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SIGNPOST

Journal of Dementia and Mental Health Care of Older People



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Tony Jameson-Allen
Sporting Memories Network.
www.sportingmemoriesnetwork.com

Editorial



Welcome to the latest edition of Signpost. The Spring is here, the weather is fine and I hope there is a feeling of renewed energy and enthusiasm around us all.

I am delighted to have been asked to write the editorial for this edition. I am a consultant clinical psychologist working in stroke services and have recently taken up the role of joint Head of the Older Adult Psychology Specialty for Cardiff and Vale University Health Board. Part of this role is to chair the steering group for this journal. This is an interesting development as many years ago, at the start of my psychology career, I was the assistant psychologist working in the Service Development Unit (now the Practice Development Unit), as deputy editor of Signpost!

There are some really innovative and creative articles in this edition as well as a reflective piece by the founder of the journal – Simon O'Donovan.

Simon has taken the opportunity in this edition to reflect on his years of working with people with dementia and older people with late onset severe mental illness. He was the driving force behind establishing 'Signpost' and the original editor and should be delighted with the quality of articles that are regularly published within this highly respected journal. Within his article Simon comments on the 'quiet revolution' (in which, it must be said, he has played a major role) that has

taken place for this cohort of people over the years, as well as, sharing his thoughts on the future development of services. Simon also offers information about himself, including his preferred choice of desert island discs (a list to which I can closely relate!).

A very interesting article by Karen Phillips describes the transformation of the communal area of a care home. Karen is Chief Executive of The Fed (The Federation of Jewish Services), a charity providing social care services to the Jewish community of Greater Manchester. This includes the running of a care home for older people at the Heathlands Village on a 5 acre site alongside a children's centre and community centre – a one stop shop for all ages. Karen describes how in fifteen-months the lives of the residents of the care home - as well as their relatives, staff and volunteers – have been completely reconfigured and greatly enhanced. The designers have taken into account how light and the design of spaces affects people who have dementia, and how, in some cases, 'getting the light right' can make more difference than medication.

'Sporting Memories Network', by Tony Jameson-Allen, is a truly inspirational article. It describes a social enterprise founded on a vision to tap into the passion that is shared by spectators and participants of all the major sports across Britain. The overarching aim is to improve people's mental and physical well-being, including those living with dementia and memory problems. Various sporting teams and organisations from Leeds have been involved and memories have been shared by fans from football, rugby league and cricket. The work has developed to include training in reminiscence therapy and a suite of websites called Replay has been launched and includes motorsport, track and field and tennis. It seems that the idea of 'Memories Games' has been embraced by professional clubs across a number of sports. This work demonstrates that sport is a universal language for those living with

dementia and can provide a focus for social interaction and engagement.

Finally, Rachel Brewer offers us a summary of the National Dementia Conference held earlier this year – the main aim of which was to provide a review and update on developments in dementia care. The points of particular interest include the interaction of mood and dementia; new evidence about the efficacy of functional imaging in determining the subtype of dementia; differing patterns of cognitive impairment; predicting those more likely to convert from Mild Cognitive Impairment (MCI) to Alzheimer's Disease; and very importantly, the recent guidance for managing medication in the elderly. We all realise that there is a great need to reduce inappropriate prescribing in older people and that medication reviews are essential.

I think you will agree these articles offer personal reflection and also innovation and 'new beginnings' which should enthuse us all to be bold and take action. Happy reading.

Future direction.....

P.S. Given the changes over the past 12 months we feel it might be a good time to consult our readers on the content of Signpost and also on what you might wish to include in future editions. We will in time send out a questionnaire to gather these views, but those who might like to offer initial thoughts on this can e-mail Matt (Matt.Lewis@Wales.nhs.uk) or Angharad (Angharad.Jones6@Wales.nhs.uk).

Thanks for your support.



Simon O'Donovan

(Si to his friends and family), is the outgoing Clinical Director of Mental Health Services for Older People in Cardiff and Vale University Health Board. He is about to retire early (due to some health issues and a desire to seek a better life/work balance) and will therefore be ending his involvement with Signpost.

Simon has been working in older people's mental health services for around 30 years in a variety of roles, mostly recently with specialist clinical roles in the Safeguarding Vulnerable Adults Team and then for the last 4 years the Younger Onset Dementia Service. He has been Clinical Director for about 10 years, and feels that the time has flown by! He feels that he's given the role his best shot and that it's time to now pass the baton on. We asked him to reflect on his career for us, and write about some of his achievements and proudest moments.

How have things changed over the years?

I have witnessed many changes over the years and hopefully contributed to a quiet revolution in the care and treatment of people with dementia and older people with late onset severe mental illness. Standards of care I believe have improved immeasurably and this is evidenced by an increased life expectancy for those we serve. We have new and improved medications to pre-

scribe, increased access to more appropriate aids and equipment and massively better environments of care. It was commonplace when I started in the speciality of old age psychiatry for people to die as a result of pressure ulcers and most statutory service provision took place in institutional care. Thankfully we don't see such poor outcomes these days.

Reflecting on that word 'speciality', this is another area of huge change. 'EMI' or 'Psychogeriatrics' used to be an area perceived not to require special skills and an area where staff were placed if they had performed badly in other areas of mental health care. Today this has turned on its head. Staff choose to work here and there is a recognition that skills training is an essential requirement to work with this client group. We also have a workforce which is more psychologically minded and less concerned about providing task orientated care. But there is a way to go, I think, in getting the skill mix and staffing establishment quite right across the service, including in community teams. This is another huge change, having a less inpatient focused service and well developed community services that can provide crisis support and specialist liaison to district general hospital wards and care homes.

What have been your best achievements?

It is important to say that at every step of the way there has been a huge team effort and to recognise the fantastic contribution my colleagues have made over the years. No one single person can make significant change without committed colleagues who share the same vision for improved services. However, I guess looking back

the establishment of the Solace Carers Support Service was a great stride forward in engaging clients and carers in care and service planning. The development of the Salaried GP Service for Mental Health Inpatients (all ages) addressed a very real inequity in access to primary care physician involvement, especially for longer-term inpatients.

The establishment of the Younger Onset Dementia (YOD) Service has probably been my one outstanding career highlight though. It's something that so many of us have worked hard at over many years and suddenly we have a fully established YOD Community Team and Inpatient Ward. I guess the reason I am so pleased about this development above all others is that the needs of this sub group have for so many years been unmet and it has been a longstanding area of deprivation. And I'm delighted to be returning to the Team Leader role for this service after I retire and have my month off.

What about your proudest moment?

This is a tough question to answer, but I guess moving services into the new purpose built facilities in Llandough Hospital was the culmination of many years planning and developmental work. Hopefully achieving AIMS accreditation for all our acute wards will follow this year and that will be another measure of success and a demonstration of how far we have come in a relatively short space of time.

There are a few other moments that spring to mind – having the proofs of my one and only publication delivered to my door (Simons Nursing

Assessment – long out of print. I sound like JR Hartley!) was very nice, passing my PhD viva was another proud moment and one which opened lots of doors for me and then getting final proof copies of each edition of Signpost was always a great feeling. Of course, being appointed as one of the first Consultant Nurses in Wales was a fantastic achievement, both personally but also I feel for the service, giving it recognition as an area worthy of focus and investment in leadership.

How do you see the future direction of travel for the service?

I have over recent years been pleased to be involved in developing the National Dementia Vision for Wales and before that the NSF for Older People in Wales. More recently, I've been involved in the development of the UHB Three Year Dementia Plan. But I do fear that for all the fine words we have had very little investment in older peoples' mental health services and all of the recent innovation and service development has been achieved through realigning existing resources (including several ward closures). This is all well and good but we are faced with a massively increasing population need over the next few decades and I really worry that very little has been done to plan ahead and future proof our services.

There really does need to be a concerted effort in undertaking capacity planning, reviewing finances currently available and clearly identifying the resource gap which undoubtedly exists and will only grow as years go by. We need to further develop community services to avoid the need

for more inpatient beds, and longer term care provision is ripe for change, in my view. We have talked over many years about developing specialist 'dementia villages' – community team base, day care services, very sheltered care, residential care, nursing home care and extended psychiatric assessment, all in one new build resource centre with good in and out reach managed under a social enterprise or consortium. There needs to be some real ownership of the dementia agenda and political sign up to a radical rethink of current service models.

What might people not know about you?

I'm quite a private person, so probably quite a lot! I'm proud to be a gay man working in a position of seniority in NHS Wales. I've been with my partner Ade for coming up 30 years and we hope to convert our civil partnership to a marriage this year. We have two dogs, Billy and Sadie – who has recently joined us after being rescued out of a canal in Romania. I've been vegetarian since I was age 17 and a devoted Kate Bush fan since about the same time. Seeing her perform live in 1979 and then again last year was such a thrill. Our love of Cornwall means we will probably end up there when we properly retire, but with a base up here in Cardiff as well to keep in close touch with our wonderful circle of friends and families.

Desert island discs

- Kate Bush – 'Cloudbusting'. Reminds me to try and stay positive and optimistic. 'I just know that something good is going to happen.'
- Joni Mitchell – 'Clouds'. 'I've looked at life from both sides now.' Helps me remember

to keep looking for happiness.

- Audrey Hepburn – 'Moon river'. Gets me every time. The classic love song.
- Brian Wilson – 'God only knows'. For Ade.
- James Taylor – 'You've got a friend'. A lovely song I used to be able to play on the guitar.
- Genesis – 'Ripples'. Reminds me life is short and to live for the moment.
- 'Danny boy'. My late Dad's favourite song.
- 'The Lord is my shepherd'. Touches me deeply and helps me connect with my Catholic upbringing.

Aside from these I could have added loads of classical music. I listen to Classic FM most days, if I'm not listening to a good radio play or comedy.

Luxury object

A well stocked wine fridge, with a good Marlborough Sauvignon Blanc being my favourite.

Book

The 'Tales of the City' series by Armistead Maupin is something I keep coming back to and intend to read in its entirety when I have my month off in May.

Key lesson for life

Do your best. Keep trying. If you fall over, dust yourself off and start over again. Always look for the positives. Learn from others. Keep smiling!

Message for readers

I think we have become too preoccupied with investigating complaints and dealing with clinical

incident investigations. We don't spend enough time celebrating the excellent services we have and reflecting on our good practice. We should all be proud of the work we do and the mostly positive experiences people have when receiving care and treatment from us. We need to share our work more, through publications and conference presentations and keep reporting upwards on the plaudits our services receive.

The other important thing, thinking about our individual work with clients, carers and families, is to keep dignity at the heart of everything we do. Treat people with kindness, compassion and respect. Make every effort to engage with people in a meaningful and supportive way. Support clients and families as you would wish to be supported. Take time to reflect and focus on the positives. Make every moment count.

Simon O'Donovan
Clinical Director
MHSOP, Cardiff and Vale UHB



Tony Jameson-Allen

Tony qualified as a Mental Health Research Nurse in 1995, and was fortunate enough to have some truly memorable experiences during his time in clinical

practice. He has always had a great interest in Dementia care, and attended the Dementia Care Mapping training facilitated by Professor Tom Kitwood.

Tony was also instrumental in leading a Care Home team to care for their patients without the use of any psychotropic medication. He has managed other Care Homes, won NHS wards and worked as a Clinical Team Leader before becoming a project manager for the Dementia Services Collaborative in the North East, Yorkshire and Humber in 2002. Working with colleagues at the National Institute for Mental Health in England, he also worked in partnership with people living with dementia to produce a number of practice guides and toolkits regarding good practice. He has recently co-founded the Sporting Memories Network, established to promote and develop the use of sporting memories to improve the well-being of older people and to help tackle dementia, depression and social isolation.

Chris Wilkins and I are the co-founders of this social enterprise. Sporting Memories Network was founded on a vision to tap in to the passion that is shared by spectators and participants of all the major sports across Britain. The overarching aim was to improve people's mental and

physical well-being, including those living with dementia and memory problems.

Our vision is to roll-out the use of sports based reminiscence across the UK and beyond, demonstrating its potential not only for improving the wellbeing of people with dementia but also for those who are experiencing, or at risk of developing, depression, social isolation or who have been recently bereaved.

At the heart of our projects are different forms of partnerships; partnerships with people, clubs, communities, organisations and public bodies. We believe, by establishing and working in strong, community based partnerships, that we can embed an approach that can support people to live well with dementia, to support those living with depression and to help alleviate loneliness and isolation.

Early days – Skills for Care

Sporting Memories Network is a social enterprise registered in England and Wales. Its primary purpose is to create city or county-wide projects that offer community based, volunteer-led sports based activities for people over the age of 50. After establishing a strong advisory board, our initial tasks were to create resources that would be meaningful and appropriate for users, and then to design a training course that would equip facilitators with the necessary skills to engage in sports based reminiscence work. These resources and the training course then needed to be put to the test!

The opportunity came via a successful bid to the

Skills for Care Workforce Development Innovation Fund. This provided the necessary backing to trial the resources in fifteen care homes in Leeds, West Yorkshire over a six month period. The care homes were asked to nominate members of staff to attend training. A broad skill mix attended the initial half-day training sessions, with some homes asking for volunteers from their staff and others taking a more traditional approach with senior management attending. Each home received a comprehensive sports reminiscence manual along with packs of 'Replay Cards' and the weekly 'Sporting Pink' newspaper that is published by the network to provide regular new content. The focus was to test whether the resources could be easily used by staff and volunteers and crucially, whether these resources resonated with residents.

In his evaluation of the project (Evaluation of the Workforce Development Innovation Fund (WDIF) 2012/13: Leeds Care Homes Sporting Memories, Dr Michael Clark, Personal Social Services Research Unit, LSE), Dr Michael Clark set out the factors involved in the project. "The theoretical underpinning of the Sporting Memories work is one of a psychosocial model (e.g. Spector & Orrell 2010). The model crucially considers the interactions between psychological and social features and the factors that are open to change from intervention. It helps to think about where interventions are trying to make a difference (e.g. social factors, or psychological ones, or combinations and interactions of these) and where and how they may also benefit other areas, such as biological factors.

Dr Clark noted that the Sporting Memories work helped encourage people who were previously not inclined to engage with life in the care home to socialise and participate. One interviewee stated that these residents subsequently became more involved in other activities as well. Initially, we believed that our work would prove of most interest to gentlemen, but this was not always the case. One home reported that interest amongst its female residents started as soon as they heard that members of staff were attending training on the Sporting Memories work. The work was adaptable to include people of various ages and people with different needs/diagnoses, including dementia, stroke and frailty.

The key learning aspects reported from this initial pilot were:

- Staff reported the resources were easy to use and gave them new ways of connecting with their residents.
- Residents who didn't often engage in traditional activities (mostly men) had enjoyed the resources and had taken real interest.
- The reminiscence guide had been useful and easy to refer to.

Leeds- a city united – Skills for Care part two

Following the pilot and evaluation in 2012/13 we submitted a further bid to the Skills for Care WDIF to test out the approach across a wider selection of social care settings. Grant funding was provided to engage not only care homes, but also day centres, leisure centres' and a number of the neighbourhood networks that provide care and support for older people in Leeds.

We approached the city's main sporting clubs to ask for their support in the project and asked sports fans across the city to share their memories. Leeds United Football Club, Leeds Rhinos (Rugby League), Leeds Carnegie (Rugby Union) and Yorkshire County Cricket Club were all happy to help, and gave us permission to use their Sporting badges on our website. Leeds City Council also showed their support for the work by allowing us to launch the work at an event attended by councillors, sports clubs, project participants and some members of the press in the impressive Council Chambers at Leeds Civic Hall.

The training venue was Elland Road, home of Leeds United. Almost 100 staff and volunteers attended our redeveloped training course over two days, which had been developed in partnership with SMN advisor Charlie Murphy (who was on hand to co-facilitate these sessions). The course covered an introduction to the theory and background of reminiscence therapy, explored the specific skills required for facilitating effective reminiscence for people living with dementia and memory problems, and gave everyone the opportunity to learn how best to use the resources provided.

At the training sessions we also introduced facilitators to the action-learning model. This aspect was designed to ensure that the trained facilitators were able to share ideas, provide feedback on their progress and benefit from peer support. We also provided a platform for 'live' evaluation, to ensure our action-learning sessions informed progress and that discussions and feedback re-

ceived at these sessions were recorded and contributed to the final evaluation.

At a learning set meeting, some participants spoke of their experience of doing SM work in a care home, and particularly where they had drawn together people from different parts of the home who usually wouldn't meet each other. They found the groups worked well. One experience suggested participants were happy to sit with different people when talking about the sports when usually they were fixed in their own chairs when back in their residential areas. (Evaluation of Sporting Memories Work with the Leeds Community and Care Settings Network April 2014. Dr Michael Clark, Research programme manager, NIHR School for Social Care Research London School of Economics)

The wide variety of different of organisations involved in this pilot meant that our facilitators sometimes had different approaches and different experiences of the programme. However, the overall feedback we received in regards to our training was very strong and positive, with those who attended the action-learning sessions appreciative of the opportunity to share their progress in a safe environment, with peers. As well as our training being very well received, the resources we supplied were also praised as being easy to use and of high quality.

Sports Stars

In June 2012 we launched a suite of websites called Replay. 'Replay Motosport' gained the support of former F1 driver David Coulthard who shared some of his own favourite memories to launch the site. Liz McColgan gave her backing

to 'Replay Track and Field' and John Inverdale launched 'Replay Tennis' on the first day of the Wimbledon championships. Much has been written recently about the value of having 'celebrity' supporters and our own experience has been nothing but positive, having now gained the backing of over 50 sports stars and memories from over 400 stars, musicians and celebrities. Their willingness to share and promote the project, particularly across social media has provided many opportunities to promote positive messages about older people, dementia and ageing.

(See Bill's Story <http://www.sportingmemoriesnetwork.com/latest-smn-news/bills-story-reaches-12500000-people-on-world-alzheimers-day-/?keywords=bill%26%23039%3Bs+Story>)

Council Commissions

With celebrity endorsement and the interest in the Leeds project came a small but select amount of press coverage. This helped raise some awareness of the work we were doing and led to enquiries from a few councils and clinical commissioning groups (CCG). In Scotland we were approached by East Lothian council to run a small pilot group specifically for older men at one of their libraries.

The John Gray Centre in Haddington houses the town's library and local archive. Staff from the centre were trained to facilitate sporting memories and supplied with the resources. The group was publicised locally, with the sessions scheduled to run for two hours every Tuesday morning. There were no requirements other than for older men with an interest in sharing sporting stories to turn up for the session.

Eight men turned up for the first week and the staff reported the session had run smoothly and everyone had found it enjoyable. The group went from strength-to-strength, with eventually sixteen men joining. Their ages ranged from 59 to 97. Some had physical or mental health issues, some were living with dementia or memory problems, and some attended for the companionship. However, although they all came from different backgrounds and had different stories, they all shared a common bond – the love of sport. For two and a half hours, medical diagnosis, age and background became immaterial as the men swapped stories, shared memories of sporting legends or their own experiences of sport from over the years, enjoyed pies and Bovril and played sports or went on day trips.

A brief evaluation by Ageing Well East Lothian led to funding from NHS Scotland to roll out this model across the county. The group was visited by BBC Radio Four's All in the Mind, the episode can be listened to on the network's website <http://www.sportingmemoriesnetwork.com/media-coverage/bbc-radio-4--all-in-the-mind-3rd-june-2014/>

In Grimsby, North East Lincolnshire CCG commissioned a sporting memories project as part of their work on A Call to Action, exploring non pharmacological interventions in their attempt to reduce prescribing of anti-psychotic medication. A number of care homes were involved. One home embarked on a sporting memories project to capture the sporting history of each of their

residents. This went beyond simply recording the weekly sessions.

residents' reminiscences and personal histories.

Residents and relatives actively engaged in the project, as did the wider community, the local press, the local football club and sport and leisure centres'. As a result of this care home's work, one resident aged 96 and living with dementia was able to revisit the local ice-rink where she once skated competitively and was able to enjoy, once again, the feeling of taking to the ice. Using a frame, and with the ice rink staff supporting her, she was able to go to the centre of the rink on skates and experience all the sensory stimulation of going round the rink in a specially adapted sled. The work of the home is still continuing with a wall in the main lounge documenting residents' sporting memories.

The work in Grimsby was featured in a film that was made for the 2014 Dementia Friendly Awards where the network was voted Best National Dementia Friendly Initiative <http://www.sportingmemoriesnetwork.com/latest-smn-news/network-recognised-as-best-national-initiative-at-dementia-friendly-awards/>

In Bristol, the city council joined forces with South Gloucestershire County Council to commission groups across their localities. The city's sports clubs embraced the project proposal, meeting with ourselves and showing a real eagerness to engage and support their older fans now living with dementia. Gloucestershire County Cricket Club, Bristol City, Bristol Rovers and Bristol Rugby all offered support and input, with weekly groups being hosted at their stadia and in some cases, former players being trained to facilitate

Bristol City worked with a local school to teach pupils about dementia and about the history & heritage of sport in their area. Year 7 pupils interviewed relatives to capture their sporting memories. All those involved then attended a game as guests of honour of the club.

Gloucestershire County Cricket Club staged three Memories Games™ which gave our volunteers the incredible opportunity of working with the club whilst it hosted the first one day international in the England V India series. Unfortunately, the weather chose not to behave on Gloucestershire's big day, and the sell-out crowd were greeted by pouring rain and a lake instead of a field! But the planned game did give us the opportunity of discussing the match a few weeks earlier on the BBC Test Match Special when we had the slightly surreal experience of spending a few hours in the commentary box with Aggers, Blowers and (Sir) Geoffrey Boycott before discussing sporting memories and dementia on the lunchtime interview with Aggers and Gloucestershire legend Mike Procter.

Memories Games™ raising awareness

The concept of the Memories Games™ has been embraced by professional clubs across several sports. Our initial match was the result of an inquiry by a championship football club who wanted to do something to raise awareness of dementia.

Since that initial game, which saw fans sharing memories of their time supporting the club,

alongside memories from club legends, captains, managers and club chairmen, we've been fortunate to work with many wonderful clubs from football, cricket, rugby league and rugby union.

In June we were invited by the Marleybone Cricket Club (MCC) to make the 200th anniversary of Lord's Cricket Ground a Memories Game™. To be able to write about memory and dementia in the match day card that marked such a major milestone for the Home of Cricket was incredible. The MCC arranged for us to have our gazebo on the Nursery Ground. We had a team of volunteers from a local school and from Lord's who interviewed spectators, and the MCC invited residents from a local care home to enjoy the day from the splendour of an executive box. At lunch the school children interviewed all the visitors from the care home to capture their memories of sport. A big treat was in store as the children were then invited into the hallowed halls of the pavilion to interview the President of the MCC, Mike Gatting. Following a very enjoyable and successful day, we later worked with the MCC to train twelve staff members in the delivery of sporting memories sessions.

The Memories Games™ have also offered the chance to develop intergenerational aspects of the projects, working in partnership with schools, youth councils, national citizen services students and colleges & universities. This was used to great effect at a major sporting event in 2014, when students from Leeds Trinity University worked with the network across two days of Le Grand Depart of Le Tour de France. Their sterling efforts in interviewing spectators at the huge

spectator hubs led to us working on a documentary with BBC Radio Leeds that was broadcast over Christmas on memories, Le Tour & dementia.

Another example of our inter-generational work was seen when students from Glasgow Caledonian University joined older people from sporting memories groups in the city, Scottish athletes (including gold and bronze medal winners) and the 'Clyde-sider' volunteers from the Commonwealth Games for a memories event in the city centre in November. The students were on hand to record the reminiscences of all involved as part of our official legacy project of The Games. The memories that were shared will be used across sporting memories groups throughout Scotland and the UK.

2015 – An Inter-generational Rugby World Cup?

Over the coming months we will be working in England with young rugby ambassadors and volunteers on a series of local and national events and activities that will celebrate the history and heritage of the game, introduce younger people to Rugby and to sporting reminiscence with older people in their communities.

We will also be working in partnership with schools and youth organisations across the UK in a project funded by Spirit of 2012 trust where younger people will be encouraged to work with older people to capture memories of London 2012, other Olympics and Paralympic Games and sport in all its guises; helping to tackle loneliness and support older people living with demen-

tia and depression.

Life Changes Trust

In February 2015, the Life Changes Trust Dementia Programme confirmed a grant award to the network to fund 55 new weekly sporting memories groups across Scotland's central belt. The Sporting Memories Network already runs 31 sporting memories groups across Scotland and the Life Changes Trust will also support these over the coming three years. Working in partnership with older people who are living with dementia, their carers and peers, weekly groups for older sports fans will be established in accessible, local venues. The groups will be hosted by libraries, sheltered homes, sports clubs and community centres.

Sporting memories groups will promote physical and mental wellbeing and provide opportunities to try out playing new sports. The project will create a network of groups that are dementia friendly, engaging older people living with dementia and their carers who might otherwise find they become isolated and are no longer engaged with sport or their peers.

Monthly meetings of the 'Supporters Club' will provide a forum for carers to also enjoy the activities, gain information from supporting organisations and join together with others living with dementia to help shape the groups and develop the projects further.

The Future

Last summer we were invited to give a ninety-minute guest lecture to the FIFA Masters pro-

gramme at the International Centre for Sports History and Culture at De Montfort University. In front of thirty two delegates from twenty eight countries including a current world champion rower, professional athletes, sports agents and some of the finest young sporting & business minds from across the globe, we were able to champion the importance of celebrating our sporting history and heritage and the importance of recognising and including older people, some living with dementia, in the celebration of sport and sporting achievements. The response of the Masters delegates was uplifting and we have subsequently been invited to provide a similar lecture as a permanent feature on the programme and look forward to speaking with the 2015/16 programme later this summer. Hopefully, these lectures will translate into real progress over the coming years.

Sport is a universal language. It can provide a focus for conversation, interaction and activity that is familiar, comfortable and enjoyable. We hope to continue to roll-out this approach in partnership with like-minded organisations and people.

In May 2014, Sporting Memories Network was awarded Best National Dementia Friendly Initiative in England by Alzheimer's Society. Named amongst the top 50 New Radicals by The Observer for initiating social change through innovation, the network was also presented with the Best National Football Community Scheme at the Football Business Awards 2014. The network chairs a new national task group as part of the Prime Minister's Challenge on Dementia, exam-

ining the role of sport and leisure in creating dementia friendly communities. We have also recently been awarded funding from Comic Relief to develop our digital resources for use on a one-to-one basis, which is a great development for us.

Tony Jameson-Allen

Co-founder

Sporting Memories Network.

www.sportingmemoriesnetwork.com



Karen Phillips

From an early age, Karen had a strong desire to help those in her community. At

just 17 years old, she began volunteering at a local care home on Cheetham Hill Road in Manchester

and this fuelled her commitment to working in the community.

In the early 1970s, she began working with the Chest, Heart and Stroke Association, where she ran two successful schemes in South Manchester and Trafford. Both schemes supported people with speech problems recovering from strokes and both used volunteers to run clubs and provide stimulation and support. In the mid-1980s Karen became a single parent – bringing up her three lively young daughters, whilst also training to become a Probation Officer sponsored by the Home Office. She then worked in Salford for five years and specialised in adult and young offender support.

In 1992, Karen took a 2 year sabbatical from her career in probation and opted to work within her own community. She took up a position as Social Work Manager at Jewish Social Services (JSS), a local Jewish charity that supported people living in poverty, or in need of social care support. The two year sabbatical became almost a lifetime commitment. She was swiftly promoted to the role of Director, followed by CEO, and helped to restructure and professionalise the organisation in anticipation of the Community Care contract culture.

Propelled by Karen's drive and ambition, JSS grew into a substantial and professional charity, securing vital funding contracts with three Local Authorities to provide services to people in need across much of the Greater Manchester area. Appreciating the importance of a community-wide perspective, Karen sought as many opportunities as possible for collaboration, partnership and merger. This culminated in the creation of The Federation of Jewish Services (The Fed) in December 2007.

The Fed offers support to older people, children with special needs, family carers and people with mental health issues. It provides independent living, residential, nursing and end of life care. Today it employs over 350 staff as well as being supported by more than 500 volunteers.

Karen's aim is for The Fed to be a centre of excellence, the organisation of choice for the entire community – a flagship project for the region.

Her tireless work within social care has not gone unnoticed and, in the 2011 New Year's honours list, she was awarded an MBE for her services to the Manchester Jewish community. She describes this as "a humbling and wonderful experience," but insists that this was not her award, but one that belonged to all staff and volunteers at The Fed.

Later in 2011, Karen formally accepted the appointment of Deputy Lieutenant of the County of Greater Manchester. She was presented with her commission by Her Majesty's Lord-Lieutenant of Greater Manchester, Mr Warren Smith JP, at the Annual Lieutenancy Reception in May 2011. The main duties of the Lord-Lieutenant and her Deputies relate to citizenship ceremonies, as well as civic, social events and presentations. Her name was put forward for the position in recognition of her social care achievements and her ability to promote collaboration and volunteering within the community.

Outside of her professional work, Karen supports a number of local charities and was previously a Director of the Langdon Community. Her precious spare time is spent with her husband, children, step children and grandchildren.

The August 2014 issue of *Signpost* included an article by Professor June Andrews, Director of the Dementia Services Development Centre (DSDC) at the University of Stirling. She talked, amongst other things, about how environmental issues impact on the symptoms of people living with dementia, and how these can be reduced by making 'simple relatively low cost changes' (I'm not sure I would quite agree with the term "low cost"). They looked at how light and the design of spaces, including the outdoors, affects people who have Alzheimer's disease and other forms of dementia. They found how, in some cases, 'getting the light right' can make more difference than medication.

This impelled me to make contact and share our story. Writing on Christmas Eve 2014, we've just said goodbye to a merry band of engineers, electricians, joiners and plumbers, who have been with us at Heathlands Village since September 2013, helping us to put the theory of environmental design into practice. We have completely transformed the communal areas of our care home.

It's a full fifteen months since the builders' portacabin hamlet appeared overnight in our staff and visitor car-park. As they vacate, we look forward to repossessing our lost parking spaces, and more importantly the official handover of our new 'communal hub'.

The lives of the 170 residents of our care home, and the hundreds of relatives, staff and volunteers, who spend much of their time here, have

gone through more than a year of disruption – (mostly with patience and very good humour, might I add), as our main public areas – both inside and out – have been completely reconfigured. Now all we need is for the furniture to arrive alongside the barista-style coffee shop to be perked and ready to go, and our new-style home will be ready to launch.

The building is largely unrecognisable. Walk into our home today and you'll immediately be struck by the space and brightness, with public areas flowing into each other and wall-to-wall, floor-to-ceiling patio windows directly accessing our newly laid out secure gardens. It's magnificent. The bottle-necked corridor, clogged with walking frames and wheel-chairs, which led to the main restaurant, is gone replaced by wide access from a light-filled glass-roofed atrium. No more undignified queuing for lunch. Off this area is our resited village shop and medical suite and just a few yards along the main corridor, a hair and nail bar and recreational therapy area.

Getting to this point hasn't been easy. We've endured power and water cut-offs, collapsed drains, lift closures, room relocations, temporary dining rooms, redirected corridors; a trench dug from the front to the back of the building, right across our main corridor; hanging wires, power-hammers, dust and debris - our own vibrating Jurassic Park at times. But we would go through it all again to create the environment we are now close to completing.

A little bit of history

Heathlands Village opened in 1972, at that time, a modern flagship care home for older people – a million miles, (actually just two) from its predecessor – 'The Old Home' on Cheetham Hill Road. They left behind the long hospital wards with facing rows of metal beds, replacing these with cosy rooms for four residents and up-to-the-minute care facilities.

Over time the home went through extensions and piecemeal modernisation. Then in 2009 the charity running the home merged with another Manchester charity – Manchester Jewish Federation, known as ‘The Fed’ and from this point began the fundamental transformation of a site originally built to care for older adults, to an intergenerational community facility. Underused or mothballed areas were converted to accommodate community projects, and a children’s centre with outdoor play area and a community centre. The footfall grew and changed as the site began to be used by service-users and visitors of all ages. Residents began to enjoy the sight and sounds of children playing. Service-users from the community pop in for supper and a game of pool; afternoon coffee, an exercise class or a game of Rummikub.

Today’s resident is far older and frailer, both physically and mentally

Two fundamental facts have driven our plans: 1) People are living longer and 2) The public funding pot has shrunk, then shrunk, then shrunk again. Furthermore, the bar which must be reached to qualify for public funding has been raised proportionately. The 60% of our residents who rely on public funding to enter our care are far older and frailer, both physically and mentally, than his or her 1970’s counterpart, and thus have much more complex care needs.

Back in the day when Heathlands was built, many publicly funded residents could today be described as the ‘walking wounded’ – meeting the criteria at that time to qualify for financial provision for their care needs. By today’s standards, they were relatively youthful and capable of managing with little support.

Improvements to staffing levels and training address only half the problem

As the resident profile has changed, we have had to adapt. Resident to staff ratios must reflect increased care needs. Training must provide our

staff with the skills and understanding to care for people living with dementia - 80% of our residents. Staff need to know how the condition affects a person’s memory, coordination, cognition, communication and mood.

Improvements to staffing levels and training address only half of the problem. As Professor Andrews points out, care has to exist in the right physical environment. We recognised that we urgently needed to make radical changes to the layout of our main internal and external communal areas no longer fit for purpose for the post-millennium resident. We needed to create surroundings which enabled people who are often confused and forgetful, to find their way about and access amenities, particularly outdoor space, and activities, as easily and independently – as possible. Research told us that this would help them live the fullest life possible with a major positive impact on well-being.

Old improvements had created confusion for today’s residents

Developments to Heathlands Village since the early 1970’s had created a confusing environment for the people being cared for decades later. By way of example, the GP surgery was housed at the opposite end of the floor from the physiotherapy room, and in a totally different area from where the optician saw his patients: we needed to relocate these services into one central medical suite.

In addition, security needed a total rethink. Having a number of entrance and exit points, removed from the reception area, made it difficult to monitor who was leaving or coming into the building. We needed to reduce these to one point which could be clearly viewed by our reception and security staff.

To reach our old gardens (which were not enclosed), meant crossing a car-park and access road – a potential hazard for people with im-

paired senses, perception and mobility.. Many residents had to wait for a member of our care staff to help them if they wanted to spend time outside. By rerouting the roadway, moving the car park, and re-landscaping the gardens we have created new safe recreational spaces, immediately next to the building. Now many more residents can access and enjoy the fresh air and Manchester sunshine independently, without the risk of meeting a car or going a little 'walk too far'. Our old coffee lounge, tucked away down a corridor and round a corner, was greatly underused – residents literally forgot it existed. By linking it directly to our main lounge we created a much brighter more spacious, L-shaped main sitting area and contemporary coffee shop .

Bringing 'the outside world in'

A major aim, when Heathlands Village merged with The Fed, was to create an appealing modern environment which would attract people of all ages from the surrounding community - to volunteer, use our services, pop in to the new central coffee bar for a drink and bite to eat, and where relatives and friends would want to spend more time with residents.

The more people spend time in our home the less isolated our residents will be. By creating a vibrant communal hub our residents can continue to feel part of things. We want to see an end to the days when our older people are sequestered on the periphery of our communities in "God's waiting room".

People may live longer but the quality of their life declines we hear. We need to change that – with the right care and environment we hope to maintain our residents sense of wellbeing helping them continue to feel they are a valued part of their community; encouraging as much independence as possible. Old age need not mean a miserable existence.

About The Fed and Heathlands Village

The Fed is the leading social care charity for the Jewish community of north and south Manchester. It looks after people of all ages - from babies with special needs, to older people.

Its head office is based at Heathlands Village, Prestwich from which it also runs a care home for older people. It also has a south Manchester office situated in the centre of Hale, near Altrincham, Cheshire.

Every month, The Fed supports 1,000 people, more than 170 older people who live at Heathlands Village and hundreds more living in their own homes.

Its 300 plus social workers, support workers, case workers, nurses, social care workers, coordinators and behind-the-scenes staff, and 500 plus volunteers, provide care, advice and support through a range of services:

Social Work | Carers' Services | Volunteer Support | Mental Health Services | Residential Care | Day Services | Nursing Care | Dementia Care | Palliative Care | Children's Groups | 1:1 Respite for Children with Special Needs | Supported Independent Living | Community Cafe | Referral & Advice Service

Together they make up one fantastic charity which is not replicated anywhere else in the UK.

The Central Hub redevelopment (Phase 1 of our building plans outlined above) is almost complete but Phase 2 is yet to begin - the building of two specialist houses – smaller care units with domestic style living for people with greater dementia care needs who experience anxiety, confusion and often considerable anger.

**Karen Phillips, MBE DL
CEO The Fed**



Dr Rachel Brewer graduated from Leicester University Medical School in 1999, following which she started General Practice training.

Her interest in psychiatry lead her to working in General Adult and Old Age Psychiatry services in 3 Welsh hospitals. In 2008,

she joined the Cardiff Memory Team as a Specialty Doctor. The role incorporates clinical work; assessment, diagnosis and management of memory conditions including subtypes of dementia, teaching commitments and involvement in research trials.

To fulfil her academic curiosity she is half way through an MSc in Neuroimaging for Research with the University of Edinburgh.

A personal privilege is being a trustee for the 'Forget me Not Chorus' charity, which supports people with dementia and their carers.

Dementias 2015 : 17th National conference.

'A review and update on current developments in the dementias : in the fields of research, investigations, clinical care and service and policy issues'.

A personal reflection on take home topics and tips:

In February 2015, I was privileged to attend the National Dementias Conference in London. It is an annual event specialising in dementia, so you may ask –what's new?

Particular points raised which evoked great interest and made me 'sit up' included:

- the interaction of mood disturbance and dementia
- new evidence about the efficacy of functional imaging in determining the subtype of dementia
- patterns of presentation of cognitive impairment we may not consider
- predicting who will be more likely to convert from Mild Cognitive Impairment (MCI) to Alzheimer's Disease (AD)
- new diagnostic category of MCI in Parkinson's disease
- recent guidance for managing medication in the elderly : STOPP/START criteria

Mood and dementia

I am very aware that a diagnosis of dementia can impact on the mood of the patient, but was surprised by the findings from the Dementias 2012 report which looked at the experience of the person living with dementia. 77% of people with dementia feel anxious and depressed. This prompted my thoughts; are we detecting and managing these conditions that are prevalent in so many of the 850,000 people with dementia currently in UK? We may screen for these symptoms at the initial assessment, but are we proactively looking for them after the diagnosis? Can we lower that rate?

This linked to points raised by Dr Liz Sampson from University College London, who talked about behaviour and pain in people with dementia. It is a timely reminder to look at mood/behavioural changes being part of the presentation of the dementia disease, part of its progression and/or a consequence of the diagnosis.

Depression is a known risk factor for developing

dementia, as are vascular risk factors. The duration of depression is associated with hippocampal size; the longer you have depression, the smaller the hippocampus. Early signs of cognitive impairment often include non-cognitive symptoms; including mood and depression. Depression, apathy and anxiety are associated with amnesic MCI and episodic memory loss and visuospatial impairment are predictors of conversion to AD. Even in the prodromal stage, total lack of recall even with prompting is highly predictive of progression to AD. This may be complemented by volumetric MRI (Magnetic Resonance Imaging) and amyloid PET (Positron Emission Tomography) scans as markers for likely progression.

It was fascinating to hear a talk about MCI-PD (Mild Cognitive Impairment in Parkinson's Disease), a newly defined concept first looked at in 2012. Apathy and depression may be a prodrome to Parkinson's disease, and present with neuropsychological symptoms. Apathy is a significant indicator of worsening cognitive impairment in this group, as apathy is associated with memory and executive dysfunction. Predictors of conversion to PDD (Parkinson's Disease Dementia) in patients with PD include poor visual and spatial deficits and poor verbal fluency. Such patients have an increased chance of converting within five years. The Sydney Multicentre Study (Hely 2008) showed PDD in 83% of 20yr survivors. Usually the onset of dementia in PD occurs after 10 years of the initial symptoms.

Neuroimaging

Of particular interest to me was the future of neuroimaging tools to aid a diagnosis. Currently available imaging biomarkers include:

- Structural imaging: (Computed Tomography (CT) and Magnetic Resonance Imaging (MRI))
- Functional imaging:(Perfusion (HMPAO))

SPECT and Glucose (FDG) PET and FP-CIT SPECT for Dementia with Lewy Bodies (DLB) and PDD and Amyloid PET for Alzheimer's disease.

Imaging biomarkers included in the new diagnostic criteria for DLB (McKeith et al, 2005) and Alzheimer's disease (McKhann et al, 2011).

We already use structural imaging, in accordance with clinical judgement and the NICE guidance for Dementia (2006). This helps to exclude other cerebral pathologies and to clarify the subtype diagnosis.

Professor John O'Brien and his colleagues published a paper in the European Journal of Neurology in 2010, *stating FDG-PET and perfusion SPECT are usual adjuncts when the diagnosis remains unclear*. In my clinical practice I would want to know which would be helpful in the differential diagnosis of a degenerative dementia.

Professor John O'Brien presented a more recent study that was published in 2014, funded by NIHR (National Institute of Health Research), which looked into this question. The hypothesis was that FDG-PET would be significantly superior to HMPAO SPECT. This proved to be correct. Subsequently *the recommendation would be to adopt FDG-PET as a diagnostic tool for dementia within the NHS when functional imaging is indicated*.

PET is commonly used in the oncology field, and the costs of SPECT and PET are now similar, so it seems more likely that PET will be used more in the future, if available. I suspect future amendments to imaging guidelines and revised diagnostic criteria.

'What about the patient's experience undergoing imaging?' was a question going through my mind, as the patient's experience is paramount too. I was surprised at the results of a qualitative

analysis looking at this. It found that the length of the scan did not increase the individual's stress (as measured by heart rate). Things people deemed more important were diagnostic accuracy of the scan and the empathy of the staff, rather than the duration of the procedure or radiation dose.

Primary Care

Dr Nick Cartmell was particularly inspiring! He is a G.P. in Devon and Clinical Lead in improving dementia care in Devon and the South West. He explained clearly and logically his approach, which I felt had many valid points we can learn from.

As we are aware many people in care homes have dementia, possible 60-70%. However figures documented for the diagnosis of dementia are far fewer. He posed the question, '*can the diagnosis of the person in the care home be made by a G.P. avoiding an unnecessary referral to the Memory Clinic?*' He felt in most cases the diagnosis could be made by a G.P. Obviously there will be cases where specialist investigations and assessment may be indicated.

I was pleased to hear Dr Cartmell say that he talks thoroughly to his patients before referring them to the Memory Assessment services, especially about why the referral is being made. You have to 'tick' if cancer has been mentioned when referring to a cancer specialist. *Why not the same for dementia?* I appreciate not all G.P.s may feel experienced enough (yet...!) to broach this or may feel it could impact on the relationship in primary care....but it is certainly a valid point to debate.

Before referral to Memory Services, identifying and treating infections is essential, adequately treating depression and appropriate baseline blood screen +/- CT head scan.

I work in secondary care so it was enlightening to hear first hand from a G.P. about the annual QoF Dementia review he provides. This includes topics such as driving, discussing Lasting Power of Attorney, the sharing of information, reminder about local patient/carer support, consideration of involvement of palliative care services and a medication review. I was particularly delighted to hear that an *annual review* of medication was carried out, particularly looking to reduce the anti-cholinergic burden.

Medication

This information was neatly linked to newer guidance about reviewing medications in elderly patients: **STOPP/START criteria**. The appropriateness of medications in the elderly was previously based on the Beers criteria from the US. The ***STOPP/START (Screening Tool of Older Person's potentially inappropriate Prescriptions and Screening Tool of Alert doctors to the Right Treatment)*** criteria, are the European consensus on medications and older people to reduce inappropriate prescribing. A medication review is essential and certain medications can increase the risk of delirium. These include: opioids, benzodiazepines, dihydropyridines and antihistamines. Ideally we should avoid such tablets and also unnecessary polypharmacy (>5 tablets).

Following the conference I have read more literature about anticholinergic medications, and the effect of medications with anti-cholinergic properties on cognitive function. A review by Professor Chris Fox published in 2014, concluded that such medications have '*significant adverse effects on cognitive and physical burden*'. Reducing the anti-cholinergic cognitive burden is an important strategy to adopt.

A criticism from a member of the audience was that the focus is on the *diagnosis* of dementia, rather than *prevention*. A regular review of medi-

cation is one useful strategy to implement. There were many issues I have learnt from this conference, and will consider in my daily clinical practice of dementia assessment, diagnosis and care. Education is vital for early life protection of known risk factors, and we now have more tools to help in the cognitive assessment, diagnosis and ongoing review of care.

We also need to eliminate the impression that dementia is a 'normal part of ageing' and there is nothing we can do! Worldwide prevalence of dementia is decreasing. This is probably in part due to identifying known risk factors and optimizing their management in midlife (e.g. hypertension and diabetes, and stopping smoking) must be prioritised.

Dr Rachel Brewer
Speciality Doctor
Cardiff and Vale UHB

About me...



Professor June Andrews FRCN is the Director of the Dementia Services Development Centre at the University of Stirling in Scotland

(www.dementia.stir.ac.uk). Her previous post was Director of the Centre for Change and Innovation in

the Scottish Government where she was a Senior Civil Servant. In that post she was responsible for supporting improvement in clinical performance within the National Health Service on a range of conditions including depression, cancer and diabetes, and a range of services including General Practice, and hospital outpatients in addition to nurse employment. Her appointment followed a nursing career where she was the Director of Nursing of Forth Valley Health Board. Earlier as Secretary of the Royal College of Nursing she led an association of 35,000 nurses negotiating pay and conditions and representing their interests in the media and at with the Scottish Government. Professor Andrews is a psychiatric and general nursing qualified nurse with over thirty years experience. Most of her clinical nursing work was with older people with mental health problems.

The Dementia Services Development Centre (DSDC) at the University of Stirling works with health and social care services across the UK and throughout the world to improve care for people with dementia and support for their families. It does this through research and teaching and translating knowledge into practical tools many of which are available through the website. The DSDC and its website are supported by the

Dementia Services Development Trust a small charity that set up the DSDC exactly twenty-five years ago. The areas of interest include design of buildings that reduce symptoms, training, artistic expression and framing of dementia, supporting dementia friendly community initiatives, improving education of qualified and unqualified carers and care workers, and provision of distance learning post-graduate qualifications in dementia studies. Through Professor Andrews' leadership over the last ten years it has grown in stature and influence and gained many awards for training and design.

Professor Andrews is a graduate of the University of Glasgow where she studied philosophy and English literature before beginning her nurse education and studying at the University of Nottingham. In recent years her work has been recognized by the Chief Nurses of the Four UK countries with a Lifetime Achievement Award (2012) and the Nursing Standard awarded her the Robert Tiffany prize in 2011 for international work. The British American Project of which she is a Fellow awarded her their first and only Founder's award for service. In 2014 she was awarded a Fellowship of the Royal College of Nursing of the UK, the highest honour that they can bestow. She was listed in the Health Service Journal as one of the two dementia clinicians in the UK in the top 100 influential clinicians in 2013. In addition she has been named as one of the fifty most inspirational women in the National Health Service. She was a charity trustee of the Life Changes Trust and sits on the boards of two commercial companies.

Professor Andrews is particularly interested in improving the public understanding of dementia, which she does through the media and public speaking, and accessible easy to understand guidance which is based on the research evidence of what is practical and makes a difference.

Who are you and what do you do?

I'm Professor June Andrews FRCN, the director of the Dementia Services Development Centre (DSDC) at the University of Stirling. The purpose of the centre is to improve services for people with dementia and their carers and we do this through a range of activities, including research, teaching, consultancy, innovation, publishing and generally challenging received thinking about dementia. We did that 25 years ago when we were set up, and now that we are 25 years in, we are challenging the things that we used to say! You have to keep moving!

If it is ever possible, could you describe a typical day?

I have four typical days:

One is where I have to stay at home and write. They make me do it! There I am in my room at home near Edinburgh, keyboard at the ready with a nice bird table outside and a river running past the window and a few deadlines to make me anxious enough to decide what has to be said. Just one more cup of tea then I'll start...

My second typical day is when I set off for Stirling University where I work with the team in the Iris Murdoch Building, the first dementia friendly public building ever, we think. The grounds are full of wildlife and we have a great view of the Ochil Hills, which are either covered in snow or heather, but the DSDC has a beautiful dementia friendly garden nestled up against the building. We might have staff meetings and discussions, but more often than not we are entertaining visitors – a group of forty architects and hospital managers from Germany for a design school, a team of police officers for training, people with dementia and their carers having a coffee morning to share their priorities for what we should do next...It is never the same and always shaped by what the visitors are doing. We have a footfall of

about 1,000 people through our conference centre every month of the year. We don't often see our post-graduate masters students because they are studying by distance learning all over the world.

The third typical day is travelling. I love to tweet pictures of the airports wherever I am. From September to Christmas last year I was in Saudi Arabia, Nova Scotia, Washington and Hong Kong. Travel has not hotted up this year yet, but I've got my Singapore and New Zealand guidebooks out already. The thing I love about the journey is not being contactable for hours on end. And on arrival there are so many curious, and sometimes shocking things to see, as well as brilliant examples of dementia care. The people are always great, because they've invited me because they want to make things better. No pushing at closed doors on the world tour! When looking at the old lady with dementia, in a straight jacket and tied to the bed, I know that the reason we are there is because someone in that hospital in that country wants to make it better, and my job is to help in any way we can.

The fourth typical day is looking for money. The DSDC is supported by a charity, the Dementia Services Development Trust. We work internationally and so we have to charge for our services. For UK work, people naturally assume that we are government funded, but unfortunately, that's no longer the case. The upside of that is that we are completely independent. The downside is that we have to spend a lot of time pursuing funding. But we have been so lucky. For example, our new website at www.dementia.stir.ac.uk has been funded by the Trust and is interactive with virtual dementia environments funded by the Robert Bosch Foundation and the Nominet Trust. Furthermore, the Trust this year has funded the Dementia Festival of Ideas (<http://festivalofideas.org.uk>) and is supporting our massive survey The Big Ask.

What do you most enjoy about your work?

Recently I have enjoyed writing a book *Dementia; the one-stop guide* which is full of practical advice for families, professionals and people living with dementia. It has been a great insight into the media, and popular culture. The publisher was clear that “and Alzheimer’s” had to be added to the subtitle, so that it could be found on Amazon. The greatest joy for the publisher was it being serialized over two weeks in The Mail on Sunday. My hair stood on end at the way the language had been changed. But those two things alone are probably what got it into the Amazon top a hundred selling books, if only for a week, above Jeremy Clarkson and 50 Shades of Grey. It has been so interesting passing in and out of television studios where the interviewer is fascinated for all of two minutes, and then you are history. You don’t make money from books, but if this effort has got the information into the hands of those who really need it, it has been worth it. Although it is “populist” it should be put in the hands of every GP whose diagnosis level is below 50%, and every person who runs an acute hospital. The press saw the chapter on how to protect a person with dementia in the acute hospital as an attack on the NHS, which it was not. It’s a clarion call to families to look after their own and not expect the NHS and social services to do it for them.

What are the greatest challenges for you and/or your organisation?

There is so much to do, and so little time. That’s the main thing. Also there is a bit of a backwash from the current “popularity” of dementia. Those of us who were working in this field before it got fashionable were thrilled at first at the additional attention, but so much of what is happening is superficial and untested. I’m not against an experiment, but when whole swathes of policy are based on things for which there is very little evidence it’s a bit frustrating. The great success of

“dementia friends” in England, for example is that there are a million and apparently there is a plan for two million more. This is against a background where, when I was working in London a month ago, there were GP practices with diagnosis rates sitting around 20%. Lots of friends waiting for you then, if the doctor ever puts a name to your problem...I’d swap a million dementia friends for a few more competent diagnosticians and some improved hospital care.

Where would you like to go from here?

Mainly, I’d like to continue being useful, and that means keeping your eyes open. I want this year of the Dementia Festival of Ideas to go like a fair, and to make waves with the results of the Big Ask. In particular I want to focus more on the framing of dementia. Who tells us what to think about it, and how to describe it? Not people with dementia – that’s for sure. I’d like the courage to dare to do right and be ever more challenging!

Most of all, I want lots of feedback from *Dementia; the one-stop guide*. If I’ve not got it right, I need to do another edition, very soon.

Professor June Andrews

Dementia Services Development Centre

www.dementia.stir.ac.uk

Intellectual Disability and Dementia Research into Practice

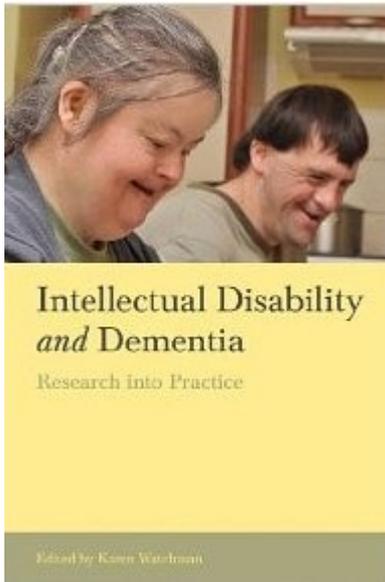
Edited by: Karen Watchman

Foreword by: Diana Kerr

Publisher: Jessica Kingsley Publishers, May 2014 (330 pages)

ISBN: 978 1 84905 422 5

Price: £29.99



Intellectual Disability and Dementia is a must read for everyone working with people with intellectual disabilities who have a diagnosis of dementia. It provides a wealth of information and is a very welcome contribution in this

field of work.

Karen Watchman is Alzheimer Scotland Lecturer in Dementia at the Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland. She has experience of supporting people within both dementia care and intellectual disability services and was previously Director of Down's Syndrome Scotland.

With advances in medical care, people with an intellectual disability have a significant increase in life expectancy and increased risk of developing dementia; we need to be fully aware of how we can support them. Individuals with Down's Syndrome are more prone to age-related cogni-

tive decline and a number of studies have confirmed that the prevalence of dementia increases sharply between ages 40 and 60.

In the UK people with intellectual disabilities are commonly referred to as people with learning disabilities and this is reflected in some of the references.

This book offers the latest information, international research and evidence-based practice with contributors from the UK, Holland, Ireland, Canada, Australia and the US. They discuss best practice for understanding person-centred care for support services, medication, assessments, interventions, outcome measures, research and working together for the benefit of the individual.

There are three parts to the book:-

Part one: The association between intellectual disabilities and dementia: What do we know? (Pages 24-94)

Part two: Experiences of dementia in people with intellectual disabilities: How do we know? (Pages 114-161)

Part three: Service Planning: What are we going to do? (Pages 184-286)

There are case studies from the perspective of people with intellectual disabilities and dementia

from page 114, who have been meeting together since 1998. There were nine participants over the age of 50 recruited from the London area.

The three case studies from page 126 of the lived experiences of people with intellectual disabilities who were unaware of their dementia diagnosis show how the staff and family interacts and the importance of adapted communication; case studies like these are rare and extremely valuable.

Staff knowledge and training from page 204 discusses key legislation, such as NICE dementia guidance (2006), and the need for effective training and leadership to all staff working with older people in the health, social care and voluntary sectors.

I work with people diagnosed with dementia and their carers so I am really pleased that this book has valuable information which will benefit my clients, colleagues and others. I chose to do a role emerging placement at a charity for adults with learning disabilities so have knowledge in both these areas.

Note: The Alzheimer's Society produced two fact-sheets in October 2014 after working in partnership with the British Institute of Learning Disabilities (BILD). These are in easy read format and called 'What is dementia?' and 'Supporting a person with dementia'.

Jayne Phillips
Occupational Therapist



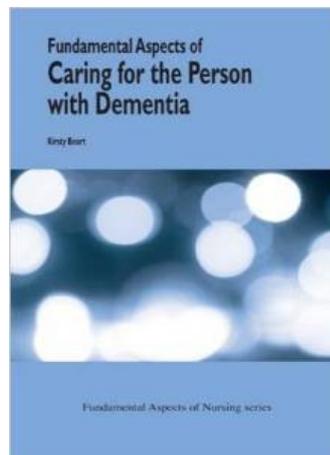
Fundamental Aspects of the Caring for the Person with Dementia (Fundamental Aspects of Nursing)

Edited by: Kirsty Beart

Publisher: Quay Books Publishers, July 2006
(160 pages)

ISBN: 978 1856423038

Price: £19.99



This is a an informal and relatively easy book to read with the most powerful element being that much of the content is based around the experiences of people living with dementia.

It therefore lives up to its aspirations of inviting the reader to read the book with the aim of seeing the perspectives of the person living with dementia and those close to them.

The first section of the book is well researched and presented with some clarity, and considers dementia care in the context of the humanistic approaches and person centred care which remains the cornerstone of excellent care. In addition to this, the author provides a concise account of the background of dementia care including key aspects of policy and practice. The only concern with this element of the book is that it was written some time ago and pre-dates essential elements of policy such as The National De-

mentia Strategy (2009) and the Prime Ministers living with the illness. Challenge on Dementia (2012).

The first section concludes with a description of the process adopted in relation to the interviewing of people with dementia and their carers and gives a taste of the themes covered within the second part of the book.

Part two of the book, includes the invaluable practical aspects of caring for someone living with dementia which would be relevant both the family carers and professionals. Interwoven into the parts of the book where theory is incorporated into the lived experience are the voices of those who have been affected by dementia. Some of the areas considered are the emotional effects of dementia on not just the person with the illness but the wider family and the relationships within the family, the effect of dementia on mood and personality and coping with daily activities.

There is a specific section relating to younger people living with a dementia diagnosis.

The book draws on effective coping strategies for supporting people living with dementia with an enormous range of practical, emotional and supportive approaches to support. Some examples of these include the use of technology, psychosocial interventions, access to services and planning for the future. What was really helpful was that each chapter concluded with a section titled 'how we can do to help ourselves and others' reinforcing the fact that people living with dementia can still exercise autonomy and determine for themselves what can help and hinder them when

Additionally the author has included a number of internet sites that can further assist and educate, but due to the fact this book is now dated it may be that some of these are no longer appropriate or available.

This book had an easy to follow structure, and was quite poignant to read as the experience of real people living with the challenges that dementia presents shone through, it may have been helpful if some of the very personal experiences could have been from the many people who are living well with dementia to help to give the book some balance and also inspire some hope and optimism if the reader was someone personally affected by the disease.

**Gillian Drummond,
Dementia Quality Lead,
Greater Manchester West Mental Health NHS
Foundation Trust.**



Leadership for Person-Centred Dementia Care

Edited by: Buz Loveday

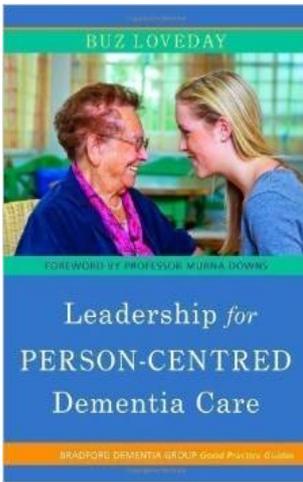
Publisher: Jessica Kingsley Publishers, 1st Ed 2012

ISBN: 978 18459052290

Price: £42.83 paperback

Price: £10.20 kindle

This concise book focuses on the essential elements of dementia care leadership guiding the reader through the necessary knowledge, skills and actions to develop a person-centred culture



of care in dementia care services.

There are 6 chapters which explore the goals of and the barriers to person centred care; empowering and supporting staff to practice person-centred care; building a learning community, training and reflective practice; effective communication systems and understanding feelings and needs.

This is a very readable text that honestly refers to both the good and the not so good of dementia care twenty years on from Tom Kitwood first writing of 'a new culture of dementia care'. It is a very practical book and there are excellent examples and ideas to support person-centred leadership and team working. It will be of great value to those both new and those familiar with a dementia care leadership role.

I enjoyed reading this book and found it convincing, inspirational and affirming. I would recommend it as a must read to dementia care leaders at all levels within statutory and non-statutory sectors.

Christine Sampson.
Head Occupational Therapist
MHSOP and MH Specialities
Cardiff and Vale UHB

Did you know...

In this section we review new products and ideas which may be of relevance to people with dementia or those working and caring for them.

Please note that we do not specifically endorse any product and aim to provide neutral information



The Flipper Remote Control is a simple television remote control which may prove useful for people with visual or cognitive difficulties.

It only has 6 buttons – On / Off, Channel Up / Channel Down, Volume Up / Volume Down, and mute. The buttons are large and tactile for ease of use.

The remote control is very universally compatible and works with televisions with built-in freeview and televisions with a separate media box, including Sky, Virgin and almost all other Freeview boxes. In the very unlikely events that the flipper remote was not compatible with your television, you would be offered a full refund on your remote and your postage.

Normally, people would need 2 remotes if they have a separate media box – one remote for the television and one remote for the box, e.g. Free-

view or Sky or Virgin. The Dual-Function feature on the Flipper remote allows you to turn both your television and your Freeview / Sky / Virgin boxes on / off, thus removing the need for 2 remote controls which helps reduce confusion.

One of the best features of the Flipper remote control is the ability to set-up a 'favourites' list. You can choose between 2 and 25 of your favourite channels on your television or media box (including Sky and Virgin) and then just cycle through these channels, missing all the other channels in the process. This therefore reduces digital television, Freeview, Sky or Virgin into fewer and more manageable channels. A problem that some people have is, whilst watching television, accidentally ending up on a channel that they do not recognise and being unable to find their way back to a familiar channel. This 'favourites' feature eliminates this. It also has a lock feature which protects against somebody accidentally reprogramming the remote control.

The remote costs £19.99

<http://www.alzproducts.co.uk/flipper-big-button-remote-control.html>

Ground-breaking new national service empowers public to take part in vital dementia research

A nationwide online and telephone service that helps people to take part in dementia research studies launches today (24 Feb 2015). *Join Dementia Research* promises to accelerate the pace of dementia research by allowing people with and without dementia to register their interest in studies, helping researchers find the right participants at the right time. This new initiative has been developed as part of the Prime Minister's Challenge on Dementia and the launch follows Saturday's announcement of £300m for dementia research with a direct call for the public to get involved.

Join Dementia Research is a collaboration between the National Institute for Health Research (NIHR), Alzheimer's Research UK, Alzheimer's Society, Alzheimer Scotland and UCL Partners, and has been funded by the Department of Health and NHS England through the SBRI Healthcare Programme.

A recent poll has shown that almost two thirds of the general public (62%) would be willing to take part in dementia research, but more than four out of five people (81%) wouldn't know how to volunteer. *Join Dementia Research* is designed to overcome these barriers and give everyone the opportunity to play a role in changing the outlook for people with dementia now and in the future.

The lack of access to willing volunteers is holding back critical research into the condition with government figures showing that less than 5% of people with dementia take part in research studies. The first of its kind in the UK, this innovative

new service will boost research participation by connecting people interested in research to suitable dementia studies across England, Scotland and Wales. After piloting the service in a small region for six months, more than 1,800 people have signed up and already over 200 of them have participated in studies through *Join Dementia Research*.

The joindementiaresearch.nihr.ac.uk website offers a secure and easy way for someone to register their interest, discover studies that interest them, and ultimately connect with researchers to take part in their studies.

Anyone aged 18 years or over can sign up themselves, or on behalf of someone else, either by registering online or by contacting the helplines of Alzheimer's Research UK (0300 111 5 111) and Alzheimer's Society (0300 222 1122). By signing up to the service, people give permission for researchers to contact them with details of studies in their area that match their profile. People can then decide if they would like to participate in those studies on a case-by-case basis. By registering, people do not have to take part in any studies and can opt-out at any time.

Current research studies range from clinical trials of new treatments to surveys identifying what works in improving the quality of life of people with dementia.

Still Alice.

The film, *Still Alice*, has recently come out in cinemas and has sparked some discussion about whether it is a good, or a bad, thing for dementia awareness. The film follows the fictional life of Alice Howard, a 50-year-old linguistics Professor in America, who is happily married with 3 children. Whilst giving a lecture, a word eludes her; then whilst going for a run on a familiar path, she

becomes lost and confused. She is eventually diagnosed with a rare, hereditary form of Alzheimer's Disease which, genetic testing reveals, has also been passed on to her eldest daughter.

The film then follows Alice as she tries to get to know, and accept, her "self" with Alzheimer's disease. We follow Alice as she questions whether she is 'Still Alice'.

The film has raised some debate about whether it does raise awareness of dementia. Some people believe that it certainly does, whilst others believe that the film should have followed an older person living with Alzheimer's disease, as around 95% of people living with Alzheimer's disease are aged 65 years and over. Perhaps the best way to decide would be for you to watch the film yourself, and see what affect it has on you.

Two health professionals (Prof June Andrews and Dr Catherine Bailey) have recently reviewed the film, and you can read their reviews here:

<http://theconversation.com/still-alice-is-far-from-a-good-thing-for-dementia-awareness-38007>

<http://theconversation.com/films-like-still-alice-are-crucial-to-keeping-debate-about-dementia-alive-38675>

Ministers announce a new dementia plan in Wales.

On the 2nd of April 2015, the Health and Social Services Minister Mark Drakeford announced that Ministers will be providing an extra £1 million to support a new dementia plan in Wales, with £800,000 going to fund new primary care support workers.

The 32 new primary care support workers will work one-to-one with people living with dementia to provide support, information and advice on

where to access the best and most appropriate care for each person, in the hope that more and more people will be able to live well with dementia.

Ministers also hope to raise awareness of dementia in local communities, and the new primary care support workers will be integral to achieving this. The new money also means that the Alzheimer's Society's dementia friends and champion's campaign will continue to receive funding for at least the next 3 years.

The dementia friends campaign was started to increase the general public's awareness of dementia. The Alzheimer's Society have been going into different workplaces across the U.K and training members of staff to be dementia friendly. Some of these members of staff then complete additional training to become dementia champions and then they, in turn, can train others. The campaign has seen 9,800 people trained as dementia friends in Wales so far, and 400 people trained as dementia champions. This number should hopefully continue to increase with the campaign's additional funding.

The new dementia plan also hopes to see more G.P. surgeries complete the Welsh Government-funded training. Thus far, 30% of practices in Wales have undergone this training, which then led to almost all of these surgeries appointing a dementia lead and formulating a dementia action plan.

Finally, the new money will also be spent to fund four new primary care link nurses, who will be able to provide training to the staff working in the 675 residential and nursing homes in Wales about how to identify dementia, provide post-diagnostic support, link up with G.P. surgeries, and how to make their buildings more dementia friendly.

This £1 million is in addition to the £130 million

that has been invested in mental health facilities for older people across Wales, which led to funding for the Alzheimer's Society special patient information pack, a free, 24-hours Wales Dementia Helpline, and providing books on prescription and dementia in every public library.

<http://gov.wales/newsroom/?f=datepublished&v=02-04-2015&view=Search+results&lang=en>

Events

Dementia Awareness Week 2015 will take place in England, Wales and Northern Ireland from 17-23 May.

The theme for 2014 was 'Don't Bottle it up', and it was all about getting people to talk about their concerns. If you think you can help the Alzheimer's Society there are many ways that you could participate, for example, take part in a memory walk, go parachuting or ...come up with your very own idea for an event!

Organise a benefit performance, hold books and cake sales or do a collection. To find out more, visit the [Dementia Awareness Week](#) website and see how you can do your bit to help raise awareness.

The Dementia Challenge 2015: Defeating the Disease

Date: 2 June 2015

Location: The Mermaid Conference & Events Centre, London

Organisers: [dementia-challenge2015](#) This conference will provide crucial opportunities for learning and knowledge exchange for all those working with or affected by dementia.

Speakers include:

- Alistair Burns, National Clinical Director for Dementia, NHS England;
- Nikki Crowther, Alzheimer's Society;
- Gillian Leng CBE, Director for Health and Social Care, National Institute for Health and Care Excellence (NICE).

Inside Information: Heart

Date: 21st May 2015, 7pm-9pm

Location: [University Hospital of Wales](#) (Cochrane Building, 4/F)

Organisers: Professor Judith Hall, Dr Cristina Diaz Navarro, Dr Balachandran & Emma Lewis

Cost: £5 [Book online](#)

[Clod Ensemble](#) returns to Cardiff with the award-winning [Performing Medicine](#) project. In this new season of illuminating talks, demonstrations and workshops, leading artists and clinicians invite us to reconsider the ways in which we think about our bodies; our expectations of the healthcare profession; and the relationship between medicine, healthcare and the arts. All events are open to the public – no experience is necessary.

This season is brought to you by Clod Ensemble in association with [Cardiff University School of Medicine](#) and [Wales Millennium Centre](#) and is supported by [The Wellcome Trust](#).

The human heart is a symbol of love, kindness and courage but how does it actually work and what happens when it goes wrong? In this session, you will get to grips with the anatomy of the heart, experience a simulated demonstration of a medical emergency and explore a dancers perspective on this most celebrated part of the human body. This event will be illustrated by students from Cardiff School of Art and Design.

Women's Running 10k Race Series

Date: Various

Location: Various locations across the UK

Distance: 5k or 10k

Registration fee: £20

We are delighted to be the official charity partner for the Women's Running 10k Race Series 2015. These runs are for women of all abilities and there are 10 races to choose from across the UK.

- [Cardiff - Sunday 31 May](#)
- [London Finsbury Park - Sunday 7 June](#)
- [Southampton - Sunday 14 June](#)
- [Bristol - Sunday 28 June](#)
- [Milton Keynes - Sunday 5 July](#)
- [Nottingham - Sunday 12 July](#)
- [Liverpool - Sunday 19 July](#)
- [Glasgow - Sunday 30 August](#)
- [London Brockwell Park - Sunday 13 September](#)
- [London Finsbury Park - Sunday 27 September](#)

You can enter all races through the [website](#).

Angharad Jones and Matthew Lewis

Deputy Editors *Signpost*

Assistant Psychologist

Cardiff and Vale UHB

NB:

If anyone wants to include forthcoming events in future editions, please email either of the deputy editors.

Information about Signpost

Anyone Can Contribute to Signpost

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

Contributions

All contributions must demonstrate a positive attitude towards this group of people and their carers. Contributions can be made in the form

of an article, care study, letter, question, announcement, review or other appropriate proposal.

Contact Details

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

Tel: 02920 715787

Email: Amanda.Furnish@wales.nhs.uk

Books Available for Review:

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

- How We Think About Dementia—Personhood, Rights, Ethics, the Arts and What They Mean for Care. Julian C. Hughes, 2014.
- Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement. Sue Read, 2014.
- Excellence in Dementia Care - Research into Practice (2nd Ed). Murna Downs and Barbara Bowers, 2014.
- The Forgiveness Project - Stories for a vengeful age. Marina Cantacuzino, 2015.

Signposts Editorial Panel

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

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

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

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

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

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

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

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

