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# SIGNPOST

## Journal of Dementia and Mental Health Care of Older People

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**Cover picture**: Artwork kindly provided by Olwyn Tucker, created at the Wesley Church Solace group.

# Editorial

*Christina has worked in Cardiff for twenty five years and has provided clinical psychology input to a number of multi-disciplinary community mental health teams for older people in both Cardiff and the Vale of Glamorgan. She has also worked as a tutor on the South Wales Training Course for Clinical Psychology. Her current post is with the Practice Development Unit, which provides support and training for professionals working with older people with mental health problems in the Cardiff and Vale University Local Health Board. Christina is also the manager for all clinical psychologists working with older people in the Cardiff area. She holds the position of Co-Director of the Dementia Services Development Centre – Wales. Her particular interests are the neuropsychology of dementia and developing services for younger people with dementia.*

Welcome to this the first edition of 'Signpost' produced solely in an on-line version, now freely available to all who are interested in older people with mental health needs. Our decision to move to this format prompted me to look back at the very first paper edition of Signpost. Signpost was first developed in 1988 and was produced in a newsletter form for staff working with older people with dementia in Cardiff. Although the Format of the journal has advanced over the years the underlying purpose of the journal remains the same: to provide information and education in a helpful and reader-friendly way. As you read this edition of 'Signpost' please do consider whether we are meeting those aims and if there is something you think friends or colleagues may be interested in please do send them a link to the journal. As a free journal without any publicity budget we are dependent on 'word of mouth' and recommendations to reach our potential audience.

Reflecting on the changes over the years one major change that I have seen is a move from regarding people as 'suffering from' dementia to the more positive and life affirming 'living with' dementia. This is particularly encapsulated in the articles in this edition. Barry Pankhurst has provided us with a recent account of his feelings about living with dementia. He describes the frustrations and fear that he experiences on a daily basis but also continues to 'fight' the illness. Dr. Rachel Brewer's inspiring article describes how the 'forget-me- not' choir has come in to being and how people living with dementia and their partners are discovering that a good quality of life can be achieved together, despite dementia. Although carers support groups are a valuable resource in many areas we still need to consider their aims and whether they are meeting the needs of carers; the article by Bethany Larham and her colleagues provides a very interesting evaluation using a qualitative method and includes helpful recommendations. This edition also includes an article from Janet Roberts, Call Helpline Manager describing the work of the Wales Call Helpline and how it can be accessed 24 hours per day for help with mental health issues.

A new item in this edition is the introduction of the 'Did You Know' section focusing each time on a piece of technology which may be helpful to people. Let us know your views on the inclusion of this new section. Finally, it is appropriate that our ' This is Me ' section captures the career of one nurse who has read Signpost throughout her years nursing older people and also highlights an area requiring service and practice development. An interview with Bev Keyse describes the emerging recognition of palliative care for people with dementia.

**Dr. Christina Maciejewski**

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# Foreword

*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. His background is working as a Consultant Nurse in Safeguarding Vulnerable Adults. He has contributed to national policy and strategy development and has a strong interest in client and caregiver wellbeing and experience of services.*

I was reminded recently that Signpost has now been in existence for some twenty-five years, in all its various forms - from local newsletter to national subscription journal. This issue sees it launch in another format, a free on-line journal hosted by the Dementia Services Development Centre Wales based at Bangor University. This is great news, not only because it sees it sees the partnership between Cardiff and Vale University Health Board and DSDC Wales strengthened but more importantly it delivers the potential for Signpost to be accessed by a greatly increased readership. Please let your colleagues know about us and forward them the link http://www.bangor.ac.uk/imscar/dsdc/noticeboard.php.en?menu=5&catid=4351&subid=0

Also if you would like to have your work promoted then please consider writing for Signpost. Further information about contributing can be found on page 40.

Barry Pankhurst's article in this issue, 'What does it feel like to have dementia?', brought home to me the importance of talking openly with clients about how they are coming to terms with their diagnosis, adjusting to life with the illness and managing the symptoms it presents them with. It is all too easy for professionals to shy away from such discussions, either because they feel ill equipped to deal with their own emotional responses to difficult questions such as 'How am I likely to change?' or 'How long have I got?' or they are more used to answering such questions from carers, the client being presumed too cognitively impaired to understand and remember detailed information.

And yet with earlier diagnosis and access to treatments which have the potential to delay illness progression such discussions are even more essential than ever before, especially in light of the Mental Capacity Act 2005 which provides the possibility for clients to make Advance Decisions about their future care and treatment when they lack capacity to participate in decision-making in the future and to appoint a decision-maker to act on their behalf when that time comes.

Of course it is important to work at a client's pace regarding the information which we give them, answering only the questions which they ask and giving the level of detail which they request rather than over-burdening them with unwanted and distressing facts. It is also impossible to be categorical about these matters as each individual's rate of decline and symptoms onset will be somewhat different. Talking in generalisations may also only serve to irritate. Giving clients small amounts of information, supported by sharing the discussion with their main supporter, if the client allows it, and backing it up with appropriate written information can be more meaningful and help the person to take on board what might otherwise be overwhelming and depressing knowledge about what is after all a life changing and shortening illness.

Barry also provides us with a vivid description of how frustrating dysphasia can be for the person who knows what they want to say but can't find the words. The 'maze of bewilderment' must be such a frightening experience and yet when we are faced with clients who have more profound communication difficulties we often find it very difficult to make contact and then sometimes give up and stop trying, just at a time when people will be feeling more isolated and less understood. A couple of recent experiences with my younger onset dementia clients have stopped me in my tracks and made me rethink my approach. I would like to share these with you now.

The first experience happened when I was leading a cognitive stimulation therapy session involving a client who finds it difficult to construct sentences and speaks in jumbled apparently meaningless jargon. During a quiz of theme music, catchphrases and visual clips from the best comedy programmes from the ‘80s I asked the group if we could go around the room and all do an impersonation of Frank Spencer. Hers was by far the best and the most full of humour, gesture and facial expression, in addition to the 'Oo Betty!'. Sitting with this client, mirroring her expression and picking up on some of the content to interpret meaning and then responding accordingly can work with great effect and help her to feel communicated with and understood, as well as an equal member of the group. Song and dance also have a vital place in making contact with her, as do objects including her treasured jewellery collection and gloves.

The next client only has a few words. She can smile and nod in all the right places though and we all feel she has a level of awareness and insight way beyond her verbal communication ability. Recently in a structured music therapy session I was very moved to watch as she smiled and played the chimes, running her finger up and down the row of hanging metal tubes in time with the musical piece being followed and repeatedly saying, 'It's nice isn't it!'

The last experience I wanted to share with you is regarding a lady who has recently been transferred to an extended assessment unit we are developing locally for people with younger onset dementia who meet NHS continuing healthcare eligibility. There is a tendency for us to under-estimate client's understanding and this was a case in point for me. A best interest decision had been made with her family to move her to this unit and we assumed it would be better not to forewarn her of her transfer. And yet in the days leading up to transfer she commented in a somewhat distressed state that 'Something big is going to change'. On the day of the move she was somewhat reticent to leave her acute assessment ward, saying that she liked it there and felt safe and comfortable. Then on arriving in her new unit and being shown her bedroom, which the staff had newly decorated and personalised with family pictures and pieces of her artwork, she cried and said 'I will be here until I die'. The level of her insight and awareness was a shock for us all, but with gentle reassurance and lots of hugs she soon settled.

I suppose for me these three examples reinforce the need to keep trying, to not give up on our attempts at making meaningful contact with clients no matter how cognitively or speech impaired they are and that communication using words is only part of the picture. Facial expression, tone and pitch of voice and appropriate touch are all so important to back up verbal messages, which obviously should be simplified and repeated as necessary.

I feel it also important to reflect upon the fact that in the field of dementia care generally and specifically within our younger onset dementia service particularly the ethos we have should be, ‘We are all in this together’. Within our Friendship Club, or as one carer called it his partner’s 'Group Hug', all members, clients, carers and staff, have equal status and an important role to play. Sharing the experience clients and carers are going through in their dementia journey is truly humbling and we all feel honoured to play a small part in supporting them through it, as best we can. We hope to write further of our work in the next issue of Signpost.

To finish I would like to reiterate that a main aim of Signpost is to focus on clients' and carers' experiences of their situations and using services. So contributions are very welcome from people with a dementia diagnosis, older people with late onset mental illness, the carers and families of these groups and of course voluntary and third sector workers, health and social care staff and professionals who serve them.

**Simon O’Donovan**

# The launch of the Forget-me-Not Chorus

*Dr. Rachel Brewer graduated from Leicester University Medical School in 1999 before completing her house job/junior doctor year in Coventry in 2000. After returning to her Welsh roots, she gained experience in Primary care as a General Practice trainee, and has worked in General Adult and Old Age Psychiatry posts in four South Wales Hospitals. These invaluable experiences contribute to her current role as a Specialty Doctor in the Memory Team, based at the University Hospital Llandough. Dr Brewer has now embarked on an MSc in Neuroimaging for Research and is delighted to be a trustee on the board for the Forget-me-Not Charity.*

The **Forget-me-Not Chorus** is a Cardiff based charity that supports carers and people with dementia through weekly singing and creative workshops. Each week a 40 strong chorus meets to sing, rehearse and have fun under the baton of musical director Kate Woolveridge. The chorus was formed in January 2012 by founders Kate Woolveridge and Sarah Teagle, who had both been working with the group since 2010 under the umbrella of Welsh National Opera and Cardiff and Vale Alzheimer's Society.

In the charity's first year we embarked on an ambitious programme of work with three projects: ***Tapestry*** working with writer Louise Osbourne on the stories behind the people in the chorus, a ***Summer Celebration Picnic*** and a ***Christmas Carol Concert.***

The **Forget-me-Not Chorus** with Kate at Bethany Baptist church Rhiwbina, Cardiff

**Aims and Objectives:**

The chorus provides a comfortable and 'safe' environment, in which to empower both the people with dementia and their carers. All are encouraged to use their voices in song to express themselves. The power of music provides an escape from the everyday routine of caring and provides a sense of normality, giving families the opportunity to experience a positive activity together.

*'We're all on the same footing in the choir as everyone's participating and it's not in any way condescending to the people who are ill'*, one member commented.

Singing can be used to improve confidence, encourage verbal communication and for participants to travel on a journey with the person they love, showing that a good quality of life can be achieved together, despite dementia. This is reflected by the comment, '*The choir's opened up a whole new world for us. Everyone there has different problems through dementia but everyone is united in the music. It's really inspiring'.*

Each project is designed to take the participants on a journey together, and an end of project performance enables them to share this with their wider family and friends.

The smiles speak volumes – fun was had by all at our Christmas Concert 2012.

An evaluation of creative therapy has emphasised the positive effects of creative or artistic approaches to dementia care. Findings showed that there are improvements in creative self expression, communication, pleasure and general engagement in people with dementia. Just by being in the room of the Forget-Me-Not (FMN) Chorus, anyone can endorse these findings. No matter what the individual's singing ability or cognitive deficits, everyone's contribution is invaluable.

The group's songs have a special resonance for them; some lyrics having personal meanings and poignancy. They also embrace the challenge of less familiar songs. The eclectic choice of music encompasses folk songs, popular songs and operatic repertoire which reflect the wide and varied musical tastes of the FMN Chorus. The diversity of the songs, along with learning harmonies and occasional use of instruments, adds to the variety and keeps it lively and fun! A regular feature is coffee and biscuits (with occasional cake!) in the break, which is a great chance for friends to catch up on news.

### The 'Big night'

Wales is renowned for its passion for singing and rugby, so what better venue to launch the Forget-Me- Not Chorus than at the Millennium Stadium!

**'Tapestry'** was the launch concert on 24th May 2012 at the International Players' Lounge, Millennium Stadium. It was the celebratory story of the FMN Chorus, their childhood, loves, losses, toils, joys, tribulations and triumphs woven together through word and song. Everyone provided personal memories to build a colourful jigsaw. Composer Louise Osbourne linked the words to create the production, telling the story of their lives interwoven with favourite songs.

The feedback from participants and the audience has all been immensely encouraging. Most important are the feelings the choir experience and gain from the whole process and journey, not just the final production. It is known that as well as cognition, behaviour and mood can be affected in types of dementia, and a pilot-controlled trial showed findings that suggest that music can improve behaviour and psychological symptoms in people with dementia and their care givers. One chorus member told me, *'It changes my mood. If I feel angry before I come, as soon as I arrive I start to feel happier as we all smile'.*

There are implications for research into psychosocial approaches. It is proposed that mutual benefits can be gained by peer support intervention improving the well being of both carers and people with dementia. Psychosocial therapy involving social interaction and personalised music have promising outcomes, as has the positive effects of reminiscence therapy as acknowledged by The British Association of Psychopharmacology.

**And it didn't stop there!.....**

We were graced by the summer sun at our **Summer Celebration Picnic** and felt warm despite the winter weather with the standing ovations at the **Christmas Concert!**

Summer concert 2012 -graced by sunshine!

FMN Chorus preparing to sing at the summer picnic

Well earned refreshments after the summer singing

The packed audience listened to a range of music from the Hallelujah chorus to a fun selection of Disney favourites! The joy showed in the faces of the singers and in the hearts of the listeners.

**Inspirational women of the year!**

Kate was nominated for and won **'Inspirational woman of the Year 2012' award** on **ITVs Daybreak**. Clips from rehearsals and interviews with the singers were aired, and everyone was so excited! Kate's genuine enthusiasm and bubbly personality are infectious, and her well-deserved personal accolade has been a great promotion for the charity as well. It has been featured in newspapers and the Good Housekeeping magazine - and Lorraine Kelly is now our patron!

Kate and her award from ITV's Daybreak

**What's next….?**

The creative team wishes to consolidate the successes of the past year, and develop the process to ensure all members continue to have a positive experience. 2013 is filled with anticipation of more delights. A date for the diary is May 6th, Bank holiday Monday where the FMN chorus will be performing at the National Museum of Wales, Cardiff, and a gala fundraising event is to follow later in the year.

**Follow and support us!**

The Forget-Me-Not Chorus is supported financially by kind donations by private individuals, a grant from the Waterloo foundation and recently by Lottery funding. From small seeds, great things can blossom and the Forget-Me-Not-chorus is destined to flourish.

**For more information:**

www.forgetmenotchorus.com

the Forget-me-Not Chorus
using the power of song to support families affected
by dementia

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# A Qualitative Evaluation of a Support Group for Carers of a Person with Dementia

*Bethany Larham lives in the North West of England and is a Trainee Clinical Psychologist at the University of Liverpool. Bethany is passionate about working in the field of Clinical Psychology, and has particularly enjoyed roles in Child & Family Services and Adult Mental Health. Bethany has a degree in Psychology and Criminology, a Postgraduate Certificate in Psychological Therapies and a Postgraduate Diploma in Public Health (Analysis).*

*Sarah Butchard is a Clinical Psychologist working within the Older People's Mental Health Service of Mersey Care NHS Trust. She has a special interest in support after a diagnosis of dementia and the effects a diagnosis of dementia has on family relationships.*

*Ashley Bruen is an Assistant Clinical Psychologist within Mersey Care NHS Trust. Ashley particularly enjoys working within Child & Family Services and Older Adult Mental Health. Ashley has a degree and masters in Applied Psychology.*

This report explored the experiences of those who attended a newly-established Carer Support Group offered to individuals caring for someone with a diagnosis of dementia.

## National Context

A chronic and degenerative disease of the brain, dementia is estimated to affect 800,000 people in the UK (Alzheimer's Society, 2013) and 35.6 million people worldwide with 7.7 million new cases per year (World Health Organisation, 2012). Changes associated with dementia may involve memory loss, mood changes or difficulty with language (Alzheimer's Research UK, 2011) which can impact upon emotional regulation and behaviour. Therefore, individuals with dementia usually require increasing levels of support to carry out everyday tasks. The majority of people affected by dementia are cared for in the community (Marriott, Donaldson, Tarrier & Burns, 2000), with more than 60% of people with moderate dementia living at home (Ballard, 2005). The nature of dementia means that it can be highly stressful for the person and their family to manage (Cuijpers, 2005), and it is increasingly being recognised that caring for people with dementia can be extremely challenging (Sorenson, Duberstein, Gill & Pinquart, 2006).

Research reveals that caring for someone adversely affects wellbeing (Schoenmakers, Buntinx & DeLepeleire, 2010), usually with financial, social, physical and psychological consequences (Zarit & Femia, 2008; Haley, 1997). Teri (1994) reports that up to 50% of carers experience depression, whilst Brodaty and Gresham (1989) reveal that carers for people with dementia often feel isolated and become psychologically distressed. These negative factors associated with caring are often referred to as the care-giver burden (Cooper, Selwood & Livingston, 2008) and whilst carers often report some positive aspects of caring, unfortunately a key narrative is that of feeling unsupported and struggling to cope (Schoenmakers, Buntinx & DeLepeleire, 2010). It is clear that carers for individuals with dementia tend to have needs above and beyond that of the general population.

Providing carers with support from trained staff can help families to minimise their psychological burden (Moniz-Cook, Elston, Gardiner, Agar, Silver, Win & Wang, 2007). A number of supportive strategies appear to improve carer wellbeing, including education, stress management and coping skills training (Marriott, Donaldson, Tarrier & Burns, 2000). Burns, Nichols, Martindale-Adams, Graney & Lummus (2003) found that providing behavioural management training and stress-coping support increased general wellbeing in carers and also decreased their risk of depression. Other research points towards the importance of providing carers with emotional support, enabling them to discuss their feelings of guilt or anger (Beart, 2008), whilst Brodaty and Gresham (1989) found that supporting carers postponed moving the individual with dementia into full time care. There are clear benefits to addressing the needs of people caring for those individuals with dementia and services should be provided in line with this.

Kitwood (1997) advocates person-centred dementia care, and argues that the person with dementia retains capacity to have meaningful relationships. Therefore, the relationship with the carer –usually the person they have most contact with– is of vital importance (Brooker, 2009). Evidence suggests that "people with dementia have a significant level of awareness of their carers' state of psychological health" (Ablitt, Jones & Muers, 2009: 1246) which if poor, is likely to have a negative impact upon the relationship. Therefore, it is important not only for the wellbeing of the carer that they receive support, but also imperative for the person with dementia.

Proctor, Martin and Hewison (2002) reveal that our ageing population means the number of people with dementia will rise, making the role of the carer even more vital. The Audit Commission (2004) states that the importance of carers has been increasingly recognised by the government, and providing services that meet this group's unique set of needs is now the focus of much guidance and policy (Stirling, Andrews, Croft, Vickers, Turner & Robinson, 2010). Carers are finally being recognised as a vital resource (Department of Health [DoH], 2009) and have a legal right to have their needs assessed and suitable services provided (National Institute of Clinical Excellence [NICE], 2001). The National Collaborating Centre for Mental Health (2007) recommends evidence-based support for carers, including group psycho-education, peer support groups, training courses about dementia, information on services and benefits they could be entitled to, communication and problem solving. The National Dementia Strategy (DoH, 2008a) recommends that comprehensive information is provided for those with dementia and their carers. However, critics report that services to support this group are generally lacking (Guerra, Ferri, Fonseca, Banerjee & Prince, 2011) and it is suggested (DoH, 2008b) that services for carers should be piloted to see how the NHS can best support them.

## Local Service Context

The Carer Support Group evaluation was conducted within the Psychological Services department of an Older Adult Community Mental Health Team. The staff team comprises Clinical Psychologists, Psychiatrists, Physiotherapists, Support Workers, Nurses and Occupational Therapists. A Post-Diagnostic Support Group for people with dementia and carers had already been established and well received. However, from the success of this group, an unmet need was identified: to provide support exclusively for carers. Therefore, a proposal was put forward to develop the Carer Support Group, and permission granted to pilot it. If successful, the service aimed to deliver a rolling programme of Carer Support Group courses to carers.

The Carer Support Group was developed in line with current literature and policy recommendations already discussed. It spanned 6 weeks and covered: facts and myths about dementia; understanding the world of dementia; understanding behaviour and communication; practical solutions to memory problems; wellness and wellbeing; future plans. Individuals were identified as suitable for the group by staff members and given information; six individuals chose to participate in the programme.

## Rationale

Evaluating the experiences of those who attended the piloted Carer Support Group will enable the provider to assess whether it is a valuable service which should continue to be offered. Recommendations can be made on how the group could be improved if it is offered again. Involving the users of services in evaluation and development is considered good practice (DoH, 2004) and views should be disseminated to staff who can make necessary changes as a result (DoH, 2009). The DoH (2005) states that services for older people can only become person-centred when the views of those who use the service are acknowledged and taken into account. Therefore, it was agreed that the Carer Support Group would be evaluated by exploring the experiences of those who attended.

## Aims

i. To qualitatively evaluate the Carer Support Group by exploring the experiences of those who attended

ii. To make recommendations based on these findings (to report to key stakeholders within the service)

## Method

### Ethical Approval

After discussion with the Research and Development Lead, it was confirmed that no ethical approval needed to be sought for this service evaluation.

### Design

Qualitative methodology was used to elicit rich data from the small sample. As the participants were familiar with one another, it was agreed that a focus group would be utilised. This was considered the most useful means to explore participants' experiences of the group. Individual interviews were also offered to accommodate those who were unable or unwilling to participate in a group.

### Participants

### Recruitment

As the research set out to explore individual's experiences of the Carer Support Group, all those who had attended the group (n=6) were approached to take part. The Carer Support Group facilitator had informed those who attended the group that an evaluation would be conducted at the end, with participation voluntary. All group members consented to being contacted. A letter and information sheet were sent to group attendees by the facilitator, requesting that they made contact if they wanted to participate. Three individuals agreed to take part in the focus group; one agreed to take part in an individual interview; one chose not to participate; and one did not respond to the invitation or follow-up answer-phone message.

### Demographics

All participants had been identified as carers for individuals with dementia and attended the Carer Support Group. The mean age of participants (n=4) was: 72 (range: 67-75) and all identified themselves as White British. Three of the four participants were currently full-time carers. All participants had been caring for a spouse (wife n=2; husband =2).

### Materials

An invitation letter was sent to potential participants, with a supporting information sheet. A consent form and demographic information sheet were devised for completion by participants. A copy of the content covered at each session of the Carer Support Group was provided to act as a prompt. The semi-structured schedule was developed by the researcher and reviewed / revised by three clinicians to minimise leading questions.

### Procedure

### Focus Group

The evaluation was conducted three months after the group had finished, assessing whether lasting changes had been made. Participants (n=3) attended the hospital site for the focus group which was facilitated by the researcher and research assistant, and lasted one hour and ten minutes. The information sheet was provided again and the opportunity given to ask any questions. Participants gave informed consent and completed the demographic information form. They were briefly reminded of the purpose of the study and informed that both positive and negative views were being sought. Raw data were captured in vivo by the facilitators using a flipchart. This allowed for participants to review and clarify the data and expand if necessary. The focus group was audio recorded with the participants' consent to enable reviewing at a later date.

### Interview

One participant opted to take part in an individual interview due to his caring responsibilities. The interview was conducted three working days after the focus group,

in the participant's home. It lasted 40 minutes and followed the same procedure to that of the focus group.

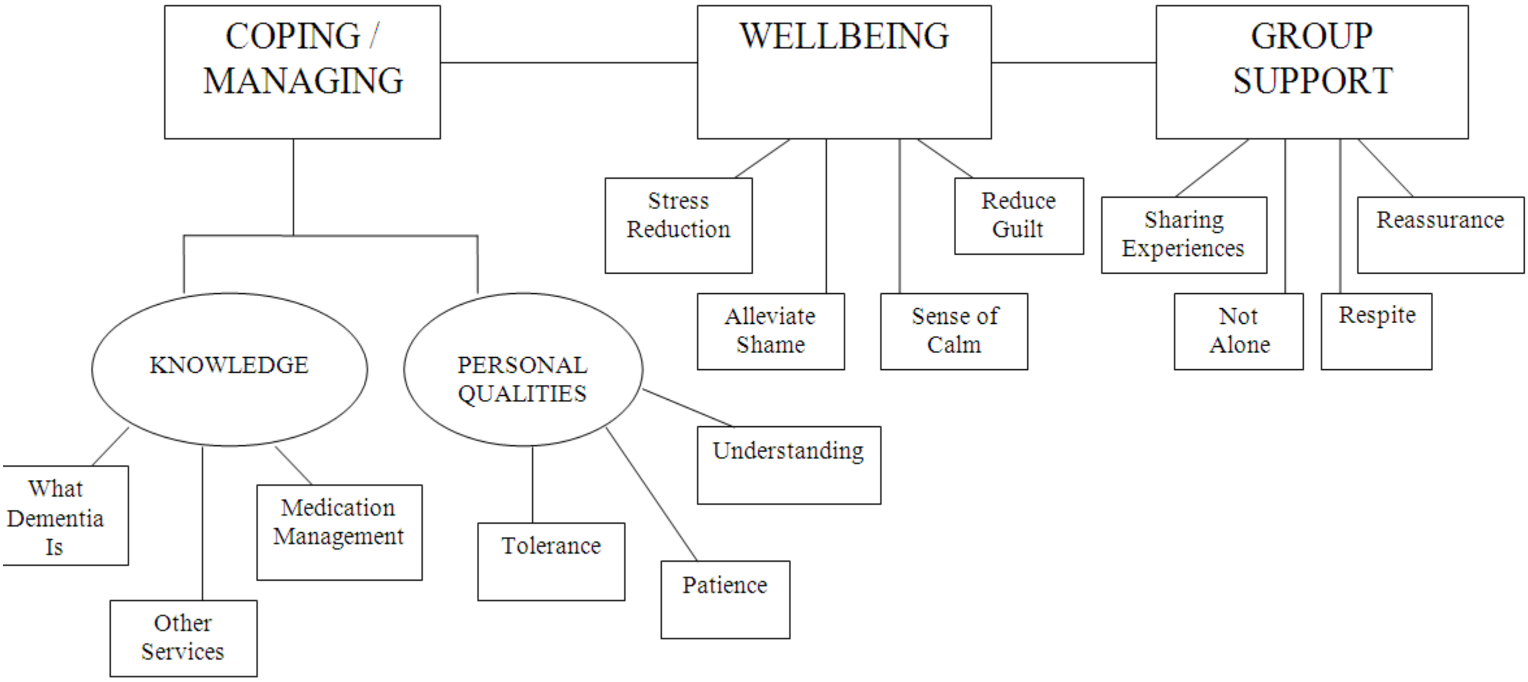
## Analysis

Thematic Analysis was deemed to be the most appropriate qualitative method for analysing the data. It is a flexible approach, which generates a detailed account of data (Braun & Clarke, 2006). As this was an evaluation of experiences, deeper interpretation of meanings was deliberately limited to best capture participants' own words, phrases and themes – sometimes referred to as semantic level analysis. Themes were abstracted from the data set and were articulated by the majority of the respondents (as suggested by Meehan, Vermeer & Windsor, 2000).

Taylor & Ussher (2001) state that: the researcher takes an active role by identifying and reporting areas of interest. Therefore, to minimise impact of the researcher's own interpretation, initial areas of importance were identified, clarified and discussed with participants in vivo. The focus group data and interview data were combined and themes extracted from the whole dataset. Audio recordings were reviewed along with reading and re-reading the written notes, enabling the researcher to immerse themselves in the data. Patton's (1990) criteria were used to ensure the themes had internal and external homogeneity, i.e. themes were discrete and did not overlap. Codes and themes identified by the researcher during the analysis process were independently reviewed by five clinicians.

The thematic map was constructed and revised, until all themes appeared to accurately represent the data in a coherent way (see Figure 1).

***Figure 1: Thematic Map of Experiences of the Carer Support Group***



## Results

Three key themes were derived from the data set: coping/managing; wellbeing; and group support. The overwhelming opinion was that the group had been a worthwhile experience:

> *"it was great... good work".*

Themes were named with direct quotes or language used by participants. Each theme will be explored in turn, with reference to their subthemes. See Figure 1 for the thematic map constructed from the data, demonstrating how the themes and subthemes relate to each other.

## Coping / Managing

It was reported that the Carer Support Group improved individuals' ability and knowledge of "how to cope" and "manage" their situations. This appeared to be an important benefit, and overarches a number of subthemes.

### Knowledge

Participants stated that a key benefit of attending the group was improved knowledge in key areas. Having a biological understanding of what dementia is was valued, and the group enabled participants to

> *"find out about aspects of the condition".*

Being given accurate information about dementia allowed attendees to separate facts from myths. Receiving information about other services was identified as a key strength of the group. Participants all disclosed that they benefitted from this information and welcomed being educated regarding further sources of support. One participant stated:

> *"you found out about places that could help you, ones you probably wouldn't have found by yourself".*

This was seen as a practical source of support which complemented the Carer Support Group. Managing medication was deemed to be an important benefit for participants, in understanding what the medication was for and strategies for ensuring it was taken as directed.

### Personal Qualities

Participants discussed how they had been able to develop their personal qualities through attending the group, which felt distinct from knowledge though still an important aspect of coping / managing. They felt that they had become more tolerant of the situation they were in and able to react better to the person they were caring for.

> *"Today he put two cardigans on, but I've just learnt to say 'oh well'."*

Participants described how they felt a lot more patient:

> *"it might take two or three times longer for him to do something now, but you just wait patiently and help out if they'll let you".*

A sense of improved understanding was prevalent, with participants being able to see things from the perspective of the person with dementia and therefore providing better care.

> *"Before I had a chip on my shoulder about it all, [now] I'm more understanding… take it as it comes".*

Developing the personal qualities of tolerance, patience, and understanding all contribute to an overall improvement in being able to cope / manage.

**Wellbeing**

Participants acknowledged how difficult it is to be a carer and how this affected their wellbeing:

> *"it's hard… So hard. You feel sorry for yourself... you think 'why me?' and go into your shell".*

There was a sense that attending the group had helped to improve their wellbeing. They reported a reduction in stress levels since attending the group. This had enabled them to perform their caring role better and help them to retain a sense of calm, even in more difficult moments. Actually attending the sessions provided them with "me time" and enjoyment, and enabled participants to reduce guilt that they had been experiencing:

> *"I still feel guilty sometimes, but not the major guilt I felt",*

which improved their wellbeing. Shame was also identified within the data, with the group helping to alleviate this somewhat:

> *"It's only since I've come here that I've told people about it, I could say and not feel, like, ashamed about it".*

Reducing this sense of shame appeared to increase the overall wellbeing of the attendees, along with stress reduction, reducing guilt, and enabling a sense of calm.

**Group Support**

The final key theme was the benefit of receiving support in a group setting:

> *"it's helpful in a group… [They were] nice people".*

For most participants, attending the group was the only source of support for them and they did not receive the support from other professionals they thought they should have had:

> *"We didn't get the sympathy I thought we should've had from our doctor [GP]".*

Being able to share experiences helped to normalise the experience of caring for someone with dementia:

> *"[It was] interesting to hear other people talking about what I'd been going through"*

and

> *"[you] understand that people are in the same boat as you".*

It was also identified that they shared experiences with the group which they had not felt able to discuss with other people:

> *““[before the group] I hadn't even talked to anyone else about it [partner having dementia]”;*

> *“I used to not tell anyone [he] had Alzheimer's – it's like a stigma, isn't it?”*

and that sharing these experiences was well received by the group:

> *“everybody's sympathetic about it”.*

Receiving reassurance that carers were doing the same as their peers seemed to be a major benefit of group support:

> *“You think ‘should I have done this, should I have done that?’ Then you realise… It's ok. We're trying our best and that's… ok.”*

Participants discussed how the group support made them realise they were not alone, whereas before some reported feeling isolated because they didn't know anyone else in the same situation:

> *“Felt like an outcast”.*

Finally, the subtheme of respite was identified, as participants stated that having group support gave them time away from the situation and person that they were caring for.

**Additional Comments (not captured in the thematic map)**

A number of questions were asked that were more direct, to elicit opinions on more practical aspects of the group. Participants agreed that the location was accessible and the room suitable for purpose. The day and time which it was held also suited all participants. The number of sessions provided was deemed appropriate by all participants, with one stating:

> *“we did everything we needed... [we] wouldn't have got anything more out of them if we'd attended 17 sessions”.*

In addition, every participant said that they would recommend the Carer Support Group to someone else who was in their position.

One participant identified herself as at a “different stage” from the other attendees, because her partner's dementia was more advanced and he was being looked after in a care home. She stated:

> *“I wish, in a way, I had something like this before, when he was living at home”.*

She reported that it had been extremely helpful and she was grateful to have been offered the group, but she felt that she would have benefitted more if it had been available to her earlier. Though this was not the prevailing experience, it seemed to be an important point to include in the analysis as the report aimed to consider all experiences, not simply the prominent story.

## Discussion

Aim (i): To qualitatively evaluate the Carer Support Group by exploring the experiences of those who attended

All participants reported that attending the Carer Support Group was a positive experience. They discussed the enjoyment they experienced by attending, and described it as a “pleasant experience”. This was despite the difficult situations the attendees were trying to manage, and the sensitive, emotive issues which were discussed in the group. No participants expressed a negative experience, despite prompts which attempted to elicit a range of views, and all reported that it had been “useful” in some way. Three linked themes were elicited from the data; these themes are also evident in the literature.

Participants reported being able to better cope and manage by attending the group. Participants valued the opportunity to improve their knowledge through information giving, which reflects other findings (e.g. Boise, Camicioli, Morgan, Rose & Congelton, 1999) that carers require practical advice, and information on how to access community agencies. The written information was particularly valued, which supports work by Selwood, Cooper, Owens, Blanchard & Livingston (2009), and they also found that by giving information on memory problems and management strategies reduced the risk of abusive behaviour perpetrated by the carer. It could be argued that this is reflected on some level in the participants in the group, as they report having nurtured the personal qualities of tolerance, patient and understanding, which would make abuse less likely to occur. Being able to cope / manage also links to the other key theme of wellbeing, where Marriott, Donaldson, Tarrier & Burns (2000) found that improved management skills in carers reduced the stress experienced by care-giving, thereby improving their wellbeing.

The theme of wellbeing was eminent in the data, and this was also supported by the literature (e.g. Burns, Nichols, Martindale-Adams, Graney & Lummus, 2003). Beart (2008) found that caregivers commonly felt sad, frustrated, stressed and guilty and it helped to discuss these feelings, which was reflected in this evaluation. Participants felt that by attending the group, some of these negative feelings were reduced and positive feelings experienced. Teri, Logsdon & Yesavage (1997) found that depression was decreased when carers became more capable in managing their situation, and their confidence in their skills was improved, supporting the finding in this evaluation that wellbeing was improved.

Levine & Zuckerman (1999) report that it is extremely important for carers to be given emotional support and attention; in this evaluation participants reported that group support provided them with this. NICE (2001) recommend peer support groups and psycho-education in groups for carers of those with dementia, and receiving support in a group format was certainly a key benefit to this intervention. Being able to share experiences with others and listening to others who were in a similar positions helped carers to normalise their situation. This key theme also links to wellbeing, with research (e.g. Schoenmakers, Buntinx & DeLepeleire, 2011) showing that carers who feel well supported both professionally and personally have improved wellbeing, and talking about experiences alleviates stress (Beart, 2008).

Benefits were reported from attending the Carer Support Group, including better coping / managing, improved wellbeing and positive experiences in relation to group support. These areas are also referred to in the literature, therefore it seems as though the findings from this report sit well with the current evidence base. It appears that in providing the Carer Support Group, Brooker's (2009) values for person-centred dementia care are upheld: valuing people with dementia and those who care for them; treating people as individuals; looking at the world from the perspective of the person with dementia; and providing a supportive social environment. Research has found that distress in carers leads to poor quality of life and poor mental health (Rosness, Mjorud & Engedal, 2010) and that carer stress can contribute to a breakdown in relationship and the onset of poor care conditions (Beart, 2008). Therefore, it seems important to continue providing support to individuals who are caring for others with dementia in line with current policy, and that the Carer Support Group has been a positive experience in its pilot phase.

**Limitations**

1. As this evaluation was conducted three months after the group ended, it was useful for assessing if there were lasting changes, but the question remains whether they could accurately recall their experience of the group. Future research could evaluate the group immediately after completion, in addition to a later stage to provide more rich data on the participants' experiences.

2. It was encouraging that four attendees contributed to the evaluation, though the experiences of the remaining two attendees are unknown. It is not possible to generalise the findings of this report beyond those who participated and therefore conclusions drawn were tentative. There is a possibility that those who were willing to take part in the evaluation are likely to give more positive feedback. However, this cannot be established and therefore the report can only accurately reflect the views of those who took part.

3. This report took a qualitative approach to explore the subjective accounts of participants' experiences. However, this does not give an objective measure of change and it might have been beneficial to have collected pre- and post- measures to assess objective change in areas such as stress, wellbeing and coping.

4. Whilst both positive and negative experiences were sought, participants were

aware that the researcher and research assistant were working in the same service as those who facilitated the Carer Support Group. Therefore it is possible that participants might have censored their responses.

5. Whilst this Carer Support Group appears to have been valuable to those that attended, the findings of this report cannot be generalised to other Carer Support Groups. This report focussed on one cohort; it would be useful to repeat the evaluation for future cohorts, to compare findings and continually improve the group.

6. This Thematic Analysis was conducted from an experiential/realist standpoint to explore how participants found the Carer Support Group. As suggested by Braun & Clarke (2006), in depth interpretations were not made from the participants' comments. Future research could explore the responses regarding the Carer Support Group in more depth, taking a different epistemological position.

## Recommendations

Aim (ii): To make recommendations based on these findings to report to key stakeholders within the service

1. Qualitative feedback from those who took part in the evaluation showed that the Carer Support Group provided a valuable service, and it is recommended that it continues to be offered.

2. Future evaluation of the Carer Support Group could be conducted to provide further evidence of how it is received by those who attend. To provide a more comprehensive evaluation than this report, quantitative pre- and post- outcome measures could be utilised to document efficacy. Future Carer Support Group evaluation would benefit from all attendees participating in the evaluation.

3. One participant expressed how they would have preferred earlier input from the Carer Support Group. It is recommended that attempts are made to offer the group to carers as soon as possible after diagnosis of dementia. This is in line with previous research which reveals that prompt identification of carers is important (DoH, 2001) and that carers benefit from early access to services (Audit Commission, 2004; Proctor et al., 2002).

4. Methods raising awareness of the Carer Support Group could be considered. This report identified that some carers struggle to access services and have limited support (also noted by Millard & Baune, 2009). Therefore, promoting the Carer Support Group to GPs and other agencies that have contact with this population could be considered.

5. The evaluation did not have access to carers who had been offered yet declined the group. It might be useful for the service to record who has declined the group, to ascertain reasons why and perhaps adapt the way the group is presented to potential participants.

6. The DoH (2005) recommends that staff are trained so they can communicate effectively with those they provide care for. Whilst staff supporting the person with dementia will be highly trained in appropriate areas, their knowledge of working with carers might be more limited. Materials from the Carer Support Group could be adapted to create a package to be delivered to staff, raising their awareness and knowledge (as suggested by Audit Commission, 2004).

7. It is recommended that service user involvement continues to be promoted within the service, in line with national policy. Service users were enthusiastic about giving feedback on the service they received.

8. The findings from this report have been summarised for distribution to key stakeholders: the Research and Development Lead; and the Carer Support Group facilitator. It is recommended that they are further disseminated to other appropriate parties.

## Conclusion

A Carer Support Group was evaluated by exploring attendees' experiences via focus group and individual interview. Thematic Analysis conducted on the data generated key themes: coping/managing; wellbeing; and group support. Participants described the group as a welcomed and valued service, helping develop a range of skills and knowledge to benefit themselves and the person they cared for. It was recommended that the group continued to be offered, promoting it to potential referrers and identifying carers who may benefit as early as possible.

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# "What does it feel like to have dementia?"

*Barry Pankhurst is a British citizen who is living with dementia in Indonesia. Mr Pankhurst has a diagnosis of mixed dementia with Alzheimer's disease and Parkinson's disease. Here he writes an article about his own experience and distress, which is left as he wrote it in his own words.*

Recently I was asked "What does it feel like to have dementia?" Well let's put it like this! Delve down deep into the very depths of you soul and imagine your worst nightmare and you wont even come close to what any type of Dementia can do to a person or the person you knew!

No there aren't any what you might call symptoms as with a cold or the flu as dementia is furtive and just seem to creep up on you from behind without you realizing it, for some people it seems to hit them very hard right from the start and whether that has anything to do with a persons age is debatable, I know in my own case I started to realize I had a problem when I was 58 years old having seen the same thing with my late grandfather and then my late father-in-law, it was just like my mind was lost in swirling clouds and I noticed that I could not remember my recipes anymore and also kept forgetting that I'd put products in my oven for baking!

Yes I do still realize that I have dementia and can still tell what its doing to me as a person 'as in sometimes' turning me into a person with a Jackal and Hyde personality, yet before the illness I was the most placid of people with a good sound logical mind!

There is a list of what they call the 7 stages of Alzheimer's and Dementia but it doesn't necessarily mean that every sufferer will follow the stages as listed since any type of dementia seems to affect each individual in different ways and at different stages of the illness progression, so yes tiredness, depression, and definitely irritability are all part and parcel of the illness so its not (as some people still seem to think) just a case of being forgetful.

At the moment with my own condition I'd say that my physical condition has deteriorated much faster than my mental condition, sometimes when we go for our morning and afternoon walk I fell as though I'm wearing lead boots and it becomes an immense effort to put one foot in front of the other, this becomes worse at the end of the day when I start to (what's called) "Sundowning" and the mind starts to follow the setting of the sun and drains every once of energy out of my body then added confusion sets in thick and fast!

Yes I also battle with frustration everyday at not being able to practice my once loved profession that needed a lot of eye to hand coordination but know my coordination has got lost within a labyrinth of other dementia problems… imagine this! You studied and now fully understand your own profession, well try to imagine how you would feel if all of a sudden all those years of studying and the knowledge you gained are slowly being eroded away out of your memory bank and that your mind is turning into an empty shell!

Many of us with dementia have speech problems that can manifest itself at any time during the illnesses progression although having said that (it doesn't mean that every sufferer will have speech problems) I now have speech problems that Sumi said started about a year ago and has become progressively worse, 'what happens' maybe Sumi or someone will ask me a question 'But' when I go to reply the mind and voice becomes frozen and all that comes out is a slurred stammering, yes the words of a reply are within me but they wont come out which then makes me even more frustrated and bewildered and I often end up in tears, yes a grown man in tears… but that's what dementia does to a person… and sometimes when I sit at the computer with all good intentions of typing I end up just staring at the monitor screen as any form of communication has got lost in the minds maze of bewilderment.

Sudden noises of any type cause me a lot of anxiety and I end up like a trembling frightened jelly, it can be from the daily noise from people talking, children crying, or even the passing traffic, I've also now become extremely insecure when left alone, you could say scared of my own shadow and I seem to see plenty of shadows and images that really aren't there, and night times can be horrific from the terrible nightmares that have me screaming and lashing out my arms and legs in my sleep…

Well that gives you just a very, very brief look into my daily dementia mind, first thing this morning I was having a bad cloudy day full of doom and gloom but we have to try and keep fighting this illness no matter how hard and stressful it becomes since if we give in then the dementia sneaks in further through the back door of the mind.

Without a doubt dementia is one of the curliest illnesses, yet I still say I'm far better of health wise than many other people in this world.

But as I said please remember that no two people suffer from dementia in exactly the same way…

**Barry Pankhurst**

Living with dementia in Indonesia

# Who do you turn to for Support and Information when Dealing with Dementia and Mental ill Health in Wales?

**C.A.L.L. Mental Health Helpline available 24/7 on freephone 0800 132 737 or text the word help and your message to 81066 [www.callhelpline.org.uk](http://www.callhelpline.org.uk)**

C.A.L.L. Helpline has been providing support and information to those suffering from mental ill health, their families, carers and professionals since 1995. During that time the service has developed from very limited opening hours to a 24/7 service and now responds to over 2,000 callers every month from across Wales.

Callers to the helpline may already be accessing mental health services but need additional support or information at a time when their usual support systems are not available. Other calls can be from individuals who are suffering mental health problems and do not know where to start to access the help and treatment they need. Providing information to family and friends forms a big part of our work as they can be concerned about someone who may have mentioned suicide or just do not know how to help someone who is depressed.

The helpline covers a vast range of symptoms and conditions - our helpline workers do not diagnose callers' medical problems, but work with the caller if they have a diagnosis or encourage them to seek appropriate help for their issues.

Many people with severe and enduring mental health problems can feel isolated by their illness and lack human contact. For those situations the helpline becomes part of their support in the community. People can contact the helpline for support when they need it or can talk for a while if they feel lonely. The helpline can provide reassurance and encouragement at times when a person's key worker is not available.

Unfortunately, dealing with suicidal callers is very much a day to day occurrence for the service and we view these calls as an opportunity to try and make a difference. If we can get the person through until the next day, then it is another day to try and help them deal with their problems and build up their support systems.

Raising awareness of these services to those who may need help can be initiated by ordering free promotional leaflets, posters and cards. These can be ordered online at [www.callresources.org.uk](http://www.callresources.org.uk) or email [janet.roberts2@wales.nhs.uk](mailto:janet.roberts2@wales.nhs.uk)

The Helpline's Department also operates the Wales Drug & Alcohol Helpline. Information on this can be found at www.dan247.org.uk

**Wales Dementia Helpline available 24/7 on freephone 0808 808 2235**
**www.dementiahelpline.org.uk**

The Wales Dementia Helpline provides support, information and agency signposting for anyone diagnosed with dementia or caring for a family member or friend living with dementia.

The helpline can assist by offering emotional support and a listening ear. At times people may need to talk through their fears and feelings with someone who is not emotionally involved, but who understands their situation. Sometimes callers to the service are already involved with agencies but just need to offload their troubles - if that enables them to get through another day, we are happy to listen.

As a Wales-wide service we have a comprehensive database of services, both statutory and voluntary, which may be able to help. Services can be local or a national agency, it all depends on the needs of the caller.

Many of our callers ring because they are finding it hard to carry on caring and find themselves in need of support themselves. We find that listening and allowing them to talk about their situation can sometimes be all that is needed. We encourage callers to access support and passing on contact numbers for agencies, providing free self help or agency leaflets can reinforce the feeling that help is available and that they are not alone.

The helpline is open to anyone to ring at anytime; there is no referral process, no age limitations – just immediate support at anytime of the day or night.

**Janet Roberts, Call Helpline Manager**

C.A.L.L.

Community Advice & Listening Line
Mental Health Helpline for Wales
0800132 737
Llinell Gyngor a Gwrando'r Gymuned
Llinell Gymorth Iechyd Meddwl ar gyfer Cymru

# ‘We need a Bev on every corner’

**From midwife to end of life – Beverley Keyse reflects on care pathways, dream wards and her work as a Liaison palliative care Nurse for dementia.**

*Beverley Keyse is a Specialist Liaison Nurse Palliative Care at Cardiff and Vale University Health Board. She commenced nurse training in Morriston Hospital in 1976 and worked briefly in general medicine before entering student nurse training for psychiatry in 1981. On qualifying in 1984 she commenced working in older persons services. In 2000 she moved to Cardiff and Vale NHS Trust working in Mental Health Services for Older People. In April 2009 she was appointed as Specialist Liaison Palliative Care for Mental Health Services for Older People after successfully obtaining a Bsc.(Hons.) in Palliative Nursing.*

**What sparked your interest in palliative care?**

I became concerned with end of life care for those with dementia while working as a Ward Manager on an Extended Assessment Ward within Mental Health Services for Older People. This ward was for people with psychiatric symptoms associated with dementia. It became apparent that the way some of the patients died depended on the skills and knowledge of the nurse in charge at the time. Whilst I had had a wealth of experience in end of life care some of the junior staff were not comfortable with the issue and felt ill equipped to provide the level of care required. I thought, ‘There’s got to be a better way of providing best practice and consistent care for patients when they are dying’.

The opportunity arose to do a degree in professional practice – there was a module called ‘The foundations in palliative nursing’. I can remember sitting there and thinking, ‘Am I in the right place’? There were senior nurses from McMillan and similar – it came to me - ‘Bev Keyse, ward manager, mental health’ – and there was a gasp! An unbelievable gasp. I got that ‘impending doom’ feeling. I was the only mental health nurse they had ever had enrolled on the course.

Shortly after completing the course the Directorate Manager met with me as my role was being redefined and asked, ‘Well, what would you like to do?’ As I had completed my degree I thought it was a perfect opportunity to use it to improve patient care

**How does your role work?**

Theoretically we should all be receiving palliative care – it's about living your life to the full. However, it is usually evoked when the patient is approaching the last stage of their life. I pick up referrals from MHSOP areas anywhere within the Directorate, get the patient information and make the first contact, identifying the problems and what is needed. I then usually do a joint assessment with the Palliative Care Team, and determine the appropriate plan of care. I'm proud to say this is usually within two working days. We combine our skills - specialists in palliative care alongside myself as specialist in dementia care. This way I am able to indicate signs and symptoms in patients who are unable to communicate effectively to the Palliative Care Team so that they can recommend treatment or medications, which I then monitor. So I'm sort of the ears, eyes and voice for patients who have dementia and palliative care requirements.

**What do you enjoy about your role?**

People think I'm mad when I say I find this job really rewarding, but it's such a privilege to spend the last minutes, seconds, days of someone's life with them and to ensure that their death is well managed and pain free. I suppose I get the same job satisfaction at the end of life as I would at the beginning as I originally wanted to be a midwife!

What I find the most rewarding is knowing I've done the absolute best for that patient, that they've had the best death they could possibly have. I always try and find the relatives a role – I say to them 'let us do the caring, you do the loving'. This one gentleman always springs to mind – his wife was dying, and he took about two hours to give her 30mls of water – but there is a time when you have to say 'that person doesn't need that now, they need something different' – so we gave him another caring role which we told him was more important to his wife at this point. We suggested he used hand cream to moisturise his wife's hands and put some Vaseline on her lips. He later returned to the ward as a volunteer.

Another great example – we had a man on the ward who was a gardener – we pushed him out on the bed into the garden and he died in the garden with nurses around him. How wonderful!

Finally, I have had a brilliant team in the Staff from MHSOP and Palliative Care Teams. They are so supportive and I cannot thank them enough for making this role work.

**What do you least enjoy about your role?**

What distresses me the most is that I don't know that person very well – it's a very vulnerable part of their life and I only get to know them from the point of referral. I find that sad. However, this means I can be objective – I can assess things better.

**What further developments would you like to see in dementia palliative care?**

This area is still in its infancy. It is slowly getting more recognised. There was a study done in North Wales in 1996 which recognised that patients with dementia and patients with cancer had the same symptoms at time of death. However, palliative care is still not embedded in dementia care and vice versa.

I would like to see palliative care in dementia there from diagnosis to death. There is a small window of opportunity to discuss what patients would like. I would much rather that person had that voice. When patients have a diagnosis of cancer they have a lot of support from the beginning to discuss end of life issues – patients with dementia don't have that and ideally I'd like to see this happen.

But Rome wasn't built in a day! We are getting there. I've just completed a module on end of life care for inpatients and there were five mental health nurses on it.

**What is your greatest achievement?**

The embedding of the Integrated Care Priorities (ICP) within general practice. When I started in post we had forty-eight deaths within the Directorate – only two were on the ICP. This year we had forty-nine deaths and only four were not on the ICP. People are being placed on the ICP appropriately to receive good quality end of life care – it is seen as a gold standard.

The ICP document talks about comfort, pain, communication - making sure somebody understands – involving them and talking to them. Making sure the family is up to date and understands what is happening. If I was in hospital I would want to be pain free, not agitated – to me, everybody should be assessed for this. This is basic nursing care, and this is the minimum of what we should expect – what it enables us to do is ensure we are ticking all the boxes. Care priorities should be care priorities at all stages of an illness.

**The Liverpool Care Pathway has received a lot of negative press recently. What are your views on this?**

It is a different idea from our ICP – the biggest issue is about relatives not being involved. With the ICP, I take a blank document to the relatives and I go through it stage by stage – I encourage question asking – taking the mystery out of it helps a lot. There is nothing on there that would hasten death – that's not what it's about – it's about recognising that a patient is dying and seeing what we can do to make their quality of life better. The families can see being on the ICP is nothing to be frightened of – it's just to ensure that all the patients' needs are met.

I think it is quite frightening for people when you talk about withdrawing food and drink – but if you have problems with swallowing and what they are swallowing could be going into their lungs and causing discomfort it's a different matter. It is not deemed in the person's best interest to have a PEG if they have advanced dementia as they would most likely be unable to tolerate the surgical procedure and artificial feeding would cause distress and agitation. Also we need to ask, 'Who are we doing this for'? The relatives may be very distressed by the patient not having food or fluid and then our role is to support them by giving appropriate information. I think a lot of the problems which have come about are due to a lack of communication. It is important to get the relatives feelings – we need to look after the whole family.

**Is the palliative care role going to continue to exist when you leave?**

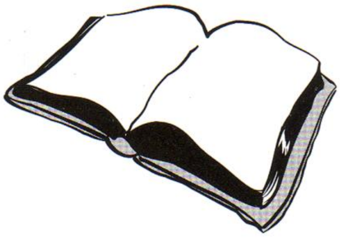
Unfortunately this is an unfunded post – senior managers are trying to get funding for it but as this moment in time I think it might end when I leave. But some of the changes I brought in are quite embedded in practice now and there are very strong links between the service and the Palliative Care Team.

**If you won a million pounds to spend on a palliative care/dementia ward, what would your dream features include?**

A relative's room – we're often dealing with quite elderly relatives who need the opportunity of staying within the area, having a break and to have permission to go to this room and say, 'This is my little sanctuary here but I'm not that far away'. A lot more side rooms (we have these at Llandough and are very happy with them). Fund my post! Not for me, but for anyone - to carry it on for future generations of patients with dementia. Finally, the development of a training module specifically for palliative care in dementia.

**Beverley Keyse**

# Book Reviews



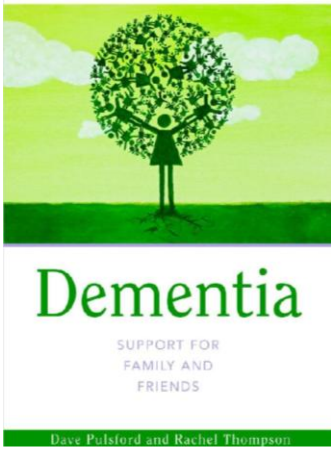
## *Dementia – Support for Family and Friends*

**Authors:** David Pulsford and Rachel Thompson

**Publisher:** Jessica Kingsley Publishers

**ISBN:** 978 1 84905 243 6

**Price:** £13.99



The authors Dave Pulsford and Rachel Thompson, both nurses with considerable experience in the area of dementia, have brought out a volume which fulfils the promise of its title. The book is comprehensive in as it covers all aspects of dementia care, ranging from information on practical caring approaches to medical and legal advice. Moreover, its clarity and directness make it suitable for most readers, even those who have little or no prior knowledge of the field. The book's division into the early, middle, and late stages of dementia helps readers to orientate themselves amid the abundance of material, as do prominent headings and concise chapters. Direct quotations, mostly from family carers, add a personal dimension and make the book come alive. Small drawings interspersed in the text also help to prevent the chapters from becoming too dry and formidable and hence make the book more accessible. A few graphs further illustrate what has been explained more abstractly.

It is only to be expected that the book should look at the dementia complex from an Anglo-centric perspective, as it is mainly addressed to readers in the United Kingdom, the United States, Canada, Australia and New Zealand. However, I do find the assertion problematic that some other cultures and growing immigrant groups may not think of dementia as a disease. After all, such views are not culturally specific but are also held by many native British people who have not had the opportunity to learn about the subject in a book such as this. I am not sure what qualifies the authors to state as a fact that there are South Asian languages which do not have a word for dementia. Neither did the English language, I would suggest, since 'dementia' is ultimately an international medical term which has come to replace the older notion of 'feeble-mindedness'. The sources in the appendix reconfirm the authors' firm Anglo-centricity as they do not acknowledge that Age UK actually provides services in the Welsh language.

Despite these misgivings, I think that the book is full of valuable advice and insights and can be recommended to anyone who wishes to know more about the ins and outs of dementia care and support.

**Johannes Gramich**

Social worker in mental health, older people.

Transforming the Quality of life...

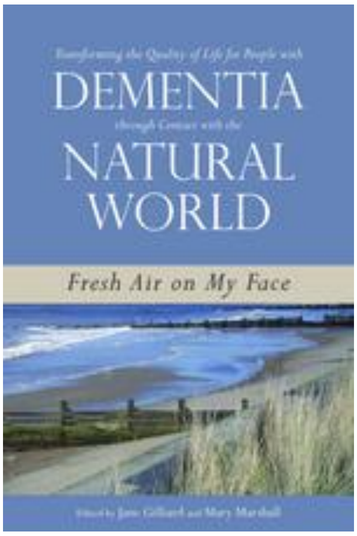
***Transforming the quality of life for people with dementia through contact with the natural world***

**Authors:** Edited by Jane Gilliard & Mary Marshall

**Publisher:** Jessica Kingsley Publishers

**ISBN:** 978 1 84905 267 2

**Price:** £15.99



This book is a collection of different ideas and work out there that incorporates nature to aid the quality of life for people with dementia. The aim of the book was to inform and inspire people with dementia, their relatives and everyone else with an interest by providing examples of ways people with dementia can enjoy nature. The book covers a huge variety of topics and each chapter follows a different theme, from farming groups to spiritual care. It also covers projects out there at the moment, including the ‘Forget Me Not Centre’ and the ‘AlzheimUr CENTRE’.

The contributors to each chapter were deliberately chosen on the basis they had not written about this topic before, or indeed had not written at all. Interestingly, this included people with dementia. Due to the different backgrounds of the contributors, each chapter is written in a different style; some more informative, some more anecdotal. This means that some chapters may reach out to people yet others may offer no interest at all.

My favourite chapter was ‘no roof but the sky above my head’ by James Mckillop. This is an inspiring account about how being re-introduced to the outside community after being diagnosed with dementia improved James’ quality of life. The opportunity to engage with people again in the fresh air improved both James’ confidence and his mood. James honestly tells the reader how he did experience problems when he first gained the confidence to venture outside after his diagnosis, yet the rewards of personally experiencing the changing seasons and the joys the outside world brought made him determined to overcome these problems. He says there is ‘no charge (as yet) to step outside, breathe in and savour life’s tapestries’-

a message all readers, whether they have dementia or not, should listen to.

Overall this book successfully informed me about the array of different day centres and activities available that use aspects of nature to help those with dementia. Due to the variety of topics and writing styles in this book, I believe it has the potential to appeal to most people. Also, by using both professional and client opinions, it provides a strong argument for the innate need in human beings to remain in contact with nature. However, the wide mix of topics and writing styles meant the book did not flow for me as a whole. It is a handy book where you can pick out a particular chapter of interest, for example how people with dementia can enjoy gardening, yet as a whole book it felt a little disjointed. This is a book you would dip in and out of rather than read in one go.

**Rebecca Pearce**

A psychology undergraduate at Cardiff University undertaking a placement year with Cardiff and Vale Mental Health Services for Older People.

Understanding Care Homes...

### *Understanding Care Homes: A Research and Development Perspective*

**Authors:** Katherine Froggatt, Sue Davies & Julienne Meyer

**Publisher:** Jessica Kingsley Publishers

**ISBN:** 978 1 84310 553 5

**Price:** £19.99

*Understanding Care Homes: A Research and Development Perspective* presents a collection of recent research and developmental work within the older-persons' care home sector. This refreshing and non-biased book challenges the unhelpful and negative portrayal of care homes depicted by the media. It is a practically-sized paperback presenting examples of good practice, with each chapter guiding the reader through a broad range of research methods, interventions and developmental suggestions contributed by experts in this field.

The editors, Froggatt, Davies & Mayer, have chosen to focus on recent research and developmental progress that includes collaborative approaches to care, both within homes and external health and social care services. Divided into 3 sections, the first focuses on individual residents, person-centred approaches and how to improve care. The second section looks at the role of family, friends and staff, and includes an intriguing chapter on the role of the natural environment within care settings. The third section explores partnership-working between care homes.

This book will be valued by any professional wishing to perform research in an older-adult care home. It will help to prepare them for the unexpected problems they will certainly encounter upon entering such an intimate and private environment. A chapter by Jan Dewing explores the fascinating concept of "cultures" that develop within a home, the need for a researcher to understand them and the challenge of working within them in a non-biased way. Equally, home managers and health and social care staff would gain valuable pointers for evidence-based interventions when working with older adults (including those suffering dementia and with learning disabilities), the challenges of setting up "friends of care home groups" and networking between homes. Although a familiarity with research methods and health and social care terminology would aid the reader, all processes used by the contributors are explained plainly. This makes *Understanding Care Homes: A Research and Developmental Perspective* accessible to anyone with an interest in the sector.

I could not help but be moved by Wilson, Cook and Forte's chapter that explores some of the narratives of older adults. Snippets of stories told by older adults include issues surrounding their struggles to deal with the change in lifestyle that moving into a care home involves, being aware of their own cognitive decline and the need to develop meaningful relationships with residents and staff members. As a support worker in a home, I found that the book honestly and explicitly addresses some institutional boundaries to researching within this sector; for instance, the strong tendency for staff to engage in "gate-keeping" activities, whereby the instinct to protect the older adults is more pertinent than the need to share working practices with a researcher. I was also delighted that the editors acknowledge the obvious gap in research regarding the needs of the staff within a home and of any carers or family members.

The book is engaging and easy to navigate. The reader can dip in and extract required information easily. *Understanding Care Homes: A Research and Development Perspective* successfully contributes to and expands upon the current push for high standards of quality care for those in older-adult care homes.

**Annie Oliver**

Support Worker

## 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.*

## Age UK Mobile Phone

As technology becomes increasingly advanced, many mobile phones offer a dazzling array of features and apps. Yet to some older people, particularly those with dementia, these may prove unnecessarily complicated and confusing. Age UK has launched a mobile phone to address this issue. After filling in a form, the personalised phone arrives pre-programmed with useful numbers and clear, uncluttered features. Up to eight numbers can be stored and dialled at the touch of a button.

The phone costs £55.00 and comes with one of three non-contract price plans.

http://www.ageuk.org.uk/products/communications/mobile-phones

## News and Web

**Alzheimer's Society Dementia Friends initiative** went live on the 12th February. The scheme aims to improve public understanding of the condition and illustrate the small things that people could do to make a difference in their community.

Dementia Friends is a key part of the Prime Minister's 'Challenge on dementia' which aims to create dementia friendly communities across the UK. In addition to encouraging people to sign up as Dementia Friends, the Alzheimer's Society is also inviting people to volunteer as a Dementia Friends Champion. These will support and train Dementia Friends, while attending training courses themselves and receiving on-going support.

www.dementiafriends.org.uk

**Admission of people with dementia to care homes drastically increases the prescription of antipsychotic drugs** from 1.1% to 20.3%. The study, conducted by researchers from Queen's University Belfast gathered information from over 250,000 people over the age of 65.

The study was unable to determine the appropriateness of the prescriptions – it is possible that people moved into care due to greater mental health problems. However, lead researcher Aideen Maguire claims 'there is probably inappropriate prescribing going in'. Similar studies have shown high levels of antipsychotic drug prescribing in Britain for elderly people in care homes.

The Medicines and Healthcare Products Regulatory Agency (MHRA) states that antipsychotics are not appropriate for most people with dementia.

www.bbc.co.uk/news/uk-northern-ireland-21524108

**A forward thinking community in Bruges** demonstrates how cities can adapt to assist and support people with dementia: www.bbc.co.uk/news/health-21516365

***The following websites provide further information on topics featured in several of this issue's articles:***

### Choirs

Alzheimer's Society information about Singing for the Brain, including details of local choirs and a short video clip: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=760

BBC documentary about a Singing for the Brain project, broadcast in 2009 but still available to watch online: www.bbc.co.uk/programmes/b00pdv0w

### Carers Support Groups

Dementia Support Group contains a forum for discussion, links and interesting film clips such as a Urdu Educational Video: www.dementiasupportgroup.com

Crossroads www.crossroadscaring.com are a nationwide charity providing support to carers, while the branch Crossroads Care in the Vale http://www.crossroads-vale.org.uk provide specific support for carers of people with dementia. Although their support and social groups are only provided to local residents, their informative website includes news stories and a free newsletter.

### Palliative Care in Dementia

Alzheimer's Society provide a detailed fact sheet about end of life care: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=428

The National Council of Palliative Care is an umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. The website contains an online library and free download of documents including those on issues surrounding palliative care and dementia: http://www.ncpc.org.uk

# Information About Signpost

**Anyone Can Contribute to Signpost**

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

**Contributions**

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

**Contact Details**

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

**Tel:** 02920 715787

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

## Books Available for Review:

*Helping grieving people - when tears are not enough (2nd edition)*. J.Shep Jeffreys.

*Comforting Touch in Dementia and End of Life Care*. Barbara Goldschmidt and Niamh van Meines.

*Counselling Older People with Alcohol Problems*. Mike Fox and Lesley Wilson.

*Involving Senior Citizens in Group Music Therapy*. Joseph Pinson.

*How we treat the sick*. Michael Mandelstam.

## 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.

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**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.

**Melanie Jeffries** is a Dementia Care Advisor working within Mental Health Services for Older People in Cardiff and the Vale of Glamorgan.

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

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