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SIGNPOST

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Editorial



As I write this editorial I am reflecting on the changes in the field of mental healthcare over the last 24 years that Signpost has been in production and the challenges for the future. I believe this edition of Signpost ably reflects many of the current exciting areas for future development. The issue includes

an article by Lorraine Cullen and Jenny LaFontaine describing the role of the Dementia Care Adviser in Worcestershire. Whereas these posts have been in development for a little while in England they have only recently been introduced in Wales and we have yet to see their full potential.

We also have two articles exploring how arts and creativity can be used to aid assessment and also enrich the lives of people living with dementia. Claire Ford describes, among other experiences, the inspiration she gained whilst a Churchill fellow visiting the programme at the New York Museum of Modern Art. Phil Thomas describes the collaborative arts project entitled 'In Your Mind's Eye' which aims to bring professionals from the nursing and artistic worlds together to add to the body of knowledge about the assessment of patients with dementia. Both these articles describe the role that the arts can play for people with dementia and emphasise what can be achieved once we open our minds to potential.

We also include an article by Pamela Noble in which she describes a local cognitive stimulation group and goes on to describe how the group members have gained in confidence and enthusiasm as the group has progressed and jelled. What struck me overall about this article is that the author was describing a group of people enjoying themselves and making the most of life.

I was particularly drawn to a quote from Anne Basting in Claire Ford's article

'Alzheimer's is a hundred year old myth that is over the hill. The entire scientific, technological and political framework needs to be reassessed...'

As Signpost enters a new phase in its production by becoming an e-journal based on the Dementia Services Development Centre– Wales web-site I am confident that it will continue to bring you the mix of articles that embrace this challenge.

Dr. Christina Maciejewski

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Foreword



Dr Simon O'Donovan has worked in mental health services for older people in Cardiff and the Vale of Glamorgan for some 25 years and has a recent background working as a Nurse Consultant with a specialist remit in

Safeguarding Vulnerable Adults.

Simon has been Clinical Director for 6 years and since 2011 has been identified as the Clinical Lead for the Board's Younger Onset Dementia Service.

WE ARE THE ONES WE'VE BEEN WAITING FOR

"Change will not come if we wait for some other person or if we wait for some other time. We are the ones we've been waiting for. We are the change that we seek." (Barack Obama, 2008)

I really like this motivational quotation from Barack Obama. It sums up my thinking about change. Yes change is difficult, takes considerable effort and requires detailed planning and consultation, but it also needs vision and action.

In respect of service modernisation, the need for change is pressing. With the forecast dementia population increase (31% in Wales between 2007 and 2021, UK Dementia Report 2007), and the similar increase expected in the severely mentally ill elderly population (which has received little attention by comparison), we need to plan for services that are community-focused and can accommodate increased demand without a massively increased bed provision.

This is a time for action and a 'Let's get on with it, but carefully!' mentality. After all, if we wait any longer to change the way we currently provide services for the next generation of clinical and managerial leaders it will be too late.

So in this article I would like to tell you about our service modernisation programme, what we have achieved so far and what our plans for the future service look like. This is in the spirit of sharing and learning, as there is so much service innovation and best practice across Wales and the UK to inspire and direct us.

How did we start?

In 2009-10, the health and social care partnership of Cardiff and the Vale of Glamorgan were supported by the University Health Board's (UHB) planning department to undergo a Programme for Health Service Improvement. This enabled the partnership to achieve a shared vision which set the scene for service transformation. But despite the unanimity achieved

between health, local authority and third sector partners, further enablers to initiate real change were required.

This focused review of services and future direction was followed in 2010-11 by the development of the National Dementia Vision (NDV) for Wales (2011) and its associated action plan for improving services, which built on the previous National Service Framework for Older People in Wales (2004). This focused on developing comprehensive community services for people with dementia, older people with later life severe mental illness and the carers of these groups and reducing dependency on hospital-based services.

Following NHS reorganisation and a period of settling into new management arrangements, in 2011-12 the Integrated Health and Social Care Board supported the Mental Health Services for Older People Directorate with a Service Review which set out a programme for service change and improvement. This consolidated previous discussions and enabled a focused action plan to be developed. In the following paragraphs I would like to tell you about some of the main outcomes of this Review and the direction of travel for the whole service pathway.

Memory Team

Whilst Cardiff Memory sits within another Division/Directorate, the review has helped both parts of the service to come closer together and through a Public Health supported work stream focus on improving the referral and diagnostic pathway, for example by providing structured training inputs to colleagues in primary care. The collaboration has also supported the service with taking forward the Dementia Intelligent Target aimed at reducing the time interval between onset of symptoms and diagnosis. (The Dementia Intelligent Targets form part of the 1000 Lives + campaign in NHS Wales.)

Carer support services

For some considerable time in Cardiff and Vale we have had a specialist Solace Carers Support Service which sits within mental health services for older people and aims to support carers through the provision of a range of individual and group based psycho-educational supports. Over recent years the service has been reviewed to widen its remit and support the carers of older people with severe later life mental illness in addition to those whose relatives have a dementia diagnosis. Good partnership working takes place with Alzheimer's Society and Memory Team colleagues to provide a range of early interventions, such as post-diagnosis support groups, and cognitive stimulation for people with more advanced illness. A Dementia Care Advisor has also recently been appointed to work between the Memory Team and the Solace Carers Support Service to support these activities and provide increased opportunities for monitoring and review of clients post-diagnosis, identifying and signposting when the caregiving situation is in need of increased support from the Community Mental Health Team for Older People (CMHT OP).

Integrated CMHT OP management and IT

We are fortunate to have had integrated Community Mental Health Teams CMHTs for Older People for some time in Cardiff and the Vale of Glamorgan. To consolidate the multi-agency approach, we aim to develop a centralised shared team base for Cardiff and work towards integrated team management and care management processes when possible. This will better position us to meet the requirements of the Mental Health Measure (Welsh Assembly Government, 2010).

Crisis home treatment and out of hours service

We are well advanced in planning for enhancing CMHT OP staffing across our localities to enable a 7am-10pm, 7 days a week service. This will aim to provide enhanced out of hours support to known clients and crisis support to newly identified clients and caregiving situations, both with the intention of admission avoidance and maintenance of people within their home/care home setting. Earlier discharge from hospital will also be facilitated. The Health Board has seen this as a key priority and out of its Capacity Plan allocated £750k recurring to realise this service development.

Younger onset dementia service

We have used NDV monies to appoint a Younger Onset Dementia Care Advisor and 1.5 whole time equivalent Family Support Workers. In addition to this we have added several Consultant and Clinical Lead sessions to form a start-up Younger People with Dementia Service. This is a post-diagnostic service, working with the Alzheimer's Society and Memory Team to follow clients and carers throughout the illness trajectory, coordinating their care management and supporting the whole family, especially through transitions in care.

Care homes old age psychiatry liaison service

We have recycled some resource to initiate the development of an in-reach support service to care homes. This service, which comprises speciality doctor sessions, a specialist liaison nurse post and a dementia care advisor, provides advice on treatment and care management to avoid breakdown in placement. It also aims to enhance person-centred care and non-pharmacological approaches through the provision of training and staff support. Over forthcoming months we will aim to expand the service, to increase quality of care and capacity especially in EMI nursing homes. The service will also support the work required to meet the Dementia Intelligent Target around reducing the prescription of anti-psychotic medication to people with dementia in care homes.

Tiered day hospital pathway

We have worked over several years to modernise the day hospital pathway to focus provision on patients with acute mental health needs and ensure step down support with a focus on discharge planning. To this end we have developed an acute assessment and treatment day hospital service with a shortened length of stay and

the provision of cognitive stimulation and psychological therapy sessions to promote a recovery model aimed at admission avoidance and earlier discharge from hospital. Tier 2 day hospital services are then provided in the three localities which focus on rehabilitation and ongoing support for patients with enduring mental health needs. We hope to work with local authority and voluntary sector partners to provide an integrated service in tier 2 day services in the forthcoming period.

Purpose built acute in-patient assessment unit

All of our acute assessment and treatment in-patient services, together with the tier 1 day hospital service, will move into new purpose-built accommodation at University Hospital Llandough (UHL) later this year. More appropriate environments will be provided, hopefully enabling our in-patient services to become Royal College of Psychiatrists AIMS accredited with excellence (all units already have accreditation status), which will give us recognition as a flagship area of best practice. The MHSOP Acute Unit will also enable more flexible and therapeutic care to be provided, for example through the provision of a number of crisis/high care beds, the availability of increased therapy facilities including multisensory rooms, with roof terraces and enclosed gardens for physical exercise and outdoor activity.

Extended psychiatric assessment in-patient units

Whilst we are having to reconfigure some of our services around the MHSOP Acute Unit, we aim to continue providing high quality extended psychiatric assessment in-patient care in each of our localities for patients with enduring mental health needs and associated challenging behaviours. We have recently moved two wards into a refurbished community unit which provides group living facilities and single bedrooms for this patient group and already have a unit in Barry Hospital which has previously won recognition for its purpose-built dementia care design. In the next phase of development we aim to scope the possibilities for a dedicated in-patient facility for younger people with dementia.

Managed bed process

To ensure best use of our bed resource and the admission of patients assessed as being most in need of our services, we convene a weekly bed management meeting with senior clinicians and managers in attendance, including CMHT OP team managers. All patients referred for in-patient assessment are risk assessed before inclusion on a managed waiting list and collective decisions are made about prioritised admissions. This meeting also enables close attention to be given to discharge planning and move on for patients identified as delayed transfers of care. Levels of prescribed nursing observation are also reviewed at this meeting, to enable a better understanding of risk. Reports are issued to the Division from this meeting on a weekly basis to communicate activity and patient flow.

In-patient acuity and managing risk

As a result of this managed bed process, in-patient acuity has undoubtedly increased over recent years. We are experiencing more Mental Health Act admissions than previously and our incidents of violence and aggression have been rising. As many of our patients suffer co-morbid medical conditions, we have also seen an increase in medical complexity of our in-patient cohort, one measure being an increased incidence of falls. Following participation in the RCP National Audit of Violence, the service undertakes a rolling audit of violence and aggression incidents and undertakes review following any serious or untoward incident involving patient or staff harm. The service also undertakes a rolling audit of falls and hospital-acquired fractures, with a focus on falls prevention. A reduction of fracture incidence has been seen since this programme commenced.

Salaried GP and Clinical Case Manager Service

We are fortunate to have available a Salaried GP and Clinical Case Manager Service which works across the Mental Health Division. The service was established in response to escalated clinical governance concerns about mental health in-patients not having access to primary care physicians, both in respect of acute medical illness but also chronic physical health problems. Fifteen GP sessions and 6 Clinical Case Manager sessions are provided and several GP clinics are held. The remaining sessions are allocated for ward visits, for patients who are too medically or psychiatrically unwell to attend Clinic. The service has been running for just a year, but evaluation has shown high uptake of service and positive health outcomes for a patient group who previously had much unmet need.

Hospital old age liaison psychiatry service

For several years we have had in place a Hospital Old Age Liaison Psychiatry Service, comprising a Consultant Old Age Psychiatrist, two Specialist Liaison Nurses, a Medical Secretary and to be appointed Dementia Care Advisor (DCA). The service has also recently moved into refurbished accommodation in University Hospital of Wales (UHW). In addition to providing consultation, advice and support to general hospital wards across UHW and UHL in managing patients with significant psychiatric symptoms and challenging behaviours, the service will play a pivotal role in helping the UHB in implementing the Action Plan developed in response to the RCP Dementia Care in General Hospital audit. This includes developing and implementing a cognitive impairment pathway, introducing the Butterfly Scheme (see previous issue of Signpost) and providing a range of training inputs to staff and teams. The DCA post will also be key in following patients known to the CMHT OP through their hospital stay and up to discharge planning. Being the main point of contact for carers and supporting the delivery and audit of a carers' satisfaction survey to highlight areas for improvement will also feature large in this work. This will help us meet the Dementia Intelligent

Target for improving dementia care in the general hospital setting.

Education and training

As stated already in many of the above paragraphs, much of this work is supported by considerable training activity. The Dementia Training Initiative supported by the Welsh Assembly Government and delivered through the Dementia Services Development Centre Wales will have an ongoing effect if the Training for Trainers' programme and accredited training packages continue beyond the duration of the funded scheme. We see the work of the DCAs being key to continuing this training activity, but also recognise that all of us will need to support wider learning if real and lasting improvements are to be made.

Of course, Signpost is perhaps one of the most important vehicles we have to demonstrate our commitment to training and education. It has been available now, in its various forms, for some 24 years and we are aiming to make some changes to its production also as part of this whole service review. What we are intending to do is finish Signpost in its print format and make it available, free of charge, via the DSDC Wales web-site. This will hopefully mean that it will reach a far greater readership and that its important contribution will be more widely appreciated.

Looking back to the first issue, printed in October 1988, I wrote "Signpost is an exciting new venture which provides a forum for open discussion and a focal point for sharing of ideas and problems which are familiar to us all when caring for the special needs of this client group." When we re-launched it as a national subscription journal in December 1996, I thanked readers for their written contributions, their positive feedback and their supportive comments. I do the same now and look forward to the next phase in the development of Signpost with optimism and enthusiasm.

I hope this brief overview will illustrate what a tremendous time of change it is in Cardiff and Vale and that we have been able to make considerable improvements to services over recent years, despite being in a difficult resource environment. It is time to feel hopeful for the future service and genuinely proud of what we have achieved. Hopefully those who come after us will feel that we have designed a service fit for purpose and worthy of a 21st Century NHS and Social Care provision.

Reflections on establishing and delivering a Dementia Adviser Service: The Worcestershire Dementia Adviser Service



Lorrain Cullen has worked as a Dementia Adviser as part of the Alzheimer's Society Worcestershire Dementia Adviser Service since the service launched in early 2010. Before that she worked for Worcestershire County Council Home Care

Services for 19 years. During 2005/2006 she gained her Counselling and Advanced Cert at Kidderminster College. In July 2008 she graduated with a degree in Social Welfare from Worcester University and took a position as a Senior Homecare on a pilot scheme for the Side By Side Dementia Service.



Jenny La Fontaine is a Senior Lecturer in the Association for Dementia Studies at the University of Worcester. She has worked as a Mental Health Nurse for nearly 30 years, specialising in working with people living with

dementia and their families. She has worked as a Consultant Nurse in services for younger people with dementia and as an Admiral Nurse. She has an MA in Social Gerontology and is currently undertaking a PhD. Her research interests include family experiences of dementia, interventions for families, early intervention and practice development.

The National Dementia Strategy for England 'Living well with dementia' (DH, 2009), sets out an action plan to improve the lives of people living with dementia and carers in England. The strategy has three main aims:

1. To improve the awareness of dementia among the public and health and social care professionals.
2. To ensure that diagnosis is made as early as possible; this would allow early intervention to be more effective.
3. To deliver high quality care and support for people living with dementia.

To achieve these aims, seventeen key objectives were identified, including:

Objective 4: Enabling easy access to care, support and advice following diagnosis. A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

As part of the local response, Worcestershire County Council, NHS Worcestershire, The University of Worcester (Association for Dementia Studies) and Alzheimer's Society, worked collaboratively to bid for, deliver, and evaluate a Department of Health funded Dementia Adviser demonstrator project. The Worcestershire Dementia Adviser service started to take referrals in March 2010 and continues to offer information and signposting to people with dementia and carers following a diagnosis of dementia.

The Worcestershire Dementia Strategy

Worcestershire has the highest population of older people in the West Midlands, and the highest prevalence of dementia. The number of people with dementia in Worcestershire is set to rise to over 10,000 by 2020 (NHS Worcestershire & Worcestershire County Council, 2011). In 2010, 1/3 of people with dementia in Worcestershire had received a diagnosis.

It is now widely accepted that early diagnosis and intervention can improve outcomes for people living with dementia. In particular, early intervention maximises choice and autonomy, helping individuals and families adapt to the illness and be able to discuss and make plans for the future. An opportunity for future planning can be missed if the diagnosis is later (Bannerjee, et al. 2007). Following an early diagnosis access to the right information, emotional and practical support are essential.

In response, the Worcestershire Dementia Strategy (2010) has been developed and prioritises early intervention. Since March 2010 the Dementia Adviser Service has been providing information and signposting to people post-diagnosis and in July 2010, Worcestershire Health and Care NHS Trust, working in partnership with NHS Worcestershire and Worcestershire County Council established the Early Intervention Dementia Service (EIDS) to improve diagnosis and early intervention. Dementia Advisers work alongside colleagues in the Early Intervention Dementia Services to provide continuity and support to people from assessment onwards.

The Association for Dementia Studies (ADS) at the University of Worcester has been closely involved with

the development and evaluation of both the Early Intervention Dementia Service (EIDS) and the Dementia Adviser service.

Worcestershire Dementia Adviser Service

Alzheimer's Society Dementia Advisers provide people with information about dementia and signpost to other support and services from the time of diagnosis onwards and remain a point of contact for information throughout a person's journey with dementia. As a minimum people will have contact with their Dementia Adviser twice a year, to check how things are going, identify if there are any concerns or changes and to identify areas where support can be offered.

Two Dementia Advisers took up post in Worcestershire in December 2009 and began receiving referrals in March 2010. Initially, the source of referrals to the service was varied, including, self-referrals, family members and through the voluntary sector, and included referrals of carers of people with dementia who had received a diagnosis several years prior. With the launch of the Early Intervention Dementia Service (EIDS) in July 2010, both services were integrated. A pathway from Early Intervention Dementia Service to Dementia Adviser service was established and implemented.

The experience of delivering a Dementia Adviser Service

Over the first 18 months, a number of challenges and opportunities existed in the development of the service.

Embedding the service

The challenge of embedding a new service where the Alzheimer's Society had a limited presence was significant. Understanding of the role of Dementia Advisers within partner agencies was inconsistent. Terms such as "information" and "signposting" were insufficient in explaining the role and sustained efforts to raise awareness were unsuccessful. As a result the benefits of the service were not widely appreciated and confidence in the service seemed low.

In response, Dementia Advisers offered to shadow colleagues within local teams and demonstrate the Dementia Adviser role by describing the work that was being carried out with the people being referred. Over time a clearer understanding of our way of working, along with the skills of Dementia Advisers and the positive outcomes for people living with dementia developed. This is an activity we have repeated with positive results.

The referral pathway is now well established and colleagues in the Early Intervention Dementia Service have reported more confidence when planning discharge, from knowing that the people living with dementia and their families have a point of contact and ongoing support.

Providing continuity of contact through the journey

Providing a point of contact from diagnosis onwards and thereby offering continuity when accessing information and support, is part of the aim of the Dementia Adviser Services. As dementia progresses, a person's information and support needs are likely to change, so it's particularly important that people know who to contact as needs change.

Over the last eighteen months, people have had contact with the Worcestershire Dementia Adviser Service in different ways. It has been common for initial meetings to be face-to-face in a person's own home. These initial meetings can take between 1 and 2 hours. Further contact may take the form of a meeting in the local office, or another convenient location, a telephone conversation, a letter, or an email.

Dementia Advisers and colleagues in the Early Interventions and Support Service also conduct joint visits. Joint visits seem to give families an opportunity to put a face to the name of their Dementia Adviser early on and learn first hand about the Dementia Adviser Service. It also creates the opportunity to start building the important trusting relationship between a person with dementia and their Dementia Adviser.

Dementia Advisers have needed to be flexible in our approach in order to respond effectively to a person's needs and preferences. This appears to be resulting in positive outcomes for the people who use our service, evidenced by the numbers of people who have made contact with the service for further information or signposting.

In service evaluation interviews conducted by colleagues at the Association for Dementia Studies (ADS) at the University of Worcester, people commented on their experience of the service:

"So if I've got a problem or I want to ask anything, I phone [DA] now, yeah"

"We did, we met, she was the first person that we met after you'd been diagnosed, and now every month she's at the meetings isn't she?"

Signposting to other support and services

In our first weeks and months in post Dementia Advisers spent time getting to know the local area and familiarising ourselves with the support and services available and the organisations providing them. Support services, and organisations were all entered onto Guidebook, the Alzheimer's Society's database of support and service. Guidebook provides accurate and reliable information on local and national services that might support people living with dementia. Dementia Advisers are able to print a one-page record of a service, to leave with a person with dementia, to help with memory prompting and accessing services. Guidebook printouts include important information about services such as whether there is a fee, who can be contacted for more information, and a photograph of the venue to help with finding the service.

The biggest challenge in signposting has been the limited availability of some services. In some cases, people with dementia and their families have wanted to take part in social activities, or attend day services that are unavailable or inaccessible. The need for transport to access services has been a barrier for many when attempting to access services.

Dementia Advisers have been well placed to identify gaps in provision and where needs could not be met for other reasons and have ensured instances of unmet need were communicated to local commissioners and service providers. In some areas, where identifying appropriate support and services was particularly challenging, Dementia Advisers have needed to be resourceful, creative, and persistent in supporting people. With this has come a certain amount of frustration.

The information needs of people with dementia and their carers

In the weeks following the launch of the Dementia Adviser service, a high number of carers who were caring for a person with later stage dementia were referred to the service. At this time information requests came largely from carers who were struggling to cope with caring. Some families reporting feeling close to crisis; they did not know where to go to get support or what services were available to them. Large numbers of carers although they had been living with dementia for some time sought more information on the diagnosis itself, if only to try and make sense of some of the situations they were facing.

As the Dementia Adviser Service became established and the referral pathway from the Early Intervention Dementia Service was implemented increasing number of people with dementia had contact with the service shortly after receiving a diagnosis.

Working directly with people with dementia required Dementia Advisers to take a person-centred approach to information giving. In practice this meant taking into account a person's understanding of their dementia, and their coping strategies and adjustment following diagnosis. Often people did not know what information they needed or wanted immediately after diagnosis and it took time to discuss and identify with their Dementia Adviser what information was relevant to them. Time spent with a Dementia Adviser enabled people to identify and prioritise their own information needs. For some, information was more accessible when presented in bite-sized chunks, whilst others required much more detail on a wider range of topics. In our experience it meant a lot to some people with dementia to have a familiar voice on the end of the phone; someone to be there along the way should questions or concerns arise. As a carer of a person with dementia said:

"But I can see that there will, I feel there will be a time when I need, when we need perhaps more help, it's a comfort to me to know... that it is out... that there is help there if I need it. That's

the main thing, not to feel alone. And I, I feel, you know, had we been down in our old um, you know, had we been down in [previous home town] that we wouldn't have had the support."
(Family Member).

The importance of listening well to people with dementia cannot be understated. A vital aspect of the Dementia Adviser role is to recognise and acknowledge a person's emotions, to listen to their story, recognise concerns and stresses. Meetings between a Dementia Adviser and a person with dementia have included discussions on all aspects of dementia, as people take the opportunity to talk and think about dementia. It is only through careful listening that a better understanding of the needs of the person living with dementia and their family can be reached.

Sometimes the needs of the person with the dementia and those of the carer differ. Here the role of the Dementia Adviser is to balance the needs of the person with the dementia and carer sensitively and appropriately to ensure both voices are heard and validated. Time to talk together can give families the opportunity to support each other with adjusting to life with dementia. For more on this see Keady and Nolan (2003).

For some it can be difficult to speak openly in front of others, and concerns may not be raised if people are worried about misunderstanding, upsetting, or disagreeing with family members. In other cases, carers have taken on the role of speaking on behalf of the person they care for. It has been important for Dementia Advisers to stay mindful of this and to find ways to involve people with dementia in discussions and decision-making. One way we have done this is through the use of prompt cards to help people with dementia identify the subjects that are important to them.

Evaluation of the Worcestershire Dementia Adviser Service

The Association of Dementia Studies at the University of Worcester carried out an evaluation of the Dementia Adviser Service as part of the Department of Health funded demonstrator project. The evaluation was conducted collaboratively with the Alzheimer's Society, NHS Worcestershire, Worcestershire Health and Care NHS Trust, and Worcestershire County Council. Evaluation included seeking the views of people living with dementia and their family members at two time points, interviewing the Dementia Advisers every month through the lifetime of the project and interviewing stakeholders about their views of the service. Outcomes of the evaluation validate the experiences and observation of Dementia Advisers in setting up and delivering the service.

The experiences of people with dementia and carers

People reported feeling more confident about knowing who to go to in the event that support was needed. This was particularly evident when the connection was achieved through a joint visit with the Early Intervention

Dementia Service. The joint visit may have helped to increase understanding of roles and support available locally. One participant in the evaluation explained who they would go to and when:

"[EIDS Nurse] or [DA], depending on what, whether it was from a nursing point of view which EIDS Nurse is or a practical point of view, which [DA] is"

In those areas where Dementia Adviser Service was not available, concerns about lack of continuity and support were evident:

"The last one was three months ago, in fact [she] was due for another visit to ...today, or yesterday, and that has now been put back for a further three months, which makes it six months between - interviews, which I'm not happy with... But I don't consider that good enough- that we're losing continuity, whether it's medically required I can't judge but it does cause some concern" (Person with Dementia and Family Member)

Participants reported a range of ways they had benefited from the service, including receiving information concerning dementia and a range of issues associated with their needs and the specific challenges experienced:

"So we have had lots of support, paperwork, booklets, information" (Person with Dementia and Family Member)

"She came out, she brought me a file, a folder out with lots of information about you know dementia and then Alzheimer's and I have been on and off the phone to her actually" (Person with Dementia)

Such information also included the opportunity to plan for the future, to address financial concerns and to better understand difficult situations.

Outcomes were not as positive for all. Those who did not have an initial face-to-face meeting with a Dementia Adviser and colleague from Early Intervention Dementia Service and only had the opportunity for telephone contact were less likely to report feeling more confident about accessing support and services. Those who had not gone on to have regular contact with a Dementia Adviser or other support services such as Dementia Cafes were also less likely to report increased confidence.

"Now I think the thing that worries me is ... things could run on quite a bit, and you may find yourself a few months, a year or two down the line, in a difficult situation where you then have to contact everybody in, in a panic because things have gone wrong. And perhaps the thing that would've been, would prevent that uh, happening is some kind of review, be it ever so tiny, be it only a telephone call every six months

or so to say well, "We saw your Mum so long ago" you know, "you're on our books" as it were, "we're just reviewing where you are. What's the situation? Are things worse? Uh, do you think you need, do we need to do any kind of review? Do we need to come and advise about uh, other services that might be available?" And then I think you would feel you were still in the loop" (Family Member)

Whilst it should be noted that the Dementia Adviser Service does not aim to provide ongoing intensive support to families, some participants reported a lack of support in this area.

What makes a good Dementia Adviser?

The evaluation has also highlighted the range of knowledge and skills needed by a Dementia Adviser in order to deliver a person centred service. The requirements of the role were identified as.

- Being alongside the person living with dementia and their family in their journey with dementia, which includes making contact with them on a regular basis, dependent upon their needs;
- Carrying out an assessment of need through which the requirements for information and advice, support and signposting can be determined;
- Providing information and advice which is sensitively tailored to the expressed needs of the person in receipt of the service, which can range from:
 - Information concerning dementia itself;
 - Coping strategies for managing specific issues such as understanding the impact of dementia upon behaviour;
 - Living well with dementia;
 - Future planning;
 - Benefits and entitlements;
 - Signposting, which involves the provision of information about local and county wide services that are available and which can also involve assisting the person to access those services as appropriate to their needs;
 - Providing sensitive assistance with planning for the future, including information about finances.
- Promotion of the role and service, and raising awareness about dementia to individuals, groups and organisations within the local community;
- Networking and developing partnerships with key agencies and individual professionals;
- Developing local knowledge so that signposting activities can be carried out effectively;
- Responsiveness to populations who may be hard to reach;
- Identification of unmet need.

Conclusion

A diagnosis of dementia means a gradual process of adjustment, a process during which access to information and support will be important for many. Having the opportunity and being given the time to think and talk things through with a trusted, skilled and knowledgeable adviser, to better understand your dementia and to find out about the support and services available to you, will be essential if people are to live well with dementia.

Despite the challenges faced in setting up and delivering a new service, people who have had access to the Worcestershire Dementia Adviser Service have reported improved outcomes in understanding of dementia and access to support. To deliver the service effectively Dementia Advisers have had to be creative, resilient and highly skilled, and be particularly aware of the dynamics of person with dementia, carer, and professional, relationships.

The Dementia Adviser Service in Worcestershire has now been extended. Funded by Worcestershire County Council, five Dementia Advisers now provide a service across the whole of Worcestershire.

To find out more about the Worcestershire Dementia Adviser Service contact Gill.carter@alzheimers.org.uk

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The Signpost team is sorry to announce that a long standing and valued contributor, Dr Jim Ellis, passed away just after his last article was published. Dr Jim Ellis was a former Open University tutor and became involved in dementia services as a result of his wife's diagnosis and subsequent experience of Alzheimer's Disease. Inspired by his experience

he wrote many articles about dementia care and was involved in several organisations and services. Dr Ellis was a volunteer companion in a nursing home for those with dementia. His particular interest was one-to-one psychosocial interactions which he described in numerous articles. He was also involved in dementia awareness sessions for nurses, Alzheimer's Drop-in Centre and Support Group, and was a member of the Alzheimer's Society's Consumer Research Group. There were many who benefitted from Dr Ellis's generous contributions and we are sure he will be missed by all who knew him.

The Alzheimer's Society concept 'Music for the Brain' is useful in developing the debate about the positive effect of music for people with dementia and alerting carers and professionals to its potential. However, singing has been used in many nursing homes for people with dementia for some time. Often this is led by a visiting keyboard player; sometimes it is a visiting specialist organisation like the Nordoff Robbins music therapy service or the Glyndebourne Opera education group for people with dementia. Perhaps we need 'Poetry for the Brain', but there is not the same drive or framework for researching poetry and its benefits for those with dementia. Not surprisingly there are fewer discussions in the literature.

There is now a significant nucleus of professionals who understand the deep effects of music which has been recognised since Plato discussed it in ancient Greece. Plato had no doubt about the 'decisive importance' of music and poetry. Elaborating on this he recognises the profound effect of music: '.....rhythm and harmony sink deep into the recesses of the soul and take the strongest hold there.' (Cornford, 1941). In more recent times rhythm has appeared as a component of therapy. Applying coma therapy while interacting with her mother Clarke (2004) writes of 'dancing fingers' to break through the dementia. This one-to-one interaction contrasts with much of the 'Music for the Brain' therapy and its emphasis on group work.

Hymns and Songs

My own experience has been with one-to-one situations which often have arisen quite spontaneously as a result of an initiative by the person with dementia. One

gentleman loved singing the hymns he had learned as a boy simply by hearing them so many times. A reference to a particular hymn would be enough to have him sing with enthusiasm words he had learned over eighty years before. I would also have a tape available of hymns sung by a youthful Aled Jones which he found very moving and served to embellish the experience. At the monthly services in the nursing home he would join in confidently with me sitting beside him. He liked to have his hymn sheet although his fading eyesight did not allow him to read it. No doubt years of the tactile experience of a hymn book or hymn sheet conveyed continuity and security. It would all help to consolidate the occasion.

Even more surprising and spontaneous was an incident with another resident when we were sharing responses to 'A funny old world', a volume in the 'Pictures to Share' series (Bate 2008). Led by the resident we had been concentrating on the images rather than the highly appropriate words which were set in the spaciousness of the left hand side page. Then we came to a photograph of an ecstatic mother clutching her little child with them both full of laughter. On the opposite page were the first two lines of the well-established song 'When you're smiling'. My companion's eye fell on the words and she began to sing. I joined in, carried along by her enthusiasm and I felt we had lived a moment of joy for the resident by transporting her to another world where she was enveloped by happiness.

Sometimes the music and the performer are the key ingredients. This is particularly so with George Formby and his strongly rhythmical ukulele but the lyrics are important too as I have found with 'When I'm cleaning windows'. Some residents seem to be genuinely amused by the images created: 'The blushing bride she looks divine / The bridegroom he is doing fine / I'd rather have his job than mine / When I'm cleaning windows'. Even without the tape I have found some positive response when the resident has attempted to join in with my rendering of the words. This occurred particularly with 'I'm leaning on the lamppost at the corner of the street', another Formby song, more sentimental and perhaps sparking a real memory with the first words creating a simple but strong image.

A completely unforeseen and unplanned episode involved myself and three residents. Initially it was an unremarkable occasion when I joined a resident sitting alone at one of the dining tables. We chatted as we usually did about her early days on the family farm until one of the care assistants brought along two other residents. One of them was waving her arms about as she often did and quite spontaneously I began singing the Hokey Kokey. Two people joined in enthusiastically. There was no question of standing to do this, as all these residents needed help in walking, so we did our own sit-down version. Everyone was able to move their arms and two tried some movement in the legs. It was all rather haphazard but assessed by the vigorous response of these residents with different degrees of

dementia it was a really worthwhile activity. There were whoops of exhilarating laughter and shouts as if the contents of a container had been released. A need had been met it seemed.

Many of our musical experiences were far less spectacular and were often nothing more than a tape/disc of popular song or even my own efforts to sing a few lyrics quite unaccompanied. I noticed that these personal attempts of mine were often more effective for the resident than simply listening to the tape for it emphasised the social aspects of the live experience with two of us interacting and my companion trying to sing a few words.

Poems

The poems we used to share were always those which were most likely to be accessible in terms of meaning and general appeal. It was often clear that they were recalled from school days and sometimes the memory of several lines would have remained. A strong feeling of achievement was often present with people obviously pleased with their ability to offer something from within themselves. An example of this arose in a happy session I had with a gentleman who had a long established interest in steam locomotives. He was always keen to tell me about the old semaphore signalling system and its 'failsafe' device and was fascinated by the DVDs of steam trains I used to bring along for us to view together on my portable DVD player. The poem that we both enjoyed so much was W.H.Auden's Nightmail originally written to accompany the Post Office film.

My companion very much appreciated the way in which the words, rhyme and rhythm reflected the speed of the train. In the first five lines the train is moving at speed initially then we feel the effort of the Beatock climb:

*This is the Night Mail crossing the border,
Bringing the cheque and the postal order
Letters for the rich, letters for the poor,
The shop at the corner and the girl next door
Pulling up Beatock, a steady climb.*

Later in the poem the rhythm quickens as we hear of the many letters and their varied content. This is another strength in the poem for people with dementia as the images are concrete rather than abstract:

*Letters of thanks, letters from banks,
Letters of joy from the girl and boy,
Receipted bills and invitations.....*

Poems with a strong, clear narrative like The Highwayman have been particularly successful. This poem has many of the qualities of Night Mail especially the powerful rhythm, this time reflecting the galloping horse:

*The road was a ribbon of moonlight over the
purple moor,
And the highwayman came riding –
Riding – riding -*

*The highwayman came riding, up to the old inn-
door.*

The whole poem is rather too long to hold the interest of some residents so I tell the story in brief first then omit some stanzas as I read the poem. This approach seems to work quite well with people exhibiting mild dementia. For those with more severe dementia and short term memory loss further modifications are necessary. We always try to end the session before interest begins to fail. The penultimate stanza makes a powerful, summarising finale:

*And still of a winter's night, they say, when the
wind is in the trees,
When the moon is a ghostly galleon tossed
upon cloudy seas,
When the road is a ribbon of moonlight over the
purple moor,
A highwayman comes riding –
Riding - riding -
A highwayman comes riding up to the old inn-
door.*

Quite different are the limericks of Edward Lear. These have worked well with residents who have more advanced dementia. The limericks could well have been written especially for people with dementia since they have so many characteristics that aid accessibility. They have brevity, strong rhythm, rhymes and concrete, humorous images. The mini story of each limerick relates to subjects familiar to all as with:

*There was an Old Person of Mold
Who shrank from sensation of cold;
So he purchased some muffs, some furs and
some fluffs,
And wrapped himself from the cold.*

Perhaps I should not have been surprised to find that Lear's The Owl and the Pussy-cat was known by every resident without exception, clearly remembered from school days with affection and perhaps not heard since then. I read it many times on visits over a protracted period and never failed to engage people in delightful response from the memorable opening lines:

*The Owl and the Pussy-cat went to sea
In a beautiful pea-green boat,
They took some honey, and plenty of money,
Wrapped up in a five-pound note.*

It has all the key features of the other poems with the added humour of fantasy. The rhyme within lines ('O let us be married! too long we have tarried') and the repetition all combine with the other features to make the poem ideal to stimulate a range of people with different degrees of dementia. The poem ends as strongly as it begins

*And hand in hand, on the edge of the sand,
They danced by the light of the moon,
The moon,
The moon,
They danced to the light of the moon.*

Conclusions

Overall, poems and songs can be appreciated at several levels. With more advanced dementia there is likely to be less understanding at a literal level, but my own experience of sharing poems and songs has suggested an understanding at an emotional level (Ellis, 2010).

All of the experiences described here have taken place as part of an on-going relationship between myself and residents (Ellis, 2009). To sit down with a resident as a 'cold-caller' would be less likely to produce the silent, subtle understandings that are present in an on-going companionship. The interaction of resident and companion is a delicate one developed over a period of time. The material, whether it be song or poem, is the catalyst. If chosen appropriately it can greatly enhance the relationship.

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Cognitive Stimulation Therapy Group



Pamela Noble qualified as a social worker in 1979. She has worked with people with a diagnosis of dementia for many years, also working and learning from carers and the person with dementia. In January 2011 she joined Solace.

Solace primarily supports carers in their journey of supporting their loved one. My role is described as that of an administrator, which has never been one of my strong points! The job title is Volunteer Carers Support Worker and it has given me the most enjoyable fulfilled work of my working life.

When I arrived at Solace Cognitive Stimulation Therapy groups were already in progress. I assisted a nurse Tim Nicholls in running the groups. However, Tim was unexpectedly unable to facilitate the group so I had to hit the ground running and I had only been in post for 2 weeks!

Cognitive Stimulation Therapy (CST) is based on the handbook "Making a Difference" (A. Spector, L. Thorgrimsen, B. Woods & M. Orrell). CST is a series of sessions that take place over a seven week period with two sessions each week. The basis of cognitive stimulation therapy is to provide person centred care, helping the person to regain/develop self esteem. The principle that I work to is achievement; to help everyone feel that they have achieved without making it a serious occasion. Ensure that everyone has fun, lots of laughter and that they feel they are in a 'safe environment'. There are no mistakes, everyone's input is important and valued.

The programme starts every time in the same way, attention is drawn to the board which gives the day, date, season, group name and theme song. The activity for that session will also be displayed here.

Every participant is welcomed, refreshments are provided, and once people have settled down the group

is then divided into people with dementia and carers. Each group has their own room. The carers are offered information during their sessions; here we invite speakers to attend, such as a solicitor, pharmacist, nurse, occupational therapist, Age Concern etc.

The first session can always be a bit strained as people are meeting for the first time and they do not know what is expected of them. I aim to make it as pleasant and easy for everyone as I can. Prior to attending the CST group 'getting to know you' forms are sent out. These assist in selecting resources to use and at what level to pitch the group, to best suit both the group's and individuals' needs.

A typical session

Once the group have chosen a theme song, handouts are given to everyone so that they can read the words (if they need to) and join in. We then go over the board to refresh and orientate everyone to what we are doing. The date, day, season, group name and theme song are identified. Soft ball is played. This can become quite competitive and is always really enjoyed by the groups. A discussion about current affairs is also encouraged; I would choose a topic that is light hearted from the press. Everyone's opinion is valued and appreciated.

Now to the job in hand - The identified activity

I have built up a large resource base which provides a lot of scope for all the sessions

Physical games: skittles, pitch and toss.

Sound: a sounds effect CD that the group has to try and a sound to a picture.

Reminiscence: Discussion on their earliest childhood memories, looking at old pictures etc.

Food: this links with reminiscence, I ask what has been their favourite foods and then make it for us to taste/eat.

Money: again dovetails with previous sessions. I have some pre-decimal coins which we use to compare old and new and discuss what you can get for your money.

Faces/Scenes: there is a plethora of famous welsh folk sports personalities, politicians, actors, the list is endless.

Word Association: this session is based on the interests of the group (e.g. travel, geography, food, fashion). For example if it is sport, trying to name as many sporting activities as possible, then the competitors.

Being Creative: potting up bulbs that are already sprouting so there is a quick result, flower arranging, and pottery.

Orientation: using local and world maps identifying where you were born, worked, travelled etc.

Number games: playing darts, pool and then counting up the scores

Word games: hangman, crosswords

Finally to end the session a group quiz and afternoon tea.

I find that by week two most people have settled into the routine and genuinely look forward to coming; they are building friendships. The atmosphere is one of realisation, this being that they are all 'in the same boat'. The support that they give to each other is superb; if someone cannot remember then it isn't a problem due to their understanding of each other's difficulties.

Quotes from a CST group held in 2011

"We are all the same; I thought it was me being stupid"

"We have fun and laugh a lot"

"We don't want it to stop"

"No-one in the room can make a mistake"

Following on from the end of this particular group they wished that CST could continue and so the group decided that they would meet every week in each others' houses in rotation, they asked if Jan (SOLACE coordinator) and I would come along to help. The carers had found that the improvement in the person with dementia was so noticeable that they wanted more than the monthly maintenance session and wanted to continue with trying to maintain the results shown. Also the support and friendships that had grown in the carers' forum was invaluable and they didn't want to lose these friendships.

Norwegian Church - videos of memories

This came about due to the wishes for the CST group to continue, but also I was increasingly recognising that the monthly maintenance CST group attendees were showing signs of deterioration. The time gap of this style of interaction was too long.

The internet is a wonderful resource and whilst trying to find a location to be able to meet I stumbled upon 'tea dance at the Norwegian Church'. This church is situated in Cardiff Bay, originally it was for Norwegian sailors that were employed by the Norwegian merchant fleet. The church was built in 1868. As export of coal from Cardiff docks declined, the building was passed to local control, but as financial constraints occurred the church closed.

Without maintenance the building fell into dis-repair and was vandalised. To avoid total destruction when the development of Atlantic Wharf was being undertaken the Church was carefully dismantled in 1987 by The Norwegian Church Preservation Trust. Parts of the interior of the church were rescued and stored. The Trust, in partnership with a Norwegian Support Committee, based in Bergen, raised £250,000 in Wales & Norway to dismantle and re-erect the Church on its present site. The site was provided by Associated British Ports and the building now occupies a very prominent position on the Cardiff Bay Waterfront. The Trusts objectives were to "advance the education of the public, by promoting the permanent preservation and maintenance of the Church as a museum". The church is now used for many different occasions and they have a great hall for group gatherings, meetings etc.

It was agreed that we would meet here, so at the beginning of July 2011 seven of us met, no one else came for the tea dance, so we put on some CD's and had a dance of our own.

The following week we all met again but this time the numbers had grown, I had spoken to some carers and said that we had had a good time and they should join us if they wanted to.

The numbers have grown over the weeks, we now have twenty six people on average who attend every week. Because of its success we have had to restrict the numbers to invitation only to those people who have attended the CST/carers sessions.

The Norwegian Church has become a social event; people meet there and have lunch before coming in for a session.

A typical session will be some physical activity e.g. throwing two soft balls at the same time, it is surprising how many times the balls are thrown to the same person and they are left with catching both or neither! It takes a degree of concentration and co-ordination, eye and hand control to keep this game going. There is always a friendly competitive edge to all the games, but praise is part and parcel of playing. A parachute is used and again the idea is to keep two or more balls bouncing/moving around inside the parachute. Throwing quoits, throwing bean bags onto a score chart on the floor again requires hand and eye co-ordination and the concentration to count your own score. Carers and people with dementia all join in; they attend and participate. They then move onto sitting and talking. There is always a general buzz about the room.

We are fortunate to have a number of piano players in the group, so the rest of the afternoon becomes a sing-song; Percussion instruments are given out so everyone can join in. Some group members encourage the singing, competitive fun is always had when one side of the room is singing 'Pack up your troubles in your old kit bag', and whilst the other half are singing 'It's a long way to Tipperary'. That takes concentration!

Life Story Work

Dementia is such a cruel illness that slowly takes away every part of the person that you love. So the life story work has become a key approach of the CST work. People who attend the groups still have the capacity to consent to be videoed and are still able to discuss and share their life story.

The relationship that is built whilst attending the CST group provides me with an insight into their childhood, when they were young people, what their job had been and their interests/hobbies. I have had the time to get to know them and have learnt what their favourite food is and what food they dislike. A trust is continually being developed between us all.

I explain and discuss with the individuals if they would like to be videoed and have a permanent record of themselves talking, laughing, and sharing the naughty things that they got up to when they were young. Whatever they want me to record, I do. You cannot capture the facial expression, smiling, and the body language with just an audio recording device. Their carer is made fully aware of the reasons why a permanent record would be beneficial and more often than not they also take part in the life story recording.

Permanent memories

This DVD is produced only available to the family, no duplicates are held. This is their own personal record. The DVD could be shown to nursing/residential/domiciliary staff if that should be needed in the future. It is far more powerful to see someone saying what they like and what they dislike.

When permission is gained I also record some of the activities that we do at the Norwegian Church. These are then edited and a copy is given to everyone. Again this sharing may be useful, for memories of each other e.g. a couple dancing. It may have been years since they have managed to do this. They are in a very safe environment because the room is closed off. Everyone in the room is in a similar position, either a carer or being cared for.

Singing; everyone loves doing this even if they are very hard of hearing. The body language between the couples/friends is evidence of the enjoyment and relaxed approach. Everyone enters the room with a smile. People now know each other so well they can tell if someone has had a bad week, so listening hugs and reassurance is always there and at hand. I think the same premise goes for the carers. They feel safe in that room. They are with others, with the same understanding and empathy and who are all trying to cope.

People have shared with me that when the person with dementia is anxious, if they play the DVD then they will sit and watch and sing along. They also recall some of the faces, it creates a distraction and a diversion.

Volunteers

Solace has a number of volunteers who help at the Norwegian Church and we could not manage without them.

'A' - an ex-carer that came upon Solace by chance. Thank fully he has never left and has grown to be my organiser.

'V' - a young Hungarian lady had already signed up to volunteer and again came upon Solace by chance. V also helps with the Cognitive Stimulation Therapy groups so she is already a known face to them at the Norwegian Church.

'D' - was co-erced by a family member to come. After week one he was hooked and now refuses to do a shift in work if it interferes with his volunteering

'C' - One young lady who helps in a very special way to edit the DVDs. She takes out all my mistakes! She has a degree in film making and video editing so the finished article is as professional as one can get. She makes sure the music is the favourites of that person giving their life story. C has said she has laughed and cried so many times doing this work but without her the families would never have the DVDs and the memories that are created.

For me I have seen positive results in carrying out the Cognitive Stimulation Therapy sessions and then continuing with a weekly maintenance session. The benefits are so obvious for the person with dementia and the carer. And there are no side effects as happens sometimes with medication!

The Future

Because of the success of the Norwegian Church and the obvious advantages of the group meeting weekly, Jan and I applied for money to fund another venue, the bid was successful.

So this means for people attending the Cognitive Stimulation Therapy 7 week session they will then be offered the opportunity to attend weekly sessions at local Church.

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Dementia: enriching life with creative expression



I am Claire Ford and I currently work as a freelance Creative Practitioner with hard to reach groups. I use many techniques and skills within creative facilitation and design specifically around the group or individual. The Arts empower, engage and develop

overall confidence and well-being but most importantly, transform lives.

Dr Gene Cohen, the founder of the National Centre for Creative Aging (NCCA) suggests that as cognitive ability deteriorates with dementia, creative abilities increase, enabling new ways of communication through creative engagement. Dementia is predicted to double in the next decade, with the arts to be seen as a powerful vehicle, providing rich life opportunities for people affected by dementia.

Becoming older can be a frightening and daunting experience. Not only does health and mobility decrease but there can be numerous losses of family members and friends. So how do individuals feel when they develop dementia? The loss of memory can affect relationships, communication, language, problem solving, functioning in daily activities, behaviour changes and emotions. The disease affects not only the individual but families, carers and friends alike too.

Today's culture can be ignorant to dementia, concentrating on the negatives and the sadness of the disease, unaware of the unlocked potentials of the individual. Our culture needs to shift and alter to open up further opportunities and access for this audience. This will improve health and well-being, decrease depressive tendencies and empower individuals in their lives. Sixty four percent of people living in care homes have dementia¹ therefore we should be doing more to assist and promote satisfying and dignified lives. Individuals with dementia are known to have vivid imaginations and this "personal imagery can lead to all sorts of good things for creative processes"².

The USA is developed in this thinking, promoting the arts as an access tool to unleashing creative potential. The arts provide stimulation, engagement and

empowerment, raise awareness, develop relationships with loved ones and contribute to this change in culture. Artists and Creative Therapists are closely collaborating with medical staff to provide unbelievable care programmes around the US. Due to the extortionate medical costs in the US, these programmes are vital in cutting medical costs and improving overall health and well-being.

I was awarded a Travelling Fellowship which was funded by the Winston Churchill Memorial Trust to support the development of knowledge and skills in Arts and Dementia Programming. Travelling for ten weeks in six US cities, including Milwaukee, Chicago, Minneapolis, New York, San Francisco and Washington DC meant that I could explore creativity at an entirely innovative level, observing, taking part and facilitating art activities. I had the phenomenal experience of shadowing, discussing and debating with leading practitioners and clinicians in the field of arts and dementia.

The "Meet Me at MOMA"³ programme in New York (Museum of Modern Art) is where my planning began. It is internationally recognised for its commitment to access programmes for hard to reach groups. Groups include mental health, blind and partially sighted and individuals with dementia. The programme began back in 2006 for individuals with dementia and their caregivers with the aim to enhance their quality of life through mental stimulation, communication, personal growth and social engagement.

A specially trained Educator chooses around three to four art works around a given theme such as 'Feminism'. The discussion begins with an overview prepared by the educator on art history, developing later onto interpretation and expression. A discussion question such as 'What do you see in this painting?' usually inspires conversation. These open ended questions provide opportunities for realisation and reminiscence as well as creativity and imagination. There is no right or wrong answer at MOMA. If the participant reminisces about one's life then there is the prospect to delve in further.

I was overwhelmed with excitement when it came to my observation at 'Meet Me at MOMA!' I could not believe how many participants there were, filling the corridors, sticking on their name badges and no wonder the museum had to close. As the programme began, I suddenly became aware of one participant in particular. Whilst walking into the gallery he was bubbly and loud but as soon as he saw the art work he settled and really

related to it. Not only did he appreciate everything that was going on in the paintings but he recalled his own life stories throughout them too. The 'Meet Me at MOMA' programme was obviously a time where he could transform and feel a purposeful joy from the art works.

A quote from a 'Meet Me at MOMA' carer participant –

*"We both love the programme. All the instructors have been wonderful, dedicated, knowledgeable, and sensitive. It is so important to let the people with memory loss articulate their feelings, impressions and reactions"*⁴

Not only does this quote demonstrate the participants' enjoyment and engagement but it also shows that MOMA listen and take into consideration the needs and values of someone with dementia. They feel appreciated and valued within the museum to explore and intellectually discuss pieces of art.



Photo 1. SPARK programme at John Kohler Art Centre

Timeslips is a storytelling programme developed by Anne Basting. Timeslips can be interpreted into various environments and situations, from museums and galleries to health settings and care facilities. It uses the imagination to make up brand new stories by looking at a variety of images. Images were looked at in the broadest sense from sculpture to colour and dance. The same approach is used by the Museum of Modern Art (MOMA) too. The pressure of getting an answer right is demolished and this open ended, imaginary world is entered which empowers and satisfies everyone involved.

Carers and loved ones feel obliged to reminisce, ask questions and build on the history that once was. But this can cause anxiousness, depression and a sense of loss for the individual with dementia. So surely art access programmes should be available here in the UK too? Could more be done to make carers aware of the disease and what will benefit their loved ones? Or is this

all down to our stereotypical culture and the way we see dementia?

Anne Basting also the author of 'Forgetting Memory' says

*"Alzheimer's is a hundred year old myth that is over the hill. The entire scientific, technological, and political framework needs to be reassessed to better sense patients and families in order to help people maximise their quality of life as they move along the path of cognitive ageing"*⁵.

How do we begin changing our culture? Popular culture is everywhere we turn with film, newspapers and news stories alongside the struggle with the economic culture; therefore it is a constant struggle to make change.

'Creative Aging' does not only mean being able to paint or play a musical instrument but in the broader sense can mean a change in reactions or new way of self in the world. Take the famous artist, Georgia O'Keefe for example. At the age of 78 she painted her most celebrated works and was highly successful. This provides insight into how older generations perceptions change on their own life. As people get older they begin thinking of new activities and hobbies they can undertake such as their family tree, painting and travelling etc. But is this 'Creative Aging' or having more time on their hands to undertake such hobbies? Numerous studies show that creativity in old age increases empowerment, lowers medication and depressive tendencies and improves overall life and community. These additional activities in later life could indeed result in positive feeling and improved health.



Photo 2. SPARK programme at John Kohler Art Centre

Richard Taylor, a psychologist and author of the book 'Alzheimer's from the inside out' wrote a book from his view point of being diagnosed with Alzheimer's disease at the age of 58. Richard captivates you on his personal journey through his diagnosis, challenges and decline of having dementia. His honesty and commitment

throughout is powerful not only for the reader but in making a change to those affected with Alzheimer's too. Throughout the book he mentions his love for music and how his skills in writing and storytelling developed with the disease.

"I am going to do more singing. I feel safe, sound, healthy, and alive when I sing!"⁶

Dance, theatre and movement also play an important role in overall health and well-being for those with dementia. Kairos Dance is an intergenerational dance company directed by Maria Dubois Genne in Minneapolis. The 'Dancing Heart' programme is based around the older population and for those with dementia. The Kairos Dance team enable all participants to dance in one way or another, either by foot, walking aids or by sitting. Anything is possible and there are no limits in the eyes of Kairos.



Photo 3. Kairos Dance with Veterans Group, Minneapolis

I walked into a room of around thirty veteran men who all suffered from dementia. I had reservations of how the Kairos team were going to engage and get all these men to dance, but sure enough they did. Enabling choice of song, dance, stories and themes really empowers and engages participatory arts in this type of setting. I have never felt such emotion. When three men started crying and reminiscing about their dancing days it became clear and apparent that the arts should be statutory for our health and adapted into a new 'medication'. That day everyone left happy and elated.

I also wanted to experience the intergenerational side of Kairos. Around ten participants came together from various generations to share their love of dance. It bridged a gap between the generations and provided strong relationships and a new 'family' to form. At regular intervals during the year the intergenerational group perform for many different audiences across Minneapolis. These involve all participants' ideas and abilities.

I got talking to a member of the intergenerational dance group – Dianne, who has Cerebral Palsy down her right hand side. She needed prompting with conversation and was pretty quiet and distant. But before long she came out with,

"People are like stories, they have so much to tell, if you only open their pages and read what they have for you".

Dianne's phrase stuck with me for the rest of my fellowship and will do for a very long time. It felt as though this was a phrase she felt supported by and that meant a lot to her. So why are we not listening and reacting to the positive outcomes of the arts back here in the UK? When we could be enhancing these specific access programmes to improve lives.

Similarly I was speechless when I realised the seriousness of being stuck in a lift for two hours with four individuals with dementia and their carers. After completing what was a fantastic SPARK programme at the Milwaukee Public Museum it was time for lunch. Everyone jumped in the lift and that is when it hit us... WE WERE STUCK! A wooden broom stick was lodged down the shaft, dangling us between two floors. The nervous laughter began.

The carers and I were all becoming very worried when role reversal set in. Those with mid stage dementia began singing and laughing to keep us occupied! One lady even sang a nursery rhyme in French which was extraordinary and certainly took our breath away. To me this is a prime example of 'Creative Aging' in action! Nobody knows what was going through their minds that day, but they were able to react to a panic stricken situation creatively before any of the younger adults stuck in the lift that day.

Carrying out this life changing fellowship has enriched my life and I now hope to change and enhance the older generation. We need to appreciate those who once taught us and provide stimulating activity to transform our culture.

As this generation is predicted to double in the next decade, the arts can contribute to this ideological shift in how we think and wrongly stereotype 'Alzheimer's'. Altering our perceptions from deficiency to rich, satisfying, expressive experiences, that today is possible.

"We shouldn't discard the elderly; we should find ways to cherish them"⁷.

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Claire's daily US blog is available to view at:

www.enrichinglifewithcreativeexpression.blogspot.com

Development of physiotherapy guidance and treatment-based classifications for people with Huntington's disease



Lori Quinn and Monica Busse write about the creation of a physiotherapy guidance document for Huntington's disease on behalf of the Members of the European Huntington's Disease Network (EHDN) Physiotherapy Working Group

Background. Huntington's Disease (HD) is a degenerative neurological disease that results in a triad of clinical symptoms, encompassing motor, behavioural and cognitive impairments. Researchers have developed a better understanding of the complex nature of the movement disorder in this disease, however to date, physiotherapy intervention is not consistently provided [1].

The literature in support of physiotherapy for people with HD is lacking. Two reviews have noted that to date there has been only a small amount of evidence in support of physiotherapy within HD [2, 3]. For example, a before-after trial with a sample size of 40 found an intensive rehabilitation programme of 6 sessions per week demonstrated an improvement in motor function over the two year period [4, 5]. Positive findings from environmental enrichment studies in mice also provide some support for the basis of physiotherapy for people with HD. In mice models of HD, those placed within an environment providing physical, mental and social stimulation have a slower disease progression, and maintain motor function for longer compared to those housed in more isolated conditions [6, 7].

Clinical guidelines are evidenced-based recommendations for clinical practice in specific conditions [8, 9]. The availability of guidelines facilitates uniformity of care and standards of practice with the aim of improving quality of care provision. One of the difficulties in developing clinical guidelines for complex neurodegenerative diseases such as HD is that individuals present with a range of physical, cognitive, psychological and social care needs over an extended time frame. Researchers have argued that in order for therapists to develop consistent approaches to common patient problems, so that the efficacy of any one

approach can be tested, better categorization is required.

The Physiotherapy Working Group (PWG) of the European Huntington's Disease Network (EHDN) therefore set out to develop a guidance document, to provide a written framework for the physiotherapeutic management of people with HD. The aims were to provide, where possible, a scientific evidence-based document to inform the optimal, individualised physiotherapeutic management of people with HD. This included the provision of a framework for the physiotherapeutic management of people with HD, using categorization of common signs and symptoms of physical and motor functioning. The group also aimed to highlight the scientific evidence for physiotherapy (PT) practice with people with HD, evaluating the effectiveness of any intervention strategies presented in the literature. The ultimate goal of the guidelines was to enable uniformity of care internationally.

Methods

The Physiotherapy Guidance Document for HD was created through a combination of available scientific evidence and expert consensus. A literature review was completed (1950-2009) using a PICO (Population, Intervention, Comparison, and Outcome) approach. Thirty-one papers were reviewed in the full guidance document: 3 reviews, 9 PT related studies, 11 gait specific, 1 muscle strength, 3 balance and mobility, 1 dystonia, 2 upper limb specific and 1 paper regarding multi-sensory stimulation were identified.

The identified evidence was then summarised independently and then discussed at a European Huntington's Disease Network (EHDN) Physiotherapy Working Group (PWG) meeting. Amendments were made to the document based on members' feedback. In a second phase of development, sections of the Guidance Document were reviewed in detail by subgroups of 2-3 members of the PWG. Feedback from the subgroups were directed back to the authors, and integrated into the final document.

Following publication and dissemination of the Guidance Document, the PWG developed 7 classifications to address the heterogeneity of patient conditions in people with HD. The goal of these classifications was to provide structure for standardised data collection of interventions and outcomes, and consequently inform evaluation of complex interventions and advance research into care and evidenced-based service delivery for people with HD.

Here we report the summary recommendations. Greater detail on each topic as well as the review of the literature can be found in the formal physiotherapy guidance document:

<https://www.eurohd.net/html/network/groups/physio/physiotherapy-guidance-doc-2009.pdf?eurohdsid=d7e987cc87f9d541b70dc6497d223d66>

The reader is also referred to the original paper where the framework development is described [1].

Framework for patient management.

An important component to patient management in a neurodegenerative disease such as HD is to consider people at all stages of the condition, including those who have the mutation for HD but are not displaying motor symptoms (pre-manifest)[1, 10]. It is further suggested that physiotherapy management of people with HD should be modified according to individual problems and to the stage of the disease. Currently, intervention focuses on symptomatic management, however there is increasing support for early intervention where an impact may be made on biological processes with the potential to influence on the natural history of the condition.

Evaluation and Outcome Measures.

The physiotherapy evaluation for people with HD should be both anticipatory and responsive to the disease stage. The physiotherapist should work in collaboration with the patient and evaluate their individual considerations [11]. The World Health Organisation International Classification of Functioning, Disability and Health (ICF) [12] can aid assessment of a person's level of functioning, and further facilitate consideration of the triad of motor, cognitive and psychiatric symptoms that are often seen in HD. It can be used also for goal setting & treatment planning, and focuses on aspects of a person's health and health-related wellbeing in terms of activities and participation i.e. the description of the tasks (activities) and/ or life situations (participation) the person wishes to be involved in, and the impact that impaired body function or structure is having on these aspects.

Caregiver involvement, wherever possible, is strongly encouraged, particularly if the patient has difficulties communicating through cognitive or physical impairment. The objective evaluation should include assessment of neuromuscular (e.g. bradykinesia, dystonia, chorea), musculoskeletal (e.g. posture, range of motion, pain, muscle strength), and cardio-respiratory and cardio-vascular impairments (e.g. vital signs, breathing function, exercise capacity). Standardized tests can be utilized as outcome measures that may be sensitive to changes related to any physiotherapy intervention. The Berg Balance Scale, Tinetti Mobility Scale, Timed Up and Go Test, Four square step test and the Functional Reach Test have all been found to be

valid and responsive clinical measures in HD and are considered useful to detect those at risk of falls [13-16].

Physiotherapy Interventions.

Since pharmacologic interventions to date have been ineffective in altering or slowing the disease process, healthcare practitioners and patients themselves continue to look for alternative therapies. While physiotherapy has been shown to be of benefit for some neurodegenerative diseases, such as PD and MS, the evidence supporting its use for people with HD is limited. Nonetheless, utilizing traditional physiotherapy techniques with applicability to the special needs of this population may provide some benefit for a disease that currently lacks any effective treatment regimes.

The main goals of physiotherapy intervention will generally change over time. In the early stages, interventions will be primarily preventative. As the disease progresses, interventions become restorative in nature, addressing specific physical impairments and resulting activity limitations. In the later stages, intervention is primarily compensatory, in which therapists develop strategies to maximize a patient's functional ability despite progression of the disease. With regards to falls risk, a clear justification of benefit of any particular management strategy compared to the risk that the situation presents should be elucidated. Therapists working with people with HD should acknowledge and facilitate independent mobility for as long as is reasonably possible [1].

Similar to healthy individuals, exercise, including strengthening and cardiovascular conditioning, is recommended for people who are pre-manifest and in the early stages of the disease. Exercise may be helpful in minimizing any neuromuscular or musculoskeletal effects that come with disease progression. As the disease progresses and specific problems become evident, therapists must begin to ascertain those impairments that may be contributing to specific activity limitations or participation restrictions. For example, involuntary movements could contribute to balance problems, but inactivity may also be a contributing factor. Impairment-based diagnoses that may impact on function include: dystonia; bradykinesia; moderate-severe chorea or ballismus; rigidity; impaired respiratory function and fatigue. It is important to manage the secondary effects of such impairments. For example, for patients with chorea, protective equipment can be provided, and for patients with dystonia, loss of range of motion and muscle imbalance should be prevented. Functional problems that may occur include: impaired fine motor skills and manual dexterity, impaired sitting posture and sitting ability, impaired mobility, transfers and gait; impaired balance/ and risk of falls and reduced cardiovascular and general physical fitness [1, 13, 14, 15].

The potential impact of psychiatric impairments and a patient's cognitive status cannot be overlooked. Therapists should consider whether or not a patient has memory loss, depression, aggression, obsessive-

compulsive tendencies, or anxiety, to name a few, and these impairments must be taken into account during the design of any intervention plan [17].

Treatment-based classifications.

Seven treatment-based classifications specific to HD have been developed using the Guidance document as a reference point. The primary findings discussed above for the Guidance document were utilized to categorize patients more specifically based on primary impairments and activity limitations (see Table 1). Within each classification, we determined signs and symptoms as a method for categorization. We then listed general aims, and provided specific intervention strategies and outcome measures. Clinical validation of these classifications is currently underway across the EHDN network.

Classification	Description of clinical findings	Stages of Disease
A. Exercise Capacity and Performance	Absence of motor impairment; potential for cognitive and/or behavioural issues	Pre-symptomatic/early
B. Planning and sequencing of tasks (including bradykinesia)	Difficulty and slowness in performing functional activities (dressing, bathing, ADLs, sit to stand, etc). Presence of apraxia or impaired motor planning; slowness of movement and/or altered force generation capacity	Early-mid
C. Mobility, Balance and Falls Risk	Ambulatory for community and/or household distances; balance, strength or fatigue resulting in falls or high risk for falls	Early-mid
D. Secondary adaptive changes and de-conditioning	Musculoskeletal and/or respiratory changes resulting in decreased participation in daily activities	Early-mid
E. Abnormal posturing (seating and bed positioning; manual handling)	Inappropriate alignment due to adaptive changes, involuntary movement, inability to facilitate or coordinate movement	Mid-late
F. Respiratory dysfunction (inco-ordination of diaphragm)	Impaired respiratory function and capacity; limited endurance; impaired airway clearance; risk for infection	Mid-late
G. Palliative Care	Unable to ambulate; dependent for most ADLs; difficulty maintaining upright sitting position; range of motion and pulmonary issues	Late

Table 1. Seven treatment-based classifications developed for physiotherapy management of people with HD

Summary

Due to the progressive nature of HD, the needs of people with this condition change over time, and the role of the physiotherapist should be flexible in response to the clinical need over the prolonged course of the illness. Although the evidence supporting physiotherapy interventions for people with HD is limited, there is some suggestion from HD literature and from other similar neurodegenerative diseases that exercise and other physiotherapy strategies may be useful in minimizing the effects of this devastating disease. The Physiotherapy Guidance Document has been developed based on expert consensus and available evidence and is freely

available to the HD community. It does, however, continue to be a work in progress and will require review and updating as new more robust research becomes available.

Limitations, Implications and Future Directions

The development of this Guidance Document and the subsequent classification system is the first step in the process towards solidifying the evidence base in physiotherapy in HD. An important next step is clinical validation and revision of the classifications, in an effort to promote standardization of care. Once standardization of care is achieved, we can take the next important step in evaluating the efficacy of physiotherapy and exercise-related interventions through pragmatic controlled clinical trials.

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Genetics and Huntington's Disease

From the Conference "Understanding and Managing Huntington's Disease in a Multidisciplinary Environment" 18th November 2011

This lecture was presented concisely and clearly by Mrs. Ruth Glew, a Registered Genetic Counsellor, from Cardiff. Ruth explained that Huntington's Disease (HD) the children of an affected person have a fifty percent chance of inheritance (autosomal dominance), with the affected genes being found on Chromosome 4. Onset can be at any age, but it is rare in juveniles. It is not uncommon for HD to be diagnosed in late life, when it can often present in a slightly milder form. If the father is the affected parent then onset tends to be earlier.

Genetic counselling for families of affected people is routinely offered and plays a huge part in understanding and adapting to the diagnosis and in decision making with regard to predictive testing.

Ruth told us about some difficult cases, including one involving a young family where, because of the illness, all the children had had to be taken into care.

Predictive testing is not to be taken lightly as once the test results have been revealed, there is no going back to "not knowing". There are also difficult ethical dilemmas, especially where one generation may refuse a test while the next generation is asking for one.

It is vital that the diagnosis is confirmed and that the implications of the result are properly discussed before a decision is made about whether or not to proceed with the test, which is always done in a regional centre such as the one in Cardiff.

If a positive test result is received, the individual then has access to ongoing support from the Genetics Department, which can help with issues such as planning for the future, family planning, opportunities for research etc. We were left in no doubt about the vital part played by genetic counselling in the multidisciplinary team approach to the holistic management of people and families affected by HD.

Dr. M. Delyth Alldrick
Cardiff and Vale UHB

Neuropsychiatry of Huntington's Disease

The complexity of Huntington's Disease (HD) and its progressive course, means that individuals with HD require the care of a variety of specialists. Cardiff University School of Healthcare Studies held a course on 18th November 2011 entitled 'Understanding and Managing Huntington's Disease in a Multi-disciplinary Environment'. I have focussed on Dr Rickard's presentation on the neuropsychiatry aspects of the condition.

Dr Hugh Rickards has been a Consultant in Neuropsychiatry for 14 years with the Birmingham and Solihull NHS Trust. He runs a specialist multidisciplinary clinic for people with HD, and been the author of several papers on the subject of behavioural change in relation to HD. His passion for the subject was reflected in an enthusiastic, comprehensive presentation, ensuring an engaged audience. He provided factual information with statistics, but I found his holistic approach and referral to personal anecdotes very refreshing. The importance of lateral thinking and viewing the wider picture was encouraged.

Dr Rickard's talk highlighted the intricacies of HD and its presentation, often with no discreet patterns. Brain changes include generalised atrophy, especially in the caudate and less activity in the striatum. There are complex interactions which may result in changes in motor function, executive function as well as interference with the limbic system (affecting mood/emotion).

Such a complex array of presentations could result in a misdiagnosis. Incorrect diagnostic labels or inaccurate family history may contribute to this. He demonstrated this by referring to an example of over 50 years ago patients with HD or a psychotic presentation were misdiagnosed as schizophrenia. With current knowledge this is less so now. Misinterpretation of the presenting symptoms e.g. restlessness, agitation and movement disorders were described as 'behavioural', whereas the overall clinical picture indicates HD.

I have considered this in relation to my practice within the Memory Team. In early stages of a memory condition, some people may consult with minimal cognitive difficulties. Despite aiming for an early diagnosis, the clinical picture may change over time so caution with 'labels' may be advisable. Through thorough history taking one can detect possible 'atypical' features and the pattern of symptom development.

Some diagnoses could be considered as part of a spectrum. e.g. Parkinson's Disease Dementia (PDD) and Dementia with Lewy Bodies (DLB).

This prompts me to propose a willingness to review a diagnosis if new symptoms emerge or there is a change in the clinical picture. Admitting uncertainty and allowing time as a diagnostic tool may be appropriate. Alternatively thorough re-examination of the patient and notes, collating past and present facts and features may shed more light.

Dr Rickards covered common mental disorders in HD. He quoted that 63% of people with HD had a depressive disorder, the 2nd most common is anxiety disorders 29% and 3rd alcohol abuse. The anxiety disorders cover social phobia and agoraphobia which he remarked are not frequently talked about. Lots of mental symptoms cannot be readily classified and also a personality change can be due to a general medical condition, such as HD.

Dr Rickards quoted some symptom clusters associated with HD:

- Personality / frontal
- Depression/ anxiety
- Psychosis

I considered this with respect to my clinical role in assessing people with memory difficulties. Predominance of these symptoms may emerge in different types of dementia or at stages of its presentation. This may impair clarity of the clinical picture or contribute to uncertainty of the likely diagnosis at a specific time. Also classic presentations of common problems present in an atypical/indirect way. From the talk, I drew a parallel between HD and certain types of dementia with regard to the presentation of pain. In both conditions it may be masked, so producing irritability, possibly secondary to impaired communication. Clues to the diagnosis of depression e.g. facial expression and body language may be less evident in HD and in cases of dementia. Of particular interest, he said that some people accept that 'people with HD will be fed up'. People may think it is 'natural' to be down having such a diagnosis, as with AD, post stroke or after a diagnosis of cancer. I suggest - isn't blandly accepting such psychiatric elements to a diagnosis as 'the norm' doing a disservice to people? 14.4% of people with HD attempt suicide. Management of depression includes antidepressants e.g. SSRI, the consideration of medication for chorea, as well as non pharmacological - social interventions, general support and management of concurrent symptoms e.g. swallowing problems. Dysphagia can cause depression/anxiety contributing to a downward spiral. In HD the irritability threshold is much lower, for example having an excessively angry response to a minor stimulus. Causes of irritability include, hunger, cognitive overload, perseveration, pain and additional illness (e.g. infection). Management is focussed on the cause, the expectations of relatives and use of medication.

Cognitive impairment in HD presents with an early lack of ability to multitask as well as plan and organise. He referred to a primary school teacher who felt she had 'lost the eyes in the back of her head' whilst in a classroom setting.

Drawing comparisons with people with the commonest type of dementia - Alzheimer's Disease, there are NICE guidance for prescribing medication for people with AD, but no specific drugs are licensed to treat the cognitive impairment that may accompany HD. Despite this, Dr Rickards informed us that aerobic exercise and an enriched environment may have a positive influence. Another point of interest is which service should manage people with HD? Years ago, HD was nursed in the back wards of asylums. Recently it has been 'excluded' from NHS adult psychiatry services (being deemed physical and not mental...). I can see a correlation between this and the debate when managing patients with dementia; to whom they are referred and when? Memory service, neurology, psychiatry - it is a thought provoking debate.

Indeed Dr Rickard certainly provided much food for thought, and I am grateful he shared his experience and knowledge in this specialist field. I may not directly come in to contact with this condition often, but the whole course has enhanced my general approach to all consultations; questioning more, challenging information and it is important that everyone is considered as an individual, and not a classic text book case.

Dr. Rachel Brewer
Memory Team
Cardiff and Vale UHB

Multidisciplinary Working in Huntington's Disease

Having gained much from the earlier sessions on the morning of the conference concerning the genetics, clinical management and neuropsychiatric perspective of Huntington's Disease I was keen to hear the afternoon presentations concerning evidence based practice in Multi-disciplinary working. These presentations also gave me an opportunity to consider the implications for presentation on the Mental Capacity Act. Catherine Clenaghan outlined the role of the Huntington's Disease specialist nurse. She reminded the audience of the need for a co-ordinated service from all the different professionals involved as the individual with Huntington's Disease and their carers practitioners of Julia Barrell's may find themselves having to attend multiple appointments with different professionals.

Confusion over these appointments coupled with the cognitive difficulties present in Huntington's Disease can lead to high levels of DNAs. A single point of contact and a multi-disciplinary team approach can go some way to mitigate against this and improve the care for patients. Catherine also spoke about the support that she provides for patients in relation to making advanced decisions about their future care.

Reflecting on this after the conference I considered how difficult it might be for a person with Huntington's Disease to make such an advanced decision, especially if they had been aware of the care received by previous generations in the 'back wards' referred to by Dr. Hugh Rickards. The specialist nurse can provide information and advice about current specialist services and choices available.

The presentation by Dr. Graham Manley on dental care also highlighted for me the practical application of the Mental Capacity Act. He described ongoing research on titrating anaesthesia to reduce involuntary movements and allow dental work to take place. His video presentation showed a patient who was able to give informed consent to such a procedure which allowed him to have dental work which considerably improved his quality of life. Dr. Manley also commented on the situation where the patient does not have mental capacity to consent to a procedure and the difficult best interest decisions that have to be taken balancing the need for cosmetic procedures requested by relatives with the risks associated with anaesthesia. This provided a very real example of the workings of the Mental Capacity Act with people with Huntington's Disease and exemplified the complexity of some of the decisions faced by the patients and the professionals supporting them.

Dr. Christina Maciejewski

Consultant Clinical Psychologist

'In Your Mind's Eye' – Using art in the assessment of dementia



Phil Thomas is the artistic director of the Gwanwyn Festival of arts and creativity for older people (organised by the charity Age Cymru). He holds a masters degree in Ethnomusicology and has a background in

music and the performing arts over some thirty years. In recent years he has worked as a freelance arts project manager and joined Age Concern Cymru in 2007 to develop the Gwanwyn festival and to act as an advocate for the artistic and creative interests of older people.

'In Your Mind's Eye' is a collaborative project between the Gwanwyn festival of arts and creativity for older peopleⁱ (organised by the charity Age Cymru) and the dementia assessment unit (Seren Ward) at the Royal Glamorgan Hospital, Llantrisant. It is an ambitious attempt to move forward from the use of art sessions as recreation and therapy for patients in mental health care facilities. The project is a nursing led initiative (as opposed to being a part of formal clinical research) in that it is intended to;

- a) use observation of patients engagement with the artwork created by the project to give nursing staff a more holistic understanding of the patients in their care
- b) improve the living environment for the patients
- c) involve the local artistic community, amateur and professional, in the project, thus raising public awareness of the work of the unit.

The project is in its early stages and is an attempt to bring professionals from the nursing and artistic worlds together to add to the body of knowledge about the assessment of patients who have reached a critical stage in the progress of their dementia.

Background to Gwanwyn Festival

Gwanwyn is a month-long national festival held across Wales in May of each year, celebrating creativity in older age. It was inspired by the Bealtaine Festival which has been running in Ireland for over 15 years under the auspices of the older people's charity Age and Opportunity.

The aim of the festival is to:

- Celebrate the opportunity of older age for renewal, growth and creativity, hence the connotations of new-life in the name 'Gwanwyn' meaning 'springtime' in the Welsh language.
- Promote the benefits of exploring creativity, developing a critical voice and participating fully in the artistic and cultural life of local communities and Wales as a whole.
- Offer opportunities for greater participation by older people in the arts, such as painting, photography, music, drama, storytelling, literature, dance or film during the month of May.
- Highlight existing artistic work and creativity of groups and individuals who are older people themselves or whose work revolves around the concepts of older people and creativity.
- Promote the participation of older people in the arts throughout the year and highlight existing or new opportunities available locally.

Gwanwyn is a collaborative initiative between key national organisations lead by Age Cymru, the Arts Council of Wales and the Welsh Assembly Government; working closely with local arts groups, active retirement and community groups, public libraries, museums, schools and care centres. Since Gwanwyn's inception in 2007 it has grown in size and reputation to the point where, in 2011, it involved more than 80 community groups; 300 activity sessions; almost 10,000 participants. In a new departure for the Gwanwyn festival 'In Your Mind's Eye' has received further financial support from the Rayne Foundationⁱⁱ.

About the project

'In Your Mind's Eye' had an unusual beginning. A chance meeting occurred in July 2010 at the Act on Dementia Conference, Royal Welsh College of Music & Drama, Cardiff during a performance of an opera about dementia, entitled 'The Lion's Face'ⁱⁱⁱ. This meeting took place between the author and Ann Orrells, the nursing manager of Seren Ward. Further discussions resulted in a decision to try to find a way to use art to find out more about the patients in the unit. It was clear from the outset that the pace of progress would be governed in large measure by the care regime within the ward^{iv} and that sudden or radical changes to the environment might be unsettling. A supportive and patient response from our funding bodies has enabled us to make slow but steady progress with a project that focuses on exploration of new ideas rather than fulfilment of predetermined quantitative objectives.

A team of professional artists was recruited and brought together for a meeting with nursing staff to visit the unit; elicit support from the nursing staff; identify spaces within the unit where art forms might reasonably be

deployed to good effect. A number of areas of work were highlighted where the skills of our professional artists could be put to work with nursing staff, patients and other external design professionals to create the art that would be a part of our exploration and begin the slow process of changing and improving the ward environment:

Maureen O'Kane - a professional, award winning mosaic artist working nationally and internationally, who specialises in producing original, site specific public artworks for interior and exterior locations.^v She would work with nursing staff and patients over a number of sessions to create a new sign for the ward in the form of a ceramic mosaic.

Sol Jorgensen – A contemporary visual artist from the Vale of Glamorgan who has been taking on the role of the 'living camera' for the project by creating drawings of the participants. Jorgensen would attend the unit and create drawings of some of the patients and staff which, with permission, would be displayed around the ward. Sol has also been working on the creation of a 'gallery' in the public area at the entrance to the ward which, with the help of some interpretive signage, gives the public and other hospital staff some idea of the project that is taking place within the unit.

Jan Gardner^{vi} – A visual artist and painter from North Wales who is acting as creative consultant for a mural project planned for early 2012. Jan will mentor other volunteer artists in the creation of a mural to convert the room currently used as a 'smoking room' into an extension of the enclosed garden around which the unit is built.

Alice Briggs^{vii} – A visual and photographic artist from West Wales who also works for the museum service in Ceredigion. Alice is collecting and curating a photographic mural project for the ward depicting local landscapes and workplaces of possible relevance to patients. Alice is working on the creation of 'vinyl wallpaper' which will display images of local landscapes and more challenging depictions of workplaces in the locality that may be familiar to patients.

Jamie Smith – A musician brought into the project through ongoing help from Live Music Now (Wales) who has been delivering musical stimulus to patients and it is hoped to possible further participation by musicians with the help of Live Music Now (Wales).

We plan to encourage the keeping of journals on the ward to capture the observations, opinions and views of staff and patients. It is hoped to pass this accumulated data to clinical psychologists at a later date for analysis and comment. We very much want to know what effect we are having and to inform what we might do in future.

The use of participatory arts in health settings is still an under-researched field according to the 2011 Evidence Review of the impact of participatory arts on older people carried out in the UK by the Mental Health

Foundation. Funding of participatory arts programmes is invariably short term and often focuses on payment for the activity sessions themselves rather than for the evaluation of such programmes within any wider context. Though initial funding for 'In Your Mind's Eye' is finite, it is hoped that the archive of observational material will provide a useful source for future research and that, when further funding is available, the project will be able to be re-visited and further developed at intervals.

What have we achieved so far?

It is in the nature of work with patients living with dementia that progress is often slow. It takes time for patients to get to know and trust a new presence on the ward and it is important to ensure that any change to the physical environment takes place without intimidating or worrying the patients for whom the unit is their home. Nevertheless a start has been made and the project is gathering momentum.

At the first meeting between artists and nurses it was unanimous that the entrance area of the ward was a priority for attention. The artists, in particular, felt that this area had a particularly 'institutional' feel that could be potentially unwelcoming to new patients and unhelpful in terms of giving confidence to family members who would be bringing loved ones to stay at the unit. It was decided that Maureen O'Kane would begin a series of workshops with staff and patients to create a new sign for the ward. These sessions took place over a number of weeks with enthusiastic support from the ward staff. The sign was finished and eventually installed in September. The improvement to the appearance of the entrance to the unit is remarkable and the new sign has drawn sustained interest from patients, public and other hospital staff.

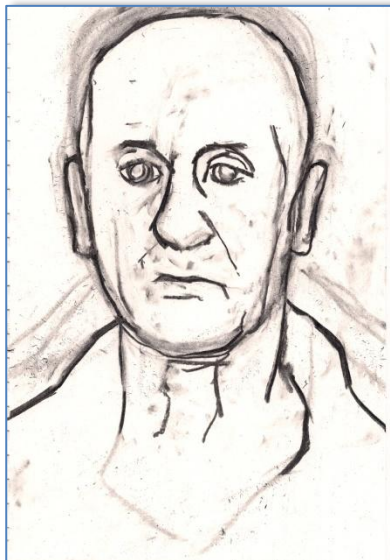




Vale of Glamorgan artist, Sol Jorgensen, has been visiting the ward on a regular basis to begin to get to know the patients and to record images of the activity and participants in different ways.



She has produced some stunning drawings which are soon to be mounted in the ward itself and also as part of the public 'gallery' which has been created outside the entrance to the ward.



Work is ongoing in other areas of the project. Alice Briggs is putting together photographic images from a variety of sources and is compiling a kind of 'vinyl wallpaper' which, we hope, will encourage patients to interact with the artwork in a variety of ways. Some images will encourage the patients to relax, reflect and reminisce; others will challenge them to look at familiar locations, such as former workplaces in unusual ways. In the New Year we hope that Jan Gardner will begin work on creating a garden-themed mural in what is now the 'smoking room'. We hope that this will change and soften the interface between the ward and the garden space.

What will happen in future?

Perhaps the most exciting part of 'In Your Mind's Eye' is that the artists, patients and staff have begun a journey without having full knowledge of the destination. Perhaps, given the nature of dementia, Alzheimer's disease and related conditions, this is appropriate. By the time you read this we hope to have more artwork on display inside and outside the ward and journals will be in place so that we can begin observing and recording the reactions. At some point in the future we hope to enlist the help of clinicians and academics to analyse these 'raw' observations and begin to understand some of what is happening. There is a Taoist saying:

"The journey is the reward".

The team working on 'In Your Mind's Eye' certainly hope so.

References

- i The Gwanwyn festival website can be found at www.gwanwyn.org.uk
- ii Details about the Rayne Foundation may be found at www.raynefoundation.org.uk/
- iii 'The Lion's Face' is an Opera Group production in coproduction with Brighton Dome & Festival and Watford Palace Theatre. More details can be found at <http://thelionsface.wordpress.com/>
- iv Seren ward deals mostly with patients whose dementia has progressed to the stage where they cannot remain at home and require assessment to determine the appropriate future care plan for them
- v Maureen's details can be found at <http://momosaic.blogspot.com>
- vi Jan's details can be found at www.jangardner.com
- vii Alice's details can be found at www.alicebriggs.co.uk

If readers wish to exchange experience of this or their own projects in this area they can contact the artistic director of Gwanwyn festival, Phil Thomas on philip.thomas@agecymru.org.uk

The use of GPS tracking devices in Alzheimer's Disease

We all know that nowadays technology progresses at an incredible speed and allows us to do almost anything we can think of. All that is required is to gather a group of people with enough will and motivation to turn those ideas into real useful products or services.

Luckily, some enterprises take this road and focus all their efforts on Research and Development (R & D) to develop products to make life easier for Alzheimer's disease sufferers and their families. This article will describe one of those developments that will contribute to changing the lives of thousands of families around the globe.

Wandering is one of the more serious difficulties for people who have Alzheimer's disease (AD). A person who has AD may experience the desire to go out and walk and hopefully maintain as much normality as possible in their daily routines. This desire is a need to encourage movement and exercise which can help to reduce anxiety, agitation and restlessness. But the progressive cognitive decline can lead to people wandering or getting lost due to their failing memory. The person who wanders does not realise the dangers of this situation and does not look for aid. In the best case scenario the family will experience hours of not knowing where to find their loved one until the person is found. Unfortunately in many cases there is not a happy ending and the seriousness of this problem is that people are not found soon enough.

One problem that creates another one

When a person with AD loses their way and is lost, the family experiences great distress. They do not know if the person is safe and well and whether they will be able to find them.

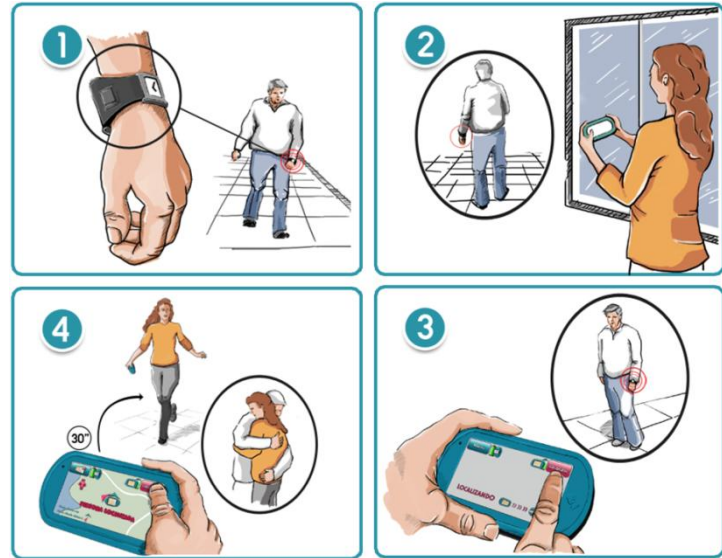
The person with AD also experiences a large degree of distress and suffering, especially if they are lost for a number of days. Finally the individual may even become too scared to go out. The families may also begin to consider and think about not allowing their family member to leave the house by themselves at all and this causes a huge amount of stress that will weigh heavily on the caregivers and family. This in turn could accelerate the process of cognitive impairment.

Tips to protect a loved one from wandering and getting lost

- Encourage movement and exercise to reduce anxiety, agitation and restlessness.
- Ensure all basic needs are met (toileting, nutrition, thirst).
- Involve the person in daily activities, such as folding laundry or preparing dinner.
- Inform your neighbours and local emergency services of the person's condition and keep a list of their names and telephone numbers.

- Give them an identification wristband with a phone contact.
- Use a specialised GPS locator for AD. This is a much more sophisticated solution but will allow the caregiver to know where the sufferer is in the case of wandering.

What is a GPS locator for people with Alzheimer's?



A locator for people with AD consists of a device, with a safety lock, and a portable receiver or a call centre service that provides the caregiver with a way to know the position of their family member.

The GPS device that the person with AD wears can be very small (41x35x14 mm.) and very light (barely 36 grams). Commonly there are two options:

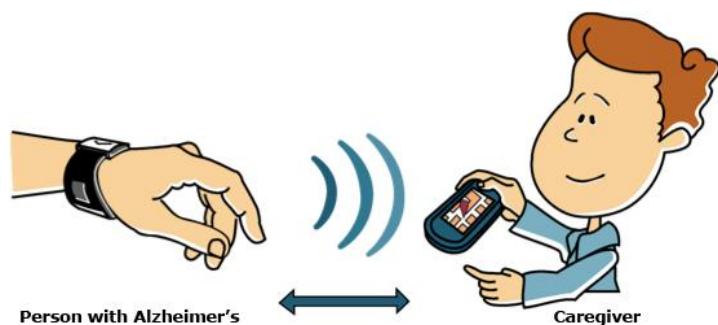
- There are specific devices in the form of a bracelet or a wristwatch with a safety lock.
- Also, there are multi-purpose devices similar to a cigarette case (for locating people, animals and objects), which can be carried in a pocket or attached to a belt with an adapter.

The family could also choose from two localisation systems:

- Direct Localisation System:** a portable receiver with a screen where they see a map and the position of the person wearing the GPS device. All alerts are received directly by the caregiver.
- Call Centre System:** a contract with a service provider and a call centre with operators, who will monitor the position of the person that carries the GPS device. Alerts are received in the call centre and a phone operator notifies the family about the incident.

For the purpose of this article we are ruling out other options for location through the internet because they are not adapted to the profile typically possessed by a caregiver.

Direct localisation system



The family is given two devices:

- A GPS wristwatch with a security clasp for the person with memory problems and
- a portable receiver (monitor) for the family or the caregiver.

To locate the person, the family simply press the "locate" button on the screen of the portable receiver and a map appears indicating the exact position of the person wearing the GPS watch. When the caregiver presses the button on the receiver, they hear the phrase: "locating" and after a few minutes (30 seconds to 4 minutes), they hear "person has been located" to inform the caregiver that the system has located the person wearing the watch. If the family need to find the loved one, they simply have to carry the portable receiver and update the position to ensure that the person is still in the same place. Additionally, the family can set up a security area of 0.5 miles, 1.5 miles or 4 miles around the house, so that if the person who has memory problems becomes disoriented and starts walking in the wrong direction or steps out of the set boundaries, the wristwatch will trigger an alarm to the caregiver's receiver.

It is recommended to adopt a routine of removing the GPS wristwatch at night, put it on charge and put it back on the wrist in the morning. The person with memory problems will hopefully adapt to the new routine.

The wristwatch has a battery life of approximately 3.5 days, so the family can be reassured that if they do not charge it every night, it will not run out of battery. The caregiver can check in the receiver's display information about the battery level of the wristwatch and other information. With this kind of localisation system, the person who controls the localisation and the alarms is a direct family member or the primary caregiver.

Call centre localisation system



The family is given a GPS device, commonly a multi-purpose tracking device with the size of a cigarette case, with an adapter to clip on the belt of the user. The family must register with a call centre service. Once activated, the person who has AD should always carry the GPS case on his/her belt.

To locate the person, the family must phone the call centre, and the operator will tell the family member where the person who is wearing the device is.

The operator can set up a security radio. If the person with AD walks out of the security area, the GPS device sends an alert to the call centre and the operator phones the family.

In both cases (direct localisation system or call centre system), it is recommended to set up a routine to recharge the batteries everyday. Unlike the direct localisation system, the person who can access the information of the battery levels etc of the GPS device is the operator, not the family.

"Since we got Keruve, we have had peace of mind. My father can go out, take walks, be with his friends and we don't have to live with the anxiety of not knowing if he's lost because we can locate him anywhere at any time if we think he may need help. Peace of mind is what we found."

Isabel Lorenzo. Spain

"After my husband went missing for 4 days, we decided to put a Keruve wristwatch on his wrist. This decision has brought peace to my husband and I. Now, he can continue going on his daily walks every morning. He walks really well, but I don't!"

Marie-Madelaine, France

Technical information for the curious

What is GPS?

GPS stands for Global Positioning System. This system allows devices that integrate a GPS receiver to know its own position. It operates through a network of 27 geostationary satellites covering the entire surface of the Earth.

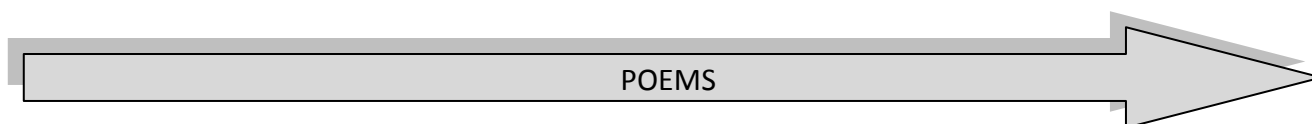
When the device requires its geographical coordinates, it enables the reception of satellite signals, calculates its distance from several satellites and performs various calculations of "triangulation".

The first Keruve prototypes were piloted in Spain with 10 families in 2007, with great success. After that, we commercially launched the product in Spain at the end of 2007. We had many pre-orders, therefore in 2008 we just served the pre-orders (we had only 3 staff for all operations). In 2009 we started doing an active commercialisation of Keruve in Spain, to hire more employees and opened our subsidiary in France. We continued to grow in Spain and France, and started

receiving orders from all over the world. In 2011, we started the Keruve international expansion plan, we started commercial activities and marketing in United States, Germany, UK and Italy.

All our customers are very satisfied, and because of this we sell Keruve directly to the customer, our R&D department receive direct feedback from customers and evolve the product focused on Alzheimer's patients and their family needs.

NOTE: A regular GPS device (like a car GPS navigator, or a running GPS watch) could only calculate its own position, but it cannot transmit its position wirelessly. In contrast, a GPS tracking device, not only integrates a GPS receiver, it also integrates a wireless communication system (commonly it integrates GSM, mobile telephone network) through which it could send the position information to the caregiver away from it (e.g.: a portable receiver carried by the caregiver).



Miss M

I am locked in a different world
My week is booked
But I am often overlooked
They try their best
But now I find it hard to get myself dressed
Getting old doesn't come alone
Now the buggers have put me in a home
I no longer live alone
But how I want to go home
When I was young I had so much fun
Visiting far away places with Dad and Mum
I felt so free
But now I am under lock and key
So when you turn off the light at night
Remember... That I once had a life

Remember who I am

A while ago
An average Joe
A hard working family man
Loyal husband, loving father
This is who I know I am

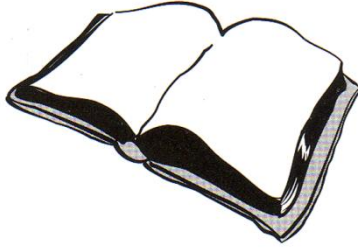
People stop and stare
My boss says i shouldn't be there
Arguments in with my spouse
At risk of losing my house
This is not the man I am

Who have I become? What have I done?
A strange place, an unknown face
Isolated, frustrated, cast aside
When all I want is my family at my side
To be the man I know I am

Melanie Jefferies

Marie Roberts

Book Reviews



Creativity and Communication in Persons with Dementia.

A Practical Guide

Authors: John Killick and Claire Craig
Publisher: Jessica Kingsley Publishers
ISBN: 978 1 84905 113 2
Price: £19.99

This book provides ideas and examples of ways in which carers, family members and friends can engage in creative activity with people with dementia. It describes how these kinds of activities can play a crucial role in maintaining and enhancing communication, reinforcing personhood and identity, restoring self esteem and building confidence often diminished in people with dementia.

Killick, a well established name in the field due to his numerous creative projects with people with dementia, and Craig, an occupational therapist who specialises in creative therapies, firstly explore the concept of creativity - what exactly it is and its particular relevance for people with dementia. They then go on to discuss opportunities to engage in a wide range of creative mediums. These include poetry, painting, drama, textiles, storytelling, working with metal and wood, photography, collage and music-making. A chapter is dedicated to each of these art forms, brimming with rich and varied ideas. Suggestions are provided on how to approach the practicalities of organising, running and facilitating sessions, adaptations to suit varying individual needs and personalities as well as different environments and also how to reflect on the experience.

Killick and Craig strongly encourage an attitude of openness and expectation towards the sessions. Letting go of preconceptions, both of the person's abilities and of the definition of art, and self-consciousness will facilitate the creative process for everyone involved. It is stressed throughout the book that the creation, from a painting to a poem, is the product of the person with dementia.

Therefore facilitators' inputs are purely guidance, support and encouragement, allowing freedom and control for those with dementia. This provides the opportunity and promotes the aim for the person with dementia to have a voice and express themselves through forms not necessarily dependent on, or limited to words. I am not entirely in agreement with the authors stress on the facilitators' strictly limited role. Realistically some people with dementia may require more involvement and assistance due to lack of confidence or becoming distracted, and a lack of this

would most likely end with them giving up very early on in the session.

The authors also discuss other benefits of the creative arts such as socialisation, feelings of accomplishment and increased confidence, self discovery, sensory experience and evoking of memories. Reflecting on sessions, the benefits are not limited to the person with dementia or within the sessions, but extend to family, carers and friends. These positive outcomes also have the power to improve overall quality of life for persons with dementia.

It is refreshing to have a book written where the outlook is of dementia having few barriers or boundaries on creativity. The book challenges the negative stigma often partnered with dementia by demonstrating through examples of past creative projects, what people with dementia can achieve. Woven throughout the book are several wonderful personal accounts from Killick and Craig in their experience of working creatively with people living with dementia. Many have exceeded their own and others' expectations of them. I find this book an inspirational read; it presents a wealth of ideas, suggestions, guidance and experience in the field of creativity and dementia. Most importantly it demonstrates how persons with dementia and those around them can gain from engaging in creativity activity.

Emma Fox

A Psychology undergraduate at Cardiff University undertaking a placement year with Cardiff Memory Team

ART THERAPY AND CREATIVE COPING ...

Art Therapy and Creative Coping Techniques for Older Adults

Author: Susan I. Buchalter
Publisher: Jessica Kingsley Publishers, 2011
ISBN: 978 1 84905 830 8
Price: £19.99

Buchalter makes a persuasive argument for her idea that a number of creative projects, ranging from art, music and movement through to poetry and creative writing, can provide positive benefits by tapping in to the feelings, needs and fears of the individual. She asserts here that her work helps to highlight those generally less-well represented in/by recent publications: senior clients

'who suffer from depression, anxiety, bipolar disorder and other personality disorders. Most of the articles and books in circulation focus on seniors who suffer from Alzheimer's disease and/or dementia, have significant disabilities or reside in nursing homes. This book is geared toward higher-functioning clients ...'

That clarification comes on the first page of the introduction (page 13) and thus clears the way for what follows. Whether depression and anxiety are ever experienced by those who are experiencing a form of dementing illness might be a topic for discussion elsewhere.

That moot point aside, this is an interesting read that addresses a number of topics and utilises exercises that consider issues as diverse as awareness, creative expression and coping skills. A number of illustrations also serve to offer directions for further work plans.

The uses of collage may often be overlooked, but can offer in-roads into therapeutic activities for those who might resolutely stick to the belief that they cannot either draw or paint, and that therefore art therapy is not for them.

Art therapy should be encouraged; as an often under-utilised option or alternative range of activities its benefits are not to be undervalued. This paperback will provide ample scope for positive interactions with the identified client groups.

Stephen Weeks

Retired Mental Health Nurse



SPIRITUALITY AND PERSONHOOD...

Spirituality and Personhood in Dementia

Author: Albert Jewell

Publisher: Jessica Kingsley Publishers

ISBN: 978 1 84905 154 5

Price: £19.99

This paperback book highlights the importance of spirituality and personhood for people with dementia. The book is formed by eighteen chapters, written separately by different individuals, covering a variety of topics, for example 'A Situated Embodied View of the Person with Dementia: Where does the Spiritual come in?' These individual authors are from a variety of different backgrounds theology, pastoral, clinical psychology, psychiatry, cognitive behavioural therapy and many more. Albert Jewell has effectively sourced these people to give the reader a comprehensive overall view of the topics highlighted in the title of this book.

This book includes many personal accounts. The realisation that it can be high achieving people who develop dementia is apparent. Brenda's quote; 'I've really wanted to live... a life that's worthwhile' I feel this accurately illustrates the reoccurring feeling of loss, as a theme throughout this book. There is also a desire for continuity and familiarity in life. The spirituality topic in this book is not necessarily from a religious context. The core values of love, generosity and altruism are consistent throughout all religions and illustrated accurately.

The Carer's Perspective (chapter 3) as a reader I found particularly touching. Written by Marianne Talbot she recalls her personal journey through her mother's Alzheimer's disease. I found this chapter very emotional because it illustrated Marianne's changing thought pattern from thinking about her mother pre-diagnosis, to a more person-centred way of thinking

'I had been resisting day care, thinking she would hate it. I was wrong'

Human beings are social creatures and she felt 'guilty to know she was inhibiting Mum's autonomy and her self-expression' through prompting her mother to live with her. Marianne recalls that her mother was a Christian. She perfectly recollects an occasion where students came to her mother's care home, her final Christmas.

'I doubt the choristers will ever feel as appreciated as they did that night'

as Marianne's mother joined in and sang alongside them. Marianne's story effectively describes the battle faced by many family care givers. They obviously have the best intentions for their relative and face a struggle with specific environments to ensure happiness, safety and peace of mind.

In short this book explores the relationship and importance of spirituality and personhood in dementia. I was surprised to learn that although religion for the older generation could be significant for them, spirituality encompasses much more than that. Personhood is described effectively through multiple personal accounts each echoing common themes previously mentioned. This book would be useful for any individual interested in the topics it covers, due to the varying backgrounds of people writing the chapters.

Stacey Brinton

Assistant Psychologist

Specialist Handbooks in Old Age Psychiatry

Authors: Bart Sheehan, Salman Karim, Alistair Burns
Publisher: OUP Oxford
ISBN: 978 0 19921 652 9
Price: £34.99

This pocket-size handbook is particularly useful for junior trainees. It has a clear table of contents and easy to use index for quick references of facts. The introduction provides some interesting epidemiological facts about mental health problems in older people which give a solid basis to start on the topic of old age psychiatry. It is also a useful resource for psychiatry trainees taking MRCPsych examinations as the prevalence of dementia; depression and delirium in various settings are frequently asked questions in the examinations.

I was impressed by the addition of descriptions of neuropathology, neurochemistry and genetics of the various dementias which was very easy to understand and digest. At first glance the book appears to be a handbook that provides basic clinical information on how to take a history and various investigations required to make a diagnosis but the book also provides relevant academic information. This gives it a more dynamic use as a clinical handbook but also a textbook for succinct information required in order to understand the origins of the clinical diagnosis. The book contains comprehensive information on dementia including various rating scales that can be used which I felt was exceptionally helpful for trainees.

The chapter on services was excellent. It was concise and clear in detailing the various services that are currently available, illustrated with interesting case examples. The chapter on ethical and legal issues gave a good insight into a potentially difficult area and explained the issue of mental capacity well, using straightforward language that was therefore easily understood.

As a junior trainee I would strongly recommend this book to all trainees who are in old age psychiatry placements or those undertaking examinations such as the MRCPsych or MSc in psychiatry. It would also potentially be useful to medical students and doctors studying for the diploma in geriatric medicine.

Dr. Sylvia Baker

CT3 Psychiatry Trainee

Group and Individual Work with Older People

Author: Swee Hong Chia, Julie Heathcote and Jane Marie Hibberd
Publisher: Jessica Kingsley Publishers, 2011 (204 pages)
ISBN: 978 1 84905 128 6
Price: £18.99

Being written by three professionals, this paperback provides a thoroughly-based read from an Occupational Therapy perspective. Their subtitle, 'a practical guide to running successful activity-based programmes' offers a straightforward summary of their aims, while also confirming that this is a UK publication, and thus has more distinct links to, and for, an English readership.

It isn't the easiest option to decide upon two representative chapters (from the 14 herein) to show the importance of this publication, but a considered appraisal should suffice here: chapter three reminds the reader of the pitfalls and privileges of (effectively) 'Communicating with Older People', while the tenth provides valuable groundwork resources in 'How to Facilitate Reminiscing with Groups and Individuals'.

It is intended that this collection of pieces can be utilised for either individual or group work, and that is evidently a specific strength of the text. Therapeutic work – and workers, can often provide springboards for personal development or group interactions because they are willing to display a clear purpose while maintaining a flexible outlook.

A couple of sections consider the size of the group, and offer confirmations that 'the larger the group, the more 'social' the occasion may be (whereas) the smaller the group, the more 'meaningful' the reminiscing experience may be' (page 129). The important reminder is made that some might be more reluctant to engage or contribute within a larger group setting.

This well-judged collection concludes with a selection of chapter-by-chapter references (including web-links as appropriate) subject and author indexes – and by the time the reader gets to that point, they will have been given plenty of food for thought.

Stephen Weeks

Retired Mental Health Nurse

Achieving a culture of person-centred dementia care in acute hospitals



Jo Crossland is a Dementia Care Practice Development Consultant and Trainer with Bradford Dementia Group at the University of Bradford. Her role involves supporting change in care organisations as

well as delivering training in dementia care to frontline care workers throughout the UK and overseas.



Professor Murna Downs is Head of the Bradford Dementia Group at the University of Bradford. Her research interests focus on quality of life and quality of care for people with dementia and their families. She

edits Excellence in dementia care: Research into practice and the Bradford Dementia Group Jessica Kingsley series of Good Practice Guides on Dementia Care.

In this paper, we will describe some of the challenges that exist when trying to ensure that high quality person centred care is provided to people with dementia and their families by a skilled and effective workforce. We will discuss the value of training in acute hospital settings, and some of the approaches that need to be in place to enable training to be effective, and how these may be introduced.

Reasons to be concerned about the quality of care in hospitals

It is universally acknowledged that the number of people with dementia in the UK is growing, from an estimated 750,000 today to double that number within the next 30 years. Although the majority of people living with dementia are older people, there are at least 15,000 people living with dementia who are under the age of 65 (DoH, 2009).

Recent reports suggest that older people occupy up to 70% of acute hospital beds at any one time, with an estimated 40% occupied by people with memory problems. Of these people, the majority are not known to specialist mental health services, so consequently do not have a specific plan of care in place to support general hospital staff in the delivery of appropriate and timely interventions (Alzheimer's Society, 2009; Department of Health, 2010).

People who have dementia stay in hospital longer than people without cognitive impairment (DoH, 2011). In addition, they fare less well in terms of mortality and institutionalisation (DoH, 2009). Concerns such as a higher risk of hospital acquired infection and increased risk of dehydration and malnutrition can all be linked to length of stay in hospital (see British Geriatric Society: <http://www.bgsnet.org.uk>). This has inevitable resource implications for NHS Trusts already under pressure to scrutinise budgets.

Drivers to improve the quality of care in hospitals

The publication of the National Dementia Strategy (DoH, 2009) helped to highlight the need for people with dementia to be afforded the same level of care as people who are cognitively well. One of the priority objectives in the Department of Health's (2010a) Quality outcomes for people with dementia is improved quality of care in hospitals. As part of the drive to improve dementia care, the Royal College of Nursing (RCN) is currently engaged in a national project supported by the Department of Health regarding ways to improve the quality of care for people with dementia in acute care settings (<http://www.rcn.org.uk/development/practice/dementia>).

Recently published findings (2011) give a voice to people with dementia and their family carers, with 98% of responses believing that education and training for staff would improve the experience of being in hospital for people with dementia. A similar survey of professionals highlighted that 69% of those involved believed that education and training was significant in improving dementia care.

Training – a necessary first step

Despite the widespread call for training, dementia awareness training is not currently mandatory for staff working in acute hospital settings. A scoping report commissioned by the Department of Health (DoH, 2010b) highlighted a lack of consistency in the approach or content of dementia training. Indeed, currently only 5% of hospitals in England and Wales require their staff to undertake any form of specialist dementia training (Alzheimer's Society, 2009; Royal College of Psychiatrists, 2010).

The Alzheimer's Society (Alzheimers.org.uk) suggest that ensuring staff have appropriate dementia training

could lead to cutting the length of stay in hospital for people with dementia by an average of one week saving up to £80 million for the NHS. In addition, providing dementia training is clearly one route towards improving the quality of dementia care as well as having the potential to improve job satisfaction among staff.

Objective 13 of the National Dementia Strategy (DoH, 2009) focuses on an informed and effective workforce. Equipping teams who deliver care with the key skills, knowledge and understanding can help towards ensuring people with dementia are afforded high quality care in hospital.

Training is just one component in embedding improved quality of care

Preliminary findings from the RCN study on dignity in dementia within general hospital settings (Royal College of Nursing, 2011), emphasizes that in addition to training and education, senior management support and appropriate leadership are central to improving dementia care. The RCN survey of practitioners (Royal College of Nursing, 2011) identified the following as major barriers to improving care and all clearly impact on staff being able to attend dementia training including pressures of workload, staffing levels insufficient to be able to release people from the clinical area, and increasingly restricted budgets. In addition, there is now a well worn mantra that training alone is not enough (Lintern, Woods and Phair, 2000). There is often no tangible change to care delivery following training and this raises questions regarding the cost benefit of such training and the utility of investing further in this approach (Lintern, Woods and Phair, 2000; Atkin, Holmes and Martin, 2005).

Bowers (2008) provides a helpful review where she identifies a number of essential elements before, during and after training which help to ensure it leads to a change in practice. These include paying attention to the selection of staff, matching course outcomes to staff role requirements and ensuring staff are well prepared for the training course. Bowers (2008) stresses that after training staff need the opportunity to apply the learning and to receive feedback and supervision to support the application of this learning to practice. One such approach is to have the opportunity to reflect on applying new learning to practice.

The opportunity to reflect on practice is recognised as a fundamental way of learning from experience (Jasper, 2003). Reflection enables practitioners to think critically about a situation or experience, and supports the development of new knowledge. New learning is intended to build on existing knowledge and experience to further develop understanding (Titchen, 2004).

Clinical supervision provides an opportunity for practitioners to reflect on their practice and to develop clinical knowledge and skills (Paget, 2000; Mann, Gordon & MacLeod, 2009). The quality of supervision for staff is influenced by the skills of the supervisor, and without a robust framework for supporting all parties involved in supervision, its benefit may be questionable

(Butterworth, et al, 2008). When time is at a premium, due to staffing levels and other workload pressures, a structure to guide and enable reflection is likely to be more helpful and effective for practitioners in developing practice (Mann, Gordon and MacLeod, 2009).

Bradford's 'training plus' approach to sustainable change in care practice

In Bradford, alongside our short courses in person-centred care, we coach supervisors and mentors in the use of Dementia Care Mapping for guided evidence-based reflection. Dementia Care Mapping (DCM) is a process for evaluating the quality of care which emphasises team ownership and action planning and ongoing monitoring. It uses structured and direct observation to describe the quality of care received, from the perspective of the person with dementia (Kitwood, 1997a). As the care team "owns" the information that is gathered, they have responsibility for using this information to implement and monitor the effects of, change in care practice. In this way we are supporting practitioners to ensure people with dementia are afforded quality care in hospital.

Summary

The quality of care provided to people with dementia in acute hospitals need to change. Training in knowledge and skills has a part to play in securing that change. Recently acquired knowledge and skills require appropriate supervision and guided evidence-based reflection in order to become embedded in everyday practice. Training supervisors in the use of Dementia Care mapping can assist with providing a structured and evidence-based approach to reflecting on practice. Structured support to care teams reflects on the experience of care from the perspective of the person with dementia which can lead to sustainable change in practice. Bradford's 'training plus' approach is currently being tested in the acute care setting. The aim is to develop informed and skilled teams of practitioners who are able to reflect on practice in a considerate and constructive way. Practicing in this way with necessary knowledge and skills will have the opportunity to embed and be rewarded.

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The Bradford Dementia Group is a signatory to the Dementia Action Alliance and offers both undergraduate and postgraduate degrees in Dementia Studies by distance learning, alongside an international practice development programme in Person-Centred Care and Dementia Care Mapping. See www.bradford.ac.uk/health/dementia



THE WALES DEMENTIA CARE TRAINING INITIATIVE UPDATE

The Wales Dementia Care Training Initiative Update

The Wales Dementia Care Training Initiative has been funded by the Welsh Assembly Government in response to the work undertaken from 2008-2010 in developing National Dementia Action Plans for Wales.

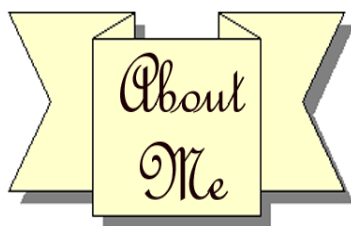
The initiative employed an initial investment of resource in the financial years 2010-11 and 2011-12 to increase training capacity and expertise in Wales, to lead to sustainable improvements in attitudes, skills and knowledge of those providing support and care to the growing number of people with dementia.

Train the Trainer in Dementia Care across Wales has commenced covering health and social care. Over 100 people have attended this training which has exceeded our original target number. The initiative has made strides towards improving education and training in Dementia Care within district general hospitals within all six Health Boards throughout Wales. This has involved study days, advice and support in implementing the Intelligence Targets. The training has been well received with a very positive response. Attendees have

been very enthusiastic and motivated to learn as much as they can about Dementia Care in order to improve quality of care. DSDC Wales have been very successful in facilitating training in both independent and social care settings across North and South Wales.

Given the positive response the Welsh Government are supporting the extension of the South Wales post for a further five months.

About Me



Del Payne

**Ward Manager
Iorweth Jones, Cardiff
and Vale UHB**

Who are you and what do you do?

My name is Delphina Una Anne Payne. No wonder I am known as "Del". I started nursing in 1989, went on my first elderly placement and there and then decided to dedicate my career to looking after patients who present with dementia. I am due to retire next July. I am a ward manager/ sister.

What are the most enjoyable parts of your career?

I always feel a surge of warmth and love in my heart when a patient acknowledges me. This may sound odd to people who have not worked in the field of dementia but that special look or touch I have often received when I know that they know that I know, is worth more than any amount of money. For me, the centre of my career has been the patient. This and the sense of achievement I get when I know the team has the same values as me.

What are the least enjoyable parts of your career?

As my career has progressed, I have seen many changes occur within nursing and not all for the best. Red tape irritates me like a rash. Certain policies and procedures cause me to complain and I know I have been a bit too outspoken at times, letting my heart rule my head but at 54 years of age I doubt I will change now. I guess I am a bit of a marmite person...you either love me or hate me. I love marmite!

If you could nominate one person for an award, who would it be, and what would it be for?

Can I choose two people? The first is Debbie Brown, the deputy ward manager I worked with for nearly 8 years until April this year. She is a prime example of work life balance. I admire her greatly for putting everything into all that she does. She is undoubtedly the best mother ever. Likewise, in work, each patient is special to her, individual and treated as such.

The second person who deserves an award is Mandy King, nurse lecturer practitioner. She has nurtured me, her gentle voice like soothing balm having to often tell me that my quirky sense of humour is not appropriate (hence saving me from getting into trouble!), and has always believed in me. My self esteem soars when I am in her company.

Of what achievements are you most proud?

I am the proud mother of two wonderful daughters and three beautiful grandchildren.

If you won 10 million, how would you spend it?

I am a very mumsy, stay at home woman and have never been abroad apart from a trip to France where I became so homesick I had to return within 2 days. What am I like?! I would obviously make sure everyone I knew and loved had portions but not so much that they would have any values left. I would buy them a fleet, if that is the word, of chip shops (oh yes I would). Anyone who knows me well is aware of my great dalliance with the chip butty. I would not give money to particular charities, preferring to buy items for individual needs. I would also build some bungalows for people with dementia who want to still live with their family and create a dementia village. I have always found it dreadfully upsetting to part spouses especially. Imagine looking through the window of a bungalow to see husband and wife pottering around their living room in safety together doing their own thing.

Is there any question you would have liked us to ask that we didn't and what would your answer have been?

I would like you to have asked if I had religious beliefs.

I am a born again Christian and know that God has guided me throughout my career. Some people will be surprised at my acknowledgement of this because I do not come across as the stereotypical Christian. I have had times over the years when I have blatantly strayed from the Christian path but have been forgiven. I must say I try each day to be more Christ like and less Del like but often go to bed thinking "tomorrow's another day, try again Del". Great that He accepts me as I am, warts and all. I pray each day for the patients, staff and visitors and will continue to do so when I retire.

News Continued

Centre opened for dementia research

A health centre dedicated to research into new treatments that would prevent the onset of Alzheimer's and Parkinson's diseases has been launched by Cambridge University.



The university has teamed up with drugs development company Elan Corporation to provide the Cambridge-Elan Centre for Research Innovation and Drug Discovery, which will benefit from their combined expertise and work on world-leading research focused on innovative therapies for the diseases.

This 10-year agreement paves the way for a long-term collaboration between Elan and Cambridge University.

Cambridge scientists have spent more than 10 years on interdisciplinary research in order to understand the fundamental molecular origins of neurodegenerative disorders such as Alzheimer's and Parkinson's diseases.

It is hoped the partnership could lead to the development of new treatments that would prevent these diseases.

Source:

<http://www.cambridge-news.co.uk/Cambridge/Centre-opened-for-dementia-research-29112011.htm>

Cancer drug improves symptoms of Alzheimer's in mice, study says

Published 10 February 2012

An existing cancer drug seems to improve many of the effects of Alzheimer's disease in mice, a study published in the journal *Science* has found.

Researchers in Ohio found the drug bexarotene was effective in increasing levels of the protein ApoE, which in turn sped up the clearance of amyloid-beta, a hallmark of Alzheimer's disease. They also discovered that the drug quickly improved memory deficits and behaviour. This supports previous research which has shown that ApoE helps clear amyloid plaques in the brain.

Source:

http://alzheimers.org.uk/site/scripts/news_article.php?newsID=1158

WEB REVIEW



<http://www.alzwell.com/index.html>

ALZwell caregiver support

ALZwell have been publishing since 1996 as a resource for Caregivers to people with a dementia. Their goal is to provide knowledge and wisdom to caregiver's to make their journey easier.

The website is more specific for caregiver's and offers information on the basic medical explanations of the different types of dementia. But also it offers information to the caregiver about 'Being a caregiver'. This information included guidelines, difficult behaviours, communication skills, elderly depression, activities etc. This information is really practical and useful and it is a quick reference for people to read when they are unable to speak to others or professionals about how to respond to certain situations or that a certain behaviour is increasing or becoming more difficult to deal with.

The website takes into account the varying stages that a person may go through with their illness and what the carer may have to deal with. There is also a section for finding a care home and by signing up you will be sent information about care homes in your area.

They also give information about other important elements such as diabetes care, healthy aging information, retirement planning. They also share a list of books and other websites to recommend you so that you may gain more knowledge and understanding of the illness.

This website was really useful to look around and as a person who works within the dementia services I was not aware of this website and in fact I think it is a website I could recommend to caregiver's for information and support in the future.