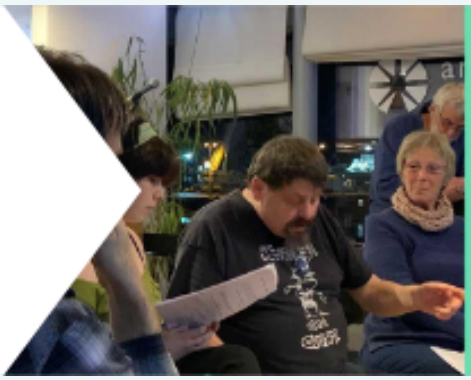
DEEPNESS DEMENTIA

Media

Living Well With Dementia



Hello and welcome to our very first special festival/arts edition from Deepness Dementia Media, I am Anne Scott the Newsletter Editor, and this month we are bringing you articles and films shown at the Scottish dementia arts festival. the festival was a wonderful experience for all who attended, there were smiles, hugs, tears, and laughter. If you were unable to attend this year's arts festival then come along to next year's event and join us in this wonderful experience.

FIRST SCOTTISH DEMENTIA ARTS FESTIVAL 2023

I hope you enjoy reading our latest news. Please share this newsletter with your friends, family, and colleagues.

The newsletter will come out monthly with lots of features and dementia news, including news from Deepness Dementia, the dementia community, dementia activism and dementia rights.

Please send your feedback about the newsletter, whether you liked it or how it could be better. If you want to contribute or send in something for the newsletter, please get in touch with me at scottanne@live.co.uk

Please do circulate and share this newsletter on social media and if you want to sign up for all our mailings, the buttons above...

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.

bold Bringing Out Leaders in Dementia

Being bold at the First Scottish Dementia Arts Festival

Once upon a time, Ron Coleman sat in a café in Stornoway thinking “I am fed up with people using the word ‘suffering’ to describe me and others living with dementia, we need to do something different”. He then thought of how his friend and peer, also living with dementia, Ronald Amanze commented,
“We are all artists!” and so the nugget of the idea of the First Deepness Scottish Dementia Arts Festival was born.

Ron Coleman’s Welcome!

Ron went on to say “Mindfulness, I hate it, there’s nothing like getting dementia to make you mindful, you learn to live in the moment. Today we’re challenging the stigma of dementia by doing, doing stuff makes you feel better, this is my journey”.

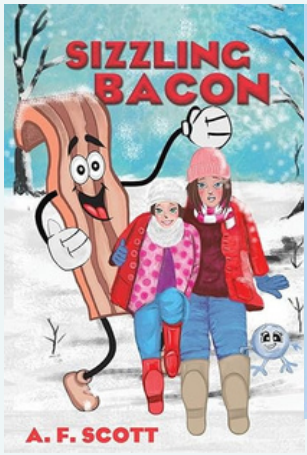
And so it came to pass that on Monday the 13th of November 2023, Dawn Irvine, Magdalena Schamberger, and myself from bold – Bringing Out Leaders in Dementia were listening to Ron’s anecdote at the Eden Court Theatre in Inverness at the opening ceremony for the festival. A festival to focus on all that those living with dementia CAN achieve and create with not a ‘sufferer’ in sight.

Ron Coleman’s Welcome!

Jane Harlington from Blue Pig Studios

After Ron had told the above story and welcomed us to the Festival, he invited Jane Harlington, an artist from the Blue Pig Studio on the Isle of Lewis who curated the Art Exhibition at the festival to say a few words. Jane was inspired by a book she was introduced to the previous evening entitled ‘Sizzling Bacon’ by Anne Scott the Editor of the Deepness Dementia Media Newsletter who lives with dementia.

Jane told us the story of Anne and her daughter Evie and how after diagnosis Anne's whole life changed; she became aware of the lack of understanding about dementia and decided to write this children's book to raise awareness. Jane was very touched by this story and moved the whole room with her heartfelt words inspiring her to buy a lion balloon to represent courage & hope which she felt resonated with Anne & Evie's tale and the whole ethos of the Dementia Arts Festival and left us with the with the words 'You Matter, We Matter'.



Sophie Bancroft & Tom Lyne entertain us with Jazz

We were then treated to a festival of art in the form of music with some Jazz from the amazing Sophie Bancroft and Tom Lyne. Sophie & Tom featured heavily in the Dementia Arts Festival programme running Jazz Singing Workshops. Sophie has also written some beautiful songs for Dementia the Musical and its stars Nancy and Agnes but more about that later.

Finally being treated with a bit of magic from Jim the Magician, who told us a story of Ron's insistence to magically produce a 'good' bottle of wine at the opening of the Dementia Arts Festival, even though Ron doesn't drink wine!

Instead Jim magically produced Ron's favourite drink - tea (with lots of sweeteners!) out of an empty paper bag!

But then surprising us all, by pulling a bottle good wine, for Karen, out of his jacket sleeve...!!

Jim the Magician entertains us with some magic

After some refreshments and cake, we all gathered again in the La Scala Cinema at Eden Court to be entertained and enlightened by a radio play called “What are we going to do about Mum?”. At first, you were aware of the cast and their microphones but as the tale unfolded you forgot the cast were there in front of you and listened to the conversation.

The cast of ‘What are we going to do about mum?’

The radio play is about 3 sisters and their varying degrees of concern about their Mum who is now on her own after losing their Dad. Two sisters live on the island close to their Mum but another sister lives on the mainland and the dialogue consists of various phone calls between them all. It was a brilliant observation of the family dynamics that emerge with the possibility of a dementia diagnosis for a loved one.

It covered concern about how to help, being too overwhelmed with caring for young children to think about helping, and complete denial that a Mum who was once so dynamic and capable could have any cognitive impairment at all. The thought-provoking radio play was followed by a rich discussion with the author explaining it was based on personal experience after her own Mum’s diagnosis and an audience member bravely sharing that this play mirrored exactly how it had been for her.

And so we were off on the Dementia Arts Festival journey with our first very moving and informative day coming to an end with a delightful programme of arts to come. In the next blogs we’ll cover the amazing art on display, the 100/6000 Gathering and poetry, music, song-writing, jazz, excerpts from musicals, the bold partners we connected with and so much more that we enjoyed in our time at the First #ScotDementiaFestival in Inverness.

Links to find out more about all the organisations and people mentioned in this blog are below:

Deepness Dementia Media
Jane Harlington, Blue Pig Studio
Sizzling Bacon by A.F. Scott
bold - Bringing Out Leaders in Dementia
Sophie Bancroft
Jim the Magician

A Box of Smiles workshop with Ronald Amanze
(Co-facilitated with Jim Campbell)

Every morning at breakfast at the Premier Inn in Inverness, myself and Jim would talk and get excited about the amazing Box of Smiles. It was on the third morning that Jim said he was looking forward to my Box of Smiles workshop that afternoon when I panicked! What? I didn't know I was put down for a Box of Smiles workshop. I can't do that, it's too soon.

In a calming way, Jim was so amazing and beautiful and replied saying he would co-facilitate the workshop with me and after some reassuring chat we agreed.

Breakfast at the Premier Inn, Inverness

A Box of Smiles is simple, yet so beautiful. Everyone loves a box of smiles. Think about what makes you smile and write it down. Just write down 5 to 6 sentences about what makes you smile. It could be going for walk, eating an ice cream, sitting in the sun, watching a good TV show. We can always think of something that makes us smile. When I am finding it hard to smile about life, I do my Box of Smiles and soon enough I am smiling again. It's so beautiful.

How do you define a smile?

A smile can be so magical...a smile can be so comforting...a smile can be so rewarding...a smile can be so warm...a smile can be so beautiful...and a smile can be so curious...a smile can be so creative...a smile can be so fascinating...a smile can be so energising...a smile can be so intriguing...a smile can be so exciting...a smile can be so therapeutic...

And after all that is said and done, a smile is what we all need at sometimes in our lives.

In the Box of Smiles workshop, we ask everyone to write a few lines about what makes them smile. Then one by one, they recite it to the whole group and I record it on my iPad. With a bit of help and direction from myself to read out their smiles slowly, it becomes so beautiful.

Willy the Clown and myself

Then with a few tweaks to the voice recording I add some amazing music to it and we have a beautiful recital, a beautiful song, which is put together into a Box of Smiles.

As we waited for the start of the workshop, Jim and I wondered whether anyone would turn up! There was a Clown Workshop going on next door, so we could go to that if no one showed.

But slowly, a few beautiful people arrived, then a few more and before we knew it there were fourteen of us. So many beautiful amazing people.

Our workshop was interjected with laughter from the Clown Workshop happening next door, with new Clowns appearing to join us. Check out the X post (formerly known as Twitter) with Willy the Clown and picture above.

https://x.com/Arts4Dementia/status/1725126377391690115?s=20

I'm still putting music to our Box of Smiles in Inverness, to create an end product, but check out below an example of one I did a couple of years ago.

https://youtu.be/klPOBRi7bH0?si=fsJNoM-Yy-eDESS6

The Box of Smiles workshop was a huge success! If it was not for Amazing Jim, I would have cancelled the workshop as I was struggling with personal stresses relating to my home and health circumstances and the challenges I am tackling with my local council, which seem to follow me around in my head like hidden stress and anxiety.

I was very inspired by Jim's encouragement and working with Jim was a fun, joyful, productive experience.

We are now talking about getting funding to take the Box of Smiles across the whole of Scotland and maybe the UK. Such a simple idea, yet so beautiful.

Everyone needs a Box of Smiles.

Thoughts and Observations on Dementia Arts Festival by Mike Deeprose

Thoughts from Attending Events and Workshops at the Festival

It had been generally noted at the festival that the official program was somewhat convoluted, which together with the flexibility on event timing, meant that we missed things and weren't always sure of what we were attending. With Elizabeth's (Anni B) overall health, she tends to rest especially after lunch, so attendance to and workshops and discussions was limited.

The cinema screening's we attended, were enlightening, especially the conversation between Ron & Karen, which opened up a number of question in our own situation.

The Radio play, "What are we going to do about Mum" was a good production and a valid representation of situations existing within dementia suffering families, which as a carer I could empathise with. Unfortunately as each situation is different, there is no "one size fits all", answer.

Ann particularly enjoyed the workshop with "Forget Me Notes", a considered selection of songs and involvement of the audience in the building of a "values tree" provided an insight to some questions aspects of life with living with mental health issues, especially if you are on your own. It has encouraged Ann to give more thought to a "playlist".

The interaction of Ron's role with Alexa "Caught in This Moment of Time", was a thought provoking well-acted and enjoyable performance with the unexpected bonus of Karen singing. Followed by the dance, which was a clear and emotive expression of thought on dementia. A good evening!

Why I do Art (Willie Gilder). On meeting Willie, as with so many others, it was not obvious that he suffers from dementia. The narration of part of his personal journey as an artist with dementia, was an education as to the variety of impacts it can have on people, and how he had managed to counteract some of its effects.

Considerations/Reflections

We are newcomers to Deepness Dementia Ltd and many aspects of dementia, we are not necessarily aware of the logistics, and whether some of these thoughts are a repetition of things in hand, and the thinking regarding the current geographical area being covered.

Does the implementation of the results of “Creating the Dementia Arts Festival Manifesto” stem from an interaction of Deepness Dementia Ltd/The Festival hierarchy, is it autonomous or is it down to the board, and how are the benefits monitored.

During the event where a forest was built from aspirations, the tables generally had been occupied by groups with their own artistic elements. The introduction identified the table by group name which, albeit unintentionally divisive, appeared to separate each group and excluded individual/couples artists or not, who were also attending the festival.

It wasn’t clear as to the lines of communications between groups other than perhaps in the culmination of their artistic presentation, the impression was that much of the work was carried out independently rather than providing a unified front.

An underlying message at the festival was for autonomy for dementia/art, by those suffering from dementia. Without the help from Carers etcetera, is this practicable and would it impact in slowing if only by numbers involved, development of Dementia Art (Festivals, Seminars, Exhibitions, etcetera), and dementia awareness in general.

The Kingdom Centre shopping Mall Glenrothes, frequently has empty shop in which the Glenrothes Art Club have on occasion set up a display of members work. Are there other towns have an underused shopping facilities.
As a means of promoting dementia art, if sufficient artwork can be obtained from artists who have dementia, might such underused facilities be considered (possibly with local art club and/or Dementia group help) for Dementia/Arts Exhibitions? I am aware that this is an over simplified view, but feel that it bears investigation.

Conclusions

A super event which Ann and I were delighted to be able to attend especially with the level of support from Deepness Dementia Ltd. It was good to meet up with so many people and learn more about the approach being made develop the arts for and by people involved or suffering from Dementia
It was interesting to note the demographic area covered and in the light of some of the above observations, gives rise to several questions regarding the way forward.
We look forward to attending next year’s festival

The intention of this feedback was to present the viewpoint that we came away from the festival, with and to express hopefully constructive thoughts that may, or may not already be under consideration. Whether they are, or end up as invalid or impractical, is for others to decide.
My apologies if my mental ramblings create any consternation with those involved.

La Scala Cinema

The Wobbly Dog
Ron Coleman and Karen Taylor discussing what it's like, as couple, to live with dementia.
Length - 30 minutes, 30 seconds

FRANKIE goes to BELFAST
World Premiere at Scottish Dementia Arts Festival.
A Deepness Film
Length - 32 minutes, 42 seconds

Willy Gilder's 'Unheard Voices' - Gerry King

Willy Gilder interviews Gerry King as part of his 'Unheard Voices', mini bold mini commission.

Length - 15 minutes, 24 seconds

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Michael Cheung ... Washoku

‘Healthy Eating and Dementia’ Prevalence of Dementia in other parts of the world.

This month I am looking at food heritage in Japan and find out why the Japanese have a longer life span than some other countries.

“Japanese Food : Intangible Cultural Heritage”.

Recommended by the Japanese government. In 2013 UNESCO (The United Nations Educational, Scientific and Cultural Organization) decided to register “Washoku” (traditional Japanese cuisine) as an Intangible Cultural Heritage1 during the intergovernmental panel at Azerbaijan, Baku.

Until now Gastronomy Art of France, Mediterranean Cuisine, Traditional dishes of Mexico, and Traditional kashkak of Turkey have been registered as Intangible Cultural Heritage, but the food culture of the country as a whole having been recognised as Intangible Cultural Heritage are only France and Japan. “Washoku” is the fifth culinary Intangible Cultural Heritage registered by UNESCO.

What is Washoku?

The word "Washoku" is comprised of two components "Wa" and "Shoku". "Wa" means Japan and "Shoku" means to eat. Washoku, or Japanese cuisine, is widely recognized for its ingredients that developed out of Japan's geographical, climatic and regional features.

The standard Washoku meal is traditionally comprised of rice and soup served alongside one main meat or fish dish, and one or two vegetable side dishes including those from the mountains and sea, like vegetables, mushroom and seaweed. This standard is known as "one soup three dishes" - (ichiju-sansai), and it is said that this Japanese way of eating provides ideal nutritional balance. Moreover, an emphasis on using "Umami" over animal fats has led to health benefits for Japanese people, such as longer life expectancy and low obesity rates.

UNESCO “Japanese Food : Intangible Cultural Heritage” – an interesting article

UNESCO “Japanese Food : Intangible Cultural Heritage” - Discover Nikkei

Have a look at this YouTube video on Washoku?

Washoku, traditional dietary cultures of the Japanese, notably for the celebration of New Year - YouTube

Quote: If there’s a history of dementia or Alzheimer’s disease in your family, you may already take supplements in order to boost memory and protect against age-related memory decline. However, researchers at Yale University claim that the body do not absorb nutritional supplements quite as effectively as natural foods.

Two recipes for this month

Tan-Men – Japanese – ramen/Udon noodle soup

Tan-Men is a type of Japanese noodle soup made with ramen or udon noodles. It is usually served with various toppings such as pork, vegetables, eggs, and bamboo shoots. The soup is usually made with a light soy sauce-based broth. Tan-Men is often served as a quick, easy, and hearty meal.

Ingredients

- 1 packet of Udon or Ramen Noodles
- 100 g of pork fillet or a pork chop with fat and bone removed, cut into short strips.
- 1 – 2 eggs
- 1 plant of Pak choi – cut into 3 cm pieces.
- 50 g string beans or similar, cut into 2 cm pieces.
- Miso stock/paste – follow instruction to make 500 ml of stock.
- 1 dessertspoon of ginger paste

Method

1. Bring the Miso stock to boil, add the pork and boil for 5 minutes.
2. Add the Udon / ramen noodles.
3. Boil the egg for about 5 minutes making sure it is not hard boiled, peel off the shells and half it. You can add two eggs.
4. Add the green vegetable and cook for about 3 minute.
5. Decorate the soup according to the photo.
6. Serve hot.

Watch this video for interest.
https://www.youtube.com/shorts/m93kdEty64E

Sushi

How To Make Sushi: A Beginner's Guide - A Tasty Kitchen

Note: Video includes recipes and ingredients

for all of Michael's wonderful recipes click...
.https://www.deepnessdementiamedia.com/dementia-resources

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James McKillop: Defying Dementia Stereotypes Through Art, Activism, and Resilience

Introduction

Dementia is a diagnosis that, for many, brings a sense of despair and isolation. But within the Dementia Alliance International community, there are individuals like James McKillop who have not only defied the stereotypes surrounding dementia but have become inspirations to others. James, a long-time DAI member and co-host of our UK Support Group, has not let his diagnosis define him. Instead, he has used his journey to inspire and empower, both through activism and creative expression.

In 1999, the world had a limited understanding of dementia. People living with this diagnosis were often treated harshly, considered incapable, and denied the opportunity to live fulfilling lives. James experienced this first hand at the time of his diagnosis when individuals with dementia were often misunderstood, mistreated, and stigmatized.

Support and Empowerment

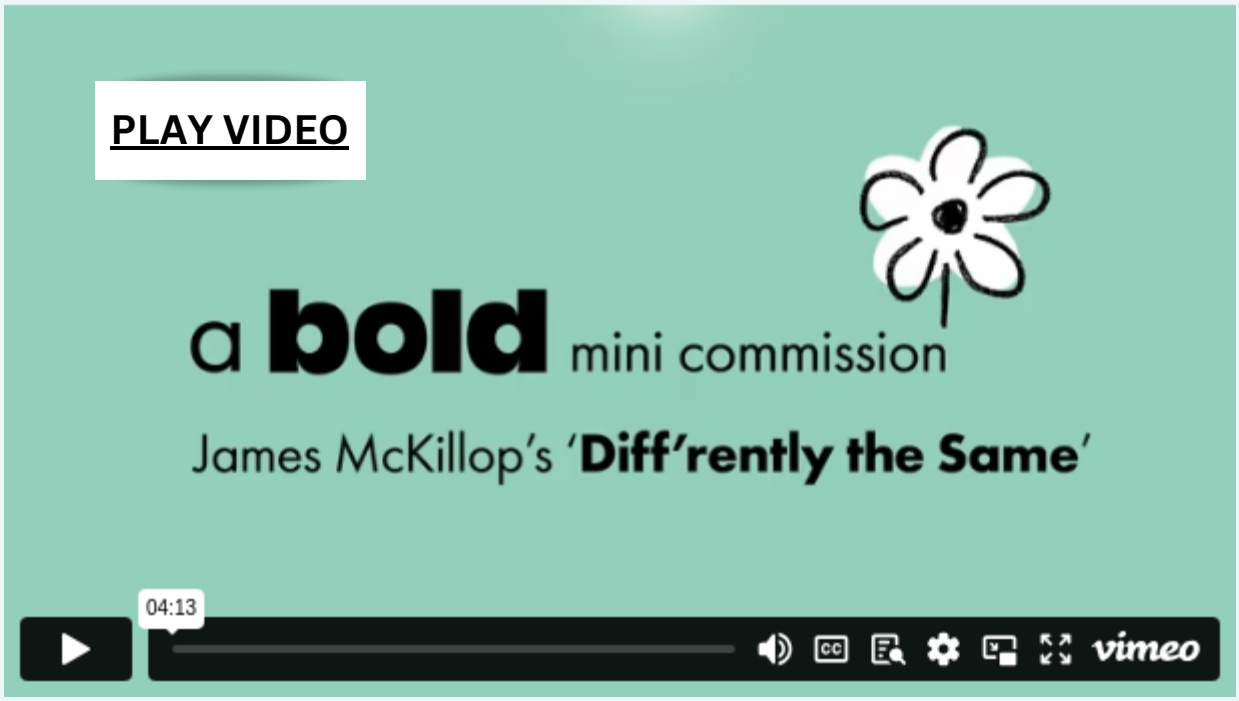
James's story took a remarkable turn when Brenda, who was working for Alzheimer Scotland, came into his life. What started as a routine visit to complete a form for state benefits turned into a pivotal moment of hope. Brenda recognized something in James, something that needed nurturing. She offered him the chance to help at the Christmas Fair in George Square in Glasgow, and in doing so, she used her personal and official time to help reintegrate him into the world.

Brenda's support was instrumental in preventing James from going into a care home. With her encouragement, James began to demonstrate that even if some tasks from his past were now challenging, he could relearn old skills and even develop new creative talents.

James's creative journey continued to evolve under the guidance of Lorna from BOLD, an organization dedicated to supporting individuals with dementia. Lorna recognized James's latent talent for poetry, and under her mentorship, his poetic abilities flourished.

A Message of Hope and Resilience

James's journey serves as a beacon of hope for anyone facing a dementia diagnosis. He emphasizes that life doesn't end with such a diagnosis; it merely takes a different path. In response to the fear surrounding dementia in the UK, he created the song "Diff'rently The Same." Through this song, he aims to inspire others, to instill hope in their hearts, and to encourage them to defy the myths and stereotypes associated with dementia. One poignant line from the song beautifully encapsulates his perspective: "Doggedness enables me, to cope Diff'rently The Same."



A Tribute to Love

In addition to his other creative endeavours, James penned the song "I Still Love You" for his wife of 50 years, Maureen. This touching composition underscores the enduring power of love, transcending the boundaries of memory loss and showing that deep emotional connections persist even in the face of dementia.

'BOLD Creations': A Testament to Resilience

James's creative journey extends to the book "BOLD Creations: A Book of Creative Work by Dr. James McKillop." As a part of Cohort 6 of the BOLD Programme, Lorna Hill's guidance helped unearth James's poetic talent. This book, now with updated music included, serves as a testament to the resilience and creativity that can flourish even in the presence of dementia. You can download the PDF here: /wp-content/uploads/James-McKillop-Booklet-October-2023-FINAL-with-updated-music.pdf

Conclusion

James McKillop's story is a testament to the indomitable spirit of the human soul. He has not only defied the misconceptions and stigma surrounding dementia but has used his journey to inspire others to live their lives fully, regardless of their diagnosis. His activism, music, and poetry have allowed him to spread a message of hope, resilience, and love. James's journey is a reminder that, with a dementia diagnosis, one can still thrive and live "Diff'rently The Same."

Since you're here...

We're asking you to support our members, by donating to or partnering with our organization. With more than 55.2 million people living with dementia, our work has never been more important. Donating or partnering with us will make a difference to the lives of people with dementia: https://www.dementiaallianceinternati...

Membership of, and services provided by Dementia Alliance International is FREE, and open to anyone with a diagnosis of any type of dementia. Join DAI here: /get-support/become-a-member

Read our newsletters or regular blogs, by subscribing here: /blog

About DAI: Dementia Alliance International (DAI) is a non-profit group of people with dementia from around the world seeking to represent, support, and educate others living with the disease that it is possible to live more positively than advised with dementia. It is an organization that promotes a unified voice of strength, advocacy and support in the fight for individual autonomy, improved quality of life, and for the human and legal rights of all with dementia and their families.

PLAY VIDEO

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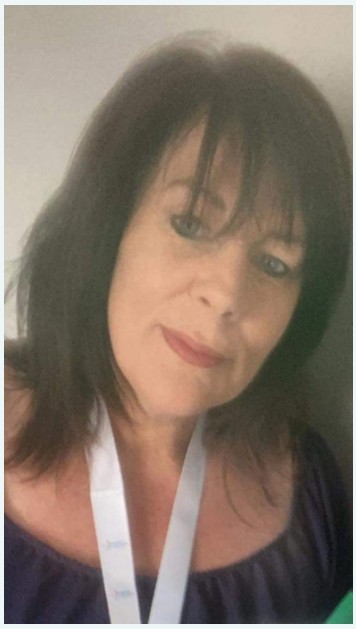
Anne Scott... Current affairs and dementia



Known harm caused by benefits system 'just the tip of the iceberg', MPs hear
(16th November 2023)

What is known publicly about the harm caused by the benefits system – including deaths by suicide linked to the actions of the Department for Work and Pensions (DWP) – is just "the tip of the iceberg", MPs have been told.

Experts were giving evidence yesterday (Wednesday) to the Commons work and Pensions Committee in the first session of its inquiry into safeguarding "vulnerable" benefit claimants.

Labour's Debbie Abrahams, who has led parliamentary efforts to highlight deaths caused by DWP's safeguarding failures, had asked whether the number of suicides examined by the department through its internal review process was "the tip of the iceberg".

Chloe Schendel-Wilson (pictured), co-founder and director of The Disability Policy Centre, a thinktank linked closely to the Conservative party, agreed with Abrahams.

She said it "feels like we're still playing catch up" and that there appeared to be "a huge systemic problem where things are just not being picked up". Nikki Bond, interim head of research and policy at the Money and Mental Health Policy Institute (MMHPI), said it was "absolutely the tip of the iceberg".

She said that people were self-harming or contemplating suicide every day because they feel "trapped" and "think it's their only way out".

She said MMHPI had "reams of evidence" that the disability assessment and sanctions systems were "a significant source of harm".

Henry Parkes, principal economist and head of quantitative research at the Institute for Public Policy Research, said “the reason why we don’t know the full size of the iceberg is because our processes to understand how this is failing are flawed at the moment”.

Schendel-Wilson, Bond and Parkes all agreed with Abrahams’ suggestion that there should be an independent organisation to examine deaths linked to DWP’s failures.

Schendel-Wilson said: “If there was any other area of the public sector where these sorts of failings were going on, people would rightly expect a lot more transparency and a lot more accountability, and there would be a lot more public outrage, I think, if this was going on in the health system.”

In a second evidence session yesterday, Professor Ben Baumberg Geiger, professor in social science and health at King’s College London, told the committee how one of the architects of universal credit, Devon Ghelani, had admitted to him that they were not thinking about “health problems and caring responsibilities at all” when they created it.

He said Ghelani told him: “We just weren’t thinking about that. We sort of assumed that this was going to be an operational problem that other people could deal with down the line.”

Baumberg Geiger said this was not a helpful approach and under a benefits system like universal credit that has “really strong requirements” and “makes a lot of assumptions about what people can deal with”, many people will be made “vulnerable”.

Asked by Conservative MP Siobhan Baillie about the “urgency” of the government’s efforts to reform the work capability assessment as a way of reducing the “sheer numbers of people” with mental ill-health on out-of-work benefits, he said there was a need to “stop talking about things as if there’s something cheap that’s going to magically solve the problems”.

He said there were ways to help some people with mental distress into work, by providing significant levels of support, removing sanctions and "not threatening people", as well as doing much more to provide inclusive, flexible workplaces, and allowing people to work from home, as disabled campaigner Catherine Hale has suggested for people with energy-limiting impairments.

But pressed by Baillie on whether that could be done at scale, he said: "Avoiding magical thinking, I think, is really important in this area because I've only been working on these issues for 15 years or so, which is long enough, but I know people have worked on it for longer, and [there has been] so much magical thinking from people saying 'these people don't have many barriers to work and we can fix it magically like this'."

Baumberg Geiger, who has previously spent time on secondment in DWP, said the department's current consultation on plans to restrict eligibility by tightening the work capability assessment was "very bad".

He said there was "a lack of evidence base" for its proposal to remove the "substantial risk" clause that currently protects many disabled people at risk of harm if found fit for work or work-related activity.

Abrahams told the committee that she had visited the Museum of Austerity mixed-reality installation* in Manchester earlier this month.

She accompanied Gill Thompson, whose brother David Clapson is featured in the installation and died due to diabetic ketoacidosis after he had been sanctioned.

The production uses the verbal testimony of family members and state-of-the-art technology to recreate the circumstances that led to some of the countless deaths of disabled claimants in the post-2010 decade of austerity.

Professor Lisa Scullion, professor of social policy at the University of Salford, said her research with veterans within the social security system and her earlier work on the five-year The Impacts of Welfare Conditionality project had shown that “conditionality is ineffective in moving people towards the paid labour market, particularly in relation to people with more complex needs and mental health issues”.

She said: “The research has shown that over many years.

“People feel trapped, dominated, powerless, and particularly where they are being pushed towards precarious, low paid work, or work that isn’t appropriate for them, or courses that aren’t appropriate to supporting them into meaningful work.

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Michael Cheung...Voice-recognition

An interesting article developed in China about Voice-recognition. Worth a look at.

Voice-recognition based screening for MCI and dementia in older Chinese adults.

Extract: Xin Xu • 19 Jul 2023 AAIC 2023 Alzheimer's Disease Dementia Mild Cognitive Impairment Clinical Care Diagnostics

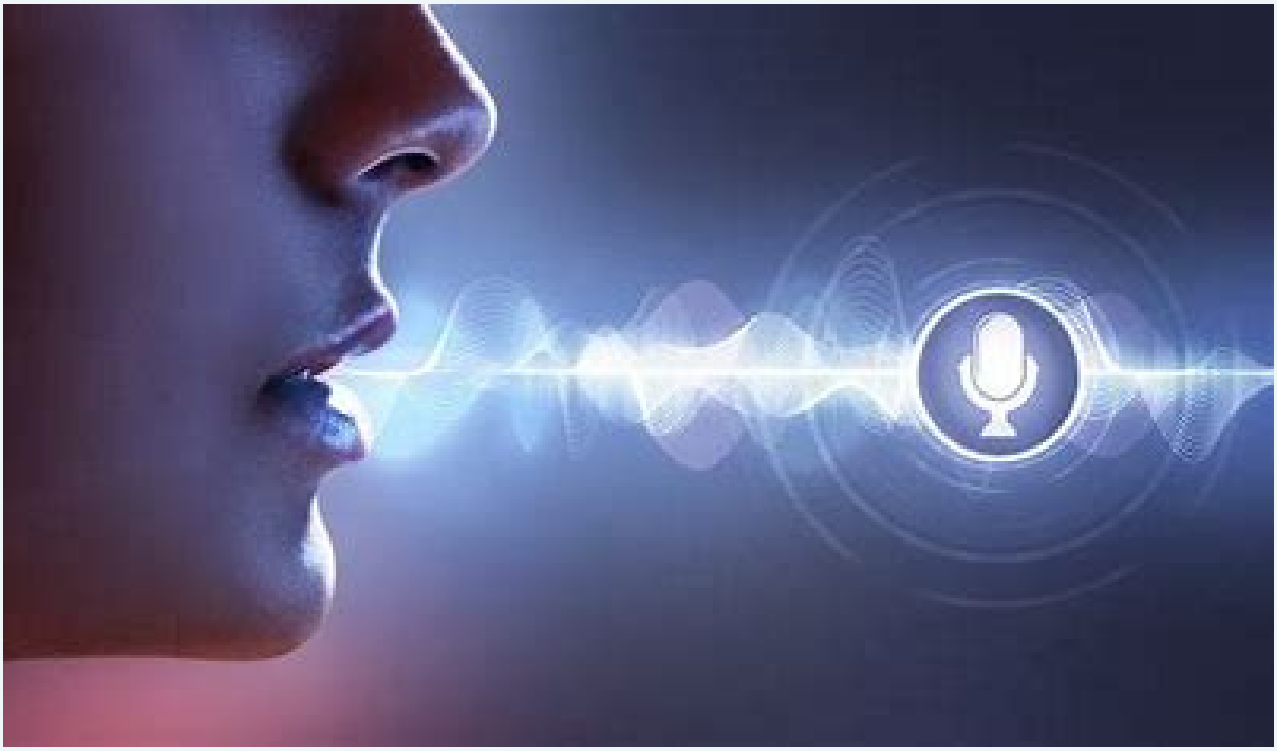
Xin Xu, PhD, School of Public Health and The Second Affiliated Hospital of School of Medicine, Zhejiang University, Hangzhou, China, shares the findings of a large-scale implementation study of a voice recognition-based digital cognitive screener for mild cognitive impairment (MCI) and dementia in older Chinese adults.

The tool was developed in response to the challenges posed by China's very large elderly population, achieving a wide reach for community-based cognitive screening.

By using voice recognition technology, individuals can easily operate the screener despite education or language barriers. Administration efficiency and implementational feasibility was assessed in over 10,000 participants, which demonstrated a completion rate of 97.5% in 5.6-6.1 minutes, regardless of gender, age, or education status.

The predictive validity for MCI and dementia was close to 90%. This digital tool offers a more efficient alternative, producing time savings and requiring no specialized staff for administration, while having comparable effectiveness to the pen and paper equivalent. This interview took place at the Alzheimer's Association International Conference® (AAIC) 2023 in Amsterdam, Netherlands.

https://www.vjdementia.com/video/lnirhike5f0-voice-recognition-based-screening-for-mci-and-dementia-in-older-chinese-adults/



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Teepa snow... Supporting Personal Agency Throughout the Journey of Dementia

In this article, Belle Fox-Martin, who is living with brain change, shares some of her thoughts about personal agency. First, what exactly is the definition of agency? It is typical described as the capacity of an individual to act on their will. When you lose personal agency, you lose the feeling of control or influence over your own life, which, in essence, removes one's own humanity.

Belle shares:
I have been dealing with and thinking about personal agency in reference to brain changes and dementia. With the progression of brain change, my personal agency has diminished over time. With each diminishment, I have had to consciously and unconsciously readjust and adapt to utilize what agency I have left to work with. I am fortunate that my executive skills are still pretty sharp, and I can still generally 'steer the boat' enough to cope and adjust.

I assume this must be true for others, which highlights the importance of your work. I would imagine that even people nearing the end of the road of dementia maintain that inborn drive of personal agency, even though they cannot fully express it. How they are supported is the determining factor of whether or not their agency is recognized and uplifted. Your work allows the uplifting. It is all about human dignity.

What Belle has so eloquently described is indeed the very core and foundation of our mission at Positive Approach to Care. The recognition that all individuals, including those living with neurodiverse conditions, have personal agency is critical to improving the global culture of care. However, it is also essential to go a step beyond this awareness. It is the act of enabling individuals to exercise their own agency as much as possible, and in whatever capacity they are able to, that is the key to truly effective support.

This may involve something as simple as encouraging an individual to participate in meal planning and preparations if that is something that is enjoyable and purposeful for them. Or, it may involve being certain to include the individual in discussions about their health and care wishes. Towards the very end of life, it may involve taking the time to carefully notice the individual's responses to the care that is being provided and responding accordingly.

Teepa speaks often of the importance of obtaining permission before care or support is provided. When neurodiversity is involved, permission may not always be given verbally or clearly. Or, words of permission may be used, but body language may be saying something else entirely, indicating that perhaps our ask was not fully understood. It is our duty to know those we support so that we can recognize their verbal and nonverbal messages as fully as possible.

Even with those we do not know well, paying attention to basic cues is frequently enough to realize whether or not they are granting permission for a particular action to occur. Doing things to people against their will violates their personal agency, and, as Belle expresses, their human dignity.

When we use and celebrate an individual's remaining abilities, instead of seeing only their losses, we support their personal agency. We strive for the day when this is the standard of support for all humans.

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Labour admits dropping disability rights pledge from policy plan

Labour has finally admitted that it is not currently planning to implement the UN Convention on the Rights of Persons with Disabilities (UNCRPD) into UK law if it wins power at the next general election.

The admission was made by the party's shadow minister for disabled people, Vicky Foxcroft, after concerns over Labour's failure to include the pledge in an influential policy document.

Activists from Disabled People Against Cuts (DPAC) were outside the Labour conference in Liverpool this week (pictured) to raise awareness of the issue among party members and to call on a Labour government to "make UNCRPD law", a policy that is part of the new Disabled People's Manifesto.

Disability News Service (DNS) reported last month that Labour policy documents failed to include its previous pledge to incorporate the convention into UK law.

Instead, the National Policy Forum (NPF) report, which will form the basis for Labour's general election manifesto and was approved by delegates this week, refers only to the party honouring its "commitments" to the convention and ensuring that its "principles are reflected across government".

There is no mention in the report of implementing the convention into UK law, which disabled activists believe would have a transformative impact on disabled people's rights, for example by providing rights to independent living, inclusive education, an adequate standard of living, and freedom from cruel, inhuman or degrading treatment.

Vicky Foxcroft, Labour's shadow minister for disabled people, who has repeated the pledge to implement the convention into UK law at least twice in the last 12 months, would only tell a Disability Labour fringe event this week that the party would "honour our commitments" to the UN convention.

She later told DNS that "the wording in the NPF is the wording at the moment."

That wording is: "We will honour our commitments to the United Nations' Convention for the Rights of Disabled People and ensure its principles are reflected across government to create policies which remove barriers to equality and focus on disabled people's representation at all levels of government."

Foxcroft then added: "We've still got time until the next [election].

"I think it's one of those where in government you have to hold us to account in terms of whether we are actually committed to it."

When DNS asked for a definitive position on whether a Labour government would – currently – implement the convention into UK law, she admitted: "It doesn't say that at the moment."

Rick Burgess, from Manchester DPAC, one of those protesting outside the conference on Tuesday, said the current situation, without UNCRPD implemented in UK law, means that "ultimately, our rights remain negotiable on a case-by-case basis".

If the convention was incorporated into UK law, disabled people would be able to use the legal system to defend their rights, and policy-making processes would have to pay regard to the convention.

He said: "It lifts everything to a higher level of rights-based policy-making."

Burgess said DPAC was "calling for the UNCRPD to be brought into law by whoever wins the general election".

He said: “It’s particularly important with Labour because they did have a commitment to bring it into law and they seem to have dropped that.

“Between now and the election we have to try and get a promise that we can hold them to, that they will bring it into law.”

He said there was now a “window of opportunity” because it was always harder to extract such promises from parties once they are elected.

He said: “Disabled people will support them if they make it law.”

Another DPAC activist at the protest, Rhi, from Liverpool, said attention had rightly been focused on the Conservatives in government but it was also important to push Labour because it had “back-stepped on commitments they have made”.

She said the convention had a vital role in areas such as accessible housing – which she said was a “real problem” – and social care.

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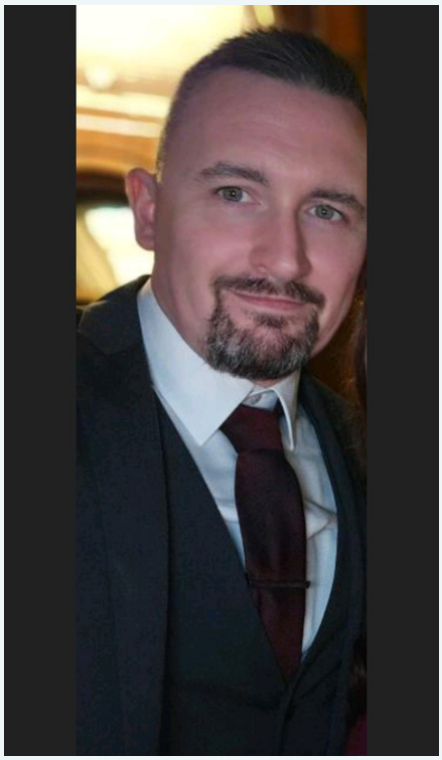
Craig Colligan...Understanding Personhood and Nurturing Dignity in the Context of Dementia



Dementia is a neurological disorder affecting millions worldwide, gradually robbing them of their cognitive abilities. While the signs and symptoms of dementia are well-documented, the impact on a person's sense of identity and personhood is often overlooked. This article aims to delve into the concept of personhood and explore its relevance in the context of dementia.

Defining Personhood

Personhood refers to an individual's intrinsic worth and their sense of self. It encompasses not just the physical aspects but also the beliefs, values, memories, and emotions that shape a person's identity. Personhood emphasizes that individuals with dementia are more than their disease and should be respected and treated as unique individuals irrespective of their cognitive decline.

Challenging Assumptions

There exists a common misconception that as dementia progresses, a person loses their personhood. However, research and advocates for person-centred care refute this notion. Instead, they argue that personhood is retained throughout the dementia journey, albeit often obscured by the symptoms of the disease.

Preserving Personhood

To preserve personhood amidst dementia, it is crucial to focus on nurturing the person's remaining abilities, providing meaningful activities, and encouraging social interaction. Simple gestures like addressing the person by name, offering a choice, and engaging in conversation can help foster a sense of dignity and individuality. Caregivers and healthcare professionals should prioritize a person-centred approach, tailoring care plans to the specific needs and preferences of the individual.

Validation and Empathy
Living with dementia can be isolating, mainly due to the challenges of expressing oneself. Validation therapy and empathetic listening allow individuals with dementia to communicate their thoughts and emotions effectively. By actively acknowledging their experiences, emotions, and memories, we show that their personhood is valued, ultimately improving their overall well-being.

Promoting Autonomy
Preserving personhood entails supporting autonomy as much as possible. This involves involving individuals with dementia in decision-making processes concerning their care, such as choices about daily routines, meal preferences, and recreational activities. Not only does this empower them, but it also maintains a sense of control, dignity, and personhood.

The Role of Memory
While dementia may impair memory, fragments of personal history and identity often persist. Capitalizing on these fragments can offer opportunities for connection and validation. Looking through old photo albums, listening to familiar music, or reminiscing on cherished memories can evoke emotions and create a sense of continuity, reinforcing personhood.

The Importance of Relationships
Meaningful relationships with family, friends, and caregivers play a vital role in preserving personhood. Engaging in activities that emphasize companionship and shared interests can foster a sense of belonging and offer emotional support. For individuals with dementia, the presence of familiar and caring faces can aid in maintaining connectedness and validating their sense of self.

Personhood is central to understanding and caring for those living with dementia. By recognizing and respecting the unique identity and worth of individuals with dementia, we can prioritize person-centred care, nurturing their dignity and well-being. It is essential for society as a whole to challenge stigmas, advocate for greater awareness, and support research to further enhance our understanding of personhood and 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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Storytelling Resource launched to help people open up about their experiences with dementia

Published on 04 October 2023 01:44 PM

Pictured: (L-R) Dina Roggero from About Dementia, Shona Cowie from The Village Storytelling Centre, Dr Kainde Manji, Head of Dementia at Age Scotland, and Helen Mill, executive director of The Village Storytelling Centre.

A pioneering initiative using storytelling to encourage people to open up about their own experiences of living with dementia has been launched by Age Scotland's dementia policy forum, About Dementia

.The new Storytelling Resource is aimed at people who run groups and organisations working with people living with dementia.

It is hoped people using the resource will open up about any challenges they might be facing, such as circumstances with carers, finances, or issues in the community relating to transport or accessibility.

About Dementia has co-created the resource with The Village Storytelling Centre and it has taken two years to trial and develop the package.
The programme was officially launched at the Scottish Storytelling Centre, in Edinburgh.

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Centre and it has taken two years to trial and develop the package.
The programme was officially launched at the Scottish Storytelling Centre, in Edinburgh.

Age Scotland's Head of Dementia, Dr Kainde Manji, opened the event.

The launch event was packed to capacity with people with a shared interest in supporting people living with dementia, from representatives of organisations and community groups to health professionals and those with lived experience.

Interactive activities gave people a taster of what is included in the free resource, which contains six workshops and all the materials needed to run them.

Through a series of scenarios, the tool encourages participants to connect with their own experiences and offers a safe space to share as much or as little information as they like, on their terms.

The workshops present fictional scenarios, based on real life events faced by people with dementia, and participants are encouraged to give the characters advice to resolve these challenges.

In doing so, participants can choose to share similar experiences – helping those who run the groups to identify service needs which might not have already been recognised.

For example one session might introduce a character called Jim who has a new carer who made him a cup of tea with milk and two sugars. Jim was upset because he drinks his tea black and without sugar and now he wonders how he will ever build up trust with her when she does not even ask how he takes his tea.

Tasters of the sessions were lead at the launch event.

Workshop participants would be asked to advise the character of what steps he should take next and write them on a "postcard" to Jim.

While running pilot workshops for the resource, About Dementia found many participants would comment on similar situations they had experienced like Jim's and could relate with the advice offered by other participants.

Themes for the sessions include finances, hobbies and activities, human rights, care and support, and community issues.

Feedback from the workshops will then be submitted to About Dementia, who will use it to provide an increased understanding and awareness of what needs to change in the dementia policy landscape.

Dr Kainde Manji (left) with Helen Mill.

Dr Kainde Manji, Head of Dementia at Age Scotland, said:

“Listening to and including the voices of people living with dementia is absolutely central to good policy making.

“Storytelling is a proven method to enable this to happen – it allows people living with dementia to engage with familiar situations at one-step removed.

This enables us to talk about challenging topics without personalising them to an individual.

“The new resource will ensure that community groups can facilitate meaningful policy-based conversations with their members, in an accessible way.”

Helen Mill, executive director at The Village Storytelling Centre, said:

“At the Village Storytelling Centre we believe that everyone has stories worth sharing and that Storytelling has the power to change lives.

This project is a perfect example of that belief because it places value on the real life stories of people with lived experience of dementia and ensures that those stories shape policy and services that affect their lives.

“It has been an absolute pleasure to work alongside the About Dementia team to develop this resource.”

For more information on the Storytelling Resource, or to register your interest in receiving the free materials, email: aboutdementia@agescotland.org.uk

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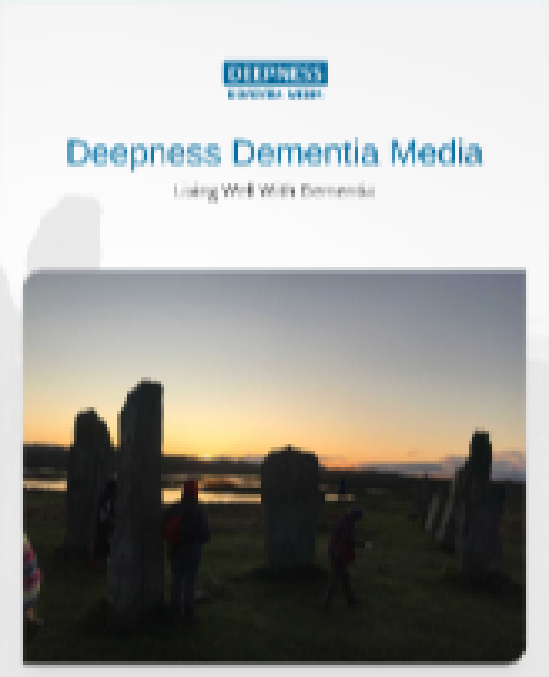

Deepness Dementia Media is a platform that gives people tools for living well with dementia designed collaboratively with those with dementia leading the process. By coming together in a supportive, energetic common space makes up a huge difference to the well-being of those going through dementia. As 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