living well with dementia

Professor Alistair Burns, the National Clinical Director for Dementia in England, highlights the knowledge and awareness of Dementia and the opportunity for change.

active ageing

Sandra Hartley and Gillian Yeowell from Manchester Metropolitan University discuss how to stay physically active, and the benefits of physical activity for health and well-being.
Welcome to Issue 3 of Innov-age. There are times when we all forget someone’s name or why we had gone upstairs but we don’t always acknowledge when our ability to remember things slips into a more serious decline.

The changes can be very subtle and it’s only when a more serious lapse in memory occurs that we tend to seek help. I remember my grandfather reaching this stage when he had to drive from town following a bus because he could not remember the way home.

When we do seek help we are flung into a bewildering world of information, from a number of different sources about dementia, which can add to the confusion.

In this issue we aim to summarise some of the best advice and draw upon the guidance and expertise of leading experts. We are particularly honoured to be sharing thoughts with Professor Alistair Burns, the National Clinical Director for Dementia in England.

We also get to hear about an exciting development in Australia for caring for the elderly and other initiatives closer to home including a summary of the main literature in the field of dementia in the Cochrane Corner.

The biggest take home messages for me are that as we get older we need to keep physically and mentally active in order to stave off and reduce declining brain function but there is little we can do to stop the destructive cognitive decline associated with Alzheimer’s and other types of Dementia.

There is however a tremendous amount of on-going research into cause, prevention, cure and treatment and the Alzheimer’s Society (www.alzheimers.org.uk) alongside many other funders are ploughing money into research in all four of these areas.

In the meantime the stress on the sufferer, family and friends can be enormous and should not be underestimated and help should be sought sooner rather than later.

Jackie Oldham
Honorary Director, Edward Centre for Healthcare Management Research

Front cover Image: The Many Faces of Dementia Sculpture, Boston.
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Living well with Dementia

Alistair Burns MBChB, FRCP, FRCPsych, MD, MPhil, DHMSA

Professor Alistair Burns is Professor of Old Age Psychiatry and Vice Dean for the Faculty of Medical and Human Sciences at The University of Manchester, Clinical Director for the Manchester Academic Health Science Centre (MAHSC) and an Honorary Consultant Old Age Psychiatrist in the Manchester Mental Health and Social Care Trust (MMHSC). He is a Past President of the International Psychogeriatric Association and is also on the board of the European Association of Geriatric Psychiatry. He is the National Clinical Director for Dementia in England.

He is Editor of the International Journal of Geriatric Psychiatry and is on the Editorial Boards of the British Journal of Psychiatry and International Psychogeriatrics. His research and clinical interests are in mental health problems of older people, particularly dementia and Alzheimer’s disease. He has published over 300 papers and 25 books.

Dementia is a national priority. There are an estimated 800,000 people in the UK with dementia (a number set to rise significantly in the next generation) with an estimated cost of £23 billion a year. A diagnosis of dementia can have a profoundly negative effect on individuals and their families.

Table 1 outlines some of the key timelines in relation to dementia in England. The National Dementia Strategy in 2009 set the tone with 17 objectives and the tag line of “Living well with Dementia”; the Public Accounts Committee drew ten conclusions about dementia care and the “Time for Action” Report (which highlighted that there were an estimated 1800 deaths and 1600 strokes as a result of the prescription of anti-psychotics) had 11 recommendations. The general election in 2010 re-emphasised the reach of dementia and it became a priority for the current Coalition Government, culminating in the Prime Minister’s (PM’S) Challenge in 2012 stating the ambition of NHS England, established on 1 April 2013, that two thirds of the estimated number of people with dementia should have a diagnosis and post diagnostic support.

Table 1

<table>
<thead>
<tr>
<th>Event</th>
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<tbody>
<tr>
<td>National Dementia Strategy</td>
<td>February 2009</td>
</tr>
<tr>
<td>Antipsychotics Report “Time for Action”</td>
<td>November 2009</td>
</tr>
<tr>
<td>Public Accounts Committee</td>
<td>January 2010</td>
</tr>
<tr>
<td>General Election</td>
<td>May 2010</td>
</tr>
<tr>
<td>Prime Minister’s Challenge</td>
<td>March 2012 (3 groups, plus updates)</td>
</tr>
<tr>
<td>NHS England Launched</td>
<td>April 2013</td>
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The importance of patients and their carers cannot be over emphasised and the statements are entirely in keeping with this aspiration.
In terms of outcomes, a series of “I” statements (table 2) have been developed which put patients and their carers at the centre of what we do. They were developed from similar work in cancer a number of years ago. The importance of patients and their carers cannot be over emphasised and the statements are entirely in keeping with this aspiration.

Three things were important in the PM’s Challenge. First, for people over the age of 55, dementia is the most feared illness. Second, the amount of money spent on dementia research is low compared to other disorders and in terms of numbers of people in clinical trials, around 15% of people with cancer are in a clinical trial compared to less than 1% in dementia. Third, less than half of the estimated number of people with dementia receive a formal diagnosis.

The PM’s Challenge has three stands of work – Health and Care, which concentrates on the diagnosis rate and support for people with dementia, research which emphasises the need for additional resources (doubling of research money into dementia and the aspiration of 10% of people with dementia being in a clinical study – already the numbers in trials are approaching 4%), and Dementia Friendly Communities (among the aspirations of which are that there will be 750,000 dementia friends by 2015, details at dementiafriends.org).

There are a number of areas which are important in dementia and generally reflect the journey of people with dementia from Diagnosis to End of Life Care. These are summarised in the easy to remember mnemonic in table 3.

**Two thirds of people who have dementia will receive a formal diagnosis and post diagnostic support.**

**NHS England** has pledged that dementia is a priority and the ambition is that two thirds of people who have dementia will receive a formal diagnosis and post diagnostic support.

**Post diagnostic support** is very important and is the key to improving quality of life for people with dementia and their carers.

...continued on next page
A diagnosis of dementia is of limited value without the after-care that should be provided. Dementia advisors are now available in many parts of the country and a recent evaluation by the Department of Health showed they were an effective resource to support people and their carers. Admiral nurses are another example of a way of providing support.

Care of people with dementia in hospitals is vitally important. It is estimated that 25% of people in hospital suffer from dementia, a number which is greater on care of the elderly wards. An initiative called Commissioning for Quality and Innovation (CQUIN) has demonstrated the benefits of finding people with dementia in hospital and providing them with an assessment and onward referral for care if needed.

The reports suggest that in the first quarter of 2013 some 10,000 people were referred for an ongoing assessment and this will be further developed to include a package to support carers emphasising the need for a clinical lead in every hospital.

Reduction in the use of antipsychotic medication is an important aspect of dementia care and in many ways an easy biomarker for the quality of care. The audit report published by the Information Centre in 2012 suggested there had been a reduction of 52% over the previous five years.

Prevention of dementia is of primary importance and there is good evidence to suggest that perhaps 10% to 20% of dementia cases could be prevented by rigorously paying attention to the treatment of vascular risk factors. There is some evidence to suggest that dementia may be on the decrease. The Cognitive Function and Ageing Study (CFAS) funded by the Medical Research Council recently described a second phase of work looking at the numbers of people with dementia in 2011 compared to 1991. There was evidence that the number of people with dementia is 24% less than expected with the rise in the older population over the last 20 years. This may have significant implications for the numbers of people with dementia in the UK.

The diagnosis rate is taken from the numbers of people estimated to have dementia on the Quality and

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### The Common Core Principles for supporting People with Dementia

**Principle 1**
Know the early signs of dementia.

**Principle 2**
Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.

**Principle 3**
Communicate sensitively to support meaningful interaction.

**Principle 4**
Promote independence and encourage activity.

**Principle 5**
Recognise the signs of distress resulting from confusion and respond by diffusing a person’s anxiety and supporting their understanding of the events they experience.

**Principle 6**
Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.

**Principle 7**
Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.

**Principle 8**
Work as part of a multi-agency team to support the person with dementia.
Outcomes Framework register who die in primary care every year. The paper offers the real prospect that the number of people with dementia has actually decreased, potentially as a result of better treatment of strokes and heart attacks but also potentially through the benefits of improving education. The numbers are impressive in terms of the potential reduction but it should be noted that the response rate for the study was significantly lower in 2011 than it was in 1991.

Training and education in dementia is important and Health Education England has a commitment to provide training for 100,000 people in the NHS (linking to social care) by March 2014. This is likely to be in three tiers - basic information awareness training, more advanced training, then specialist expertise. The aspiration is that 10% of staff should be dementia experts, 50% dementia trained and 100% dementia aware.

The common core principles for supporting people with dementia have been Skills for Health and Skills for Care (table 4).

Public Health England has dementia as a priority and issues such as the prevention of dementia and the real possibility of vascular risk factor reduction is important. Dementia appears in the NHS Health Check by raising the possibility that dementia is potentially preventable.

In summary, dementia is coming of age. Awareness is at its highest and the challenge is to translate that into practice leading to real change that improves quality of life for people with dementia and provides support for them and their carers allowing people to live well with dementia. One of the biggest issues is to get dementia accepted as a challenge for the whole of society. In the words of colleagues at the University of Birmingham, the aspiration is that dementia is a diagnosis that opens doors not closes doors.

Alistair Burns
National Clinical Director for Dementia
NHS England

One of the biggest issues is to get dementia accepted as a challenge for the whole of society. In the words of colleagues at the University of Birmingham, the aspiration is that dementia is a diagnosis that opens doors not closes doors.
Active Ageing

The benefits of physical activity for health and well-being

Sandra Hartley is a Senior Lecturer in the Health Professions Department at Manchester Metropolitan University (MMU). She has a shared role as Programme Leader and Examination Officer of the MSc (Pre-Registration) Physiotherapy Programme and is responsible for ensuring quality provision of teaching, learning and assessment for a diversity of students. Prior to her move into education, Sandra worked as a physiotherapist in the UK and abroad, in a variety of settings, within both the NHS and Private Practice. Her research interests are health and wellbeing, active ageing and long-term conditions.

Dr Gillian Yeowell is a Senior Lecturer in the Health Professions Department at MMU. She is a Chartered physiotherapist and Health and Care Professions Council (HCPC) registered, and is a fellow of the Higher Education Academy. Her current role involves research, research degree supervision and teaching, learning and assessment on a number of programmes at MMU. Her research interests include: health and wellbeing in the older person; exploration of culture, including cultural competence; practice-based and practitioner research.

It is hard not to be aware of the growing global population of older people; one needs only to read the newspaper or watch the news to appreciate this. In the United Kingdom alone there are estimated to be 10.3 million people aged 65 and over; a figure that is rapidly increasing.

So why has there been all this attention recently? Well, ageing brings with it the inevitable changes in the structure and function of the systems of the body; you only need to peer periodically in the mirror to be aware of this. Even more importantly, there is a gradual decline in physical and mental functioning with an increased susceptibility to health problems.

In fact, older adults are the most prevalent group using health services and it is estimated that they make up over 60% of health and social care budgets. However, since the global financial crisis and its effect on the UK economy, the government is committed to keeping their health and social care budget in check.

Advances in medical science have led to increased longevity. What would seem important is not just the quantity, but also the quality of these additional years both for the older person and for society as a whole. As Abraham Lincoln said, “in the end, it’s not the years in your life that count. It’s the life in your years”. In fact, the desire to retain one’s youthful looks has led to a plethora of anti-ageing products flooding into the market, promising a quick fix solution. However, maintaining physical and mental capacity is a more enduring and, we would suggest, a far more worthwhile pursuit.

Whilst there are no magical potions to thwart physical and mental ageing, physical activity has been found to not only slow down the ageing process but also reverse physical changes that take place when sedentary and help to prevent chronic illnesses from occurring.

More specifically, physical activity can increase muscle strength and joint mobility, and aid cardio-respiratory function; thus improving the capability as we get older to carry out activities of daily living. It can also improve mental wellbeing by reducing episodes of depression and anxiety, as well as helping to increase self-esteem and improve cognitive function; therefore providing the potential for us all in our later years to live a more fulfilled social life.

Taking into consideration all the advantages to being physically active, it is no surprise that the Government has endorsed guidelines promoting physical activity for everyone.

These recommendations highlight the level of physical activity that should be achieved to ensure beneficial effects. The guidance for healthy older adults is to undertake 150 minutes of moderate intensity aerobic exercises a week in bouts of 10 minutes or more. One way of achieving this is to do 30 minutes of physical activity at least 5 days a week. A moderate level of activity is being achieved when the individual feels warmer, there is an increase in heart and breathing rate but they can talk. These may include activities such as fast walking and ballroom dancing.

If the individual is already active at a moderate intensity, it is deemed that 75 minutes of vigorous intensity, or a mix of moderate and vigorous activity, should take place throughout the week. A vigorous level of activity is being achieved
activities, which range from groups that have come into being throughout the country. These older adults to engage in physical of voluntary run community exercise activity there have been a number in an attempt to encourage more of places to access physical activities, health restrictions, and lack of confidence in carrying out the activity are just some of the obstacles that have been highlighted. Finding ways to enable older adults, particularly those who are sedentary or exercise very little, to engage in some form of physical activity would therefore seem valuable. Even more worthwhile though, would be if we could facilitate a change in behaviour in order to encourage lifelong participation. Interestingly, older adults from the Black and Minority Ethnic (BME) population, individuals with health conditions or people of a lower socioeconomic status are particularly less inclined to engage in physical activity. Why this is the case is not entirely clear as there is a lack of research investigating these subgroups specifically.

In an attempt to encourage more older adults to engage in physical activity there have been a number of voluntary run community exercise groups that have come into being throughout the country. These activities, which range from gardening to dancing, Zumba to Nordic walking have clearly influenced some older adults to participate in exercise that they previously would not have done; in fact Sandra’s mother is just one such case. Not only have the exercise groups, which she attends at her local church, improved her physical fitness; they have increased her social life too.

She now has fun meeting her new friends, who also provide her with much needed social support. However, this is not by any means a radical adoption by all and there is no evidence that these groups have improved the long-term participation of older adults in physical activity. Another interesting point to add is that men are less likely to attend these exercise groups than women, but there is no certainty as to why. We therefore feel these issues need to be explored further, as it may be that the potential benefits of community exercise groups have not been fully realised for a diverse range of older adults.

Therefore, with many questions unanswered, this became the stimulus for us to pursue research in this area. The aim of the first strand of our study was to explore experiences of exercise group participation from the viewpoint of a diverse range of older adults (65 and above), who live in the community. The objective was to gain an understanding of what these older adults attain from attending exercise groups and what would influence their attendance. To conduct this research we undertook focus groups with older adults who attended community exercise groups in Greater Manchester. This included individuals with chronic health conditions, people from BME groups, people of a low socioeconomic status and men.

The findings from this research have been analysed and submitted for publication. The paper is currently under review and we hope to make this publically available soon.
Insight - Alzheimer’s Society

Hayley Misell, Alzheimer’s Society Service Manager for Manchester, Oldham, Rochdale, Heywood and Middleton.

Hayley and her team provide services to people living with dementia and their carers to help them through their journey from diagnosis and beyond.

Hayley manages the delivery of services across five areas in Greater Manchester with a team of eight including two befriending managers, three dementia support workers, a dementia adviser, a dementia café co-ordinator, and an administrator.

In Manchester, Oldham, Rochdale, Heywood and Middleton the estimated number of people with dementia is more than 8,500. Approximately 4,500 of those people have a diagnosis, which means just under half, without a diagnosis, are missing out on vital support and care to help them live well.

As a services manager, early diagnosis is vital to achieve my aim to reach as many people as possible to provide practical services and support. It is important for my team to achieve early intervention, which will help keep people living independently for longer.

Some of our current services include a dementia adviser service at the point of diagnosis in Rochdale; a dementia support service, where a support worker works with the person living with dementia and the carer throughout their journey; carer information programme (CIP) across Manchester and Rochdale, which supports people to care for their loved ones, with detailed information and coping strategies; Memory Wellbeing Cafes in Heywood, Middleton and Milnrow, where there are social activities and guest speakers; targeting more black and ethnic minority communities so they can gain support; as well as a very popular befriending service to keep people independent and maintain a high quality of life.

For more information advice and support call the Manchester office on 0161 342 0797 or email hayley.misell@alzheimers.org.uk. Alzheimer’s Society provides a National Dementia Helpline, the number is 0300 222 1122 or visit www.alzheimers.org.uk
The Silver Line

Esther Rantzen’s new charity, The Silver Line, a helpline for the elderly will be launched nationally on 25th November 2013.

The helpline aims to provide a number of services to the elderly population including, sign-posting callers to a range of services that exist around the country, a befriending service to combat loneliness, and a support service to those who may be suffering abuse and neglect, and if appropriate to transfer them to specialist services to protect them from harm.

The Silver Line states that there are 10 million older people (over the age of 65) living in Britain today and many of them (51 per cent of people over 75) are living alone. Esther Rantzen’s previous experience setting up ChildLine demonstrated to her that people find it easier to confide to a stranger on the telephone and reports that some older people have asked to receive regular calls from the befriending team, Silver Line Friends.

Over the last 10 months The Silver Line pilot has been running in the North of England, taking around 4,000 calls, and receiving 400 requests for regular calls from Silver Line Friends. All the calls are free to the caller, and lines are open night and day, 24/7.

To find out more please visit www.thesilverline.org.uk

The Belong Garden - A Sense of Place

The Belong Village dementia garden that won silver at RHS Flower Show Tatton Park is being rebuilt at Belong Warrington, a state-of-the-art care village that specialises in supporting people with dementia.

Carolyn Hardern who designed the garden after consulting older people, largely based the design on research into the benefits of outdoor spaces for people living with dementia, focusing on a sense of place, reminiscence, orientation and sensory enjoyment. The figure-of-eight paths eliminate dead ends that can lead to stress and confusion, a memory wall that is decorated with archive pictures attempts to evoke memories of days gone by, while the raised beds provide an opportunity for activity.

Belong Warrington opens in 2014 aiming to provide a number of facilities for the local community, as well as specialist nursing and dementia care in private households and 18 stylish independent living apartments for older people.

To find out more please visit www.belong.org.uk

Upcoming Events...

Next steps for dementia care - commissioning, the Dementia Challenge and the Care Bill
26th November 2013
The seminar aims to discuss the progress of the Challenge on Dementia, and the key issues for raising awareness, improving outcomes and developing research. Planned sessions focus on the commissioning of dementia care following the authorisation of Clinical Commissioning Groups and new duties for local authorities, and the impact of the Care Bill on funding and personalisation of services. This event is CPD certified.

2013 Bionow Awards
28th November 2013
The Bionow Annual Awards Dinner celebrates and showcases the very best of this world class sector. This year the Innovative Ageing Award of the Year is sponsored by Edward Healthcare and MIMIT (Manchester: Integrating Medicine and Innovative Technology). www.bionow.co.uk

Nursing in Practice one-day training event on Dementia and Mental Health
London
4th December 2013
Manchester
5th December 2013
The course will focus on the basic clinical knowledge and skills required to confidently support patients with dementia and the most common mental disorders. Discussion will be encouraged to share experiences and solutions, as well as the use of case studies and examples to reinforce learning. A Certificate of Attendance will be issued for each session after the full day’s attendance.

Safeguarding Vulnerable Older Adults in Health Services
15 January 2014
This conference, supported by the Practitioner Alliance for Safeguarding Adults, takes a practical approach to safeguarding vulnerable older adults in health services, updating delegates on national policy, legal issues and case studies of excellence in practice.

To find out more please visit www.healthcareconferencesuk.co.uk/safeguarding-vulnerable-older-adults
Cochrane Corner

The Cochrane Collaboration is an international network of more than 28,000 dedicated people from over 100 countries. They work together to help healthcare providers, policy-makers, patients, their advocates and carers, and the general public make well-informed decisions about health care, by preparing, updating, and promoting the accessibility of Cochrane Reviews.

Cochrane Reviews are internationally recognised as the highest standard in evidence-based health care. This article summarises a selection of Cochrane Reviews assessing interventions for people with, or carers of people with dementia.

**Physical activity** appears to delay the onset of dementia in healthy older adults and slows down cognitive decline to prevent the onset of cognitive disability.

**Cognitive stimulation**, a form of ‘mental exercise’, appears to be beneficial in memory and thinking, communication, interaction and quality of life for people in the mild to moderate stages of dementia but not severe dementia. No evidence was found of improvements in the mood of participants or their ability to care for themselves or function independently, and there was no reduction in behaviour found difficult by staff or caregivers. Family caregivers, including those who were trained to deliver the intervention, did not report increased levels of strain or burden. Cognitive stimulation involves a wide range of activities that aim to stimulate thinking and memory generally, including discussion of past and present events and topics of interest, word games, puzzles, music and practical activities such as baking or indoor gardening. Typically this is carried out by trained staff with a small group of four or five people with dementia for around 45 minutes at least twice a week. Family caregivers have also been trained to provide cognitive stimulation to their relative on a one-to-one basis.

**Functional analysis** appears to have a positive effect on the frequency of the person’s reported problem behaviours and the caregiver’s reaction to them. No effects were found for incidence or severity of mood and other problem behaviours or for caregiver mood or burden. Functional analysis is a behavioural intervention that is described as the first line alternative to drug therapy for challenging behaviour. The therapist is required to develop an understanding of the function or meaning behind the person’s distressed behaviour. It uses this understanding to develop individually tailored strategies aimed at both the person with dementia and the caregivers, to relieve the distress caused by the behaviour. It can be applied in home settings where the family or informal caregiver is offered support from a therapist, or in care homes, hospitals or assisted living settings.

**Aroma therapy** appears to have a beneficial effect on agitation and neuropsychiatric symptoms of people with dementia. Aroma therapy is the use of pure essential oils from fragrant plants (such as Peppermint, Sweet Marjoram, and Rose) to help relieve health problems and improve the quality of life in general. The healing properties of aroma therapy are claimed to include promotion of relaxation and sleep, relief of pain, and reduction of depressive symptoms. Hence, aroma therapy has been used to reduce disturbed behaviour, to promote sleep and to stimulate motivational behaviour of people with dementia.

**Reminiscence therapy** improves cognition and mood 4 to 6 weeks after the treatment. Care-givers participating with their relative with dementia in a reminiscence group reported lower strain, and people with dementia were reported to show some indications of improved functional ability. No harmful effects were identified.

Reminiscence therapy involves the discussion of past activities, events and experiences, with another person or group of people. This is often assisted by aids such as videos, pictures, archives and life story books.

**Cognitive rehabilitation** provided preliminary indications of the potential benefits of improving activities of daily living in people with mild Alzheimer’s disease. Cognitive rehabilitation focuses on identifying and addressing individual needs and goals, which may
require strategies for taking in new information or compensatory methods such as using memory aids.

**Music therapy** may be beneficial for older people with dementia.

**Light therapy** does not appear to have any positive effects on managing cognitive, sleep, functional, behavioural, or psychiatric disturbances associated with dementia.

The **light therapy** in the included studies were: a light box placed approximately one metre away from the participants at a height within their visual fields; a light visor worn on their heads; ceiling mounted light fixtures; or dawn-dusk simulation that mimics outdoor twilight transitions.

**Cognitive training** had no effect in improving cognitive functioning, mood or activities of daily living in people with mild to moderate Alzheimer’s disease or vascular dementia. Cognitive training focuses on guided practice on a set of tasks that reflect particular cognitive functions, such as memory, attention or problem-solving.

Other therapies had insufficient evidence for to allow any conclusion about their efficacy for people with dementia or cognitive impairment.

These include: validation therapy, acupuncture, homeopathy, transcutaneous electrical stimulation, massage and touch.

Validation therapy is based on the general principle of validation, the acceptance of the reality and personal truth of another’s experience.

Caring for people with dementia

**Cognitive reframing** has the potential to reduce anxiety, depression and stress. It did not affect carers’ coping or sense of being burdened. Cognitive reframing is intended to reduce carers’ stress by changing certain of their beliefs, such as beliefs about their responsibilities to the person with dementia, their own need for support, and why their relatives behave as they do.

**Respite care** appears not to have any positive effects for people with dementia or for their caregivers for any outcome including rates of institutionalization and caregiver burden.

No evidence was found for any intervention aimed at prevention or management of wandering in the domestic setting.

For more information


Dementia Care - making it personal

I write this article just as we prepare for a whole team Dementia Care training session. Dementia care services are in a profound period of change and transformation and there is a sea change in public understanding and interest in the challenge we all face. To address this challenge, we need to move more rapidly and more drastically towards personalised healthcare programmes.

In our training session, we are setting ourselves a simple but significant challenge – to deliver “great days”, not just for our clients but for each other too. What we do is very difficult and supporting each other is essential. So what would a great day for Bob look like? What would it take for us to deliver that? What are the barriers? How could you help? Could we do that again? These are some of the key questions explored.

This is all about being “person centred” and putting yourself in your client’s position, imagining how this service you are about to deliver might feel, this is the very start of the process. Indeed Dawn Brooker in her 2004 review describes this as fundamental to the care process*.

This is why so much focus is given to understanding who your client is. Gathering a simple life story is a very important first step. However, this is not as straightforward as it sounds and often the process involved can be easily flawed, particularly in caring for someone with Dementia as it is natural for those close to the individual to jump in and volunteer the information, to provide the gaps we apparently cannot get from the client directly.

What is essential is that each carer adds to this their own understanding of the person. They must build their own rapport and understanding of the individual in the here and now. This recognises that the needs and concerns of an individual with a Dementia may very well differ from their historic ‘profile’, so it is a delicate process of understanding that is needed.

The key and overriding ‘talent’ is empathy. It is now the single most important driver in the recruitment of all new members to our own team.

The willingness to put one self in the other person’s shoes, to see the world from their perspective and think all the time, how can I understand them? This is how you can start to build a relationship, this is when you start to understand a person in the here and now and this is when you can imagine how your service might feel.

Whilst empathy is a character trait, and not easy to change, it can be done and it can be encouraged. I see for my team that I must find a way to value empathy as much as we value the important range of skills and expertise that we need.

If empathy is our foundation then effective communication is how we build beyond this base. There are some very innovative approaches to communication in Dementia care but the basics are very simple and very effective, including:

- Stop, do not speak, put yourself in their shoes, and take a mental deep breath (not a real one!).
- Engage your body language.
- Unless inappropriate make sure there is a reassuring smile on your face.
- Customer care makes a great deal about the importance of having a smile on your face, in Dementia care it is usually essential and clinically important. An anxious and confused client looks around the room for clues and bearings, the welcome and engaging face is an absolute requirement, the alternative, a stony “I’m rather busy” look is not what that client needed and an opportunity to calm or support their anxiety has been missed.
- If you are a ‘bubbly person’, check your tempo, match your client’s.
- Sit if they are seated, but ask first.
- Use an appropriate title of address – first name terms are for friends and when you have been invited or given permission to use them.
- Talk with someone, not at them, do not argue or challenge their concern, go with it and focus on

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Dan Lingard, CEO and founder of iPersonally, the innovative designers of Dementia Care Centres and Assistive Technologies, is a former software executive working with brands such as IBM and the BBC. After 20 years in international commerce Dan set up iPersonally to lead the development of his vision for a new generation of “consumer” focused care services for people and their families, living with Dementia.
Recognising and Developing Brain Potential

People today appear more afraid of dementia than they are of cancer and heart disease. Yet surprisingly, whilst we talk about 800,000 people in UK with dementia, it’s estimated only about 40% of people are actually diagnosed.

It is true that currently there is nothing to prevent the pathology of the disease, but neuroplasticity, the ability of the brain to change throughout life, has huge implications on cognitive function (www.sharpsbrains.com).

This adaptability means that certain strategies can work towards improving overall quality of life with a patient diagnosed early with dementia.

Imagine the brain as muscle - the more it’s ‘exercised’, the better it will perform; even the damaged Alzheimer brain clogged with neurofibrillary tangles and amyloid plaques, has ability in the early stages, to develop coping mechanisms and bolster mental skills. The healthy brain can generate 700 new cells a day (less as we grow older) but with cognitive adaptation - rehearsing and working on skills with perception, attention, memory and language for example, poor performance can certainly be improved.

Similarly to diabetes or cancer, the earlier the diagnosis is made, the better the outcome.

Mary encourages anyone with worries about their memory to have an assessment; this can, in many instances, reassure all is well and if screening results do indicate referral to a medical specialist, then something positive is being done, support and treatment options will now be a reality.

This is one such strategy used by Mary at Memcheck. This is a memory clinic and advice centre, utilising the unique CANTABmobile assessment which screens for very early changes in episodic and visuospatial memory.

CANTABmobile administers a Paired Associative Learning (PAL) test on an iPad, and is used on people aged 50-90 years, taking about 10-15 minutes to complete. It also screens for depression and monitors Activities of Daily Living.

The Alzheimer’s Society website is a useful source of information regarding other approaches to an early diagnosis of dementia (www.alzheimers.org.uk).

The Florence Nightingale Foundation Travel Scholarship is an annual award with ‘...a real opportunity to study practice elsewhere...to enhance patient/user care in the UK’. In February 2013, I travelled to New South Wales, Australia for a month to investigate further how a Geriatric Flying Squad reduces unplanned admissions in the over 65s.

As an Advanced Nurse Practitioner for older people having worked in both an Acute Medical Unit and an Acute Medical Ward for older people, I have direct experience of frail elderly people who are unplanned emergency admissions to hospital. Indeed, 65% of people admitted to hospital are above 65 years of age. In addition 80% of emergency admissions who have a length of hospital stay greater than two weeks are patients in the over 65 age group (King’s Fund 2012). Recent media attention has also focused on the increasing pressure on Accident and Emergency departments and the ‘perfect storm’ of increasing demand and reducing financial resources.

The challenge is to find models of care which assist in avoiding unnecessary hospital admissions and enable older people to remain in their own homes longer. With this objective in mind I was curious to discover more about the ‘Geriatric Flying Squad’ in Australia, which is an innovative scheme and is already achieving this objective of reducing unplanned admissions in older people.

Seeking new solutions

The domiciliary Geriatric Flying Squad
War Memorial Hospital in Sydney is a small, sub acute hospital for the elderly with two rehabilitation wards and outpatient services. The domiciliary Geriatric Flying Squad (GFS) is based within the hospital, although it functions through doing outreach home visits.

The service is led by a nurse consultant who is supported by a nurse specialist in aged care, two social workers, a physiotherapist, an occupational therapist, a clinical psychologist, a consultant geriatrician and a dietician. In addition to this, outpatient services, such as podiatry, in War Memorial Hospital can be drawn on.

“The number of people attending A&E is rising in many places and even where the increases are small, the number of frail elderly patients with complex conditions is increasing so more patients are being admitted”.

Chris Hopson, Chief Executive of the Foundation Trust Network

The referral system to the GFS is an open one. Referrals may be received by the patient themselves, General Practitioners, family members, friends, carers, Aged Care Assessment Team (ACAT), community services, police or paramedics where there is concern that the person is functionally declining in their own home. These patients should be 65 years or older (although the criteria was reduced to 45 years for indigenous Australians).

Instead of the traditional divide between ‘health’ and ‘social’, the Geriatric Flying Squad looks to integrate these facets of care for the elderly. Initial comprehensive geriatric assessments are frequently done jointly between the nurse...
consultant/specialist and a social worker. The average consultation time for a new referral is one hour. The response time from initial referral to initial review is twenty four hours, Monday to Friday. On average the GFS receives between six to seven new referrals each week and carries a caseload of up to sixty patients.

Wherever deemed appropriate, a referral is be made at this initial consultation to other members of the multidisciplinary team, e.g. clinical psychology. If assessment from another member of the multidisciplinary team is required this would commonly occur within a seven day period. The overarching aim is to provide a ‘one stop shop’ service for the elderly in their own home without waiting many weeks or months for intervention. Thus, the service is geared towards rapid response, early intervention and giving both patients and their carers or families a single point of reference to co-ordinate their care - the GFS nurse consultant or nurse specialist.

The length of the programme for each patient is between six to eight weeks. Although there is flexibility to extend the programme if it is felt the patient would benefit from a longer period on the service. Also, if the nurse consultant or nurse specialist feels hospital admission is necessary, they have direct admission rights to the local geriatric medical admission unit or in-patient rehabilitation beds at War Memorial Hospital. This means admission through an emergency department is avoided.

The GFS takes full advantage of the integrated health information technologies available in New South Wales. Each of the nurses has a wireless laptop to enable them to operate a paperless service and complete their assessments in the patients’ homes using their laptop. Electronic patient records are widespread as all community services (which encompasses social services also) are expected to input patient information into the Community Health Information Management Enterprise (CHIME) records. Furthermore, the GFS have access to their local hospitals’ electronic records including pathology reports and radiological imaging for their patients. Also, electronic monitoring of Emergency Department admissions means that any patient who presents three times in a twelve month period with a chronic disease is ‘flagged’ and has to have an explicit management plan as to how their emergency admissions would be reduced. This may include a referral to the GFS.

The initial success of the domiciliary GFS has led to a further two years funding being granted from the Council of Australian Government. In addition I also observed a Nursing Home Geriatric Flying Squad and a similar domiciliary rapid response team the “Healthy at Home” in Newcastle, New South Wales.

In the first year the domiciliary GFS reported:

• 166 patients were kept living in the community.
• 33% (52/166) avoided imminent presentation to the Emergency Department.
• 34 patients required hospital admission.
• Of these, 88% (30/34) bypassed the Emergency Department thorough direct admission rights.

Other observations which could be translated to UK community services include:

• The speed of the service that the domiciliary and residential aged care facility teams provide is not currently matched by community services in the UK.
• The integration of healthcare technologies as seen in New South Wales could also be used to improve patient care.
• Having a key coordinator for your care is crucial.
• Earlier conversations with patients about End of Life care and advance care planning.

A full report is being submitted to the Florence Nightingale Foundation.

My observations and learning points

As all the GFS teams and the Healthy at Home team sat within the State of New South Wales, they all benefitted from the excellent integrated electronic health record systems driven by the Government in this region. Not only were records integrated within the community with the Community Health Information Management Enterprise (CHIME) system, they also benefited from the integration between primary and secondary care electronic records. The intelligence generated from these systems, such as ‘flagging’ patients with three Emergency Department visits in a twelve month period for a robust management plan was impressive and would be advantageous in elderly care in the UK.

Jacqueline graduated from Glasgow Caledonian University in December 1994 with a BA (Hons) in Nursing Studies and a Registered General Nurse (RGN) qualification. In 2002 she was appointed as the first nurse clinician in surgery in Manchester Royal Infirmary and pioneered this role in cardiothoracic surgery. In September 2006 with a desire to broaden her experience she became an Advanced Nurse Practitioner in acute medicine, for older people at Manchester Royal Infirmary.
What is your current position and what was your career path that took you there?

I am currently Professor of Rehabilitation Science at Glasgow Caledonian University in Scotland and Deputy Chairman of Glasgow City of Science. I originally trained as a physiotherapist in a hospital school as at that time physiotherapy was not a degree subject. I worked full-time as a physiotherapist for five years in the National Health Service in England and in the later years I also undertook a part-time Masters Degree in Physical Habilitation at Liverpool University. I then went on to undertake a full-time PhD at Manchester University studying the effects of electrical stimulation on the thigh muscles in people with osteoarthritis of the knee.

I moved to Scotland to take up the Directorship of a research consortium for Nursing and Allied Health Professionals. I am now also Deputy Chairman of Glasgow City of Science a partnership organisation promoting cutting edge science in Glasgow, the impact of science on the lives of the citizens of Glasgow and inspiring children to study science subjects through delivering exciting science events. I am also an Honorary Professor at the University of Manchester.

What challenges do you face in your current position and which has been the greatest one?

My work involves encouraging organisations across Glasgow to work together in partnership. This involves developing and maintaining existing relationships and partnerships. Challenges include relationship building to develop new strategic alliances with enthusiastic individuals and organisations across the public, private and voluntary sectors.

In your opinion, what are the top issues affecting the care of older people?

The main issue is the projected number of people who will be past working age, the ‘baby boomers’ generation, compared with those of working age. This will have an enormous impact on the ability to provide sufficient quantity and quality of healthcare. A consequence of advanced healthcare is that inevitably the numbers of frail elderly people will also increase and so enabling people to maintain their independence in their places of residence and activities of daily living will become increasingly challenging.

What changes in elderly care do you anticipate in the next few years?

I think that there will be more use of technology such as SMART homes, telemedicine and telehealth which use new technology to monitor peoples’ activity, environment such as temperature, lighting and bodily functions such as pulse rate, blood pressure. This will enable people to stay independent for longer and will enable monitoring of medical conditions, early diagnosis of problems and rapid response to medical emergencies.

If you hadn’t become a physiotherapist, what might you have done?

I love to build things and so perhaps I would have become an engineer or an architect. I also have an interest in photography.

What experience has influenced your career the most?

Undertaking my PhD as this taught me so many skills that have been useful throughout the rest of my career. My PhD supervisor (and now great friend) was, and still is, such an inspiring person.

What advice would you give to someone contemplating following in your footsteps?

My career path has been so varied and so I would say go with the flow, look for opportunities but always look to create your own. Take a risk and do exciting things you never know where it may lead you.

Where do you go for advice and information?

Trusted friends are always the best source of advice and for information I use my tablet computer or smart phone to surf the internet, I’m a typical geek!

Who would you most like to work with?

I am lucky as for part of my week I work at Glasgow Science Centre which is full of interesting creative people who are passionate about science and invent new fun ways to experience it.

If you were stranded on a desert island what would be your one luxury?

A tool kit so that I could build things for comfort, entertainment and possibly to sail away....

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As dementia got even more of a hold

**ALEX WILKINSON**
*Carer & Professional Letting Business Manager*

Until the age of 82 Mum was still leading an active and independent life and even travelling long haul on her own. Her last trip was to fulfil a lifelong ambition to swim with the Manitees in Florida. It came as quite a shock therefore when she returned from this trip and started to display some signs of vascular dementia. Mum was always fiercely independent and highly opinionated with an incredible memory for the slightest detail – particularly remembering all the things I ever did that she did not agree with!

Some of the fight had gone and was replaced by a more meek and mild individual who was actually easier to get on with. I know many of my friends found the opposite to be the case with their relatives displaying more anger and aggression as dementia began to take hold. We were lucky however and have enjoyed a few years of relative calm with her managing to live in her own home with the help of carers in the form of an agency and a single privately arranged carer without whom it would not have been possible.

Gradually however, things started to decline and, as mentioned in Issue 1, we started to struggle with managing Mum’s continence alongside other problems such as leaving the gas on and taking her clothes off. Weeks when she did not really understand what was going on around her were interspersed with days of heightened clarity and complete self-awareness. During these times she would become very anxious and depressed and she could not understand why she could not walk – despite being unable to walk for months! We struggled on, trying to manage the distress by sitting with her and putting in more support, but the biggest help was when the GP prescribed antidepressants – something we maybe should have thought about earlier.

Gradually however as her dementia got even more of a hold it became more difficult to manage looking after Mum in her own home. Things came to a head when she started to manage to make her way to the front door to shout out for help to people passing in the street. We tried respite care but she really needed specialist support and we started to look around at EMI dementia units. These are specialist units for elder care provision with trained staff. The unit she is in is lovely with a wide expanse of gardens and plenty of space with her own en-suite bathroom. She seems reasonably happy and the staff are spot on for gentle and supportive care; so gone are the daily worries about what she was up to when the carers weren’t there.

Many people have asked me how I knew when it was the right time, and whether I felt guilty about moving her from home to a care home environment. I’m sure it depends on individual circumstances but I just knew it was time. The guilt is a more difficult one to answer but you have to do what’s right for the person as well those around. I sought the advice of Mum’s main carer, her GP, social worker, friends and family so the decision did not fall entirely on my shoulders.

We managed for nearly 9 years to keep her at home, and whilst there were times when it was stressful and difficult, most of the time it was straightforward and helped by the fact that although dementia is not a great condition it can lessen the pain of growing old because the loss of insight makes things easier to bear.

Again one of the biggest take home messages for me is help is out there, we should not feel isolated and we should not be afraid to use it. I don’t think Mum will be with us for much longer but I know she is safe and being well cared for in the later stages of her life.
In our next quarterly issue of Innov-age we will be looking at technology, projects and organisations using telehealth to help provide patient care. The team will be sharing their understanding and introducing a range of telehealth practices, as well as current eldercare issues...

We will be introducing a new Innov-age resident telehealth expert in our Issue 4 lead article. You will also hear more from our regular contributors including Tracey Howe, who will be summarising the findings of The Cochrane Collaboration Reviews, and we will welcome more new contributors to Innov-age.

To subscribe for free or comment on any of our features please email the team at info@innov-age.org and visit our website www.innov-age.org for more information.