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SIGNPOST

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Contents / Editorial...

Contents:

Signpost is edited by:
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Welcome to the latest edition of Signpost. I hope that 2015 has been a happy and productive year to date. I was very pleased to be invited to write the editorial for this edition and I hope you enjoy reading the articles as much as I did. It is always uplifting and motivating to hear about the work going on across the country and the dedicated and passionate people who underpin and drive this work forward.

I am a Clinical Specialist Dietitian in Eating Disorders and the Mental Health Clinical Dietetic Lead for Cardiff and Vale University Health Board. Within this role I support the Nutrition and Dietetic services delivered to adults and older people presenting with mental health difficulties. The Dietitian plays a key role in supporting these individuals to meet their nutritional requirements and improve their physical and mental wellbeing. The Mental Health Dietetic Team are core to the delivery of mental health services across the age spectrum and in arrange of care settings.

Within the current edition there are a number of innovative and thought provoking articles, which I will reflect and summarise.

John Killicks article explores the scope and value of writing, poetry and Dementia. He gives us an insight into his work individually and with groups. Although language appears to be increasingly challenging with the progression of Dementia, John explores how communication can be encouraged and prompted through the use of various stimuli. John acknowledges the ethical considerations within this work including ownership and permission rights, whilst also supporting the likely therapeutic benefits of this rewarding work.

Sam Fisher et al describe the development of a Peer Support Group for stroke survivors and their carers. The group was developed to support individuals in adjusting to and coping with change following their stroke. This peer group was co-designed and is co-facilitated by stroke survivors together with Clinical Psychologists and aims to provide information, emotional and practical support. The article reflects the success of the group and also demonstrates the advantages and effectiveness of co-production with service users.

The 'Engage and Create' article describes an 'Ignite' session and how this social enterprise utilises Montessori principles to support and enhance communication with people diagnosed with Dementia. The 'Ignite' sessions are described as cognitive stimulation sessions through a structured virtual art gallery tour. The sessions aim to initiate and engage a *response* rather than a focus on *memory*. To open up and maximise the space for communication through the 'Ignite' sessions appears to be a flexible approach to communication and Dementia, across different environments

Angharad Jones reflects on her facilitator role within a group she runs as part of a Memory Team Service. This is an honest account of the challenges of managing a group where the aim is to encourage a 'flexible, participant-led discussion'. The strength and power of the group environment is evident throughout this reflection. Additionally, the enrichment the clinician experiences through engagement in this space with the participants is a very warm and empathic account. There is an open and honest acknowledgement of how through sharing this space with the participants encourages the facilitators to engage in self reflection following the group. The power of how much the facilitator can learn from the 'expert, and 'truth holder' participants within a group is evident through this reflection.

Suzy England and Catherine Dennisons article on 'Sight loss and Dementia' describes the impact of the coexistence of both conditions. The article helps the reader gain a better understanding of the broader implications of sight loss and Dementia and overall impact on activities of daily living and cognitive performance. The article explored how associated factors including depression and isolation, secondary to loss of independence are associated with individuals disengaging in meaningful activities. Therefore, by maximising sensory input through improving sight can help maintain independence and overall wellbeing. The practical guidance within the article is very helpful including the '3 C's' and reference to the 'Dementia and Sight Loss Interest Group'.

I hope that you enjoy reading these articles and they support you in remaining advocates for Dementia.

Annette McLean (Dunne) BSc (Hons) MSc RD
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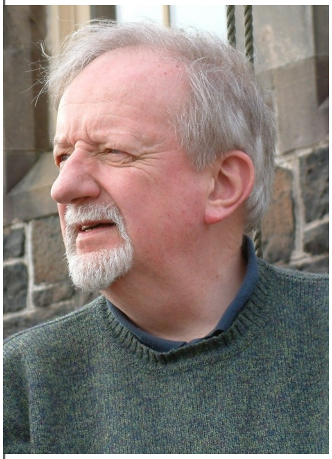
TELLING IT LIKE IT IS: POETRY AND DEMENTIA...



John Killick

John Killick has written five books on aspects of communication and creativity and dementia, and edited seven books of poems by people with the condition. He is currently poet in residence for people with dementia at the Courtyard Centre for the Arts, Hereford, and writer in residence for Alzheimer Scotland.

TELLING IT LIKE IT IS: POETRY AND DEMENTIA

Writing is a most significant expressive medium because it provides the opportunity for people with dementia to explore verbal possibilities, for them to put their thoughts and feelings out there, and to evaluate them in some measure, rather than they being locked inside them. It also enables those without the condition to get to know their preoccupations and interpretations of what is happening to them; this is essential to maintaining contact with them as persons, and learning to relate to them in positive ways.

I have been practising in this area for twenty-two years. It is different from the other creative outlets, like painting or singing, because most people with dementia are unable to pursue the art physically. This means that I have had to turn myself into a listener, transcriber and shaper of the words on the page. I started this working one-to-one, and latterly have experimented with group composition.

The process is one of relationship-building through general conversation, followed by silence from myself whilst the person speaks on whatever subject interests them. Their words are written down or tape-recorded and later transcribed. If a poem emerges, well and good; there will always be a text to hand back in any event. Permission for any sharing that may occur has to be sought.

Here is a poem by Peter Van Spyk, a man attending a day centre:

IT CAN BE DONE

This is heaven
because for a lot of people it helps them.
You do it on a one-to-one
and that’s right.
I feel I’m very lucky
because I’ve got something like poetry.

I’ve lots of memories, good and bad.
Most of my friends, they never say a thing
I think they’re frightened:
I’ve got a friend in London
and he’s only phoned once in three years.

We’ve just come back from Madeira.
My wife noticed it and told me.
I said “I’ve got Alzheimers”.
I could see the same signs.
He was there with his wife.
She had it. On the last three days
we stayed together,
we found a rapport.

Some people can't handle it.
They think, how can they carry on?
But I don't think I want these things round
my neck ---
I want to live!

I'm not wanting to get rid of myself,
I've never even thought of it.
I really mean it:
if you take your courage in both hands
it can be done!

Aside from any qualities this poem may have as a work of art, we can appreciate Peter's attitude towards his diagnosis, and the nature of his resolve to stay in charge of his life; we can encourage him on this basis. So there is often a practical outcome of this work.

On the other hand, some poems, like the following by Mary Williams, are to be valued primarily for their objective content: outward-looking and reminiscent; Mary doesn't say what she feels; this is implicit in the telling:

WATCHING GRANDMOTHER DRESS

Once I slept with my grandmother and
watched her dress.
First one petticoat, then another, then an
other, then another, then another.
And I said, how many do you wear,
grandmother?
And she said, only one more.

She'd start with her flannelette one ---
always wool next to the skin ---
then her linen ones,
and then her skirt.
And over the top she'd wear her apron.
She was a tiny little woman.
And in her hat she'd wear
a long hatpin to hold it on.

Poems of this kind allow people to celebrate their lives: an important contribution to wellbeing.

Of course dementia affects fluency of both thought and language, and there are some individuals with whom it is difficult if not impossible to communicate with on a verbal level. With those who appear to be losing language but can still contribute something, the communal poem offers real possibilities. I have found that a group of up to eight people with the condition, carefully selected to represent a range of abilities, with staff or volunteers to assist those with the more severe difficulties, can work well. There needs to be a stimulus to set people talking. This can be an object to taste or smell or touch, or a piece of music, or a poem (particularly one with a dominant shape), or a painting or photograph. In every case multiples must be provided: a single artefact is insufficient to consistently engage interest as it is passed around. In the case of a picture (my favoured stimulus) it must be large, have some sense of mystery about it, be mounted on card and laminated. Everyone studies the picture and calls out reactions to it. These are written on a flipchart. By a process of negotiation a final version with title is arrived at. Some poems assembled by this method can be long and detailed. Here is an example of a cogent and insightful one composed by a group of seven persons; the original stimulus is not needed for enjoyment of the finished product:

GABRIEL

Don't you know that's Gabriel
blowing his horn?
And that's the dark world

where we are
and up there, that's where
we aspire to be.

It takes a lot of facing, to know exactly
what it's supposed to be.
It takes a lot of focusing
to excel at what you've got.

In a one-to-one with someone who is linguistically challenged, time and patience are needed, but the reward, when it comes, can be commensurately greater. One need not disguise the confusion. With skill it can be integrated into the whole. It may be that the poem emerges from a much larger body of material. Here the skill of the facilitator is in perceiving a common thread of coherence within a mass of perseveration. It offers reassurance to the participant when something of value is rescued in this way. Here is an example of the end-product of such a process, a poem by Ann Boyd on the subject of language itself:

THE WORD COLLECTOR

It's amazing what you can get in.
I read a lot about it myself.

Well, from what I can remember.
From being a small child, as I got older,

started collecting them. Oh well
you're a good judge for it, I'm sure.

Always look out for people who've got
a little something different.

Of course, people have borrowed
from me for quite a while now

so not got everything here now.

There are, of course, issues arising from this work, such as who does a poem belong to? Though it consists of the words of the person (none of these have been added to) it has been shaped by another. It is surely best thought as a collaboration, where the facilitator has succeeded in maintaining the authenticity of the original utterance.

Another issue is that of confidentiality. It is important if work is to be shared that permission is granted. This can usually be obtained verbally and in writing, but conditions may change and a situation can arise in which doubts creep in as to whether the agreement still obtains. This applies to other art-forms as well, but somehow where words are concerned there is an added responsibility for the practitioner. I put an emphasis on sharing because work of this kind has the potential for challenging the stigma which is still rife in the area of dementia.

These, and many other characteristics of writing with individuals, are considered in depth by the Australian Trisha Kotai-Ewers in *Listen to the Talk of Us: People with Dementia Speak Out*, the only full-length study so far published on the therapeutic aspects of the work.

One significant characteristic is the contribution that natural speech can make to the future of poetry. Peter Elbow in his groundbreaking book *Vernacular Eloquence* speaks of the qualities which have been overlooked in the rush to literacy: a directness of language and feeling which is to be treasured. The poetry of people with dementia is truly 'telling it like it is' and accomplishing a quiet revolution in the process.

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References

--The poem ‘It Can Be Done’ is from *The Elephant in the Room,* Cambridgeshire Libraries. Copies of the book can be obtained free from them.

--The poem ‘Watching Grandmother Dress’ is from *Bee’s Knees and Pickled Onions,* published by The Courtyard Centre for the Arts, Hereford. Copies are available for a small charge.

--‘Gabriel’ and ‘The Word Collector’ are from a forthcoming selection from the same source.

--Trisha Kotai Ewers’s book *Listen to the Talk of Us: People with Dementia Speak Out* is published by Alzheimer’s Western Australia.

--Peter Elbow’s book *Vernacular Eloquence: What Speech Can Bring to Writing* is published by Oxford University Press.

Stroke Peer Support Group.....

Stroke Peer Support Group

Dr Sam Fisher, Dr Julie Wilcox, Prof Reg Morris, Chris Stamataskis, John Griffiths, Cliff Barber and Ken Nazareth

Stroke Rehabilitation Centre
University Hospital Llandough, Cardiff and Vale UHB

Introduction

In Wales, it is estimated that there are approximately 6000 ‘first time’ strokes per year (Welsh Government, 2012). Stroke is the single largest cause of adult disability in the UK with mobility and speech problems being the most obvious. However, it is widely acknowledged that a significant proportion of people who have a stroke will experience debilitating and long term cognitive, behavioural and emotional difficulties (Nys et al.; 2007 Ayerbe et al.; 2011; Robinson, Bolduc and Price, 1987). These problems often interact, for example difficulties with memory and information processing may have an adverse effect on behavioural and emotional functioning. Psychological difficulties are associated with longer hospitalisation, poorer functional outcome, increased mortality (e.g. House et al., 2001; Pohjasvaara et al., 2001), increased health service usage (Naylor et al 2012) and reduced ability to manage physical conditions effectively. Cognitive and psychological difficulties can also lead to a loss of independence and confidence, reduced social participation and difficulties returning to work.

Stroke survivors and their carers often report that the psychological consequences of their stroke are the most challenging to cope with, and psychological difficulties are the most frequently cited type of unmet need (Rothwell et al., 2012). Additionally, research has demonstrated that carers often develop emotional problems such as depression, anxiety and post traumatic stress and that psychological support for carers can have a positive impact on the survivor’s rehabilitation and recovery (Visser-Meily et al., 2006). Thus, efforts to support people with stroke and their families in the longer term will need to address the common and complex psychological consequences many people experience long after their physical recovery may have taken place.

The importance of psychological intervention following stroke has been recognised and incorporated into national guidelines and frameworks (Department of Health, 2007; NICE, 2009; Royal College of Physicians, 2012). However, there is an outstanding need to increase psychological resources within these services (NAO, 2010). Furthermore, community care within stroke services has consistently been found to be poorer than hospital-based care (Care Quality Commission, 2011). Indeed, in a survey of more than 2,700 stroke survivors and carers by the Stroke Association (2013), respondents said that their emotional and psychological needs often go unrecognised, with many reporting feeling ‘abandoned’ on leaving hospital.

Evidence suggests that peer support can provide emotional, informational and affirmational support for individuals affected by chronic conditions (Dennis, 2003; Piette et al. 2013). Peer support engages a person who has experiential knowledge rather than formal training (Morris and Morris, 2012). Preliminary studies of peer support in stroke services reported positive findings in terms of well-being and increased social support (Handcock, 2009; Morris and Morris, 2012). Benefits have also been reported by stroke survivors who have become peer supporters, including increased self-esteem and confidence (Morris and Morris, 2012). Peer support embraces the principles of prudent health care in using co-production to offer an effective intervention at a time where this type of support is most needed (Stroke Association, 2013).

Context

There is currently no specialist community stroke service in Cardiff and Vale (i.e. offering follow up over 6-weeks post discharge) and access to community psychological support is limited. NICE (2012) have highlighted that improving community-based treatments and access to psychological interventions within stroke services is paramount. For many people, it is only when they are discharged home that they recognise the full impact of the stroke and, with limited stroke specific community services people often feel that the support is no longer there for them. As such, the Psychology Department set out to implement a group based on the peer support model for stroke survivors and their family members in order to increase the provision of psychological and informational support in the community. The group aims to support individuals in adjusting to and coping with change following their stroke and to address issues that may arise after they have left hospital Stroke survivors who are further on in their recovery post-stroke, offer social, practical and emotional support to people who have more recently experienced a stroke.

The peer group for stroke was co-designed and is co-facilitated by stroke survivors together with Clinical Psychologists and runs weekly at the Rehabilitation Day Hospital at University Hospital Llandough (UHL). It was initially set up by a trainee clinical psychologist as part of his doctoral training programme. A number of stroke survivors received training in running groups and they have become the peer supporters. Individuals who have more recently been discharged from hospital post stroke are invited to attend the five-week group along with their relatives. The group aims to provide information, emotional and practical support, covering topics such as fatigue, coping, relationships, emotional difficulties and problems with memory and concentration. The group also discusses matters such as practical tips, benefits, exercise and socialising. The group has now run five times with over sixty five people with stroke and their family members attending.

Evaluation

There is ongoing evaluation of the groups and analysis of the first three groups has been undertaken by Chris Stamatakis (Trainee Clinical Psychologist). In this evaluation period, forty-seven stroke survivors and their relatives were randomly assigned to either a five-week peer support group intervention or a waiting-list comparison condition. Mixed multivariate (MANCOVA) and univariate (ANCOVA / ANOVA) analyses were used to compare mean scores over time on a range of self-report measures. Additionally, mediation analysis was used to explore the processes underlying peer support. All participants completed measures of psychological distress (General Health Questionnaire, GHQ-30), perceived social support (Multidimensional Scale of Perceived Social Support), quality of life (EQ-5D-3L) and activities of daily living (Barthel Index). Intervention group participants completed a group process questionnaire (TFI-19). Assessments were completed at baseline, post-intervention (five-weeks) and at follow-up (four-weeks).

Analysis of outcome data revealed that participants in the peer support group reported decreased psychological distress and increased perceived social support (see Figures 1 & 2 below) and quality of life over time. These changes were significantly greater when compared to control group scores (F(4,41)=9.27, p < .001). Further analysis revealed that perceived social support mediated the relationship between group condition and psychological distress.

Figure 1: Graph demonstrating score on the General Health Questionnaire (GHQ-30) before and after the intervention and at one-month follow up for those attending the peer support group (intervention group) compared to those waiting to attend the group (comparison group). Lower scores on the GHQ-30 denote lower psychological distress.

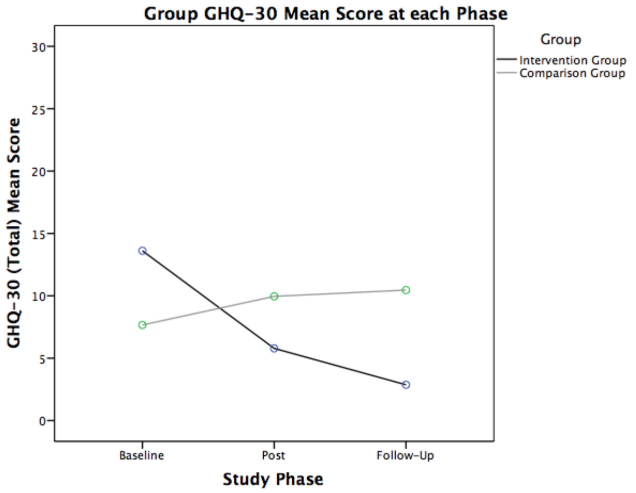
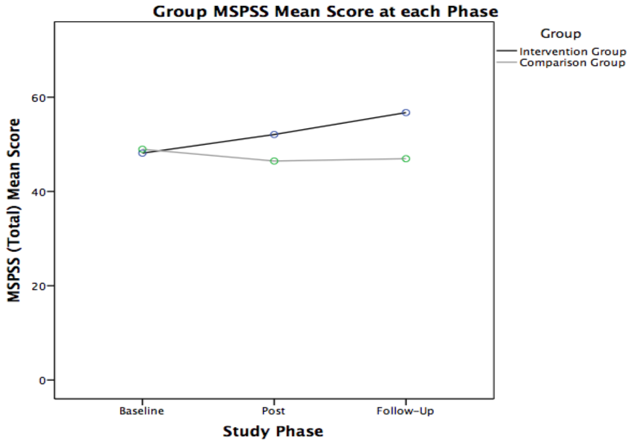
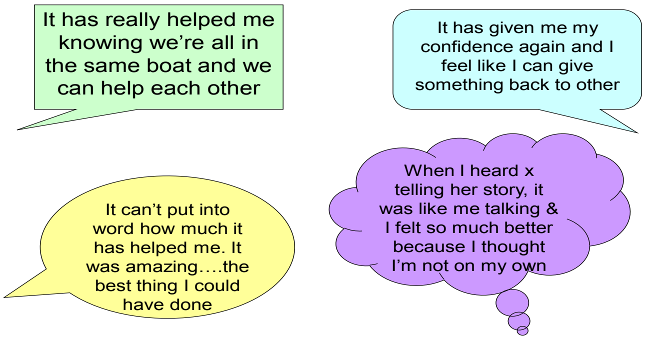


Figure 2: Graph demonstrating perceived social support scores before and after the intervention and at one-month follow up for those attending the peer support group (intervention group) compared to those waiting to attend the group (comparison group). Higher scores denote greater perceived social support



There has been an extremely positive response in terms of qualitative feedback from those who have attended the group as well as from the peer supporters. Group members reported feeling encouraged and supported by the group and the many commonalities, for example, fatigue or emotional difficulties. Importantly group members reported an increase in well-being and hopefulness. Figure 3 illustrates quote from some group members.

Figure 3: Examples of subjective feedback from participants attending the peer group.



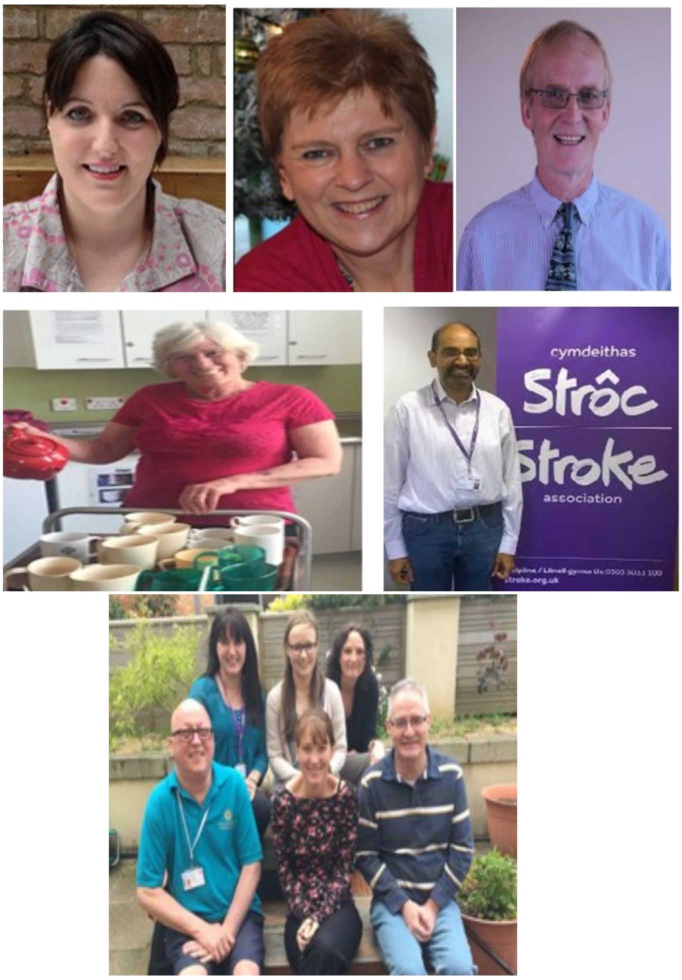
Conclusion

Peer support can facilitate improvements in psychosocial wellbeing for stroke survivors and their relatives and social support was found to be an important mechanism underlying peer support. Thus, the peer support group provides an effective and cost effective way of offering longer-term support to stroke survivors and their families in the community. We believe that co-production has been pivotal to the success of the group as peer supporters, relative to professions, are able to offer a different type of knowledge and empathy with regards to living with stroke.

The peer group initiative clearly adds value to the more traditional 'medical model' as it can potentially continue outside of NHS premises and eventually with minimal or no health care support. It demonstrates the significant resource and strength of many individuals who have experienced stroke and offers them an opportunity to use their skills and strengths to support others who are earlier on in their recovery journey. Moreover, it offers an opportunity for peer supporters to engage in a meaningful role which in turn enhances their own emotional well-being and confidence, as well improving the psychological well-being of group members.

Thanks to the staff at the Rehabilitation Day Hospital at University Hospital Llandough for their help and support in running these groups.

Members of Peer Support Group



Top Photo's *(left to right): Dr Sam Fisher , Dr Julie Wilcox, Prof Reg Morris*

Middle Photo's *(left to right) Barbara Hellet, Ken Nazareth*

Bottom Photo*: Back row (left to right): Dr Sam Fisher (Clinical Psychologist); Grace Kelly (Trainee Clinical Psychologist); Lindsay Manning (Life After Stroke Co-ordinator, Stroke Association) Front row (left to right): Cliff Barber (Peer supporter), Amy Perrot (Assistant Psychology Volunteer) and John Griffiths (Peer supporter)*

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Ignite...

Rachel Mortimer

Rachel is a social entrepreneur and professional artist. Her background is an eclectic mix of media organisation (ITV, Saatchi's), teaching and caring. Having gained a Montessori Diploma with distinction she is currently completing a BSc Psychology.

Rachel has been an expert witness for The National Institute of Clinical Excellence (NICE), an advisor to The National Police Missing Persons Unit, a speaker at many events and conferences including National Care Forum, NHS Wales OMNI Conference, Creative Dementia Arts Network, Hampshire and Brighton & Hove Councils. Engage & Create currently delivers part of the dementia education programme at Brighton & Sussex University Hospitals.

In 2013 Rachel was awarded a Fellowship from The School of Social Entrepreneurs sponsored by Royal Sun Alliance. In 2014 she won the SE Assist programme (Legal & General), Juice FM's chosen social enterprise 2014/15 and is a founding member of the Brighton & Hove Social Enterprise Network.

Engage & Create

Engage & Create was founded following my first visit to a dementia care home. I had been asked to teach painting to residents but, for many, it was a much-needed opportunity to interact. Some residents, like Margaret, occasionally struggled to find the words to express themselves, but this did not mean they had nothing to share. Seeing how our conversations appeared to have some positive impact on the residents' wellbeing, I kept returning. The more images and paintings I brought in with me, the more people wanted to contribute their thoughts and, in turn, share stories (including staff!). It was then that the concept of Ignite sessions was born.

An Alzheimer's Society survey of 12 care homes in the UK suggested that the residents received approximately two minutes of meaningful conversation every 6 hours (excluding care-giving activities). (Brookes 2008, in Alzheimer's Society, Home from Home report, 2007)

I believe that our wellbeing is heavily correlated with our opportunity to share our stories and for our stories to be validated and respected by others. If we do not have this opportunity, then we are more likely to encounter social isolation, boredom, loneliness and/or depression. The Ignite Programme was developed to provide people at all stages of dementia with a space to communicate, interact and share their stories.

As a social enterprise, our purpose is to improve quality of life for people living with dementia and those caring for them; we believe the two are equally important. Our vision is a world of dementia care where meaningful conversations forms part of everyday life, where people are supported, encouraged and up-skilled (where necessary) to communicate and inspire conversation in support of those living with dementia.

At Engage & Create we want to focus on what people living with all stages of dementia can continue to do, supporting the theme of ‘living-well’. We show care workers how they can enable people with dementia to take part in a meaningful conversation regardless of their individual challenges. When discussing paintings and images, all that is required is a reaction – positive or negative! This journey of joint discovery is called an Ignite session.

As a trained Montessori teacher, the sessions were designed according to Montessori principles, which are aligned with person-centred care. Doctor Maria Montessori was the first female physician in Italy in the early 1900’s. She started her work with a group of ‘unreachable’ children with a broad range of mental health problems, in an asylum in Rome. By observing their behaviour she developed learning tools such as practical and sensorial apparatus, which were presented in a prepared environment. The Montessori Method appeared to have a significant effect on the children, to such an extent that they passed state educational tests, which attracted much international attention (Lillard, 2005). Nowadays there are Montessori schools all over the world producing some of the most innovative minds of modern times.

I frequently have relatives and carers describe those they care for as ‘unreachable’. By using Montessori principles such as guided repetition, task breakdown, enabling environments and progressing from simple to complex, we hope to establish an interactive and personal relationship with people living with dementia.

An Ignite session is a structured virtual art gallery tour delivered using an iPad or tablet. These cognitive stimulation sessions engage people using artworks from gallery and museum collections to spark discussion. Irrespective of the stage of a person’s dementia, the session is an experience where *response* is the focus, not *remembering*, creating an opportunity for people to communicate and to be heard. An Ignite session is a safe space where people are not judged. Anything goes, and sometimes it pretty much does! With this safety comes confidence and, often, communication. For some it may be sitting on the edge of their seat, eyes wide, listening intently. Margaret, a resident whom I mentioned earlier, began with just a few words and the occasional nod. But, as the sessions progressed, so did her confidence. At the end of the sixth session we looked at a colourful painting of figures dancing. When asked what she thought of it Margaret sat up, looked me straight in the eyes and said,

“The mood and the colour of that piece move right through me”

The format of the sessions is simple and structured. Neither facilitator nor resident need have any knowledge of art. Sessions are themed, e.g. Family or Daily Life, with artworks shown in a digital format on the backlit iPad or tablet – a perfect tool to zoom in and explore the art. The accompanying materials include dementia friendly questions to provoke discussion, along with historical information to give context and 'chat points' which provide an opportunity to reminisce. The design makes it possible for the sessions to be delivered to small groups or individuals. More often than not, staff and relatives join in the discussions. There is a wonderful sense of excitement as their loved one starts to express their views, and it can have added benefits too, as June explains;

"It was absolutely amazing to hear Ray so engaged. Also from watching the way you worked with him, I've learnt so much more about how best to talk with him. This has really changed our lives" June, Hove

The Ignite Programme is now available as a licence to individuals in health or social care organisations in order to offer a package of high quality experiential training, session materials and ongoing support. The training also includes The Pop-up Dementia Experience. Trainees experience sensory deprivation, both visually and through touch, whilst listening to audio of confusing sounds. They are asked to complete what look like simple every day tasks. We can never know what it is like to live with a dementia but being faced with some basic restrictions can help some people empathise with certain elements of living with a dementia. Combined with the Communicating Artfully technique – connect, communicate, confirm - used to facilitate the sessions, participants can become skilled communicators with people at all stages of dementia. New sessions are provided each month with new digital images of artworks and accompanying materials, so the licence holder is fully equipped to begin. Supporting facilitators is important to us, and we do so via online groups and Google Hangouts, so they can get the most out of the programme for their residents or patients.

"In a few weeks we've seen Keith go from sitting silently in a chair barely communicating, to fully participating in sessions. We realize now it's been so long since we heard his opinion" Care worker, Maycroft Manor, Brighton

The versatility of Ignite sessions makes it possible to deliver them in a gallery, as a focus activity in a care home and even one-to-one at the bedside in hospitals.

Using the session themes as a starting point for meaningful activity, we provide inspiring ideas for follow-on creative workshops, such as craft activities and sensory sessions.

We believe that meaningful conversation is important for every person and can make a huge difference to wellbeing. We hope that by providing inspiring training combined with quality materials we can spread these wonderful sessions so that people in health and social care settings everywhere become skilled communicators.

Working in dementia care has opened up a whole new way of being for me. Everyone's life is a series of moments; *this* moment is all we really have. People with dementia teach us to slow down, truly listen and to appreciate the moment we are in.

Rachel Mortimer
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Angharad Jones

Angharad is currently working as an Assistant Psychologist at The Memory Team, Cardiff and Vale UHB.

She completed her undergraduate and postgraduate Psychology degrees from Durham University and is hoping to begin her clinical training in the near future.

Outside of work, she has a passion for fantasy books and films (especially Lord of The Rings and Harry Potter), playing the piano and baking.

‘*The whole is greater than the sum of its parts’: capturing the ethos of a psycho-educational memory group from the perspective of a group facilitator.*

Setting the scene

Thursday afternoon. A memory strategies group. As people bustle in to the supermarket behind me, I wait in the entrance to meet the people attending the group. When we are all assembled, we head up the stairs to the quiet meeting room, where the group is held. Some people are eager to climb the stairs and tackle the topics we are discussing this week. Others find the climb more difficult, either due to physical reasons or due to their anxiety about what they will face when they reach the top. Tea and coffee and biscuits are handed around whilst people take their seats, and there is small talk about what people have been up to over the last week. As the weeks go on, the group’s dynamics develop and most people begin to feel more familiar and comfortable with each other. They notice who has not arrived and often ask after that person. Their empty seats represent the challenge of attending the group. Some people find practically getting to the group a challenge as they don’t drive. For some, the challenge is coming to a room full of strangers, or discussing problems they would rather not think about.

Background

The group was developed a number of years ago by the small clinical psychology service within the Cardiff Memory Team in response to frequent requests for information about managing memory problems. An alternative group existed for those people with a diagnosis of dementia, but not for people with other, milder memory difficulties, such as those with mild cognitive impairment (MCI). The term ‘MCI’ implies a difficulty with day-to-day memory but a difficulty that is not significant or severe enough to that individual at present to be diagnosed as a type of dementia. However, a ‘difficulty’ with memory can mean something very different to different people, and so there is wide range and variety of people who attend the groups. A difficulty with memory can develop for all sorts of reasons. It can signal the beginning of an illness such as dementia, but can also be due to vascular conditions or external factors, such as stress, depression, anxiety or pain, or as a side-effect of some medications. Some people with memory difficulties will remain stable, or improve, whilst some will go on to develop a form of dementia (Kurz and Ridha, 2012).

Group format

"*I feel I'm improving and have the means (booklet) to improve further. The relaxation tape was very successful" – group member.*

The group sessions have a psycho-educational format and the content of the group was developed using literature about memory strategies, including works by Narinder Kapur, Linda Clare and Barbara Wilson. Everybody that attends the group is given a booklet which covers the different topics we address each week. One week, we discuss different memory aids, for example calendars, clock that display the date and time, bath alarms and so on, that could help day-to-day life. Another week, we focus on strategies that could help the members remember people's names.

We practice relaxation techniques almost every session. One of the things that I commonly hear as a facilitator is how much frustration and anxiety can result from living with a memory difficulty. This can lead to a vicious circle – the memory difficulty causes frustration and anxiety which, in turn, exacerbate the memory problem. Group members often report that the more frustrated they become, the harder it is for them to think clearly. Relaxation typically forms a core part of cognitive rehabilitation work, so it is a core element of our group sessions as well.

Group members often find the memory strategies booklet useful, as it is a cohesive reminder of what we discussed each week. Some group members will make notes during the session or record their thoughts and reflections in the booklet. Others may find this too challenging. Group members take this booklet home with them and, if they want, they can share the contents of the booklet with their families so that they can help enforce a new strategy or discuss ideas mentioned in the booklet.

The 'connected consciousness' of the group.

The booklet contains the bare bones of what we discuss; what gives the sessions their richness is the flexible, participant-led discussion that occurs around the discussed topics. During the sessions, there is an 'emergence of connected consciousness.' As Macy and Johnstone (2012) describe,

Something very interesting occurs when a group of jazz musicians improvises together. A number of separate individuals, all making their own decisions, act together as a whole. As the music flows, any of the musicians can take the solo spot, that leading role gliding seamlessly between players..... There are two levels of thinking happening at the same time here; choices made from moment to moment by the group as a whole and by the individuals within it....The players act *freely while being guided by their intention to serve the purpose of the group.*

The participant-led discussion is what keeps the sessions fresh for me. The booklet is reviewed and sometimes modified after a session but, essentially, the material we cover is very similar for every group. It is the people who attend that keep the group vibrant, as the topics of discussion can vary so widely.

Although the group is facilitator-led, it is the group members that are the ‘experts’ and ‘truth holders’ of living with memory difficulties and the group is often unified by their shared experiences. The sessions are based on the principle of ‘distributed intelligence’, where “no one part has to have the whole answer. Rather, the intelligence of the whole emerges through the action and interactions of the parts” (Macy and Johnstone, 2012). I always attempt to be aware of the discussions and group dynamics occurring around me, and my place within these.

Through their conversation, group members address many themes – they discuss the feelings of frustration and annoyance that often accompany their memory difficulties. They sometimes talk of feeling lonely even when surrounded by their families and friends. Uncertainty about the future is also a recurring issue that is raised during the group sessions.

My challenges as facilitator

Encouraging the development of a dialogue, as opposed to a monologue, during the sessions is crucial. Through dialogue, different perspectives and ideas can emerge. Penn writes that “with the discovery of one or more new voices, we become positioned differently to retell the old story, to find a lost one, or to create the beginning of a new one” (Penn, 2001, p. 47). Some people will attend the group with hopelessness, and their monologue will be negative and problem-saturated. This monologue, although initially often well tolerated by other members, can eventually result in a conversation which is negative, stuck or hurtful.

During one session, a member said that they would “*go to Switzerland*” if they were ever diagnosed with dementia whilst another member of the group had just received a diagnosis of dementia. I instantly felt the need to protect this member of the group by changing the subject quickly. However, I feel that creating a space where the members feel safe to voice concerns and worries that they may not feel able to share with family and friends is extremely important as a facilitator. At the beginning of each session we openly discuss the principles of the group. These include allowing everyone to have their say, and respecting other people’s opinions. Another of our principles is that the group is confidential. To shut down this person’s concerns so abruptly would not have supported the sense of the group as a safe communicative space.

Instead, we discussed what the phrase “*go to Switzerland*” offered that person. Through discussion, the person decided that it gave them the feeling of being in control of at least one aspect of their lives. Dementia, along with many other things, is out of our control and many people struggle to live with uncertainty. For this person, the idea that they could choose to "*go to Switzerland*" gave them the feeling that they were still in charge of their future. During our discussion, group members also said they felt they regained some control by coming to the group. Attending the sessions and attempting some of our suggested strategies offered the group a sense of taking charge of their memory difficulties.

As a facilitator, I believe it is important, yet challenging, to find a balance between acknowledging somebody's worries whilst working to move the conversation into a more productive and supporting dialogue. Griffith and Griffith suggest that a supporting dialogue offers "a respectful reflection on multiple perspectives that stand side by side within the same conversation. Out of this speaking, listening, reflecting, a criss-crossing of perspectives arises within which new ideas are born" (Griffith and Griffith, 1994, p.8).

Balancing the voices of the group is another thing I find challenging as a facilitator. This is especially true when thinking of the quieter group members. It is difficult to know when somebody wishes to say something or when they wish to simply listen to the other voices around them. I am aware of not embarrassing the quieter members by giving encouragement or asking questions when they are not wanted.

An awareness of my own wellbeing

I am aware that during the sessions I become 'Angharad' to the members. Although some of the members may have met me previously in clinic, they come to see me differently. Although I am still there in my professional capacity, the setting is informal and warm and, when the group comes to an end, many members ask whether they can continue coming to the next group and seeing me each week.

I personally find it difficult to then see a member of a group in clinic, perform the cognitive assessments, and sit with them whilst the Doctors gently break the news that their condition has deteriorated and they now have a form of dementia. I irrationally feel that in some way I have let that person down. Accepting that dementia, and many other things, is out of our control can be difficult for the professional, as well as the patient.

Concluding thoughts.

"*I have enjoyed coming to the course. People were very friendly, and chatting together was helpful in many ways. It was nice meeting people who have similar memory problems as my own" – group member.*

During the sessions, there are many voices to be heard, and many group processes to be aware of. Often when I return home after a group session, I am still processing what occurred during the day's session and I often find myself wondering how the members are getting on during the week interval.

The group runs for seven weeks and each session is an hour and a half. During the sessions, we discuss different strategies that could help make day-to-day life easier for people living with memory difficulties.

But, for many members, the group is much more. It is a place where they meet people experiencing very similar problems to themselves. They can share their experiences and frustrations, and difficult questions and themes can be discussed and teased apart openly. Sometimes all we can do is acknowledge a problem and sit with it. Other times, we can celebrate the positive impact that one of our suggestions has made on somebody's life. Due to the nature of the group, some of the positive changes can only be temporary, but these should still be enjoyed in that moment, and celebrated. I see the group as an act of 'doing hope'. Hope is emotional, it is spiritual, and it is also a 'doing' – in it together – interpersonal act (McGoldrick et al., 2007).

I feel extremely grateful and privileged to be able to share the group space with its members.

Angharad Jones
Assistant Psychologist
The Memory Team, Cardiff and Vale UHB

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Suzy England

Suzy is Occupational Therapy and Sight Loss Consultant with Thomas Pocklington Trust. Thomas Pocklington Trust is working to bring about positive change to the lives of people with sight loss. Suzy's role is to promote increased awareness and detection of, and referral and support for, sight loss amongst occupational therapists. She leads a programme of activity which includes development and roll out of CPD learning materials and tools for practice.

Catherine Dennison

Catherine is Head of Health and Wellbeing Research at Thomas Pocklington Trust. She manages a programme of research to increase knowledge of sight loss and identify practical ways to improve people's lives. A key focus is increasing awareness and understanding of
co-occurring dementia and sight loss.

Dementia and Sight Loss Interest Group

The Dementia and Sight Loss Interest Group was set up in 2008 as part of Vision 2020 UK, to develop and promote a better understanding of the issues facing people affected by sight loss and dementia and how best to support them through involvement in research, developing resources, having a presence at events and writing for publications.
To find out more about this group see www.vision2020uk.org.uk/interest-groups/dementia-and-sight-loss-interest-group/

Sight loss and dementia

Introduction

The risk of having reduced sight greatly increases with age, with 1-in-5 people aged 75 and 1-in-2 aged 90 and over, living with sight loss (Access Economics 2009). In the UK two million people are living with sight loss. Many people with sight loss have other health conditions, among these can be dementia. Estimates suggest over 120,000 people are living with both conditions (RNIB 2012). Co-morbidity will be especially high among those living in care homes where over 80% of residents have dementia or significant memory problems (Alzheimer's Society 2013) and rates of sight loss are high.

Both dementia and sight loss are under diagnosed. With an ageing population, an increasing number of people will experience both conditions. This article will look at the impact of sight loss and steps that can be taken in response.

A common scenario

Mary is 83 and living with dementia in her own home. Mary was diagnosed with Alzheimer's 18 months ago following her daughter noticing she was becoming increasingly forgetful. Since her diagnosis Mary has attended an early memory loss group which has helped her develop strategies for managing her memory loss such as diaries and checklists. She has also become a regular attendee of a local dementia cafe where she has made friends. Over the past few weeks Mary has spent large amounts of time at home not engaging in her usual activities. She was an avid fan of knitting and enjoyed watching DVDs of her favourite TV series. She always enjoyed cooking and up until recently had been going into town on the bus once a week.

Activity reduction is a common scenario for health and social care professionals to come across. How would you interpret Mary's change? Would you consider that perhaps deterioration in her vision is making activities more difficult and impacting on her quality of life? If so, how would you respond?

Hidden sight loss

Sight loss often goes undetected and can be overlooked, especially where there are other health conditions that mask the symptoms. For example, when a person has difficulty recognising their neighbour when they meet them in the street this could be interpreted as a symptom of their dementia, however it is common for people with age related macular degeneration to have difficulty recognising faces, due to central vision loss. Another person may report seeing visual hallucinations such as children or animals. Hallucinations can occur with some types of dementia, however it is also common for people with sight loss to experience hallucinations and distortion in vision known as Charles Bonnet syndrome.

The forms of sight loss

Sight loss can occur as a result of eye conditions that affect different parts of the eye, damage to the optic nerve that carries visual information to the brain or damage to parts of the brain where visual information is processed e.g. due to stroke, head injury and some types of dementia. Common eye conditions that affect older people include cataracts, glaucoma, macular degeneration and retinal complications from diabetes as well as refractive error (commonly known as long or short sightedness) which can cause vision to be blurred. These conditions can all result in changes such as blurring, partial loss of visual field and, in some cases, blindness.

For more information on sight loss conditions refer to RNIB's guides to individual conditions: www.rnib.org.uk/eye-health/eye-conditions
It is common for people with dementia to experience visual perceptual difficulties. The nature of their difficulties will depend on the form of dementia they have. Difficulties may include: decreased sensitivity to differences in contrast (including colour contrast, such as black and white, and contrast between objects and background); reduced ability to detect movement; reduced ability to detect different colours (e.g. problems telling the difference between blue and purple); problems directing or changing gaze and problems with depth perception (Alzheimer's Society 2012).

Older people with sight loss may have a combination of different conditions that affect their sight. For some people sight loss can be gradual and they may not notice the changes. For others it can be much quicker.

Impact of dementia and sight loss

The effects of having both sight loss and dementia concurrently are much more severe than those resulting from either dementia or sight loss alone (Trigg and Jones 2007). The ability of someone with dementia to cope with sight loss is reduced when compared to someone with an otherwise similar health profile, but without dementia. This can significantly impact on activities of daily living and cognitive performance (McKeefry and Bartlett 2010). Many of the strategies for maximising independence in activities of daily living for people living with sight loss often depend on developing cognitive strategies to overcome visual challenges, such as learning how to use eccentric viewing. Likewise activities which incorporate more sensory input are often recommended for people living with dementia. Where activities become more difficult to carry out due to dementia or sight loss the person may stop activities, which may result in depression, isolation and an increased risk of falls due to inactivity.

Why is improving sight important?

Maximising sensory input when living with long term conditions such as dementia is important for maintaining independence and wellbeing. Imagine how blurry, patchy or double vision may impact on a person living with dementia. One professional shared her story about her mum who had Alzheimer's and cataracts. Prior to cataract surgery her mum rarely initiated conversation and was disinterested in activities, both attributed to her Alzheimer’s. However, after cataract surgery, she began talking about the birds in her garden, restarted her previous activities and showed interest in going out again.

What can be done about sight loss?

It is common for older people and professionals to think deteriorating sight is part of normal ageing. However, 50% of sight loss is avoidable, for example through wearing the correct glasses or cataract surgery (RNIB 2012). These are some top tips:

1) Look out for the signs of sight loss

How valid are your assessments if you’re not asking questions about sight? How often are assessments conducted that have visual compenents e.g. MMSE. When information is shared with a person, e.g. an appointment letter or information leaflet, is it presumed the person will be able to see it?

Don’t be afraid to ask questions about sight, consider including these four essential questions:

Do you have difficulty reading small print?
Do you have difficulty recognising faces?
Do you miss or overfill cups when pouring liquid?
Do you have difficulty judging steps/stairs/kerbs or tripping/falling?

Source: Visibility

2) Consider the 3 Cs of spectacles

It is important to check the condition and use of a person’s spectacles and the 3C’s mnemonic is a useful reminder:

Clean - are their spectacles clean?
Current - is their prescription up to date?
Correct - are they wearing the correct spectacles for the task they are undertaking?

Where there are concerns regarding spectacles e.g. adjusting to a new lens prescription, recommend that the person visits their optician or optometrist for further advice.

3) Encourage eye examinations

The NHS recommends most people have their eyes examined at least every two years, or more frequently if recommended by an optometrist. An eye examination can pick up the first signs of an eye condition before changes in vision are noticed. This can enable access to vital treatment at the right time, which could prevent sight loss. NHS sight tests are free to those over 60 and to those with other entitlements, such as people with diabetes or a family history of glaucoma (in Scotland they are free for everyone). Those over 70 are entitled to free eye tests every year.

Anyone who cannot access a ‘high street’ optometrist unaccompanied, because of a physical or mental disability, can arrange a domiciliary eye examination. Information on local providers can be found from local optometrists, or local clinical commissioning groups (CCGs). Eye examinations can be adapted to suit the needs of a person living with dementia e.g. longer appointments. The optometrist should be informed of a person's other health conditions and needs prior to the appointment.

4) Keep records of a person’s sight loss

Include notes about a person's sight, and recommendations for their support, in documents such as care plans, whether paper or electronic. Sharing information about the person’s sight with colleagues, other professional services and families, can help them respond to sight loss too.

5) Link up with vision rehabilitation services

Vision rehabilitation officers (ROVIs) may be based within the local authority, often as part of sensory impairment teams, or in partner voluntary organisations. They are specialists in providing support to people with sight loss and vision problems with orientation, mobility, activities of daily living or communication skills.

6) Provide information on falls

Sight loss and dementia are risk factors associated with falls. Talk to the person about falls prevention and provide information on minimising the risks. People respond better to such information when it is set in terms of supporting their independence rather than protecting them from injury.

RNIB and Alzheimer's Society have practical factsheets: www.rnib.org.uk/information-everyday-living-home-and-leisure-safety-home/reduce-your-risk-fallswww.alzheimers.org.uk/site/scripts/documents_info.php?documentID=145

Consider a referral to a falls prevention team or occupational therapist who can offer a home safety assessment and modifications to the home to help reduce the risk of falls.

7) Make modifications to the environment

Simple adaption's to the home can make a big difference, such as improving lighting, helping to reduce clutter, and considering colour and contrast to make everyday objects stand out from their background. For further information take a look at Pocklington's guide ‘Good practice in the design of homes and living spaces for people with dementia and sight loss’ www.pocklington-trust.org.uk - Good practice guide

It may be useful to seek support from a vision rehabilitation officer or local sight loss society.

Suzy England and Catherine Dennison.
Contact: research@pocklington-trust.org.uk

About me...

Rik Cheston graduated from St Andrew's University in 1984 and completed a PhD in Social Psychology at Stirling University before training as a Clinical Psychologist. Other than for four years working at Bath University, he worked in the NHS from 1990 until 2012 when he took up his present post.

Who are you and what do you do?

I am Richard Cheston and I work at the University of the West of England in Bristol as a Professor of Dementia research. I also work as a Clinical psychologist, for one morning each week, at the RICE memory clinic in Bath.

What do you most enjoy about your role?

There are a number of challenges about working in a University again, not least the fact that I probably work longer hours now than when I worked as a Clinical Psychologist in the NHS. However, the nature of the work is different, and I don't miss the pressure of working day-in and day-out with people in great emotional distress. In that sense things are less pressured now than before, and I tend to feel more valued now than I often did in the NHS.

I particularly enjoy the opportunity to take forward a different way of thinking about the emotional impact of dementia: we are interested in exploring the way in which the threat of dementia impacts on people, and whether the principles of Terror Management Theory can help us to understand more about the way in which people affected by dementia cope with the illness.

What has your role taught you about working with people with dementia?

In recent years I have been increasingly interested in thinking about dementia as an existential threat – something that has been explored within Terror Management Theory or TMT. The two essential principles of TMT are that people cope with threat better if they are able to establish meaning in the world and to have higher levels of self-esteem. One route to creating both meaning and higher self-esteem is to invest in social relationships, but there are many others, including drawing on a nostalgic past.

These principles have been rigorously tested and refined within social psychology, and seem to have significant potential to help us to understand all manner of threats, from our own, personal, sense of mortality, to much broader threats towards the systems and cultures that enable us to derive meaning and purpose. We currently have two studies that are directly exploring the implications of TMT for people affected by dementia: an Alzheimer's Society funded study looking at something called mnemic neglect (essentially the tendency to have a better recall for information that is not threatening);

while Sanda Ismail is doing a PhD with me looking at the impact of nostalgia. However, I think there are many other ways of thinking about how the existential threat of dementia may make an impact. For instance, TMT suggests that when faced with an existential threat, we tend to invest more heavily in those values which reflect our “cultural world views”. It seems to me that this is something that so many people that I have known who are affected by dementia do: they often talk about a world that they have known in which they were valued and respected, in which their contributions were recognised and in which they felt loved, trusted and connected to the world around them.

My clinical work fits into this in the sense that the goal of psychotherapy is to help people to make sense of the world that they experience whilst also enhancing rather than diminishing their self-esteem. I have been involved in a number of research studies that look at the impact of psychotherapy groups on the levels of depression and quality of life of people affected by dementia, but I have also tried to look at the process by which people create meaning from their diagnosis. One of the things that has come out of this work is the way in which, for some, there is a balance to be struck between thinking about the diagnosis (which risks being emotionally overwhelmed) and turning away from it (which also carries risks). Sometimes even mentioning the word “dementia” is too threatening to be tolerated, and so people come up with euphemisms, or just talk about “it”. I’ve called this the “*Voldemort*” phenomena, after the way in which in the Harry Potter books, the villain is often too frightening to be openly discussed.

What has changed in the time that you have been working?

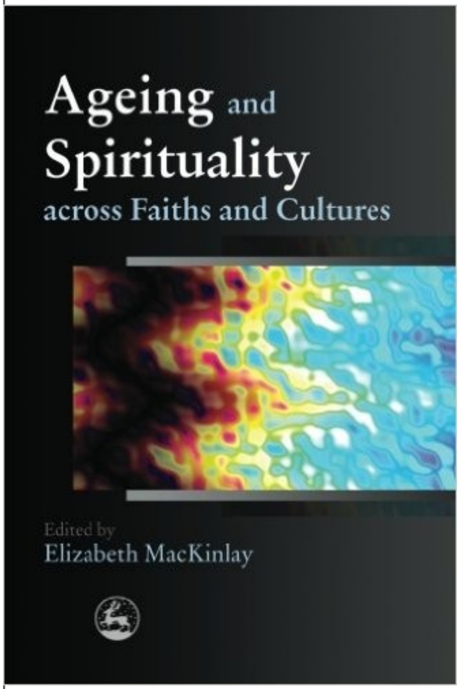
As a clinician, I became interested in how I could help people to adjust to the emotional impact of dementia. One way of doing this seemed to be by running groups in which people affected by dementia could explore the significance of the diagnosis within a secure, therapeutic setting. When I first started to work this way, in the mid 1990s, the notion of doing psychotherapy with people affected by dementia was rather odd – but it is great to see that it has become much more accepted now, even if provision of therapeutic opportunities is still a long way from being ideal.

Where would you like to go from here?

Well, just as we are all mortal, so we have a finite career as a researcher or as a clinician. I hope that in the next ten years or so that I can continue to explore some of these issues, and to test out whether TMT does indeed help us to understand the experiences of people affected by dementia, and to develop or adjust our clinical interventions to take account of any new insights. More generally, I hope to be able to continue to support people using psychotherapeutic ways of working with people affected by dementia in the NHS and beyond.

Ageing and spirituality across faiths and cultures

Edited by: Elizabeth MacKinlay
Publisher: Jessica Kingsley Publishers, April 2010 (272 pages)
ISBN: 978 1 84905 006 7
Price: £22.99



Spirituality is an evolving concept. There are two main interpretations of spirituality; however, both approaches acknowledge the search for meaning. For some individuals, divine presence is central while for others, spirituality is a secular concept involving inner life, personal belief and the focus on self.

Current health and social care practitioners are increasingly called upon to provide person centred care to older people from a range of religious and secular backgrounds. Within the spiritual component of person centred care, practitioners are encouraged to spend time, give attention and listen to facilitate individuals to find meaning and support. It is therefore important in delivering holistic care to older people that practitioners understand the wider context in which they are living, ageing and dying and how their faith and belief systems may influence their attitudes to the care being provided.

This book began its formation in the process of the 4th National Conference on Ageing and Spirituality hosted by the Centre for Ageing and Pastoral Studies in Australia in 2008. It is a collection of 17 essays which examines ageing in the context of the growing number of religions and cultures that make up Western society. Each essay is written by either academics or practitioners about the beliefs and practices of their older people. The essays cover major religions such as Christianity as well as needs of groups such as aboriginal ageing. Each essay includes issues and provides suggestions for appropriate care while the final one offers recommendations for the development of future policy and practice. I particularly like Chapter 7 because of its focus on indigenous ageing pertaining to culture and spirituality. It has potential implications for disadvantaged groups such as older asylum seekers or older people who are homeless in the United Kingdom. It has a refreshingly style of writing because the medium of poetry has been used to examine issues pertaining to ageing and spirituality.

Although heavily Australian focussed, the book is relevant to practitioners working with multicultural and multi religious communities in the United Kingdom. This inspiring book which has a good balance of theory and practice will provide front line practitioners with the knowledge they need to deliver sensitive and appropriate care to older people of all belief systems.

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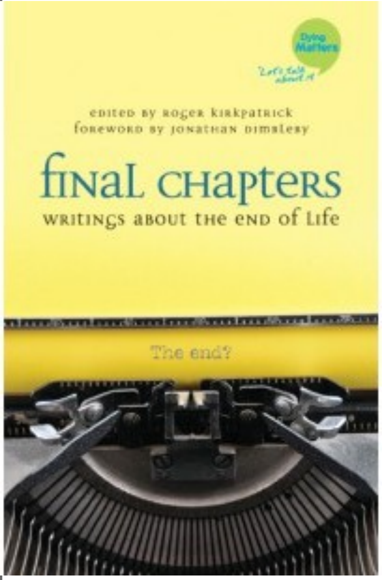
Final Chapters: Writing about the end of life.

Edited by: Roger Kirkpatrick
Publisher: Jessica Kingsley Publishers, February 2014 (128 pages)
ISBN: 978 1 84905 490 4
Price: £8.99 Paperback, £8.94 Kindle



Final Chapters is the result of a creative writing competition run by the Dying Matters Coalition in 2012. When the completion was launched the Coalition suspected that more people would find it less upsetting to write about dying than talk about it. Their suspicion was most likely correct as they report that nearly 1,400 stories and poems were entered into the completion. Final Chapters presents a collection of 30 short stories and poems about death, dying and bereavement from this competition.

The stories and poems presented are moving and thoughtful, on occasions disconcerting and at times amusing. The book demonstrates the range of human thoughts and emotion experienced when encountering death, bereavement and loss, but which are seldom talked about. Written by fathers, mothers, sons, people who are dying and professionals the published pieces portray how it feels to be facing death, grieve for a loved one or provide care for someone who is dying.

The collection includes a moving poem about losing a son to cot death, a poem about the intensity of grief and stories of intricate family relationships. As a clinician I had a particular interest in those poems and stories written by fellow heath care providers, those which focus upon the care relationship and those about dementia. The Night Shift that Changed Me tells of how a doctor's care and compassion is further enhanced by her own experience of grief. The Mother Thief is a frank story about a daughter's relationship with her mother's carer. This story offers a forthright insight into the feelings and thoughts that can be evoked when carers are involved. The issues and feelings raised in this piece are ones which are seldom discussed or acknowledged. The Enhancing Dementia Recipe struck a particular resonance, written by a nurse it creative, eloquent and at times wryly amusing. It demonstrates how dementia care should not be provided, yet sadly on many occasions still is. Personally I would like to see this story being read by all people who provide care and treatment to an individual who has dementia, as it presents a very powerful message.

At the end of the book there is short biography of each author. Authors come from a variety of backgrounds ranging from creative writers and poets to a range of professionals. A number of these biographies also offer the reader an insight into the inspiration or experience behind their story, prose or poem, which for me added further strength and emotional depth to these particular writings.

This book offers readers the opportunity to read about death, dying and loss from a number of outlooks. These are subjects which even today are still to a large degree taboo in society. It should also act as a catalyst to encourage conversation about these areas. This book would make a welcome addition to any care giving setting. It should be read by all professionals who wish work with people with life limiting conditions and those who wish to gain further insight into death, dying, loss and bereavement.

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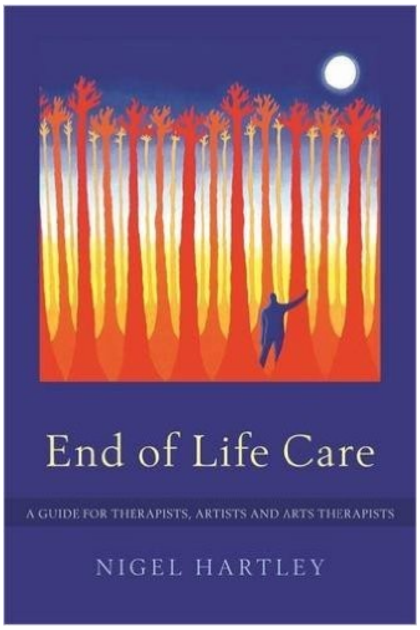
End of Life Care: A Guide for Therapists, Artists and Arts Therapists

Edited by: Nigel Hartley
Publisher: Jessica Kingsley Publishers, February 2014 (128 pages)
ISBN: 978 184905 133 0
Price: £22.50 Paperback, £21.38 Kindle



In an increasingly ageing population the role of end of life care in hospice and private settings will be an ever increasing necessity. In order to provide this service a wide variety of staff is required, and in this book Hartley makes a compelling argument that arts therapists should certainly be a part of that staff group. The author, a former music therapist himself and Director of Supportive Care at St. Christopher's Hospice, gives the reader a very detailed and insightful report of his experiences as an arts therapist.

Hartley gives a very personal and honest account of his thoughts and feelings he experienced when working together with patients coming to the end of their life. While talking about how rewarding an experience it can be, he does not shy away from talking about practical and emotional difficulties an arts therapist might encounter.

For example Hartley advocates that therapy sessions in an end of life care setting should be complete in themselves as the patient might be too poorly to engage in another session or might pass away in the course of the therapy which can be difficult both emotionally and practically. He also gives an example of mourning for a patient who had died that he had developed a strong bond with and highlights the importance to have a supervisor who can discuss and help the therapist through emotionally difficult sides of end of life care therapy. Many more case studies considering the therapists' and patient's point of view make the book very accessible and therapy settings more palpable.

Practical advice includes providing a sample funding application to potential funding bodies and a sample project form. He also gives advice on how to integrate into a hospice care team as an arts therapist and describes different contexts in which work as an arts therapist might take place such as the patient's bedside or a patient's private home and the practicalities of it (what instruments are best to choose, best modes of transport). Additionally, other therapists provided short professional autobiographies describing how they came to be therapists in different settings which also includes a personal experience of one therapist in a 'How to get started' chapter about the application and interview process at St. Christopher's. All of the information given is highly relevant and without a doubt most useful particularly for, but by no means limited to, aspiring or current arts therapists.

Overall Hartley seems to have covered every thinkable aspect in connection to end of life care, only a fraction of which could be covered in this short review. With its clear language and vast amount of shared experiences combined with useful references throughout, this book is a most useful guide particularly for arts therapists in end of life care, but would provide an interesting, informative and insightful read for any professional working in a care setting.

Alex Stach
Placement Student
Cardiff University

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Jigsaw puzzles

There are jigsaw puzzles available that have been designed for people living with memory difficulties.

Each puzzle consists of thirteen pieces that can be assembled within the frame and on a specially printed backing board that is designed to assist and encourage the users.

The puzzles are made from plastic making them extremely durable and easy to clean. The size and shape of each piece, the colours used, and the unique backing board system have all been designed and tested to help users of all abilities complete the puzzles unassisted. Images have been carefully chosen to allow for visual impairment, to stimulate memories and conversation and to give the user a valuable sense of achievement and pride.

The example are available from the Alzheimer's Society and cost £14.99.

Music Player

Music can have a profound effect on us all, and can really help to lift our mood – or even get us moving!
The Simple Music Player is specifically designed for easy use by those with dementia, without any assistance, and is a valuable tool for improving quality of life, especially if living at home.

Simple Music Player overcomes the difficulties of operation by strong design features:

- Lifting the lid automatically starts the music
- Closing the lid stops the music
- Pressing the only visible button skips to the next track
- Styled to look like a vintage radio
- Volume is fixed by friends, family or care partners
- Playlist is setup by friends, family or care partners and is uploaded on to the radio via a USB cable.

This radio is available from the Alzheimer's Society and costs between £97 - £149. It is available in red, green and walnut.

News and Web...

Dementia Services Development Centre – Stirling

The International Dementia Conference is being held at The Vox, Birmingham on 3-4 November 2015 and is for everyone involved in supporting people with dementia, both in the UK and internationally. The programme will showcase the latest research alongside best practical guidance on helping improve the lives of people with dementia. The themes of the conference focus on care, and will address critical issues across the range of professions and organisations that support people with dementia and their carers.

Study by University of Cambridge claims that the number of people living with dementia is levelling off in parts of Western Europe.

The study shows that the proportion of older people living with dementia in the UK has fallen. This is in direct contradiction to the predictions that the number of cases would soar.

The report analysed twinned dementia studies that were conducted in the same way, but decades apart. Data from five studies from the Netherlands, Spain, Sweden and the UK was analysed. It showed that the proportion of people in the Netherlands and Sweden, and women in Spain, living with the condition had stabilised over the periods covered by the studies (ranging from 20 – 30 years). The proportion of people living with dementia in the UK, and men living with dementia in Spain, had fallen.

Data from previous research had suggested that 8% of the population would be living with dementia in 2011. This new research believes the figure was 6%.

An ageing population was thought to have led to more people living with dementia. However, the scientists involved with the study believe that improvements in the health of the general population and education surrounding the risk factors for dementia may be potential reasons behind the study’s findings.

Lead researcher Prof Carol Brayne said the expected rise "had not occurred". She told the BBC News website: "Effectively it has stabilised rather than gone up. The age-specific prevalence has gone down so even though the population has got older, the number [of patients with dementia] has stayed the same."

However, charities have warned that there is no way of knowing whether this improvement will continue. The Alzheimer’s society’s chief executive, Jeremy Hughes, said: "With no cure, few effective treatments and an economic impact exceeding that of cancer or heart disease, dementia remains the most critical health and social care challenge facing the UK."

Prof Brayne concluded that "Dementia is still common in the older age group. It still doubles every five years after 65.What we're hoping from this research is that it will provide more evidence for focusing research beyond drug discovery."

Teacups & Memories

Fragile? Art & Craft Workshops for people living with dementia.

Amgueddfa Cymru – National Museum Wales

The Exhibition: *Fragile?*

Fragile? is an exhibition of contemporary ceramics at National Museum Cardiff, showing the beauty and variety of contemporary ceramics practice. The exhibition explores the artistic and expressive possibilities of clay as a material, including the contradiction between two of its innate qualities – durability and fragility. The exhibition includes items from the National Museum's collection, shown alongside exciting new ceramic installations made especially for this exhibition.

COLWINSTON Charitable Trust

Fragile? is generously funded by The Colwinston Charitable Trust and supported by The Derek Williams Trust.

Dementia-friendly workshops – Free! But limited availability so please book in advance

On October 1st we will be running a day of free workshops for people living with dementia and their carers, with activities inspired by the *Fragile?* exhibition. The workshops will be relaxed and friendly. No previous experience is required for any of the activities. Tea and biscuits will be provided and chatting is encouraged! Some sessions may be photographed, so that we have a record of our activities, but you can always 'opt out' of being photographed.

Workshop schedule

Explore the exhibition, 11am-1pm. Maximum 10 people – please book in advance

In the morning, we will take a look at some objects in Fragile?, which is an exciting exhibition of contemporary ceramics at the Museum. You will not be given a full tour of the whole exhibition as it is quite large! There will be tea, cake, and music with different ceramic items available for you to touch, hold and chat about. A family member, friend or helper is very welcome to attend with you.

Lunch, 1 – 2pm. Maximum 20 people – please book in advance

We would love for you to join us for lunch if you have taken part in either or both of our sessions today. Family members, friends and helpers are also invited.

Teapots and Clay pots, 2pm-4pm. Maximum 10 people – please book in advance

In this hands-on session, you can have a go at modelling with clay, and to smell and try different kinds of tea. A family member, friend or helper is very welcome to attend with you.

For more information, please contact:
Jennifer.Dudley@museumwales.org.uk or
Sian.Lile-Pastore@museumwales.org.uk

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Information about Signpost

Anyone Can Contribute to Signpost

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

Contributions

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

Contact Details

Practice Development Unit, MHSOP, Llandough Hospital, Penarth, CF64 2XX.
Tel: 02920 715787
Email: Amanda.Furnish@wales.nhs.uk

Books Available for Review:

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

- How We Think About Dementia—Personhood, Rights, Ethics, the Arts and What They Mean for Care. Julian C. Hughes, 2014.
- Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement. Sue Read, 2014.
- Excellence in Dementia Care - Research into Practice (2nd Ed). Murna Downs and Barbara Bowers, 2014.
- The Forgiveness Project - Stories for a vengeful age. Marina Cantacuzino, 2015.
- Mindfulness-Based Interventions for Older Adults. Evidence for Practice. Carla Martins, 2014
- Person Centred Thinking with Older People - 6 Essential Practices. Helen Anderson, Helen Bowen and Gill Bailey, 2015.
- Grandma's Box of Memories. Jean Demetris, 2014