. In working with persons who are living with a dementia, the sense of being overwhelmed by the vastness of what needs to be done/changed is very real. Therefore foregrounding particular aspects of the total landscape of practice provides us with an opportunity to focus, to build energy to see what is possible/achievable and ultimately to flourish. Maureen Gaffney (2011) used a similar idea when she raised the importance of persons 'using their valued competencies':

> *'Flourishing means feeling that you are using your valued competencies, and so doing what you were put into the world for ... Using your valued competencies, is not just about using some aspect of your intelligence or talents, it also means using the most important lessons you have learned in your life, including what you learned from your mistakes, or from your experiences during bad times. In fact, part of the experience of being at your best is the realization that there is as much to be learned – and sometimes more – from the setbacks in your life as from the successes' (Gaffney, 2011, pp.11-12).*

So if we create settings that focus on enabling all persons to be challenged with support, take risks and be helped to learn from such risks and maximise the use of individual talents, then there is a strong chance of a flourishing existence for all persons being created.

Co-existence

This condition requires us to see ourselves as equals in the world. It is the case that in everyday life/practice, our particular context can feel like a lily pond, with all the roots tangled and impenetrable. Such contexts can appear resistive to change, growth and development. However, like the tangled roots of a lily pond, the beauty in these contexts lies in the interconnectedness of persons and the energy created by all those who make up such contexts – this is indeed their strength. If we

see these connections as positive forces for change rather than resistance, then we can create relationships that are attuned to what is happening inside and outside of us. Being attuned to these connections enables us to recognise when disconnections are happening and for us to be able to rise to the challenges associated with them. Pierre Teilhard de Chardin (2001) suggests that love alone is capable of uniting living beings in such a way as to complete and fulfill us. He suggests that love is the only thing that joins us by what is deepest in ourselves. Loving kindness focuses on bringing that deep love to the surface as a manifestation of our flourishing as persons. Through our own flourishing we are able to give loving kindness towards others in the contexts and situations we find ourselves in our work. Speaking loving kindness is like feeling a breeze on our faces, hearing the rustle and brushing of grasses and leaves as the wind gusts and lulls. It is something that is sensed more than actually spoken although it can be heard in the tone of voice, in the softness of the eyes and in compassionate acts.

McCormack, Titchen and Manley (2013) have articulated the necessary conditions in care environments for human flourishing, including:

- Respect for all persons
- Cultures that value feedback, challenge and support
- Commitment to transformational learning
- Leaders who possess the skills of enabling facilitation
- Organisations with a person-centred vision
- Strategic plans that support person-centred and evidence-informed cultures of practice
- Continuous evaluation of effectiveness
- Equal valuing of all knowledge and wisdom

These conditions of course can only be activated when the right energies are instilled in the climate of the setting, energies that are manifested through a commitment to loving kindness and respect for the interconnectedness of humanity.

Embracing the known and yet to be known

The need to be ready for boundaries to be pushed is a key factor in enabling human flourishing to happen. *'I would love to live like a river flows, carried by the surprise of its own unfolding'* (O'Donohue, 1997). On the other hand, we have to be alert to the fact that the river floods when its banks are breached and so we must also respect our limits if we are to flourish in times of crisis. When we move around our workplaces with our eyes, ears, sense of smell, touch and taste wide open, 'hidden gems' emerge. As we rush around at work, our senses are often half shut down. If we do not pay attention we can miss the gems and the beauty around us.

Living with conflicting energies

Gaffney (2011) argues that 'challenge' is a key element of flourishing and that without challenge we would languish in the safety of established habits and norms. Challenges

aren't always of our own making, but instead can arise from unexpected and unanticipated avenues and directions. Saltzberg (2002) suggests that to develop focus requires a letting go of negative emotion towards others and to hold strong our sense of being grounded in the space. Being really present for a particular person, persons or situation can also help us to re-frame connections as an opportunity for holding strong to our values and our response to its challenges as a means of enabling our own and others' human flourishing. This is not easy, but it is something we can strive for.

Being still

Creating different and complementary spaces for different purposes is an important consideration in enabling human flourishing. Respecting stillness in the busyness of practice settings is a challenge, but without it persons are likely not to reach their full potential. Creating spaces for quiet reflection and stillness is a real challenge in busy care environments. There is a need for us to pay more attention to the workings of such environments and how they function. It is becoming more common for dementia care environments to have 'quiet times' where the routines of practice are abandoned and silence is valued. However, helping care workers to use these periods of silence as periods for quiet reflection, critical engagement and meaningful connection with others are essential in an environment that enables all persons to flourish.

Embodying contrasts

We know that for persons to flourish, feeling respected and showing respect are key ingredients. Being respected as a person enables growth whilst simultaneously creating the conditions for the demonstration of respect for others. Routine practices easily become rituals whereby the focus shifts to that of completing the task as quickly and easily as possible rather than in a way that is respectful of the individual needs, wants and desires of the person living with a dementia. In our care settings, we need to build into our practices opportunities for care workers to engage in reflective learning and explore their creativity through the exploration of different ways of engaging. The use of art and creativity in learning is an important way of helping care workers to explore different ways of being, different ways of engaging and different ways of doing practice. Being able to contrast what is possible through creative exploration with what exists creates openings for new understandings, reflections, knowledge and being to emerge.

Harmony

It is all too easy to seek out prescribed structures, processes and tools in dementia care, as if there is a set starting point and a prescribed destiny. Contemporary dementia care is dominated by an endless array of models, tools, frameworks and indeed 'gimmicks' that are designed to provide the solution to being person-centred. No model,

tool or framework can compensate for our own commitment to loving kindness. Being deliberate and intentional about creating places that enable all persons to flourish is the only way of creating these cultures. Models, tools and processes give us guidance and direction, but can never replace the work needed to transform practice settings.

Conclusions

The challenge of achieving Kitwood's dream of 'the person coming first' in dementia care should never be taken for granted or underestimated. Person-centredness has become the dominating language in the way that care is provided and services organised. However, what substance lies behind the espoused values of person-centredness? The overreliance on 'quick-fixes' and 'glossy packages' that promise to create person-centred cultures should be avoided. Kitwood placed significant emphasis on 'love' and it is hard to imagine loving relationships being created through such approaches. Instead, I argue that the Buddhist principle of 'loving kindness' provides a set of values that when worked with everyday, can help to create settings where all persons flourish. Kitwood was (rightly) very focused in his work on the person living with a dementia. However, it goes without saying that care partners need a similar focus, as without them experiencing loving kindness in their relationships with colleagues and others, their ability to engage in this way with the person living with a dementia is limited. The challenge for all of us is to adopt a caring approach to how we meet needs; nurture effective relationships; promote social belonging; create meaningful spaces and places; and, promote human flourishing. For as Kitwood (1997) asserts, we need to acknowledge all persons' need for love, because love is at the heart of caring relationships.

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iPads For Older People: Changing How We Care

Tim Lloyd-Yeates is the founder and director of Alive! He also leads Alive! training courses and creates and facilitates sessions in Bristol and the surrounding area. He is passionate about empowering older people, especially those now living in residential care and is campaigning for care home residents to have access to their interests, to activities and a rich quality of life. Tim is a Dignity Champion for the Department of Health and volunteers on a care home visiting scheme; he is a trained facilitator for Cognitive Stimulation Therapy and a Quality of Life Assessor for the Dementia Quality Mark awarded by Bristol City Council for residential care homes specialising in dementia care.

When someone goes into a care home, many of the things which are important to them: networks of friends and family, hobbies and interests, learning and the ability to make choices, disappear from their lives. Touchscreen technology can be a tool for reuniting older people with these things that they have lost. Alive!'s founder and Chief Executive Tim Lloyd-Yeates discovered this from working as a freelance presenter in care homes over 5 years ago. He saw the potential that this technology offered to older people, many of whom were living with dementia and hard to reach. He also saw the very real need for bringing life back into care homes.

Social Isolation

It is well documented that social isolation is a huge and growing problem in care homes, with a high incidence of depression, loneliness and other mental health problems. Depression occurs in 40% of people living in care homes, with significant impacts on quality of life and physical health.

Many care home residents have little or no contact with their families or the outside community and endure hours of non-activity every day. The sight of groups of older people sitting in a communal lounge staring lifelessly at a TV screen is, sadly, very familiar.

Reconnections

One of the main purposes of Alive! activity sessions is to help give older people access to the things that they have lost going into care, such as; learning, access to hobbies and interests, access to the outside world, variety, discussion, interaction with others, laughter and fun. All the things that contribute to a good quality of life.

A recent evidence review from The Social Care Institute for Excellence (SCIE) found that music, dance, poetry, creative writing and visual arts have physical and psychological

benefits for people in care. The arts "have the potential to be really important and are likely to be a major differentiator for care providers in the future." (Executive Director of the National Care Forum).

Peter lives in a residential care home in Bristol, he has limited ability to talk and walk. Before Alive! was commissioned to work with Pete there were concerns he was becoming lonely and isolated. Avon & Wiltshire Mental Health Partnership originally asked us to come and work with Pete. We used an iPad to reconnect him with his favourite things; the music of Leonard Cohen, The Epsom Derby and photos of places in the world where he has lived and worked, including Schipol Airport in Amsterdam, a Kibbutz in Israel and Kuala Lumpar.

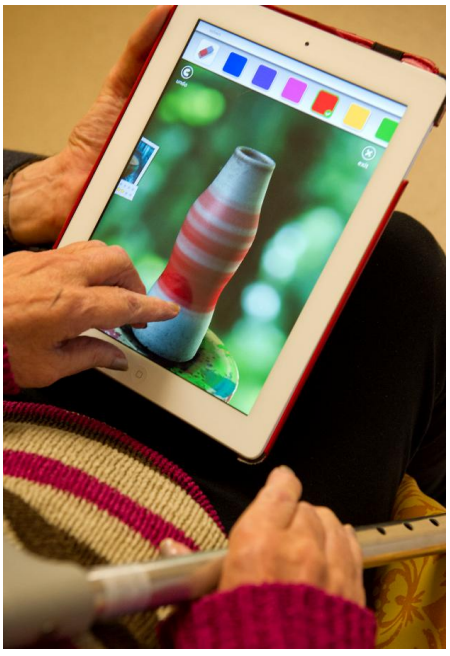
After a successful trial, Alive! Sessions are now bought each week by Pete's sister Wendy. She says, “Pete really enjoys his weekly one-to-one sessions with Alive!, which he has been having for a year now. I told them about Pete's past, his jobs, interests, and countries in the world he had travelled to and they took all the information on board and utilise it to engage him with things that interest him on an iPad and through different media. Pete does not speak at all but he smiles a lot and takes part during Alive!'s visits because they are very imaginative and creative and Colin, Tim and their colleagues seem able to reach him."

‘I was working at the desk today when Colin was doing the one to one. It was lovely to see Pete smiling and trying to talk to Colin. Colin and Tim make the sessions so fun, needless to say I didn't get much work done! Thanks for all your hard work with Pete. It really makes a difference to him.’ Carolyn Activities Coordinator

Tim Lloyd –Yeates is a recognised innovator of using touchscreen technology with people living with dementia. In this this interview he outlines the benefits of this approach.

What makes touch screen technology unique as a tool for working with older people?

“One aspect is that it can be all things to all people. Touchscreen technology can be used in a facilitated way and individually by older people and people living with dementia. Within reason, it can be whatever that person wants it to be. You can create works of art, you can create pieces of music, you can listen to birdsong, you can plan a garden. There’s no limit really to what you could create for the future, what you could do in the present in terms of using applications for fun or amusement, or what you could find from the



past in terms of reminiscence or things that you have enjoyed in your life. So it acts as an interactive companion or a gateway that is easily accessible to help people connect with their past, present and future."

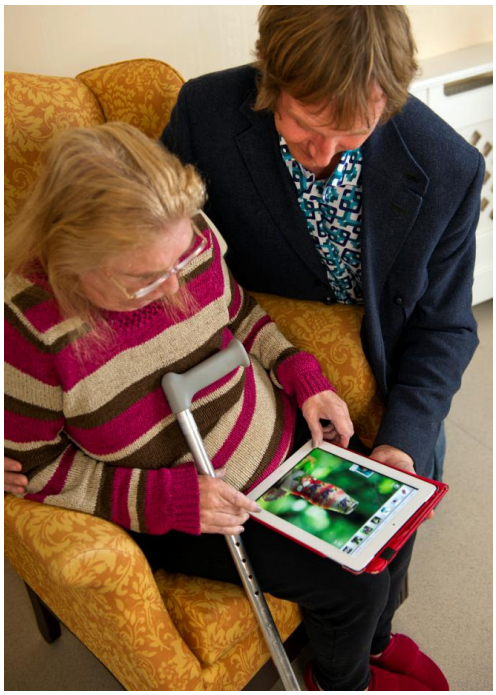
How does the iPad help you to engage with people that are harder to connect with?

"The iPad helps us to find things that are special for each individual and this means different things for different people. So if we make the assumption that everybody likes different things, where are we most likely to be able to find all these things? Music, images, films, places - things that are special to people. The answer is probably the internet. What's the easiest, quickest, most mobile, most tactile, most intuitive way of being able to access the internet? Probably an iPad (or similar Android tablet). However, there's an important point to raise, which is that the iPad on its own doesn't help us to connect with people who are vulnerable. We approach this in three ways. The first is personal connection: eye contact, open body language, offering touch, learning people's names, having positive intention to make a good connection with someone. The second is learning something about them, what are the special things they like? Finally, it's the technology. So connection, plus life story, plus technology. These are the three things that really make the difference. The technology on it own is really clever but there are lot's of examples of when that would fail. If you introduce it in the wrong way, without a connection or in the wrong place then people won't engage with it."

So what do you think are the main benefits of iPads for people living with dementia?

"The main benefits are being able to respond to things that that person wants to see or hear or interact with. It could be Sudoku, a painting, a film or a piece of music and they can all be conjured up instantly, in the moment. It has an amazing ability to react in real time and the versatility is incredible. What separates it from other technology such as laptops and desktops, is that as well as being a good tool for a facilitator to evoke memories, you can then pass the machine to the person living with dementia and they can then use it themselves. We know that many older people find traditional operating systems, laptops, mice, keyboards, much more intimidating that touch screen technology."

How has the iPad changed the way that you work with older people?



"It has allowed us to be more in the moment. Years ago we used to travel with all the things that we thought

older people might like to interact with such as music, poetry, quizzes etc and we would have to use our best judgement. We would put all these things in a big bag, go to a care home and what we could present would be limited to what we had in that bag. What we can do now is be fearless. We can walk into a room and concentrate on making connections. We can ask people what they are interested in, what they have done and allow people to make any kind of suggestion, trusting that our machine will usually be able to find it. What usually happens is residents teach us about things that we don't know about. They will teach us about people we have never heard of and places that we have never been and the internet finds it for us. We don't need to know about that stuff, so the iPad makes it more immediate, more interactive and more relevant to them, which in turn binds their interest to the session. People often ask 'why are people so enthusiastic in an Alive! session?' or 'how do I motivate my residents?'. It's by giving them content that they care about."

Lasting Impact

All Alive! presenters now have an iPad, which they use to access music, film clips, poems and images that are projected onto a large screen. Allowing older people to make personal requests and choices. Recently we've had requests for Jimi Hendrix, 'If' by Rudyard Kipling and 'That lovely Michael Jackson doing his Moonwalk'!

The effect of the Alive! sessions is that afterwards 89% of residents had improved mood and levels of engagement Not only this, but care home managers and staff felt inspired to use the internet to help their residents re-live their most important memories and have reported that as a result they have improved rapport with their residents as they find out more about them.

Alive! uses iPads in a variety of care settings. In a local hospital, patients were amazed at how we could accommodate requests using the iPad. We explored people's hobbies, interests, life experiences and stories together with music, artefacts and discussion-empowering residents and looking at the person and their life. Participants made several requests for content and were delighted when their request was instantly met. In one of our sessions, a lady called Betty asked for a song that her mother used to sing for her as a child. Our presenter was able to find it for her, and the family were overjoyed and grateful with the amazing effect of the song on their mother who had not heard the song in years. During another session using the iPad, two patients discovered they had been at school together 50 years ago, which led to them share stories of how they used to play. Everyone listened to the stories and it brightened up the whole ward.

As well as delivering activities in care homes across the South and South West, Alive! also provides training for care staff and influences policy makers. Their ultimate goal is a world

where all care home residents have a good quality of life with access to choices, learning and meaningful activity.

Below is some more detailed information about some of the Apps that we use

How we use Apps

Bloom

An app that we have found to be particularly therapeutic for older people living with dementia is Bloom HD. Part Instrument, part composition and part artwork, Bloom's innovative controls allow anyone to create elaborate patterns and unique melodies by simply tapping the screen. A generative music player takes over when Bloom is left idle, creating an infinite selection of compositions and their accompanying visualisations.

Using Bloom at the beginning of a session and passing it around for everyone to add their notes to, means that there is a shared experience of making music together, a shared experience and social interaction, even without words.

Gaze HD

As well as using these apps as the main focus, they can also be used to add extra stimulation to a session. Reading poetry or reminiscing about seaside holidays, the experience is enhanced by apps like Gaze HD (an app that allows you to play videos of fires or crashing waves at the seaside) brings the moment Alive! and has the feeling of being transported to another place.

Life Journal Pro

For making connections with family and friends we often use apps like Life Journal Pro or Keynote to help capture the care home resident's amazing life stories and histories. Not only does this help empower people to capture their memories, but the finished text and photos can be emailed to relatives and friends.

It is hard to imagine not being able to enjoy your passions or interests anymore and being expected to enjoy the same things as everyone else. Being re-united with these interests has a profound and emotional response for the older people that Alive! works with.

Design Can Help Dementia Care

Professor June Andrews is Director of the Dementia Services Development Centre at the University of Stirling. She has a Chief Nursing Officers of the UK Lifetime Achievement Award and received the prestigious Robert Tiffany International Award. She headed the Royal College of Nursing in Scotland, and directed the Centre for Change and Innovation within the Scottish Government in addition to her career in the NHS. She advises health departments and service providers around the world, and is a Trustee of the Life Changes Trust, an independent charity disbursing grants totalling £50m across Scotland. She is non-executive director of Target, a real estate investment Trust.

Because of a reduction in the relative population of younger people in some countries, there is anxiety about whether or not there will be enough health and social care workers to care for the increasing number of individuals with dementia. If we could find a cure it would reduce the level of disability, and much research is focused on that search. But what do we do in the mean time?

Research shows that much of the disability in people with dementia is made worse by other people and environmental issues. Dementia impairments include memory loss and difficulty in learning and understanding things. We know that the impairments of dementia do not build up at the same rate as the underlying disease processes. You may find brain damage in people who had no symptoms and quite severe symptoms in people with mild neural damage. So in the meantime while we struggle with finding a cure, we can make the situation better with simple relatively low cost changes in the behaviour of caregivers or the environment in which the person is living independently or being cared for that will reduce the symptoms.

The DSDC has had a particular focus on the effect of environmental design, both in care homes and in the person's own home, including the outside spaces that they access.

We have a particular interest in light. In some cases, getting the light right in the environment can make more difference than medication. All older people have yellowing of the cornea of the eye that restricts vision. They need light at much higher levels to see the same as younger people. If you cannot easily remember where things are, it helps if you can see where they are. Remembering, then, is not quite so crucial. This helps when memory is starting to be a problem.

Second, sleep is affected by diurnal rhythms in the body that, in turn, are affected by the

hormone melatonin. If the production of this hormone is disrupted, it can cause nocturnal wakefulness. People who are already confused get up in the night and may wander into danger—or at the very least frighten and worry their household. Melatonin is naturally produced in the body as a result of light falling on the retina of the eye. In older people, daylight exposure needs to be increased because of the thickening of the cornea that reduces the efficacy of any light. If you can expose a person with dementia to daylight, particularly in the early part of the day, you can contribute to the reduction of nocturnal disturbances.

Simple design changes or changes in routine can thus make a significant difference to two important dementia symptoms. Currently, not many health or social care professionals make recommendations about lighting or daylight exposure to family caregivers or people with dementia. Exposure to daylight is often impossible in hospitals.

Hospital environments are particularly harmful for people with dementia for a number of reasons, some of which are avoidable. In acute hospital settings, patients with dementia are sometimes sedated to deal with their stressed behaviour, and they may miss out on eating and drinking as they sleep through meal times. They miss out on exercise and may be actively discouraged from moving about. Often there is no one to talk to and nothing to do during the long days in the hospital. Research shows that patients with dementia often refuse pain relief, even when they clearly could use some.

All of these factors make patients with dementia vulnerable to depression and delirium while they are in a hospital. The net effect is that an expensive modern intervention, the acute hospital admission, which is intended to provide temporary help, healing and access to assessment, actually causes more harm and makes dementia symptoms worse. In the UK, it is not unusual for an acute hospital episode for a person with dementia to stretch out longer than expected, and to end with the loss of their home and admission to an institution.

A key question is how to get dementia design information implemented. Information about dementia-friendly design is freely available from DSDC through our website at: http://dementia.stir.ac.uk/design/virtual-environments. Checklists are available to help anyone introduce design ideas that will reduce stress for a person with dementia and help them overcome the difficulties associated with the condition. Advice on assistive technology is available to download at: www.dementiashop.co.uk/node/287. By presenting information in this open and accessible way it is hoped that change will happen. However, experiences tell us that just knowing what is right does not incentivise systems to do what is right.

Even though this sort of information is available for free or at very low cost, the

problem remains that in buildings which are intended for populations that will include a large percentage of people with dementia and related conditions, features that support cognitive impairment are not required by legislation or regulation. This contrasts with the regulations that require features supporting physical or sensory impairment. The person with dementia may be frail and elderly and any sensory and physical impairment is increased by dementia, because the person is challenged to use or understand any recently designed adaptations. While it is important to lobby for legislation to improve the situation, the questions remains, as with a cure, what do we do in the meantime?

If you are in the position as a clinician or manager of trying to make a case it is often very persuasive to point out that dementia friendly buildings reduce the burden of care and therefore the cost of care for people with dementia, while increasing the quality of life. This explains the high take up of these concepts in the independent sector, where attention to cost of care is crucial for survival of the business. Care homes compete with each other to demonstrate their dementia friendliness in a way that is not matched in the public or hospital sector. They advertise to their potential customers that they have these features and dementia design competitions for care homes are hotly contested every year with increasing numbers of high quality entries.

Commissioners of public services and those commissioning public buildings need to insist that the providers, including architects can give evidence that they understand and are able to incorporate dementia friendly principles in the buildings and services that they provide, and make that part of the contract. Education for this is available, for example in the DSDC design schools that are offered to architects, managerial and clinical staff across the UK. http://dementia.stir.ac.uk/design/design-school. It is significant that the design schools include coaching in how to make change happen and how to tackle blocks in the system.

In the interest of people with dementia we need to make this change happen.

‘I am very excited about the potential for working with other countries as I know there will be a lot for me to learn from them.’

Jackie Pool has dedicated her professional career of more than 30 years to improving the lives of people who are living with dementia. Jackie qualified as an Occupation Therapist in Liverpool in 1988 and since then has worked in health and social care services, continuously developing her knowledge and skills in supporting individuals with dementia.

She is recognised as a leading dementia specialist and was awarded the National Dementia Care Award 2011 for Best Dementia Care Personality. Her publications about providing support to individuals with dementia and their families are used around the world and Jackie speaks regularly at conferences and through social media networks about the work she continues to develop. She is currently working with Bangor University on a National Institute of Health Research (NIHR) funded study of the impact of cognitive rehabilitation approaches with individuals with dementia.

Who are you and what do you do?

My name is Jackie Pool and I am an Occupational Therapist specialising in dementia care. I began working with people living with dementia 30 years ago as an OT Support Worker in an NHS continuing care ward. As you may be aware, the field was not person-centred in those days and I remember being shocked by the way that the patients were being cared for. That was the start of my journey to try to make a difference to the experience of individuals with dementia, their families and also the paid carers. After studying and qualifying as an OT I worked in the NHS as a clinician and then later, for Hampshire County Council as an OT Advisor to the care homes. I set up my own practice: Jackie Pool Associates in 1994 because I wanted to cross the boundaries that existed then between the different public sector services. I was continuing my professional development and a key moment for me had been in 1990 when I first met Tom Kitwood and realised the potential of the person-centred approach in dementia care. I was writing about the positive outcomes for my patients and when these were published, I began to be asked to speak at Conferences about the approaches I was using. This quickly moved

into being asked to run courses for others and suddenly I had a Training Organisation, which was not the original plan but still a good use of my knowledge and skills.

I now focus on creating workforce development and dementia care leadership materials and I supply these to Training Providers for in-house training and to external Training Providers and Colleges. In addition, I act as a Dementia Ambassador, in a voluntary capacity, in Hampshire and this is to support the development of Dementia Friendly Communities. I also work at a national level with Government bodies and I am involved in an exciting research programme to trial the use of cognitive rehabilitation for people in the early stage of their journey with dementia. This is the GREAT trial and is a large multi-centre trial led by Professor Linda Clare, University of Bangor

Can you describe a typical day?

I don't really have a typical day. Sometimes I can be at my desk developing training materials and other times I may be out there delivering the training. I also have to run the business side of the company so that includes marketing, tendering for contracts and liaising with customers. On top of that there will be times when I am supervising the Therapists involved in the research programme – we mainly do that by Skype. Someone once asked me how many hours I work – and I can honestly say that I work all of them!

What do you most enjoy about your work?

I enjoy the fact that my days are different and that I get to meet so many people who are passionate about improving the experience of people who are living with dementia. I enjoy the creativity in putting together materials that will be helpful in that too. But what I most enjoy is seeing the impact of that on the work of others, when they tell me that they have supported an individual with dementia to achieve something.

What are the greatest challenges?

We have made a massive cultural shift into an understanding of person-centred approaches but, particularly in the current financial climate, there is a view that it costs time and money to practice these. I am frequently saying that we do not necessarily need to do more, we just need to do what we are already doing, but with a different attitude and approach. While some activities may take a little longer because we have slowed the pace to match the needs of the individual with dementia, the resulting benefits may actually mean that time has been saved in other ways – from not now having to 'manage' the distressed behaviour of the individual who has been rushed, for example.

The need for training in dementia care has now been embraced but I think that the biggest challenge is in supporting care workers to put into practice what they have learned. For me, this comes down to good leadership and a sense of team. Whenever I hear about poor care, it seems to me that a lack of leadership is at the heart of the problem.

Can you tell us about your Dementia Champions Campaign?

I started the Dementia Champions LinkedIn group as an antidote to all the negative media stories about the scandalous care practices. Whilst it is important to raise awareness of the vulnerability of people with dementia and to improve their protection from harm, it is demoralising to the good care providers to have their reputation marred by these stories.

We now have over 600 members from all over the world and we share stories and ideas for good practice.

I also developed a web site: www.dementia-champions.org which aims to also promote positive practice. The idea is to raise the standard (or emblem) for good dementia care.

When my Mum developed MND and dementia she had very complex needs and required specialist support. We spent some time looking for a good care home that could provide this and, as many others have said before me, I realised that, even when you are in the 'know', how hard it is to get the right help and support. Because of this, I created a free-to-use resource that helps families know what a good dementia care home should look like, with pointers for what they should see and hear in response to the questions they ask. I receive lovely feedback from families telling me how helpful the resource has been. I also get messages from care providers who have found the resource useful in benchmarking their own services.

What did you think of the 2013 G8 dementia summit?

I am delighted that the Government continues to be committed to improving the experience of people living with dementia and to reduce the prevalence. I am sure that it is good for their political profile to be seen to be taking the lead on a global platform but it is good for our country too to be viewed as leaders in the knowledge and skills required. I am not sure about the ambition to find a cure by 2025. As we know, there are many conditions that cause dementia so finding a cure for them all would be impressive. But a cure or a preventative method for some causes would be wonderful and certainly this is more achievable if countries collaborate with each other.

I did think it was a shame though that the summit was peppered with negative language about dementia, which illustrates that we still have some way to go in truly embracing a person-centred culture

Where would you like to go from here?

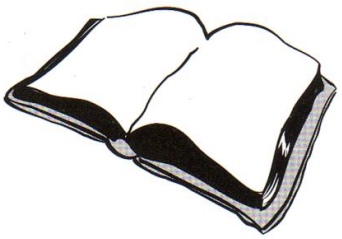
My biggest achievement is the development of the Pool Activity Level (PAL)Instrument which is used around the world by care workers to help them to understand the cognitive ability of an individual with dementia and to translate this knowledge into supporting the person to be able to function during personal and leisure activities.

I am now developing the MyPAL version which will be for individuals with dementia and their

family members to use at home and with domiciliary care providers. It will be an online tool which will automatically create a Guide for supporting the person and they will also be able to take it with them if they go into a Hospital or a Care Home.

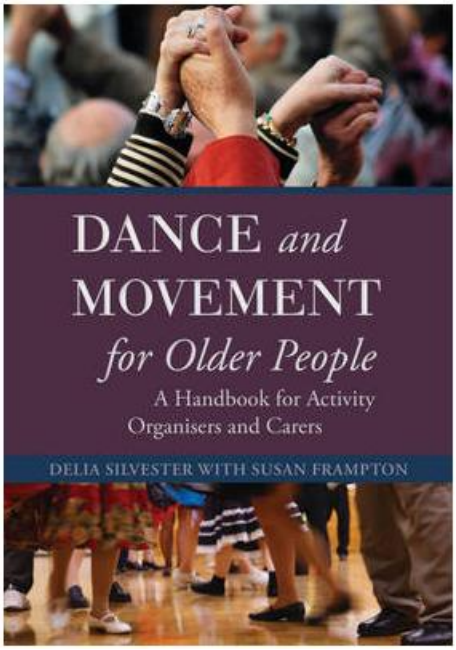
I am also now creating partnerships overseas and will be in South Africa soon to support the delivery of my Bee Inspired Dementia Care leadership programme there. I am very excited about the potential for working with other countries as I know there will be a lot for me to learn from them.

Book Reviews



Dance and Movement Sessions for Older People

Authors: Delia Silvester
Publisher: Jessica Kingsley Publishers
ISBN: 978-1849054706
Price: £17.99



This is a very important and timely book for anyone who is either thinking of initiating or is already leading dance and movement classes for older people or those living with dementia.

This well researched and clearly presented volume offers a wealth of practical suggestions on all aspects of planning and delivery of sessions from health and safety considerations and logistical implications to ideas for individual dances and significant occasions on which to base themed dance events. More importantly though, the book is infused with the love, care and (com)passion it takes to be an effective and affective leader in the provision of dance and movement for some of the most vulnerable members of our society.

The book includes step-by-step instructions and music suggestions for dances from a wide range of genres, cultures and time periods, as well as links to two online videos. Drawing on the wealth of experience built up by Silvester and her colleagues in Dance Doctors, the company she founded, it offers an accessible, inclusive and practical resource. It will provide a good introduction to anyone new to the field, including non-specialists interested in bringing dance and movement into activities with older people, those who are frail and/or who have limited mobility.

By writing '*Dance and Movement Sessions for Older People',* Delia Silvester has placed in our hands an invaluable tool which will enable us to empower people to re-engage with the joy and freedom to be found in self-expression through dance and in doing so, she has created an opportunity for us to make a much needed positive impact on the quality of life of our elders.

Malcolm Burgin & Gill Roberts

ALIVE! Regional Managers

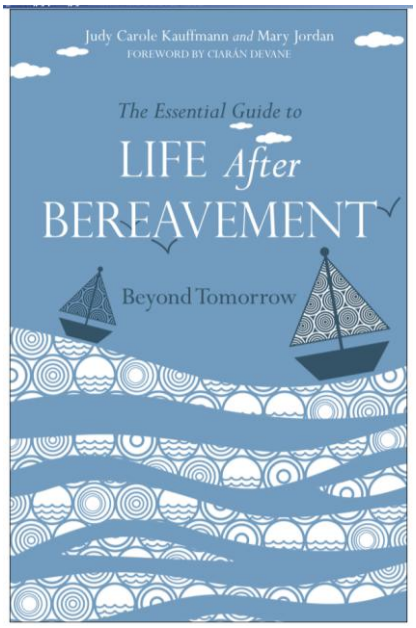
The Essential Guide to Life After Bereavement – Beyond Tomorrow

Authors: Judy Carole Kauffmann and Mary Jordan

Publisher: Jessica Kingsley Publishers

ISBN: 978-1849053358

Price: £12.99



This informal and very easy to read book aims to provide help and advice to those who have been bereaved or are supporting someone who has recently lost a loved one. Many sections within this book, particularly 'breaking bad news', would be very useful for persons in caring professions who may find themselves having to give news of a death to a vulnerable individual. This book not only gives immediate advice to those going through a bereavement, but also provides sensitive guidance to help in the weeks and months that follow the loss.

The case studies of personal experiences within this book demonstrate the reality of bereavement and the difficult situations which may arise as a result of a death. Knowing that others may also have been in similar situations during bereavement would allow the reader to relate to and gain a sense of comfort from the very honest reflections within this book. It is also important to mention that not only does this guide give very detailed emotional advice; it also provides the reader with a wealth of practical information from funeral arrangements to dealing with family conflicts. There is also a great deal of information on how the reader may choose to break the news to others around them, with particular emphasis throughout on how best to help an individual with a dementia to cope with grief and loss after receiving bad news.

Kauffmann and Jordan clearly advocate the principle of openness about the death of a close friend or relative to a person with a dementia. They strongly express that one should never assume that the person has not understood the news of a death and should therefore not be ignored when it comes to discussions and funeral arrangements. However, the authors effectively clarify that there are also occasions where it is actually unkind to remind an individual with a dementia that they have suffered a loss and provide helpful strategies that help the reader decide themselves the best decision about a death.

"It is very possible that the person with dementia may forget what has happened or may not be able to understand the finality of death".

In short, this book comprises both emotional and practical support for anyone who is

currently experiencing bereavement or is helping another person through a loss on either a familial or professional level. The advice that the authors give is both honest and compassionate throughout and covers numerous difficulties that bereavement may cause, including how to make person-centred decisions about information relating to the loss given to somebody with a dementia. Additionally, the authors have included a resources section at the end of the book which details many helpful contacts and websites that could be an invaluable source of support to the reader, whatever their circumstance.

Chloe Fitch

Psychology undergraduate placement student

Cardiff Memory Team

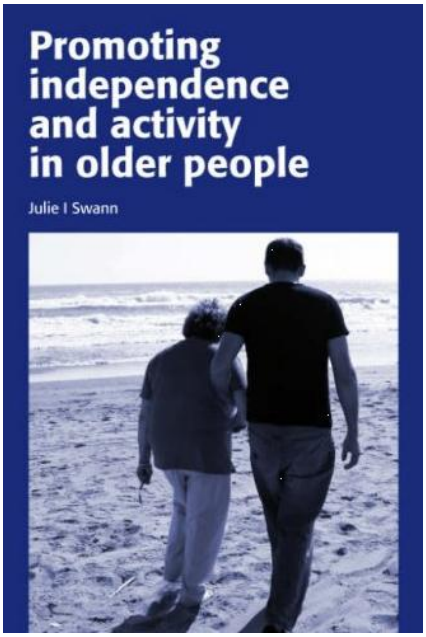
Promoting independence and activity in older people

Author: Julie I Swann

Publisher: Quay Books

ISBN: 9781856423342

Price: £19.99



Promoting independence and activity in older people focuses mainly on older people in residential care settings, but the issues covered are also relevant for older people living in the community. This book begins by discussing the journey into care, and covers issues and challenges faced by people as they age and adjust to changes in physical and cognitive ability.

The book is structured into parts, each containing chapters regarding a particular topic, such as mobility, recreational activities or rehabilitation. The short chapters make the book a manageable read, and are useful as a reference guide for care practitioners to refer to when particular issues arise during the course of care. This book would be a helpful read for the family of a person entering life in residential care, as it is written in simple, easy to

understand language, with definitions of new terms included, and helpful information such as a checklist of what to look for when choosing a care home for a relative. Each chapter is neatly summarised with a box of key points, which helps to reiterate the information covered and can act as a quick reference guide for both staff and the relatives of someone needing support.

There are many practical examples included throughout the book. Tables of problems that may occur in the course of providing care and solutions to overcome them, such as challenging behaviour during the provision of personal hygiene, are a helpful resource to both formal and informal carers. A chapter on turning a garden into a multi-sensory experience (Chapter 5) could be considered a bigger project, but the author provides practical advice in a step-by-step format so that it could be achieved, and the importance of creating the garden is highlighted through discussing the positive impact it can have on residents, staff and visitors alike.

Part ten of the book discusses the conditions of stroke, Parkinson's disease and multiple sclerosis, giving a background to each condition and highlighting the effects of each on people's lives. This section offers practical advice on how to help people diagnosed with strokes, PD and MS in everyday situations, and what staff in care homes can do when faced with problems regarding mobility, activities of daily living and communication, with a discussion of how environments can be adapted to suit people's needs. This section flows easily into part eleven, which covers rehabilitation, and provides information about the different members of rehabilitation teams and what services they can offer, making this part of the book useful to the families of older people currently accessing rehabilitation services.

This book is an enlightening and enjoyable read, with a clear, easy to follow structure, including some excellent resources and examples. The author shows that quality of life can be achieved when problems due to ageing occur, and the sensitive and thoughtful way in which this book is written provides an insight into how both informal and formal carers can maintain the independence, activity and dignity of older people.

Jen Yates

PhD Student

Dementia Services Development Centre
Bangor University

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.

Aquapaint

Aquapaint is a creative product specifically designed for people with dementia. When water is painted on to the pre-drawn design, colours emerge to complete the picture. As the water dries the image fades ready to be used again. There are four themes available – classic sports, marvellous machines, pets and animals and the seasons - which each contain four images.

Each pack costs £14.99.

www.mindfulgifts.co.uk/paint-projects

Alzheimer's disease diagnosis blood test breakthrough identified.

King's College London recently published a study, which identifies a set of 10 proteins in the blood that may predict the onset of Alzheimer's. This may be a significant step towards developing a blood test for the disease.

The study has been considered a 'major advance' in the development of a blood test to identify the condition when people are asymptomatic so hopefully enabling intervention at early stages of the disease, so enhancing quality of life for longer.

This is so important when considering the ageing population, and age being one of the biggest known risk factors for dementia.

A recent article published in the British Medical Journal on 12th July 2014 acknowledged that testing for 10 lipid metabolites which had >90% sensitivity and specificity in predicting who would develop mild cognitive impairment, Alzheimer's disease and who would not, however, acknowledged the need for further larger studies.

Sources:

Mental Health today, News 11th July 2014 http://www.mentalhealthtoday.co.uk/alzheimers-disease-diagnosis

The BMJ 12 July 2014 349:1-40 No7966. Clinical research

1 in 3 Alzheimer's cases preventable, says research.

Researchers based at Cambridge University published findings in The Lancet Neurology, indicating that a third of cases of Alzheimer's disease could be linked to modifiable lifestyle factors e.g. lack of exercise and smoking.

Age is still the biggest known factor, but other risks for Alzheimer's disease include:

Diabetes

Mid-life hypertension

Mid-life obesity

Physical inactivity

Depression

Smoking

Low educational attainment.

This study considers the effect of overlapping risk factors, and how reducing these factors could affect the future of Alzheimer's disease cases. *Researchers estimated a 10% reduction in risk factors would reduce cases by 8.8% or 200,000 in the U.K. by 2050.*

This concurs with Professor Peter Elwood and his colleagues' findings at Cardiff University. Last year they published results from a 30 year research study involving men in the Caerphilly area of south Wales. This showed the positive benefit of lifestyle changes and five healthy behaviours:

Regular exercise

Low body weight

Not smoking

A healthy diet

Low alcohol consumption.

Their research showed that when the male participants adopted this healthy lifestyle, there was protection from development of dementia; *by almost 70%.*

Addressing physical inactivity will have secondary benefits such as reducing obesity, hypertension and diabetes, and have a positive effect on some mental health issues.

Sources:

www.plosone.org 9th Dec 2013. Healthy Lifestyles Reduce the Incidence of Dementia and Chronic Disease: Evidence from the Caerphilly Cohort Study. PLOS ONE

BBC News Health. http://www.bbc.co.uk/news/health

New campaign urges businesses to become more dementia friendly.

The Alzheimer's Society and Public Health England recently launched the Dementia Friends campaign. More businesses are encouraged to become aware of the issues surrounding dementia, the issues affecting the public they deal with and also employees who care for someone with the condition. This campaign has the backing of the West London Mental Health NHS trust, as it recognises that despite the high prevalence of the condition, especially over the age of 65, people can live well with dementia and 'we as a community have a responsibility to help them do so.'

Sources:

Mental Health Today News 12th May 2014.

http://www.mentalheathtoday

Information about Signpost

Anyone Can Contribute to Signpost

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

Contributions

All contributions must demonstrate a positive attitude towards this group of people and their carers. Contributions can be made in the form of an article, care study, letter, question, announcement, review or other appropriate proposal.

Contact Details

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

Tel: 02920 715787

Email: Amanda.Furnish@wales.nhs.uk

Books Available for Review:

Lesbian, Gay, Bisexual and Transgender Ageing – Biographical Approaches for Inclusive Care and Support. Richard Ward, Ian Rivers & Mike Sutherland, 2012.