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SIGNPOST

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Contents

2. **EDITORIAL**
Dr Christina Maciejewski

4. **FOREWORD**
Dr Simon O'Donovan

10. **REFLECTIONS ON A COMMUNITY MEMORY TEAM AND RESEARCH**
Professor Tony Bayer

20. **REFLECTIONS ON SIGNPOST AND MUSIC THERAPY**
Dr Julie Wilcox

25. **MUSIC THERAPY IN DEMENTIA CARE: CONNECTING WITHOUT WORDS**
Michael Fulthrope

32. **ESTABLISHING THE BIGGER PICTURE: BRAIN IMAGING IN DEMENTIA**
Hannah Bowker

35. **END OF LIFE CARE: WHAT MATTERS FOR PEOPLE WITH DEMENTIA**
Martina Kane

40. **ABOUT ME**
Lucy Young

43. **BOOK REVIEWS**
David Shannon
Katie Glare
Peter Davies

48. **DID YOU KNOW?**
BibblePlus

48. **NEWS & WEB**
Rosalind Cooper

50. **INFORMATION ABOUT SIGNPOST**

Cover picture: Teapots by Nikita McBride, Emma Hutchinson, Georgia Hall and Lily Glover-Wright, second year art students, Cardiff Metropolitan University. Displayed in Mental Health Services for Older People gardens, Llandough Hospital, Penarth.

Editorial

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

Welcome to this edition which celebrates 25 years of the production of Signpost. I began my career as a qualified clinical psychologist working in Cardiff 26 years ago and thus have been aware of the journal throughout my professional life. I have seen the journal change and grow from its original format produced on a typewriter and distributed to colleagues working locally to its current new format as an e-journal. In this edition we are fortunate to have a number of contributors to early editions of the journal who have reflected for us on their earlier contributions and the progress that has been made in the care of people with dementia and late life onset mental health problems.

Dr Simon O'Donovan developed the idea of Signpost and was the original editor of the journal. His foreword in this article celebrates the recent development of Cardiff's Younger Onset Dementia Service, highlighting the progress and change that can be made.

Professor Tony Bayer has led the Memory Team in Cardiff throughout the time that Signpost has been produced. In this edition he reflects on how the pioneering model of memory assessment services has been taken up by other services but also reflects on changes in service provision that have been necessitated by the six fold growth in new referrals to the service each month.

This edition also features a range of articles describing current practice and issues. Hannah Bowker describes the range of structural and functional imaging techniques which are now routinely available to aid diagnosis and monitor changes over time. This informative article highlights the advances that have been made in brain scanning techniques.

In his article on Music Therapy Michael Fulthorpe provides a clear explanation of the nature of music therapy and the opportunity it provides for non-verbal communication before going on to describe his recent work with younger people with dementia.

Martina Kane's article on End of Life Care for People with Dementia encourages us to challenge the taboos in our society about discussing death and to consider what is needed to allow individuals with dementia to die with dignity, free from pain and in the place they feel comfortable.

Rebecca Pearce provides a comprehensive introduction to the use of mindfulness based therapy in mental health services and describes the development of a resource pack for use with older people.

Dr. Julie Wilcox, consultant clinical psychologist in stroke services in Cardiff and Vale reflects on her time as the assistant psychologist working on Signpost. Having reflected on all the changes to Signpost over the years I was pleasantly reassured by the realisation that the experience of the assistant psychologists who work so hard to bring this journal to you have changed little. This brings me to my final reflections on the development of the journal over the last 25 years. The journal has developed from the early ideas and drive of Simon O'Donovan as editor, through the hard work of numerous assistant psychologists who went off in search of contributors to those very contributors who continue to drive the journal forward and challenge our readers with innovative and informative articles.

Dr. Christina Maciejewski

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Foreword

Dr Simon O'Donovan is Clinical Director for Mental Health Services for Older People in Cardiff and the Vale of Glamorgan and leads the Younger Onset Dementia Service. His background is working as a Consultant Nurse in Safeguarding Vulnerable Adults. He has contributed to national policy and strategy development and has a strong interest in client and caregiver wellbeing and experience of services.

I am really pleased to write for this twenty-fifth anniversary edition of Signpost about the Younger Onset Dementia Service currently under development in Cardiff and Vale University Health Board.

The Daffodil Public Health Wales Report indicates that for Cardiff and the Vale of Glamorgan there should be 107 people with dementia under the age of 65 (in 2012), rising to 122 by 2030. The Alzheimer's Society states that there are more than 17,000 younger people with dementia in the UK. However, it argues this number is likely to be an under-estimate and the true figure may be up to three times higher.

Each person's experience of dementia is unique. Although the symptoms of dementia are similar whatever a person's age, younger people with dementia have different needs for support. They may:

- Be in work at the time of diagnosis
- Have a partner who still works
- Have dependent children still living at home
- Have ageing parents who they need to care for
- Have financial commitments, such as a mortgage
- Be more physically fit and active
- Be more aware of their disease in the early stages
- Find it hard to accept and cope with losing skills at such a young age

The course of the illness may also be different in so much as it is likely to more rapidly progress in working age adults and be more complex and challenging in its presentation. Also rarer dementias are more commonly diagnosed.

The need for the development of a specialised dedicated service for people with a dementia diagnosis under the age of 65 and their carers and families was first raised in this area at a South and East Cardiff Sector Forum held in September 1994. But from that date until the National Dementia Vision for Wales was launched in February 2011 little progress was made, except for the development of a highly valued but part time (17.5 hours) Information and Support Officer post which became available through grant funding in the Alzheimer's Society in circa 2005 (now Health funded).

The National Dementia Vision for Wales prioritised "creating a new young onset dementia service for Wales" and allocated a sum of money to each Health Board to appoint posts to kick-start service developments. The Cardiff and Vale allocation was £69,200 recurring and this enabled a full-time Band 6 Dementia Care Advisor and 1.6 wte Band 3 Family Support Worker roles to be appointed. Resource realignment within the wider service saw an additional 0.5 wte Clinical Lead sessions and 0.4 wte Consultant Old Age Psychiatrist sessions allocated to form the start-up Younger Onset Dementia (YOD) Community Service.

The YOD service became operational in November 2011 and over the first two years the following service components have been developed around the assessed needs of clients and carers.

- Post Diagnosis Memory Clinic – Clients with a diagnosis of a primary progressive dementia (alcohol related cognitive impairment is not included in our eligibility criteria) are referred to the YOD Service after they have gone through the assessment and diagnosis pathway with Cardiff Memory Team. Six monthly clinic review appointments are offered on the last Friday of each month. Two clinics are run simultaneously and a Consultant Old Age Psychiatrist is available if an individual's mental health is a cause for concern or medication review is required.
- Post Diagnosis Support Group – Clients are offered, some months after their diagnosis, access to a closed programme of psycho-educational support. This addresses coming to terms with the diagnosis, understanding symptoms of dementia and how to manage them, sharing diagnosis with the family etc. A monthly Keeping In Touch support group is offered after this in order that friendships formed can be maintained.
- Care Coordination – For clients who are more complex in their presentation, who experience behaviour and psychiatric symptoms of dementia or for whom there are significant risk or vulnerability issues, access to specialist secondary mental health care services are available. Clients are transferred from the 'Primary List' to the 'Secondary List' when they require allocation of a Care Coordinator under the Mental Health Measure (Wales) and the development of a Care and Treatment Plan including psychiatrist review.

- Family Support Worker – Clients on the Secondary List still living at home have access to Family Support Worker sessions. These aim to provide community support, social activity and recreation and carer respite. Clients living alone or where the caregiving situation is at risk of breakdown are prioritised for input.
- Cognitive Stimulation Therapy Group – A Friendship Club is offered once a week in the Assessment and Recovery (Day Hospital) Unit at Llandough Hospital for clients on the Secondary List. The Sterling University Dementia Services Development Centre Making A Difference Programme is followed in the group, with sessions usually comprising introductions and orientation, welcoming song, themed music and film clip quiz, physical activity, relaxation session, soup and sandwiches (which provides an opportunity for carer support) and planning for the next session.
- Carers Support Group – Two Carers Support Groups are held bi-monthly (one in Cardiff at lunchtime; one in the Vale in the evening, to allow working carers to attend). These groups aim to provide support for carers and families of younger people with dementia separate from older age carers support groups and to allow access to timely information and education regarding prognosis, managing challenging behaviours etc.

The service also has close working relationships with:

- Ty Hapus/Alzheimer's Society – Ty Hapus is a charitable status service commissioned with the Alzheimer's Society, providing a Drop-in Cafe and a Day Care Service for six younger onset clients.
- Cardiff and Vale Local Authorities – If a client needs assessment for a package of community care a referral is made to the relevant Local Authority for this to be commissioned.
- MHSOP Community REACT Service – If a client needs crisis intervention to avoid admission to acute mental health inpatient care a referral to Community REACT is made. Usually same or next day urgent or emergency (within 4 hours) assessment can be undertaken and out of hours care can be provided for a time-limited period.
- MHSOP Assessment and Recovery Unit – If a client needs an assessment period within a day hospital environment with access to multi-disciplinary support a referral is made to the ARU.
- MHSOP Inpatient Services – If a client needs admission for acute mental

health assessment this is facilitated by the YOD Service and the Consultant and Care Coordinator provide in-reach support for the duration of their inpatient stay.

As above, most referrals to the service come via Cardiff Memory Team. However this is not always the case as younger people with dementia often have a more convoluted route to diagnosis, e.g. they may be known to Adult Mental Health Services before reasons for cognitive impairment become apparent or they may be diagnosed by Neurosciences Services such is the degree of complexity around their presentation.

As of today's date (11/11/13) there are 104 clients on our caseload – 41 on the Primary List, being reviewed at Follow Up Younger Onset Dementia Memory Clinic, and 63 on the Secondary List, receiving Care Coordination and Care and Treatment Planning under the Mental Health Measure (Wales).

Of the 63 clients on the Secondary List,

- 3 clients are aged 41-50
- 16 are aged 51-60, and
- 44 are aged over 60 years (includes 17 over age 65 as the service does not transfer clients when they reach their 65th birthday as continuity of care is viewed as being crucial for clients mostly with rapidly progressing conditions).

- 39 clients have a diagnosis of Alzheimer's disease
- 8 clients have a diagnosis of Fronto-temporal dementia
- 3 clients have a diagnosis of Vascular dementia
- 3 clients have a diagnosis of Posterior Cortical Atrophy
- 2 clients have a diagnosis of Dementia with Lewy Bodies
- 2 clients have a diagnosis of Huntington's disease
- 2 Downs and Alzheimer's
- 2 Alcohol related dementia
- 1 Mixed Alzheimer's/Vascular.

- 41 clients are living at home supported by their carer
- 2 clients are living at home alone
- 4 clients are in residential or nursing placements
- 5 clients are in high cost placements under Continuing Healthcare funding

- 10 clients are inpatient within MHSOP Inpatient services (1 acute assessment – male; 9 extended assessment – 7 females, 2 males).

Regarding the need for inpatient services, there has long been a recognition that more age appropriate facilities were required in house. Because of the risk posed by caring for younger clients with challenging behaviours who are more physically active alongside elderly clients who are more frail, historically more high cost out of are specialist placements have been sought. There has been an acknowledgement by the Health Board locally that the cost spent on high cost external CHC placements could be reinvested to develop a specialist dedicated Younger Onset Dementia Inpatient Unit.

Subsequently there has been Board support for developing a 14 bedded Younger Onset Dementia Inpatient Unit in St Barruc's ward at Barry Hospital (7 female beds; 7 male beds, provided in group living units) and a Repatriation Business Case has been progressed to bring clients back into more appropriate NHS provision. This Business Case has enabled additional Multi-disciplinary Team members to be appointed to the Younger Onset Dementia Service to the following extent:

- 0.4 wte Band 3 Family Support Worker
- 0.5 wte Band 6 Physiotherapist
- 0.5 wte Band 6 Occupational Therapist
- 0.5 wte Band 8b Clinical Psychologist
- 0.4 wte Band 6 Speech and Language Therapist
- 0.4 wte Band 6 Dietician
- 0.4 wte Band 3 Admin

(with all post-holders working across community and inpatient services).

An additional 2.0 wte Band 5 Qualified Nurses, 1.0 wte Band 3 Health Care Support Workers and 2.0 wte Band 2 Nursing Assistants have also been appointed to increase ward staffing levels and skill mix to accommodate the increased therapeutic support needs of clients.

Stephen

Stephen was a 60 year old retired postman who presented at the District General Hospital for ENT surgery – cancer of the tonsil. When he was in-patient it was discovered that the communication impairment he presented with was not so much to do with the pain of talking as an inability to form words and express himself. A Neurology assessment was undertaken and a diagnosis of Primary Progressive Non Fluent Aphasia was given on the basis of imaging results and clinical presentation.

Unfortunately Stephen was discharged home without follow up support before the Younger Onset Dementia Service could visit him in hospital. His sister was at home with him but she was due to leave the UK, as she lived overseas and had only come home to support her brother through his hospital stay. Stephen had no friends or family who could offer support living in Cardiff.

Stephen presented to the YOD Service with significant risk factors and high vulnerability, for example he lived alone, could not safely cross the main road he lived nearby, could not handle money and was vulnerable because of this (he had written his PIN card number on the back of his card), and could not use the telephone due to his language deficits.

After initial assessment and allocation of Care Coordinator, the YOD Service referred Stephen to the MHSOP Community REACT (crisis and out of hours) Service. Intensive support including three times daily support visits to administer medication, prepare food and undertake shopping with Stephen was arranged, until a Local Authority package of community care could be commissioned. Support from Speech and Language Therapy concerning swallow assessment and Dietetics regarding access to fork mashable diet and supplements was also essential, as there had been significant weight loss).

Stephen was maintained at home for six months until his throat cancer re-emerged and advanced. Risks became such that inpatient care was necessitated, for instance he could not self-medicate when in acute pain and he refused to put his heater on and became at risk of hypothermia. In close liaison with his sister and Palliative Care Team it was decided to admit him to MHSOP Inpatient Services so that he could have access to a single room with his own television and continue with aspects of his lifestyle, for example watching Jeremy Kyle each afternoon and evening.

Sadly Stephen died within four weeks of being admitted to hospital. The YOD Service, with invaluable support from MHSOP Community REACT, Cardiff Local Authority and Palliative Care, was able to support him living independently for several months and then to provide a highly supportive environment until the time of his death.

Conclusions

Reflecting on two years practice in this field, I have come to realise the most important thing in working with clients with younger onset dementia and their carers is that a highly individualised, person-centred approach is essential. This goes without saying of course, but the highest level of dignity and respect in care requires detailed knowledge of the person and an understanding of their interests, lifestyle, ways of being, communication style and so on.

Another important lesson perhaps is that we are all in this together. Using first names, wearing casual clothing, sharing refreshments together and so on helps convey equal status within therapeutic groups, for example, and building trust demands an openness and sincerity that my previous clinical role did not demand of me.

Also working closely with clients, carers and families through the progression of dementia can be personally distressing. Supporting people through an illness which encompasses so many aspects of loss can touch you profoundly. An awareness of self and access to personal support and professional supervision seem to be of paramount importance.

And of course, we are still learning. It will be interesting to see how the service develops over the next two years and I would be happy to write again for Signpost when it is fully established.

Resources

Alzheimer's Society Factsheet: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164

Talking Point Forum: http://forum.alzheimers.org.uk/forumdisplay.php?27-Younger-people-with-dementia-and-their-carers

Frontotemporal Disease Support Group: http://www.ftdsg.org/

Lewy Body Dementia Association (USA): http://www.lbda.org/

Huntington's Disease Association: http://hda.org.uk/

Footnote

I would like to thank Dr Christina Maciejewski on behalf of the service for chairing the Younger Onset Dementia Steering Group over many years and leading us to the point we are now at

Simon O'Donovan

Reflections on a Community Memory Team and Research

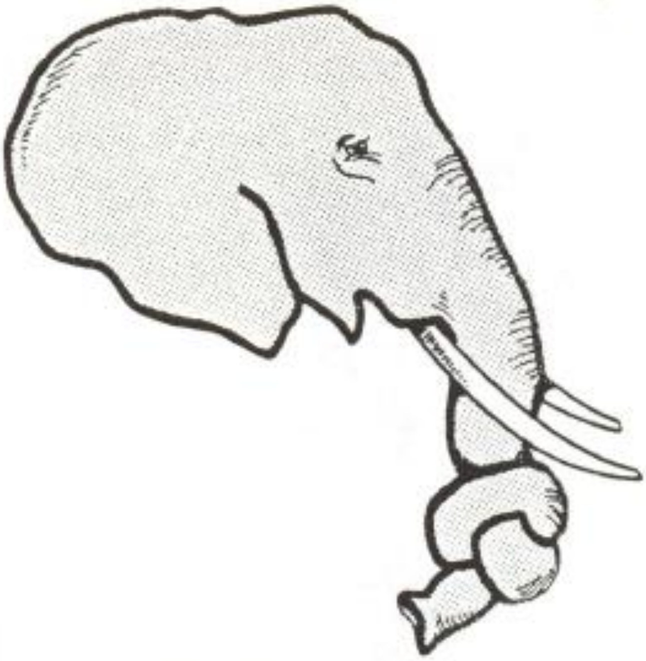
Tony Bayer is Professor of Geriatric Medicine in the Cochrane Institute of Primary Care and Public Health in the School of Medicine at Cardiff University and Director of the Memory Team, based at University Hospital Llandough. He has a longstanding interest in cognitive impairment and dementia and set up one of the first Memory Clinics in the country in the mid-1980s.

Community Memory Team

The objectives of the Community Memory Project (early identification and diagnosis of dementia, ongoing support and advice to patients and their families, and involvement in training and research) were seen as innovative when it was first funded by the then Welsh Office in 1988. They have not changed over the subsequent 25 years and it is pleasing that the success of the model has since been copied across the UK and beyond and the principles incorporated into national government policy.

Some aspects have been harder to maintain than others. The memory clinics were originally community-based and so convenient for patients, but the informal agreements that allowed this have been overtaken by the growth in NHS bureaucracy of recent years and now all the clinics are held in local hospitals. The multidisciplinary nature of the clinic team has been maintained, though unfortunately the social worker input was withdrawn after a few years as there was concern from social services managers that the incumbent would be 'deskilled' by mixing too much with health staff. Hopefully the present moves towards greater integration of health and social services will eventually lead to the post being re-established.

The '20 new patients every month' has increased 6-fold, but unfortunately staff numbers have not grown at the same rate and we now must rely more on primary care and third sector organisations to provide ongoing support after diagnosis. More positively, there is much greater understanding and less stigma attached to diagnosis of dementia, access to neuroimaging as part of the assessment process is now freely available and use of symptomatic drug treatment for Alzheimer's disease is now routine. Hopefully in another 25 years we will have even more effective interventions and timely diagnosis and treatment will be standard practice for all the ever-increasing numbers of people with dementia.



COMMUNITY MEMORY PROJECT

Telephone: 486932

The Community Memory Project are (from left to right) **Judith Evans** Social Worker, Doctor **Tony Bayer**, **Vicky Richards** Community Psychiatric Nurse, **Gwen Phillips** Clinical Psychgologist and **Elizabeth Dawkes** Administrative Officer.

A multi-disciplinary team for the identification, assessment and management of patients with memory difficulties and related problems.

COMMUNITY MEMORY PROJECT

> "What will help patients and their families most is early referral, a careful assessment, a probable diagnosis and a reasoned prognosis....
> This should then lead to a clear and positive plan for future care, with continuing support from a flexible and sensitive multidisciplinary team of professionals experienced in dealing with the changing and varied problems which may arise."

The Community Memory Project developed from the Memory Clinic held weekly at the University Hospital. As previously unrecognised cases of early dementia were diagnosed, the need to provide continuing support to patients and their relatives as the illness progressed became increasingly apparent. With the aim of providing a basis for sustained contact between patients, their family and services, the Community Memory Project was set up in early 1988, supported by the Welsh Office under the Good Old Age initiatives.

The first year has been a period of development with each member of the team arriving with a different set of experiences and skills to offer. Without any similar projects anywhere in the country on which to base our work, the first 12 months have been an exciting and challenging time for all of us.

Our objectives are:

1. Early identification of dementia and related problems.
2. Ongoing assessment and monitoring of identified patients.
3. Support and advice to patients and their families, help with co-ordinating services, and provision of a package of care to minimise the likelihood of medical and social crises developing.
4. Involvement in training, bringing together carers, both professional and informal, to exchange views and information on Alzheimer's disease and related disorders.

WHY COMMUNITY MEMORY PROJECT ?

To complement the University Hospital Memory Clinic (which still runs weekly), 5 other clinics are now in operation. These are very much community based, held in health centres and clinics around South Glamorgan. To cover as wide a geographical area as possible these are currently based at Rhiwbina Clinic, Riverside Health Centre, Trowbridge Health Centre, Penarth Health Centre and Broad Street Clinic, Barry. Local clinics are more accessible for patients and relatives and provide a more familiar and relaxed setting than the hospital. Appointments are arranged at the most convenient site for each patient.

All patients are seen only with the knowledge of their GP but we encourage anyone working in the field to instigate referrals; other health professionals, workers in social services and the voluntary organisations.

The term dementia can include a whole range of cognitive disorders, but in its early presentation a prime feature is that of short-term memory loss, particularly memory for day to day events. It is very often the memory difficulties that relatives notice as being the first indication that changes are taking place in the patient. As a proportion of our clients' symptoms are not related to a dementing illness as highlighted in Professor Pathy's talk, it is more appropriate for the name of the clinics to focus on the presenting symptoms rather than diagnosis.

The Clinics

Gwen Phillips, the clinical psychologist in the team, is involved in all the clinics, with backup provided by Dr.Charles Twining. Elizabeth Dawkes,our secretary, is responsible for sorting out the clinic appointments as well as the day to day administration of the Project. Dr.Tony Bayer is involved in the University Hospital Memory Clinic on Wednesday mornings and Dr.Siwan Evans and Dr.Pat Howarth are involved with the community clinics. Very often we are accompanied by interested observers who want to watch what we do, and we are always happy to accommodate this whenever possible. Arrangements can be made through the Community Memory Project office.

It is not necessary to reiterate Professor Pathy's description of the clinic procedure, though perhaps worth emphasising that we see a wide variety of presenting symptoms. Amongst those who have a likely diagnosis of dementia severity ranges from the very mildly affected to those who already have well advanced disease, and the assessment procedures need to adapt flexibly to these differing presentations. Apart from memory impairment there are likely to be other cognitive problems causing some difficulties in day to day life. Identifying the different areas of impairment and explaining to relatives the nature of the problems can help clarify what is often a very strange and perplexing set of behaviours. Speech problems, for example, frequently accompany memory problems, with word finding difficulties in particular being noticed, as well as lack of fluency and flow and conversation becoming more and more empty. In later stages perceptual difficulties are very common, with problems being experienced in tasks such as dressing and laying the table. The problem lies in co-ordinating and executing previously well learnt skills. The emphasis of the clinic is to identify accurately the particular set of problems for each patient and their family and to suggest an individualised plan for care.

The Project

The clinic setting, however, is only part of the Project. Each week the patients from the clinics are discussed within the team, the other members being Vicky Richards, community liaison sister and Judith Evans, our social worker. Both have considerable experience working with this client group, Vicky having been a ward sister at Whitchurch Hospital for a number of years and Judith working at the Royal Hamadryad Hospital when not with us.

During our weekly review meeting for each patient, a key worker is identified who will take on the role of co-ordinating care for that case. Which one of us becomes involved depends on the individual needs of the patients and their families at that time. It is difficult to make a strict distinction between the roles of the different team members, but there is always a need to provide a backup to the clinic after the likely diagnosis has been first discussed with the family. Many relatives are unaware of the implications of particular diagnoses, and the key worker assesses the problems and possible solutions at this especially difficult time. All families are encouraged to contact the Community Memory Project whenever they feel they wish to seek advice or just to chat. We aim to be very accessible to our clients, to provide the support when most needed.

Support and contact outside the clinic setting is provided depending on need. Individuals and families may be under considerable emotional strain and relationships stressed. Whoever is appointed key worker will be involved with working with these problems. Vicky's experience enables her to provide practical advice on aspects of management, from suggestions of how to get round the problems created by memory difficulties to advice on how to handle the many difficult behavioural disturbances that can so often present and cause such stress to carers. Judith can work with families to make plans for the care of patients, act as co-ordinator for these plans and help with decision making, giving information as to what help is available. Gwen is particularly able to provide advice on psychological approaches to care, and Tony, Pat and Siwan can help sort out medical problems, advise on starting, or more often stopping, medication and liase with other medical services. One of the major objectives of the Community Memory Project is to enable sufferers to remain as long as possible in the community and by providing support and guidance help families arrive at elective decisions rather than wait for crises to develop.

With the accumulative effect of 20 new patients every month and with a policy of never closing a case unless the time arrives when we hand over to the psychogeriatric services, we have our work cut out! To monitor patients through the course of their illness we need to organise a tight review system, whilst also maintaining links with other professional and voluntary organisations who are involved. Furthering this need for communication and exchange of ideas, we have organised a series of monthly workshops entitled "Caring for the confused and forgetful". Each workshop has followed a similar format with 9 or 10 "carers" joining us at West Wing for a varied day looking at medical and psychological aspects of the dementias, problem solving approaches to difficult behaviours and reviewing the services relevant to this group. Interest in the workshops has been considerable and we have a long list of people wishing to attend. We take great care in trying to ensure that each group of participants is well-balanced, with representatives of health and social services, from hospital and the community, from voluntary organisations and the private sector, and of course relatives or friends caring for patients with dementia. Consequently there may be some delay before we would be able to invite you to join a workshop, but <u>if you are interested in more information concerning this or any other aspects of our work, please contact us at:</u>

Community Memory Project
West Wing
Cardiff Royal Infirmary

telephone: 486932

Alzheimer’s research

Research has been described as the process of going up alleys to see if they are blind. Some of the issues raised in this article (i.e. the role of aluminum) have not stood the test of time. However, most have been developed further over the years and have provided great insight into the causes, course or symptomatic treatment (if not cure) of Alzheimer’s disease.

Genetic studies have been the focus of very considerable research activity since the article was written, with Cardiff established as an international centre in this field. Within the last few weeks there have been another 11 genes reported that have been shown to increase the risk of Alzheimer’s disease and these suggest a possible role of the immune system and inflammation, pointing to new alleys to explore.

The article also refers to the critical part played by the accumulation of amyloid in the brain of patients with Alzheimer’s disease. It has now been recognized that this does not cause any symptoms for perhaps 20 to 30 years, with dementia developing only in the end stages of the condition. Therefore any preventive treatment logically should start early, in middle age. Recent research findings suggest that the numbers of people developing dementia are fewer than predicted based on prevalence figures from 20 years ago and would seem to suggest that risk can be reduced, perhaps through more active treatment of high blood pressure and cholesterol and from the benefits of greater access to education earlier in life.

Whilst the ‘new drugs’ mentioned in the article (THA, HP029 and physostigmine) were never widely available because of dose-limiting side effects, the next generation of similar drugs (donepezil, rivastigmine and galantamine) were much better tolerated and have become the standard of treatment for mild to moderate Alzheimer’s disease. This was only possible because of the generosity of patients and carers giving up their time to take part in clinical trials that proved the value of the new treatments. It is disappointing that the number of those participating in research studies is still very low. Certainly the postscript calling for research volunteers is as relevant today as it was 20 years ago.

Professor Anthony Bayer

Clinical Director

Cardiff and Vale Memory Team

RECENT RESEARCH INTO ALZHEIMER'S DISEASE CAUSES, COURSES AND CURES

Of the many different medical conditions which may result in dementia, Alzheimer's disease is the commonest. Although it is eighty years since the characteristic pathological changes of the condition were first described, it is only in the last thirty years that any significant research has been undertaken into the disorder.

In the 1960's it was first realised that pre-senile and senile dementia were essentially the same disease, both showing the typical "plaques" and "tangles" first described by Dr. Alzheimer. The greater the pathological changes in the brain, the more severe the loss of mental function. Identification of accompanying chemical changes taking place in the brain of the person suffering from Alzheimer's disease followed, particularly the decrease in levels of acetylcholine in certain areas of the brain, and for the first time there was a basis for a rational approach to the development of new drug treatments.

Simultaneously, the search for the cause of the disease soon identified a link with genetic factors and Down's syndrome, and circumstantial evidence began to incriminate aluminium. Current research is distinguishing between the rare familial form of Alzheimer's disease, with its early onset, rapid course and "Autosomal dominant" pattern of genetic inheritance, and the much more common spordaic form of the disease with which we are more familiar. Greater understanding of the underlying abnormalities in Alzheimer's disease is opening up exciting new possibilities for future treatment and hopefully, the prospect of further major research breakthroughs cannot be too far away.

IS ALZHEIMER'S DISEASE INHERITED?

For several years it has been recognised that genetic factors can play a role in Alzheimer's disease, their importance becoming less as age of onset of symptoms increases. In nearly all cases, however, another factor or factors must also be involved.

Consequently for most close relatives of an Alzheimer's patient, the statistical risk of getting the disease is just slightly greater than that for the general population. The likelihood of not developing the disease is many times greater. As Alzheimer's disease is relatively common in old age, a family might have more than one case purely by chance.

It is in the very rare familial form of Alzheimer's disease that an"autosomal-dominant" inheritance is shown, with

CONTENTS

RECENT RESEARCH INTO ALZHEIMER'S DISEASE *Dr. Antony Bayer* **3**

THE SPECIAL NEEDS OF YOUNGER PEOPLE SUFFERING FROM EARLY ONSET ALZHEIMER'S DISEASE *Pam Noble* **6**

ALZHEIMER'S DISEASE AND DOWN'S SYNDROME *Tina Maciejewski* **10**

UPDATE ON THE NORTH CARDIFF SECTOR-BASED PLANNING GROUP *Simon O'Donovan* **11**

HUNTINGTON'S DISEASE *Audrey Tyler* **14**

CARE FOR PEOPLE AFFECTED BY HIV/AIDS *Clive Rees* **16**

RESOURCE LIST OF HELPFUL ORGANISATIONS **18**

SECTOR-BASED PLANNING FORUM, VALE AND WEST CARDIFF *Dr. Sally Furnish* **20**

PLUS OUR USUAL FEATURES:

TRAINING NEWS - 22, ANNOUNCEMENTS - 8, ETC.

a 50% chance of the condition being passed on from parents to children. Such families have more than one immediate relative affected in the current generation AS WELL AS cases in preceding generations AND an onset of the disease at a relatively early age (in their fifties). No more than a few hundred such families are known throughout the world and I have heard of only one possible family in Wales (NOT in South Glamorgan).

Whilst the number of patients with familial Alzheimer's disease is small, they are of great importance in the scientific search for the cause of the disease.

Recently a research team in London has been able to identify in one of these families a specific genetic defect (an abnormal gene) on chromosome 21. This links in with the observation that patients with Down's syndrome (a condition in which chromosome 21 is also abnormal) tend to develop Alzheimer's disease in mid life. The abnormal gene appears to be involved in the formation of excessive ambunts of amyloid, a protein substance found abnormally deposited in the brains of all Alzheimer's patients.

These findings are important because they identify the specific genetic abnormality responsible for at least some cases of Alzheimer's and suggest the central importance of amyloid production in causing the disease. This may therefore lead to new treatments, such as ways to lessen the impact of amyloid on the brain, to frustrate the expression of the gene responsible for familial Alzheimer's or to eliminate other factors required for a genetic predisposition to be awakened.

THE POSSIBLE ROLE OF ALUMINIUM.

Aluminium is the third most common element in the environment. However, most forms cannot be absorbed into the body and in the past it has generally been regarded as harmless.

Several studies in the last decade have linked aluminium with Alzheimer's disease and autopsies have shown that the brains of Alzheimer's patients contain significantly more of the metal than normal. However, it is far from clear whether aluminium is directly involved in causing the pathological changes or is merely taken up excessively by the already diseased nerve cells.

The accumulating evidence incriminating aluminium is impressive. In animal experiments, injected aluminium can cause the formation of brain "tangles" resembling those found in Alzheimer's disease. In humans excess aluminium in the fluid used for kidney dialysis can cause a dementing illness, though the patients do not show the typical pathological changes of Alzheimer's disease. Studies from Norway and Southampton indicate a slightly increased frequency of Alzheimer's disease in areas with higher aluminium content in the water supply.

Importantly, researchers in Newcastle have claimed to have found high concentrations of aluminium in both the "tangles" and "plaques" characteristically found in Alzheimer's brains, though other researchers have generally failed to replicate their findings. Recently it has been found that Alzheimer's patients have a defective form of a common protein, transferrin, which binds aluminium in the blood and prevents it from entering the brain. Less effective binding of the metal may mean that more is free to enter the brain.

Increasing concern about aluminium has led some people to worry about the risk of using cooking pots, aluminium-rich deodorants and antacids and even drinking tea. Whilst there is at present no scientific evidence at all to suggest that any of these are linked to Alzheimer's disease in any way, those concerned may prefer to use alternatives. A recent study found that of a wide range of drinks tested, mineral water from a Health Food shop had the highest and Pepsi Cola had the lowest aluminium content!

HOW RAPIDLY DOES THE DISEASE PROGRESS ?

Carers and service planners often ask if it is possible to predict how long a patient may survive. Clearly it is impossible to make dogmatic statements about anyone's life expectancy, whether or not they have a dementing illness. Certainly there is an excess mortality for dementia over that expected in age matched controls and this is even more marked in patients with multi-infarct dementia than in Alzheimer's disease.

Life expectancy and the pattern and rate of the course of the illness will vary widely from person to person, however, statistical evidence does mean that some generalisations can be made. There is broad agreement between published studies concerning the average life expectancy of patients with dementia. In community surveys the interval between detection of disease and death is about five years. For patients referred to specialist services the time interval from diagnosis to death is 3 to 4 years. Whilst for those in institutional care the life expectancy from admission is about 2 years. The average life expectancy for all patients from the time of first diagnosis of dementia (when symptoms have often already been present for some years) to the time of death is about 3 years. Thus in a population of dementing patients resident in the community, an annual death rate of 10% or more can be expected, whilst for those in institutional care a rate of 20% or more is to be expected.

Most studies agree that decline is most rapid in young (age under 70 years) patients, in those with poor physical health and in those with more severe symptoms at first presentation.

A recent series of Alzheimer patients followed up in London attributed death to bronchopneumonia in two-thirds of patients and to heart disease in one sixth. In one third of patients no mention of the presence of a dementia syndrome was made on the death certificate, thus leading to a gross underestimation of the frequency of the condition. More routine autopsies should help to improve diagnostic skills and ensure greater accuracy of death certification and awareness of the true prevalence of the disease.

DO NEW DRUGS WORK IN ALZHEIMER'S DISEASE?

Newspaper articles and reports on radio have drawn attention to the progress being made in the drug treatment of Alzheimer's disease.

While there remains no drug which has been completely proven to significantly reverse or slow the progress of the disease, experience with some agents is very encouraging, particularly when given early in the course of the illness. Certainly it may now be possible to improve the test performance under research conditions of about half of carefully selected patients with Alzheimer's disease, though whether this improvement can be sustained or translated into a worthwhile benefit in terms of everyday life remains to be proven.

The drugs which are currently giving the most encouraging results are those which act by increasing the levels of acetylcholine in the brain, either by inhibiting its breakdown or enhancing its action. Acetylcholine is reduced in the brains of patients with Alzheimer's disease and drugs such as physostigmine, THA and HP029 will raise the levels towards normal. Care needs to be taken to give the correct dose, or troublesome side effects can occur, particularly with THA which may cause temporary liver problems in up to half the patients taking it.

Our own experience with physostigmine has so far been problem free and several patients have now been taking the drug for several months with apparent positive effects, particularly on visual memory and certain types of learning. The improvement is likely to be greatest in patients with only mild symptoms.

Another drug, acetyl-L-carnitine, has also given worthwhile results in preliminary studies and has so far not been associated with any significant side effects. Whilst not as powerful as some other agents being investigated, its apparent lack of toxicity means that it may be especially useful in frailer patients and those who live alone.

A report in the last few weeks from Canada has suggested that the use of small doses of a drug to remove aluminium from the body may slow the progression of Alzheimer's disease by up to fifty per cent. Whilst these results are very preliminary, they open up yet another new exciting approach to possible treatment.

Dr. Antony Bayer

University Department of Geriatric Medicine

POSTSCRIPT: For more information about research going on locally, or if you know of a patient who might be suitable for a trial of one of the newer research drugs, contact Miss Jennie Powell, Mrs Triona Warner or Tony Bayer at the Research Unit, Cardiff Royal Infirmary, telephone Cardiff (0222) 492233 ext. 5293, or leave a message with the Community Memory Project, telephone Cardiff (0222) 486932.

Reflections on Signpost and Music Therapy

They say that a week is a long time in politics – well 25 years in the development of mental health services for older people is a lifetime! It is, after all, a generation. Much can happen in that time and much certainly has happened to my knowledge within services in Cardiff. From my own experience there have been significant developments in stroke services from the early days in the 'old' St Davids Hospital to the recent opening of the state of the art Stroke Rehabilitation Centre at University Hospital Llandough which we hope will become a centre of excellence for this patient group.

I started working as an Assistant Psychologist in Cardiff Health Authority in 1994. The post was split between the Memory Team and the Service Development Team (now the Practice Development Unit) and this arrangement remains to this day. The Service Development Team was then housed in the Royal Hamadryad Hospital but this institution closed in 2002.

Part of my duties with the Service Development Team was to take on the role of Deputy Editor of Signpost (this arrangement for the assistant post has remained the same to this day). Having had no experience of anything remotely connected with publishing it really was quite a daunting task but so interesting. Legitimately contacting eminent authors, requesting them to contribute to the journal (and then nagging them to adhere to the deadline), proof reading finished articles and designing page layouts were all unfamiliar skills but ones which were soon acquired to some degree at least. It really was a very happy time and there was a great deal of support from the rest of the team – Simon O'Donovan (Signpost editor in those days), Sally Furnish (Head of Older Adult Specialty) as well as social work and nursing colleagues. The experience and skills I gained from this post helped me gain a place on the South Wales Clinical Psychology Training Course. This trend has continued to my knowledge, with most if not all deputy editors successfully completing clinical training!

Signpost itself has become a highly acclaimed international journal and has made a significant contribution to the literature on mental health in older people. I wish Signpost and the team a very happy 25th Anniversary and hope it will continue from strength to strength in the future.

A Reflection on the therapeutic importance of music – then and now

In 1994 when I was an Assistant Psychologist working with the Service Development Team (and Deputy Editor of Signpost) I wrote an article on the therapeutic potential of music with people suffering with dementia (Signpost No 28). My reason for doing this was a reflection of my love of music (I used to be a music teacher) and the benefits I had seen from music with this and other client groups and medical conditions. A complementary article was also included in this early edition of Signpost, written by Rev Haydn Thomas, who reflected on the importance of music to his wife throughout her life (she became an accomplished organist) and the subsequent comfort music could offer her during her later life when she developed dementia - a truly moving description.

Over the years examples of the benefits of music have frequently been seen in the media and in the community. The Daily Mail in 2005 reported with the headline “Beethoven, the best medicine for your heart”. The article suggested that Beethoven’s slower symphonies were found to reduce the circulation, inducing a state of physical calm which may have benefits for stroke and heart attack victims. It has also been reported that music can reduce the need for analgesia during surgery (“Music meets surgery: two sides to the art of ‘healing’ “ – Morris and Linos, Surgical Endoscopy, 2013). The Tenovus ‘Sing for Life Choir’ was started in 2010 to measure the health and psychosocial benefits of singing for cancer patients and their families. Research demonstrated that each choir member benefited from an improvement in their mental health and wellbeing. ‘Singing for the Brain’ is a service provided by Alzheimer's Society which uses singing to bring people together in a friendly and stimulating social environment. The benefits of music have also been demonstrated in film – “The Quartet” and “Song for Marion” stand out as recent examples.

In this latest anniversary edition of Signpost the article ‘Music therapy in dementia care’ brings this discussion right up to date. The article is written by Michael Fulthorpe, a music therapist, and provides a very interesting, evidence based account of the success of music therapy within dementia care. In particular he describes a piece of work undertaken within the Young Onset Dementia service in Cardiff. The benefits of this closed music therapy group for clients, staff and family members have been clearly outlined and the interesting question was posed as to what may have emerged for this client group if the music therapy sessions had been able to run for a longer period of time. This evidence suggests that we need to create more opportunities for music and art therapies within our services.

There seems no doubt that music has significant healing benefits and can reach out to those who for one reason or another have reduced communication or other mental or physical health conditions. As Oliver Sacks stated in ‘Awakenings’ – “The power of music to integrate and cure …… is quite fundamental. It is the profoundest nonchemical medication.”

Dr Julie Wilcox
Consultant Clinical Psychologist
Stroke Rehabilitation Centre
University Hospital Llandough

SOUNDS WITHIN

The therapeutic potential of music is an age-old belief. We may be reminded of Novalis' aphorism: *"Every sickness is a musical problem and every cure a musical solution"*. Pythagoras believed that when music was part of a person's everyday life it was of great benefit to their health and well-being. More recently, researchers investigating the pain attenuating effects of preferred versus non-preferred music, discovered an increase in pain tolerance in the group of patients receiving preferred music, and that this may be important when clinically utilising music to help patients cope with pain (i.e. dentistry, athritic pain, etc.) (Hekmat & Hertel, 1993). Oliver Sacks, in his book **Awakenings**, describes how people with Parkinsonian symptoms could suddenly regain the power of motion and action with the imagining of spontaneous inner music, and with this the sense of substance and restored personality and reality. However, just as suddenly, when the inner music ceased, all motion and actuality would cease (Sacks, 1990).

Although these phenomena can never fully be explained, their effects can certainly be utilised in clinical and therapeutic settings.

In each of the above examples, the response to music is due to brain mechanisms involved in the perception and processing of musical information. All emotional responses to music must originate in the brain. In the case of the Parkinsonian patient, it is common to experience a 'freeze' in initiating movement. Parkinson's Disease affects the basal ganglia - the hub of the brain. Particularly affected are the areas of the substantia nigra and putamen, and these are necessary for relaying stimuli that relate to the initiation of movement. Problems arise when a movement has to be initiated, as, for example, in starting to walk. Patients are more successful when they are given an external cue to start the movement. It is at this point that music has proved effective. As an auditory cue it can activate neural pathways to enable the person to initiate walking. By singing a song or providing chanting, the person is able to take the first step and then establish the body sway that is necessary for maintaining the rhythm of walking (Heal & Wigram, Eds. 1993). Rhythmic music can also act as a stimulator for exercise with this group of patients.

Although language is generally accepted as dependent on the left hemisphere of the brain, the rhythm and melody of speech (which convey so much of its emotional meaning) depend more on the right hemisphere, and indeed the right side of the brain seems to be the basis of the interpretation and reading of music - skills that in some ways are very similar to language. To illustrate this, two case studies can be highlighted. An eminent Italian conductor had a left hemisphere stroke in 1977, which left him almost totally unable to read, write, speak, do calculations or copy gestures, and his right hand seemed weak and clumsy. Yet he could still read music well and could play the piano and other instruments. He resumed conducting, though could not speak to the orchestra. When a similar problem struck a French organist and composer who had been blind since the age of two, he lost his ability to read **words** in braille, but he could still read braille **music** and compose in braille, even though the patterns of dots used in braille to represent musical notes are identical to those representing letters in the alphabet (Blakemore, 1990).

To date, relatively little research with music has been directed towards patients suffering from Alzheimer's Disease and other types of dementia. It used to be that music therapists followed a Reality Orientation approach in working with clients with dementia, with music providing the structure to

reinforce reality. More recently, however, Validation Theory has become more accepted (Feil, 1990). In this case, it is the experience of the person at that moment which needs to be validated. If the client is unable to respond with her name, or does not know what day it is, but joins in singing a song from his/her youth, with melody and lyrics accurate, then this is recall of material in long term memory storage (information which was originally laid down by rote learning) and it is these skills and material which are preserved. This may explain why patients with severe dementia, who are unable to verbally express themselves, or have a severe receptive dysphasia, can sing along with a well-known song, or part of it, such as the chorus, and derive a great deal of pleasure from that experience, when on a day to day basis they feel frustrated and socially isolated because of a failure or inability to communicate in a meaningful way.

One American study that has been conducted, attempted to investigate the effects of music on Alzheimer's patients' memory, social interaction and mood. This controlled research was carried out over a six-month period. Sixty individuals from a privately funded home for elderly people were randomly selected from approximately two hundred patients clinically diagnosed as having Alzheimer's disease. They were divided into three equal groups - one group was given six 30-minute music sessions during which music of the 'Big Bands' of the 1920s and 1930s was played each week. This group was also given percussion instruments so that they could actively participate in the music. A second group was given several puzzle activities. The third group received no special treatment, but was involved in the usual recreational activities.

The groups were evaluated by a questionnaire, administered verbally to each participant by the institution's nursing director, at the start of the study, and analysis of this pre-intervention questionnaire showed there was no significant difference between these groups.

A second portion of the questionnaire assessed the patient's disposition and social interaction. A focussed 30-second observation was directed on one subject for three periods during each activity session for the first two weeks of the study. This same procedure was repeated during the final twelve sessions of the study

A blind analysis was undertaken and there was a significant effect between groups on recall, social interaction, and general mood. An analysis was also performed to identify the group(s) showing improvement, and it suggested that the group who listened to music was significantly different from the others - i.e. there was a significant change in recall, interaction and mood in the treated group. Several faults can be observed in this study, but the general idea of music being beneficial is, I believe, made quite strongly. One fundamental criticism of such research is the assumption that everyone likes big band music - for some people, being subjected to this musical genre in a highly structured and time limited way, might be inappropriate. For music to be used as an effective therapy, it needs to be sensitive to individual differences, that is, reflecting mood and personal preference.

It has also been suggested that music could be used as a complementary tool of cognitive assessment, as highlighted by Aldbridge and Brandt (1991). They point out that items which the Mini Mental State Examination fails to discriminate (such as minor language deficits) or neglects to assess (such as fluency and intentionality) may be elicited in the playing of improvised music. Musicality and singing are rarely tested as features of cognitive deterioration (Aldbridge & Brandt 1991).

On a more practical basis, music sessions can be carried out in a group situation, in a non-specialist, inexpensive way. Simple pre-recorded extracts of various styles of music can evoke memories, stimulate emotions and calm behaviours. Such sessions can create an atmosphere in which to socialise, actively participate, and, most importantly, enjoy. The carer of a Welsh-speaking sufferer, who used to be an active chapel member, often relates the joy and transformation his wife experiences when she hears recordings of Welsh hymn-singing. She used to be a gifted organist and would often sit at the piano and play familiar hymns and also sing them accurately, despite advancing dementia. The ability to play has now left her, but she and her husband are still able to listen to recordings of hymns and to enjoy singing them together. In the acclaimed film **Black Daisies for the Bride**, which focuses on the past and present life experiences of four elderly women who are severely affected by dementia, we see in Kathleen Dickinson an elderly lady who has no verbal communication skills, who seems to live in a world of her own, yet is contacted, through music, by a music therapist. He sings for the elderly residents, and as he approaches Kath singing "Oh, you beautiful doll", she stops polishing the window sill and turns to greet him. She then performs a beautiful dance, with perfect time and rhythm and appropriate gesturing. For several minutes there is a genuine connection between Kath and the therapist, demonstrating once again how successful music can be as a therapy in breaking through to a severely demented person's 'world' and creating an effective means of communication, however brief that moment may be.

From a biographical viewpoint, the use of music can be linked to aspects of former life history and personal life achievements - stressing the importance of the unique human value of each individual. A situation was related personally to me of a lady who had achieved great recognition for her piano recitals (she had performed in front of royalty), and whose various distinctions were framed above her bed in a residential home. In spite of this, she was subjected, on a daily basis, to Radio 1 and was too disabled to move to turn it off or change the channel. She would simply sob and scream. The conclusion we can reach from such anecdotal evidence is that in everyday experiences, caregivers have many opportunities to recognise individual differences and take account of their client's uniqueness, including their personal likes and dislikes. Mistakes are inevitable - not everyone likes Vera Lynn - but lessons can be learned and musical preferences can be taken into account.

Several organisations are recognising the importance of music in health gain. The Council for Music in Hospitals has, for over forty years, been arranging live concerts in hospitals, residential homes, hospices and day centres etc. throughout Britain, bringing great benefit and improving the quality of life for countless numbers of patients and residents.

On a more local level, "Live Music Now/Cerdd Byw Nawr", from Cardiff, provide similar types of concerts - tailoring the content to meet the needs of their audience. "Community Music Wales", also from Cardiff, provide more creative, improvisatory type of music sessions. They utilise electronic equipment, such as the sound-beam and synthesizer pads, so that patients/residents can create musical sounds even with limited movement.

The success of such musical sessions has been demonstrated in a local Alzheimer's Disease Society Day Centre which has recently experienced both these local groups of musicians, and they report that their members became animated and enthusiastic during the sessions, despite some severe disabilities.

Such observations should encourage exploring the use of various types of music on mood states at progressive stages of Alzheimer's disease and in health gain in general. It is an inexpensive and practical way of enhancing each person's quality of life.

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Footnote:

The photographs in this article are of a workshop entitled 'Music For All' which recently took place in the Dorothy Lewis Home for The Elderly in Canton, Cardiff. They are taken by Steve Garrett and the workshops are run by Cardiff Community Music, telephone: (0222) 387620.

We have been asked to point out that the residents seen in the photographs do not have mental health problems.

Julie Wilcox
Assistant Psychologist
Service Development Team (EMI)
Royal Hamadryad Hospital
Cardiff.

Music Therapy in Dementia Care: ‘Connecting Without Words’

Michael Fulthrope has a MA in music therapy from the University of the West of England and a BSc in Social Sciences from the University of Bath. He has almost ten years experience in the health and social care sector, working in a variety of roles including dementia, mental health, neuro-rehabilitation and learning difficulties. Music is central to his life and he enjoys sharing it with others.

George, a 90 year old man was sat in the lounge of his care home, his faced looked drawn and his posture stooped. Two other residents were sat around in the room but seemed lifeless; any conversation between them appeared to be just too difficult. I handed George a harmonica, an instrument he had played throughout his life. He held it to his lips and played a glissando chord and immediately a smile beamed across his face. Maggie, 93, and Edith, 82 soon looked up and caught George’s eye, who soon began playing a lively Irish jig. Within moments, it was as if the room had been filled with new found energy and optimism. George’s musical performance was obviously impressing the ladies, Maggie tapped her feet in time with the music and smiled broadly, while Edith had risen to her feet and was dancing across the room with her walking stick. George’s eyes glistened with delight as the musical ‘conversation’ unfolded.*

George, Maggie and Edith were all living with dementia, yet in the moment described the condition seemed to have no significance at all. From an observer’s perspective, three people were simply enjoying a shared musical moment together.

The above vignette was not a music therapy session; in fact at this stage I was unaware of the music therapy profession. However, this visit to a dementia care home highlighted to me the transformative power that music possesses. George was my grandfather and the effects of his harmonica playing in the latter stages of his life inspired me to learn more about music, emotion and the brain. This exploration led me to train as a music therapist.

What is music therapy?

A music therapist in the UK will have trained to a Masters Degree level and will be registered by the Health Care Professionals Council (HCPC)[i]. The training requires numerous hours of personal psychotherapy and supervised professional placements alongside core theoretical and practical musical studies. Several academic assignments are graded during the training, concluding with a final year research based dissertation.

The British Association of Music Therapy (BAMT)[ii] defines music therapy as "*a psychological therapy which uses mainly musical improvisation to build a relationship between therapist and client*" (BAMT, 2013). Music therapists work with a range of clients, both individually and in groups and from young babies to those living with older age dementia. Dementia work is perhaps particularly effective as many people with the condition suffer from extreme isolation due to loss of language and cognitive skills (Wall and Duffy, 2010). Music therapy provides an opportunity for non-verbal communication and social interaction and through unique techniques may allow isolated people to be heard (Abad, 2002). To feel listened to and attended to are fundamental human needs which correlate directly to a person's quality of life.

The unique qualities of music

It is strongly contested that music itself has inert therapeutic qualities. For example, Neurologists such as Oliver Sacks have devoted much time to the study of music and the brain and describe some fascinating case studies (Sacks, 2007). A BBC documentary first broadcast in 2008 further investigated some of Sacks case studies and also showed how music can have an immensely emotive effect on the brain. The latter was highlighted by fascinating MRI scan results on the presenter Alan Yentob whilst he listened to particular musical pieces[iii].

Recent scientific research carried out by prominent psychologist Daniel Levitin and his team in Montreal highlighted music contains anti-anxiety properties. Levitin's studies also discovered how the brain's reward centre responds to music and can release dopamine, a chemical often released with pleasures such as sex or eating food (Chanda and Levitin, 2013). The healing power of music is evidenced in literature dating back thousands of years which transcends across many cultures (McClennan, 2000) but today we are beginning to use advancing technology to scientifically analyse its properties. Such complex musical analyses are still in their infancy but Levitin and others are excited to what future research may discover.

Last year, a You Tube clip of Henry[iv], a man with dementia who becomes extremely animated when listening to an iPod went viral. There are certain parallels between Henry's response to music and to my opening vignette, as both highlight the potential of music to enliven people with dementia. However, we must remain wary of not simply prescribing iPods or harmonicas in dementia wards as a 'quick fix'. The reason being is the human interaction and 'positive person work' (Kitwood, 1997) witnessed when the carer and interviewer engage Henry in conversation about his favourite music is perhaps the most powerful element of the clip. This notion of social interaction is also prominent in the opening vignette, where arguably it was the human connections that emerged from

George's music which really enlivened him and shifted his energy so markedly.

It is in this area of interaction and making connections with people through music where music therapists are particularly skilled. Developing a combination of advanced musical ability and an astute empathic ear are fundamental to the training, and when these skills are used within a safe therapeutic musical relationship with a client, there is a great potential for therapeutic growth. Music has its own healing properties and furthermore, it is a universal and non-threatening medium that everyone can relate to in some way. Music has played a central role throughout the lives of many dementia clients and familiar songs can often trigger strong memories and emotions. The 'Singing for the Brain'[v] project has been a national success and those who have witnessed the groups in action may be very familiar with the powerful effect singing has for those with dementia. A person may struggle to remember names, places or what they had for breakfast yet almost miraculously, they can often recite and sing all the words from a familiar song. Such instances are witnessed frequently in music therapy sessions and can bring physical and psychological benefits to clients (Abad, 2002, Clair, 2000, Cuddy and Duffin, 2005); an experience which is powerfully exemplified by Henry during his clip.

Music therapists also work in a way that maximises what a person with dementia *can do* rather than focussing on what has been lost. This leads nicely on to my next vignette, taken from my final year music therapy placement.

The work

The work took place within the younger onset dementia (YOD) service of Cardiff and Vale University Health Board Mental Health Services for Older People (MHSOP). The YOD service holds a weekly 'Friendship Club' (Cognitive Stimulation Therapy Group) which is based on the Stirling Dementia Services Development Centre 'Making a Difference' programme[vi]. It was within this 'Friendship Club' that a 6 week closed music therapy group was set up.

Within the group, one client had very limited verbal communication and could only manage a few words. Despite her difficulties with communication she appeared cognitively very alert and due to indicators such as her timing of vocal sounds and her expressive facial expressions there was a real sense that she had a lot to give.

Music therapy allowed this lady to really express herself in a communicative manner without the need for words. Instead she was able to find her own way to be heard through musical improvisation and song. During group music improvisations, all clients and staff would be invited to play a variety of instruments and/or use their voices, or to simply listen if they preferred. As the music unfolded, this particular client would often choose to tip an ocean drum[1]

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[1] *Ocean drum = a percussion instrument containing metal beads. When the drum is moved around, the beads inside swirl around creating sounds often associated with the ocean.*

on her lap, creating a dramatic wave like "*swooosh*" sound or would gently brush her fingers across the chime bars to make a twinkly metallic sound. Other times she would choose a loud maraca and vigorously shake it in her arms or play it with a steady pulse. Whatever sound she produced would be appropriate in the group context in terms of dynamics, rhythm, and overall musical texture. When she received either musical or verbal feedback from others regarding her own sounds, her face would often light up with delight and she would often then become more vocal. One staff member witnessed the client's new behaviours within the group improvisation and commented afterwards "*It's amazing what music does for her….. her eyes!".* In another musical improvisation, the therapist chose to sing a line from a famous Beatles song *"All you need is love"* as everyone played their chosen instruments. This sparked an immediate response from the client. She looked up, smiled and then made vocal sounds which appeared to follow the pitch and melodic contour of the song.

Music therapy seemed to unlock this lady's potential for non-verbal communication. The fact she felt able to be heard within the group possibly also had a knock-on effect of encouraging verbal responses as she would often make comments during the group such as "*nice*", "*yes*", and "*lovely*". It would have been interesting to see what may have emerged for this client and for the other younger onset dementia group members if music therapy was able to run for a longer period of time.

Last year's MHSOP review paper stated:

"*There are future investment needs around addressing critical therapy deficits and supporting younger onset dementia service developments...*" (MHSOP, 2012: 9).

It is suggested that music therapy with its unique, universal and non-threatening approach would be a strong and creative choice to improve service provision.

In total, over twenty clients accessed music therapy during my placement within the MHSOP and the sessions were very well received by clients, staff and family members. The music therapy work incorporated tailored one to one work, small closed groups and larger open groups. Feedback included;

"*Having witnessed the intervention, music therapy was able to engage clients with different needs and abilities for significant periods of time and there were definite gains in terms of well-being during and after the sessions*" (staff).

"The after effects of X attending music therapy were noted on almost every occasion with X seeming much happier and content. I believe that to improve the service offered to the client's music therapy should be available everyday" (staff).

"*Thank you so much for what you have done for us*" (client).

The flexible and improvisational approach of music therapy means that it can be tailored to the individual no matter what form or stage of dementia and/or mental health the person is experiencing. This sits well with the NICE guidelines for dementia care, which advise that interventions are tailored to the person's preferences, skills and abilities (NICE, 2012: 36).

Indeed music therapy has been recommended in the NICE guidelines to address non-cognitive symptoms and challenging behaviour for people living with dementia. (NICE, 2012). Furthermore the NICE guidelines state that unless the person with dementia is severely distressed or there is an immediate risk, non-pharmaceutical options such as the therapeutic use of music "*should be followed before a pharmacological intervention is considered*" (NICE, 2012: 30). Pharmaceutical advances mean that dementia medication is constantly improving and for many people, these drugs can certainly improve their quality of life. Yet certain pharmaceutical interventions carry dangers of "*severe adverse reactions*" including "*cerebrovascular risks*" and even the possibility of "*death*" (NICE, 2012: 31). It is therefore is paramount that alternative approaches to manage dementia are fully explored.

The dementia situation

"*There are around 800,000 people with dementia in the UK, and the disease costs the economy £23 billion a year. By 2040, the number of people affected is expected to double - and the costs are likely to treble*" (Department of Health, 2013).

Such shocking statistics are forcing governments into action. Indeed, David Cameron has promised to more than double research funding for dementia to £66m by 2015 (The Guardian, 2012). Wiener (2007) highlights the global impact, with dementia prevalence likely to quadruple worldwide by 2041. Focussing on the local area does not brighten the situation. A recent public health report sighted estimations that the number of people over 65 years with dementia in Cardiff and Vale will rise from 5,144 in 2012 to 6,849 in 2025, a 33% increase[vii].

The report also shows estimated early onset dementia projections (for those aged 30-64) and although acknowledging these figures to be relatively small the report highlights that "*this group may have a greater need for specialist care and treatment than other age groups*" (Hopkins, 2013: 22). The Clinical Director of the Cardiff and Vale YOD Service strongly understands this premise and when reflecting on the music therapy work stated... "*We are developing the YOD service and multi-disciplinary team over the next year or two. I definitely see a place for music therapy and art therapy within the ideal service model*".

Conclusion

The increasing strain on resources is painfully obvious, meaning that cost-effective treatments for dementia will become ever more desirable. Music and dementia has been thrust into the public's awareness in recent years, helped by the fantastic success of projects such as 'Singing for the Brain' and by You Tube clips such as Henry's. Music therapy as a profession needs to continue to improve the ever increasing body of evidence[viii] and perhaps the health profession and society as a whole needs to creatively adapt to the dramatically expanding field of dementia care and create more opportunities for music and the art therapies to infiltrate the sector.

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Footnotes

[a] Heath Care Professionals Council – www.hpc-uk.org

[b] British Association of Music Therapy website – www.bamt.co.uk

[c] BBC documentary (2008); Oliver Sacks: Tales of Music and the Brain – http://www.bbc.co.uk/imagine/episode/oliver_sacks.shtml

[d] Henry: You Tube clip - www.youtube.com/watch%3Fv%3DFw7Y78aqf_I

[e] Singing for the Brain : Alzheimer's Society - www.alzheimers.org.uk

[f] Dementia Services Development Programme, Stirling - http://www.dementia.stir.ac.uk/creativity

[g] Taken from Daffodil Cymru: Dementia estimates for Wales (2013) - www.daffodilcymru.org.uk

[h] To view examples music therapy research, see the Evidence bank - www.nordoff-robbins.org.uk

Establishing the Bigger Picture – Brain Imaging in Dementia

Hannah Bowker is a Psychology undergraduate at Cardiff University. She recently worked with the Cardiff Memory Team at Llandough Hospital on a university placement year.

‘Brain imaging’ involves capturing images of different parts of the brain and is extensively used in both the clinical and research domains. There are a number of different types of brain scan, which provide images of varying detail. This article will discuss how brain scans are used for assisting in the diagnosis of dementias, whilst also describing how specific brain scanners produce these images.

In some conditions, a definitive diagnosis can only be established after a post-mortem has been conducted, Alzheimer’s disease (AD) is one example of this. The pathology of AD occurs on a cellular level and can only be examined via histology of the brain tissue post-mortem. However, biological brain changes also occur in patients with AD and other dementias. Brain imaging techniques can be used to establish the areas of the brain that deviate from what one would expect to see in normal ageing which may indicate a specific type of dementia. In addition, the development of the disease can be monitored, allowing the pathology to be tracked and ensure the most effective treatment is provided.

Structural Imaging Computerised Tomography (CT)

CT scans provide information about the structure of the brain and are often used to assist diagnosis of dementias. These scans involve passing an x-ray beam at various angles through the head. The strength of the beam is then measured after it has passed through the skull and brain tissue. The strength of the x-ray beam is reduced when passing through dense bone; appearing white on the scan image whereas soft tissue and fluid appear darker. Multiple images of the brain are created as the patient passes through the scanner, forming a series of 2-dimensional cross sectional images.

Typically, patients with AD may show loss of cells in the medial temporal lobe, specifically the hippocampal region which is involved in memory functioning. In contrast, patients with frontotemporal dementia show brain shrinkage in the frontal and the anterior temporal lobes. Although beneficial for establishing areas of the brain that have reduced volume, CT scans are unable to differentiate the pathology underlying the change. Furthermore, minor changes in the brain that can be indicative of early AD may not be identified by CT scans and white matter changes due to vascular pathology may not always be seen clearly. This is a major disadvantage of CT images as grey and white matter changes are shown to occur at different stages of the disease process in disorders such as AD (Serra et al., 2010).

Magnetic Resonance Imaging (MRI)

MRI is another type of structural imaging technique which uses strong magnetic fields to produce clearer and more detailed images of the brain. These scans work because hydrogen atoms in the brain produce a small magnetic field. When placed inside a larger magnetic field, the hydrogen nuclei will either align with the larger magnetic field in a parallel orientation (known as low-energy nuclei) or a perpendicular orientation (known as high-energy nuclei). The scanner then produces radio waves of a specific frequency, which causes some of the low-energy nuclei to align against the magnetic field. When this radiation is discontinued, the scanner detects the energy emitted as the nuclei return to their low-energy state. These changes in energy level are detected by the scanner and provide a detailed image of the brain. The images obtained are of a higher resolution than those obtained with CT and vascular changes are seen much more clearly.

Functional Imaging

Whilst both CT and MRI scans are used to establish abnormalities in brain structure, alternative scanners are used to measure vital functions of the brain. These functional imaging techniques are based on the premise that loss of nerve cells result in reduced blood flow to the same areas of the brain and subsequently, reduced levels of oxygen and glucose in these areas. In support of this, research has shown that decreased metabolic rate of these substances correlates with more severe cognitive impairment (Herholz, 2003). Furthermore, the region of this decrease may indicate the type of disorder. For example, individuals with frontal dementia will show less activity in the frontal cortex compared to individuals with semantic dementia, who will show under activity in the temporal cortex and amygdala, highlighting the different regions of the brain affected in different disorders.

Unlike structural imaging, functional imaging is advantageous as it can detect subtle changes in the brain which may suggest early stages of the disease process. For many disorders, including AD, early diagnosis is crucial as early intervention may have the potential to slow the patient’s cognitive decline.

Positron Emission Tomography (PET)

One type of functional imaging technique which can be used to assist the diagnosis of neurological conditions is PET. This type of scan involves introducing a radioactive tracer into the body via injection or inhalation. The tracer consists of a radioactive substance which attaches itself to a natural chemical of interest. Once the tracer is introduced, it emits particles called positrons. When a positron is destroyed it releases bundles of energy called photons, which travel in opposite directions and are recorded by the scanner as they arrive at detectors spaced 180° apart. The information gathered from the detectors allows the pathway of the energy to be tracked, producing an image of the brain's functions.

PET scans are not widely available and are mainly used as research tools. However, they are especially useful in allowing differentiation between types of dementia. For example, certain PET scans are able to identify amyloid plaque in the brain of patients with AD, which can only usually be determined via histology. The amyloid deposits can also be identified at a very early stage, even before the patient's symptoms are sufficiently severe to cause dementia. In addition, PET scans offer better spatial resolution than other types of functional scan and can detect even small changes in brain functions that other imaging techniques may overlook.

Single Photon Emission Computed Tomography (SPECT)

SPECT scanning is similar to PET as it involves the injection or inhalation of a radioactive tracer. The tracer produces a single photon emission as it decays. The location of this emission is used by the scanner to generate three-dimensional images showing blood flow around the brain (Lucignani, 2008). SPECT is a useful technique for exploring brain chemistry and is less expensive to perform than PET and potentially widely available. However, it has lower spatial resolution than PET, especially when imaging deeper structures of the brain. In addition, SPECT is less precise for establishing the source of a photon emission as it involves only a single emission. By comparison, PET uses two photons travelling in opposite directions and therefore provides greater information to determine the source of the emission.

Dopamine Transporter (DAT)

DAT scans are used to distinguish between disorders such as Dementia with Lewy Bodies (DLB) and Parkinson's disease dementia (PDD) from AD. DAT scans involve injecting an active substance into the bloodstream which attaches itself to structures that transport dopamine. The scan can then detect reduced levels of dopamine in the brain. These reduced levels indicate a loss of nerve cells in that area of the brain which can help to distinguish DLB, PDD and AD.

Conclusion

It is evident that both structural and functional imaging techniques provide knowledge about the areas and functions of the brain that are affected in dementia. Imaging techniques not only distinguish one disorder from another, they also allow the progression of a disease to be monitored. For this reason, they are extremely powerful tools for use in both clinical and research areas. However it is important to note that dementia cannot be diagnosed by a scan. Nevertheless, scan results can contribute to identifying the likely cause of a diagnosis of dementia and brain imaging techniques play an increasingly important role in establishing the complete diagnostic picture.

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End of life care...

End of Life Care: What Matters for People with Dementia

Martina Kane is Senior Policy Officer at the Alzheimer's Society. Since joining the Society in January 2011, Martina has worked gathering evidence and writing a report on dementia and end of life published in October 2012. She also researched and co-authored 'Dementia 2013: The hidden voice of loneliness' about social isolation and loneliness among people with dementia. In addition she has worked to support the All-Party Parliamentary Group on Dementia Inquiry into the diagnosis of dementia 'Unlocking Diagnosis'.

I think, at the end, it wants to be so the person is least stressed or upset or in [as little] pain as possible, so they can be calm and go with dignity. When they get to the point of no return, as it were, I think they should be allowed to go peacefully.

- Daughter of someone with dementia

One in three people will have dementia when they reach the end of their lives (Brayne et al 2006). Yet, too often, people with dementia are not dying in the places that they would wish, and in some cases die in pain and without being treated with dignity. The End of Life care strategy (Department of Health, 2008) suggests:

‘Although every individual may have a different idea about what would, for them, constitute a “good death”, for many this would involve:

- Being treated as an individual, with dignity and respect;
- Being without pain and other symptoms;
- Being in familiar surroundings; and
- Being in the company of close family and/or friends.’

This is just as true for people with dementia as it is for people who have other health conditions. Yet there are particular features of dementia which cause problems around ensuring that someone can have a ‘good death’ and which means that there may need to be more thought and planning put into their care than is currently the case.

All of the 800,000 people with dementia in the UK will face additional complications at the end of their lives, regardless of whether their death is caused by the dementia or by another disease (Alzheimer’s Society 2012). Diminishing mental capacity and difficulty with communication are particularly difficult, especially where the person is unable to communicate basic needs, such as hunger and thirst, or discomfort and pain. Professionals, particularly people who may not be specialists in dementia or end of life care, may also lack the skills to deal with the challenges presented when someone who has dementia is at the end of their life. They may communicate insensitively, or be unwilling to discuss death and dying. They may not be able to detect or meet the needs of someone with dementia. They may have difficulties working with the relatives of the person with dementia or in making decisions about the person’s care.

For the report ‘My Life until the end’ (Alzheimer’s Society 2012), the Alzheimer’s Society spoke to a number of people with dementia, carers and former carers about the issues surrounding end of life care for people with dementia. The report identified some key areas of concern which are explored here.

Dignity

A key concern for many of the former carers who contributed to the report was the lack of dignity in treatment for the person they cared for in their final days. There were frequent and distressing reports of very poor, undignified treatment, particularly in hospital. Numerous participants reported that the person with dementia had not been helped to the toilet or changed, so they had to sit in their own faeces or urine for some time. There were also reports of inappropriate food and drink, and comments that some staff were rude or uncaring and there was not due attention paid to a person's privacy, such as not drawing a screen while the person was being helped to undress. The Department of Health commissioned VOICES survey also found that 29% of relatives of people with dementia said that the person was only treated with dignity by hospital nurses some of the time (Department of Health, 2012). This was higher where the person had dementia on their death certificate compared to other conditions.

Dignity in treatment involves meeting the basic standards of care, and a failure in this can be additionally upsetting if it occurs in the final days of someone's life. While there may be additional barriers created by a person with dementia's reduced mental capacity, or their experiencing difficulty communicating, with good training and adequate resource staff can use the principles of person-centred care to ensure that all people with dementia are treated with dignity at the end of their lives. Tools such as the Alzheimer's Society 'This is me' document (Alzheimer's Society 2010), which records the preferences and wishes of the person with dementia, can encourage care which sees the whole person, not just the symptoms.

Free from pain

Pain is acknowledged to be under recognised and under treated in people with dementia. There is academic evidence to suggest that people with dementia in hospital receive fewer interventions to alleviate pain that people without dementia (Sampson et al 2006). Pain from pre-existing conditions (such as arthritis) or discomfort (such as constipation), which cannot be communicated, can often go untreated (Scott et al, 2011).

Making assessment of pain routine practice, and encouraging medical professionals to use all communication from the person with dementia (including facial expressions and other non-verbal communication) in order to assess whether the person with dementia is in pain, are the first steps to ensuring that people with dementia do not reach the end of their lives in pain. Routine use of pain assessment tools can be helpful in promoting this and ensuring that it is done in a consistent manner.

Place they are comfortable

There is a drive within end of life policy to support people to be able to die in the place that they would choose (Department of Health 2008). Yet while few state that hospital would be their place of choice, many people, including those with dementia, die in hospital. In 2010 30% of people with dementia recorded on their death certificate died in hospital. 63% died in a care home, and only 6% died in their own home (Alzheimer's Society 2012). It is also possible that the true figure for deaths in hospital is even higher as many elderly people with less advanced forms of dementia may be admitted to hospital for a different condition and have that condition recorded on their death certificate.

Care of patients in hospital is still largely crisis driven which means that end of life care can often be poor (National Confidential Enquiry into Patient Outcome and Death 2012). By contrast, the VOICES survey asked about end of life care in care homes (Department of Health 2012). They found that relatives of people who had dementia recorded on their death certificate were more likely to rate the care in the care home as good or excellent and less likely to rate it as fair or poor than relatives of people who did not have dementia on their death certificate. This points to the possibility that some care homes are developing good practice in end of life care for people with dementia, and can provide a good experience for people, experiences which should be replicated in more settings.

Many of the problems identified, including unplanned admissions to hospital which were contrary to the known wishes of the person with dementia, stem from a lack of co-ordination in care (Alzheimer's Society 2012). Carers frequently report having to state details of care plans to each of the different professionals involved in care. By contrast, some of the best experiences had occurred when care had been well co-ordinated, no matter the location.

It is clear that there is still development needed to ensure that every person with dementia experiences joined-up care at the end of their lives. Suggestions in the Palliative Care Funding Review (Hughes-Hallett et al 2011) if implemented would greatly benefit people with dementia.

Wishes are known and acted on

The difficulties outlined above highlight the importance of planning with people with dementia for their future care. Not having a clear idea of what the person with dementia would want can lead to extensive problems as mental capacity diminishes and decisions have to be made on their behalf. Yet there are still many cultural barriers which mean that many people with dementia may not communicate early enough what they would want about their end of life care, so decisions then need to be made at the time in ignorance of their wishes.

The double stigma that surrounds dementia and death needs to be tackled, not only with the general public to encourage people to talk about what they would want before dementia even develops, but also with health professionals working with people with dementia in the early stages of the disease. Very few people who contributed to the 'My life until the end' report remembered the subject of end of life care being discussed with the person with dementia by health professionals. Many reported that it was not discussed at all, or it was only discussed because the conversation was initiated by the person with dementia.

It is clear that planning care, even if it is an unstructured conversation about the person's wishes, makes decision-making easier at the end of life (Wendler and Rid, 2011).

Understanding the person's wider wishes, such as their idea of a good death and spiritual, cultural, emotional and family factors that they would want taken into account, is particularly important when making decisions on their behalf.

What needs to change

In many cases the present health and care system is not meeting the challenge posed by dementia. While there is good practice developing in some areas, an integrated approach is needed across the whole country. A sea-change in attitudes to both dementia and dying would encourage planning in advance. Routine pain assessment should form part of a system of person-centred care for all people with dementia in all settings.

Each person with dementia is different and it is essential that the wishes of each individual are understood and carried out so that people with dementia can die with dignity, free from pain and in the place they feel comfortable.

The full 'My life until the end: Dying well with dementia' report can be downloaded for free at www.alzheimers.org.uk/endoflife

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‘They take you on a journey of what their lives have been’

Lucy Young currently works in REACT, a crisis service for older adult mental health and people with dementia. She has been in post as a Dementia Care Advisor for a little over a year. Previous to this Lucy has worked as an Assistant Psychologist for approximately 6 years after graduating in Psychology in 2005. Constantly developing her academic study alongside her working positions, she has worked in various Assistant Psychologist posts in both private healthcare and the NHS. Away from work Lucy enjoys hitting the gym and spending time with her family and friends. She tries her hand at creative baking when time allows but is not quite 'British Bake Off' standard yet - but the fun is in the practice!

1. Who are you and what do you do?

My name is Lucy Young and my job title is Dementia Care Advisor. This title vaguely outlines what I do, however it is a lot more than just giving advice! I work in a service called REACT (Response Enhanced Assessment Crisis and Treatment). I work with people with dementia and families when they are termed to be in a ‘crisis’. This can range from direct therapeutic interventions with those who have a diagnosis of dementia, therapeutic work with main carer and/or family, psychoeducation, signposting for other services, advice or help on approaches and overall support with what people need. I also work closely with families in highly stressed situations.

2. Can you describe a typical day?

No, I can’t sorry. Due to the nature of REACT every day is very different. Some days I can walk into the office and it is non-stop. We can take up to any number of referrals in a day, where I also carry out first assessments with people with dementia. Sometimes the phone will not stop ringing and we have a number of visits to do, so some days are very busy to say the least. However, there are other days when I have more planned work and this time is protected when I am work intensely with families or people with dementia. This is always related to specific needs.

3. How is your role unique from other members of your team?

My role is unique in that there is only one of me within the REACT team, but also the Dementia care advisor roles have only existed for 2 years. I do not like to describe my role as unique, but more that my skills and approach are different to that of other team members. I value and respect that every person’s role is important in a crisis service (as they are in other services). However, working as a Dementia care advisor in a crisis team often means that the family are also experiencing high levels of stress and often this means they are seeking quick solutions. A lot of work can be about building a relationship with the person with dementia and/or the family in highly tense environments so that I may work with them to possibly help find some solutions. This is not always easy as you can imagine, when people are stressed they are not always willing or able to engage. My role also varies in my therapeutic approach (having a psychology background). Also my work and individual interventions will continue even after REACT discharge. I work with people beyond the crisis to ensure that they have the support and skills to deal with similar future situations, or sometimes people are ready to accept help once the crisis has passed. Unfortunately it is difficult to explain my role in a succinct manner as every person/family I work with are very different and no two cases are the same. But ultimately I assist, support, advise, care, signpost, counsel, offer help in response to the situation to those people with dementia and/or their family or support network.

4. What do you enjoy most about your role?

The biggest part of my role that I enjoy is the people. Working with the older generation - they offer so much history and take you on a journey of what their lives have been. Their reminiscence is something I could sit and do all day. Their lives have been very different to the existence of today's world and I find them fascinating!

I also enjoy meeting new people and some really lovely families that despite their struggles are always so grateful for any help. A lot people we meet in REACT are unaware that there are services that can offer such a high level of support. To help these people through a crisis and find a more settled way of life is extremely rewarding.

5. What are the greatest challenges in your role?

Meeting people who are in desperate need of help or some kind of support but refuse to engage with it. Especially carers, trying to engage family members in seeking their own support can be a huge challenge at times. But when you finally help to alter that view, it is a great feeling.

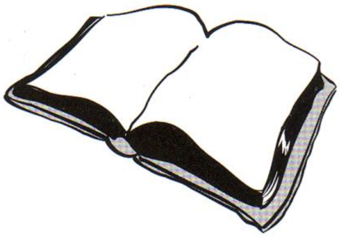
Another challenge in my role is walking into a situation that is highly stressed and complex and working out where is the best place to start. At times my role is about balancing what is needed and what is timely for the person with dementia and the family. It's all about judging the right time and the right intervention, easier said than done!

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

I hope to develop psychoeducational sessions in the near future, to offer to carers that are in crisis. This would be a rolling group that people could attend at any time. I feel this would be a light introduction to invite people to a support group and help people understand what they are about and hopefully to reduce the fear of the unknown.

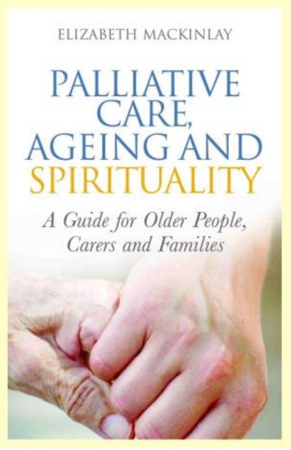
Further in the future I would like to think more about how crisis affects younger family members, particularly in younger onset dementia. At this time I feel there is a lack of support available for younger family members and how dementia impacts their lives, what their understanding of it is, whether this be Mum, Dad, Grandmother or Granddad. However this is more of a personal professional interest at this time, but something that my role definitely has to consider - it’s not just the person with dementia, it is everyone around them, too.

Book Reviews



Palliatice Care, Ageing and Spirituality – A Guide for Older People, Carers and Families

Author: Elizabeth MacKinlay
Publisher: Jessica Kingsley Publishers
ISBN: 978 1 84905 290 0
Price: £12.99



Perhaps in an attempt to appeal to as wide an audience as possible, this book states that it is “written especially for older people who are facing death” (Pp. 12). I found this disorientating initially, as the language and tone of the writing seems to have professional carers or clinicians in mind, adopting as it does a third person perspective for much of the book. For me this seemed to act as a barrier when re-reading certain sections from a patient or family perspective.

Indeed, I believe that in some respects this book may be inappropriate for dying people themselves, as it contains at times, strong assumptions of what a good death looks like – particularly in terms of healing past relationships and the roles of forgiveness and prayer. Although it may be useful to have a sense of what a 'good' death might look like, this may give the dying person (or perhaps most pointedly their relative) reading this book the impression that there are ‘things to be done’ before dying, and so potentially adding to demands on them at this difficult time.

Similarly, the idea that a dying person might ‘hold onto life’ equally exposes a certain view of the dying process that fails to acknowledge that we are not in full control of our dying.

Once I realised this small book works best for a trainee clinical/pastoral audience, I felt more able to enjoy it and appreciate the anecdotes and important points the author was drawing together. For example, the author emphasises the importance of understanding that there is no ‘right way’ to grieve and the fact that death marks ‘the end of a life but not of relationship.’ Chapters on ‘ethical and moral issues in dying’, ‘intimacy in dying’ and ‘dementia in dying’ are written with sensitivity and insight and more practical information on ‘signs that death may be near’ is useful for an audience new to palliative care. The sections entitled “summaries” were also a useful addition in directing the reader to main points in each chapter.

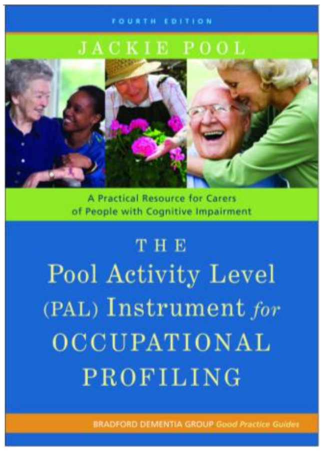
Rather disappointingly at times important themes were alluded to in the book but not explored to a level of depth that might have been given more insight to professionals as to the ‘greyness’ of concepts in this important field. The complexity of some of these ideas, such as the protective nature of denial, the phenomenon of collusion and the lack of clarity when it comes to identifying the dying phase were identified but under-explored. For example, the role of denial was not fully acknowledged as a response to suffering not requiring intervention, as not everyone has the capacity or resources to turn towards their suffering. Such an analysis of these 'grey places' would have allowed this book to be of tremendous value to professional carers/families. As it is, Palliative Care, Ageing and Spirituality – a guide for older people, carers and families works best I feel as an introductory text for health professionals considering a move to hospice or palliative care and may be of particular interest for those training in pastoral care.

David Shannon

Counselling Psychologist

Bangor University

The Pool activity level (PAL) Instrument for Occupational Profiling 4th edition by Jackie Pool. Jessica Kinglsey publishers



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The UK has an ageing population. With this trend set to continue (Cracknel 2010) it is vital that resources designed to maximise independence and engagement in activity amongst the older population continue to be recognised. The Pool Activity Instrument for Occupational Profiling, written by Jackie Pool, is an exemplary resource that provides a 'practical resource for carers of people with cognitive impairment'. It has been widely used in many settings, both hospital and community based.

The purpose of this book is to provide a method to promote occupation and activity among people with a range of cognitive impairments. Pool identifies four levels of cognitive impairment– Planned, Exploratory, Sensory and Reflex and firmly advocates that meaningful activity and participation in activities of daily living are not only vital but can be achieved at each stage of a dementia. Its target audience are any carers and professionals involved in the care of people with a cognitive impairment.

The PAL instrument provides clear instructions to engage people in activity and provides examples of activities in daily living. It allows carers to build up an activity level profile of each persons' abilities, likes /dislikes and provides examples on how to engage and grade an activity for a person functioning at each of the four stages. This edition also contains additional case studies which are particularly useful to assist with applying these in a practical everyday way. The activities suggested in page 12 provide a useful “starter pack” for first time users of the activity levels.

The instrument is not only well respected amongst healthcare professionals, it is endorsed in the National Institute for Health and Clinical Excellence Clinical Guideline for Dementia as a therapeutic intervention to identify and individualize performance with activities of daily living (Nice, 2006).

This edition has made several changes according to user feedback, and includes a new chapter on ‘planning and implementing sensory interventions’ by Dr Leslie Collier of Southampton University. This addition adds a new focus to the sensory level of functioning and provides valuable insight into the importance of sensory stimulation and the impacts of sensory deprivation within dementia, while examining how to overcome these challenges within activity.

Whilst the idea of a person centred approach is valuable certainly within community settings, the use of this tool should be investigated within acute and community hospitals which are often overwhelming for patients with dementia (Heath & Sturdy 2010). To use a tool to advocate activity would be beneficial. The use of the PAL should be researched in the context of relatives of patients in hospitals to ensure a person centred approach to care is maintained.

Overall, the Pool activity instrument for Occupational profiling appears to be gaining in strength, direction and increasing its evidence base. Its use, ability and practical applications continue to grow and when used effectively promotes occupation in an effective person centred way.

Katie Glare

Occupational Therapist

Royal Berkshire Hospital

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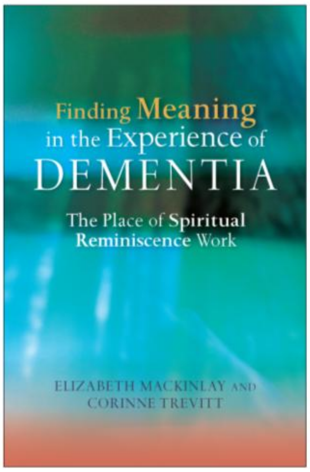
Finding Meaning in the Experience of Dementia. The Place of Spiritual Reminiscence Work.

Author: Elizabeth MacKinley & Corinne Trevitt

Publisher: Jessica Kingsley

ISBN: 978 1 84905 248 1

Price: £22.52



The challenge to find meaning in the face of illness and suffering has occupied the efforts of philosophers for millennia. However, it is also the very personal challenge faced by those living with the effects of dementia, as well as for their families and those who care for them.

In this book MacKinley and Trevitt invite us to recognise that despite the negative impact of dementia, there is always the possibility for spiritual growth and discovery and that spiritual reminiscence offers a means of supporting and facilitating this quest for meaning.

Drawing on ten years of work and research in this field they firstly set out the underlying principles of this form of intervention. As we all know, reminiscing on personal life events enables the dementia sufferer to cling on to their sense of identity and connectedness as they resist the encroaching effects of their condition. However, MacKinley and Trevitt propose that it is not the reminiscence of facts which is of primary importance, but the underlying sense of meaning associated with those life events and relationships. It is that underlying stream of meaning which actually offers the individual the spiritual resources to give meaning to the present and to have hope for their future.

Secondly, they deal with the areas of human nature which encapsulate the spiritual dimension of a person's life – ethics, transcendence, wisdom, humour, hope and love. They also give first hand evidence of how issues of dying and death can be faced by drawing on the individual's own sense of meaning.

Finally, they give very practical suggestions as to how to run either short or long running structured programmes of spiritual reminiscence for groups of dementia sufferers.

This book is not a heavy philosophical exploration of meaning, but a practical reflection on years of supporting dementia sufferers. It draws heavily on first hand encounters and much of it is dedicated to airing the voices of those who participated in the authors' programme. It offers practical advice to those wishing to use spiritual reminiscence as a means of supporting sufferers, but is also a valuable resource for those seeking references for further research into this developing area of care.

The book shows that spiritual reminiscence for those beginning the frightening journey into a future shaped by dementia is a valuable tool in helping them come to terms with their fears, their future and questions of meaning. However, the work fails to address how to support the spiritual needs of those with more advanced cognitive impairment and very limited communication skills.

The main positive impact of this book on reading it was the reminder that dementia sufferers may loose much of their functioning abilities, but never their humanity and that the search for meaning in life is far too important a topic to be left to philosophers.

Rev Peter Davies

Hospital Chaplain

Cardiff and the Vale University Health Board

Did You Know...

In this section we review new products and ideas which may be of relevance to people with dementia or those working and caring for them. Please note that we not specifically endorse any product and aim to provide neutral information.

BibblePlus is a UK based company which produces dignified bibs specifically designed for adults. With the appearance of a bandana, the bibs are discreet and available in a wide range of colours and patterns, including checks, union jacks and stars.

The Bibbles are handmade in Nottingham from cotton and fleece. They aim to protect clothes and absorb dribble, while looking like an attractive and functional piece of clothing. There are three sizes available, with prices ranging from £4 - £5.

www.bibbleplus.co.uk

News and Web

Wales's Commissioner for Older People, Sarah Rochira, is conducting a review into residents' perceptions of 100 care homes.

The aim of the Residential Care Review is to investigate quality of life and care from the perspective of those who use them, as well as friends and relatives.

The review will provide a basis for recommendations to public bodies and providers of care.

www.olderpeoplewales.com

A survey into home care visits reports widespread disadvantage to older people following cuts reducing their duration.

The study, conducted by The Guardian and the Department of Health, received 1,440 responses across England. Seventy-three percent of people indicated lack of time during visits as the greatest obstacle to quality care.

Opportunistically, the contact itself appears to be positive, with only 15% reporting negative experiences of staff. However, with two thirds of councils commissioning 15 minute visits, quantity is compromising quality.

Staff pay and training were additionally highlighted as an issue

By the end of the current financial year, £2.7 billion will have been cut from the adult social care budget across English councils over the past three years.

www.theguardian.com/society/2013/oct/30/homecare-cuts-home-visits-older-disabled-people

Lloyds Banking Group has worked alongside the Alzheimer's Society to develop a charter for people with dementia. Supported by the British Banker's Association, the charter aims to enable people with dementia to continue looking after their own finances.

The Dementia-Friendly Financial Services Charter is part of the Alzheimer's Society Dementia Friendly Communities programme.

www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200436

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

Neuroimaging

Contribute to brain research by playing games – the Wellcome Trust Centre for Neuroimaging has developed a mobile phone app to test memory, impulsivity, attention and decision making: www.thegreatbrainexperiment.com

The Alzheimer's Society's website gives details on getting involved with research, including studies involving neuroimaging: www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200425

Mindfulness

www.getselfhelp.co.uk/mindfulness provides information of mindfulness including free scripts, exercises and mp3 downloads.

The Mental Helath Foundation are conducting a campaign to raise awareness about mindfulness. Find out more at **www.bemindful.co.uk**

Information About Signpost

Anyone Can Contribute to Signpost

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

Contributions

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

Contact Details

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

Tel: 02920 715787

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

Books Available for Review:

Comforting Touch in Dementia and End of Life Care. Barbara Goldschmidt and Niamh van Meines, 2012.

How we treat the sick. Michael Mandelstam, 2011.

Puppetry in Dementia Care. Karrie Marshall, 2013.

Signposts Editorial Panel

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

Dr Christina Maciejewski is a Consultant Clinical Psychologist working within Mental Health Services for Older People in Cardiff and the Vale of Glamorgan.

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

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

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

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

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

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

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