NHS pay has been cut by 12%-15% since 2010
ENOUGH IS ENOUGH

Staff in the NHS are struggling to earn a living wage

The story so far:
• Since 2010 NHS staff have had a 12% to 15% pay cut in real terms as inflation has continued to rise.
• Senior managers in the NHS have had an 11% rise since 2009.
• City banking bosses continue to receive huge bonuses despite the economic crash they caused
• MPs have announced an 11% pay increase for themselves from 2015.
• Staff have had a range of other cuts to pay, pensions and terms and conditions.

Since 2010 there has been:
• A 15% pay cut in real terms – up to one-third of income for some staff.
• A 3.2% pension contribution increase, work longer and get less.
• Changes to on call.

• Removal of unsocial hours when off sick.
• Changes to absence management.
• Cuts to mileage.
• Performance pay.
• Removal of preceptorship.
• Cuts to injury benefit.
• Registration fee increases.
• Car parking charges increased.

It is a harsh reality for some:
• 40,000 NHS staff earn below the living wage.
• Many NHS staff are now dependent on in-work benefits, increasingly staff are dependent on food banks to help make ends meet.
• NHS staff have been denied a holiday this summer due to tightening personal finances.
• Some NHS staff are leaving the service as they can no longer afford to work for the NHS.
Editorial

Straddling traditional divides to improve care

I am pleased to introduce this special edition of the journal, which focuses on dementia.

Most reports are forgotten quickly, but some hang around longer and have enduring impact. They change the way we work, often in ways that are not immediately recognisable at the bedside. Two of the most influential reports – the 2013 Francis Report and the subsequent Berwick Report are changing the face of healthcare as we know it. The care described in the Francis Report, according to Berwick, should never happen again. This was also said following the Mental Welfare Commission for Scotland’s report Starved of Care (2011) into the care and treatment of Mrs V.

An interesting debate throughout my career has been that of the management of delirium and dementia within acute care. From Mrs V came the recommendation of the development of psychiatric liaison teams within acute care. Their purpose being to make it easier to refer patients with dementia for appropriate diagnosis, management and ongoing support.

Much of the current literature quotes a prevalence figure of 20-25% for people with dementia occupying acute beds – many without diagnosis. Referral is acceptable if the referral is of a person-centred nature. Sadly, this is often not the case and ‘behavioural management’ is the underlying reason. This causes an increase in referral for any behavioural reason whatsoever, typically for delirium. The diagnostic criteria for delirium are quite clear – the most obvious feature is acute onset and this is definitely not the case with dementia. So why are patients not diagnosed first and referred second? Would it not be more beneficial for a patient to have timely treatment for what is an illness with a high mortality rate (delirium) when unidentified?

There is an overlap with dementia and delirium. Generally there is a much greater risk of developing dementia when suffering from repeated bouts of delirium. Undoubtedly those people with dementia are at high risk of developing delirium. How helpful is it for psychiatry to attend with their list of diagnostic criteria and decline to assess patients due to inaccuracies in diagnosis? Behaviour is behaviour, isn’t it?

Patient welfare resides with all of us involved in their care. We, as mental health nurses, have unique skills and should not be afraid of this overlap, between delirium and dementia or between acute care and mental healthcare arenas. Mental health professionals offer much in respect of understanding human behaviour, and acute colleagues have much to teach us in understanding physical health and its impacts upon mental wellbeing. Funnilly enough, this is another recommendation in the Starved of Care report. MHN

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Sharp rise seen in number of dementia diagnoses

The number of patients with recorded diagnosis of dementia has increased by 62% over the past seven years.

Provisional figures from the Health and Social Care Information Centre (HSCIC) show 344,000 patients had a recorded diagnosis of dementia in 2013-14. This is a rise from 319,000 in 2012-13 and from 213,000 in 2006-07, when the data was first collected.

The statistics show the numbers of patients registered with GP practices in England who have a recorded diagnosis of dementia and this is the first time the HSCIC has published a standalone report on this subject.

It shows the increase in recorded diagnosis has been steady since this data was first collected. The rise may be due to the ageing population, an increase in the number of people being diagnosed, improved recording of diagnoses or a combination of factors. The report also shows:

- The percentage of registered patients with a recorded diagnosis of dementia (prevalence rate) has increased in all four NHS regions of England between 2012-13 and 2013-14.
- There is regional variation in the level of recorded diagnosis, with the North and South having the highest levels at 0.68% and 0.67%, the Midlands and East of England at 0.62% and London, with its different age profile notably lower at 0.39%.
- Looking at variation in the level of recorded diagnosis by clinical commissioning group (CCG), the CCG with the highest level at March 2014 was the Isle of Wight at 1.1%; where 46.4% of all patients registered with GPs are aged 50 and over.
- The lowest recorded level was in Tower Hamlets CCG, at 0.25%, where 15.5% of all patients are 50 or over.
- The provisional 2013-14 data has been produced to assist the monitoring of progress towards objectives, including the Department of Health’s ambition of increasing the proportion of people with dementia who have a recorded diagnosis so that they can receive the appropriate care and support.

HSCIC chair Kingsley Manning said: ‘We are all aware of the challenges facing our ageing population and these figures will be vital for those planning and monitoring the effectiveness of dementia treatments and services.’

The full report can be seen at: http://www.hscic.gov.uk/pubs/qofdemprev1314.

Businesses risk losing billions unless they adapt to dementia

Public Health England (PHE) and the Alzheimer’s Society, who recently joined forces to launch the Dementia Friends campaign, have released a new report on the future financial implications to the nation’s businesses of dementia, and called on employers to adapt their working environment to support the increasing numbers affected by the condition.

The report, from the Centre for Economics and Business Research (Cebr) reveals that by 2030, dementia caring obligations will cost companies more than £3 billion.

As the population of England ages, the number of people with dementia is expected to rise to 1.09 million by 2030. The report predicts this will have a huge impact on businesses as the number of workers reducing hours, changing work patterns or even quitting, due to the demands of caring, is expected to grow.

Findings also show that the number of people who will have left employment to care for people with dementia is set to rise from 50,000 in 2014, to 83,100 in 2030.

Yet, if companies increased their employment rate of dementia carers by just 2% over the years to 2030, for example by offering more flexible terms of employment, the retention of these skilled and experienced staff would deliver a saving of £415 million.

With a growing need for those over the age of 65 to stay in employment, by 2030, the cost of skills and experience lost from the workforce due to dementia will rise from £628 million to £1.16 billion.

Businesses have started to recognise this issue, with 1 in 12 companies (8%) having made attempts to accommodate the needs of a member of staff with dementia, and more than half (52.1%) considering taking such action in the future.

So far more than 20 major businesses have already signed up and are committed to supporting staff and customers with dementia.

Over 100,000 employees from businesses including LloydsPharmacy and M&S are now Dementia Friends and a host of other companies such as Barclays, Lloyds Banking Group, Argos, BT and Bourne Leisure (Butlins, Haven and Warner Leisure Hotels) have also pledged for their staff to become Dementia Friends.

Duncan Selbie, chief executive of PHE, said: ‘It is encouraging to see that so many businesses are willing to make changes to accommodate those living with and caring for people with dementia.

‘I’m delighted that more than 100,000 employees across the country have already become Dementia Friends.

‘Making positive changes like this creates a more supportive environment generally and businesses have an important part to play in this.’

The report also highlights that businesses which are not sufficiently dementia friendly will lose out. The value of the ‘dementia pound’, which is the spending power of households affected by dementia, is set to double to £22.7 billion by 2030, from £11 billion in 2014, due to the rise in the number of people affected by the condition.
New report highlights cost of dementia to the UK and outlines extent of impact on people and carers

The cost of dementia to the UK has hit £26 billion a year – enough to pay the energy bills of every household in the country, according to a new report by the Alzheimer’s Society.

Dementia UK: The Second Edition reports that people with dementia, their carers and families shoulder two-thirds of the cost themselves. The charity is urging the government to end the artificial divide between health and social care which unfairly disadvantages people with dementia.

The report, which was prepared by the London School of Economics and King’s College London, is the most comprehensive review of dementia in the UK to date.

It reveals how people with dementia and their carers are left footing a £5.8 billion social care bill for help with everyday tasks such as washing and dressing.

The 1.3 billion hours of unpaid care that carers, usually spouses or adult children, provide would cost the state £11.6 billion if they did not provide it for free.

Meanwhile the current cost of dementia diagnosis and treatment to the NHS comes in at £4.3 billion and local authorities pick up a further £4.5 billion.

The new research also reveals that numbers of those affected by dementia is soaring. By the next general election in 2015, there will be 850,000 people living with dementia.

If current trends stay the same and no action is taken, this number is expected to bypass two million by 2051.

In addition to Dementia UK, Alzheimer’s Society has published Dementia 2014: An Opportunity for Change, which provides a snapshot of how well people with dementia are living in England, Wales and Northern Ireland. It draws together evidence from a survey of over 1,000 people with dementia. Key findings include:

• Just over half of people with dementia (58%), reported to be living well.
• Nearly two-thirds (61%) said they had felt anxious or depressed recently.
• 7 out of 10 people were living with another medical condition or disability as well as dementia.
• Of those looked after by a carer, 43% said their carer received no help with their caring role.

Jeremy Hughes, chief executive of Alzheimer’s Society, said: ‘This new research exposes the staggering financial and human impact of dementia. It’s plain to see that our social care system is on its knees, leaving an army of tens of thousands of unpaid carers bearing the brunt.

‘If you have cancer or heart disease you can quite rightly expect that the care you need will be free. That is just not the case for people with dementia. Families are forced to break the bank to pay for basic care for a loved one.

‘These spiralling costs cannot continue unchecked. Some 225,000 people develop dementia in the UK every year – that is one every three minutes.

‘While government has woken up to the challenge dementia presents, today’s report reveals we need radical solutions and serious funding commitments to put social care on a sustainable footing.’

The Alzheimer’s Society is calling for a successor to the Prime Minister’s Challenge on dementia, which is scheduled to end in just over six months, and says it should prioritise:

• A 66% dementia diagnosis rate across all areas so that people do not miss out on the support currently available – with a commitment now to reach 75% by 2017.
• No one to wait longer than 12 weeks from seeing their GP to diagnosis.
• A guarantee that everyone has access to a dementia adviser or equivalent following a diagnosis to help them live as well as possible at all stages of the condition.

Jeremy Hughes said: ‘While in recent years there has been a small improvement in dementia diagnosis rates, a postcode lottery still prevails. Everyone with dementia should have access to the certainty of a diagnosis and the right support to come to terms with and manage the condition.

‘If we do not see a nationwide effort to improve diagnosis rates we could see more than a million people living with dementia without a diagnosis by 2051.’

Pearl McCreadie, 58, from Widnes in Cheshire, cares for her husband John, 78, who has mixed dementia (vascular dementia and Alzheimer’s disease). She said: ‘I gave up work when John was diagnosed with dementia – caring for him is now my full-time job. It’s a lot of responsibility and it’s difficult to manage him on my own.

‘Mostly I don’t get a minute to myself until 10 o’clock at night because I’ve been on my feet all day, helping John to wash, shave, clean his teeth, ensuring he’s taken the right medication, and making sure he’s happily occupied. Often I have to get up in the night when he wakes too.

‘He’s my husband so of course I don’t begrudge it – I love him and only want the best for him, but there needs to be more support for carers. I’ve spent all my savings on adjusting the house and I don’t have any money left at the end of the week for extras.’

Martin Knapp, LSE professor of social policy, said: ‘The cost of dementia is high, but the key question is what does that cost buy? We need to make sure that people with dementia and their carers get effective and cost-effective treatment, care and support.’

Professor Martin Prince, professor of epidemiological psychiatry at King’s College London, said: ‘This report highlights that the numbers of people with dementia now needing care and support already pose a significant challenge for health and social care, government and society. Their needs will only be met through concerted and focused attention.

‘The scale of the future dementia epidemic in the UK can probably be limited through more attention to prevention – our progress towards achieving healthier brain ageing needs to be monitored in regular national surveys.’
I always seem to be commenting about how the date I write this can often be overtaken by events. This is certainly true this month. As I write you this you have got just under two weeks left to return your ballot on the NHS pay dispute. By the time you are reading this, the count will have happened and we will know the result. If the decision of the membership is in line with the recommendation from the national health sector committee then strike action will follow.

I know from regularly speaking to our members in the NHS that strike action really is the last resort and not something that our members do lightly. But from a government that came to power promising that it would be ‘fair’ we have seen the complete opposite come about. This is not just in the fact that NHS workers have faced pay cuts while millionaires have had tax cuts (on top of increasing wages), but as we explored at the end of last year, the effects that austerity has had on the poorest in society and especially those with poor mental health.

Another momentous ballot will have been decided by the time the ink has run dry on the printing of these 2,500 journals. And that will be whether Scotland will become independent. For me there is a little irony that even though I am from the North, it is the north of England, but at the moment I am sat on the Tarmac waiting for my flight to leave to Edinburgh.

Even though I am just going to help out at one of our professional conferences for CPHVA members, I am looking forward to being in the country for ‘D-Day’.

During the referendum campaign I have spoken to many of our Scottish members, and it has been fascinating to hear eloquent arguments both for ‘yes’ and ‘no’. For this reason I was glad that Unite’s lay committee took the decision to take a neutral stance, encouraging individuals to vote in the way they saw fit.

Another trend that I have picked up in private discussions has been the head versus heart argument, which in itself has been fascinating.

This edition of Mental Health Nursing is of course devoted to the issue of dementia and a few months ago we held a Scottish conference on the subject in Glasgow.

There were many interesting presentations, and even to a novice in the subject such as myself, it gave me much to think about. One that has stayed with me has been the discussion that was had about the language of dementia.

Dr Peter Gordon spoke about ‘fighting talk’ and pointed out a few sources that went further into the subject. Working in health do we ‘get’ that the future is uncertain more than others do, or are we just as vulnerable to the need to be told certainties even when they do not exist?

I was at the Houses of Parliament a few weeks back at an All Party Parliamentary Group (APPG) looking at early intervention in the first 1,001 days of life.

An MP commented that at this point in time all parties were fine-tuning their manifestos for next year’s general election. His comment was that they were being primarily influenced by people from the Treasury and so to get anything included it would have to show a cost benefit.

My response back was how sad it is to hear that politicians are so un-aspirational that they do not want our country to be the best place to live – but the cheapest.

The only certainty is that tomorrow is uncertain, be it yes or no. MHN
Dementia and stigma: a review of the literature on the reality of living with dementia

Alison Kilduff examines the literature on the effects of stigma and ageism in dementia care

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Abstract
This paper provides a review of the literature on the reality of living with a diagnosis of dementia in terms of stigma and ageism, and their effects on care.

Key words
Dementia, stigma, ageism

Reference

Introduction
With the numbers of individuals diagnosed with dementia-related disorders expected to significantly rise in the next few decades from 670,000 to approximately 1,340,000 (Department of Health, 2009), it is imperative that health and social care professionals are equipped with knowledge, skills and understanding to meet the needs of people living with dementia.

Individuals living with a diagnosis of dementia are significant users of mainstream health and social care services. At any one time in an acute hospital, one third of the beds will be occupied by someone living with dementia.

Furthermore, a report by the Care Quality Commission (CQC, 2013) highlighted that people living with dementia are far more likely to go to hospital with avoidable conditions, such as urinary infections, dehydration and pressure sores than their peers.

Once admitted, they will stay much longer in hospital, be more likely to be readmitted and are much more likely to die in hospital than similar people without dementia.

Counting the Cost (Alzheimer’s Society, 2009), explored carers’ perceptions of dementia care in hospital settings and identified several key areas of dissatisfaction.

These included nurses not recognising or understanding dementia; a lack of person centred care; patients not being helped to eat and drink; a lack of opportunity for social interaction; not as much involvement in decision-making as wished for (for both the person with dementia and carer); and the person with dementia being treated with a lack of dignity and respect.

Recent evidence from the Francis report (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) described a culture of secrecy and defensiveness, in which there was an absence of human kindness and disinterest in family and carer concerns.

Common themes in the evidence heard in the inquiry consisted of patient’s call bells being unanswered, patients left lying in their own urine and faeces for long periods of time, and food and drink being left for patients out of their reach.

Many of these events related to the care of the most vulnerable people in our society, older people and people who were diagnosed with dementia.

In 2007 dementia was declared a national priority, which led to intensive consultation and development of the National Dementia Strategy (Department of Health, 2009).

The main strands of the strategy set out recommendations which would enable people to ‘live well’ with dementia.

Principles of the strategy included improving awareness and understanding of dementia nationally, the provision of early specialist diagnosis, effectively managing the overuse and reliance on antipsychotics in coping with challenging behaviour and the implementation of supportive, collaborative relationship with individuals and carers, to enable positive physical and psychological wellbeing from diagnosis through to end of life care.

It therefore seems timely to consider
why, five years after the introduction of the National Dementia Strategy (Department of Health, 2009) there is still evidence to suggest that individuals are not living well with dementia (Alzheimer’s Society, 2012).

This paper offers a short review of the evidence related to how stigma may be one aspect that can impact on the individual’s ability to ‘live well’ with the diagnosis.

The Alzheimer’s Society (2012) suggest that misunderstanding and stigma can elicit a particular response related specifically to the diagnosis of dementia. Furthermore, they propose that this can culminate in infringements being made on an individual’s human rights where rights to privacy, dignity, liberty, choice and decision making can be overridden.

**Ageism and stigma**

It has long been acknowledged that ageist attitudes can have a detrimental effect on care experiences in older adult care (Audit Commission, 2004; Clarke, 2005; Royal College of Psychiatrists, 2009) and that this form of discrimination can lead to older people being perceived as somehow inferior to other younger adults.

Coller (2005) cited a concerning example of ageism from the Age Concern report *Turning Your Back On Us* (Gilchrist, 1999), which showed that one in ten GPs declined to refer older people to secondary care because they have had a ‘good innings’.

However, ageism and age discrimination alone cannot account for the stigma, marginalisation, lack of choice and non-involvement in decision-making that the growing number of younger people being diagnosed with dementia experience and consistently report (Alzheimer’s Society, 2008).

It is hypothesised that even the term ‘dementia’ may elicit a particular response related to stigmatising and stereotypical views in health and social care professionals and also the general public.

Goffman (1963: 12), in his seminal work *Stigma: Notes on the Management of a Spoiled Identity*, suggested stigma is an attribute and significantly affects the person’s sense of self and perception by others. He defines stigma as being ‘deeply discrediting… he is thus reduced in our minds from a whole and usual person to a tainted, discounted one’.

**Kitwood’s views on stigma**

Kitwood (1979) defines personhood as a ‘status or standing bestowed upon one human being by others, in the context of a social relationship and social being’ (Kitwood 1979: 8).

Kitwood’s early work asserted that harm to an individual’s psychological wellbeing could be done, often unintentionally, by actions and words of people caring for individuals living with dementia, thereby reducing them to a lesser person.

Kitwood (1979) used the term ‘malignant social psychology’ to describe this process. This concept is defined as devaluing, depersonalising and diminishing the person with dementia, which in turn reduces them to less than a person. As a consequence, their rights and needs are not considered.

Kitwood and colleagues in Bradford observed and categorised episodes where people with dementia were stigmatised, invalidated or ignored. Kitwood suggests that it is rarely carried out with malicious intent or consciousness; the ‘malignancy’ is that it becomes the norm and unnoticed.

The dementia becomes the individual’s determining characteristic and all other aspects of their individuality and personality are overlooked or lost.

Although Kitwood is widely acknowledged for challenging the traditional medical paradigm that has existed in dementia care since it was acknowledged as an illness, Kitwood’s work has been criticised for lacking empiricism, in that is an unproven theory (Innes, 2009).

Addressing stigma related to the diagnosis of dementia may need to be considered as part of the solution for health and social care, if the problems that were evident at Mid Staffordshire are to be addressed.

This would prevent stigma pervading the culture of care in hospital settings and ensuring that all care was person-centred and focused on compassion and understanding.

**Dementia and stigma**

Dementia is the most feared consequence of ageing (Alzheimer’s Society, 2008), although Brooker (2007) suggests that, because of its association with mental ill health, people living with dementia suffer more prejudice than any other illness.

Gillon (2003), citing Kant, proposes that this may be because of a perceived lack of rationality, which is viewed as a part of personhood and assumed not to be present in people living with dementia.

It is suggested that the extent of unequal and unjust treatment is evident in a range of aspects related to the care and treatment of dementia, including service provision, resource allocation, research funding, media coverage, policy priorities, professional training, status and pay of dementia care workers (Brooker, 2007).

Two of the reviewed studies attempted to include the voices of ‘seldom heard groups’ (Alzheimer’s Society, 2008) and ‘hard to reach groups’ (Katz et al, 2013) in an attempt to increase the diversity and value of their studies.

In relation to first-generation migrants, who are now reaching an age when the risk of developing dementia is increased, there is a further increased risk because of the prevalence of hypertension and diabetes, which can be undetected, or untreated (Parker and Philip, 2004).

There are concerns that stigma and discrimination for individuals living with dementia extends further for groups who are already marginalised and excluded, which can lead to a reluctance to seek help and support from services.

Katz et al’s (2013) study noted that while many of the participants in the study coped with a range of complex needs, they rarely expressed dissatisfaction with the care they were receiving from services.

Katz et al (2013) suggested that as the majority of this cohort had grown up during or after the Second World War, before the development of the welfare state, some of the cohort had previously experienced worry and/or poverty in their life history and were grateful for any help they received.

Bowing (2001) suggested that this was a law of ‘inverse satisfaction’ wherein older people may be inclined to agree with the ‘fair innings’ principle in that they are ‘lucky’ in
comparison to their parents. Bowling (2001) also comments that researchers could be more robust in the design of the studies, in that if satisfaction questionnaires were more open ended and in depth, they could elicit a more transparent view of older people’s real experiences in health and social care and could yield higher levels of criticism.

This measure could be enabling for vulnerable individuals and those living with dementia and would prevent them becoming unheard and invisible.

**Early diagnosis, early onset dementia and stigma**

While the link between ageing and dementia has been recognised as being linked to discriminatory practice, there is growing evidence that stigma and discrimination are evident in the care and attitudes that younger people experience when they are diagnosed and living with dementia.

Numerous studies have highlighted several issues that significantly impacted on younger individuals living with dementia, particularly surrounding a timely diagnosis (Beeston, 2010; Alzheimer’s Society, 2008; 2012; Pratt and Wilkinson, 2001).

When reviewing the literature, there was a consensus that early diagnosis was a positive initiative and it enabled choice and decision making for the person living with dementia, which was identified as a prerequisite for ‘living well’. This was particularly apparent in some of the narrative accounts of people ‘living well’. This was particularly apparent in some of the narrative accounts of people ‘living well’.

Therapeutic nihilism — stigma or ignorance?

As the traditional dominant medical approach in dementia care has been challenged in the past 25 years and has moved to a more person-centred model, particularly following on from Kitwood’s early work in the 1980s and 1990s emphasising a psycho social approach, contemporary mental health services for people of working age are primarily concerned with a recovery model (Shepherd et al, 2008).

The recovery framework’s guiding principle is hope, with a belief that it is possible for someone to regain a meaningful life after a diagnosis of a mental health problem.

In relation to therapeutic nihilism, Adams (2010: 627), asserts: ‘underlying therapeutic nihilism is the view that there can be no recovery for people with dementia’.

Therapeutic nihilism stems from the belief that there is no recognised cure or treatment for an illness and is based on attitudes that the disclosure of this truth may be damaging and destroy a person’s hope for the future.

Moore and Cahill's (2013) recent study on GPs disclosure of a dementia diagnosis in two countries, Sweden and Ireland highlights this issue distinctly. Although GPs from both groups were aware of the evidence that early diagnosis is good practice, important and
people living with dementia felt they were a ‘lesser person’ and feared losing their autonomy.

In our society, rationality and cognition are highly valued (Kitwood, 1979a) and as individuals living with dementia are deemed to have lost rationality, along with many people diagnosed with a range of mental health problems, they can become the focus of unwarranted attention.

Last year in the media there was a debate regarding major supermarkets selling Halloween costumes based on ‘mental patients’. One costume, on sale nationally, was described as: ‘Comprising a torn bloodstained shirt, bloodstained plastic meat cleaver and gory face mask, it’s a terrifying Halloween option’ (The Guardian, 2013).

This gives a clear example of stigma and discrimination. It would be highly unlikely, due to public outrage, that a chemotherapy cap, used to cool the scalp while a person undergoes chemotherapy, would be used as part of a ‘terrifying Halloween option’ for a fancy dress costume.

The abounding stereotypes associated with mental ill health of irrationality and madness, along with myths and stereotypes associated with older age of senility, dependency and decline can have a ‘double whammy’ effect with regards to the care of older people (Robb et al, 2003).

The media’s influence on society’s perception of dementia is significant and this undoubtedly impacts on healthcare professionals’ views and perceptions, as we are all members of society. As media attention relating to dementia tends to focus on the later stages of the illness, this can become society’s perception of the entire process from diagnosis to end of life.

Conclusion
The studies that also explored quality of life indicated that individuals living with dementia were able to enjoy a high quality of life for many years when the right type of care and support was available to them (Alzheimer’s Society, 2012; Katsuno, 2005; Katz et al, 2013).

It is clear that defining people living with dementia as one homogenous group is problematic and leads to stigma and unhelpful perceptions. However, the diagnosis of dementia only adds to the stigma already faced by the individual if they are an older person, increasing their lack of status in treatment and care in which they are neither valued nor respected.

Many years after the notion of malignant social psychology was proposed by Kitwood (1997), evidence continues to demonstrate that individuals living with dementia receive inequitable and unacceptable care that devalues their personhood and sense of self.

This short review has raised a number of ethical complexities while exploring concepts related to stigma and unjust care and treatment of individuals living with a diagnosis of dementia.

Timulak (2008) suggests that, in order to make valued decisions regarding care, there needs to be an acceptable framework in which decisions can be formulated and checked.

The most influential ethical model in healthcare was proposed by Beauchamp and Childress (1994), which advocates principles of autonomy, beneficence, non-maleficence and justice. The model has been developed with a deontological approach, based on the work of Immanuel Kant (1724-1804) and places principles and duties above consequences.

Autonomy is a key concept of Kantian thinking because Kant believed that without freedom people are unable to make rational and moral decisions (Wilmot, 1997). Kant believed that people should always be treated as ends, not means.

The literature reviewed also suggested that inequalities and poor care experienced by people living with dementia is not only influenced by discriminatory attitudes towards age alone, but is specifically related to stigma attached simply to the diagnosis of dementia and would suggest that the diagnosis of dementia could be ‘tainted’ (Goffman, 1963) by stigma.

The studies involving those living with early onset dementia highlighted this issue very clearly. The moral issue regarding diagnosis disclosure emanates from basic ethical principles of autonomy and beneficence (Beauchamp and Childress, 1994). Autonomy is concerned with respecting the rights of an adult to make decisions concerning their life.

However, if disclosing a diagnosis of dementia could be considered to cause harm to that person, then the principle of non-maleficence, not causing harm intentionally, could be justified.

Concerns about catastrophic reactions including suicidal thoughts and depression are widespread according to Pinner and Bouman (2003), despite there being little evidence for this assertion.

In Moore and Cahill’s (2012) study, GPs stated they feared the ‘profound consequences’ of early diagnosis and wanted to protect their patients from the harsh reality of being diagnosed with dementia.

In contrast, all the evidence in the studies reviewed suggested that early or timely diagnosis was beneficial, even though it was often initially distressing to individuals and families, because it gave them time to adjust and helped them plan for the future.

The introduction of the Mental Capacity Act (2005) has been clear in its position that health professionals must presume competence unless there is clear evidence to the contrary. It would therefore follow that all patients have a right to know their diagnosis, unless they specifically stated they did not wish to do so.

The patients’ ‘right to know’ campaign has gained more ground in healthcare in recent years but in dementia care, compared to cancer or other long-term conditions, there is still evidence of paternalistic attitudes that can impact significantly on choice and decision making in the short and longer term.

Professionals’ attitudes towards dementia appeared to significantly affect ‘living well’, particularly in relation to a timely diagnosis and the adjustment process (Moore and Cahill, 2013; Pratt and Wilkinson, 2001; Alzheimer’s Society, 2010).

The concept of therapeutic nihilism suggests that many professional groups believe there is no hope of a meaningful life after diagnosis, a view that is clearly not held by people living with a diagnosis of dementia who participated in the studies by Katsuno (2005), Katz et al (2013), Pratt and Wilkinson (2001), Moyle et al (2005) and numerous

“Early or timely diagnosis is beneficial, even though it is often initially distressing for everyone”

Dementia special
Alzheimer’s Society studies in 2008, 2010 and 2012. The government has set out key measures to ensure that the confidence of the general public is rebuilt including criminal prosecutions, under a new criminal offence, of wilful neglect and a legal requirement of ‘candour’, both direct recommendations from the Francis report (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

According to the Francis report, candour, openness and transparency are central principles in a culture that puts its patients at the heart of its care, and ten recommendations have been made regarding candour, openness and transparency being made a statutory duty (recommendations 173-183).

Candour relates to professionals speaking out about poor care that is being delivered and also about the prevention of poor care.

The Francis report has also recommended that poor practices should be part of a new duty of candour that would be legally enforceable and ensure staff do not conceal or obstruct investigations or concerns.

The Royal College of Nursing (2013), in its response to the Francis report, states that poor care, unacceptable behaviours and attitudes are brought about by ‘burnout’ of staff facing constant changes, staffing shortages and the continuous pressure of care giving.

The Royal College of Nursing suggests that by legally enforcing a requirement on staff to disclose information on acts or omissions in care, the measure could be counter productive and lead to a greater culture of fear instead of increasing openness and transparency.

The NHS Institute for Innovation and Improvement (2012), in partnership with the Dementia Action Alliance group, launched a call to action to ensure that individuals living with dementia receive safe, respectful, compassionate care.

The call to action committed that every hospital in England would become a dementia friendly hospital and that dementia care would be a key priority for the NHS.

It will be important for health and social care providers to consider the impact therapeutic nihilism may have within their own organisation and identify objectives related to skills, knowledge and attitudes of the workforce that could enable them towards becoming a ‘dementia friendly’ organisation.

Overall, it is imperative that we respond to the individual needs of people living with dementia in a caring, compassionate manner, accepting the gradual cognitive decline – but remembering their rights and appreciating their humanity. MHN

References


**Light as an intervention to manage distressing symptoms in dementia: a literature review**

Grahame Smith presents a summary of the evidence base for light therapy in dementia

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**Introduction**

With the right support, living well with dementia can become a reality – particularly where a mental health nurse’s practice is underpinned by the best available evidence (Woods et al, 2013; Department of Health, 2012).

Contemporary evidence suggests that a comprehensive and integrated package of interventions should be offered to a person who is diagnosed with dementia and should include ‘light’ as one of these interventions (Department of Health, 2012; NCCMH, 2007/2011; NICE, 2011).

It is important to note that using light as an intervention in dementia is in its early stages. There is some promising evidence, but as yet not enough evidence for it to be formally and robustly recommended, though due to its increasing use it is essential that mental health nurses understand its value within their practice (Woods et al, 2013; Forbes et al, 2004; The Scottish Intercollegiate Guidelines Network, 2006; Dijkstra et al, 2006; NCCMH, 2007/2011; NICE, 2011; Department of Health, 2009). Based on the work of Innovate Dementia, a European-funded project, this paper aims to provide a summarised overview of the literature and evidence related to the use of light within the dementia field.

Innovate Dementia is three-year project that started in April 2012. It aims to explore, identify and develop sustainable solutions to the everyday challenges of living with dementia (Woods et al, 2013; WHO, 2012; Prince et al, 2011).

Light is a potential solution the project was keen to explore due to its increased use across North West Europe, specifically in the Netherlands and in some parts of the UK (Woods et al, 2013). The first phase of the project was to undertake a literature review of the evidence, presented in a ‘baseline’ report in March 2013. The second phase, based on the recommendations from the baseline report, was to use and evaluate an intelligent lighting system within a dementia ward environment, and this work is still ongoing (Woods et al, 2013).

The interest in using light as an intervention or light as therapy has arisen from noticing that distressing symptoms in dementia such as agitation and aggression can be worse at certain times of the day, commonly the late afternoon to evening – also known as the ‘sundowning phenomena’ (Vardy and Robinson, 2011; Ballard et al, 2009; Ballard et al, 2008; Bachman and Rabins, 2006).

Traditionally these symptoms have been managed through the use of pharmacological treatments, but due to the side-effects of these treatments there has been a move...

Using non-pharmacological interventions that includes light is a fairly recent development and on this basis there is a need for more rigorous research (Baillon, 2002; Azermaia et al, 2012; Livingston et al, 2005; NCCMH, 2007/2011; NICE, 2011).

Some of the most promising research has been in the use of light as a way of managing disordered sleep, which is another common symptom of dementia, though disordered sleep is not uncommon among older people (Brown et al, 2011; Wolkove et al, 2007; Morton et al, 2005).

This age-related occurrence is specifically linked to the ageing process. A study by Turner and Mainster (2008) highlights that age-related changes in the eye can adversely affect the older adult’s capacity to receive the required light levels throughout the day, and this in turn may negatively impact upon an individual’s sleep-wake cycle.

Turner and Mainster also make the point that if an individual is reliant on artificial lighting then this can compound the problem as artificial lighting is ‘dimmer and less blue-weighted than natural daylight’ (2008: 1439). The implication for mental health nursing practice is that people with dementia require exposure to natural daylight that is consistent with a normal rest-wake cycle, good quality light in the day and less light at night, and where access to daylight is restricted then artificial light should be equivalent to daylight (Torrington and Tregenza, 2007).

A systematic review by Dijkstra et al (2006) to ‘determine the effects of physical environmental stimuli in healthcare settings on the health and wellbeing of patients’, supports this view indicating that ‘there were predominantly positive effects found for sunlight’ (pp166). Aarts et al (2006: 47) also highlights that there is a ‘positive correlation between sleep efficiency and exposure duration to high intensity light, meaning that more light is related to efficient sleep’.

Receiving the right amount of light at the right time is also neurologically important in that there is evidence that a disrupted circadian rhythm in dementia is linked to an individual’s melatonin levels. Melatonin induces drowsiness and this action is inhibited by daylight (de Jonghe et al, 2010; Hanania and Kitain, 2002; Hatfield et al, 2004; Wirz-Justice, 2006; Riemersma, 2004).

A study by de Jonghe et al (2010) indicates that agitation behaviour in dementia, specifically the sundowning phenomena, can improve when treated with melatonin and on this basis it is postulated that sundowning behaviour is explicitly related to a ‘disturbance of the circadian rhythm’.

This study concurs with Hanania and Kitain’s (2002: 338) view that ‘plasma melatonin levels play an important role in the regulation of the sleep-wake cycle’. This disruption has a cyclic effect in that circadian disruption in dementia can in turn exacerbate existing behavioural problems.

The significance for mental health nursing practice is that to effectively manage the rest-wake cycle of a person with dementia, including any related behavioural difficulties, the mental health nurse also needs to effectively manage their exposure to light (Turner and Mainster, 2008; Mishima et al, 2001; Shani and St Louis, 2009).

At a holistic level Carvalho-Bos et al (2007: 92) argues that ‘treatments that enhance daytime activity and the stability of the rest-activity rhythm may improve wellbeing’, enabling people with dementia to live well.

In relation to the specific and controlled use of light Terman and Terman (2005) highlight that timed light exposure has some promise for the treatment of sleep disorders in dementia. Terman (2007: 497) makes the point that ‘the rest-activity disturbance of dementia has been partially allayed under light therapy’. Wirz-Justice (2006) and Skjerve et al (2004) also point out that there is some promise in using light therapy. Further to 2006, a systematic literature by Brown et al (2011) suggests that light therapy of all the non-pharmacological interventions has more ‘conclusive’ evidence in reducing disorder sleep than other interventions.

A study by Sloane et al (2007: 1524) using ‘a cluster-unit crossover intervention trial involving four conditions: morning bright light, evening bright light, all-day bright light, and minimum standard light’ on older adults with dementia concluded that ‘bright light appears to have a modest but measurable effect on sleep in this population, and ambient light may be preferable to stationary devices such as light boxes’.

In terms of using light to manage agitation in dementia research, studies to date have struggled with the complex nature of this type of research. A study Ancoli-Israel et al (2003) promisingly found a ‘shift in the peak of agitated behaviour’ – more so in mild dementia than severe dementia, though a randomised trial by Dowling et al (2007) concluded that ‘bright light therapy did not clinically affect neuropsychiatric behaviours (pp971).

The Dowling et al study also noted that it was difficult to control complex factors that may have adversely impacted upon their findings such as not being able to clearly quantify agitation behaviour and not being able to discount the impact of prescribed medication (Dowling et al, 2007).

Interestingly some studies focusing on sleep have also looked at restlessness, a form of agitation behaviour in dementia. Studies by Van Someren et al (1997), Sloane et al (2005) and Sloane et al (2007) highlight the potential of high intensity light in the management of sleep problems and also restlessness behaviour in dementia.

Further to this a study by Van Hoof et al (2009) exploring the intensity of light in managing restlessness suggests that ‘high-intensity bluish light may play a role in managing restless behaviour and improving circadian rhythmicity in institutionalised older adults with dementia’ (pp146).

Using light as an intervention in dementia is not just confined to managing sleep disturbances and agitated type behaviour. Teresi et al (2000: 417) highlights the environment is an area that is critical to specialised dementia care, which includes the use of lighting; while Boyce (2003) specifically stresses the importance of lighting quality.

Voermans et al (2007: 158) makes a further point that ‘falls in older people are a common, dangerous and frequently incapacitating problem’. On this basis good environmental lighting can help to prevent falls and it can potentially reduce agitation by enabling orientation and helping people with dementia make sense of their environment (Chang, 2004; Hughes and Adams, 2012; NCCMH, 2007/2011; NICE, 2011).

Using light to manage the environment and prevent falls is part of a package of ‘healthy’ strategies the mental health nurse can use, which includes paying attention to the use of colour, floor coverings, signage, and

As mentioned previously light as an intervention in dementia is ‘new’ and there is a need for more robust research, which includes more randomised controlled trials (Thorpe et al, 2000; Burns et al, 2002; Ayalon et al, 2006; Dijkstra et al, 2006).

This view was echoed in a Cochrane review by Forbes et al, (2004) on ‘bright light therapy (BLT) in managing sleep, behaviour, mood, and cognitive disturbances associated with dementia’. The study concluded that at the moment ‘there is in insufficient evidence to assess the value of BLT for people with dementia’ (pp2).

The Scottish Intercollegiate Guidelines Network (2006: 10) guidance for managing people with dementia also suggests that ‘Bright light therapy is not recommended for the treatment of cognitive impairment, sleep disturbance or agitation in people with dementia’.

Even though light as a therapy is not recommended the NICE (2011) guidelines for dementia suggest using high light levels and providing access to natural light. This is with a focus on improving an individual’s sleep-wake cycle.

Challenges

The challenge for researchers and practitioners interested in this area relates to knowing when to use light as an intervention, at what stage of the condition, and how much light should be used, including optimal timing and duration (Terman and Terman, 2005).

It is also important, especially in today’s climate of community care, that research explores the utility of lighting technologies within the home, their application by informal carers, and their ‘fit’ within a care package approach (Cook, 2012; Topo, 2009; Hulme et al, 2010; Carswell et al, 2009; Koch et al, 2006; Kolanowski and Whall, 2000; McCullagh et al, 2009; Prince et al, 2009).

In the search for more cost-effective solutions future research will also need to determine whether the use of light technologies in the effective management of dementia delays the transition for home-based care to hospital/nursing home care (Lawlor, 2002; Hulme et al, 2010; Woods et al, 2013).

Where light technologies are used within institutional settings there is a drive to understand the generalised impact of these technologies, but it has to be recognised that there should be a desire to understand how these technologies can be tailored at an individual level, the level where care is ultimately provided (Cutler and Kane, 2002; Kverno et al, 2009).

This increasing use of light technologies will also create a training need, not just in terms of delivering this type of intervention, but also in terms of clinical decision-making.

On this basis research will be required to assist the mental health nurse in the process of identifying when these technologies should be used and when they should not (Mason and Adeshina, 2011; McGilton et al, 2007; Woods et al, 2013; NCCMH, 2007/2011; NICE, 2011).

Conclusion

There is promising evidence that light has a significant role to play in the management of distressing symptoms in dementia – specifically disturbed sleep and associated restlessness (Montgomery and Dennis, 2004).

Light can also improve the environment for individuals with dementia, which includes falls prevention (NCCMH, 2007/2011; NICE, 2011).

As the use of light technologies in the care delivered to people with dementia is increasing, mental health nurses will be exposed to these technologies on a more regular basis. Therefore based on the work of the Innovate Dementia project the following points should be considered:

• More controlled trials are required within the area of symptom management; these trials would need to consider such technical factors as the intensity, duration, spectral content, and method of exposure of the light therapy (Woods et al, 2013).

• Lighting research has to be care-packaged focused rather than just reductionist. Future research cannot just consider the rest-wake cycle in isolation – it would need to consider rest-wake activity cycle in conjunction with diet and exercise, and it would also have to be sensitive to the community-based nature of care delivery (Woods et al, 2013).

• Future research has to consider lighting as a way of managing the environment as well as symptom management; it would also need to consider any future training requirements including the development of specific assessment tools (Woods et al, 2013). MHN

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How can training interventions for nurses promote person-centred dementia care in nursing homes?

Catharine Jenkins and colleagues describe how education can improve nursing care
et al, 2011).

At the time when people most need to communicate their needs they are least able to do it, so staff need to develop insight into the person’s experience, preferences and communication styles in order to respond sensitively (May et al, 2009).

Kitwood (1997) emphasised the benefits of a person-centred culture of care that aimed to change the approach from the previous ‘old culture’ organisationally-oriented care, where lives were managed around the timetable that was convenient for staff and institutions.

‘New culture’ or person-centred care is individually designed recognising personal preferences for practical assistance, the importance of life history and engagement in meaningful conversation and activity with the aim of providing a social environment that supports identity or ‘personhood’ (Kitwood, 1997).

Since then others have built on Kitwood’s ideas to acknowledge that caring has an impact on carers and their needs should also be recognised in recommendations for care delivery (Nolan et al, 2006; Adams, 2008). Despite the work of Kitwood and others, people with dementia living in care homes may still be cared for within institutional regimes that fail to recognise individual preferences and offer minimal meaningful activities (Harmer and Orrell, 2008).

**Drivers for change**

Concerns about the quality of care provided in nursing homes have been raised within the media (BBC, 2009; Brindle, 2014) and by the Alzheimer’s Society (2013) and the Care Quality Commission (2013). Evidence showing high-quality care is possible similarly drives change.

Hanson (2014) describes a person-centred homely approach where staff value their work and both residents and family members are highly appreciative. This and other accounts (van Zadelhoff et al, 2011; Sheard, 2008) confirm that we should confront the ‘low expectations’ of care identified by the Alzheimer’s Society (2013).

Government priorities include provision of high quality dementia care for people living in care homes (DH, 2009; DH, 2013) while the Social Care Institute for Excellence (SCIE, 2013) states that research into high-quality care is as important as that into prevention. Jeon et al (2013) explored how research around person-centred care could influence practice through an educational care planning intervention. Brown Wilson et al (2013) recommended a biographical approach to care planning, while Krumm et al (2014) emphasised the importance of palliative care principles such as excellent pain management and spiritual care.

Although staff training in dementia care is widely promoted as being inherently ‘good’, with the ultimate goal of improving the quality of life and care for residents (Nolan et al, 2008), literature reporting outcomes of such training programmes suggests that findings are equivocal and benefits inconsistent (Bourbonniere and Strumpf, 2008).

There is substantial variability in the length and type of training interventions that have been evaluated. Indeed there appears to be lack of consistency in the educational/training programmes with research teams implementing various programmes of differing intensity and length, based on different theoretical frameworks, and including many with a mixed content (McCabe et al, 2007).

Spector et al (2013) divided dementia care training evaluation studies into five categories according to approach: behavioural orientated; communication; person-centred; emotion-orientated and ‘others’.

This latter category included skills-based approaches, practice-based approaches, a goal planning intervention and a systematic consultation approach (including behavioural management techniques; positive care planning, communication skills and reminiscence).

A variety of outcomes were measured, with most studies considering impact on staff’s knowledge or attitudes and some considering staff behaviour or outcomes for those with dementia such as antipsychotic prescribing or use of restraints (Spector et al, 2013).

The lack of comparability makes it difficult to draw conclusions about topics or areas of competence that need to be covered in training for staff working with people with dementia.

In addition, it is hard to isolate the key ingredients in success, but the literature implies training should be supported by and embedded in the organisational structures and that ongoing support, supervision and organisational change may prove necessary to demonstrate a sustained implementation of the new knowledge (Spector et al, 2013; Kuske et al, 2007).

Competency frameworks for health care professionals (Tazaroucha et al, 2011; Smythe et al, 2014; Higher Education Dementia Network, 2014) are designed to provide thorough guides on outcomes for educational and training programmes while also having relevance for job descriptions.

Competency frameworks outline the achievable and measurable qualities, skills values and capabilities required of care deliverers, from the generic (communication skills, care planning, information sharing) to role-related specifics (assistance with personal care, prescription of appropriate medication, diagnosis sharing, staff guidance and support).

Competency frameworks are based on literature reviews and compiled with input from a variety of stakeholders, including people with dementia and family carers. Therefore it could be argued that if the competencies are achieved this is what good care should look like. However, the proof of the care is in the recipient’s experience.

In order to express how good care might feel from the perspective of people with dementia, the government (DH, 2013), in partnership with the Dementia Action Alliance, has phrased how the outcomes should feel for care recipients, in a series of ‘I statements’ such as:

- I get the treatment and support, best for my dementia, and for my life.
- I feel included as part of society.
- I understand so I am able to make decisions.
- I am treated with dignity and respect.
- Those around me and looking after me are well supported.
- I am confident my end-of-life wishes will be respected. I can expect a good death.

While these statements express a positive experience of care that most would support, it seems unlikely that a person with severe dementia would be able to articulate them so clearly. Proxy measurements of quality of life may also be used, for example the opinions of family members, (Mesman et al, 2011) dementia care mapping (Brooker, 2007) and analysis of behavioural indications of distress (Beerens et al, 2012).

Understanding what good and poor care look like and how they may be experienced, plus having lists of competencies to aim for, are clearly steps on the way to achieving good outcomes. However, the analysis, moral arguments, recommendations and rhetoric developed from Kitwood’s (1997) time onward
have achieved only partial impact in delivery of consistent person-centred practice within new cultures of care.

**Barriers**

Roles involving nursing people with dementia in any environment are challenging, demand physical and emotional energy and require a range of skills that when carried out well are often invisible to others (Holman, 2014).

However, the care assistants who carry out most of this work are among the lowest paid in the UK and are at high risk of job strain and burnout (Koehler, 2014; Edvardsson et al., 2009). As with trained nurses, they receive mixed messages in the media about their worth (Donelan et al., 2008) while being trained by people who may be perceived to be high on rhetoric and low on recent experience of the stark intimacy of personal care (Adams, 2008).

The nurses who lead and manage teams of care assistants may be in different, but likewise difficult, positions. Some, in first jobs post-qualification, may be charged with promoting high standards of care and ‘culture change’. Others may have chosen nursing home work to fit around family responsibilities or as a ‘step down’ from the demands of acute care toward the end of their careers.

Nursing in a nursing home is challenging. Residents have increasingly complex needs; professional decisions have to be made independently, care needs to balance with costs and outcomes, and different pressures from owners, relatives, residents, colleagues and CQC inspections (and associated bureaucracy) to be managed, resulting in low levels of morale throughout the sector.

Opportunities to ‘model’ good care may be limited by the need to spend time on medication administration and managerial aspects of the role (Smythe et al., 2014a). Nurses find they are usually the only qualified staff member on duty and are responsible for a range of clinical, ethical and managerial decisions (Bedin et al., 2012). They may not receive sick pay and some nurses report being expected to access learning in their own time (RCN, 2012).

While care philosophies may speak of a person-centred approach, unspoken messages underscore financial imperatives and homes are often under-staffed (RCN, 2012). There is a perception that working with older people is of a low status (Fussell et al., 2009) and undervalued (RCN, 2012).

Training is costly, and even when it is free, the backfill costs for qualified staff make it unaffordable for some organisations (Alzheimer’s Society, 2013) and it could be argued that the homes which need it most are least likely to access it.

The nursing home context can thus raise barriers to the education of its nurses. Even when nurses are able to access training it can still be difficult for them then to lead changes within the culture of the organisation.

**Education that changes practice**

Education and training are seen as central activities that deliver changes in practice but many training packages are found to have little or no impact after a short period of time (Mace, 2005).

Training interventions can vary in length, some awareness-raising being as brief as an hour, while academic courses at higher levels may take years to complete. There is also a wide range of free online learning packages that offer excellent resources that explain the nature of dementia, offer insight into the experiences of people living with dementia and promote a positive person-centred problem-solving approach to care (e.g. SCIE Open Dementia Programme 2009).

While knowledge and understanding are an essential foundation, alone they do not necessarily lead on to doing things differently and superficial learning tends to have little or no impact (Sheard, 2009).

There is a big step between knowing what you are aiming for and achieving it, in relation to both competencies and cultures of care. While culture is sometimes defined as ‘the way we do things round here’ (Martin, 2006) and this is observable, culture has also been likened to an iceberg, an analogy which reflects the ‘under-the-surface’ nature of values, beliefs and assumptions.

Educational interventions need to be creative, stimulating, challenging, emotionally engaging and relevant in order to address these core aspects (Rogers, 2007). They need to have outcomes that aid qualified nurses to apply and share principles of good practice, to lead confidently and support colleagues so that their needs are met as well.

In addition nurses need to be able to cope with their own stress and responses in emotionally intelligent ways, often with minimal immediate support. Nurses need to truly understand and value a person-centred approach, where life histories and compassion underpin everything from assistance with practical daily care to provision of personally relevant activities and emotional and spiritual support. Insight and empathy motivate, while clinical and leadership skills are required to enable nurses to make the vision real for residents, staff and visitors.

Adult learners thrive in environments that respect their experience, focus on relevant activities and welcome discussion and challenge (Rogers, 2007). Adults see learning as a social experience and learn best by ‘doing’ (Race, 2006).

Active experiential approaches to learning are more likely to ‘stick’ (Beard and Wilson, 2006) while reflection and discussion in small groups enables participants to build personal meanings from learning (Biggs and Tang, 2011). Educational interventions that change practice tend to be emotional, personal and interactive experiences that are felt as inspirational and transformational, affecting ‘hearts and minds’ (Sheard, 2008).

In addition the ongoing impact of educational programmes depends partly on the support available from leaders within the organisation (Cleary et al., 2010) and mutually between colleagues who attend the same training programme (Mace, 2005).

Therefore training programmes need to take into account the organisational contexts within which outcomes are expected to be applied and take steps to anticipate and address barriers within these contexts, then develop strategies that will increase the likelihood of training making a long-term difference to practice.

**Our previous research into training needs and preferences**

Our previous research, which explored the dementia care training needs of specialist staff and nurses working in acute hospitals confirmed that adult learners prefer active, experiential approaches to learning and that these were successful in changing practice long-term (Smythe et al., 2013; Smythe et al., 2014b).

We also found that while care assistants in specialist mental health services preferred to learn separately, they later revealed that some learning was difficult to implement as qualified staff were not always in tune with the person-centred approach.
Some nurses and qualified social workers ‘sent themselves’ on courses that were designed for care assistants, which alerted us to the gap in provision for this group.

The acute hospital nurses benefitted from in-practice reinforcement of classroom learning through a ‘working alongside’ approach to address particular practice problems, although this was difficult to implement in the acute setting.

**Our current study**

The current study is funded by a grant from the Burdett Trust for Nurses and builds on our previous findings.

We have designed a dual element training intervention and study that will explore which combination of interventions (classroom-based training, work-based learning and clinical supervision) have the most impact in changing practice in nursing home settings.

The programme will focus not only on knowledge, attitudes and skills, but also address leadership issues, burn-out and changing cultures of care.

We plan to evaluate the impact of the training interventions on the nursing participants, care staff, the people they care for and their relatives, by using a range of measures including evaluation tools, dementia care mapping and interviews. **MHN**

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Improving the design of mental health units to help people with dementia

June Andrews outlines the issues involved in beneficial design of healthcare environments

**Introduction**
Design of the environment is recognised as an important non-pharmacological intervention for all people with dementia and related conditions.

Much of the research literature on this relates to care home type settings (including nursing, residential and assisted living), where architects and planners have been quicker to implement the findings than in hospital settings.

In hospitals there is often a thorough approach to sensory and physical impairments (supported of course by legislation), but hardly any attention to those environmental factors that make a huge difference in care of older people with cognitive impairment, whether temporary or permanent.

**Variation**
The inpatient care of older people with mental health problem by the health service varies all over the UK.

In some places there are wards and facilities that serve patients in a specific age group, and in others older people are mixed in with younger.

In some places the wards include people with mixed illnesses regarded as organic (such as dementia) or functional (such as depression or psychosis).

In different places there is different access to physical health care.

After hospital the person may return home or to a care home. Patients who remain in hospital settings are among the most vulnerable people in the whole of the health care system.

Their needs are great and their care is highly complex. They have health and behaviour problems that cannot be managed in any other setting.

**Evidence base and cost**
The research evidence about what makes a difference for them is based on three levels of evidence; published evidence about work done with people who have dementia and related conditions, extrapolation from sensory and physical impairment, and international consensus on what appears to work, though not tested by rigorous research.

There is not enough of the first level of evidence. However, there is an increased interest in particular since the Prime Minister’s Dementia Challenge, and the awareness that dementia costs more than cancer, heart disease and stroke put together in the UK, at over £23 billion per year.

Residential care and hospital care are the most expensive elements of managing this condition.

Any evidence about how to reduce the cost while improving the quality is very important. The right design can do both.

**Avoiding problems**
The nursing workforce is often stretched and it is imperative that we do not waste any of our precious time.

Avoidable accidents and incidents are not only uncomfortable, dangerous or embarrassing for the patient and
Older people with dementia and related conditions have impairments for which design can compensate, including difficulties with memory (especially for recent events), learning, and reasoning. If it is hard to work anything out, then stress is an issue for any of us, and stress is a massive issue in older patients and dementia, causing a crushing fatigue that is not always acknowledged as a determinant of behaviour.

In addition to the difficulty in adjusting to the normal sensory and physical impairments of ageing, these patients have additional perceptual problems that can be caused by the underlying organic pathology that many of them are carrying. This includes difficulty in interpreting what they can see, and balance issues.

The Dementia Services Development Centre (DSDC) at the University of Stirling has prepared guidelines on how to design a mental health unit for older people which is designed to be useful for: Planners and commissioners of new mental health units. Architects designing new units. Procurement staff. Staff responsible for refurbishments. Clinical staff who can make modifications to their own unit. Technical staff who maintain units.

Nursing contribution
In our experience nursing staff are often asked to take part in consultation and planning meetings or work groups for new buildings, extensions or refurbishment without being given any training or education in design. Those nurses often assume that knowledge of what is practical and makes a difference resides in the architects and planners on the team.

Every nurse on such a project should ask for others who are involved to provide evidence that they have training on dementia friendly design. We know of cases where the architect or planner honestly claims that they have experience of design projects in this field. The problem is that their previous designs may not reflect the evidence base either.

Do not let them miss a chance of making things right for your patients in respect of layout, flooring, skirting and walls, handrails, ceilings, doors, signs, clocks and calendars, lighting, sound, furniture, mirrors, storage, nurse call systems, nurses stations, and essential notices.

Help from DSDC
The DSDC provides free advice on those issues through the design section of our website that includes support with building design regulations, virtual demonstration environments and information on dementia design schools that are suitable for nurses.

There are also key texts available to purchase through DSDC or from Amazon: http://dementia.str.ac.uk/design/virtual-environments-for-the-virtual-hospital

www.dementiashop.co.uk/ for books to buy and free downloads.

http://dementia.str.ac.uk/design/design-school-design-schools

http://dementia.str.ac.uk/

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Professor June Andrews is the director of the Dementia Services Development Centre, which is based at the University of Stirling and works throughout Great Britain and Northern Ireland and across the world.
The infantilisation of older people: is it a problem?

Danielle Brady and colleagues examine the phenomenon of infantilisation and its negative consequences for older people through deskilling and reduced confidence.

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**Abstract**  
Infantilisation is the act of treating an individual in a way that denies their level of maturity by virtue of age or experience. The authors argue that through infantilisation older people, perhaps with cognitive impairments, can be left without a voice and are unable to speak up against such treatment. Often their opinions on therapies and interventions are overlooked due to the challenging nature of engaging with such individuals, who often have difficulties communicating.

**Key words**  
Infantilisation, older people, nursing care, person-centred care, malignant social psychology

**Reference**  

**What is infantilisation?**  
Infantilisation is the act of treating an individual in a way that denies their level of maturity by virtue of age or experience (Gresham, 1976).

It is the act of treating an adult in the same way you would a child. This can take many forms and when looking at the infantilisation of the elderly we need to appreciate that it is a multifaceted phenomenon. This means that it can include many different aspects such as language use and tone, actions, interactions, and environment.

For example it could be the use of the phrase ‘good girl’ or ‘who’s being a naughty boy?’, it could be the use of age-inappropriate environments such as decorations normally seen in a nursery or the use of children’s toys, it could just be the tone of voice that somebody uses such as ‘baby talk’ (Whitbourne et al, 1995), or it could be treating a person as though they are incapable of carrying out simple tasks and therefore threatening their independence.

All of these aspects need to be taken into account when examining the phenomenon of infantilisation.

Kitwood’s (1990) theory of malignant social psychology highlights infantilisation as one damaging aspect that deprives an individual of their personhood leading to worsening of psychological and physical symptoms of illness.

Kitwood outlines ten aspects of malignant social psychology, which are: treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, outpacing, invalidation, banishment and objectification.

Infantilisation is described as a more extreme and persistent form of disempowerment that sees things being done for older people despite their ability to do for themselves, which can result in a loss of confidence and sense of agency, and a process of deskilling.

Infantilisation has the added component of conveying a message that the older person has the capabilities and mentality of a child (Kitwood, 1990).

**Definitional complexities**  
One recurrent issue in the study of infantilisation is the lack of a coherent and consistent definition. Many researchers conceptualise the phenomenon in different ways and use different names to refer to what is potentially the same concept.

Most researchers have taken a very narrow view of the act of infantilisation focusing entirely on language and communication without exploring it as a broader concept.

This discrepancy in operationalisation leads to problems when trying to piece together a bigger picture of infantilisation. It causes difficulties in comparison and uncertainty as to whether the same phenomenon is being discussed in all studies.

There is a moderate depth of knowledge on patronising speech/communication as one aspect of infantilisation, but there is scarce research into other forms that infantilisation may take as well as a lack of theorisation.

Infantilisation of the elderly has appeared in research in the following ways:
• Communication – using overfamiliar terms of endearment and pet names such as ‘lovey’, ‘sweetie’ or ‘darling’ to address older adults, or using a patronising tone (Ryan et al, 1991; Williams et al, 2003).

• Environment – having age-inappropriate decorations such as child-like pictures or cuddly toys (Salari, 2006).

There are other potential ways infantilisation may possibly present, which have not yet been fully explored including:
• Restriction of freedom and control of privacy (Salari, 2006).
• Interventions – child-like games and activities, or feeding and dressing adults who are still capable of doing this for themselves (Salari and Rich, 2001; Miller, 1984).

Is infantilisation abuse?
The way that older people are treated in NHS services is under increasing scrutiny, especially following a number of high-profile cases in the media depicting neglect and abuse of older people in receipt of health and social care (Francis, 2013).

So the question must be posed, is the infantilisation of older people a form of abuse? In order to answer this we must first define what abuse is itself.

Abuse is a violation of a person’s basic human rights (Human Rights Act, 1998).

It inflicts pain on an individual, either physically, psychologically or emotionally.

The World Health Organization (2011) describes elder abuse as ‘a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person’.

Within a healthcare setting it is entirely likely the perpetrator is simply trying to create and provide a safe, warm and caring environment for the individual. Can this be classified as abuse?

The answer to this question may lie in the effects that such infantilisation has on the individual being infantilised.

This process can cause a loss of individuality, something that sufferers of dementia battle with on a daily basis anyway.

Infantilisation could lead to depression and anxiety in older people as they feel they are losing control of their own life, are being treated without dignity and respect, or that they are being embarrassed and made a fool of, leading to feelings of shame (Salari, 2006).

Infantilisation could also lead to a worsening of symptoms of cognitive impairment as individuals are deskilled and treated as though they have no control of their actions or emotions, and so a self-fulfilling prophecy occurs where individuals relinquish such control (Nystrom and Segesten, 1996). All of this can have dramatic effects on an individual’s emotional and psychological wellbeing.

But can infantilisation ever be positive? Could there be some therapeutic value to the process of infantilisation by creating a safe and caring environment perhaps for older adults suffering from cognitive impairment?

As an example I will use the emerging use of ‘doll therapy’ to help care for those with dementia (Mitchell and O’Donnell, 2013).

This is clearly an infantilising act as it is encouraging older people to act as children by playing with toys and developing connections to inanimate objects.

However, anecdotal evidence suggests that doll therapy offers positive benefits to older people suffering with cognitive impairment and has been seen to improve communication and mood and reduce challenging behavior (Mitchell and O’Donnell, 2013).

It would be unwise to deny such potential benefits and the ethical considerations of such infantilising therapy clearly need to be researched more thoroughly and systematically in order for healthcare workers to provide evidence-based interventions.

Future research
The act of treating an adult who has lived an entire life – loved, worked, raised a family and made a home – as though they were a child just starting out in the world is undoubtedly of much ethical concern.

Is the care and environment we are providing appropriate or does it disregard the experience and maturity of older people leading to psychological distress? This is clearly something that must be investigated in more depth.

“Infantilisation could also lead to a worsening of cognitive impairment as individuals are deskilled”
Contemporary research into this phenomenon is important as policy clearly highlights the requirement of all health and social care staff to respect autonomy and dignity (Department of Health, 2001); challenge ageist (Department of Health, 2010a) and stereotypical (Department of Health, 2010b) attitudes, and prevent deterioration and delay dependency (Department of Health, 2011).

The Nursing and Midwifery Council (2009) specifically warns against the use of patronising language and with the NMC being the regulatory body of all nurses and midwives this is guidance that all nurses should be adhering to.

Current statistics suggest that 10 million people in the UK are over the age of 65; with the latest projections estimating a rise of 5.5 million more people over 65 in 20 years time and around 19 million older people by 2050 (Cracknell, 2010).

This rise will have a significant impact on public spending with particular impact on the NHS, where the average spending for retired households is almost double that of non-retired households (Cracknell, 2010).

With this in mind the quality and efficacy of the care that is delivered to older people is of utmost importance in social, political and economic terms.

Infantilisation is an issue that needs addressing as it has the potential to create ‘fostered dependency’ through iatrogenesis. This is where the care that is delivered creates dependency rather than responding to present dependency and care needs.

Miller (1984) described how nurses feel the need to ‘do’ for patients, but practices that neither maintain patients present self-care skills nor enable them to regain lost skills creates what Miller claims is unnecessary dependency.

Miller illustrated the gravity of this issue by demonstrating a link between increased dependency and higher mortality suggesting that it is possible that patients can be ‘nursed to death’.

Miller (1985) used a sample of 168 inpatients on six wards, in which wards were either using individualised nursing care (nursing process) or traditional ‘task allocation’ nursing.

Miller found that patients in the traditional wards had higher levels of dependency than their counterparts on individualised wards despite no statistical significance between dependency levels on admission. This phenomenon was evident once patients had been in a hospital or institution for more than one month.

Infantilisation has the potential to create this kind of dependency, as by treating an individual as a child you are encouraging them to relinquish responsibility, autonomy and independence and encouraging a reliance on the care you provide.

Miller’s research took place back in the 1980s when the care programme approach nursing process was not common practice, and it suggested that the use of individualised care plans reduced iatrogenic dependency.

Use of the care programme approach and individualised care plans should now be common practice in all UK healthcare settings (Department of Health, 2008), therefore the prevalence of iatrogenic dependency would be expected to be much reduced.

Contemporary research is necessary in order to understand how and if these practices have changed and whether care is reaching expected standards with the advent of the care programme approach process and person-centred care (Kitwood, 1993).

Conclusion

Infantilisation is a broad topic with many aspects that individually may pose a small threat, but when it becomes an institutional infantilisation this threat grows.

The biggest worry though is that these older people, perhaps with cognitive impairments, can be left without a voice and are unable to speak up against such treatment.

Often their opinion on therapies and interventions is overlooked due to the challenging nature of engaging with such individuals, who often have difficulties communicating.

However, this is no excuse to ignore the rights, views, opinions and wishes of an entire (and growing) population.

References


The truth is, there really is no such thing as an average day in the life of a carer.

Having cared for my lovely husband Jim for six years before he passed away due to Alzheimer’s, and now visiting my mum who has dementia, I can tell you it is very unpredictable. As a carer, you always have their welfare front of mind but the nature of dementia is that you can’t tell what one day will be like to the next. You have to take each day as it comes.

Jim was diagnosed with dementia aged 79. He was living well with the condition for a while until two strokes set him back and landed him in hospital, which sadly meant he deteriorated quickly.

He went in to hospital walking, talking – and fully continent – but was passed through four different wards, sedated to keep him quiet, then put in a side room. He lost a stone, and became bedridden.

Easter was imminent and I felt he was not is a safe place – so I discharged him – and was left to get him home on my own, with no idea how I would manage to care for him and get him everything he needed. There had been no referrals made or any official help or guidance given.

A dear friend Julie arranged to take a week’s holiday to come and help me. My world was turned upside down when her daughter called to tell me her Mum had been killed in a head-on car crash. I was in a state of complete shock.

Thankfully I did manage to make the six-hour drive to her funeral with one of my sons, and my family looked looked after Jim. For the next eight weeks I was completely housebound, dedicating every hour to helping Jim, who could not stand, climb the stairs or get to the bathroom.

I really struggled. I couldn’t carry him on my own, neighbours had to come in and help. Friends and neighbours were all I had on a daily basis as my three sons all lived many miles away.

A friend whose dad had Alzheimer’s came to stay and took over my phone. She was a saviour. All of sudden social services were involved, carers organised, a stair lift installed. From then on my life revolved around getting the best care for Jim.

While I was glad to have carers coming in to help me look after Jim, they really varied in quality, ability and, dare I say it, attitude.

I fought with many agencies over the quality of care. While it made me unpopular, my only aim was always to keep Jim safe and at home. He had told me he never wanted to move into a care home, so I respected this and made sure we stayed true to his wishes.

One important thing to say is that caring for someone with dementia is physically and emotionally, very hard work.

Coupled with the fact it is a lottery as to what help and advice you might receive. It certainly doesn’t come knocking! You need stamina – and help from friends and family is essential.

A carer would come in for an hour every morning. This meant I could get out and do what was necessary. Living day to day, an hour isn’t enough for much. You can’t do a weekly shop, get your hair cut, or travel far enough to visit family and friends that are slightly further afield. One of my neighbours decided he would walk our dog. He did so every day, and would pop by in case I needed any jobs doing or wasn’t coping. I couldn’t have done it without him.

The reality of being a carer is that it is very isolating. There are thousands of people all over the UK caring for their loved ones, behind closed doors.

Things are not joined up. All of the staff and agencies there to help do their own jobs very well. But they don’t talk to each other. No one gives you the information. I heard of support by word of mouth. Someone put me in touch with Crossroads, who provided me with a carer every Wednesday afternoon for two hours.

Once a social worker had arranged funding for me to get a computer, I found the Alzheimer’s Society. During that time, I made so many calls asking for advice and checking how things should be done; from the practicalities to organising finances.

Jim passed away in 2008. It wasn’t long before dementia would be a part of my life again. When my father passed away, it became clear Mum couldn’t live on her own. She lived with my sister for a year. But with my sister not well due to terminal cancer, Mum had to go into a local care home.

For six months she was gated, told she wasn’t allowed out. Thankfully the angel of a social worker that had helped me care for Jim found a home on the seafront, with a beautiful garden. She was there for three years, before her condition worsened and we had to move her to a nursing home.

I visit my mum every day – and usually stay for about an hour and a half. I’ve kept a tally. It’s almost 890 visits now.

She doesn’t recognise me or others but she still responds to me, and particularly enjoys visits from one of my sons – who lives in Norway. It’s important to focus on the time you have together in the present. Luckily it is a lovely care home and I feel happy knowing she’s well looked after.

Dementia is a condition that touches the lives of hundreds of thousands of people over the UK. These people are in hospitals and care homes, but also in their own homes, being looked after by families as well as professional staff.

One thing to know about dementia is that it affects individuals in different ways. You can only really understand the condition from meeting people living with dementia and talking to families who have been carers.

Dementia is a challenge that will affect all our lives at some point, so it’s not something we can ignore.

I was lost after Jim died – and my son in Norway suggested I write my story – and then we turned it into a website – which led to me becoming a media campaigner.

I’ll certainly keep shouting about my experiences from the rooftops, in the hope that it might help others. MHN

More on Ann Reid’s experiences and examples of her campaigning can be seen at www.annreid.co.uk
Introduction

‘My name’s Gina and I have dementia’, announces 62-year old Gina Shaw from Liverpool in the TV ad that beamed into our living rooms this spring, encouraging people to become a Dementia Friend.

In the ad, Gina bravely bursts into a solo rendition of the Beatles classic ‘I get by with a little help from my friends’, and is swiftly joined by a host of celebrities including Chris Martin, Lilly Allen, Ruth Jones and Terry Pratchett, who are all supporting the campaign.

People with dementia get by with a little help from their friends and through Alzheimer’s Society’s joint initiative with Public Health England, anybody can become a Dementia Friend.

The idea is that it allows Dementia Friends campaign will succeed ‘with a little help’ from mental health professionals

Nikki Crowther reports on the campaign aiming to change perceptions on dementia

understand a little bit about what it’s like to live with the condition.

Dementia Friends arms the general public with this knowledge and empowers them to turn this new understanding into action.

The ultimate result that we are aiming for is communities that are truly ‘dementia friendly’ where people living with dementia can continue to do the things they enjoy and the

People do not know how to talk to people with dementia

wrong thing too often leads to avoidance.

As a result people with dementia can find themselves being stigmatised or ignored. The knock on consequence is that many people with dementia who live in the community are struggling with loneliness.

It becomes so much easier for people with dementia to lead the fulfilling lives they deserve when people in their local community

understand a little bit about what

Dementia Friends forms part of the Prime Minister’s Challenge on Dementia, and builds on commitments declared at the 2013 G8 Dementia Summit, which included a call to improve the quality of life for people living with the disease.

The Dementia Friends programme is funded by the Cabinet Office and the Department of Health.

Those working within the mental health profession will already have a good understanding of the need for people with dementia to remain part of their local community and feel included.

Unfortunately however, despite more than 40% of us knowing, or having known someone living with dementia, public understanding of the condition is still worryingly low.

This lack of understanding means that many people feel they do not know how to talk to people with symptoms of dementia.

They may want to help or have a friendly conversation with that person, but a fear of doing the

Dementia Friends in numbers

Current number of Dementia Friends: Over 370,000
Target: One million
Current number of Dementia Friends Champions: 7,031

The campaign is backed by Chris Martin of the band Coldplay

I’m a Dementia Friend
The campaign arms the public with knowledge

everyday things we all take for granted for much longer, such as going to the shops or taking a walk around town.

The action people take as a result of the sessions can be as simple as helping someone find the right bus or the right aisle in a supermarket.

Every action counts no matter how big or small and that's the whole point of Dementia Friends.

We originally launched the programme in February 2013 and currently have created over 370,000 Dementia Friends. Our aim is to reach one million Dementia Friends by 2015 and we are making great progress.

Dementia Friends is very much a social movement, which relies heavily on the commitment of volunteers.

So as well as getting people to attend the face-to-face sessions or watch the film online, we are looking for people to join our army of Dementia Friends Champions.

Champions are trained volunteers who encourage their family, friends and local communities to learn a little bit more about dementia, and inspire them to help people with dementia live well by delivering information sessions.

It is very easy to get involved and we hope that mental health professionals and people with experience of dementia sign up for the programme so that they can inspire others in society to change.

Dementia Friends Champions attend a one-day training course, receive ongoing support and are part of a growing network of people creating dementia friendly communities together.

We currently have a 7,031 strong group of Dementia Friends Champions, many of whom have professional experience of dementia.

We are always on the lookout for more volunteers and would strongly encourage mental health professionals to sign up if they are able to commit time to running information sessions and creating around 100 Dementia Friends.

We are also reaching into organisations, particularly those within health and social care where increasing awareness and understanding could have a significant impact on people living with dementia.

This is an area in which mental health professionals could have a part to play, by delivering Dementia Friends sessions within their own organisations and reaching out to their professional networks.

Join us today and help create more communities that are dementia friendly. Go to dementiafriends.org.uk to find out more about the Dementia Friends programme and how we are changing the way people think, talk and act about dementia we think/hope with the help of mental health professionals, it has even greater potential to succeed. MHN

Nikki Crowther is the Dementia Friends Programme manager at the Alzheimer's Society

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Social media and the MHNA

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Reflections on a journey through dementia

Christine Webb describes how a couple coped when one became diagnosed with dementia

According to the Alzheimer’s Society there are currently 800,000 people with dementia in the UK and this is set to rise to around a million by 2021. Worldwide the figures are even more startling. Alzheimer’s Disease International (www.alz.co.uk) reports there are as many as 44 million people living with dementia worldwide and predicts an increase to 135 million by 2050.

The greatest increase is predicted to occur in poorer and middle income countries, where increased life expectancy brings with it diseases associated with increasing age. South East Asia and Africa may see as much as a 71% increase on people living with dementia.

The challenge of meeting the needs of people with dementia and their carers is well known and no longer hidden in the corner.

Most of the key documents published over recent years by leading agencies and the Department of Health identify the same challenges and give the same pledges, such as improving awareness of dementia, the need to identify dementia early and establish an early diagnosis, and the need to improve access to effective treatments.

It is clear is that there is an enormous amount of work to be done and there needs to be a continued, focused and genuine commitment to delivering at all levels if we are to provide effective and timely support for people with dementia and their carers.

Clearly some of the work being done is producing good positive results. However, there are still too many people not being supported effectively when they do recognise that ‘something isn’t right’ and approach someone for help, as illustrated by the very personal story shown below.

David and Carol’s story

I had the privilege to meet David and Carol (not their real names) while working as modern matron at an inpatient unit for older people with mental health problems.

I met up with David sometime after Carol had sadly died. I was keen to explore their journey, to look at what had been the least and the most helpful things along the way, and he was keen to share their experience.

His story was brutally honest and very humbling. It highlights how important the challenges to improve services really is.

Their journey to diagnosis was not helpful and possibly ‘hindered’ by the fact that Carol was very young at the time her early symptoms were emerging.

David said: ‘Looking back the earliest thing I remembered were everyday things. Carol would insist she had told me something but I couldn’t recall it and I would tell her things and she would be adamant that I hadn’t. This in many ways is quite “normal” and we all do it, so I didn’t pay too much attention to it at the time.

‘The next thing I recall was in the kitchen. We used to have a glass of wine together every afternoon in the kitchen while talking over the day and preparing tea. ‘Carol looked at her watch and asked if it was a quarter to three, and I replied “No love it is a quarter to four.” Carol immediately blamed the watch and insisted she needed to buy a new one. When I looked over and checked the watch the time was accurate.’

He added: ‘Carol struggled with numbers and this became more obvious as time went on. Although this was a little worrying, apart from this Carol was her usual self – her sense of humour, her reactions to things, everything was as normal.’

David and Carol had a small business that Carol ran in the local market. She loved working there and was lively and happy, enjoyed meeting people and being part of that vibrant community.

Carol’s sister helped out at times, and picked up that Carol was having difficulty giving customers their change. She was overheard asking them if she had done so correctly.

David asked Carol outright if she was having problems and she immediately told him she was, recognising the difficulties herself. She said: ‘I don’t know what is but I just can’t see numbers, I can see the number but I don’t recognise it.’

She was frightened and worried, but agreed to go to the doctors to discuss it. They saw their usual GP, who David describes as an old-fashioned family GP.

They talked about what was happening but the GP immediately dismissed it, saying Carol was ‘just getting older’. Carol was only in her early 40s.

When challenged about his response the GP replied ‘Is she doing anything strange?’ and ‘Has she ever put ketchup in an apple pie?’ When the response was an emphatic no, they were ‘dismissed’ again with the suggestion that she was ‘just getting older and it was nothing to worry about’. However, they both knew everything wasn’t ok and they felt angered by the GP’s flippant comments, but were unsure what to do next.

About two to three months later they went back, this time seeing a different GP. David recalls that he realised Carol wasn’t driving as much as she used to. She had her own little car, which was her pride and joy, and usually she was always popping out here and there visiting, shopping and so on.

One day David had gone to help his son and he received a phone call from Carol saying she was lost. She had taken her car to follow a very familiar route to visit family and had somehow taken a different route and was totally lost.

David encouraged her to try to recall her journey in order to try to trace her route and then to describe things around her. Eventually a passer-by pulled over to see if he could help. Carol handed the phone to him and he was able to give David directions.
The second GP took time to gather some history and she asked Carol if she would do a memory test. These became quite distressing for Carol, over time she grew to dread them. David recalls that she struggled to answer, and at one point the doctor said an answer was ‘near enough’, but this response caused David great frustration.

They had both gone to the doctor with a clear history of ‘things being different’, of evidence of change and to ask for answers, but again felt that they were not being listened to. They left with no referral to specialist services and no follow up, and told to ‘come back if you are still concerned’.

Carol kept holding her head and saying something was just not right. They returned again to the GP – their third visit and to a third GP. This time when the memory tests were completed they highlighted a definite decline and Carol was referred to outpatients for a memory assessment.

This story is not unusual and although there is evidence that more GPs are aware of dementia, including in younger people, much more needs to be done to increase their knowledge and confidence in screening and encouragement to signpost people to specialist services.

Carol’s experience of receiving a diagnosis and subsequent support was equally fraught. In spite of her attending outpatients (though not a memory clinic) several times and being prescribed anti-dementia medication, David could not recall actually being told Carol had dementia.

They had received no explanation, no information, and no diagnosis. David looked up the medication on the intranet and found most of the answers he felt he should have been given in a face-to-face meeting. He says he felt isolated and bewildered.

It was not until a community mental health nurse from the Young Onset Team visited that David felt he was able to have an honest and open discussion about Carol’s diagnosis, the prognosis and her death.

David says that this helped him to mentally prepare for the future and was vital to his ability to cope and to be able to best support Carol.

In addition this new information enabled them both to make decisions about their future finances and to see a solicitor about a will and lasting power of attorney. The power to make such decisions could all too easily have been lost as Carol’s mental capacity inevitably failed.

Throughout their journey good information was so important in helping David and Carol live with dementia. David talked frequently of his need for honest information, good or bad, that would help him prepare for the future. He also recognises that this may not be the same for everyone, but for him it helped to give some control over a journey that he knew would follow an unpredictable path.

They gave up Carol’s business quite early as she could no longer manage to run this herself and David already had full time employment. Fortunately his job meant that Carol could travel with him and, with the help of colleagues who understood Carol’s dementia, he managed to keep working for some considerable time.

As her illness progressed David took the decision to take early retirement to become a full time carer. David says it was about this time that the reality of being a full-time carer ‘hit’ him. He describes feeling alone, desolate and lost – feelings that he can still recall today with as much pain as when they were first felt.

The community mental health nurse continued to visit and then fortunately they got a dementia support worker he describes as being ‘absolutely wonderful’ and of ‘making such a difference to both their lives’.

Much as David loved his wife dearly he was with her constantly and feels in many ways they were both prisoners in their own home.

The support worker would visit and spend quality ‘girl’ time with Carol, doing her hair, painting her nails, going for a walk. Carol loved these visits and seemed much more alive and animated afterwards.

David took his two hours off to go to the bank, pop independently to the shops and – best of all – pick up a paper, go to a local cafe and sit with a big cup of coffee and read. He describes the benefits as immeasurable.

With the community mental health nurse and dementia support worker he felt he had people he could contact when he needed, who would respond quickly, who understood and trusted him, and who would be honest with him.

**Partnership working**

Given today’s financial climate the NHS cannot provide all the services it would like to and working in partnership with the expertise of such providers as the Alzheimer’s Society remains the way to progress.

In *Dementia 2013: The Hidden Voice of Loneliness*, the Alzheimer’s Society has produced a second report looking at the quality of life for people with dementia with a focus on loneliness and social isolation.

A positive note is that they report an increase in dementia adviser services across England, Wales and Northern Ireland – one more move in the right direction.

I sincerely thank David and Carol for allowing me to share just a small part of their story.

What is clear is that while there is a huge agenda out there – be that political, policy implementation, a push to improving practice, groundbreaking research or development for people with dementia and their carers – we all have a part to play in making things happen, of giving that huge commitment and – forgive me for stealing an expression – for making dementia ‘everybody’s business’.

Are we there yet? No I don’t believe we are, but clearly we are moving slowly in the right direction perhaps we need to remind ourselves of what is being said, stop repeating it and put our foot on the gas. **MHN**

Christine Webb is former modern matron and also the North East, Yorkshire and the Humber member of the Unite/MHNA National Professional Committee
I was pleased to be asked to give an insider’s perspective on the domiciliary care sector for this special edition on dementia.

My professional background is in legal services and I was an early enthusiast in the field of elder law and practice.

In one form or another, I was actively involved in the provision of legal services for older and vulnerable people between 1987 and 2011.

In the mid-1980s every young lawyer wanted to do commercial work or, strange as it may seem now, residential property work. Elder care was never glamorous.

I suspect the same applies to the field of mental health and other long-term conditions such as dementia. I found solace in writing related textbooks, articles in professional journals and in lecturing.

I decided to retire (very) early in 2011, go on a long holiday, and restart in a new but related field – setting up my own domiciliary care company. Having seen six or seven of our family members struggle with physical disability and dementia it also looked like a great way to plan ahead.

It was and is dreadfully difficult to find good quality care at home for our relatives and that is something I am certain that your patients/clients will have made you keenly aware of, even if your own relatives have been spared.

From a commercial perspective it is a growth area but from a professional perspective domiciliary care is, for the most part, miles away from where it should be as a service.

Everyone appears to be over-promising and under-delivering. In fact some appear to have stopped promising and just focus on under-delivering because that’s where their strengths lie.

We bought into the Home Instead Senior Care brand in 2012 and now run a successful office in Rotherham providing all aspects of one-to-one, carefully matched, companionship, home help and personal care for a growing number of local clients.

Care management is not seen as a good career path for aspiring professionals let alone middle-aged lawyers.

Domiciliary care management – in fact all care management – lacks the kudos of medicine, the law, accountancy and even financial services. The pay rates also vary widely.

As graduates seek out new opportunities due to over-supply in traditional sectors and as a few providers seek to differentiate by professionalising their care management this is changing, but only very slowly.

One of the reasons why I decided to buy into Home Instead was its desire to professionalise care provision. Most of its offices are owned by people who have successful first careers behind them. They may be lawyers, accountants, physiotherapists, nurses, teachers, social workers, pharmacists, you name it.

They are now, often after adverse family experience of dementia or other neurological conditions, seeking to ‘do it right’ for others.

Domiciliary care is plagued by indifferent management after the manner of ‘the Peter Principle’. Many managers gradually moved up the ranks from care giving to care management and, while being very nice people, they have not had any management training as there is no coherent approach to personal or professional development in the industry and they are not adequately managed from above.

The evidence suggests that the Care Quality Commission has found indifferent management hard to detect given that an inspection report might give glowing results closely followed by the exposure of, an apparently deep rooted, scandal shortly afterwards.

The problem with all traditional regulatory systems is that they are based on outlawing bad things. If there is a law against it we can control it.

Regulators create a fear factor – the ‘they can render my career over’ factor – which can have unexpected consequences. It can drive managers into their offices and away from the shop floor. True ‘management by wandering about’ is thus eliminated. If the management was indifferent and not properly supported in the first place then the result is obvious.

It can help make, essentially good, moral, people into managers who choose to see and report precisely what they want to see and report. This means they can sometimes become liars.

And it is one reason why, in my opinion, health and social care organisations can so easily get themselves into the self-delusional pickle we see reported.

In fact care management has to be focused on obtaining as much genuine feedback from its care staff, clients and families as it possibly can.

I don’t have an easy answer to implementing an alternative means of regulation. But peer pressure and, in the private sector, good commercial common sense, which recognises that ever-higher standards enable you to sell more of your services sounds like it has something to offer.

There is no ‘College of Care Management’. There are lots of individual courses available, but that is not the same thing at all as an equivalent to, say, the College of Law or some of the medical and nursing bodies.

By having an inhouse and research-based methodology of management and centralised training standards alongside external care quality assessments Home Instead seeks to emulate this in terms of the end result.

But at some point I will be the first in line to invest in a College of Care Management.

The primary business model of the social care sector is task-based rather than focused around the actual needs and wants of clients. This suits local authorities as the main purchasers of many adult care services.

They purchase blocks of time from providers and then effectively delegate the big problem of meeting the assessed needs of clients at the lowest
many of the mental health issues that particularly affect older people.

Loneliness and depression are inextricably linked and yet we have a ‘care system’ which, by de-personalising the client, by defining them as a series of tasks to be completed, exacerbates rather than relieves these problems.

So Home Instead has chosen to reject the task-based model in favour of a companionship-based model. I have always thought that was where the future of care lay and believe it still.

But it means we have to opt out of the world of block contracts, we have to set a minimum service time of an hour, and also need to educate clients and their families about taking a realistic view of care-related charges.

But, even then, some of our clients are fully funded by council direct payments so we are clearly not just looking for wealthier clients, only the more discerning or better advised ones. It is sad that the advice is often lacking, especially due to austerity cuts.

But readers will already know how important one-to-one consistent support really is and may often despair at its absence.

So word is gradually getting around. It is not coincidental that Home Instead has been rated as the number one quality provider of care at home to the elderly in Laing and Buisson’s independent industry analysis.

Nor is it a co-incidence that we have just been highlighted as an example of best practice in dementia care in the recently published Skills For Care document commissioned by the Department of Health.

Our culture does not value carers highly enough. That, at least, is what pay rates for paid carers suggest. This low rate of pay combines with a low entry threshold in terms of qualifications to help create a systemic low pay environment – one that is self-perpetuating and often replete with people who simply found they had no option but to enter the care sector to find any work at all. This is not a criticism of them but, when combined with the other management, structural and client-related factors, it tends to undermine good service.

Accepting that care work is not a career in the traditional sense, but that it can be a very satisfying post-career role, can also present a completely different recruitment strategy. Only by recruiting people who can prove to us they have a genuine caring and compassionate nature, whatever their qualifications and background, can we avoid many of these problems and work on the issue of professionalism. Enhanced police checks also have a role to play.

Also, by working hard to retain our trained care givers, the other curse of the sector, poor retention of staff is greatly reduced. This is clearly vital when seeking to ensure one to one consistency of service. Typically care giver retention is about helping them find local clients in one area, providing hours to suit them, good training, motivation and genuine teamwork.

That is a radical alternative to the short-term thinking and bullying that often characterise the sector. But it is strange when such common sense seems to be ‘radical’.

Expectations of clients and hard-pressed families are way too low. Many people accept a terrible level of service, delivered – if at all – around the care provider’s scheduling needs. That is because they have been led to expect this is all that is available. Only when people become aware of providers offering a better standard of service will expectations change.

That is primarily down to the provider, though the Care Act will undoubtedly become more important as they help join up health, social care and other professionals in a low-cost and locally managed manner. None of this is ‘rocket science’ – but whoever said it was? MHN

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Dementia special
A football reminiscence group for people with dementia: the Forfar, Kirriemuir and South West Angus experience

Susan Ramsay and Mike Ramsay describe a project that provides reminiscence therapy for people with dementia using football-related content to act as memory triggers.

Introduction
Reminiscence and reminiscence therapy requires the engagement with historical events, experiences and activity, between an individual and another person or group of people (Woods et al, 2009).

It is established in its application for those with dementia and is often viewed as a largely enjoyable and helpful psychotherapeutic activity (Alzheimer’s Society, 2014).

There is an evident qualitative evidence-base underpinning the therapeutic benefits of reminiscence therapy (Woods et al, 2009).

Forfar, Kirriemuir, South West Angus Community Mental Health Team (Older People) is an integrated, multi-agency service provider for a mixed urban and rural, geographically sizeable, area of the Angus local authority area in eastern Scotland.

Staff within the community mental health team are employed by Angus Council and NHS Tayside, but team members are operationally aligned and co-located in the provision of services to the local population.

Football reminiscence
In August 2012, the community mental health team piloted a football reminiscence project to provide an opportunity for a group of people with dementia to socialise and interact with peers.

The aim of the project was to enable them to recall memories and share their experiences of their common interest in football, using reminiscence techniques.

The group is co-ordinated and led by a qualified social worker with assistance from support workers and volunteers.

Visiting mental health nursing students have been given the chance to attend and participate, as a focused educational component, within their placement to the community mental health team.

The group was developed in response to a report produced in February 2010 that highlighted the findings of a pilot reminiscence project involving Alzheimer’s Scotland, Culture and Sport Glasgow, the Scottish Library and Information Council and a number of football clubs from around Scotland (Schofield and Tolson, 2010).

The report evaluated the benefits and effectiveness for people with dementia being involved in a project and for their carers.

Schofield and Tolson (2010) identify the potential benefit of using football as a reminiscence vehicle for men, in particular. These authors later report that the

Memorabilia and football-related materials are used to stimulate discussions.
anticipated pleasure associated with the activity, in conjunction maintenance of continuity with participants lives, may maximise the potential benefits for those with dementia (Tolson and Schofield, 2011).

Following a successful pilot period the group, whose members have named themselves the Forfar Reds, is continuing on a fortnightly basis in partnership with Alzheimer’s Scotland.

The venue for the project is the boardroom in Station Park, which is the home of Forfar Athletic Football Club.

Meeting within a football environment is seen as important by staff as an instant trigger with the core theme as there are an array of photographs and a trophy cabinet, plus the familiar signage of dressing room, manager and the like to evoke a sense of connection with the game.

This is also valued by members as it is a non-threatening, non-clinical environment, as well as being an accessible and stimulating place to meet.

**How it works**

As mentioned previously, footballing memorabilia and other football-related materials are used to stimulate discussion and social interactions.

Quizzes, photographs and other media have been used with beneficial effect. The group is timed around a 90 minute window during which a half-time pie is provided, maintaining the ready links with the game.

The members are consulted and encouraged to take ownership of the group, which has involved planning to attend football matches.

The members have enjoyed the matchday hospitality of Dundee United Football Club on several occasions, where they have attended both Scottish Premiership matches and charity events.

The group has also welcomed Hamish McAlpine, Ian Gibson and Jim McInally (all former Dundee United players and the latter a former full Scotland internationalist) as guest speakers and are exploring group outings.

In April 2014 the group also went along to a local derby between Forfar Athletic and Arbroath FC in the Scottish Professional Football League 2.

The service users and carers are encouraged to provide feedback regarding the group and to date this has been universally positive, with carers reporting that the group provides a social outlet for the person they care for as well as enabling the carers to have a break from their caring role.

The group’s experiences have begun to be disseminated, with an active member contributing his thoughts on what the group means to him within his life and ongoing experience of dementia.

Currently it is an all-male group, but this is not deliberate, and if a female service-user was interested in attending then the team would be keen to make this happen.

Overall, running the group is a rewarding, efficient and helpful experience and evaluation and development continues.

**MHN**

**References**


I don’t really class myself as a carer, but for this special issue of Mental Health Nursing I was invited to write about supporting someone with dementia from a carer’s perspective.

I suppose a very part-time, informed and somewhat bolshie carer might best describe my position.

I am an occupational therapist, a lecturer, a wife, mother, sister, and daughter whose dad has Alzheimer’s disease.

In writing this reflective piece, I hope to explore some of the dilemmas a working professional and carer faces and provide some points of reflection for readers, in the hope that we can all improve the support we provide, in partnership with people with Alzheimer’s disease.

**Triple whammy**

There is a large amount of literature, written from a feminist perspective, about the expectation of women as carers (Eriksson et al, 2013; Gutiérrez-Rodríguez, 2014; Carmichel et al, 2008), but what is not highlighted is the triple whammy of being a woman, a healthcare professional, and a member of the ‘sandwich generation’ – the group of people who care for their ageing parents while supporting their own children.

Being one of three sisters I haven’t experienced the differentiation of caring expectations across genders, but there is no question about who the majority of the caring and crisis response falls to.

I accept that I can speak the language when dealing with medical professionals and have more insight as to what could be provided, but I don’t understand why I am the one who is expected to sleep over when Mum is too tired to offer Dad the support he needs on a night, or deal with the latest crisis such as the medication not being delivered or the stairlift not working.

**Care for the carers**

As a consequence of being ill myself and needing to protect my own health and wellbeing I have now established boundaries with my family in terms of when I am available and what I will and will not respond to.

That sounds very cold and clinical when thinking about family, but I learnt a hard lesson last winter – I am not superwoman, I have people relying on me and I am a mother and wife as well as a daughter.

It took a long time to bounce back. Now more than ever I appreciate my own good health and take care to preserve that.

As a healthcare professional and occupational therapist I will now never underestimate the importance of maintaining occupational balance and would urge professionals to reinforce this concept among carers (Majnemer, 2010), to ensure their own health and wellbeing.

**Work together**

It would be really great if we had a health and social care system that was fair, equitable and supported families to take care of their elders as well as meeting all the demands of working family life.

Sadly that is not the case. At least not in my experience, where it seems that in some areas joint working is still unheard of – community matrons claim social care is none of their concern, social workers from two neighbouring local authorities cannot liaise together, it can take 40 minutes for social services to answer the telephone, day service transport is only available at 8.30am but the carer can’t come to get Dad up before 9am.

The list goes on. My reaction is: come on, get your acts together!

**First point of contact**

Communication

Some receptionists are rude and uninformed. When they do answer the phone they do not listen, do not pass information on correctly or put you through to the wrong department.

Taking time out to make telephone calls to mobilise services in the middle of one’s busy working day is an additional source of stress, and a courteous and efficient informed receptionist can contribute to everyone’s wellbeing.

My plea to all health and social care services is to ensure that the first point of contact is competent, and listens and responds appropriately.

There are no immediate answers to inadequate funding and paucity of services, but some carefully chosen words and actions by individual workers may alleviate a significant amount of stress for all concerned.

Jo Stead provides a personal view of caring for her father, who has dementia.
We are failing our senior citizens

My greatest sadness and source of guilt is that I am not able to care for my father full time.

I watch my mother struggling and Dad not getting the input he needs.

I offer what I can, which is in reality very little – a quick visit every other day, errands, chasing services to respond to his changing needs and a longer visit/ trip out each weekend.

Instead my days are spent educating the next generation of healthcare professionals but I don’t see the system allowing those skills to be used.

The rehabilitation professionals have provided some one-off advice but no ongoing input, while the nursing and medical teams have carried out medication reviews when I have requested them but there is no ongoing input or monitoring.

It seems that the professionals don’t realise that people’s needs change, or is it that the family is assumed to be coping so we are left alone?

We need regular checking in and reassurance that everything possible is being provided to meet Dads needs.

I cannot help but think that my time would be more rewardingly spent enriching Dad’s last days by using my own therapeutic skills, but unfortunately our society using my own therapeutic skills, doesn’t value carers enough.

As in all walks of life some people are more skilled than others, but they are all trying to work in a system that is grossly under-resourced.

They have spent at least three years training to become healthcare professionals, and the country has invested huge amounts of money to provide their education, but they are unable to fulfil their professional roles and to exercise the full extent of their skills due to inadequate funding, and bureaucratic systems that meet no one’s needs, least of all those whom it is meant to be providing for.

As individual practitioners in an over-stretched system it is easy to feel powerless.

Get to know people

As a carer and professional I would ask all workers to simply do their best, and to raise concerns about unmet service needs at any appropriate opportunity, but above all get to know the people you are working with, listen to them, and value and respect them.

As a young man my father stood up for social justice, trying to ensure that young people were afforded every opportunity to fulfil their potential, so please don’t patronise him or brush his family aside with platitudes.

Be honest, see the fiercely proud independent, capable headmaster he was, afford him respect and return some of the patience and understanding that he freely gave to the young people in his care.

To sum up then, work together, train your receptionists and care workers, but above all listen and do your job with empathy and respect.

I am sure that similar sentiments have been expressed many times by carers, in many ways, but maybe something here will resonate with you, the reader – in which case it’s a job well done.

Good luck and best wishes to you all in your partnership working.

MHN

Joanne Stead is a senior lecturer (occupational therapy) at the University of Huddersfield

References


Write for MHN!

Speak up! is an informal opportunity to for you to write for Mental Health Nursing about anything relevant to you and your fellow members. It can be subjective, serious or light-hearted, and you won’t be expected to provide references.

If you have something to say, then just contact the editor to discuss style and deadlines. Email mhneditor@gmail.com
If the NHS is the best health service in the world, this government didn’t make it that way

James Lazou examines the real story behind a positive report on the NHS

JAMES LAZOU
UNITED RESEARCHER

Abstract
A recent report showed the NHS to be performing well, however this is due to staff commitment and expertise rather than the way the government is running the service.

Key words
NHS, performance, management, reorganisation

Reference
Lazou, J. (2014) If the NHS is the best health service in the world, this government didn’t make it that way. Mental Health Nursing 34(5): 36-7.

Introduction
After all the headlines over the past two years you would be forgiven for thinking that the NHS was a terrible service that failed patients left, right and centre.

That is the message the government used to justify the biggest top-down reorganisation in the history of the NHS, also known as the Health and Social Care Act 2013.

It is also the message that health secretary Jeremy Hunt would like you to believe in order to justify the cuts to staff pay, hospital closure legislation and the rapid privatisation of large swathes of our beloved health service (70% of contracts going to the private sector at the last count).

That is why it was so galling when the prime minister told the House of Commons (in prime minister’s question time on 2 July 2014) that according to a recent report the NHS under his government was the best in the world.

David Cameron is misleading us with this. The report by the Commonwealth Fund did indeed release an international study in June saying that the NHS was top out of 11 major industrialised countries, but the report looked at survey data from 2011 to 2013.

Given that the Health and Social Care Act 2012 only fully came into force in April 2013 then it is clear that the data used predates Cameron’s chaotic and unnecessary reorganisation.

In fact, the report contradicts many of Cameron and Hunt’s claims about the NHS, while reinforcing what campaigners were saying at the time.

The report concludes: ‘It is a common mistake to associate universal or near-universal coverage with long waiting times for specialised care,’ pointing out that the UK ranks highly on all measures of timeliness, with short waiting times for basic medical care and non-emergency access to services after hours.

The UK also has improved waiting times to see a specialist and now rates fourth.

The UK scored first on efficiency, where the report examined total national expenditures on health as a percent of gross domestic product (GDP), as well as at the percentage spent on health administration and insurance.

Finally, the UK scored highest on overall equity, with small
Employment

differences between lower- and higher-income adults on most measures.

Living healthy lives
The one area where the UK fell down in the Commonwealth Fund report was on people living healthy lives.

The conclusion of all this must be that you and your colleagues do a good job.

Not only have you been delivering the best outcomes on a lower budget, but you have been doing so in a society with some of the worst health problems than any other country in the list.

That was before the Coalition had a chance to implement their ‘reforms’. The question is: will the service score so highly next time?

Wasteful reorganisation
Since then, we know that year-on-year the NHS has been losing money in real terms – with funding expected to go back down to around 6% of GDP, which is lower than most comparator countries.

The wasteful reorganisation estimated to have cost £3 billion caused by the government’s Health and Social Care Act has meant that the service has gone through chaos with rising waiting times, overcrowding in accident and emergency, and failing to meet targets such as those for cancer treatment – while since last April huge swathes of the NHS have been contracted out to private providers.

Some of these private providers are quickly showing their true colours with mounting scandals, including falsifying data (Serco in Cornwall); poor-quality care (BMI Healthcare in Surrey); patient safety fears and unnecessary deaths (Clinicenta in Hertfordshire); and putting patients at risk by using under-trained staff (Virgin in Croydon).

Given the increasing involvement of these private sector providers and the government’s pride at ‘giving away control of the NHS’, it is worth wondering whether the NHS will still be top by the time of the next study.

Unite knows that despite everything the government throws at you, you are working harder than ever to protect and treat the patients and service users that you work with.

This is a heroic achievement and something that all of society should value.

The best way to do that is to pay you fairly. That is why Unite has launched a major campaign to challenge this government’s vicious pay policy, of ignoring the advice of the Pay Review Body and freezing pay rates.

The government’s NHS pay policy is an insult to the good work you all do, leading to hardship for you and your families. You deserve better, you deserve a pay rise!

To find out how you can get involved with the campaign visit: www.unitetheunion.org/nhspay.

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The original Mental Elf blog was started by André Tomlin in May 2011. After two years, other specialists began contributing and the undertaking has since developed and grown into the ‘National Elf Service’.

The website www.thementalelf.net now covers a wide range of interests from diabetes to learning disabilities, and pledges to keep readers up to date with reliable mental health research, policy and guidance.

Mental Elf is a unique website in a number of ways. First it provides lucid summaries of the most recent mental health research and guidance.

Second, the guidance is searchable in a number of ways, through diagnosis or condition, by population or type of study, which helps to make it very accessible.

The posts are structured using critical appraisal skills programme (CASP) frameworks to present the findings, which allows the reader to scrutinise the process the reviewer has followed.

You can see implications for practice as well as any limitations noted. There is a facility to link through to the original research if you want to confirm the conclusions for yourself (this also avoids the inconvenience of articles behind paywalls).

You can see a biography of the person reviewing the article who is a specialist in that area and the site includes an impressive list of contributors.

This enables the site to effectively crowdsource a relevant skilled reviewer for each post.

After the biography there is a comments section, which is useful as it enables readers to see who else is interested and active in this field, which supports communities of practice to develop.

It is an intuitive site – that is well set out with good functionality – and it offers readers straightforward opportunities for feedback.

You can access Mental Elf through the website or alternatively via an App (available for Apple and Android).

The website is free and the app costs £2.99 although it appears it may be phased out in favour of other pricing structures.

The materials are written in English and are accessible in terms of informal, direct language.

Despite the fact the focus is on research and policy, the use of jargon is thankfully and helpfully kept to a minimum.

You can follow developments and updates via Twitter, LinkedIn, RSS feed, Facebook and Google+, or by subscribing to a weekly newsletter.

My only reservation with the website, apart from the name being a fairly painful ‘pun’, is that you often have to spell out its name to people who think that you can’t say ‘health’, in order for them to be able to find it! But this is obviously a very minor criticism.

Overall this is an invaluable tool for anyone with an interest in best practice in mental health, from busy clinicians looking to stay up to date with evidence-based practice, to service users informing themselves around their options.

It is also a useful resource for students who are learning how to understand and implement research in their chosen professions.

Nicky Lambert

Books and resources

If you have been involved in the creation of a resource relevant to mental health nurses, then why not send it to your journal for review? We are interested in all materials that support the education, continuing professional development requirements or practice of mental health nursing – from academic reference books to CDs, DVDs and innovative websites. Don’t hide your achievements – communicate and share them with your colleagues. To discuss a resource review, contact the journal editor via email to: mhneditor@gmail.com
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Special discounted rate

The special discounted rate applies to members under 18, members not working who are in full time higher or further education, unemployed members of the community, members who are volunteers, members who normally work under 10 hours per week, members who are unemployed, or who have been prevented from working on medical grounds, or are on maternity/paternity leave, retired or permanently disabled members.
### Membership Form - GB

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<td>Home Tel.</td>
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<td>Mobile</td>
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</tbody>
</table>

### Direct Debit Details

<table>
<thead>
<tr>
<th>Instructions to your Bank or Building Society to pay by Direct Debit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Originators ID Number</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of bank/building society</th>
</tr>
</thead>
<tbody>
<tr>
<td>Town of the Bank</td>
</tr>
<tr>
<td>Sort Code</td>
</tr>
<tr>
<td>On the selected day of the month:</td>
</tr>
<tr>
<td>Account Number</td>
</tr>
<tr>
<td>Name(s) of Account Holder(s)</td>
</tr>
</tbody>
</table>

### About Your Job

<table>
<thead>
<tr>
<th>Employer/Company Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department</td>
</tr>
<tr>
<td>Job Title</td>
</tr>
<tr>
<td>Work Address</td>
</tr>
<tr>
<td>Postcode</td>
</tr>
<tr>
<td>NMC No.</td>
</tr>
</tbody>
</table>

### Equal Opportunities

Unite the Union is committed to the promotion of equal opportunities for all and it is the Union’s aim to provide services and support to members that is free of discrimination on the basis of race, gender, religion, sexual orientation or disability. What ethnic group do you belong to?

- White British
- Mixed White & Black Caribbean
- Asian or Asian British Pakistani
- Mixed White & Black African
- Asian or Asian British Bangladeshi
- Black or Black British African
- Black or Black British Other
- Chinese
- Mixed White & Asian

Other/please specify

Do you regard yourself as disabled? For office use only (Member No.)

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