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SIGNPOST

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Dementia Services Development Centre Wales

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Contents:

Cover picture: Image kindly provided by Alive!

Editorial

Welcome to the latest edition of Signpost and a happy new year to everyone. There are some interesting and creative articles in this edition. In many respects we still have limited research evidence for the use of a diverse range of therapeutic interventions, but this should not prevent us from trying innovative and creative approaches to improving the lives of people experiencing dementia.

I have a particular interest in the article written by Re-Live that shows how the arts can be used to enhance people's quality of life by focussing on the individual and their stories/memories. The emphasis is on what someone can remember, not what they have forgotten, and looking for strengths and not weaknesses. Using storytelling, song, and dance to connect in a non-threatening and meaningful way has clearly contributed to the quality of life of the residents who experienced their sessions. In my role as a lecturer at Cardiff University my colleagues and I are aiming to become the first 'Dementia Friendly' school in Cardiff University. As part of this project a business case to allow Re-Live to provide training to all our undergraduate nursing students is being put forward. Here's hoping.

The article 'Singing on Penmon Ward for People with Dementia' is looking at developing a growing body of knowledge that indicates the value of music and singing in improving the quality of life for people experiencing dementia. I like the fact that people from a variety of different backgrounds, both in terms of experience and training, can work collaboratively towards the same goal. The emphasis on fun and enjoyment, and ultimately providing positive life experiences is commendable. Although sessions were structured, this did not inhibit spontaneity and flexibility which is so important if we are to meet the needs of the individual. What was also evident was that the positive outcomes from the sessions went far beyond the confines of the sessions themselves.

'Lifting the Fog on Dementia' continues the creative theme of the previous articles. It also highlights the challenges facing supporting people who develop dementia at an earlier age. The challenges of providing effective care to people with Early Onset Dementia have been known for some considerable time, but providing service provision to meet these care needs has been slow and inadequate in my opinion. Any strategies that are able to identify the problems faced by this client group, and more importantly creating support strategies, are laudable.

The final article 'Reflections on dementia care' offers an insightful perspective on the provision of care services in England, Wales, and Romania. Despite wide variations in the quality of care provision, and a lack of meaningful activity in many areas, there is still room for optimism. As long as we have people who are passionate about improving the quality of care and quality of life for people with dementia there is hope.

Paul Bikerstaffe

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Firstly, we would like to congratulate Rosalind Cooper and Emma-Marie Williams, the previous Deputy Editors of Signpost, on beginning their Clinical Psychology Doctorate training! Our names are Matt Lewis and Angharad Jones, and we are the new Deputy Editors of Signpost. We are both Assistant Psychologists, working within the Memory Team and the Practice Development Unit at Llandough Hospital, Cardiff. We are both very excited to be involved with '*Signpost*' and with Dementia care. We hope that the informative and accessible articles and reviews that we publish will help Professionals, care-givers and people living with Dementia learn more about the continuing developments in Dementia care.

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Singing on Penmon Ward for People with Dementia; Ysbyty Cefni, Llangefni

Pauline is a singer, songwriter, composer, a community choir leader, voice coach and arts in health trainer, mentor and practitioner. She has delivered several music projects in hospital settings, including older people with memory challenges and on acute mental health wards. She is currently leading a choir for staff in the Princess of Wales Hospital in Bridgend supported by ABM UHB Arts in Health, which also engages patients and visitors in singing by visiting wards.

From February - May 2013, residents, staff and family visitors were invited to take part in regular singing sessions as part of a 12 week pilot project at the dementia care unit in Ysbyty Cefni.

The aims of the project included:

- To introduce the benefits of singing within a hospital setting during people’s period of assessment and rehabilitation.
- To support staff and promote the sharing of skills
- To engage with visiting family/carers when possible
- To promote volunteer ethos in the local community, fostering sustainability.
- To undertake qualitative evaluation as a precursor to developing and contributing to future collaboration with the University of Bangor Dementia Research Programme
- To be the first pilot in establishing BCUHB membership of the international `Singing Hospitals Network` (see ref below)

This report sets out the background to the project, the practicalities and structure of the sessions, the outcomes and recommendations.

Background

This pilot project was the result of funding obtained following an earlier scoping and SBAR paper by the BCUHB Lead Music Therapist, which addressed the benefits and research backdrop to `Singing & Dementia’.

There is a growing body of evidence demonstrating that participation in singing activities can improve the health and well-being of older people with dementia, as shown in the following study : Camic, P.M., Williams, C. and Meeten, F. (2011) Does a ‘Singing

Together' group improve the quality of life of people with a dementia and their carers? A pilot evaluation study. Dementia (pre-publication online: DOI: 10.1177/1471301211422761)

The benefits of singing activities for older people with dementia and their carers often include:

- Social interaction in a fun and supportive group
- An improved sense of belonging and a decrease in feelings of loneliness and isolation
- A reduction in levels of anxiety
- Stimulating memory and reinforcing life narratives
- Stimulating health inducing neurophysiology
- Celebrating retained skills and nurturing new skills
- Opportunities for making choices
- Sense of purpose
- Providing care-givers with creative resources and skills that may simultaneously support their needs and those of they care for
- Creating new and happy memories

The Singing Sessions

Facilitation

The project was led by Pauline Down, a singing facilitator who has extensive experience of working with people with dementia, in hospital, care home and day care settings. She was supported by Molly Steele, a music student from Bangor University, and Dr. Cara Rogowski, Clinical Psychologist, BCUHB. Volunteers from Pauline's community choirs attended sessions to offer vocal support. Ward staff attended when they could, either to give one to one support to people attending or general support to the group.

Preparation

A deputy ward manager was allocated to the project, however contact was limited due to the work rota. This member of staff was only occasionally available on the day of the singing.

The sessions were held on an afternoon of the week identified by the staff as having no other planned regular activities such as ward rounds or reviews.

The leader arrived early each week in order to have plenty of time to talk with individuals before the session, to inform them about what was about to happen and to prepare the room.

Venue

The intention was to make the environment as easily accessible and welcoming as possible. The room that had been chosen for the activity had lots of natural light from big windows. Chairs were set out in a circle. People could also sit by the window or at the side of the room, if they wished to be there but didn't want to sit in the circle with the rest of the group. This option worked well for individuals who might not be feeling well on a particular week and also helped people new to the group to integrate at their own pace. Often people would join in from the periphery and when possible a member of staff sat with them.

Format of the sessions

From the start, an atmosphere of fun, informality, empathy and unconditional positive regard was established. Singing would last for about an hour. Afternoon tea was served in the same room following the session.

a) The sessions always began with the same opening song, which included everybody's name in turn, thus affirming every individual participating.
b) This was followed with some fun warm-ups and action songs.
c) Then followed a mixture of songs; some new, ones that involved making up spontaneous verses, songs with props (e.g. passing a beanbag, manipulating a large piece of stretchy cloth in the middle), and others with lyric booklets made by the leader. Small hand percussion instruments and spontaneous song requests were included.
d) Songs often stimulated discussion so there was space for a chat between songs, and an opportunity for the group to reminisce. Individuals were free to spontaneously sing a song of their choice or to make a request.
e) The session always finished with the same gentle African lullaby.
f) The singing ended each week with tea and a snack in the same room which meant that group members had the opportunity to continue socializing. Often they stayed for up to an hour longer, often spontaneously singing more or reminiscing and chatting.

Attendance at the session

7 to 10 residents attended every week, 1 – 3 family members attended most weeks apart from 2 weeks when no family members were there, 1 – 3 staff attended each week, 2 – 5 volunteers attended each week.
Impression from the sessions

The beginning

The very first session was lively and buoyant with an atmosphere of excitement. Two individuals with dementia danced with the leader during the first session – one man is a very good dancer and leads well!
Also during the first session, one person spontaneously added extra words to a tongue twister song.

During one session, a spontaneous birthday party for one lady took place (staff brought in cake and tea during the session). At the end of the session she thanked and kissed everybody and said what a fantastic birthday she had had.

One gentleman sang his heart out, and would often lead us into Welsh hymns and commented each week about our progression as a choir.

Some spontaneous comments during the first few weeks included:

“I enjoyed this very much”
“Thank you!”
“The singing was better today”
“Thank you, I enjoyed that very much”
“Thank you; he sings very well – he sings early every morning!”
“That was very good”
“I had a really enjoyable afternoon”
“Diolch!”
“Thank you very much. Will you come to sing with me at home?”

The middle

During the middle phase the leader began to introduce some more new songs. This had a very positive response. Everybody in the group engaged and joined in at their own level. People also began to show signs of remembering new songs that had been introduced in earlier weeks. Even though some people didn’t speak Welsh, all members sang as best they could, whatever the language of the song.

It was evident that the songs with actions, e.g. passing the bean bag, doing a clapping rhythm, using hand percussion or holding the stretchy blue cloth, were particularly good for engaging people.

Songs which involved making up verses were also good for engaging people as long as there was no pressure or obligation to come up with anything.
When singing ‘Quartermaster’s Store’, a song that had emerged as a favourite of the group, people became animated, delighted and amused when the leader began to make up verses about individuals in the group.

The latter bit

During the final phase of the project, the leader introduced another new song about trees. Each participant was invited to name his or her favourite tree, which then became the subject of the next verse. This seemed to be an enjoyable and affirming process for each individual. Offering something that involved a simple and reasonably familiar choice seemed helpful, and each were able to participate at their own level.

Foot or hand tapping, smiling, nodding and attention directed towards the facilitator were observed to be happening consistently amongst many people present.

It became obvious as the weeks progressed that the singing group was stimulating a great deal of interest and enthusiasm. One day when the leader arrived, two of the male group participants stood very close to each other in the corridor and began singing a favourite song very loudly as soon as they saw her. This caused an atmosphere of great excitement and there followed a procession of people down the corridor to the room where the singing took place, with some people singing at the top of their voices all the way. The atmosphere remained very buoyant throughout the session.

Bonding between the two men also became more evident during the final phase of the project. For example, in one session, the two men sat together and behaved like best friends throughout; teasing each other, laughing out loud, singing in full voice together and commenting positively on each other's voices. One was calling the other by a nickname he had created for him. Apparently, this friendship has lasted beyond the singing group and these two men have been witnessed socially interacting with each other on the ward.
Two other men, who were sat together and had been observing this, also started to tease and prod each other and do thumbs up to each other (both have very limited conversational ability). At one point one of them turned to the leader, indicated the other and said, “Mates!” Both grinned.

An example of how cohesive the group had become was demonstrated during the penultimate session. A new resident attended who was constantly making sudden exclamatory sounds and demonstrating extreme agitation. Despite one group member briefly complaining to her towards the beginning and asking her to ‘do it properly!’ the group accommodated her and carried on. The person who had initially seemed particularly disturbed by the noisy participant, settled down to focus on the singing. The new person stayed for the entire session, despite having demonstrated a high level of anxiety at the beginning. She visibly calmed down during each song and listened attentively, sometimes keeping the beat by patting her leg. It appeared to be a credit to both the group and to the singing that they managed to adapt in this way.

The gentleman who had danced with the leader during an early session did so again on several other occasions. His movements were fluid and he seemed at ease when dancing. In the early phase of the project he hovered on the periphery of the group, coming in and out. As the project progressed he began to come along to the room having heard the singing and would come straight into the circle and stay. One time he said, “I heard the singing and came down”. In the final phase of the project he came for the start of each session and stayed, appearing to be very settled and comfortable in the group. One time he said “do come back next week!” This is a man who is reported to be disorientated at times on the ward.

Another gentleman hovered on the periphery of the group in the first few weeks appearing to be unsettled and disorientated, and yet staying in the room for the entire session. During the final phase of the project he attended each session, sitting in the group for the duration, laughing, showing enjoyment of the songs and making comments (most often by gesture). In one session he became quite emotional on several occasions. He began conversing more lucidly than usual that time, especially with the leader and visitors. After the tea break he offered to carry the leader’s drum to the door, saying, “see you next time” as she left.

Another time, two of the gentlemen had a discussion about favourite songs and how beautiful the words sometimes were, and were trying to recall the words of one Welsh hymn in particular. The leader came back with the words and tune the following week and the hymn subsequently became a part of the group repertoire.

On a couple of occasions people who hadn’t felt up to joining the group on that day, called the facilitator over at the end of session and said that they had heard it and enjoyed it; “I could hear the singing; it was lovely”.

Sometimes group members seemed very tired and had their eyes closed during large parts of the session but would still sing and join in even when their eyes were closed.

One person, who came regularly, often looked very tired but was always calm and relaxed during the session. She joined in every song, often nodding her head gently to the rhythm. Her son who attended quite a few times commented on how much she enjoyed the sessions.

Those people who understood that the group was finishing expressed sadness about this at the last session, and asked whether it would be starting again. Some of their comments were:

- “The singing always cheers me right up!”
- “Bendigedig, dwi’n edrych ymlaen i wneud o eto tro nesaf”
- “Oh, I do love coming to the group”
- “Singing always makes me feel happy, even though I don’t sing very well”
- “That was marvellous”
- “We must do it again”
- “I think the group is a wonderful thing for people at the hospital”
- “I used to have a very good voice. It’s not so good now but I enjoy singing, that’s the important thing”

After the sessions

As the weeks progressed it was observed that in the tea break immediately following the singing, the group was becoming more and more cohesive. People began addressing one another more, initiating 'normal' conversations. After one session, singing erupted spontaneously again during the tea break and continued until 4pm. Lots of old music hall songs emerged. One person sang all the words of one song on her own after the group had begun to hum the tune unable to remember the words. There was much buoyant energy. One person spontaneously got up out of his wheel chair when we'd finally finished and started to make his own way to the toilet, to the consternation and surprise of both staff and others! In the tea break a few weeks later, the same gentleman stood up and walked over to another male participant, leant on the back of the chair, and began to converse very naturally and convivially, looking and sounding completely at ease as if he didn't normally use a wheel chair at all!

One week a conversation emerged during tea that had everybody talking together lucidly as a group. People were asking questions about each other's birthdays showing a particular interest in the year they were born and also where they grew up. Connections were made as they worked out who was the eldest, who shared a birth year, who grew up in the same area. One person seemed to have once again forgotten the usual worries that were causing ongoing distress and continued talking with one of the volunteers about people they both knew. In a subsequent session, the same person also volunteered to recite poetry, when asked for another song with the word 'blue' in it and then went on to sing the rhyme.

During the group conversation there had been much laughter. One lady who had been very tired and slumped in her chair with her eyes half closed at the beginning of the session, was fully engaged in the conversation and responding. One man was very animated at this stage, having also been very tired towards the beginning of session. His conversation was heartfelt about how lucky we are to live in such a beautiful place and talked about being 'as young as you feel'.

As people left, they hugged and kissed the volunteers and leader who had been present. Two smiled and said, "It's been a wonderful afternoon". There had been a high level of positive interaction.

Evaluation

The impact of the singing on people attending the group was evaluated in three ways. Firstly, impromptu comments during the sessions by participants were noted, as well as any remarks or reference made to the group after the sessions. Secondly, observations of the participants' behaviour took place by staff and facilitators during and after the singing sessions, with attention being paid to subtle

changes in mood and behaviour. An attempt was made to quantify these changes by using a modified and simplified dementia mapping tool, obtaining a Well/Ill-being indicator. If you are interested in the detailed results
in order to find out how it worked, contact paulinedown7@gmail.com
Thirdly staff, family and relatives were asked for their opinion about the singing.

Comments/ observations during sessions
As a result of observations, some quoted above, conversations with participating staff, family visitors and volunteers, and the comments of people themselves it became evident during the project that most of the participants were experiencing the following benefits:

- *Sense of belonging/social inclusion/group bonding*

"He became very animated when singing in the group and began to chat and joke with others around him"

- *Sharing something positive with a loved one*

By doing a normalizing activity together as equals (when family visitors were present)

- *Social interaction*.

"In the tea break after the session they were all conversing as a whole group, enquiring after each other's birth dates, everybody joined in."

- *One-to-one bonding*

People often showed signs of bonding with the person sitting next to them during the session, whether that was a leader, a volunteer, a member of staff, another person or a family visitor. Relationships/bonds built between people were not something typically seen or observed before on the ward.

- *Staff interaction with people with dementia.*

Positive interactions were observed between staff and participants. "The singing together provided a further opportunity to bond with each other and to spend quality and uninterrupted time together."

- *Sense of achievement*

"I think we're getting better!"

- *Sense of fulfilment*
- From learning and being able to recall new songs "I remembered it when you started it!" It has been observed that people remember the new songs as well as the old, demonstrating that it is possible to continue to learn new information despite, in some cases, severe memory impairment.
- *Sense of identity*

Through reminiscence "we are lucky to live in such a beautiful place!" "I used to have a very good voice you know!"

- *Enhanced emotions*

People sometimes showed emotion throughout the session and following the session. Songs can evoke memories and subsequently lead to emotional reactions.
"She really loves the singing!"
"I do feel quite tearful you know, but not in a bad way!"

"He often gets very emotional and has a big cry after the session is over but I don't feel that this is a bad thing"

- *Feeling affirmed*

As a result of choosing songs, hearing own name sung (e.g. in the opening greeting song) making up or remembering verses etc.

- *Cognitive stimulation*

"During the tea break following the session, she began to chat lucidly and have a very normal conversation with the volunteer sitting next to her, telling them about her previous job, her sons and their families and occupations, which is very rare for her these days"

- *Being occupied*

In a pleasant or relaxing way.

- *Seeming more engaged and alert*
- *Structure and routine.*

The session structure which included repetition and always began with the same opening and closing song, followed a similar pattern of song activities, incorporating both old and new each week, which appeared to anchor the group. The fact that a core of people who came regularly was familiar with the routine seemed to help new members feel more comfortable. Favourite songs tended to be ones with lots of repetition and a very obvious structure which lent themselves to spontaneous new verses and harmonies.

Staff and family and relatives questionnaires

A simple questionnaire was designed for both staff and family asking for their views of the singing on the ward (Appendix A). The focus of the questionnaire was on the possible benefits and drawbacks of this type of activity on the ward. The questionnaires were available in both English and Welsh. They were handed out to all staff and to visiting family, who were asked to return the questionnaires anonymously at reception.

No staff questionnaires were returned. However, on the final day of the project four members of staff spoke very enthusiastically about the project to the singing leader and said, "when will the singing start again?" The ward manager also came to speak with the singing leader after the session and expressed a desire for the project to continue, asking whether she knew when this might happen. Three weeks after the project ended, the leader met a member of staff by chance at Ysbyty Gwynedd. This member of staff said, "do you know when the singing will restart? You do realize, don't you, that I was your biggest sceptic but I thought that it was absolutely fantastic."

In total three family members returned a questionnaire. All three relatives were aware of the singing sessions on the ward and had taken part in them, despite one person stating that normally they did not like singing with others.

They felt the benefits of the singing for a person with dementia were:

Patient and staff enjoyment, seeing family join in activities, being involved together as family members in a therapeutic activity and that singing triggers memories. One commented that singing seemed to enhance and sometimes ease the relationships between residents and family members.
Singing was also felt to enhance the staff team's ethos. None had noticed any drawbacks to the singing sessions, apart from both staff and family not always having the time available.

Two relatives asked for the sessions to continue and increase to two to three times a week. One person noted the benefits of the sessions for a severely impaired patient who was able to sit, listen and attempt to participate in the singing, with their mood lifted as a consequence. The other relative felt that the benefit for the patients was being able to join in an activity that was mentally stimulating, for families to join in with their relatives, for staff to see the patients actively participate in activities together.

Way forward

Staff attendance and support ideally could have been more consistent.
Generally there was at least one staff member present for the entire session as agreed.

It would have been helpful if more staff had been in attendance so that there was not just one to one support for a person who is displaying a high level of agitation but also for others who may need support with accommodating that.
Recommendations

The pilot project showed qualitative evidence that a singing group for people with dementia in an acute ward is viable, acceptable and provides a range of benefits.

There were several lessons to be learned which have been documented and are available to anybody wishing to set up a similar project from: paulinedown7@gmail.com

Re-Live:
Theatre, Life Story Work and Dementia

Alison O'Connor is a Cognitive Behavioural Counsellor (University of Wales) with particular expertise in counselling older adults. She is a highly skilled group worker with extensive experience of applied theatre work in hospices, residential homes, mental health settings and with vulnerable groups across the UK. Alison was awarded a 'Creative Wales Award' from The Arts Council of Wales (2013) to explore "Transformation in Arts and Health: Stories that Change".

Karin Diamond has worked in theatre, film and television for over 20 years, with a wealth of experience in performing, writing and producing original work. In 2010 Karin was awarded a Winston Churchill travel fellowship to research 'Theatre with Older People' with Dr Yukimi Uchide in Japan. Dr Uchide is a leader in the field of creative and reciprocal approaches to dementia care. This groundbreaking research continues to influence and inspire Re-Live's training programme today.

Re-Live is a professional arts organisation run by Karin Diamond and Alison O'Connor. We create theatre and life story work with older people and those who care for them. We are driven by our belief that everyone has a story to tell, and that our wellbeing depends upon that story being validated and respected. This same belief inspires our experiential training work for professionals working with older people and in dementia care. We are excited to be part of the growing international movement that is Creative Ageing. There is a dynamic network of practitioners working with older people through the arts and we are engaged with fellow arts practitioners in Australia, Ireland and Japan.

Our journey as theatre practitioners working in care settings began in a Romanian orphanage in the early 90's where we worked using theatre to help the young people express themselves, connect with each other and find a release from the horrendous environment they lived in. In a small way our creative input allowed the rigid rules and beliefs of that institution to be stretched and questioned. Theatre allowed those children to be seen and to see themselves as something good. This glimpse into the transformational power of theatre has driven all our work since, and we went on to create theatre in prisons, secure hospitals and youth centres. All of this work has strengthened our belief in what the telling and enactment of a story can do for people – patients, inmates, staff and the whole atmosphere of institutions. It seemed possible that this approach could also lend itself to older people and the institutions they live in.

In 2006 we established Re-live, driven by our belief that many older people have lost the confidence, desire or perhaps most crucially, the opportunity to tell their story. Over the past 8 years we have worked in theatres, care homes, hospices and community centres developing our methodology of life story work and documentary theatre with older people. Our approach combines elements of reminiscence work, life review, storytelling and theatre. We accompany older participants on a journey of reflection where they decide on the story they want to tell, and after a period of rehearsal they perform their stories live. As one participant said about the process

"To be given a chance to show exactly how I had felt about certain episodes in my life was both cathartic and empowering. This has been one of the greatest times of my life" Terri, former participant

Life Story Work with people with dementia

We became curious about how our approach might connect with people living with dementia. We found a care home in Cardiff where the manager was open to the idea of us running some informal life story sessions with a small group of residents who were living with dementia. We arrived with our bag of tricks – images, smells, books, music and quickly realised that we were going to need to be responsive and really just be with the residents, trust and see what happened. We went on a journey with this group, sometimes bewildering, sometimes hilarious. We all laughed a lot, we held hands a lot, we gave people permission to tell fragments of stories or stories that didn't make sense, that weren't "true", share bits of their lives, sit silently and enjoy being connected for an hour, we allowed ourselves to make mistakes, and not know quite where our sessions might take us.

One day we were standing in the lounge beginning our warm up – we always started our sessions with a warm up, stretching and making eye contact, connecting with each other. Now this care home had a very enthusiastic manager and some wonderful staff but the actual building was unfortunately dilapidated, dull, and to our eyes, pretty bleak. We were working in a small room with nothing on the walls, the usual chairs lined around the outside, dark carpet, and a strong unpleasant odour. We noticed that the garden at the back of the house had been done up and had lovely plants and flowers. One day we suggested going into the garden and doing our warm up outside. The staff were reluctant, there were a lot of barriers being raised, too far to walk, too cold, "they don't usually go outside". We persisted, with gentle persuasion – and discovered that one of the stumbling blocks was that one of the residents didn't own a coat. We found this very sad as the expectation seemed to be that this woman did not need one as she never went outside. Was she potentially never going to go outside again?

Well she did. A spare jacket was found, everyone was dressed and we set off through the main living room down a little side corridor and out the back door.

We stood next to a rose bush, took a few deep breaths of fresh air and people started talking to each other. “Wow, what beautiful flowers” “I can smell them, can you smell them?” “I used to love gardening”. We were validating everything everyone said, praising people for taking deep breaths, looking around them, looking up at the sky, working hard to reassure people that everything is right, valid, worth saying. We were learning that so much of the anxiety around dementia was coming from the stress of getting things wrong, not “remembering” how to say it right and we worked hard to remove those pressures, emphasising the quality of interaction and not the content. We were doing this near the smoking area so a few staff members saw us and this was the start of some interest in what these two strange women were actually doing. From then on we would quite often have staff members popping in to our sessions, sitting on the arm of a chair and listening to what was going on.

There was a wonderful member of staff called Karen who was with us for the whole time and she was like a sponge; she loved what we were doing and how the residents were responding. On the second day she brought a notepad in with her and from then on she was writing and recording all through the sessions. Whereas in the beginning it seemed like none of the residents had any personal photographs or objects, by week 2 Karen was bringing things out of storage - beautiful photographs in frames, mirrors, trophies that had been won. She had been working in care for a long time and clearly had so many skills and so much potential and she seized on the tools we were showing her, and kept the work going after we left. Karen, even 6 months down the line, arranged for a minibus and brought a group of residents to a local theatre to see a performance we were putting on there. That might sound like a small step but it represented a big shift in thinking at the home.

We used music a lot, both singing and recorded music. One day we had played a selection of music and most people were clearly enjoying it and connecting, apart from one woman, June, who was quite detached. June had advanced dementia and hadn’t spoken in any of our sessions but she smiled a lot, and loved the touch exercises. We knew that she had grown up in the docks in Cardiff, a vibrant multicultural area of the city, and Karin my colleague was operating the laptop and decided to play a Bob Marley song.

As the rhythm filled the room, June started swaying and tapping her feet, then as the lyrics began she started to sing and she knew every word. Karin invited her into the centre of the circle and they danced together. It was an amazing moment – that magical ability of the brain to retain lyrics when spoken language is gone – and the body's memory for movement and rhythm. As we know, those endorphins and the emotional memory of an event for people with dementia can last for a long time, so although June probably wouldn't have remembered that dance I think some of that good feeling that she was clearly experiencing probably stayed with her for many hours after that session.

That release of emotion that can come from life story work had an impact on the behaviour of one other group member in particular. Susan's pattern was that every afternoon she would go to the front door which was locked and rattle the door, trying to get out. This was distressing for her and the staff who were always trying to distract her and stop her from doing it. During our sessions Susan talked intermittently about her younger life, her job, and also about being in a convent school where she was locked in by nuns. She would often engage for the first half of the session and then drop off to sleep. Quite a long time after we had worked at the home, the manager got in touch with us to give us some feedback. He told us that while Susan was taking part in our sessions in the mornings, she had stopped going to the front door every afternoon and in fact hadn't done so since. Karen, the care assistant who had worked with us, had kept some sessions going which Susan continued to attend and Susan had been taken off her anti-psychotic medication as a result of her behaviour being calmer and more settled.

We were delighted to receive this encouraging feedback from Dan Morgan the care home manager,

Re-Live took residents and staff members on a journey which changed the way they interacted with each other. They proved that even people with the most advanced dementia are able to contribute to and gain from meaningful activities and this changed the way that care was delivered at the home. All residents who were involved in the project responded in extraordinary ways and family members commented to me and the staff that this had opened up a part of the real person inside.

Theatre and Dementia: Belonging

We knew we wanted to link these two areas of our work; the wonderful experiences we were having in our group work sessions and the powerful life story theatre we were creating. The inspiration for Belonging began in 2010 when Karin was awarded a Winston Churchill Fellowship to research creativity in dementia care with Dr Yukimi Uchide in Ofunato, Japan. Dr Uchide founded Kesen Boke Ichiza, a theatre company which promotes a greater understanding of dementia and its effects on people's lives. Karin was honoured to be a part of the company and tour Japan, experiencing directly the power of theatre to both entertain and educate community audiences about dementia. In 2013, with support from The Arts Council of Wales, Karin embarked on a period of research which gave her the privilege of interviewing people living with a dementia diagnosis, their families, carers, advocates, doctors, care managers and nurses. Karin wrote a play called Belonging, based on the experiences and stories people had generously shared. This was rehearsed and performed with an excellent cast of professional actors and musicians. In April 2014 four pilot performances took place in Cardiff and Llandrindod Wells for an invited audience of NHS staff, carers, artists and people with personal experience of dementia and their family and friends. We were delighted with the feedback received and are currently planning and fundraising for a Wales-wide tour of Belonging in autumn 2015.

“It was absolutely amazing-a rollercoaster of emotion and so very real! Well done, a privilege to watch. Everyone needs to see this and gain insight” Susan Kelly, Care Assistant, Cardiff

"I can't tell you how much I enjoyed 'Belonging' it was inspiring. One of my staff who went to the show asked me if all staff in care homes would see it. She made a valid point, that after seeing it she felt so much empathy and compassion for the people the actors portrayed and she believed it would enable care staff that may not have had any personal involvement with dementia to empathise with not only the person but the families. This is a care staff member who finds it very difficult to engage on a personal level with residents". Dawn Curtis, Care Manager, Vale of Glamorgan Council

"With humour, humanity and total authenticity 'Belonging' takes us inside the everyday experiences of people living with dementia. The play builds a bridge to empathy and challenges, entertains, and informs all at the same time. It deserves to be seen by as wide an audience as possible and is a totally absorbing demonstration of the power of live performance". Mark Jones, Memory Team, Llandough Hospital

Memoria

Our brand new project, Memoria is our most ambitious to date. Building on the success of our training play 'Belonging', this autumn we will create a new theatre experience in which, for the first time in the UK, people living with dementia will take to the stage alongside carers and professionals and share their experiences live. They will tell their own true stories about what it’s like to live with dementia, and how it affects the people around them. We hope this ground-breaking show will lift the lid on the emotional, courageous and sometimes surreal journey of those affected by dementia. Memoria will seek to inspire, educate and ignite a much needed dialogue about dementia and its impact on individuals, families, the NHS, the media and all of us who live in Wales.

Through October and November we will work with a group of people with dementia as well as family members and professional carers who are interested in exploring their thoughts and feelings about dementia. We will work with participants on a sensitive and creative process of reflection and review, whilst at the same time building confidence and performance skills. Our previous projects have shown this to be a powerful process, combining a therapeutic group experience with an empowering opportunity for creative expression.

Whilst we place great emphasis on the transformative value of the rehearsal process for our participants, we attach equal importance to the quality of the theatre production. In keeping with the style of work Re-live has become known for, Memoria will be powerful and truthful, engaging and entertaining. As with all our theatre work, discussion and sharing of thoughts and ideas will be encouraged after the performance and we really hope some of you are able to join us. Memoria will take place at Chapter, Cardiff in November 2014. The performances will also be streamed live on the internet and we hope many families and carers will access this from their homes if they are unable to join us live at Chapter.

Our vision for the next 3 years is to make Cardiff a centre of creative excellence for people living with dementia, family members and professional carers. We want to support the creativity of people affected by dementia, and celebrate the transformative impact this can have on individuals, families and the wider community. There is a great need for imaginative, high quality approaches to the challenges posed by dementia and we feel the growing field of Arts in Health can play a vital role in the journey that lies ahead. We would love to hear from anyone interested in working with us.

For more information on our work please visit www.re-live.org.uk

Lifting the Fog on Dementia

Jayne Phillips graduated with a BSc (Hons) in Occupational Therapy from UEA in 2012. When she graduated, she worked as a Dementia Support Worker and Peer Group Facilitator for the Alzheimer's Society Norfolk. She is a Life Story Book Volunteer and Dementia Friends Champion volunteer. She is currently working as a bank Occupational Therapist for Social Care in East Anglia.

Danielle Barnes graduated with BSc (Hons) Occupational Therapy from the University of East Anglia in 2012. Since 2013 she has been working as an Occupational Therapist, rotating around different departments such as medicine for the elderly. She has been involved in developing the falls training for therapy services and is planning to become an OT steward.

Chia Swee Hong is a lecturer in occupational therapy at the University of East Anglia. He has extensive knowledge and experience in working with children and older people who have cognitive difficulties. He has written numerous articles and co-edited a number of books including "Group and Individual Work with Older People" which is published by Jessica Kingsley in 2011.

Introduction

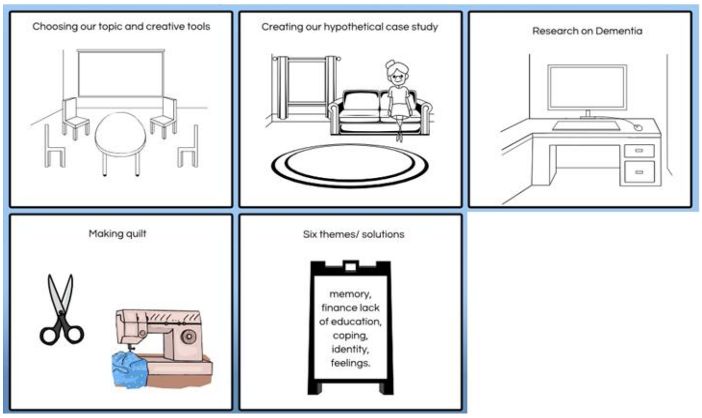
Inspired by Wilcock's vision, Jepson, Collins et al (2011) introduced a creative module to ensure that final year BSc (Occupational Therapy) students reaffirm their understanding of occupation as a tool of health and well-being. Further details about the rationale and structure of the course are found in Jepson and Collins (2011). The module spanned over a six week period. We were randomly allocated to groups of four and were encouraged to explore the importance of an individual's engagement in meaningful occupations/activities. We were asked to select a theme and creative tools. The module culminated with a presentation and demonstration of a creative tool. We selected the theme: 'Support strategies for early onset dementia' and two creative tools: creative textiles materials, photography and DVD film showing case study and how we would support the person linking Occupational Therapy and Occupational Science.

The process

Storyboard

We used a storyboard to structure our thinking process. A storyboard is a simple graphic organiser. The storyboard is used to display a sequence of events in a chronological order. It consists of a set of boxes placed in a logically sequenced order. Each box or frame is a place for us to put information, pictures, symbols or text (Andrew, 2013)

Our storyboard:



Case Study

In order to initiate the process, we developed a hypothetical case study called Shirley. She was diagnosed with early onset dementia at 55 years of age. She lives alone and has a daughter and two grandchildren. She previously worked as a seamstress and this has been an on-going hobby throughout her life. She was initially unaware of the difficulties she was experiencing at work and her work colleagues identified that she was making numerous mistakes. Shirley is determined to retain her autonomy and is finding it hard to come to terms with her increasing reliance on her daughter.

Early onset dementia

As part of the next stage of our storyboard, we did some research on early onset dementia. There are over 17,000 younger people with dementia in the UK. This number is an under estimate and the true figure is likely to be up to three times higher (Alzheimer’s Society 2012). The 2012 All-Party Parliamentary Group report concluded that there are often delays in younger people with dementia receiving a diagnosis. Following research in the local area we discovered that there was a lack of appropriate services to support individuals with early onset dementia (Lliffe et al 2003). We identified that a group of volunteers set up a day service in England as they were aware that there was a lack of support for younger people with dementia. In the early stages of dementia friends and family need to encourage individuals to stay engaged or to adapt their activities of daily living successfully (Genoe and Dupuis, 2012). There appears to be a lack of understanding about the impact of the condition on individual’s occupational roles and occupations i.e. activities of daily living and we wanted our project to link to these findings.

The creative tool

We selected quilt making as the creative textiles tool because of Shirley’s interest in needlework. The quilt was designed to allow Shirley to identify her perceived problems and create ways of working through her issues. The quilt was called ‘Lifting the fog on Dementia,’ with the fog representing the problem/issue identified by the individual, followed by possible strategies provided by the individual or therapist. Based on our research and practice placement experiences, we came up with six themes/problems for Shirley: loss of memory, finance difficulties, lack of knowledge, coping strategies, identity loss and impact on feelings. We have chosen the word ‘fog’ because quite a lot of clients we used to work with describe their condition as obscuring haze.

This is the quilt: fog clouds represent the issues/problems experienced by Shirley.

Support strategies to help Shirley resolve some of the issues/problems.

The fog is Memory Loss

Upon lifting the fog, support strategies for memory loss are provided.

Conclusion

This project has helped us to gain a greater understanding of the condition, the impact on individuals’ lifestyles and the importance of meaningful occupational engagement. It has also facilitated the development of many transferable skills such as communication, creativity, negotiation, delegation and teamwork. Two members of the group are now volunteering and working in dementia care due to interest generated whilst working on the project. The knowledge and skills gained from this experience will be invaluable in our future careers.

References

All-Party Parliamentary Group report. (2012). *Unlocking Diagnosis: The key to improving the lives of people with dementia*. London: House of Commons.

Alzheimer's Society. (2012). Factsheet 440 – Younger People with dementia. London. Retrieved October 24, 2013 from http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=164

Andrew, T. What is a storyboard? Retrieved October 22, 2013 from http://suite101.com/a/what-is-a-storyboard-a130624

Genoe MR, Dupuis SL (2012). The role of leisure within the dementia context. *Dementia,* first published on May 24, 2012 doi:10.1177/1471301212447028

Jepson, J. & Collins, M. (2011). *Creating a profession for the future*. Retrieved October 24, 2013 from http://www.medev.ac.uk/newsletter/article/100009/

Iliffe S, Manthorpe J, Eden A (2003). Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study. *Family Practice.* 20(4) 376-381

Wilcock, A.A. (1999). *Reflections on doing, being and becoming*. Australian Occupational Therapy Journal, 46, 1-11

Former occupational therapy students, Danielle Barnes, Jayne Phillips, Alison McGugan, and Freyja Delorme developed and presented the project.

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Reflections on Dementia care

Vlad Onetiu graduated with BSc (Hons) Psychology from University of Sheffield in 2012; and has recently graduated from the Europubhealth Masters programme in Sheffield and Krakow (autumn, 2014). He has volunteered for organisations dedicated to vulnerable children and adults since 2006, having worked most notably for 'Save the Children Romania' (as a children's rights teacher and as a social worker for refugees) between 2006 an 2009, the Alzheimer's Society UK (as a volunteer for projects such as the Dementia Café and Singing for the Brain. Vlad was part of the pilot team that implemented the latter project in Sheffield) between 2010 and 2012 and Lost Chord (as a volunteer for musical sessions held in care homes) between 2009 and 2012.

Vlad's extracurricular involvement has also enabled him to qualify for the Sheffield Graduate Award, which recognises outstanding involvement in community projects.

Additionally, he has worked in placements with institutions such as: the Romanian Ministry of Work and Social Protection, in August and September 2013, Public Health Wales during the spring of 2014 and Open Minds Cluj – a Romanian charity dedicated to best research and community projects for people with mental disorders, during July 2013. Vlad has gradually become interested in dementia care as a necessity for the current ageing trend in Europe, which is an important factor for the increase in the number dementia patients, which includes his grandmother. His MSc research project was a cost-of-illness study on dementia at a national level, in Romania. He hopes to publish the findings, which would make it the second independent study ever done on the economic burden of dementia in an Eastern European country, after Ersek et al.'s (2010) study in Hungary.

Between March and May 2014 I have done a practical placement with Public Health Wales, in Cardiff. I have thus had the opportunity, courtesy of Nigel Monaghan's efforts, to work alongside Phil Chick and Leslie Rudd, who collaborate on the 1000 lives project in Wales. My placement was done with Public Health Wales and focused on dementia care in the UK. During my time there I have conducted interviews and short placements with other institutions from Wales and England, which have enabled me to develop my own personal perspective, especially through comparison with what I already knew about the system in Romania, my home country. First, I am going to share some of the opinions I have heard from key professionals in the field during my internship and then I will also present a few personal observations, based on my experience in collaborating with public health experts from back home.

First of all I would like to mention that it comes very natural for me to commend the level of development in the field of dementia care that I have witnessed in England and Wales during the past 4 years. Being particularly interested in musical therapy I got involved with two important local projects in Sheffield, back in 2009: Lost Chord and Singing for the Brain. The latter, which is run by the Alzheimer's Society was in its pilot phase when I joined the team. In time, these projects have become available to an increasingly larger number of people across the UK and the benefits of music are beginning to be recognized both anecdotally and academically, as was shown in an earlier number of Signpost (vol. 18, no.1, October, 2014). For me it has been an exciting opportunity to witness the improvements brought about in the past decade in dementia care.

The main project that I was exposed to in Wales, during my internship, was the 1000 Lives Plus programme for the improvement of dementia care. Quality control is the main focus of this initiative, attempting to make this process an integral part of regular health and social care provision. The project leaders work closely with their partners, including local health boards, attempting to encourage everyone to develop a sense of ownership of the programme through setting so-called "intelligent targets". It was good to hear that, apart from the naming-and-shaming method, the project leaders had the capacity to report care that falls below agreed standards, and to hold people accountable for specific failings. I was also impressed to learn that service users were also integrated in the quality review process through the "Stories for improvement initiative", which aimed to make patient voices heard at national health board meetings and/or conferences. This was also reflected in the materials used for training in the collaborative project Managing Dementia in Primary Care. It is clear to me that there is a systemic effort to emulate Prof Tom Kitwood's well-known ideal of Person-Centred Care, which has now become assimilated in the policy-making discourse.

Another aspect that caught my attention was the level of involvement of charities and their role in further personalizing certain services for patients and their carers. I was able to talk to Susan Phelps (director of the Alzheimer's Society in Wales) about their activity in Wales and about the services that are commissioned by the Local Authority. She described a wide range of services that share a common aim: to make patients enjoy 'a life, not just a service'. The list of services includes walking groups, outreach to minority communities, adult learning programmes, registering with social services, Singing for the Brain and, particularly in Cardiff, the Forget-me-not chorus. What is important is that such services are endorsed by the NHS, as Beverly Graham (Dementia Support Manager for the Alzheimer's Society in Sheffield) pointed out. Doctors that are an important point of contact for new patients presenting with dementia refer patients to appropriate AS services. Furthermore, in the view of several professionals that I spoke with during my internship, it is charities that are usually best at serving carers' needs in England and in Wales.

In recent years, dementia has become a political priority, with signs such as the PM's National Dementia Challenge, or the use of the G8 summit in London as a 'Joker card' (in the words of Rt Hon. Hazel Blears at the National Dementia Challenge Conference held in London in May, last year) to push dementia on the international agenda. The UK joins a select group of generally Western countries that have led the way in terms of investments into research, long-term strategies and better healthcare facilities for people with dementia. This effort is backed by more grassroots projects, such as Dementia Friendly Communities or Dementia Friends. According to Kirsty Harkness (lead for working age memory service for the Sheffield Teaching Hospitals Trust), the former initiative should not be taken to mean that entire cities of the size of London, Sheffield or Cardiff will be changed according to the needs of people with dementia. Instead, for now, an achievable aim is to create dedicated sectors and institutions that train their employees to be sensitive towards people with dementia and sensible regarding the way they can support them and accommodate their needs.

The public health efforts with respect to dementia have been increasingly more directed towards prevention, as has been pointed out to me by Dr. Charles Alessi (chairman of the National Association of Primary Care). The preventive factors for dementia (especially for the vascular type) fit in well with the health promotion campaigns for cardiovascular diseases, which means that there is a lot of potential to create a large public impact in years to come, especially with regard to what is believed to be the critical population: middle-aged people. The term "screening", which seems to be possible in the near future both using more accurate questionnaires and biological tests is described as 'politically loaded' and is not considered a viable alternative to prevention. The literature shows that a diagnosis of dementia also raises the question of rights taken away or not from patients (e.g. keeping a driver's licence or the right to vote – see Appelbaum et al., 2005 and Breen et al., 2007) which is a very thorny one indeed and interferes more with the political sphere.

Nevertheless, the interactions I have had with relevant professionals involved in dementia care have also outlined some aspects that can still be improved. The first and foremost thing that was expressed by most if not all people I have come in touch with, including people presenting at the National Dementia Challenge conference, has been the need to integrate social and health care systems so as to avoid service duplication, to make more effective referrals and to deliver a quicker diagnosis. In her opening address to the aforementioned conference held in London, the Rt Hon. Hazel Blears even suggested that a pooled health and social care budget could be created. Another subject I picked up on from both Wales and England was a poor provision of palliative care for people with dementia. This includes aspects such as hospice care, electing a Lasting Power of Attorney, as well as advanced care planning. With regards to residential care, more can still be done to better accommodate residents' needs. Susan Phelps from AS Wales outlines that recent residential care reviews have exposed a lack of meaningful activities which suggest that dementia patients are not sufficiently stimulated from a psychosocial perspective. Additionally, regulations need to be effectively enforced, so as to prevent abuse or neglect from happening, as has been the case with the well-known Staffordshire Hospital Scandal, or more recently in Wales, with a care home on the isle of Anglesey (Older People's Commissioner for Wales, 2014). It is likely that, more than any sort of systemic regulation of one's duties, a cultivation of hospital/care home staff personal responsibility and engagement with problems encountered by the people served can do more to avoid such events from happening in the future. This may be achieved through appropriate educational programmes targeted at carers, in general.

Although by this time there are many comparisons that can be made with Romania, I believe that judging solely the performance, without a broader understanding of the different societies, is misleading. With a GDP that is approximately 20 times smaller than UK's, Romania also allocates a smaller percentage of its GDP to health, which means that prioritization is a difficult undertaking for any health authority. Two Romanian doctors I have spoken with remark that the system is still weak and underdeveloped with regard to caring for dementia patients, mentioning that multidisciplinary teams are not being formed on a regular basis as would be required in other EU member states. So far there was no official, politically backed strategy to tackle dementia at a national level, apart from a plan set out by the Romanian Alzheimer Society earlier this year (Romanian Alzheimer's Society, 2014). Furthermore, the general population is not well educated with regard to dementia, with one third of the total population being unaware of the true meaning of dementia (Tudose, 2006). The international economic crisis has hampered efforts to develop memory services, as the memory clinic co-managed by the Alzheimer's Society and the Dr. Obregia Mental Health Hospital in Bucharest encountered difficulties in continuing its activity after the demolition of its original headquarters, due to insufficient funds (A. Moglan, vice-president of the Romanian Alzheimer’s Society, personal communication, the 16th of November, 2013).

I have asked a close friend who is about to finish her medical training what are lessons to be learned from the Romanian care system from the point of view of a Western European system. She thought about it for a minute and then she told me that she cannot think of anything but cheap prices on medication. I got a similar answer from the two doctors I collaborated with on my research project. Romania has a poorer and weaker system in place for various reasons, including financial and historical ones. Nevertheless, while in the UK, I have come to realize that care for people with dementia, needs to be accompanied by individual initiative and, of course, compassion. In this respect I feel that there could be a few things that are worth mentioning from my experience of interacting with carers in Romania. For instance, although we lack appropriate statistics, I came to realize, while recruiting participants for my research project that an overwhelming majority of people with dementia were cared for at home by a relative or by a loved one which, in my opinion, is no small feat. For this reason I believe that the important lesson to be learned in the UK is home care, with all its benefits (which include fewer expenses from the point of view of service commissioners). As Prof. Antony Bayer suggested in his speech at the National Dementia Collaborative Conference in Llandrindod Wells, held on the 18th of March last year, we should avoid ending up as a ‘dementia clique’. I believe that the way towards achieving this entails educating people about what each can bring to the table and it definitely needs to be accompanied by a promotion of a culture of solidarity between generations – something that, in Romania, might be a product of the hardships people have been through together during the dictatorial regimes that we had before the 1990s.

Note: the article was based on interviews performed during May and April 2014 with: Dr. Charles Alessi (president of the NAPC), Sorina Maria Aurelian (MD at the chronic disease hospital “Sf. Luca”), Antony Bayer (director of the Memory Team at Llandough Hospital), Phil Chick (mental health director at NLIAH), Beverly Graham (dementia support manager), Dr. Kirsty Harkness (lead for working age memory service), Maria Moglan (vice-president at the Romanian Alzheimer`s Society), Simon O’Donovan (clinical director MHSOP), Leslie Rudd (director of the CMHDS), Susan Phelps (director of the Alzheimer`s Society Wales) and Codruta Zus (MD at PROMEMORIA medical clinic)

References:

Applebaum, P. S., Bonnie, R. J. and Karlawish, J. H. (2005). The capacity to vote of persons with Alzheimer’s Disease. The American Journal of Psychiatry, 162(11), pp.2094-2100

Breen, D.A., Breen, D.P., Moore, J.W., Breen, P.A. and O’Neil, D. (2007). Driving and dementia. BMJ, 334(7608), pp. 1365-1369

Older People’s Commissioner for Wales (2014). Closure of a Care Home on the Isle of Anglesey – Section 3 Review Report, July 2014. Cardiff.

Romanian Alzheimer’s Society (2014). The National Strategy for Dementia, especially with regard to the Alzheimer’s Disease. [Online] Available at: http://www.alzcongres.ro/getDownload.php?type=afd&id=283 Accessed: 20/04/2014
Tudose, C. (2006). Results of the Marketing Research Study “Alzheimer’s Disease in Romania” (Romanian article with English abstract). The Romanian Psychiatric Journal, nr. 1-2

About Me

Clare Freestone. Clare gained her first degree at the University of Westminster (London) in Life Sciences (Physiology) and she also has a degree in Psychology and a Counselling skills qualification.

Following this, she completed her PhD studies which involved planning and conducting clinical research into the efficacy of cough medications (funded by Proctor & Gamble). This confirmed her interest in research, and she went on to gain her first Clinical Research post in 1997, with Lundbeck Ltd.

She has since been working in the clinical research industry for 14 years and was involved in monitoring and managing Phase III-IV clinical trials working for three leading pharmaceutical companies.

She has worked across many therapeutic areas, but mainly in depression, anxiety, Alzheimer's disease and schizophrenia.

She was made redundant in 2009 and so dedicated some time to bringing up her young daughter. She is now thrilled to be back working in research and to be involved in such an interesting clinical trial within the Memory Team at Llandough.

Who are you and what do you do?

I am a researcher who is part of the Memory Team, based at Llandough Hospital and I am working on a clinical trial called 'Living Well with Memory Difficulties'. The Living Well with Memory Difficulties trial is investigating the benefits of a new treatment that aims to help people live as well as possible while experiencing memory difficulties.

The study is being run throughout the UK for people who have attended a Memory Clinic. The study is specifically looking at a new treatment called ‘cognitive rehabilitation’, which involves working with a therapist (an experienced health professional) to try to manage the impact of memory difficulties on everyday life. Initial evidence suggests that this can be helpful for people who have attended a memory clinic and also for their family members. In a previous study, participants felt they were better able to carry out their daily activities following this treatment, and felt more satisfied with how they were managing. A larger study (the 'Living Well with Memory Difficulties' study) is now being carried out to confirm whether the treatment really makes a difference and whether it should be provided on the NHS.

Can you describe a typical day?

There is no such thing as a typical day, as all of my days are quite different. However, my day usually involves a visit to a patient and their carer, at home, to either discuss the study in more detail to see if they would like to participate or if they are already enrolled in the study, then to carry out the relevant assessments and questionnaires associated with the study.

What do you most enjoy about your role?

The variety of the role (no two days are ever the same), the contact with lots of different people, the challenge and the fact I believe I am making some kind of difference to people's lives.

What are the greatest challenges in your role?

I think one of the greatest challenges is dealing with the dynamics between a patient and their carer. This can often be quite challenging when asking probing questions about how they manage their lives and how they cope living with memory problems. The day-to-day management of the study is also a constant challenge, as there are lots of study specific tasks that need to be addressed to ensure the smooth running of the study.

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

I am fortunate that my role is such that I am in the position where I am constantly learning about many different things, which are often challenging, interesting and enjoyable.

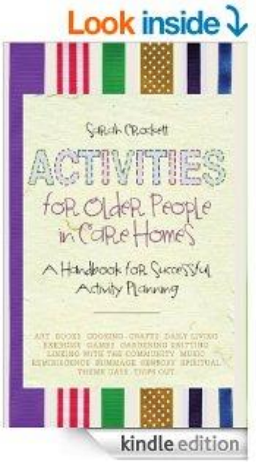
How would you like to see your role developing in the future?

I would very much like to see the study reach a positive conclusion and for myself, I would like to see the study through to the end. I have worked in research for many years and I would hope to be able to continue in a similar role in the future.

Book Reviews

Activities for older people in care homes: A Handbook for Successful Activity Planning

Authors: Sarah Crockett
Publisher: Jessica Kingsley Publishers
ISBN: 978-1849054294
Price: £12.15 (Paperback) / £6.69 (Kindle Price)



The book is split into three Parts: Part I covers the importance of activities and how to get started; Part II groups activity suggestions under 17 alphabetically arranged general headings; and part III is a 7-page Resources section containing brief details of organisations, websites, books and other literature which may be of interest to aspiring activity coordinators.

This book is designed to be an introductory text for those volunteering, or finding themselves volunteered, to take on the role of providing interesting and stimulating activities for older people living in care homes. The author assumes that this will include many residents with dementia and recognises how daunting this might be to the beginner. Accordingly she writes ‘about the things I know now, that I wish someone had told me when I started’ (Introduction, p12). That key basic knowledge is contained in Part I. This begins with a basic introduction to dementia, followed by a discussion of the role that activities play in contributing to residents’ health and wellbeing. These are written in accessible non-technical language with liberal use of illustrative examples. Both chapters feel a little sparse on detail, but there are many sources of more detailed information provided in the Part III Resources section.

The remainder of Part I takes the would-be organiser through a range of practical and administrative issues related to setting up and carrying out activities. There are many helpful tips and I would recommend reading through this Part from start to finish before organising any activities. Depending on the previous experiences of the reader and the home(s) in which they plan to hold activities some topics may be very familiar, others less so. Readers also need to consider how general guidance and tips given in the text fit into existing practices in their care homes, particularly in relation to the timetabling and recording of activities and to risk assessment.

Part II contains alphabetically arranged chapters on activities from ‘Art’ to ‘Trips out’. This Part is designed to be much more for dipping into for inspiration rather than for sequential reading. Many chapters contain detailed examples as well as ‘quick hints’, and the author is careful throughout to provide suggestions for larger and smaller groups as well as one-to-one activities. Chapters follow a standard format, listing suggested resources and outlining potential risks before making suggestions and providing detailed examples for each activity. This layout sensibly encourages would-be organisers to think systematically about planned activities.

The author provides suggestions across a varied selection of activities. It is important to remember that this book is designed to be a starting point and to provide inspiration, but for me it lacked a little in some respects. I would have liked to see more discussion of the use of technology, for example using computer tablet devices in arts, music, games, reading, and reminiscence-based activities. Touch screen technology enables such devices to be both flexible in usage and user-friendly. For instance, many classic books can be downloaded in electronic formats at little or no cost, and both font sizes and screen and text colours can be easily changed to make text easier to read. I would also like to have seen a more expansive chapter on ‘Linking with the Community’, perhaps including linking with: local dementia-friendly community initiatives; local supermarkets, as many have active local community liaison programmes; and long-established local employers, who might have examples of old advertising or packaging that could be used for reminiscence activities or theme days.

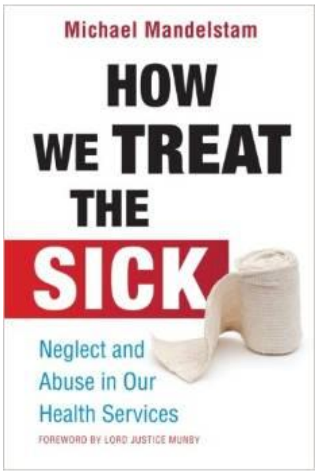
That said, I think that the author has produced a helpful volume which will be welcomed and appreciated both by its target audience and, indirectly, by the recipients of the activities which it will hopefully inspire.

Dr Alison Dawson

Research Fellow, School of Applied Social Science, University of Stirling

How We Treat the Sick: Neglect and Abuse in Our Health Services

Authors: Michael Mandelstam
Publisher: Jessica Kingsley Publishers
ISBN: 978-1849051606
Price: £19.99 (Paperback) / £17.99 (Kindle)



This sobering account of the deterioration of care for elderly patients in this country makes a strong case about the systemic nature of this failure. This book enlightens readers about the extent of the failings and continual denial that the NHS, our valued institution, could perpetuate neglectful health care. The blame for these failings is placed at every level of the NHS for not taking responsibility, from the Department of Health through to frontline nursing staff, stemming from widespread lack of responsibility and accountability.

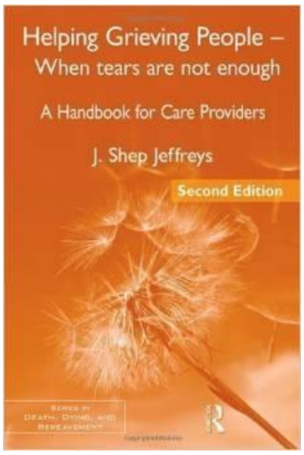
The book provides solid evidence for this argument by using detailed breakdowns of specific cases of neglect and abuse, with suggestions about how these failings have slipped through the moral, political and legal nets of society. It highlights the failings of relevant regulatory bodies attempting to bring sanction and stem the flow of bad practice, while also intelligently recognising the inherent difficulties faced by these bodies positioned in a system of bureaucracy, climate of fear and defensive practice. It reviews the workings of the NHS in a critical manner, encompassing the effect of excessive regulation and a culture of not encouraging whistle blowing.

Importantly, it reaches the realistic conclusion that in light of the fact that major issues around poor care have not been addressed over the past two decades of, it is unlikely that a major turn-around will happen in the near future. In spite of this prediction, the author makes a positive move to suggest some informed recommendations for action including a legal approach to closing a loophole relating to wilful neglect and ill treatment. More generally it suggests that the NHS needs to be run with older people in mind, given that they are the biggest customer group. A call is made for greater public awareness to force the hand of the regulators and for senior management need to be held more accountable for failings. Above all this book makes a bold address for action at every level of the NHS and indeed society, to find good solutions to this snowballing epidemic.

Stephanie Watts
Assistant Psychologist, Bangor University

Helping Grieving People – When tears are not enough: A Handbook for Care Providers (2nd Ed.)

Author: J. Shep Jeffreys
Publisher: Quay Books
ISBN: 978-0415877015
Price: £28.99 (Paperback) / £27.54 (Kindle)



This is a second edition of a best-selling book which includes new research and updated information on clinical supports. The book is distinct from others in this area in that the author writes from the perspective of both a practising psychologist and someone who has an understanding of grief following the loss a child. Jeffrey's begins the book with a dedication to his son Steven Daniel Jeffrey's who died at the age of 8.

One concept I found interesting in this book is that of the 'Exquisite Witness' which Jeffrey's introduces in the first chapter. He uses this terminology to describe anyone who steps forward to help a grieving person. He goes on to describe how such a person needs to address personal loss issues, be knowledgeable about what to expect from grieving people and have the skills to respond to them.

The book includes separate chapters on the grief of children and adolescents, the grief of parents, older adult grief, and chronic illness and disability. Focusing on the chapter related to older adult grief he clearly outlines factors that affect the grief of older adults and losses they may experience before going on to address ways to help bereaved older people and give support to family caregivers. I found it interesting to see the inclusion of consideration of factors such as death of an adult sibling and death of a grandchild. Unfortunately, due to the wide remit of this book these areas are only briefly covered. The other difficulty is that this book is written for an American audience which means that while some of the advice given on support systems remains relevant other information is unique to America.

I was interested in the chapter on Complications of the Human Grief Process. I found this a particularly useful chapter with respect to how it clearly outlined definitions and signs and symptoms of the different types of complicated grief along with some suggestions for how the care provider can offer support. The author also emphasises that if care providers have concerns they should refer the person to a mental health professional or seek consultation with an experienced mental health colleague. This chapter is followed by a short chapter of case studies which I found particularly helpful in that they raise questions which the reader is encouraged to think about rather than simply providing guidance.

My overall impression is that this is a very useful resource and introduction to the area of grief support that covers a wide area and achieves much in less than 350 pages. Those reading the book in the U.K. will have to consider which aspects translate readily into the British healthcare and legal systems. I will conclude with a quote from the Epilogue of the book

‘Most grief is normal and has a function in healing through a loss. We need to learn to manage grief and live with it side by side.’

Dr Christina Maciejewski
Clinical Psychologist

Did You Know...?

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.

Magi plug £9.99

The **Magiplug** is an anti-flood plug that can be used in a bath, sink, or basin. The pressure activated system, ensures reliability, whilst the change in colour at 36°C helps to prevent scalding. The system also benefits from being able to be attached to your existing bath chain for ease of use

How it works:

1. When an unattended bath/sink/basin reaches a certain depth the Magiplug pressure plate opens and releases the excess water safely down the plughole, preventing a flood
2. This level is then maintained until the taps are turned off

The Magiplug is a must have product for anybody that is prone to forgetfulness; a cheap but effective alternative to costly flood damage repairs.

http://www.alzproducts.co.uk/magiplug-anti-flood-plug.html

Important
Suitable Depths
Bath - Minimum 15" deep
Kitchen Sinks - Minimum 6.5" deep
Bathroom Basins - Minimum 5" deep

Any bath/sink/basin measuring **more** than the above depth recommendations will be suitable for the Magiplug.

Plug Diameter:
The Magiplug fits the large majority of plugs in the UK, however it will not fit extra large plugs with a diameter of 50mm or more.

News and Web

Family Doctors in England are to be paid £55 for every diagnosis of dementia.

NHS England are trialling this idea for 6 months in an attempt to decrease the number of people living with undiagnosed dementia. This trial has sparked controversy amongst some Professionals, who believe that the £5m used to fund the trial could be better utilised. Speaking to the BBC News, Professor Simon Wessely, President of the Royal College of Psychiatrists, said “At the moment, evidence favours either improving social care, or investing in research to find new treatments that actually modify the course of the disease. Until that happens, I see little point in this initiative.” It has also been argued that paying Doctors to make a diagnosis threatens to distort the foundations of good clinical practice. On the other hand, this trial emphasises the importance of people living with dementia receiving the appropriate diagnosis so that they, and their families, are able to access care and support services if, and when, they need them.

Source:
BBC News Health, 22nd October 2014.

On-going dementia research studies...

Here in Wales, there is a lot of current and exciting dementia research being conducted, and many of these projects are looking for people living with dementia to get involved.

Here are the details of a few of these studies:

The GREAT Study (goal-orientated cognitive rehabilitation for people with early Alzheimer’s disease and / or Vascular dementia).

This is a randomised controlled trial which aims to see what, if any, benefit can be gleaned by a group of people with mild dementia (MMSE+18) when receiving cognitive rehabilitation compared to a group of people with mild dementia who only receive the standard treatment.
This study is based in Bangor and Cardiff.

To learn more:
http://great.bangor.ac.uk
Call Catherine Lawrence (Bangor) on 01248 382356
Call Clare Freestone (Cardiff) on 02920 716978

The Alzheimer's disease Genetics study.

This is a genetic study which hopes to discover more about the genetic factors that increase or decrease the risk of developing Alzheimer's disease (AD). People with AD (especially those under the age of 65) are asked to complete a brief cognitive assessment and provide a blood sample for genetic analysis.

This study is based in Cardiff.

To learn more:
Call Nicola Denning on 02920 743427

The IDEAL study (improving the experience of dementia and enhancing active life).

This study investigates how social and psychological factors impact how people adapt to the effects of dementia and use this information to discover what interventions improve the likelihood of living well with dementia, and when these interventions should be employed.

This study is based in the Betsi Cadwaladr and Hywel Dda Health Boards, and is looking for people with dementia who are still living in their own homes.

To learn more:
http://IDEALproject.org.uk
Call Pam Martin-Forbes (Bangor) on 01248 388719
Call Sue Thompson (Swansea) on 01792 602538

The Dementia Services Development Centre to hold training days in Cardiff early this year.

Led by Professor June Andrews, University of Stirling, the Dementia Services Development Centre is holding two Dementia training sessions early this year.

The first training day is held on **February 3rd, 2015 in Cardiff City Stadium**, and will be exploring the topic of 'supporting people with dementia: understanding and responding to distressed behaviour'. Any staff working in care homes, hospitals or the community will find this helpful, and a free copy of the study guide will be given to all delegates.

For the full programme and more information:
Programme can be seen here

To book a place on the training day:
Book now

The second programme is held on both **March 11th and 12th, 2015** and is a nationally recognised training course for ensuring Best

Practice in Dementia Care. The programme trains staff working in care settings at home, care homes, nursing homes or hospitals in the changing culture of Dementia care. It enables a member of your staff to be a programme facilitator and provides materials and support for six months for them to take up to eight others in the workplace through the programme.

To book a place on one of the training days, or to organise this training in your own workplace at a time that suits you:

Online enquiry form

Information about Signpost

Anyone Can Contribute to Signpost

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

Contributions

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

Contact Details

Practice Development Unit, MHSOP,
Llandough Hospital, Penarth, CF64 2XX.
Tel: 02920 715787
Email: Amanda.Furnish@wales.nhs.uk

Books Available for Review:

We are currently awaiting a new selection of books, if you are interested in providing a review please contact us. Thank you.

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

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

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

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

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

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

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