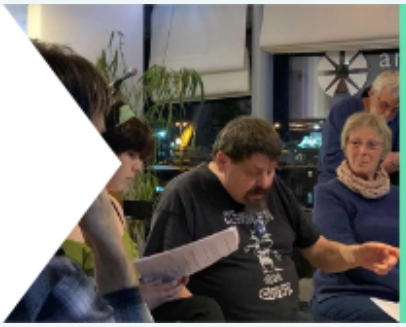
DEEPNESS DEMENTIA

Media

Living Well With Dementia



Sign up to our Monthly Newsletter

Hello and welcome my name is Anne Scott the Deepness Dementia Newsletter Editor. Welcome to this Spring edition in 2024.

We continue to make changes to the newsletter, trying out new formats and ways to produce it.

Since November we have been producing a video of the newsletter being read out, so you can watch along it being read out. We have decided for at least this newsletter not to include this video. If you have found it useful and are already missing it, please let me know.

Please do get in touch and let me know your thoughts. If lots of people benefit from it, we will bring it back. Your feedback is gratefully received.

As always you can contact me at - **scottanne@live.co.uk**

Thanks

Anne Scott

Check out below a list of what is coming up in this newsletter.

If you are viewing this in a PDF format you can click on the links and skip straight to that article. Otherwise, keep scrolling down.

Wendy Mitchell 1956 - 2024

Sadly, on 22nd February 2024, Wendy passed away peacefully.

Wendy was diagnosed with Alzheimer's disease on 31st July 2014 at the age of 58.

She continued to work as an administrator for the National Health Service, where she would train nurses on how to roster staff, until March 2015, when she retired, sad to leave, but to live "happily alone."

Soon after her diagnosis, Wendy began writing a blog, called - ***Which me am I today?,*** which continued to diarise her experiences of what she calls her "new life" with dementia, and the process of adapting she's undertaken with her two daughters.

You can read the blog here - **https://whichmeamitoday.wordpress.com/**

The blog also provided a valuable resource when it came time for Wendy to write her 3 books alongside author and journalist Anna Wharton:

- Somebody I Used To Know
- What I Wish People Knew About Dementia
- One Last Thing

Shocked by the lack of awareness about the disease, both in the community and in hospitals, she vowed to spend her time raising awareness about Dementia and encouraging others to see that there is life after a diagnosis.

Wendy was an inspiration to many including myself. I first met Wendy 6 years ago, when I was in a dark place, a year after my own diagnosis. But Wendy was an inspiration to me, inspiring and supporting me ever since to go on and do the things I have done.

Wendy's final blog

Dear everyone who has followed my story and anyone else who cares to read this…

If you're reading this, it means this has probably been posted by my daughters as I've sadly died. Sorry to break the news to you this way, but if I hadn't, my inbox would eventually have been full of emails asking if I'm OK, which would have been hard for my daughters to answer… In the end, I died simply by deciding not to eat or drink anymore. The last cuppa tea…my final hug in a mug, the hardest thing to let go of, much harder than the food I never craved…This wasn't decided on a whim of self pity as you'll discover by reading on.

Dementia is a cruel disease that plays tricks on your very existence. I've always been a glass-half-full person, trying to turn the negatives of life around and creating positives, because that's how I cope. Well, I suppose dementia was the ultimate challenge. Yes, dementia is a bummer, but oh what a life I've had playing games with this adversary of mine to try and stay one step ahead.

I've been resilient throughout my life, even from a young child, so resilience is inbuilt in me to cope with whatever life throws my way. Who would have thought, when diagnosed all those years ago, that my life would turn out quite as it did? I've always liked to have a plan, something that makes me feel in control of dementia. I 'planned' for the future by completing my LPA's and ReSPect form, and sorted my advanced care plan in minute detail with my wonderful GP.

Sadly assisted dying isn't an option in this country. With something that will affect 100% of the population, regardless of wealth, intelligence, or ethnicity, it's amazing how such little value is placed on the act of dying. For those who have read my book, One Last Thing, you will understand why I feel so strongly about assisted dying. The only legal choice we shouldn't have in life is when to be born; for everything else, we, as humans, should have a choice; a choice of how we live and a choice of how we die.

Facts and figures show how, in those countries where assisted dying is legal, people live longer. Having that 'magic potion' within touching distance enables them to choose life for much longer. In countries where it's illegal, such as the UK, people have to die sooner than they might otherwise choose. Like me, they have to have the capacity to make such a decision if death isn't to be a lonely and often violent act.

My first book was kept on some people's bookshelves for a year, or even two, because they were afraid to open it and read what's inside. But when they did they found nothing of the fear they were expecting and instead found dementia unravelled. I want the same to happen with my last book, ***One Last Thing – How to Live with the end in mind***. Some people will be afraid to open it, yet, when they do, they'll question their own reluctance to talk about the one thing that will affect us all.

To feel I had some control over the future makes the business of living so much easier. To talk about death makes it easier to concentrate on living.

To have an option within your grasp enables you to relax and live life. In America, for example, some people are eligible for assisted dying. But when they receive the magic potion that would take them from this life, having it enables them to feel in control, and many choose life instead of death for much longer.

So, what has all this to do with my death? If assisted dying was available in this country, I would have chosen it in a heartbeat, but it isn't. I didn't want dementia to take me into the later stages; that stage where I'm reliant on others for my daily needs; others deciding for me when I shower or maybe insisting I had a bath, which I hate; or when and what I eat and drink. Or what they believe to be 'entertainment'. Yes, I may be happy but that's irrelevant. The Wendy that was didn't want to be the Wendy dementia will dictate for me. I wouldn't want my daughters to see the Wendy I'd become either.

Through writing my last book, I spoke to many amazing people, both in favour of assisted dying, and against it, but also those in palliative care. Many of those specialists believe we should concentrate on providing gold-standard palliative care. But in my humble opinion, it shouldn't be a case of one OR the other. The choice should be ours to make. Yes, of course, gold standard palliative care should be available for all, but so should the choice of assisted dying. Even the most wonderful palliative care imaginable could not stem the incoming tide of dementia. It was up to me to do that.

The incredible inventors within our great NHS have enabled advancements in treatments not even imaginable some twenty or thirty years ago, but, they will never discover a treatment to prevent the inevitability of death. While all these advancements have been taking place, successive governments have ignored the growing ageing population; have allowed, through lack of investment, our greatest gift, the NHS, to crumble before our eyes. To die later surely means to need more medical intervention. Everyone but our governments have seen this happening.

Dying has been ignored, swept under the proverbial carpet. The choice of assisted dying could be the answer to so many people who actually don't want to exist when medicine can keep them alive. Those who succumb to illness may not want to have their life prolonged, simply because it's possible. Or maybe some people would just like to call time on their life because, in their mind, they've had a good life and now is the time to end before the tide of good fortune turns.

In the end, I wanted to choose the one option I said in my first book I would never choose – Dignitas, in Switzerland. After looking at every option and eventuality, this was the only place that would give me a dignified death. I've no fear of flying on my own now, as I would never ask my daughters or anyone else to fly with me, because of the complexities of the law when they flew back. But it also means my daughters can't be there with me, holding my hands in my final moments.

I was hoping to go there at the beginning of the year. However, my plans were turned upside down when I had my fall, breaking both my wrists and revealing damage to my neck and spine. I would no longer be confident to travel alone to Switzerland.

I've said for a long time that I don't want to be an inpatient in a hospital or a resident in a Care Home. It's the wrong place for me; the loss of routine, familiar surroundings, and people. For some, they may believe it's the right place, or they have no option. I'm NOT saying it's wrong for everyone, I'm saying it's wrong for me. You may say, 'But my mum's in the late stages and she's very happy in her care home'. I'm really pleased she is, truly, I am. It's just not the place I want to end my years.

Many people focus on moments of happiness. Someone I interviewed was very adamant someone in the late stages of dementia was happy because he played the piano and made other residents happy… but my argument was, what about the other 23 hours of his day? Are they spent in confusion, of wondering why he's there? Does he like being totally reliant on others? Would his former self have chosen this ending to his life? These questions can never be answered, of course, but I've taken the decision to answer them for me now, while I'm able.

I've always given people hope, or I like to think so. Have I stopped giving people hope by choosing the death I've chosen. Or have I given people hope, that IF they wish, they too can have hope for an existence of their choosing, or a death of their choice?

My life was for living, but now it's time for dying. So, if you want to do something for me, please campaign for assisted dying to be law here.

Adapting to this life with dementia is over, but I don't consider dementia has won, as that would be negative and you all know I'm a positive person. It's ME calling time on MY dementia – checkmate before IT plays its final move. As the video below shows, that was created for my first book… I was determined I wouldn't forget, and by doing this now, I haven't. Yes, I've had to die before my time, but I had to make sure I had capacity and hadn't allowed dementia to creep in overnight and take that capacity away from me.

In the end, after my accident, the only choice open to me was to stop eating and drinking.

I learnt about Voluntary Stopping Eating and Drinking (VSED) as my way out of this world during the writing of my book. I spoke at length with my daughters and I spoke at length with my GP over the last few months, always including her in conversations with my daughters, to give that 'expert' information to questions I could never have answered.

I don't feel hunger or thirst, meaning that part of the process would be less stressful for me than for others.

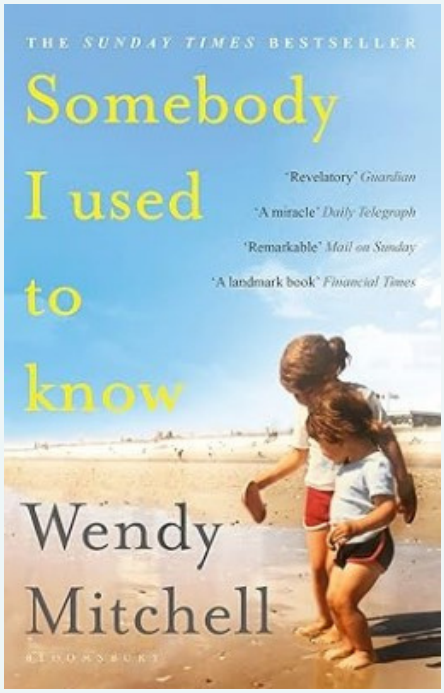
After my fall downstairs at home, my lovely friend Philly came to stay with me to help support my daughters and me. It was during this time, and after many conversations with my girls and Philly, that I decided this was my time to end this cruel life dementia had thrust upon me. I wasn't depressed, I wasn't forced or cajoled in any way whatsoever, it was solely down to my choice. I was ready.

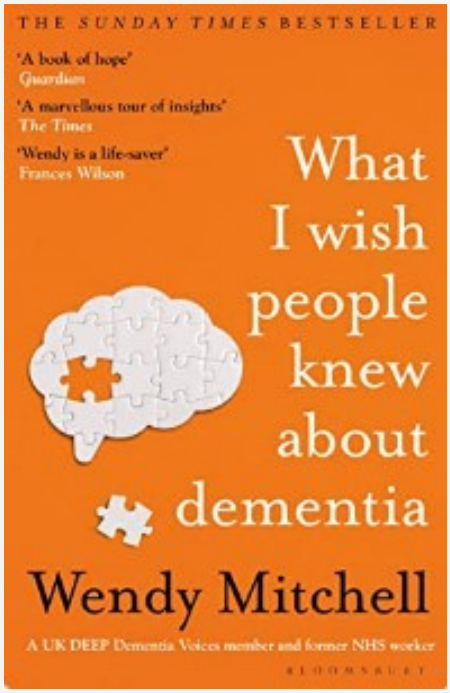
You may or may not agree with what I've done, how and when I've chosen to leave this world, but the decision was totally mine.

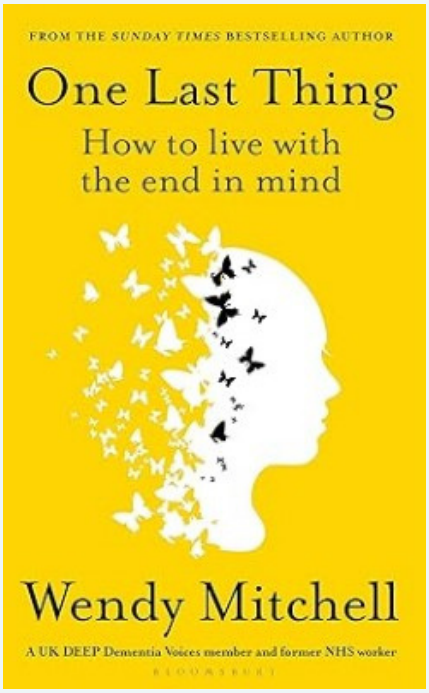
My girls have always been the two most important people in my life. I didn't take this decision lightly, without countless conversations. They were the hardest conversations I've ever had to put them through. Some people may be angry at what I've done and that's their prerogative – but don't take that anger out on anyone other than me. This was all MY CHOICE, my decision. So please respect my daughters' privacy, as they didn't choose the life I chose, of standing up to and speaking out against dementia.

Thank you to all those who have supported me along the way…your support was invaluable.

So, enjoy this video knowing that dementia didn't play the winning card – I did.







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Care Homes…by Howard Gordon

Care Homes often get bad press when things go wrong and rightly so BUT it is also important to highlight good practice.

I often write about what is wrong in the world of Dementia/Disabilities, but I also like to write about the good as well.

Sheffcare, a not-for-profit organisation in Sheffield UK, and over the last few years have made great strides in improving the lives of people living with Dementia, family members, and the knowledge and understanding of the staff at their homes.

Sheffcare was formed as a Registered Charity in 1994 when a number of residential care homes were transferred out of the ownership of Sheffield City Council into Sheffcare.

The purpose of setting up the charity was to safeguard vital services for older people in Sheffield and to offer great care at affordable prices. In 2024 Sheffcare will celebrate 30 years and the commitment to great care at a reasonable cost remains unchanged.

Their focus is always on meeting the needs and wishes of our residents and the people who use our services, doing everything that we can to enhance and add to people's lives.

They currently run nine residential homes and two-day services in Sheffield, all offering care for older people and people living with dementia. Their residential homes can offer either a permanent home, short-term respite care, or short-term 'step down' care for people leaving the hospital.

As a Registered Charity Sheffcare exists solely to provide a public benefit – no individuals or companies make a profit from our organisation. We work hard to try and make a surplus every year which we invest back into the charity.

Kathryn Rawling is their Dementia and Wellbeing Manager who does a lot of work engaging with people living with Dementia and their families in their Care Homes and the wider community, along with local and national Professionals, Academics, and Organisations.

Progression in 2023

In 2023 we took an active step towards expanding on our commitment to progressive dementia care and resident wellbeing.

Via ongoing positive networking, we can ensure that Sheffcare are well place to consider best practices and sector improvements in dementia care. Networking has provided us many opportunities which has enabled our Homes to take a proactive approach to our residents' well-being.

2023 Highlights

RE-ESTABLISHING RESIDENT'S FORUMS TO PROMOTE INDEPENDENCE AND WELLBEING.

IMPROVING STAFF DEMENTIA TRAINING VIA INDUCTION SESSIONS AND DEMENTIA AWARENESS TRAINING.

INTRODUCING RELATIVE DEMENTIA AWARENESS SESSIONS.

BUILDING ON STRONG COMMUNITY LINKS AND NETWORKING ACROSS THE CITY.

TAKING PART IN GROUNDBREAKING TRIALS TO HELP SHAPE THE FUTURE OF DEMENTIA RESEARCH.

Community Links Developing strong links with local communities and People Keeping Well (PKW) Representatives can help reduce the anxiety and stigma around the prospect of long-term care.

By bringing our communities into our homes, seeing the positive work we do, and keeping open channels of communication we can work towards a more positive approach to long-term care.

Health Watch

Firmer links have been forged with Health Watch, an impartial health and social care champion who works to ensure that people in care have a voice.

In 2023 we took part in Speak Up which allowed our residents and families to share their experiences about the pandemic and the emotional and physical impact of the lockdowns.

This work was featured in a recent Health Watch webinar.

#Reminiscence/Rehabilitation & Interactive Therapy Activities an opportunity given to Grange Crescent gifted by NHS requiring feedback from Sheffcare. **https://myimprovementnetwork.com/my-name-is-rita**

The Happiness Programme

A projector-designed device that has a great deal of potential. We are making sure we use it to the full and exploring use in the room and using it for End of life and people in bed and their room. It also if not in use by the activity workers can be left working which gives additional interaction for residents and care teams to explore. It also gives us an evidence-based tool for use in the sensory and reflex levels of PAL. **https://social-ability.co.uk**

Adopt a Care Home

In 2023 Housteads, Knowle Hill, and Burnt Tree Croft benefited from the wonderful piece of co-working that links care homes with local schools; funding has been secured on our behalf via Ignite Imagination via locality small grants. This has been an ongoing piece of work from 2018 and gives us evidence of the benefits of intergenerational work and will continue into 2024.

A film clip featuring the Dementia and Wellbeing manager and other Sheffcare staff. **https://youtu.be/XK7ZC1yzgH4**

The Music Project

Features Midhurst Road and Valley Wood with devices being patented by Alzheimer's Society and will hopefully be on sale – with the possibility that some may be gifted. Documentary film footage is available featuring Valley Wood activity worker and the Dementia and well-being manager and Sheffcare residents

The Acousmatic Storytelling and Listening post

A network working relationship that started during COVID-19 and is now in its 3rd developmental stage. This is now a piece of research via the University of Sheffield which has been a huge success. Audio clips that have been shared with relatives have been very well received.

This work was featured in the UK Dementia Congress and other interesting professional events the aim is for it to report the outcomes of the research in the Congress 2024.

What If

This networking opportunity is a soft touch resource to help us explore the importance of finding out people's choices that can be used to consider end-of-life preferences. What If is aimed at families living with dementia and will be trailed by Valley Wood. This is out in 10 settings in Sheffield and has come to Sheffcare due to networking with Chelle Wilde – GP and Neighbourhoods network lead.

Green Care

This proposed project which is still on the table. Dementia Adventure is seeking a sponsor to fund this project – if the funding is found it will involve all Activity Workers and the teams at Housteads and Deerlands. This will be a very interesting project to inspire staff.

Sheffield Dementia Action Alliance

Sheffcare are a member of SDAA and have dementia pledges and updates. The DAA where initially managed by the Alzheimer's society they are closing the link down and this will be run locally by Sheffield Age UK. It is however acknowledged by SCC and is a very positive professional partnership for Sheffcare. Once the new arrangements are established there will be an update provided.

Sheffield Age Uk Dementia Advice line

There is a Dementia advice line for professionals that could be used by our teams if they are struggling with a situation (0114) 250 2875 or e-mail: **dementiaadvice@ageuksheffield.org.uk**

Principles of PAL (Pool Activity Level) Assessment Tool trial

It is a simple set of questions designed by an OT Jackie Pool to ensure that the correct level of interaction /activities is provided for people living with dementia in our care. The levels are Planned, Exploratory, Sensory, and Reflex It will be equally helpful for those who haven't got dementia but may have other health issues causing decline. This will show a professional approach to our activity provision/resident interaction.

This highlights the fact that getting dressed and bathed should be classed as an activity. This works on the principles of focusing on what a person living with dementia can still do. Work has been carried out at Springwood Day Centre. The planned date for visiting Deerlands. This is a positive piece of evidence-based work for CQC and commissioners can witness a demonstration of good practice.

NAPA – National Activity Providers Association

Sheffcare are members of NAPA and this provides a wide range of activities to support a whole team approach and resources for the activity workers and care staff to use. These will be filed in the activity file on the P Drive.

NAPA resources are recognised as professional tools to use and NAPA also works with the principles of the PAL tool. A NAPA Meaningful Visit Guide for Family and Friends can be requested and sent via email or can be accessed via our website.

Dementia Dreammakers

Dementia Dreammakers aims to facilitate life-enhancing experiences for people living with dementia in Sheffield. They want to show that a dementia diagnosis is the start of a beginning, not the beginning of an end.

They encourage people in Sheffield who are affected by dementia to tell us their hopes, dreams, and aspirations. Through fundraising, networking, and negotiating, Dementia Dream Makers aims to make those dreams come true and provide once-in-a-lifetime experiences for people.

Apply for an opportunity on the following link -
https://dementiadreammakers.org.uk

Positive Approach to Care Work for 2024

Past connections with Rotherham MBC and new connections with Richard Annett NHS Clinical Lead Practitioner Older Adults - Acute and Community have given us the opportunity to explore PAC– Positive Approach to Care. This work is commissioned for all Rotherham Care Homes by RMBC this is very inspiring and interesting.

Richard is initially working in Township 2 to complement the Sheffield Enhanced Health in Care Homes Collaborative work to create an area of excellence. This is also featured in the ECHO dementia programme so clearly is a move regionally in this direction. The Dementia and Wellbeing Manager is very interested in exploring playing an active role in the rollout out this concept co co-working with RA as he is aiming to be what is known by PAC as a public coach.

Sheffcare
enriching lives

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Do Word Choices Matter?...by Teepa Snow

At Positive Approach to Care, we believe that the specific words we choose to use are incredibly important. Over the years, we have many several shifts in the words and terminology that we use surrounding the topic of brain change. We spoke with two individuals, Don Kent and Mel Sebastiani, to hear their opinions on this topic. Don Kent is a retired attorney who lives in Texas, and Mel is a retired television producer and writer, currently living as a photographer and artist, who resides in Delaware. Both also live with Lewy Body dementia.

One of the phrases we avoid using at PAC is suffering from dementia. We feel that those of us who are living with healthy brains do not have the right to decide whether or not someone living with brain change is suffering. When asked how he feels about the phrase, Don says that he strongly dislikes it. He explains that he certainly does have challenges related to his condition, but definitely would not describe his day-to-day existence as suffering. Just a few months ago, Don accomplished the amazing feat of climbing the 8,751 feet of Guadalupe Peak, the highest mountain in Texas! To train for this adventure, he reported that he walked more than 1100 miles and lost 90 pounds in the process. Don feels that he is living the best life he can with Lewy Body.

Mel agrees that the phrase suffering from dementia is one she despises. She feels it implies that the individual is self-pitying and has a bit of a victim mentality. She thinks it also suggests that the person has no quality of life. Like Don, Mel lives as well as possible with her condition and enjoys spending time taking photographs of the beautiful beach near her home.

Both Mel and Don state that the term dementia is one they strongly dislike, as well. They feel that the term carries a wide assortment of negative connotations, stigmas, and stereotypes. When people hear the word, they often associate it with someone who is in a very late state and doesn't realize that people with the condition are capable of living well and productive lives. Don mentions that he feels that the term dementia causes many people to discount or look down on those who are living with it. He shares a story of a meeting with his financial advisor, with whom he had had a relationship for thirty years. When he informed the individual that he had been diagnosed with Lewy Body dementia, the financial advisor turned from Don and immediately started only speaking to Don's wife.

Mel adds that, for many people, the term conjures up very negative images of "drooling fools who cannot be trusted and whose opinions don't matter." She says that if she tells most people that she has dementia, she can instantly see a variety of negative emotions pass over their faces, such as horror, pity, disgust, and fear.

Instead of dementia, both Don and Mel prefer the phrase living with brain change. They state that the old term should be abandoned altogether at this point, the way that the use of negative terminology once used to describe those living with developmental disabilities has largely been discontinued. They also do not care for dementia to be called a disease and prefer the term condition instead.

Another language shift that PAC has recently made is using the terms *typical* and *atypical* instead of *normal* and *abnormal* to explain different brains. Don feels that *normal/abnormal* doesn't bother him as much as some other words. However, Mel says she prefers the terms *typical/atypical* because she feels it is a better way of quantifying brain changes on a spectrum.

Both Don and Mel strive to change societal perceptions by showing that people living with brain change can set goals, work towards them, and live well. Don points out that many people who have a diagnosis of brain change choose to keep it a secret, so people you know may or may not be living with such a condition. They both agree that the words and terminology used can make an incredible difference in either perpetuating negative stereotypes or helping to challenge them.

We thank Don Kent and Mel Sebastiani for their contributions to this article.

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Is there an effective alternative treatment for dementia? Part 1...by Michael Cheung

Holistic dementia care focuses on the entire person. This new outlook can help those within the circle of care provide assistance in innovative ways.
Some research showed that the most effective way that you can counter the symptoms of dementia, without taking too much medication, is to live a brain-healthy lifestyle.

A brain-healthy lifestyle can involve:

- Being physically active.
- Being socially active.
- Challenging your brain.
- Eating healthily.
- Making conscious and safe choices and managing stress.

While these actions will not stop or reverse the progression of dementia, research has shown that they can help you live well for a longer period of time, slowing the progression of dementia into the middle and late stages.
A new movement in dementia care looks at more than just a brain under duress. Holistic dementia care focuses on the entire person. This new outlook can help those within the circle of care provide assistance in innovative ways.
Holistic dementia care honours independence.

Most people, including seniors, value their independence. Yet for a dementia sufferer, independence can be dangerous. Dementia sufferers are at risk for wandering, forgetting safety precautions, and becoming confused even in their own homes. Holistic dementia care would emphasize setting up safeguards such as secure locks, round-the-clock care, and a fall-preventive home design

Beyond that, the person should have as much independence as possible. People who feel they can care for themselves, at least somewhat, are less prone to depression, moodiness, aggression, or confusion. If they cannot bathe themselves, at least they can choose their clothing or dress themselves. If they cannot use a knife for cooking safely, they can still stir or mix ingredients with a spoon. With supervision, a person with dementia may be able to wash dishes.

Holistic dementia care allows dementia sufferers to control as much of their environment as is safe and comfortable for them.

- Diet shown to reduce brain inflammation.
- Nutritional Supplements shown to help slow the progression of dementia.
- Sleep instruction and aids to slow dementia.
- Stress reduction.
- Exercise.

Holistic treatments for dementia care
A 2007 study showed some promise in treating symptoms of dementia (essentially, slowing its progress) using herbal supplements and herb-based pharmaceuticals. This may be a holistic, less toxic way to help slow the progress of dementia in the earlier stages. Since these herbal treatments can sometimes be used alongside traditional pharmaceuticals, this allows for more treatment options.

Carers do well to find ways to include healthy foods, drinks, and doctor-approved vitamin supplements in their loved ones' diets. Treating the person holistically cannot harm and may very well help.

More about this topic in next month's newsletter.

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This Month's Recipe

Dumplings, Dim sum etc. - pork mince, prawns, veggie

- Chinese Dumplings - boiled dumplings (or shui jiao, 水饺)
- Potstickers (guo tie, 锅贴),
- Valentines Dumplings

Ingredients

* Dumplings Fillings

- Pork mince about 300 g
- Chives or, coriander or spring onions
- Small prawns - optional
- Sesame oil - 3 teaspoons
- One egg
- Light soy sauce 1 dessert spoon
- Packet of Chinese dumplings wrappers (from Chinese deli or Amazon) or make your own - **https://biancazapatka.com/en/homemade-dumpling-wrappers/**

Method Dumplings

1. Filling - chop the chives etc finely, mix in with the pork mince, add 1 dessert spoon of light soy sauce, 1 teaspoon oyster sauce, one egg. Mix well, until the mixture resembles a rough paste.

2. Wrap the dumplings, shown in many YouTube videos, some overly complicated, my demo is an easier version.

Ingredients

- Boiled dumplings - Chinese New Year Dish - Add 200 ml of chicken stock
- Pot stickers - Chinese New Year Dish - vegetable oil.
- Dumplings in spicy sauce - Valentines Day Dish with the addition of this sauce.
- Cheesy Shrimp Baked Spring Rolls 春捲 Chūn juǎn - Valentines Day Dish- 150 g of cooked prawns, 1 dessert spoon lemon juice, about 100 g of grated cheese, 1 spring onion finely chopped. Packed of Spring rolls wrappers (from Chinese deli or Amazon).

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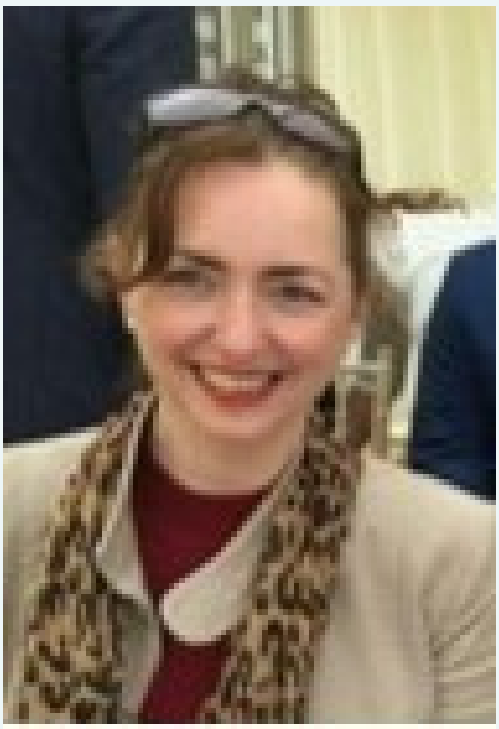
Self Massage Technique...by Louise Davidson

In this second feature with Louise Davidson, we are hopeful that Louise's corner within the newsletter becomes a regular feature.



Louise is a Board Member of Deepness. She is a therapist, dance and movement specialist with over 20 years' experience in teaching movement/dance, postural alignment, pain-free movement, stress reduction, rehabilitation and neurological balance. Originally dance trained in the U.S, and went on to manage one of the top New York dance studios.

She has continued professional training in Authentic Movement, Clinical Somatic Release, Neuromuscular movement, brain training for neurological conditions, Child infant development and trauma informed training. I have 20 years of teaching and performance experience both in U.S, Spain and the U.K.

This month Louise is looking at self management. She writes: *"A wee Short 20-minute self massage techniques for self or others for health and vitality for the newsletter. Can be done seated or on the floor"*.

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DPO Defeats 'Absolutely Unacceptable' Social Care Policy...by Anne Scott

News Equality & Rights Health & Social Care.

The proposed Fair and Affordable Care Act, which would have seen Bristol's Disabled residents forced into care homes if their independent living and at-home care costs were seen as 'too expensive', has been scrapped due to the tireless campaigning of grassroots Disabled People's Organisations (DPOs).

Campaigners from the DPO Bristol Reclaiming Independent Living have been celebrating the success of their campaign to stop the introduction of a "Fair and Affordable Care Policy", which said that Disabled people could be offered a "residential or nursing home placement if "a care package to remain at home would substantially exceed the affordability of residential care", and it warns that "exceptions" to this policy "are likely to be rare".

Following the announcement of the policy in 2023, Disability Rights UK slammed Bristol Council's plans to remove Disabled people's rights to at-home care as "absolutely unacceptable" and in breach of law.

We wrote letters to the Mayor of Bristol and the Leader of Bristol's Green Group, wherein our CEO Kamran Mallick said that it was "absolutely unacceptable" that the draft policy talks about overriding the option to receive care and support in the home if the council decides that this would not achieve "best value."

Following a hard-fought campaign by BRIL and allies across the movement, which also generated national media interest, the councillor responsible for Social Chair Helen Holland wrote to BRIL and other Disabled campaigners that the policy has been dropped and that the council will work with Disabled people in Bristol and across the country to come up with a new proposal.

Helen Holland's letter was sent to Alun Davies, the chair of the Bristol Disability Equality Commission, acknowledging the 'strong concerns that some Disabled people in our city and nationally have raised' during the consultation period.

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Scottish Dementia Friendly Communities (DFC) Network: Update February 2024
by Colm McBriarty

Hello everybody,

I'm pleased to let you know that our third Scottish DFC Network in-person event will take place at The Fly Cup, Inverurie on Thursday the 21st of March 2024.

https://www.flycup.org/

After our previous events in Perth and Kilmarnock last year, this is a great opportunity to meet in Aberdeenshire which is home to nine Network member groups. There will be lots of discussion, planning, and, of course, food!

Everybody in the DFC Network is very welcome to attend, and you are welcome to encourage other local groups to attend (and sign up to the Network). However, The Fly Cup can host a maximum of 40 people. In the unlikely event that we are oversubscribed, priority will be given to members from Aberdeenshire, Aberdeen City, Moray, Angus, and others who are within comfortable traveling distance. Hopefully, we won't have to say no to anyone though.

You will notice there is no agenda attached to this notification, and that is because I would like member groups to set the agenda. Therefore, if you would like to attend the event and/or have any ideas or suggestions for discussion, please email me.

As with our previous events, people living with dementia, caring partners and their supporters are particularly welcome to attend. We can also reimburse travel expenses and additional costs for all attendees.

So, please put the date in your diary, and let me know as soon as possible if you would like to attend if you have any questions, or if you have any ideas for the agenda.

Finally, in case you are not aware, the Scottish Government published the Delivery Plan for the national dementia strategy earlier this week.

https://mcusercontent.com/cc24a1c33495c540970926373/files/295cb94d-fa39-3516-1a0f-5b8f13d13367/dementia_scotland_everyones_story_delivery_plan_2024_2026.pdf

Bye for now,

Colm.

Colm McBriarty
Community Development Officer (Dementia)

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Supporting the Unsung Heroes: Caring for Carers of People Living with Dementia...
by Craig Colligan

Caring for individuals living with dementia is a challenging and demanding responsibility that requires patience, empathy, and unwavering dedication. While much attention is rightfully given to those suffering from dementia, it is equally important to recognize and support the unsung heroes behind the scenes—the caregivers. These individuals, often family members or close friends, play a crucial role in providing physical, emotional, and psychological support to their loved ones with dementia. In this article, we explore the unique challenges faced by carers of people living with dementia and highlight the importance of providing them with the necessary support and resources to ensure their well-being.

Caring for a person with dementia can be emotionally and physically draining. Carers often experience feelings of isolation, stress, anxiety, and depression as they navigate the complexities of the disease and the changing needs of their loved ones. The constant demands of caregiving can take a toll on their own health and well-being, leading to burnout and exhaustion. It is essential to recognize the sacrifices that carers make and to provide them with the support they need to cope with the challenges they face.

One of the key ways to support carers of people living with dementia is by providing access to resources and information. Education and training programs can help carers better understand the disease, develop effective caregiving strategies, and learn how to manage distressed reactions.

Support groups and counselling services can also provide a much-needed outlet for carers to share their experiences, seek advice, and connect with others who are facing similar challenges. By equipping carers with the knowledge and tools they need, we can empower them to provide the best possible care for their loved ones with dementia.

Respite care is another crucial aspect of caring for carers. Taking on the role of a full-time caregiver can be overwhelming, and carers must have the opportunity to take breaks and recharge. Respite care services allow carers to take time for themselves, attend to their own needs, and prevent burnout. Whether through in-home respite care, adult day programs, or short-term residential care, providing carers with respite options can help them maintain their own health and well-being while continuing to provide quality care for their loved ones with dementia.

In addition to practical support, it is important to acknowledge the emotional toll that caregiving can take on carers. Many carers experience feelings of guilt, grief, and loss as they witness the progression of dementia in their loved ones. It is essential to provide emotional support and counselling services to help carers navigate these complex emotions and cope with the challenges they face. By addressing the emotional needs of carers, we can help them maintain their resilience and continue to provide compassionate care to their loved ones with dementia.

In conclusion, caring for carers of people living with dementia is a critical aspect of dementia care that is often overlooked. Carers play a vital role in supporting individuals with dementia and ensuring their quality of life. By providing carers with the necessary support, resources, and information, we can help them navigate the challenges of caregiving, maintain their own health and well-being, and continue to provide compassionate care to their loved ones with dementia.

It is essential that we recognize the invaluable contributions of carers and work together to create a more supportive and compassionate environment for all those affected by dementia.

Dementia Lead Nurse at Keane Premier Healthcare and works for Clinical Service Manager at Advinia Health Care and Bank Registered Nurse at NHS Greater Glasgow and Clyde

Studied MSc Dementia Studies at University of Stirling

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Family Carers Not Given Support They Need, Report Finds...by Anne Scott

A report by the Centre for Social Justice (CSJ) has found that carers are not being given the support they need, meaning many are forced to work alongside caring responsibilities, or are being forced out of work altogether.

Our social care system is failing both Disabled people and carers, and the large intersection of Disabled people who are also carers, by not providing the right support to ensure carers can stay in work if they choose to, or be financially supported by our social security system if they are unable to work whilst caring for a loved-one.

CSJ's report surveyed family carers and found that nearly 400,000 family carers have left paid employment to look after a Disabled or older person in the year 2021-22.

The results of the survey also show that 65% of those not currently in full-time work say they would take up paid employment if they could, and 59% say they would take up paid work with the right support in place.

It is important to remember that our current social security system is leaving carers without the support they need, meaning many feel compelled to go back into paid employment to fill the financial gap that being on carers' benefit creates. **Those who want to balance caring responsibilities and the opportunity to work outside the home, should be supported to do so, and those who are unable to work on top of intense caring responsibilities shouldn't have to work or worry about paying their next food or energy bill.**

We resist the narratives built around a so-called 'economically inactive' class, terminology used to pressure Disabled people and carers into work, when in fact our economic and social labour is a vital – and often unpaid – part of the economy. Family carers reduce the pressure on social services and the NHS, as the current social care system is not fit for purpose and does not care for our population as it should.

Some of the recommendations we support in an effort to improve the lives of carers, both those in paid employment and those who aren't, include statutory carer's days allowed as paid time off, increase the earnings threshold for carer's allowances, free, accessible social care provisions for all and a state-funded improvement in general home adaptations for those who need them.

Dan White, a policy and campaigns officer at DR UK alongside being a Disabled carer said:

"The first thing we need to do before anything else is to fix social care and make sure it ascends to the top of the next government's priority list. I am beyond tired of seeing my fellow carers feeling pressured into work because there is absolutely no adequate financial support in place. Care is different for everyone, no two carers are alike except perhaps for the fact they are exhausted and in poverty. ***Fix social care, and drop the crass rules on overseas care workers, we need them! And pay carers a real, decent, livable, and supportive wage first.*** *If this is done, then carers could work if they wished, and if it was possible for them to do so."*

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My Wonky Brain...Willy Gilder

'My Wonky Brain' is the story of me and my dementia, told in words and pictures devised by a group of young people living in Edinburgh.

It all came about because dementia researcher Valeria Lembo was bored during lockdown, living at home on the Island of Capri. She found reading hard work, but got really into 'graphic novels'. When she and I eventually met face to face in one of Edinburgh's coffee shops we hatched a plan between us to try and produce a graphic novel about dementia - and involve some young people in doing this.

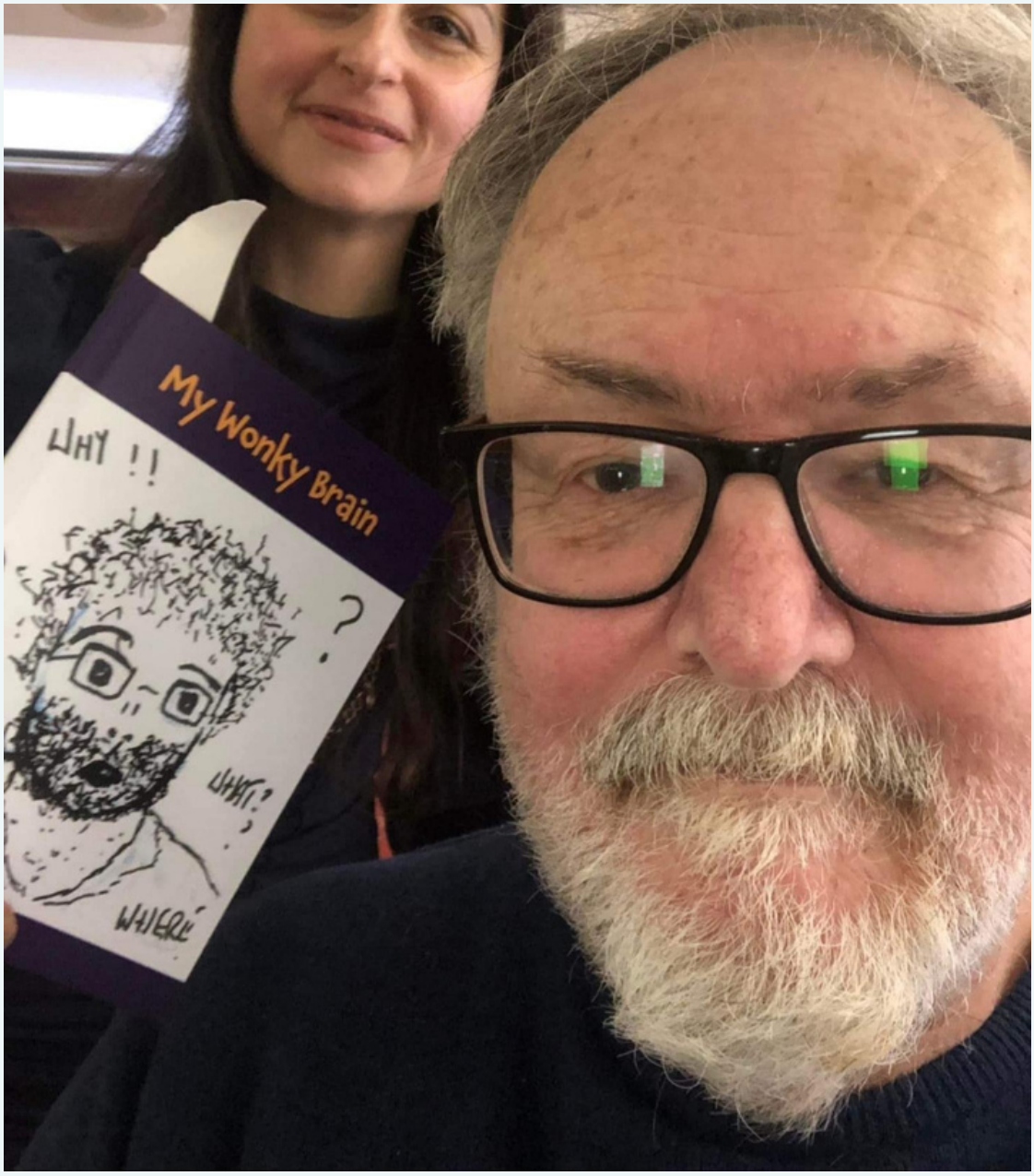
We managed to persuade BOLD to give us some money and Alex Howard from Capital Theatres to give us some of his time. We then set about recruiting a small group of youngsters, using friendly persuasion and the bribery of cake and sweets.

We all had an enormous amount of fun, with them interviewing me and drawing pictures about different events in my life.

We then gathered together all the drawings and Alex used some of his editing super-powers to pull the whole thing together into a book. This contains not just my story, but some of our reflections on the process, in the hope that perhaps other groups might do something similar.

13 yr. old Gracie was one of the group, she said:

“I learned a lot volunteering to be a part of this project. Dementia is not all about not remembering things, it’s also about different parts of the body - mostly the brain, that can be affected. It was fun because it wasn’t all grown-ups”.



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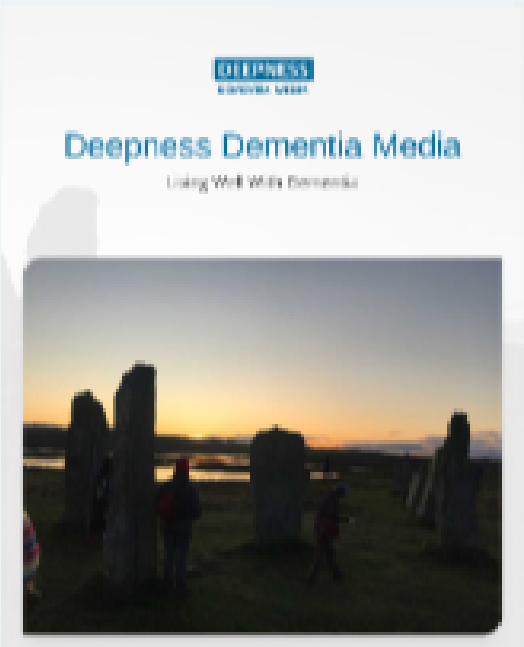

Dementia Media is a platform that gives people tools for living well with dementia designed collaboratively with those with dementia leading the process. By coming together in a supportive, energetic common space makes up a huge difference to the well-being of those going through dementia. As opposed to providing a cure, our goal is to help people become autonomous and get the most out of life. We bring a series of innovative projects - such as our radio station, online education courses, and much more - that use technology and music in a way that keeps people connected and stimulated.

“I didn’t want to die without leaving something for my family to enjoy and remember my strengths,” he says of the thinking behind the EP. “The whole concept was to create something that was a legacy for the person, and as soon as I thought about wanting to do that for myself I knew it was something other people would want to do, to leave our mark on society. It’s almost like leaving our families a gift.”

The Demented Poets EP is on sale now via Bandcamp iTunes and other outlets:

Bandcamp - https://thedementedpoets.bandcamp.com

Spotify - https://open.spotify.com/album/6pnqYVybZ3qUf6XMhOOFuK

Deezer - https://www.deezer.com/en/album/258048592

iTunes / Apple Music - https://music.apple.com/us/album/the-demented-poets-ep/1585080810

Amazon - https://www.amazon.com/dp/B09FRVYQ1F