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# SIGNPOST

Journal of Dementia and Mental Health Care of Older People

**Let's keep talking  
about dementia**

**Building on dementia awareness week  
2016**



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**Cover picture: Designed by Matthew Lewis  
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As I write the sun is shining in Cardiff, and I'm delighted to warmly welcome you

to the spring edition of *Signpost*. You will likely be reading this in, or around, dementia awareness week (15<sup>th</sup> - 21<sup>st</sup> May). This year the focus is on dispelling myths associated with dementia, and encouraging people to talk about dementia. It is a fantastic annual opportunity for us to promote awareness. Locally we have a range of activities planned including: an art exhibition about memory which features some fantastic pieces produced by people with dementia, an information stand in the hospital, and *Dementia Friends* sessions open to the community. Here at *Signpost* we would be interested to hear about any awareness activities that you are involved in.

My name is Natalie Elliott and I am a Senior Specialist Speech and Language Therapist based at Cardiff & Vale University Health Boards Memory Team. As it stands I am the only Speech and Language Therapist (SLT) attached to a Memory Service in Wales but, I'm hopeful that with the increasing heat on improving diagnosis rates and recognition of the importance of quality post-diagnostic care for people living with dementia and their loved ones, that the numbers of SLTs having designated

and specialist roles in this field will increase, and perhaps one day match other long-term conditions such as stroke.

The Royal College of Speech & Language Therapists (RCSLT) have identified that too few people understand the vital role of SLTs in the diagnosis and care of people with dementia, and they have made dementia their top priority with a campaign which highlights that SLTs:

- Are well placed to work with individuals and family to analyse the specific nature of any communication changes of persons with suspected or actual dementia to inform differential and timely diagnosis as well as management.
- Are able to assist by slowing the decline or reducing the impact of any communication impairments. Improved communication can help with behaviour, social skills, interpersonal relationships and self-confidence.
- Are uniquely qualified to assess an individual's ability to understand and to communicate that understanding to optimise a person's choice, degree of control, capacity to consent to treatment/care, and advanced decision making.
- Play an important role in the assessment and management of eating, drinking and swallowing problems (dysphagia) to prevent malnutrition and dehydration, and reduce the risk of repeated chest infections, pneumonia and choking.

RCSLT is calling on GPs, commissioners, budget holders and care providers to:

- Recognise the communication and eating, drinking and swallowing needs of people with dementia.
- Ensure people with dementia have access to the speech and language therapy services they need in hospitals, care homes and in their own homes.
- Set the highest standards for the education and training of health professionals, residential and home care staff to understand the communication difficulties experienced by people with dementia and their carers, and to ensure they have the professional speech and language therapy support they need.
- Provide education, support and training for health professionals, care home and agency staff to identify the early signs of eating, drinking and swallowing difficulties, and meet the nutritional needs of people with dementia.



To find out more about the campaign and the resources available visit: <http://givingvoiceuk.org/dementia>

Communication is an integral part of our world, it's how we: make requests, share opinion, consider decisions, tell stories, demonstrate our personalities etc.. I'm therefore not surprised that throughout this edition of *Signpost* all our authors, to some degree, make reference to the importance of communication.

We begin with an article that considers the so-

cial model of disability and it's applicability to dementia. Milligan and Thomas put forward how social, emotional and physical barriers at individual and collective level can be experienced. Empowerment is a key element "*their voices, however expressed, should be heard and facilitated.*" We are encouraged to step outside the medical model and to look more closely at the everyday experiences and perspectives of people with dementia as they interact with their environment.

Congratulations to Gwynedd and Môn Memory Clinic who have been accredited as excellent by the Royal College of Psychiatrists Memory Services National Accreditation Programme (MSNAP). I'm sure you will feel inspired when reading their piece about the process of accreditation and, the positive developments participation became a catalyst for. No doubt other Health Boards will be encouraged to follow suit.

My personal experience of undergraduate training highlighted the value of clinical placements within the university. This offers students an excellent opportunity to learn in an environment that can feel a little more protected and controlled than placement educators are able to offer in the NHS. It is good to see that Cardiff MET is now able to offer this experience, in addition to external placements. I am looking forward to working with the university team to explore how we can incorporate dementia care into these new SLT clinics. The clinical simulation suite is also a fantastic innovation; I've seen it first hand and was extremely impressed by how realistic it is. We can easily forget how

daunting it can be to come into a hospital environment for the first time. A simulation suite is an excellent way of providing students with the opportunity to grow accustomed to working on a ward.

Our final article introduces us to a psychological intervention known as START (STrategies for RelaTives). The authors provide an overview of the project and how, after following a trial to examine the effectiveness of the programme, they are delivering *Train the Trainer* workshops as part of a dissemination project supported by Dementia UK and FPOP. We are provided with a link to the START website – I recommend that you take a look and download the free resources which I hope help you get started!

Happy reading...

**Dr Natalie Elliott**

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**For those wishing to contribute to *Signpost*, either with an article or by reviewing one of the available books. Please contact either:**

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Christine Milligan is Professor of Health and Social Geography and Director for the Centre for Ageing Research at Lancaster University. Christine is a social scientist with an international reputation for her work around care, home and ageing. She has a particular interest in non-medical interventions designed to improve the quality of life and wellbeing of people living with dementia and their families at home and in community-based settings. She is currently working with local theatres and arts organisations in the development of dementia friendly spaces. She is also leading the evaluation of an NHS Testbed initiative focusing on frail older people with multiple chronic conditions (including dementia) in two Vanguard sites in the north west of England. Christine has over a hundred publications in books, refereed international journal, and book chapters and is an editor of the *International Journal of Health and Place*.



Carol Thomas is Professor of Sociology at Lancaster University, based in the Faculty of Health and Medicine. She is best known for her publications in Disability Studies, including her books : *Female Forms: Experiencing and Understanding Disability* (Buckingham: Open University Press 1997), and *Sociologies of Disability and Illness. Contested Ideas in Disability Studies and Medical Sociology* (Basingstoke: Palgrave Macmillan. 2007). She

has also researched and published widely on patients' and carers' experiences is living and dying with cancer, and has developed an interest in illness narratives. Publications on narrative analysis have followed, most notably: *Negotiating the contested terrain of narrative methods in illness contexts. Sociology of Health and Illness* 32 (4): 647-660, 2010). Carol is a founding member of the Centre for Disability Research (CeDR) at Lancaster University.

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**Dementia and the social model of disability: does responsibility to adjust lie with society rather than people with dementia?**

In the Winter 2015-16 volume of this journal, Philly Hare set out the Joseph Rowntree Foundation's (JRF) vision for a future in which the UK became a good place for people with a diagnosis of dementia to live. In her words, the JRF wanted to, "ensure that people living with dementia are more understood, more heard, more included, more connected and more supported" (p. 9). Part of the drive toward this goal was to think about how we might change society's thinking and attitudes toward dementia and what an inclusive UK society in the context of dementia actually means. One outcome of this goal was the commissioning of a 'think piece' by the authors of this article about how we might draw on the well-established social model of disability to develop this thinking (REF). We discuss the key elements of this think-piece in this article, but it is worth noting that this was paralleled by companion paper written by Toby Williamson (Mental Health Foundation, 2015), designed to encourage new thinking and debate about dementia as a human rights issue.

**What is the social model of disability?**

Before applying the social model of disability

to dementia, we need to look at what this model is, and where it has come from. The social model of disability was first coined by the disabled activist and writer, Mike Oliver in the early 1980s in his attempt to capture novel ideas about disability, developed by disabled people themselves in the previous decade (Oliver, 1983). At its core was the view that disabled people were socially disadvantaged - not so much by their impairments - but by the negative responses of those deemed to be non-disabled. Oliver and his contemporaries thus drew attention to a form of social relationship between disabled and non-disabled people predicated on social inequality. This relationship makes its presence felt in a number of ways: in interactions between individuals; through rules and practices in social institutions (such as schools and hospitals); and in the disabling structure of the physical environment including buildings, systems of travel and so forth. This perspective contrasted markedly with the dominant biomedical view of the time: that being impaired is an abnormality that causes major problems and limitations in the lives of 'the disabled'. It also takes issue with assumptions that disabled people should be pitied because it is their damaged bodies and minds that stop them participating in 'normal' activities.

Instead, the social model of disability drew attention to the social and physical barriers erected by non-disabled people in all social arenas and captured the idea that people with physical impairments are a socially oppressed group in modern societies. Before long, those with impairments beyond the straightforwardly physical began to question their apparent exclusion from this initial formulation of the model. In the 1980s and 1990s, the case was made – and won – that people who live with sensory or intel-

lectual/cognitive impairments (principally learning difficulty) are also disabled people in that they too experience similar forms of exclusion and social barriers (Barnes, 2012). Who counts as disabled was further widened in the 1990s and 2000s to include people with chronic illnesses and mental health problems (e.g. Walmsley, 1991; Beresford, 2002). Hence, the social model of disability can be seen to apply to a growing proportion of the population with lifelong, acquired or attributed impairments. In 2004, Oliver clarified his original thinking, stating:

*...the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, mental or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television, and newspapers. (Oliver, 2004 p.21).*

Because of its conceptual simplicity, the social model of disability became a banner headline for the Disabled People's Movement in the UK. Indeed, from the 1980s onwards, it has proven an extremely effective tool in campaigns for disability rights (Campbell and Oliver, 1996). Legislative achievements of particular note include the Disability Discrimination Acts (1995, 2005), the report by the last Labour Government *Improving the Life Chances of Disabled People* (Cabinet Office, 2004), and the introduction of financial arrangements de-

signed to facilitate independent living in the 1990s – namely direct payments and personal budgets (Pearson, 2012). Evidence for the significance of these developments is clearly articulated in pronouncements by the Equality and Human Rights Commission (EHRC), which laid innovative conceptual foundations for the 2010 Equality Act and the follow-up Equality Duty, now in force in England, Scotland and Wales.

Given this background and history, it is unsurprising that a small, but growing, number of researchers and activists should begin to think about how the social model of disability might also apply to people with dementia. Here, the impairments and impairment effects associated with dementia are viewed as foundations upon which social barriers are erected by non-disabled people – whether purposively, or from lack of understanding and knowledge. Adopting the social model of disability has encouraged researchers to look more closely at the everyday experiences and perspectives of people with dementia (Proctor, 2001; Blackman *et al.*, 2003; Dorenlot, 2005; Beattie *et al.*, 2005; Davis *et al.*, 2009; Brittain *et al.*, 2010; Boyle, 2014). What is disappointing, however, is not only the relatively small number of researchers that have taken this approach, but the peripheral nature of their work within disability studies. The latter perhaps arises from two weaknesses of note in disability studies in the last 40 years: firstly, the tendency to ignore or sideline older people and their particular social interests (Priestley, 2003); and secondly, the failure to understand and take account of the needs and interests of younger people (under 65 years old) with dementia. This has been compounded by the tendency of many gerontologists, psychologists and social scientists to view de-

mentia through a largely biomedical lens until relatively recently.

There are however a few key researchers who have adopted more radical perspectives that have been influential in shaping our thinking about dementia. Tom Kitwood's (1997) ideas about personhood, for example, insist that we look at, and recognize, '*the person with dementia*' and not focus on 'the person with dementia'. This kind of approach asserts that while we cannot escape the fact that an individual has dementia, and that this will impact on how they act and respond to people and things and on what they can and cannot do, the individual is not *defined* by having dementia. In other words, Kitwood's concept of personhood reminds us that people with dementia are still thinking and feeling individuals, who have different identities, personal histories, experiences, likes and dislikes. This emphasizes the need to respect, value and celebrate what individuals *can* do rather than define them by their dementia; doing the latter simply reinforces the medicalization of that individual, relegating them to 'demented body' status.

Those commentators who *have* applied the social model of disability to dementia have identified both the presence and operation of social barriers in the lives of people living with dementia (e.g. Blackman *et al.*, 2003; Dorenlot, 2005; Beattie *et al.*, 2005; Davis *et al.*, 2009; Brittain *et al.*, 2010). There are many different forms of dementia with impairment effects that manifest in different ways for different people. This means that, especially in the early, middle or late stages of dementia, the social barriers in evidence vary in the profundity of their disabling consequences. Put another way, impairment effects and disablism interact, with

differential outcomes.

In Table 1 we set out some examples of social barriers that can be experienced by people with dementia, whilst in Table 2 we provide examples of barriers that can become embedded in institutional and collective practices:

**Table 1: Individual attitudinal and behavioural barriers:**

- lack of understanding of the impairment effects that come with the stages of dementia on the part of non-disabled people (e.g. formal and informal carers, family members, general public, young people);
- lack of sympathy and tolerance on the part of some non-disabled people;
- failure to recognise the practical difficulties faced by people with dementia (e.g. difficulty recognising places and people, way-finding, locating items) – especially in middle and late stages of dementia;
- failure to understand how easy it is for anxiety, fear and uncertainty to take hold in the minds of people with dementia, e.g. in unfamiliar surroundings and settings;
- failure to find ways to communicate with people with dementia, especially where spoken language is minimal or absent;
- failure to recognise and respond to the non-verbal ways that people with dementia use to try to communicate;
- misrecognition and misunderstanding of behaviours and expressions displayed by people with dementia – e.g. these may be wrongly attributed, in an ageist fashion, to ‘just being old’;
- treating people with dementia as passive and dependent. Failing to ask what they want, how they feel, what would help to improve things in their lives etc.
- cruelty, violence and abuse directed at people with dementia;
- lack of respect, dignity and compassion – at all life stages, including during end of life care.

**Table 2: Barriers that become embedded in institutional and collective practices:**

- failure to design or adapt items, interiors, buildings, and external environments like streets and gardens, to support people with dementia enabling them to remain active, engaged and comfortable. This requires consultation with users, careful planning, flexibility and the creative use of technology;
- denial of choice, self-determination and citizenship rights (e.g. around
- failure to help get an early diagnosis of dementia because of the social stigma and fear attached to it;
- weaknesses and failures in medical treatments (e.g. inappropriate use of neuroleptic drugs), poor health and social care systems – statutory and voluntary;
- failure by some services to support the needs of family and other informal carers of people with dementia;
- stigmatising and degrading images and representations of people with dementia in the media and wider culture (newspapers, film, television, theatre, art, literature etc);
- inadequate or absent state legislation and official policies in the interests of people with dementia.
- food, expressions of sexuality, lifestyle.

A further hallmark of the social model of disability is that that disabled people should have every opportunity to be self-determining (Campbell and Oliver, 1996). This means that their voices, however expressed, should be heard and facilitated. The empowerment and involvement of people living with dementia in determining their own life circumstances and choices should be paramount, and advocacy should respect this starting point. It follows that despite the many challenges presented by dementia and its impairment effects, non-disabled people need to find innovative and imaginative ways to make rights a reality for people

with dementia (see for example Mental Health Foundation, 2015).

### **Adding theoretical weight to the social model perspective**

Applying the social model of disability to dementia has certainly been an innovative and informative move, but there are inevitable limitations, because the social model is not a *theory* of disability. Mike Oliver and other leading proponents of the social model (e.g. Finkelstein, 2001) have made this point repeatedly. So, while the social model of disability serves as a powerful banner headline for campaigns and as an effective framework for identifying social barriers, it does not theorise disability. So whilst it is an effective starting point, it lacks the explanatory power of theory. That is, we need to be able to explain *why* social barriers come into existence in the lives of people who have types of impairment – including dementia.

#### *Disablism*

In essence, then, the key question is: Why is it that the social relationship between people with and without impairments is one that involves the social oppression of the former by the latter? This is a very difficult question to answer – as are the parallel questions in older branches of equality and diversity studies: why does sexism exist? Why racism? Why homophobia? These observations suggest that the study of dementia and disability require us to pay attention to some of the theoretical work underway within disability studies. At this point, it is perhaps useful to introduce and define the concept of *disablism* – because this attempts to capture the social relationship that underpins social barriers. Following Thomas (2010, p.37) disablism:

*refers to the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorised as 'impaired' by those deemed 'normal'. Disablism is social-relational in character and constitutes a form of social oppression in contemporary society... As well as being enacted in person-to-person interactions, disablism may manifest itself in institutionalised and other socio-structural forms.*

The interaction of disablism and ageism is of particular relevance to our discussion. For example, impairment effects in early stage dementia often include short-term memory loss and difficulty making decisions, but these can also be attributed to 'just being old' in a society imbued with ageist attitudes. For many people with dementia there is a twofold discrimination underway – one of ageism and one of disablist stigma attached to behaviours that appear to signal mental illness. An older person is often stereotyped and reduced to an ageing body that is devoid of sex, gender, class, cultural knowledge etc., and this can be reinforced by staff practices and the interior design and layout of institutions such as hospitals and residential care settings. How many care homes have double rooms to enable a husband and wife to live together? Are same-sex couples even on the radar? Further, with the exception of the very few faith-based care homes in the UK, cultural needs are largely ignored because the focus is on *body care*.

For those with dementia who may be less able to vocalise their preferences, needs and desires, *others* often make decisions on behalf of the person with dementia. In doing so, they often fail to consider the former's person-centred needs. Gilleard *et al.*,

(2005) however, maintain that taking a social model approach to dementia means that those around people with dementia should review the impact that they, as 'non-demented' people, have on others; reconsider the value of hearing and responding to personal experience; and focus on abilities rather than losses.

### *Insights from Materialism and poststructuralism*

Writers and researchers in the disability field have turned to a variety of social theories to try to find answers to questions about the existence of disablism. As in any other field, different theoretical perspectives provide contrasting explanations of disablism. We summarise the two overarching theoretical frameworks in use in disability studies below:

1) Materialist scholars theorise disability and disablism as outcomes of the way basic activities are organised in society – especially, but not exclusively, economic activities. Here, the roots of social marginalisation and spatial segregation of people with impairments are viewed as being located in the historical development of capitalist production and exchange. These developments gave rise to social relationships between 'the normal' and 'the impaired' that systematically disadvantaged and disempowered the latter. This laid the foundations for medicalised systems of 'treatment and care' that subjected disabled people to professional control and enforced dependency, first in institutional regimes and later in systems of 'community care'. These perspectives have led to a great deal of research around the social exclusion of disabled people in all social arenas in the contemporary era.

2) *Theories based on ideas about phenomena (idealism) came to prominence in disability*

*studies following what is known as the cultural turn in the social sciences in the 1980s more generally. The ideas of the social philosopher Foucault and feminist variants have been particularly influential (see Corker and Shakespeare, 2002; Tremain, 2005). Here, the cultural, the discursive, and the linguistic have assumed pre-eminence in post-structuralist theorisations of disability and impairment. Materialist perspectives are dismissed as modernist systems of thought that are infused with conceptual dualisms: abnormal/normal, disabled/non-disabled. Unpicking this type of dualist thinking comes to the forefront. Many critiques of the social model of disability are raised, with a key critique focusing on what commentators see as the model's impairment/disability distinction. This, they argue, merely replicates the problematic biology/society dualism. Poststructuralists have interrogated the category 'impairment', and set about exposing what they see as its entirely socially constructed character.*

If we apply these two key theoretical perspectives to the relationship between people with dementia and non-demented members of society (i.e. between the disabled and non-disabled), we arrive at contrasting explanations of the disabling and social barriers that exist in the lives of people with dementia.

In sum, materialist perspectives would highlight how capitalist economies have no use for the cognitively impaired, especially if they are old. This is because social value is closely tied to the ability to work for wages/salaries (now or in the future); particularly being able to fit into economic roles that generate profit. People who cannot work are therefore (in crude terms): excluded from the mainstream; warehoused; kept alive using minimal social resources;

placed under the 'legitimate' control of doctors and 'carers'; kept out of the way of essential social activities etc. From this perspective, the category 'older people with dementia' is seen to combine two disadvantaged groups in capitalist economies – the cognitively impaired and the old. This means that old people with dementia are especially vulnerable to disablism.

Poststructuralist perspectives, however, highlight the cultural meanings that attach to particular body types and behaviours. The bodies and behaviours of people with dementia carry negative cultural meanings in our society – a society that values youth, beauty and celebrity. The negative meanings associated with having dementia, especially in its middle and late stages, include 'abnormal', 'undesirable', 'bizarre' – and even 'disgusting'. These cultural meanings stem from systems of knowledge ('discourses') that become authoritative in society. Such authoritative systems of knowledge are those that are specialist and influential, and these in turn give social power to those that possess the knowledge. In recent centuries, the institutions and groups that have maintained or acquired social power via their specialist knowledge include: dominant establishment faiths and churches, judiciary, state officials, scientists, and the medical profession. In matters of impairment and disease, it is members of the latter group who hold power; their specialist scientific knowledge about dementia and other conditions allows them to define and treat abnormalities of body and mind, and to oversee regimens of treatment and 'care'. Medical ideas then shape thinking in other cultural institutions (e.g. the media) and inform knowledge in the wider society. As a consequence, everyone starts to share and elaborate ideas about

what it means to be 'demented' 'mentally abnormal', 'mad', and 'a danger to themselves and others'. The proliferation of these stereotypes acts to justify institutionalizing people, controlling 'difficult behaviours' through medical or pharmaceutical solutions and ignoring what those with dementia say.

So if we look again at the social barriers discussed above, we can see that explanations for the existence of these barriers vary, depending on the theoretical stance taken. Perhaps of greater significance for this article are the consequences that follow if we begin to think through how we might dismantle the barriers. From a materialist stance, change would need to begin in the economic realm. Transformations would then follow in other societal domains. From a post-structural perspective, however, change needs to begin in the cultural realm, i.e. in the realm of ideas and knowledge. Changes are then likely to follow on in other societal domains.

#### *Dementia, intersectionality and psycho-emotional disablism*

Two further concepts, intersectionality and psycho-emotional disablism, are worth discussing in relation to contemporary thinking within disability studies. We introduce these ideas because they are particularly helpful in thinking through the social features of living with dementia.

Intersectionality highlights the overlapping parts of our identities, for example, gender, ethnicity, sexuality, age and social class (e.g. Stienestra, 2012; Walby et al, 2012). This is important because it reminds us that people are not homogenous and cannot simply be grouped together by a single characteristic, such as disability or age. When looking at individuals' biographies, it is important

to take account of how issues of social and cultural diversity, multiple inequality and other characteristics interact to shape people's life chances and capacities to resist disadvantage and social oppression. For example, if you have middle stage dementia and are female, old and 'poor' you may be more vulnerable to aspects of disablism *and* other faces of oppression (sexism, ageism etc.) than if you have middle stage dementia but are male, under 65 years old and from a professional background. Those from more affluent backgrounds are more likely to have access to resources that can protect a person with dementia from some of the social barriers listed above. While there is nothing certain or automatic about this at the level of the individual, there will be social patterns associated with intersectionality that connect with degrees of vulnerability to disablism social barriers at early, middle and late stages of dementia.

#### *Psycho-emotional disablism*

Another useful theoretical concept for helping us to understand *some* of the social barriers that confront people with dementia is psycho-emotional disablism (Thomas, 1999). This concerns the intended or unintended hurtful words, behaviours and social actions or practices of non-disabled people in their inter-personal engagements with people with dementia. There are several examples of psycho-emotional disablism listed in Table 1 above; one example relates to lack of sympathy and tolerance on the part of some non-disabled people.

The presence of psycho-emotional disablism means that in addition to coping with the impairment effects that dementia brings, people living with the condition may have to put up with insulting behavior and emotional damage inflicted by non-

disabled people. This form of disablism works along psychological and emotional pathways and can impact negatively on self-esteem, personal confidence, and sense of security. Indeed, disabled people can be made to feel worthless, useless, of lesser value, ugly and burdensome (Reeve, 2002, 2006). Psycho-emotional disablism can thus place further limits on who people can be by shaping an individual's sense of 'self' and social behaviours. Moreover, impairments may themselves be affected in problematic ways by the impact of psycho-emotional disablism. For example, a mother whose early stage dementia causes her to be forgetful may have this trait worsened by an adult son or daughter who displays frustration and keeps complaining about his/her mother's loss of memory.

#### **Policy and Place**

There is currently significant interest in dementia in both the UK. Indeed, the costs of caring for an ageing population with 'high support needs' ~~is~~ *large* in the minds of governments and policy-makers not just nationally, but internationally. We do not have the space here to critically review the significant raft of reports on services and strategy published in recent years, but it is informative to look at one authoritative document published in 2012: the World Health Organization's report *Dementia: A Public Health Priority*. This global report, one that is likely to have a significant impact on governments and policy-makers *internationally*, flags up the projected patterns of ageing and dementia across the world:

*Prevalence and incidence projections indicate that the number of people with dementia will continue to grow, particularly among the old-*

est old, and countries in demographic transition will experience the greatest growth. The total number of people with dementia worldwide in 2010 is estimated at 35.6 million and is projected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds. (WHO 2012: 2)

It is worthy of note that this report makes only passing reference to recognising the rights of people with dementia, and of working to maintain their independence, dignity, identity and personhood. Rather, the report frames dementia – and by implication those living with dementia – as a social, economic and health burden on society. Passing reference is certainly made to addressing widespread fear of dementia, to the stigma attached to dementia, and to the need to develop a ‘dementia friendly society’ – but there is little said about how this might be actively achieved. Hope is raised when reference is made to the relevance of the United Nations Convention on the Rights of People with Disabilities (CRPD, 2006) but, overall, the report takes a medicalised approach to dementia that is couched in terms of disease burden, treatment, risk, service provision and the needs of carers. From a disability rights perspective, the report leaves the reader with a disappointing sense of *déjà vu*.

### **Dementia in place**

As we have noted, adapting the social model of disability and anti-disablist thinking to people with dementia requires us to consider not just the social and institutional disadvantage that those with dementia can experience, but also the ways in which this

is played out through the everyday places they inhabit.

Those with dementia can lose their sense of time and space, making formerly familiar places unfamiliar and frightening, for example wandering through known streets at night. A standard institutionalised response to these impairment effects is to view them as ‘risky behaviours’, the ‘treatment’ for which is confinement to the home or a residential setting unless accompanied by a ‘responsible adult’. Of course, it would be dangerous to place vulnerable people in potentially harmful situations, but an anti-discriminatory perspective points instead to the need to develop accepting communities (Beresford *et al.*, 2011). This challenge has more recently been taken up through the Dementia Friendly Communities initiative – spearheaded by the Alzheimer’s Society and the Joseph Rowntree Foundation in 2012. This initiative is designed to work collaboratively with people with dementia and key partners to improve inclusion and quality of life for those living with dementia. A key vision of this strategy is that it will support the development of *enabling* environments, so people within these communities will better understand, and be supportive of, people with dementia. The overall aim is to enhance inclusion and ~~facilitate~~ the ability of those with dementia to achieve greater independence, choice and control over their lives.

This approach was originally developed to counter the exclusion of people stigmatised by poor mental health. This not only required us to develop a greater understanding of the relationship between the individual and the wider community, but also required us to think about how society judges the value of individuals and responds to

mental ill-health. It means we need to think about how 'risk' should be defined, and what is meant and understood by the participation and empowerment of individuals within a community. Understanding and valuing difference can only be resolved through the engagement of all involved.

With regard to dementia, these practices are based not just on a wider understanding of the changing behaviour patterns that occur with dementia but on developing caring communities that are supportive and accepting of social difference. For example, knowing that 'Mrs Smith' has dementia and may be confused about time and space means that we recognise the challenges she faces and watch out for her, rather than viewing her behaviour as somehow deviant or abnormal and her family as somehow failing in their duty to care. Moreover, it means working out ways of helping her to avoid potential dangers, or recognising that she may need support getting to where she wants to go.

Developments in technology – such as personalised tracking devices - may enable people with dementia and their carers to identify 'safe spaces' within the community. A feeling of safety in particular places allows a person with dementia to move around comfortably, enabling them to retain a sense of independence that may otherwise be denied (Milligan, 2009). Critically, however, these technologies rely on local networks of support to be effective (Roberts *et al.*, 2012). In other words, they rely on having local family or members of the community who are willing and able to respond when an alarm is triggered. So an accepting community becomes one that recognises the challenges and is willing to support this kind of innovation.

Where care and support for people with dementia takes place, and the nature of those places, is also important. The short-term memory loss associated with dementia means that new and unfamiliar places can add to the confusion already experienced by a person with dementia. Research has already demonstrated that respite care in residential settings can be problematic in this respect. Supporting those with dementia to stay within their own homes for as long as possible is key to helping them to maintain a sense of self and identity. The presence of familiar objects within the home – private possessions, photographs and so on – represents what Augè (1995) referred to as 'anthropological space', where the long-term memory provides a sense of safety; familiar visual cues can help the individual with dementia to more successfully negotiate that space, so extending their ability to self-help (Milligan, 2003). As a visual manifestation of a person's identity and personhood, the home places limits on the extent to which an individual can be objectified and de-personalised – something that often happens in collective institutional settings.

### **Concluding Comments**

We have aimed in this article to illustrate how applying the social model of disability to dementia can provide some important insights and observations that might help us rethink our approach to dementia. Light is also thrown on the way that disablism overlaps with ageism in society, and on how space and place acquire special relevance. Attention has also been drawn to how different theoretical perspectives can be drawn upon to help *explain* the social barriers highlighted by the social model of disability and how this has rele-

vance for understanding the exclusionary physical, social and emotional barriers experienced by people with dementia. Our paper sets out approaches to dementia that are at odds with conventional thinking in official and medical circles. We hope that this will stimulate debate about new ways forward in both understanding and meeting the needs of the growing number of people living with dementia.

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## Undertaking the MSNAP....



Karen Wood is an Occupational Therapist working in Gwynedd and Môn Memory Clinic based in Bangor.

She has worked in the Memory Clinic since it began in 2000 and previously worked in the wider Memory Service in Ysbyty Gwynedd.

Prior to qualifying as an Occupational Therapist, Karen worked in a variety of research and 3<sup>rd</sup> sector posts in the field of learning disability.

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### **Gwynedd and Môn Memory Clinic Betsi Cadwaladr University Health Board Memory Services National Accreditation Programme**

For the past 2 years the multi disciplinary team of Gwynedd & Môn Memory Clinic have been working towards the Royal College of Psychiatrists' accreditation – MSNAP (Memory Services National Accreditation Programme). As one of the original staff members of the Memory Clinic and only Occupational Therapist on the team I was privileged to be nominated to lead the accreditation process for our service.

We have now successfully achieved this and were accredited as “excellent”, the award categories being “not accredited”, “accredited” “accredited as excellent”, at the beginning of

May 2015. The two other Memory Assessment Services in Betsi Cadwaladr University, Central and East sectors were also successful in gaining accreditation, achieving high standards, resulting in the three teams being the first in Wales to achieve accreditation.

The accreditation process was long and, at times, very stressful. The team had been preparing for the process for around 18 months and the 3 Memory Services were able to collaborate through monthly meetings to support each other in working towards meeting as many of the designated standards as we could.

This included collecting evidence about all our procedures from how the service is administered to client and caregiver contact and the whole assessment, diagnostic and post diagnostic process. Much of this work was done outside of work hours so that disruption to clinical time was minimal.

We had to carry out all the audits required, for example on the availability and outcomes of psychosocial interventions, use and monitoring of medication and we reviewed all information given to clients and referring agents to make sure they were relevant and user friendly.

There was a 3 month period to complete this work and to provide further evidence using the Royal College's casenote audit and their questionnaires for referrers (mainly GPs), clients and caregivers along with a staff questionnaire. The questionnaires were anonymous and returned straight to the Royal College rather than to us. They were designed to give collateral information to supplement evidence

Once the evidence was submitted, the MSNAP team recruited a team of 4 reviewers (including members of memory services in England and a caregiver) who then spent a day with us interviewing the Memory Service team members

and manager and reviewing our evidence files. The reviewers met separately with a group of clients who had been diagnosed with dementia and a group of caregivers so that their views of the service could be obtained, thus supporting the information the reviewers had already gained from the questionnaires.

The peer review day was long and intense but we were very pleased that the outcome reflected the efforts of our team to provide a good service to our clients and caregivers and our motivation in trying to maintain development and improvements.

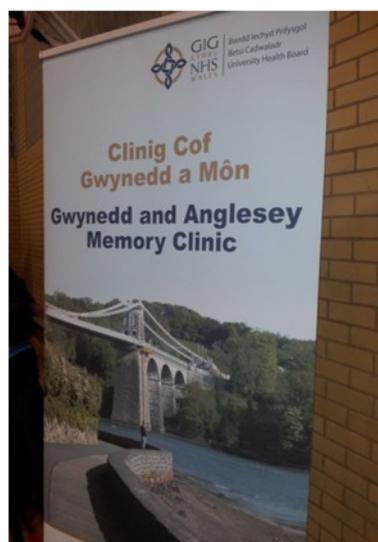
The process has allowed our small, multi disciplinary assessment and diagnostic team to be creative in our ways of working. We have been fortunate enough to be able to link in with colleagues in associated roles and other services and have been able to access seconded staff in order to develop more psychosocial interventions, to liaise with other organisations and to ensure we are listening to the views of our service-users clients and caregivers.

Some of the developments include establishing a rolling programme of group work to complement the individual provision of psychoeducation, pre and post diagnostic counselling and facilitation of tailored cognitive strategies that was already in place. We now have “Managing your Memory” groups for people recently diagnosed with a mild dementia, Cognitive Stimulation Therapy groups and Caregiver groups. We also have access to a more specialised Caring and Coping with Loss programme through which some of our team have been trained as facilitators.

Stronger links have been made with a variety of statutory and 3<sup>rd</sup> sector organisations through attending Health and Wellbeing events. These events are regularly held in our 2 counties of Gwynedd and Anglesey to provide public infor-

mation about services, health and social issues. This has promoted information sharing and networking for all the organisations involved and we, The Memory Service, are able to keep abreast of services and projects where we can then refer our clients. Such services / projects include befriending services, caregiver support and a variety of activity opportunities.

The Health and Wellbeing days have been well attended sessions. By doing these sessions, we feel we are helping to de-stigmatise dementia, generally raise public awareness of the condition and provide information for the public and other organisations. We have done this by taking information leaflets and examples of memory aids and strategies with us so that we can show how the clinic operates and ways in which a person with dementia or mild cognitive impairment could be facilitated to maintain their



usual activities and abilities for as long as possible. The feedback received has been positive. Members of the public have been able to learn more about dementia and memory problems in general and learn that there is support available to help

people live well with the condition. As well as providing an opportunity for members of the public to make general enquiries regarding dementia, it also gives people the opportunity to disclose that they or a loved one are experiencing memory problems and ask how they can be referred or what strategies may be beneficial.

Health & Wellbeing Event, Dolgellau

An extremely positive initiative has been to hold

forums for clients and caregivers in Anglesey and north and south Gwynedd who have used the service. These were informal sessions where service users and their caregivers who had been invited to talk were able to share their experiences of the process of assessment and



diagnosis with members of the team; to comment on positive and negative

aspects of the service to inform our future development. They were then also able to receive information about potential service improvement from us. The comments made were very useful and both service users and the team felt they had benefited from the sessions. As a result of the first forum and a recent GP questionnaire (to elicit views of referring agents) a newsletter about the service has been produced which will be available in our clinic, in NHS waiting areas and GP surgeries, as well as being sent to the people who attended the forum.

Last, but not least, three members of the team (including myself) have received training as MSNAP peer reviewers. This involved a day with senior members of the MSNAP team working through and learning how to carry out the role of a reviewer. The day also facilitated networking with representatives from other memory services receiving the training. Carrying out this role and participating in the networking opportunities of MSNAP, as well as contributing to the development of other memory services across the UK, and hopefully also in Wales, will certainly benefit me as an OT and the rest of the team by the sharing of good practice in all

aspects of assessment, diagnosis and interventions for the people with dementia and their caregivers who use our service.

**Karen Wood**

**Occupational Therapist**

**Memory Clinic**

**Anglesey Forum**



Kate qualified as a Speech and Language Therapist at the University of Reading in 1996. Her first post was in South Buckinghamshire, working in both paediatric and adult clinical settings. In July 2000, she moved on to the role of Dysphagia Specialist in West Berkshire. From 2003 this was combined with a role as Clinical Tutor at the University of Reading, which included running adult teaching clinics at the University.

In 2001 Kate gained a Research Fellowship with the University of Reading. This led to an M.A. in Clinical Linguistics Research (2003). Her research focussed on verb therapy in aphasia and resulted in a couple of publications (see publications section for details).

Kate moved to Cardiff in 2008 for family reasons. She then worked in Cardiff and Vale UHB Adult SLT team in the Transitional Care Unit, alongside a role as Visiting Lecturer for Cardiff Metropolitan University. She took up a post as Lecturer in Adult Neurology in Cardiff Metropolitan University in January 2012. Since then she has gained her Post Graduate Certificate in Teaching in Higher Education. She is a Fellow of the Higher Education Academy, as well as a member of the Royal College of Speech and Language Therapists and HCPC.

Kate has a special interest in developing employability skills and resilience in Speech and Language Therapy students. She is undertaking a PhD in the development of professional

identity in Speech and Language Therapists.

### **Speech and Language Therapy Clinic at Cardiff Metropolitan University**

The existing speech and language therapy (SLT) clinic facilities at Cardiff Metropolitan University (Cardiff Met) have been recently re-developed in order to run clinics for adults with communication difficulties. The service now provides therapy for people who have communication difficulties following a stroke, namely aphasia. Aphasia affects a person's ability to understand language, and to speak, read and write. It is hoped that in the future the service will be further expanded to take people with communication difficulties resulting from other conditions, such as Parkinson's disease or dementia.

This development has provided three benefits. These are improved placement provision and increased learning opportunities for SLT students; closer working with the local NHS SLT service; and additional clinical provision for people with aphasia in the local community. There is also the potential for research projects to be run from the clinic in the future.

#### **Clinic facilities**

The Speech and Language Therapy Clinic is situated in the Centre for Speech and Language Therapy, School of Health Sciences, on the Llandaff Campus of Cardiff Metropolitan University. An additional member of staff has been recruited to increase the clinical sessions available.

The clinic has a clinic room and an observation room with an adjoining reception area, and it is intended for flexible use for adult and paediatric

clients. It is well resourced with a wide range of published assessments available. Additionally the facility has access to 'high tech' resources, including computer and tablet based therapy, with technical support staff available.

The facilities incorporate a TV/video link with cameras and a one-way mirror for observations. The room is sound proofed and windows are frosted in order to protect confidentiality. The clinic is communication friendly, in that the area is colour coded and has accessible signage. It is situated on the ground floor close to an allocated clinic car park area, and it is ac-



cessible to clients using wheelchairs. Disabled toilet facilities on the ground floor are

easily accessed from the clinic area. Additional campus facilities such as a convenience store and cafés are available on site with the potential for use within communication therapy.

### **Clinical services provided**

The clinic operates as a University teaching clinic in close collaboration with the local Cardiff and Vale UHB Speech and Language Therapy adult service. Staff and resources are funded by Cardiff Met. Clinics are run by lecturing staff who are also clinically qualified. All clinical staff are registered with the Health and Care Professions Council (HCPC), and are certified members of the Royal College of Speech and Language Therapists (RCSLT).

Assessments and treatment are individualised according to client need. Treatment may be delivered to individuals or groups, as appropriate. Treatment is offered in blocks of weekly ses-

sions and clients can also be seen on a review basis if necessary. Specialist assessment is also offered on a consultation basis. Some clinics may continue to run during the University vacations when continuity of care is necessary. A client with aphasia who has attended the clinic regularly over the last year commented:

*"It's brilliant, it's come at the right time, I couldn't ask for more".*

His wife added:

*Now he can hold a conversation whereas when he first came here the words were mixed up and he got frustrated. Now coming here he's come on and the words flow better."*

### **Teaching clinic**

The clinic also functions as a teaching clinic for students from the BSc (Hons) Speech and Language Therapy programme. This helps the students to make links between theory and clinical practice. They benefit from being supported by teaching/clinical staff, as well as being exposed to peer learning from each other. There are also potential benefits to placement educators by encouraging and developing a standard level of clinical supervision.

In the clinic, students can gain their initial adult clinic experience and have the opportunity to develop skills of structured observation and data analysis, as well as some client contact and participation within sessions. A year 2 student who was recently on placement in the clinic commented:

*"I really enjoyed being given the opportunity to be involved in assessing and treating clients, seeing how different each client can be and having to adapt to suit their needs was really interesting".*

Further on in their education, students will be conducting sessions, as well as participating in the administrative duties such as arranging appointments, preparing therapy materials, planning sessions, and writing case notes and reports. The facilities also enable them to reflect on their clinical skills, through use of video feedback for example.

Clients, therefore, need to be aware that this is a teaching clinic and that students may be observing, participating in, or conducting sessions. Clients provide informed consent to working together with students. Referrals to the clinic are made by SLTs in the Cardiff and Vale UHB adult SLT service, following an agreed protocol. SLT students have developed aphasia friendly information leaflets to support this process. Students participating in or conducting sessions always do so under the supervision of a clinician. It is planned that service users will be involved in the future in evaluating the services provided by the clinic. We thank Cardiff and Vale UHB adult SLT service for their support and the work that has gone into this new development.

### **Clinical Simulation Suite**

In addition to the SLT clinic facilities, Cardiff Met has also recently developed a Clinical Simulation Suite. These teaching facilities are shared with a number of other programmes within the School of Health Sciences at Cardiff Met. The suite has been developed to look and feel like an authentic hospital ward environment with typical hospital furniture and signage, a nurses' station, a trolley for mocked up medical notes and a curtained off area with a hospital bed. Separate consultation rooms with observation facilities, as well as a pathology lab, are adjoined to the main ward area. SLT uses this simulation area for students to practise their

clinical skills in a safe and supportive environment. Learning tasks that SLT students participate in during the degree programme include practising a swallowing assessment and a communication assessment, as well as giving explanations to a patient about the nature of their communication difficulties. SLT staff role play the parts of the patients and other professionals so that students can develop skills in communication and inter-professional collaboration. The students are encouraged to work together on these tasks so that they can learn from each other. The tasks also involve reflective discussions, facilitated by staff, to help develop clinical knowledge and skills further. The suite provides us with an ideal environment to support students in developing their clinical competencies, so that they are well prepared for their roles in the future workforce.

**Kate Tucker,**  
**Lecturer (Adult Neurology)**  
**Centre for Speech and Language Therapy**

If you have any enquiries in relation to the Cardiff Met SLT clinic, please contact Kate Tucker as below:

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## START (STrAtegies for RelaTives)...



**Dr Penny Rapaport:** Penny is a clinical psychologist and researcher working in the Division of Psychiatry at UCL. Until recently she was working clinically as the Lead psychologist for older people in

Westminster (CNWL NHS Foundation Trust) and as a freelance clinical supervisor for Dementia UK, she has now left these posts to prioritise her research career.

Penny has an interest in the development and implementation of psychosocial interventions for people with dementia and their families. In addition to her work on disseminating the START intervention for family she is currently a co-applicant on the ESRC-NIHR funded MARQUE research programme (Managing Agitation and Raising Quality of life in dementia) and on the HTA-NIHR funded DREAMS-START project, developing and testing a manualised intervention for managing sleep difficulties in people with dementia.

**Kathryn Lord:** Kathryn is a Research Associate within the Division of Psychiatry at UCL. Kathryn's research interests include improving care and symptom management, in particular pain and behavioural and psychological symptoms of dementia, and also decision making and support for family carers of people with dementia.

Kathryn is currently the research coordinator for the START (STrAtegies for RelaTives) inter-

vention dissemination team. Funded by the Alzheimer's Society, the team are rolling out the START intervention into clinical practice and Kathryn is responsible for the coordination and research evaluation of this.

As well as working on the START project, Kathryn is also currently completing her PhD titled 'The DECIDE Study: Dementia carers making informed decisions' aimed at testing the effectiveness of a manual created to help carers make decisions about future place of care and residence of their relative with dementia.

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## START: STrAtegies for RelaTives

### Disseminating START: From research to practice

There are over 800,000 people diagnosed with dementia in the UK alone with two-thirds of these people still living at home. Dementia not only affects the person with the condition but also family members and friends supporting that individual through the illness. There are currently over 600,000 family members or friends who are known to be supporting people with dementia who we call 'unpaid carers'. These unpaid family carers provide a large part of the care for people with dementia and as a result they save the economy an estimated £8 billion per year (Alzheimer's Society, 2012).

Becoming a carer for someone with dementia can be both rewarding and a challenge. Previous research suggests that around 40% of all carers of family members with dementia have depression, anxiety or other significant psychological symptoms and these can lead to a breakdown of care, care home placement and abuse (Cooper *et al.*, 2007). Psychological in-

interventions to support family carers are now recommended as a key dementia care component by the government. This recognises that carers are individuals themselves who need care and support and that healthy, happy carers can actually improve health and wellbeing for people with dementia.

There are a number of interventions already available to try to support carers of people with dementia such as supportive therapy groups and dementia specific education however these are not always based upon research evidence of what we know works and are extremely varied in the terms of where, how and for whom they are made available. Often only those carers who have the most complex needs and who are already at a crisis point are able to access support. In 2009, Professor Gill Livingston and her team at University College London (UCL) carried out the START (STrAtegies for Relatives) trial. Here we will give an overview of the START project and show how, through our Alzheimer's Society dissemination grant, we are trying to help healthcare professionals deliver START in clinical practice to as many carers as possible.

## **What is START?**

START is an eight session psychological intervention aimed at promoting the development of coping strategies for carers of people with dementia. START is designed to be delivered in one to one sessions between the carer of a person with dementia and a graduate psychologist. There is a START manual which is used to guide the sessions and which the carer can keep, make notes in and look back over between and after the sessions are completed.

During our START trial, our team would spend around one hour each week for eight weeks, delivering each session. We took a pragmatic

approach to recruitment and agreed that the time and frequency of the sessions could be longer or shorter depending on the needs of the carer, making it easier for people to fit into their often busy lives. During our trial we generally conducted the sessions at peoples own homes as it may be quite difficult for carers to leave their relatives alone. However, again this is flexible and can be arranged to suit the needs of the carer so if they would prefer to come to a clinic appointment then that is also fine.

The reason we used graduate psychologists to deliver START to carers and not more highly qualified clinicians was to see whether the intervention can be delivered by relatively junior staff members, supervised by more senior staff as we feel that this is one way to make support more widely available.

As mentioned, START is delivered over eight sessions. It was developed in the style of a workbook with each week focusing on a particular topic including managing challenging behaviours, communication skills, emotional and practical support and planning for the future. Each session included practical exercises and stress reduction techniques and carers would work on their own examples to help START fit with their particular needs and circumstances. Carers were then given 'homework' between the sessions including a relaxation CD exercises to practice at home.

## **The START Trial**

Once we had developed the START manual, we wanted to test the impact it had on carers. We wanted to look at if it made any differences to how carers were feeling and also if it was cost-effective. In order to really see if START made any difference to people clinically we needed to have a comparison or 'control' group of carers who did not receive START.

A total of 260 carers from across the UK took part in the START trial, two-thirds of these people were given the START manual and the other third were our control group.

## **START Trial Results**

Our trial showed that START reduced depression and anxiety for family carers of people with dementia when measured at eight months and two years after they had received the intervention. Carers who did not receive START were seven times more likely to be depressed than those who had received START. Carers who received START also reported higher quality of life than those who did not receive START. The trial also proved to be cost-effective when delivered by graduate psychologists.

We also asked carers for their thoughts and feedback of the START intervention and it was generally well received and liked with comments such as:

‘I now feel I have all the tools before I get worse’

‘What was an added bonus was that it centered on me rather than my husband. Previously all attention and energy had been focused on them’

(Quotes taken from Sommerlad et al., 2014)

This was the first trial worldwide to show that a psychological intervention delivered by graduate psychologists, rather than qualified specialist professionals, could lead to a reduction in depressive symptoms and an improvement in quality of life for family carers. Since identifying these positive results we have been considering how we could make this available to carers who are seen by healthcare professionals across the NHS.

## **The START Dissemination Project**

Following the success of the START trial, we received funding from the Alzheimer’s Society to ‘roll out’ the START intervention through regional ‘Train the Trainers’ workshops. These three hour workshops have been delivered by Dr Penny Rapaport the Clinical Psychology co-applicant on the START trial. These workshops for qualified clinical psychologists and Admiral Nurses (specialist nurses for family carers of people with dementia) incorporate discussion and practice, introducing the START intervention and how to train and supervise others in delivering the intervention, as well as consideration of how to get started in setting up the intervention in local services. This dissemination project is endorsed by Dementia UK and the British Psychological Society Faculty for the Psychology of Older People (FPOP) who have helped to organise these local workshop events.

## **Progress so far**

We carried out our first ‘train the trainers’ session with clinical psychologists and Admiral Nurses in October 2014 and the last in September 2015. Overall then we have trained 177 healthcare professionals (148 clinical psychologists and 39 Admiral Nurses) in what the intervention is and how to train and supervise other more junior members of their team to deliver START to carers of people with dementia. In order to see if START is being used and delivered following this training, we are asking attendees to complete a questionnaire 6 months and 12 months later. This data collection is well under way. We are in the process of beginning qualitative telephone interviews with attendees about the barriers and facilitators to setting START up in local practice.

As part of our dissemination work we have created a START website <http://www.ucl.ac.uk/>

[psychiatry/start](#). On this site all the project resources are available from the training PowerPoint slides to the START manuals to be used in sessions with carers. These are all currently free of charge and available for anyone to download as and when needed. Because of the website, published articles and presentations of START at various conferences we have had enquiries from teams across the UK and as far afield as Japan and Australia about they can use START in local services!

### **The future of START**

We are really grateful for all the enthusiasm and interest we have received about the START project and how services might go about setting up and offering this intervention to family carers of people with dementia. We are happy to hear from any healthcare professionals who may be interested in taking START forward in their local area and are happy to provide any advice we can in how to do this. Finally, due to the positive feedback we have received about this work, we have begun to think about how we can continue this work once this funding finishes in conjunction with research funders.

**Dr Penny Rapaport and Kathryn Lord**  
**University College London**

Both Kathryn and Penny are currently working on a range of research projects in the Division of Psychiatry at UCL including their PhDs.

**Contact details:** Kathryn Lord, University College London (UCL), 6th Floor, Maple House, 149 Tottenham Court Road, W1T 7NF.

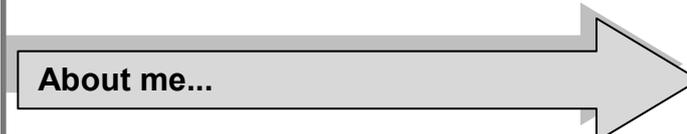
[K.lord@ucl.ac.uk](mailto:K.lord@ucl.ac.uk).

0207 679 9716.

<http://www.ucl.ac.uk/psychiatry/start>

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- Alzheimer's Society, 2012. Dementia 2012: A national challenge.
- Cooper, C., Balamurali, TBS & Livingston, G. (2007). A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *International Psychogeriatrics* , 19 (2) 175 - 195. 10.1017/S1041610206004297.



## About me...

Tracey Thomas works for the Stroke Association as a 'Life After Stroke' co-ordinator covering Cardiff and Vale, a service funded by the local health board.

### Who are you and what do you do?

I originally come from a nursing background, and then went on to complete qualifications in counselling and CBT, and so until recently, along side my Stroke Association work I had a private counselling practice. I have been in this current position at Cardiff and Vale for nearly 5 months, & have worked for the Stroke Association in various locations /positions for about 22 years.

I provide whatever help or support people who have had a stroke, or their families, require. This can be immediately after a stroke, or up to approximately one year after the stroke. I can visit people both in hospital & at home.

This help and support comes in various forms – I can offer practical support, for example, information on home adaptations, housing issues, and signposting to other services. I can support and help people financially, by applying for SA grants, benefits, or attending PIP or ESA meetings with clients. I can advise and support on return to work issues, transportation and / or driving. I offer information & advice on life style & secondary prevention, & information &

support on carers issues.

### What do you enjoy most about your role?

However, the part of the role that fulfils me the most is providing the psychological and emotional support to people who have suffered a stroke, and their families. Stroke is a sudden, often devastating trauma that can change a persons' life for ever, and many stroke survivors suffer anxiety, panic, anger, frustration, lack of confidence, depression etc. and this impacts hugely on their quality of life.

I co-present ACT courses in various community venues with the psychology team, for service users and their families, and am involved with PREPS (Patient & Relative Education Programme for Stroke) on the Stroke Rehab Unit.

A large part of my role is visiting families at home to provide ongoing support. I enjoy being able to meet clients in their own homes, in their own environments – I feel privileged to be invited in as their guest to work with them, and enjoy the opportunity to do this away from a clinical setting.

Another part of my role that I greatly enjoy is the lifestyle and health promotion work that I do with the Stroke Association. Last week I was manning an interactive information desk in Cardiff City Centre, and UHW concourse, helping to raise awareness of the lifestyle and risk factors associated with stroke, for example high blood pressure and atrial fibrillation. Members of the public can have their blood pressure assessed by us, and we often advise follow up checks with their GP. I feel this is really worthwhile – if

we can help prevent even just one or two people from having a stroke then it's a job well done!

What are the greatest challenges for you and your organisation?

My role has various different components – there is no “typical” day for me! One day I will be in the car doing home visits, another day you might find me visiting people on the stroke ward, or doing a fund-raising/health promotion event. The greatest challenge for me is having too much to do and too little time to do it! We are hoping to run a pilot soon where we will have a new co-ordinator, so that there would be 3 general co-ordinators who could also complete 6-month reviews.

Another challenge that I, and the organisation, face is the lack of stroke-specific support that is available in the community. In Cardiff we do have a young stroke day service, a stroke gym and a support group for people over 60 years of age who have had a stroke and, as a result, have language and communication difficulties. However, it would be fantastic to have more support for people out in the community, particularly in the Vale, – but this takes time to set up.

Where would you like to go from here?

We are looking at possible ideas for new services, including a choir for people who have had a stroke, replicating the very successful and award-winning Stroke Choir, which was set up in Cwmbran, and a stroke survivor has expressed interest in setting up

an art group on the stroke unit. As there is not much support for people in the Barry community, it would be great to set up a community café there in the future.

What I have found is that people like to have groups and support outside a clinical setting. By doing everyday activities – going to a café for coffee, going shopping, playing bowls, doing quizzes – people who have had a stroke are able to start integrating back into their normal lives. Enabling & supporting this integration is our goal.

**Tracey Thomas**  
***Life After Stroke Coordinator***  
***Cardiff and The Vale***



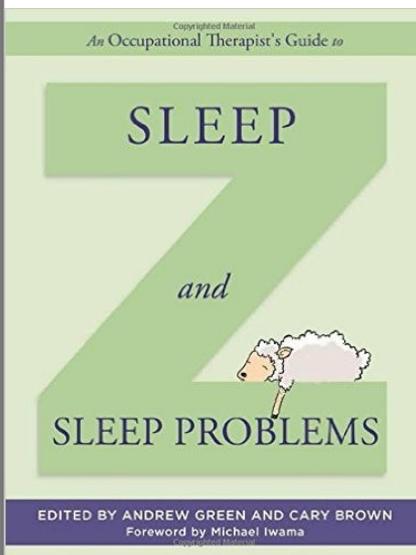
**An Occupational Therapist's Guide to Sleep and Sleep Problems (Occupational Therapists Guides)**

**Author:** Andrew Green and Carly Brown

**Publisher:** Jessica Kingsley Publishers, Feb 2015 (368 pages)

**ISBN:** 978 1 84905 618 2

**Price:** £33.64 Hardback / £26.00 Kindle



This book firstly highlights the importance of sleep in the context of occupation; if a person's sleep pattern is poor, this can affect their performance capacity within other occupa-

tional roles throughout daily routines. It considers the role of Occupational therapy in managing sleep patterns and the impact and challenges posed by specific conditions.

By identifying both physical and psychiatric health as contributors to sleep disorders and disturbed sleep, we are able to understand how we can make positive inroads to better manage sleep patterns and therefore positively affect overall performance capacity and occupational function.

Our understanding of sleep and the need for sleep has been well covered in previous litera-

ture and is succinctly recapped in Chapter three. We know we need to sleep to solidify and consolidate memories as well as our bodies requiring sleep in order to restore and rejuvenate, grow muscle, repair tissue and synthesise hormones. Common sense tells us that if we wake feeling refreshed after a good night's sleep we are more likely to be able to have a productive day; we will be in a better position to learn new information and we may be able to cope with stressful situations more effectively. It is clear that our cognitive function and physical capabilities are reduced greatly when our bodies are not rested sufficiently. We also know that certain conditions put additional strain on our bodies and minds and as a result increase a person's need for sleep further. And yet in practice we give very little consideration to sleep when looking at a person daily routine. OT models of practice, including The Allens Cognitive Disability Model and the Model of Human Occupation (Keillhofner) recognise the need to consider the full 24 hours of a person's daily routine however they don't provide therapists with the tools and knowledge to understand how best to treat this information once it has been ascertained.

Green and Brown give importance to this and placing the responsibility with the therapist to ask the client about their sleeps patterns, it's not enough to wait for the client to bring up the issue themselves, as they are unlikely to mention such issues, but we must be proactive and prioritise this line of questioning. In chapter 14

this particularly states that the perception of others is that with old age comes poor sleep however Green and Brown challenge this, suggesting this does not need to be the case. Working to manage sleep with non medical interventions, using skills Occupational Therapists have developed in assessing and adapting environments, habits and routines in order to prepare for and support the body for sleep.

The details given in chapter 8; Assessment and Non pharmaceutical management of insufficient and excessive sleep, is a key chapter for therapists. Whilst there is not a prescriptive list of how best to tackle the management of sleep disturbance, (after all, treatments must be person centred and are dependent on the reasons behind sleeps patterns as well as individuals habits and routines), but Green and Hicks successfully encourage therapists to consider board concepts and use their professional skills to personalise these to individuals. Consideration of the environment including light source, sound, temperature, layout, ventilation, décor; onto a person's routine rituals and habits before bed and on waking; the persons activity levels throughout the day, are all questions to be asked and then small changes made to trial their success. Whilst many of the management suggestions may be considered common sense, Green and Hick actively encourage this explaining that making small common sense changes can indeed get a client to feel engaged and get a sense of achievement and ownership. As a therapist this can be half the battle.

An aspect this book does touch on, is the effect sleep disorders can have on the carer, sometimes causing sleep difficulties for themselves. Again, our training ensures we consider the carer within our assessment, ensuring a holistic approach, but how much we look into this will vary greatly depending on demands and openness of the carer. Like the client themselves, it is imperative the carer is well rested and has a good sleep routine in order to fulfil their vital role as a carer. By having this as part of the assessment process, the carer may feel better supported and more able to cope with their role. It would have been interesting to see a chapter dedicated to this, especially within the Older Adult sector, where many of the carers are themselves frail elderly.

The structural format of this book brings together pieces of work from various authors; each piece having its own chapter. This allows the book to cover a large range of issues and perspectives, however it also means that there are some inconsistencies and the reader can be left wanting for more information in some areas. As expected, the use of case studies throughout the second half of the book help bridge the gap between theory and reality. Unfortunately, they are too brief and although set the tone and indicate the common examples of what therapists may come across, they do not go into the details of the assessment and treatment processes nor in deed the all important outcome. The exception to this is in chapter 11: Sleep problems in people with Learning Disabilities, the case studies here are thorough

and informative, it brings the theory alive and provides insight into the benefits and possible limitations of the OT role.

In conclusion, this book successfully reinstates the importance of sleep and its effect on a person's performance capacity and wellbeing and it is impressive to see an entire text dedicated to sleep. It reemphasises the responsibility of the therapist to draw out this information when conducting the assessment process. Whilst as OTs, many won't work with sleep disorders as a primary diagnosis, the prevalence of sleep disorder alone suggests that almost all OTs will come across the issues raised regularly and therefore require the skills and knowledge to address these issues as early on as possible. I feel there is scope to look into sleep disorders in older adults and in particular those with dementia, and their carers in more depth. It is a complex area due to the vast changes that can occur in the brain and the often complex social and risk factors that come with it.

Overall, a useful, informative and thought provoking read.

**Eleri Sewell**

**Occupational Therapist**

**ABM UHB**



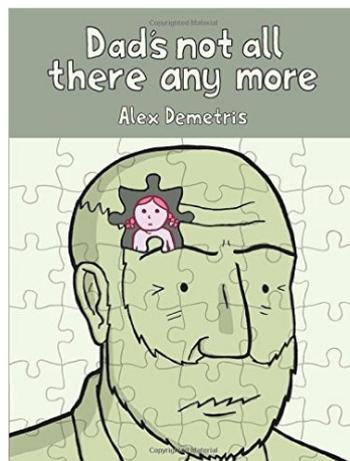
## **Dad's not all there anymore**

**Author:** Alex Demetris

**Publisher:** Singing Dragon, Dec 2015 (32 pages)

**ISBN:** 978 1 84905 709 7

**Price:** £7.99



'Dad's not all there anymore' is a short comic introducing you to John and his family. John's father, Peter, has been living with Parkinson's Disease but, when he starts experiencing

new symptoms, the comic gently explores his and his family's journey of living with a new diagnosis – Dementia with Lewy Bodies.

"Louie what?"

Although it is a fairly established type of Dementia, I believe that most people have heard relatively little about it compared to other types of Dementia, such as Alzheimer's Disease. I certainly had not heard of this form of Dementia before starting my post with The Memory Team in Cardiff. The comic provides a very accessible account of Dementia with Lewy Bodies, and also Parkinson's Disease. The illustrations depict some everyday difficulties that Peter and his wife face, which I feel would resonate for people going through a similar experience. Lots of common sticking points, such as a person's dislike of taking tablets or not taking tablets

regularly, are explored.

The narrative paints a sad picture. We see glimpses of Peter before his illnesses, Peter with Parkinson's Disease and Peter with Dementia with Lewy Bodies. We see how he journeys from a man going out for a pint with friends and sharing jokes to a man who sees things that other people cannot see. We finally see a man needing a high level of care and support and living in a "Psychiatric care home".

However, this emotionally difficult and upsetting narrative is depicted gently and calmly and with the odd burst of humour. Emphasis is given to the fact that, although Peter is now living with Dementia, he is still Peter. He still has the same sense of humour and the same things (for example, his son John's poor grammar) still irk him.

I thoroughly enjoyed this comic but wasn't sure what age group was targeted. Alex Demetris is also the co-author of another book exploring Dementia – 'Grandmother's book of memories' – which is a lovely book for children wanting to learn more about Dementia. As 'Dad's not all there' is in a comic format, I initially thought that it would also be targeted towards children.

However, whilst I enjoyed the black humour of the comic, it was certainly more adult than I expected. There is also some light swearing which, whilst being very true to real life conversations, may not be suitable for children. Perhaps it would suit older teenagers and adults?

To sum up, I felt that the illnesses were de-

icted in an accessible, informative and sympathetic way. Some of the illustrations were very powerful – Peter and his family suspended like puppets, dancing to Dementia's tune – Peter's visual hallucinations illustrated in red compared to the green and white of the rest of the comic. But this is not a dry or heavy book about Parkinson's Disease or Dementia with Lewy Bodies. It is a warm, touching and sometimes humorous snapshot of an ordinary family relating to and living with these illnesses.

**Angharad Jones**

**Assistant Psychologist**

**Cardiff & Vale UHB**



**Living Better With Dementia - Good Practice and Innovation for the Future**

**Author:** Shibley Rahman

**Publisher:** Jessica Kingsley Publishers, Jul 2015 (400 pages)

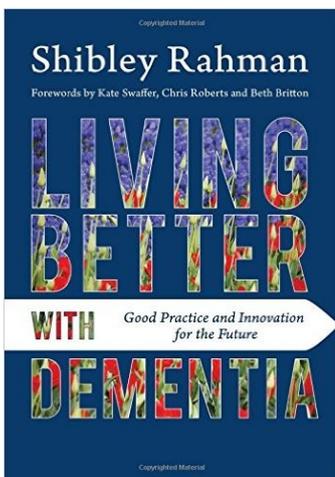
**ISBN:** 978 1 84905 600 7

**Price:** £21.00 Hardback / £16.24 Kindle

'Living Better With Dementia' follows Shibley Rahman's previous book 'Living Well With Dementia *The Importance of the Person and the Environment for Wellbeing* (2014)'. Though I had not read this before, reading 'Living Better With Dementia' has now piqued my interest in

seeing how they both compare. To anyone who has read 'Living Well With Dementia' I strongly recommend following up with the second book, as not only has it expanded upon the theories and observations raised in the first but it also develops them, bringing them into this current focus on innovation and good practice.

What 'Living Better With Dementia' brings that not many others can also claim to accomplish is



a broad and yet still in-depth analysis of numerous topics regarding living with dementia. With chapters ranging from 'Culture' and 'Diversity' to 'Delirium' and 'Global Strategies', upon finishing the book

you feel a significant range of issues have been thoroughly addressed. Rahman, who advocates rights-based approaches, set out to shed some light on particularly 'taboo' subject matters such as incontinence and GPS tracking. Not only does he manage to explore them with links to policy and research, he does so in the most considerate fashion possible. It is difficult to think about these issues without feeling discouraged, however, at the end of each of these chapters they no longer seem as daunting as they did originally; instead there is hope in the realisation that there are effective ways of dealing with these things that are not detrimental to the person's wellbeing or dignity.

Something which is particularly refreshing is how the book doesn't talk about dementia as an

experience exclusive to the individual with the diagnosis. Instead, there is a real insistence on including loved ones, carers and health professionals within this circle. Rahman doesn't ignore the fact that 'carers' (the appropriateness of this term is also discussed) require a lot of support themselves and complements this with findings from research and the Dementia Declaration.

Every point that is made, all suggestions and reflections are supported by research and policy reports which are critically evaluated. Each chapter has an extensive reference section at the end for any further reading you may wish to do.

There is one important theme that runs throughout the whole book and that is the concept of Whole Person Care. The author emphasises the value of this approach while challenging and critiquing others such as dyadic and triadic relationships which have proved to be less helpful than the more accommodating person-centred care. There is an entire chapter dedicated to this topic and it is revisited in other chapters. The effectiveness of creating dementia-friendly communities is something that is also addressed.

Although the author manages to lift the reader's anxieties or negative presumptions of the more disheartening issues, he still makes very clear the fact that, despite having referenced a number of studies in each chapter, there is still not enough research in the field of dementia. In order for those living with dementia (including loved ones) to live 'better' we need research to

develop policy and to abolish stigma.

'Living Better With Dementia' is essential reading for any professional specialising in dementia care. Normally I would not recommend this book to anyone who hasn't got a basic understanding of dementia due to some of the complex language used; as a psychology undergraduate, I have just about managed! Despite this, I really admire the way the author emphasises focusing on taking advantage of what a person with dementia can do, rather than what they can't do. Reading this book makes you realise how far we have come and the potential the future holds for people affected by dementia allowing them to live a long, fulfilling life.

*"I believe that people living well with dementia and all carers are the real champions for the future"* (Rahman 2015, Chapter 17, pg 353).

**Kirsty Campbell**

**Psychology Undergraduate**

**Cardiff University**

Did you know...

My grandfather had a fall last October and he broke his hip. This led to him being in hospital for several months and, when he was discharged, he was not able to walk any more. He still gets out and about, but now we have to use a wheelchair.

However, my grandfather sometimes forgets that he can't walk as he used to and often gets out of the chair or his bed when he's by himself. This then leads to him falling.

I was discussing this with a colleague recently and was told about bed and chair occupancy sensors. These occupancy sensors are a pressure pad which, when placed on your chair or bed, can detect when you've gotten up and left the chair or bed. This then sends an alarm to your family, care givers or monitoring centre so that they can check that you're safe and that you have not fallen.



With some occupancy sensors, it is possible to set a timer so that the alarm will only go off if

you're not back in the chair or bed within a specified time. Thus if you go to the toilet or for a quick snack and return to bed your alarm will not be activated but if you fall and do not get back into bed the alarm will be raised.

Some of these bed occupancy sensors can be combined with a radio controlled electric socket to automatically turn on a bedside light when you get out of bed. This helps reduce the risk of you falling over in the dark.



There is a lot of information about these sensors online. Examples of websites include:

- [www.dlf.org.uk](http://www.dlf.org.uk)
- [www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)

Angharad Jones  
Assistant Psychologist  
Cardiff and Vale UHB

- **A new free online course has been launched by Newcastle University and Future Learn:**

**Dementia Care:  
Staying Connected and Living Well**

A course for carers, to help you stay connected to loved ones, manage stress at home and defuse difficult situations.

**About the course**

If you are a carer for a person living with dementia then this is a course for you.

When it comes to understanding and supporting a person living with dementia, family carers are very often the most skilled and knowledgeable. Yet, you will know that carers can face a number of really stressful situations that can be difficult to deal with.

**Get advice on connecting with and caring for someone with dementia**

This course will provide you with knowledge and advice that can help you connect with and care for someone living with dementia. We will focus on everyday experiences that are seen as particularly challenging and stressful.

Newcastle University has great expertise in ageing and dementia research. We specialise in understanding dementia with Lewy bodies (DLB), so this course will shine a light on some of the stressful symptoms and communication

problems associated with this condition, as well as covering the challenges of other types of dementia including Alzheimer's disease.

**Meet other dementia carers and academic experts**

Over the four weeks, you will meet other carers and academic experts who have developed strategies and practical steps that can improve communication - something which is crucially important for building and maintaining relationships, and for effectively negotiating daily life. By the end of the course, you will develop a new understanding of:

- the brain and different types of dementia, such as Alzheimer's disease and dementia with Lewy bodies (DLB);
  - what a person with dementia is experiencing;
  - challenging situations and behaviours that can cause carer stress;
  - strategies for improving verbal and non-verbal communication;
- and some of the latest innovations for better communication.

<https://www.futurelearn.com/courses/dementia-care>

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- **Another fantastic investment from the Alzheimer's society:**

**Alzheimer's Society makes historic £50 million investment in the UK Dementia Research Institute**

Published on 1 May 2016:

Alzheimer's Society are tackling dementia with a £50 million investment to establish the UK's first dedicated Dementia Research Institute.

A quarter of a billion pounds has been pledged towards the UK's first ever Dementia Research Institute.

In partnership with the Medical Research Council and Alzheimer's Research UK, the pledge marks one of the single biggest financial commitments to dementia research in the history of both charities.

Announced by the Prime Minister in his Challenge on Dementia 2020, the Institute has been backed by £150m of government investment. It will bring together scientists and experts from across the globe to transform the landscape of dementia research and firmly secure the UK's reputation as a world leader in research and development against dementia.

To read the full article click the following link:

<https://www.alzheimers.org.uk>

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• **The hero's of 66 keep on giving:**

**On Friday (20 May) a song recorded by the 1966 England World Cup Winning Team is going on sale, with all the proceeds going to Alzheimer's Society.**



The song, We Were There - which was written by Bob Wragg from the Dallas Boys – was recorded for the England team of 1982 to wish them luck ahead of the World Cup. However, the song was never released.

Of the 1966 team, Martin Peters, Nobby Stiles and Ray Wilson are all [living with dementia](#).

The song is available for download on iTunes, with hard copies available on Amazon.

Vivienne Francis, Director of Marketing and External Affairs, said:

'The legendary 1966 World Cup Team hold a special place in many football fans' hearts and I'm sure this terrific song will ignite many happy memories. We are absolutely delighted that proceeds from this proud moment in our history are going to Alzheimer's Society.

'We were saddened to hear recently that three of the winning squad, Martin Peters, Nobby Stiles and Ray Wilson, are living with dementia. Their decision, and that of their families to be open about their [diagnosis](#) is a brave and wel-

come one. Talking about dementia reduces the harmful stigma that still clings to it.

'With the song released during [Dementia Awareness Week](#), Alzheimer's Society is calling on people to confront dementia, be aware that they can do something about it and come to the charity for help and support. Proceeds from the song will go towards funding vital research and support services for the hundreds of thousands of people affected by dementia.'

Kings College London public meeting

- 
- **Free event providing you with the chance to ask your questions...**

**Do you want to know more about dementia?**

**Join us to find out about cutting-edge dementia research at Kings College London.**

**Venue:** ORTUS Learning Centre

**Address:** 82-96 Grove Land

**When:** Friday 3rd June at 9:30am

A public open day to showcase the latest dementia research:

- Ask our panel of experts your own questions.
- Meet our scientists in interactive activities.
- Hear talks by dementia researchers.
- Join our workshop for carers.

The event is free but places must be booked in advance. To apply for a ticket, contact :  
Mr Jeremy Wiltshire, King's College London,

James Black Centre,  
125 Coldharbour Lane, Denmark Hill, London  
SE5 9NU

• **Not that we need an excuse to eat a lovely cupcake...**

### **Cupcakes against dementia**

Wooden spoons at the ready! 16 June is Alzheimer's Society's Cupcake Day, proudly supported by our friends at [Woman & Home](#). This is your chance to host a party at work, home – or wherever you like. The only ingredients you need are cupcakes, friends and fun ways to raise money to help defeat dementia.

[Get your Cupcake Kit](#)

### **A date with cake**

Cupcake Day is whisked up by Alzheimer's Society to help raise funds for people affected by dementia. They are asking people up and down the country to host, bake, buy or just eat. You can ice your Cupcake Day anyway you like, because on 16 June every cupcake counts!



## 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](mailto:Amanda.Furnish@wales.nhs.uk)

### Books Available for Review:

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

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

### Signposts Editorial Panel

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

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

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

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

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

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

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

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

