

[Sign up to our Monthly Newsletter](#)

Hello everyone May is here, lets hope we can all find some sunshine in the newsletter. My name is Anne Scott the Deepness Dementia Newsletter Editor, Welcome to the May 2024 edition of the newsletter.

If you are a regular reader of this newsletter and enjoy reading it, please do send me a quick email or message on Mail Chimp about what you like and not like. I'd love to promote the newsletter, to increase our readership, so some testimonials would be great!.

Lots of interesting articles in this month's newsletter, including World conference held in April in Krakow Poland; end the persecution of unpaid carers; clothing transitions... plus all our regular features.

Please do get in touch and let me know your thoughts.

As always you can contact me at - [scottanne@live.co.uk](mailto:scottanne@live.co.uk)

Thanks  
Anne Scott





Check out below a list of what is coming up in this newsletter. You can click on the links and skip straight to that article.

- **News from Deepness Dementia**
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- **End the “Persecution” of Unpaid Carers...by Anne Scott**



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](mailto: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...

Thank you.  
Anne Scott



# News from Deepness Dementia

We have some exciting news from Deepness Dementia. Which you can read in this section under the following headings:

- Scottish Dementia Arts Festival 2024 - **CALL OUT for Participants**
- Dementia the Musical - **Tickets on Sale for Edinburgh Show**
- Karen Taylor's **A Box of Smiles**



## **Scottish Dementia Arts Festival 2024 - CALL OUT for Participants to take part**

After the huge success of the first ever Scottish Dementia Arts Festival in 2023, Inverness, we are super excited to announce our second Scottish Dementia Arts, taking place in Edinburgh from 11th to 14th November 2024.



We are currently looking for participants to take part, either who are people living with dementia or work in collaboration with another organisation.

We are looking for performance, film, visual arts, craft exhibition and workshops.

To find out more please visit our website designated to dementia arts - <https://www.deepnessdementiaarts.co.uk>

For full needs on taking part, please see our Submissions Document - [https://www.deepnessdementiamedia.com/shared/images/content/bus\\_54552/pdf/Submission -  
\\_The\\_Scottish\\_Dementia\\_Arts\\_Festival\\_Edinburgh\\_November\\_2024.pdf](https://www.deepnessdementiamedia.com/shared/images/content/bus_54552/pdf/Submission_-_The_Scottish_Dementia_Arts_Festival_Edinburgh_November_2024.pdf)

**Proposals must be submitted by TUESDAY 30th JULY 2024**



## **Dementia the Musical - Tickets on Sale for Edinburgh Show**

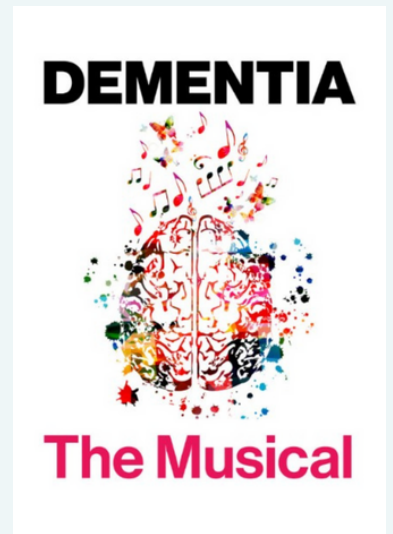
I am sure many of you know that Dementia the Musical, written by Ron Coleman, received a Creative Scotland grant and will be doing a Scottish Tour in Autumn 2024.

For those of you who live in Edinburgh or nearby, tickets have already gone on sale by Capital Theatres for the Edinburgh show on Saturday 12th October 2024.

**Matinee - 2pm, Evening - 7.15pm**

To book your tickets -

<https://www.capitaltheatres.com/whats-on/all-shows/dementia-the-musical>



## **Ronald Amanze's 'A Box of Smiles' by Karen Taylor**

Some of you will know Ronald Amanze (to the right) from his weekly radio shows or from the Scottish Dementia Arts Festival 2023.

Ronald has developed 'A Box of Smiles' which he showcased at a powerful workshop in Inverness in November 2023. Here is Karen Taylor's Box of Smiles.



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## News from aboutDementia... by Colm McBriarty



This month, I want to celebrate the start of the Network's second year (and the landmark of 150 members) to shine a spotlight on some specific member groups. The aim is to show the variety of the work that goes on in homes, venues and local communities all over Scotland to support and empower people living with dementia and caring partners, families and friends.

However, there are still a couple of spaces available so if you would like to do a short presentation on your organisation, talk about a specific aspect of your work, or share something exciting with the Network, this is your chance!



I have set aside 15 minutes or so for each of the three speakers so please have a think and let me know as soon as possible if you would like to be involved. If any of your members with lived experience would like to deliver or contribute to your presentation, they would be particularly welcome. Please don't be shy, especially if you are a smaller or newer group. If I can't fit anybody in this time, there will be more opportunities soon.

I'm delighted to say that Keira O'Sullivan from the Scottish Book Trust will be talking about their Reading Is Caring programme:

<https://www.scottishbooktrust.com/reading-and-stories/reading-is-caring>

Keira O'Sullivan from the Scottish Book Trust told us all about their Reading Is Caring programme. This provides a personalised reading support package specifically designed for people living with dementia and their carers.



## **Reading is Caring: I am a family member or friend**

If you live in Fife, the Scottish Borders, Edinburgh or the Lothians, you can sign up for free workshops now by emailing [readingiscaring@scottishbooktrust.com](mailto:readingiscaring@scottishbooktrust.com)

### **What is Reading is Caring?**

Reading is Caring is an established, free course that supports Care Partners to create personalised shared reading experiences specifically designed for the individual they are caring for who is living with dementia.

Reading is Caring builds on your existing caring relationship and demonstrates the benefits of a personalised shared reading experience with someone who is living with dementia.



### **Together, we will build on your existing relationship**

The course encourages reading aloud and bases its guidance around the different stages of the dementia journey and how to adapt the content and format of the reading materials chosen.

It's beneficial because we put the individual living with dementia at the centre of the process and personalise the reading experience to their specific needs, requirements, and interests.

*I was reading to her from a book we had a shared history with and holding her hand as she died. I think it helped. Even towards the end when she couldn't speak or open her eyes but was peaceful, we would get a raised eyebrow or twitch of the lip in response to poems and texts she knew and loved.*

*- Martha, who cared for her mother while she was living with dementia.*



## Get involved

If you live in Fife, the Scottish Borders, Edinburgh or the Lothians, you can sign up for free workshops now by emailing [readingiscaring@scottishbooktrust.com](mailto:readingiscaring@scottishbooktrust.com)

We have a flexible schedule and can arrange sessions to suit your unique circumstances. We also provide support to cover the costs of care so you can take part.



Please get in touch for more information on our latest workshop dates (listed below) and how we can help.

- If you live in Fife, the Scottish Borders, Edinburgh or the Lothians, you can sign up for free online workshops now by emailing [readingiscaring@scottishbooktrust.com](mailto:readingiscaring@scottishbooktrust.com) or using the form below.
- If you live elsewhere in Scotland, [sign up for our newsletter](#) to keep up to date with where Reading is Caring goes next and all things Scottish Book Trust.

Want to learn more about the workshops before taking part? Check out our [Reading is Caring FAQs](#).

We are currently offering a series of half-day workshops that take place online. Please visit the page below to find upcoming workshop dates. If you can't attend on any of these days, or would prefer to take part in person, do get in touch and we'll see how we can work together.

### [Upcoming workshops](#)

*It was as if when we read together, she was lost with me in the story, and we then talk about the story as if her dementia was no longer there.*

*- Rosemary, a professional carer for Margaret who is living with dementia*

Lots more information about Reading and Caring can be found here:

<https://www.scottishbooktrust.com/reading-and-stories/reading-is-caring>

You can also contact Keira directly at [Keira.OSullivan@scottishbooktrust.com](mailto:Keira.OSullivan@scottishbooktrust.com)





With a lovely bridge between reading and storytelling, Allister McKillop from Dementia Friendly Pentlands gave us an insight into the joys of intergenerational storytelling at the group.

You can read about all of their work here:  
<http://dementiafriendlypentlands.org.uk/>

### **Love to Move | British Gymnastics Foundation**

Love To Move is a seated exercise programme developed by the British Gymnastics Foundation which is both designed for older people and is also dementia responsive:

#### **What is Love to Move?**

Love to Move is an age and dementia friendly seated movement and exercise programme. The programme has its roots with gymnastics and uses specially designed coordination and bilaterally asymmetrical movement patterns, which are thought to have the effect of increasing a person's cognitive reserve. Find out more: Love to Move | British Gymnastics Foundation.



#### **Funded places for new Deliverer Training**

Through funding from sports Scotland we are delighted to be able to offer some funded places on the following course. If you have individuals in your organisation who would be able to attend the training and then set up Love to Move classes/sessions/activity, please put them forward for the course. Places are limited so please only offer this opportunity to those who are interested in setting up classes/sessions/activity post training.

#### **Dates of upcoming courses**

Course - Love to move online training course

Dates - June 10th, 11th, 17th & 18th (Mon/Tues)

Times - 9.00am - 12.30pm

#### **What are the pre-requisites?**

Course participants should be 18 years minimum. No formal training is necessary, we welcome all participants with a passion and enthusiasm for working with these communities.



## **What's involved in the training?**

Participants learn about the key elements of the Love to Move programme and how they enhance wellbeing. They are supported to be able to deliver classes in their own setting or online with the provision of lesson plans, resource book and music to guide delivery. Participants are supported with pre course Dementia Awareness E-Learning and 4 modules during the course.

## **What happens after the course?**

Post course participants are supported with online mentoring or shadowing opportunities if required. The post course assessment is completed as a practical delivery online.

## **Ready to apply?**

Step 1- create a record with British Gymnastics. This is so the system will log your qualification and generate a certificate once you have passed your final assessment. It will also give you access to our online learning.

Please click on the link below to start the process. Course Enrolment - Love to Move Deliverer Training Generic ([british-gymnastics.org](https://www.british-gymnastics.org)).

Please open the attachment on this email and follow the instructions. This is a 2-step process, you will also need to enrol on the course (also detailed in the attachment).

## **Delivery licence**

The annual Love to Move Licence costs £45 per year and includes:

- Annual CPD to support delivery of Love to Move (in various forms from e-learning, webinars and videos to downloadable resources).
- Physical tools and apparatus to use in delivery of Love to Move (a different benefit each year).
- A link to the British Gymnastics Foundation and other deliverers through a central network forum.
- Access to all resources including support videos
- The right to work/ deliver under the quality assured banner of 'Love to Move' and the 'British Gymnastics Foundation' including use of the Love to Move logo and marketing support for sessions where requested through the British Gymnastics Foundation website.



## **Safeguarding**

In order to maintain the Love to Move Licence, deliverers will be required to evidence that they have an up to date PVG for Adults at Risk and public liability insurance (Min £5 million).

If you have any questions about the funded course opportunity or you have people interested, please get in touch.

Kind regards

Sarah Logan

Development & Experience Lead Manager (Part-time Tuesdays, Wednesdays, Thursdays and Fridays) M: 07825 828 868

Sportscotland has provided funding for some funded places on their training courses so if anyone from your organisation is interested, please have a read through Sarah's email. A registration form is also included.

Our Love to Move Programme is an age and dementia friendly seated gymnastics programme which is transforming the lives of people living with dementia.

You can now try the programme in the comfort of your own home.

[Love to Move online session #01](#)

[Love to Move online session #02](#)

[Love to Move online session #03](#)

[Love to Move online session #04](#)

## **Train to deliver Love to Move**

If you are passionate about making a difference and would like to train to deliver Love to Move, find out more about our courses by clicking the button below and help us reach and benefit more people.

- [See our course dates here](#)



## Download our Love to Move booklet

If someone close to you is living with dementia, you will naturally want to do everything you can to help them to enjoy life as much as possible.

Our exercise booklet is available to help you try our Love to Move programme in your own home with your loved ones, containing some of the key exercises from the programme inside, as well as more information about why our programme is working.



- [Download a Love to Move booklet](#)

“They’ve helped me to get moving. They’ve helped me get home again.”

The Love to Move Programme has helped Jean regain her independence.

Jean wanted the chance to tell us about her story. She explained that she used to be a resident in the care home as she had lost some mobility and a lot of independence. She said it was our programme that made all the difference and helped her to get her independence back again and help her to get home again.



With your generous support, you can help more people to benefit from the Love to Move programme! Just £55 can support a group of people living with dementia to enjoy a love to Move session.

- [Donate to Love to Move](#)

## What makes our programme so effective?

Love to Move is specially designed to get older people moving and functioning better. The programme achieves this by carefully integrating the use of gymnastic foundation skills, cognitive stimulation therapy and social interaction activities. Almost every part of Love to Move is based on bilaterally asymmetrical movement patterns.



This is understood to benefit older people and those with dementia and mild cognitive impairment, by enabling the left side and right side of the brain to process information independently; thus improving cognitive function, coordination and the ability to carry out activities of daily living more independently.

Above all, the programme is fun! One of our participants has said that it brings her; “One hour of wonderfulness each week!”

- [Download a Love to Move booklet](#)

“The Programme has a demonstrable benefit in the physical, emotional and cognitive aspects of older people and those older people having mild to advanced forms of dementia appear to benefit the most.”



Research conducted by Age UK, June 2016

Colm.

### Colm McBriarty

Community Development Officer (Dementia)



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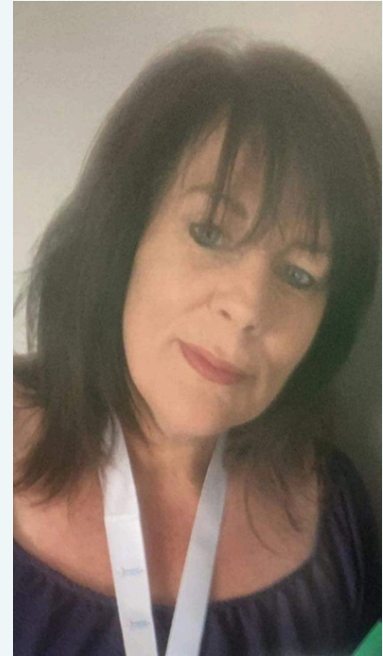


# PM Must Stop Scapegoating Disabled People For Government Policy Failures...by Anne Scott

The Prime Minister Rishi Sunak today delivered a scathing attack on so-called 'sick note culture' and that a life on benefits had become a "lifestyle choice" for far too many people.

As part of this, he announced that the Government is to consider shifting the responsibility for issuing the fit note away from primary care to "free up valuable time for GPs", while creating a system better tailored to an individual's health and work needs.

A call for evidence will be published today to seek responses both on how the current process works and how it can better support people with health conditions to start, stay, and succeed in work.



In a surprise announcement, he added that the Government will also consult on a "more objective and rigorous approach" to Personal Independence Payments (PIP), particularly for those with poor mental health.

Much of the PM's speech highlighted the increase in benefit claims associated with poor mental health, especially among young people.

He characterised his overall strategy as "about saying that people with less severe mental health conditions should be expected to engage in the world of work".

This attack on Disabled people and those with long term health conditions was reinforced by Work and Pensions Secretary Mel Stride who said: "If you go to the GP and say you are feeling a little bit depressed, and you're signed off, in 94% of occasions, a box is ticked that says you're not capable of work whatsoever." However, there's no evidence to back Mel Stride's sweeping claim or for the PM's that sick notes are being given out like sweets by gullible GP's.

In reality, the rise in mental health problems is all too real.

There are over 1.9 million people currently on waiting lists for NHS mental health services. In January this year, the NHS recorded the highest referral numbers to crisis care teams since January 2019.



In addition, **around one in four (24%) of the total population are disabled.**

That represents an increase of 3.9 million people over the past decade.

Very few people if any willingly opt for “a life on benefits”.

Certainly not Disabled people.

Disabled people are far more likely than the general population to be in poverty – which might be because they are not able to work, and/or because they face unavoidable higher costs because of their disability. In addition, we face inadequate support in education, employer ignorance and prejudice and barriers in the workplace.

Disability benefits should be alleviate poverty and allowing disabled people to live stable and dignified lives.

In fact:

- The Proportion of Disabled people and people with a long term debilitating health condition is rising.
- More working-age people in the UK are living with long-term health conditions than ever before.
- For many, poor health means not being able to work.
- There are currently more than 2.6 million working-age people who are out of the labour market due to long-term sickness.
- This trend is set to continue – projections by the Health Foundation show that around 0.5 million more working-age people will be living with major illness by 2030.

Disability benefits are vital in alleviating poverty this and need to be raised to allow Disabled people to live stable and dignified lives.

Disabled people are almost three times as likely to live in material deprivation in comparison to the rest of the population.



Moreover, the Government has already announced plans to [change the work capability assessment scheme](#) and then [scrap the work capability assessment altogether](#).

These reforms will include the abolition of the “substantial risk to physical or mental health if found not to have a limited capability for work related activity” eligibility criteria.

And devolving assessment of a disabled claimant’s capability for work to medically unqualified work coaches backed up by the threat of benefit sanctions.

In addition, disabled claimants could see their benefit reduced by £390 per month

Fazilet Hadi DR UK’s Head of Policy said “Once again the Government is targeting Disabled people for a failing economy.

Yet it is Government policies that have fuelled increases in disability and sickness.

Under resourcing of health services, social care, education, housing and transport, are excluding Disabled people from opportunity and driving us into poverty.

Deepening poverty is driving increases in disability and sickness.

The Prime Minister’s approach to systemic inequalities caused by Government policies and underfunding of public services, is to further penalise, punish and threaten Disabled people living on inadequate benefits.”

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# Do Not Attempt Cardio Pulmonary Resuscitation DNACPR...by Howard Gordon

One important aspects of living with Dementia is our choices around our end of life care.

Compassion in Dying has launched a new report, What people need from a DNACPR decision and discussion.

Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decisions are a vital part of end-of-life care, but their research (based on focus groups with older people) suggests that communication failures need urgent attention.



DNACPR research commissioned by Ombudsman.

Compassion in Dying was commissioned by the Parliamentary and Health Service Ombudsman to conduct research into older people's experiences of DNACPR decisions and discussions in England.

This is a topic that callers to Compassion in Dying's nurse-led information line regularly raise. The PHSO asked them to investigate what is happening for people, what they would like to see done differently in the future, and whether people considered complaining if they had a bad experience.

Peace of mind from good conversations.

Those who had a good experience were often grateful for the opportunity to consider their wishes. Many felt peace of mind even if the conversation was challenging at first. They talked about trust, honesty, respect and feeling like an equal partner in the conversation.

For those who had a poor experience, the impact was often significant and it left a lasting mark on the lives of the people affected. The causes of poor experiences were different from person to person. Problems spanned from how a decision was made and communicated to how it was implemented.



Several distinct and repeating themes:

- **Communication:**

People were not told that a DNACPR decision had been made and this caused significant distress. Sometimes the communication of a DNACPR decision was left to family members which resulted in guilt and loneliness.

Conversations often happened too late and in times of crisis. Sometimes a DNACPR decision was communicated in an uncaring way, which left people feeling shocked, scared and angry. Notably, it was rarely the decision but rather its poor communication that caused distress.

- **Understanding:**

People frequently did not know why a DNACPR decision was needed or what triggered a DNACPR discussion, causing confusion and frustration and raising fears of ageism.

- **Trust:**

DNACPR decisions were sometimes ignored, which caused people to feel disrespected. At other times a person's DNACPR decision and end-of-life wishes were not accessible when needed, so people lost trust in 'the system' and existing trust in the NHS was eroded.

Recommendations from participants.

At the end of the report, Compassion in Dying details the recommendations that people want to see taken forward. Everyone spoke passionately about the need for respectful conversations, clear decision-making processes and greater public awareness around death and dying.

People who had a bad experience felt strongly that the recommendations must be complemented by greater understanding and recognition from professionals of the central role that communication of DNACPR decisions has in the provision of good care. You can read the full report here (external link will open in a new browser tab or window)

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## Willy Gilder goes to the World Conference held in April in Krakow Poland...by Willy Gilder

Having come across the organisation Alzheimer's Disease International, and agreeing with their message of involvement, I thought it might be interesting to go to their World Conference held in April in Krakow Poland.

Through Age Scotland I applied for funding to do this, so ADI paid for my attendance whilst Age Scotland booked flights and accommodation. I'm glad I went, but I have to say that I found the whole experience to be a rather mixed bag.

The first hiccup was at Edinburgh Airport. I have problems with my feet, so always book Special Assistance.

A couple of days before we were due to take off my right foot decided to be particularly painful, making walking very difficult. At the airport I was wheeled through security very efficiently and then parked at Gate 15. I was told that when the plane was ready someone would come to push me to the foot of the stairs up to it. But - no one arrived. In the end Graham Galloway, who was on the same flight, pushed me as far as the plane. Without him being there I might still be stuck at Gate 15! I have since complained to the Airport about this, and they've acknowledged that someone should have been there to help, and apologised for the inconvenience.

After a rather cramped flight we arrived in Krakow, where the special assistance worked well - with a young lady going out of her way to link me up with my designated taxi. The driver was proud of his city, so gave me a free guided tour of the old city before dropping me at my hotel. I confess I had no idea that Krakow was such an attractive place, and such a major tourist destination.

Graham and I had a day in hand before the conference started, so we became tourists ourselves - exploring the medieval market square, and taking an electric buggy tour of the old Jewish Quarter. We then went to enrol at the conference venue, a large hotel on the outskirts of the city. We each got given a name badge and branded goody bag with conference programme. Enrolment started at 6pm.





That evening, reading through the programme I discovered that at 4pm there had been an introductory and orientation session for people with lived experience. I was sorry to have missed this, but it did rather sum up the conference's attitude towards those of us with brain disease - that we weren't exactly central to the discussions. It wasn't that we weren't welcome, more that we weren't written in to the proceedings as a vital and integral part.

The next day the conference got underway. Most sessions consisted of specialists from around the world sharing their latest research. To be honest, much of this was a bit dull: researchers aren't always the most riveting public speakers! Alongside these sessions numbers of organisations had stands where they promoted their work, and then there were numbers of posters detailing research projects.

Taking all of this in is quite a feat. It made me realise just how much work worldwide is going into dementia research - but there was little on working alongside people who themselves have Alzheimer's or other forms of dementia. I couldn't help but reflect that Scotland is showing the way here.

I was involved with one particular presentation. In a session on 'non pharmaceutical interventions' Ron Coleman talked about the Highland Dementia Arts Festival - and while he talked for his 11 minutes I was on stage, drawing the audience. This seemed to go down well, and we finished the session with an improvised boogie courtesy of Magda, an American dance therapist!

Whilst I'm critical of the rather dry style of the conference I loved meeting people from many different countries and organisations. I learned about Lewy Body dementia from a lady whose father had the disease. I met a lady from Northampton Mass, who was surprised that I knew her town. I talked with people from Australia and Indonesia and Japan, and finally found a British researcher now based in Australia who could explain to me the difference between my type of parietal Alzheimer's and Posterior Cortical Atrophy. I've never been able to find anyone in Scotland to explain this. It was also great to meet up with Meeting Centre enthusiasts from around the UK, and around the world. It was good to hear from Prof Rose-Marie Drpes from Amsterdam about how she developed her thinking behind the idea originally.



After the conference ended, we again had a day in hand. Graham and I first visited Heroes Square, the centre of the old ghetto. It is now marked with 33 dining chairs, cast in iron - each representing the lives of a thousand people. Later we met up with some other delegates for a tour of the rather strange underground museum, built under the medieval square at the centre on Krakow. This features the graves of supposed vampires and is all very impressive, except there's not a lot of information to explain everything.

All too soon we were back at Krakow Airport, waiting to fly back to Edinburgh. This time around special assistance worked well, and I got wheeled all the way to the tram! Back home I started to wonder about how we might influence things like the ADI Conference. There are some really interesting bits of work going on all over Scotland, and some excellent examples of involvement of people with 'lived experience'. I think we need to share some of these to a global audience.

Willy Gilder

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# Remember the Discman?...by Michael Cheung

## Remember the Discman? A Tribute to the Portable Music Players of 1998



Before the iPod and smartphones, the Walkman and Discmen allowed for technologically simple and yet distraction-free, listening on the go or at home. I am wondering if the return of the discman/CD players listening to our favourite CDs could be a way to listen to a playlist for people living with dementia

### A brief reminder of the Discman

In 1998, most portable music devices were getting to the end of an era. The MP3 players soon appeared, then there were the iPods, and earbuds would become the defining accessory soon after. At the end of 1998, the Walkman and Discman became fixtures store cupboards. The Discman and Walkman capabilities seemed limited. Before leaving home and listening to music at home, we have to think about what album – CD/cassette to carry, and maybe carry at most a few extras.



To me this is a relatively simple task for people living with dementia and their cares to cope with!

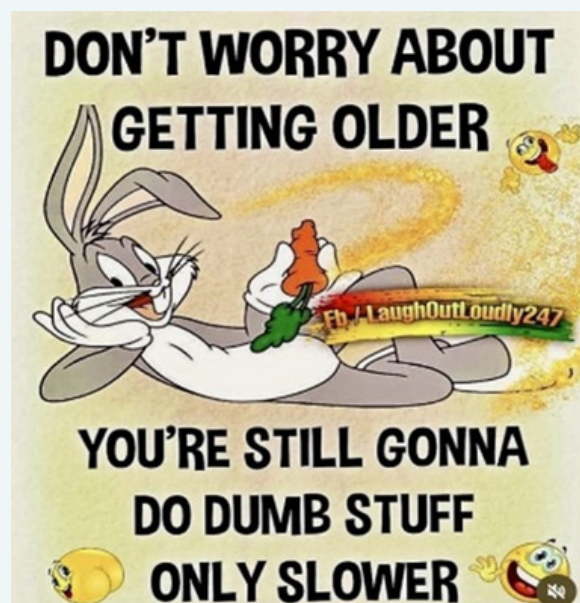
### Can CDs make a comeback?

The CD was first commercially released 40 years ago and may be having a whole new coming-of-age. With sales on the rise and collectors highlighting their pride across social media, the format might rewind to its glory years. Although CDs have primarily been replaced by all-you-can-consume music streaming services, something interesting happened in 2021: CD sales rose for the first time in almost two decades, driving over £400 million in revenue for the worldwide music industry; in comparison to the £1.0 billion earned from streaming, the figure is still significant.

On a personal note, I have a collections of nearly 140 CDs 135 vinyl, and this is one way I relax listening to my favourite music. Recently I purchased a Discman, and this is one device I used most of the time; but also use the record player/ CD unit as well.



The combining the use of Discman/CD players and CD's and probably listening to vinyl can be of benefit to people living with dementia and their carers. It is not just the physical attachment to the music that has been lost in the streaming era. In some ways, streaming has made the playlist more valuable than the music itself. Clicking like on a song provides significantly less emotional attachment for a consumer than buying and holding a CD, cassette or vinyl record. In the physical format era, fans invested in their favourite artists; something a person with cognitive impairment could benefit.



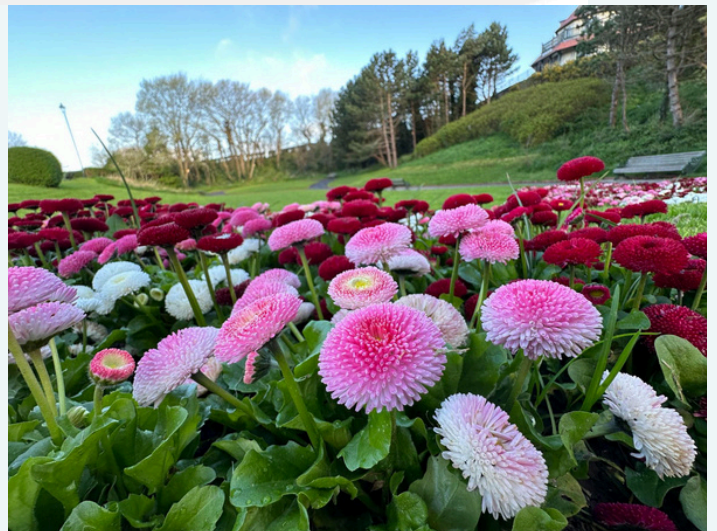
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## Photography Corner...Spring Photos by Gail Gregory



Spring is a season of renewal, signaling the end of the cold winter months and the arrival of warmer weather. It is a time when nature awakens from its slumber. The vibrant colours of the flowers, and lots of new life begins







Spring has to be one of my favourite seasons, there is just so much new life around to warm my heart.

Gail Gregory

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## Rhythm for Life...by Louise Davidson

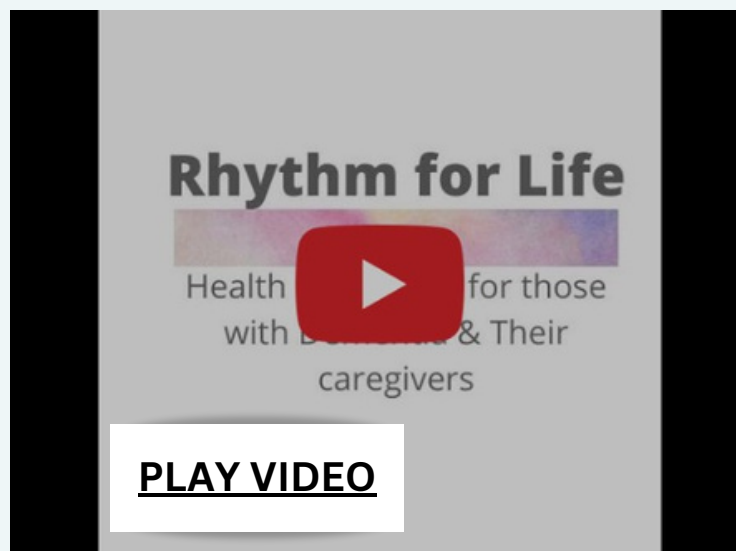
In this regular feature with Louise Davidson, we are happy to see that Louise's corner within the newsletter has become a regular feature.

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 movement. She writes: *"Nice half hour of gentle seated stretching, mobility, brain training and ending up with a wee dance :)"*.



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# The Power of Sport Activities in Managing Dementia: A Pathway to Improved Quality of Life...by Craig Colligan

Dementia is a devastating condition that affects millions of people worldwide, robbing individuals of their cognitive abilities, memories, and independence. As the global population ages, the prevalence of dementia continues to rise, posing significant challenges to individuals, families, and healthcare systems. While there is currently no cure for dementia, research has shown that engaging in sport activities can have a profound impact on managing the symptoms of the disease and improving the quality of life for those living with dementia.

Sport activities encompass a wide range of physical and mental exercises, including walking, swimming, yoga, tai chi, and even simple activities like gardening or dancing. These activities offer numerous benefits for individuals with dementia, including improved physical health, enhanced cognitive function, increased social engagement, and reduced feelings of isolation and depression.

Regular participation in sport activities can help individuals maintain their physical strength, flexibility, and balance, reducing the risk of falls and other injuries commonly associated with dementia.



Moreover, engaging in sport activities has been shown to stimulate the brain and promote neuroplasticity, the brain's ability to reorganize itself by forming new neural connections. Physical exercise increases blood flow to the brain, delivering essential nutrients and oxygen that can help protect brain cells and promote cognitive function. Studies have also demonstrated that regular physical activity can help slow down the progression of dementia and improve memory, attention, and executive function in individuals with the condition.

In addition to the physical and cognitive benefits, sport activities provide valuable opportunities for social interaction and emotional well-being for individuals with dementia. Participating in group activities such as walking clubs, dance classes, or team sports can help individuals feel connected to others, build relationships, and combat feelings of loneliness and isolation. Social engagement has been shown to improve mood, self-esteem, and overall quality of life for individuals with dementia, enhancing their sense of purpose and belonging in the community.



One of the key advantages of sport activities in managing dementia is their adaptability and accessibility for individuals at all stages of the disease. Whether a person is in the early stages of dementia and able to participate in more complex activities or in the later stages and in need of simpler, modified exercises, there are a variety of options available to suit their needs and preferences. Caregivers, healthcare professionals, and community organizations can work together to create tailored sport programs that cater to the unique abilities and interests of individuals with dementia, ensuring that they can experience the benefits of physical activity regardless of their limitations.

In conclusion, sport activities play a vital role in managing dementia and improving the quality of life for individuals living with the condition.





By incorporating regular physical and mental exercises into their routines, individuals with dementia can experience a range of benefits, including improved physical health, enhanced cognitive function, increased social engagement, and reduced feelings of isolation and depression. As we continue to explore new ways to support individuals with dementia and their families, sport activities offer a promising pathway to promoting well-being, independence, and dignity for those affected by this challenging condition.

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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# Rights and Dementia

## British Social Attitudes Survey 2023...

### by Howard Gordon

If you were shocked to hear that public satisfaction with the NHS had declined to an all-time low of 24%, the situation with social care is even worse. Just 13% of respondents professed themselves satisfied with social care services.



The King's Fund and Nuffield Trust jointly sponsored the health and care related questions in the British Social Attitudes (BSA) survey for 2023. This is a 'gold standard' nationally representative survey that uses a robust methodology to explore public views on a wide range of issues.

#### **Satisfaction with social care services in 2023**

Just 13% of respondents said they were satisfied with social care, the lowest level of satisfaction recorded since the survey began. 57% were dissatisfied with social care.

There are three main reasons for dissatisfaction with social care:

- inadequate pay, working conditions and training for social care workers (57%)
- people not getting all the social care they need (56%)
- not enough support for unpaid carers (49%)

#### **Responding to this new research, Evan John, Policy Advisor at national disability charity Sense, said:**

*"It's little surprise that so few people are satisfied with their experiences of social care, given the huge challenges facing the system right now.*

*"Social care has been chronically underfunded, under-resourced and understaffed for years, with devastating consequences. We hear countless stories at Sense from families who are battling a complex system that comes with huge costs, yet often does not meet their needs. No matter your salary, everyone is expected to make a contribution to their social care, which can leave people spending a huge amount of their income on their care costs, including those who rely on benefits. This prevents many disabled people from ever becoming financially secure, while others run into debt.*



*“With local authority budgets increasingly under pressure, more and more people are seeing their social care support cut. Sense research found that a quarter of people with complex disabilities who use social care had their provision cut last year. This puts even more strain on family carers, and leaves disabled people without the support they need to live healthy and happy lives.*

*“The social care system is on its knees and it’s vital that budgets increase substantially, so that disabled people can access the care they need and providers can afford to pay care workers well. We also urgently need a social care workforce plan, which will lay out how the government will plug the staffing gaps in the sector.”*

### **British social attitudes to individual aspects of NHS**

Just a third of people said they were satisfied with GP services, which is the lowest level of satisfaction recorded since the survey began. Satisfaction with GP services has fallen by 34 percentage points since 2019.

Satisfaction with NHS dentistry services also fell to a record low of just under a quarter, with dissatisfaction at a record high of 48%.

Levels of satisfaction with inpatient, outpatient and A&E services are all the same or very similar to the previous survey, with 35% satisfied with inpatient services and 44% satisfied with outpatient services. Both of these are at record low levels. Just 31% said they were satisfied with A&E services.

Perhaps unsurprisingly, people were more likely to have a view on services they had had contact with themselves.

[You can download the report from the King’s Fund website](#) (external link will open in a new browser tab or window).

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# Happy belated Vaisakhi...by Michael Cheung

## Happy belated Vaisakhi

**Vaisakhi** (Punjabi: ਵੈਸਾਖੀ , **vaisākhī**, is also known as **Baisākhī**), is an especially important day for Sikhs and one of the most colourful events in the Sikh calendar. It occurs during mid-April every year and traditionally in Punjab, the festival corresponds with the first harvesting of the crops for the year. Historically, the festival has been a very joyous occasion and a time for celebration. However, since 1699, it has marked the incredibly significant religious event of the creation of the Khalsa Panth.



Eating good food is a must for good Mental Health and Wellbeing



Healthy and traditional Baisakhi dishes could fit into this. Sugar and processed foods can lead to inflammation throughout the body and brain, which may contribute to mood disorders, including anxiety and depression. When we're feeling stressed or depressed, it's often processed foods we reach for in search of a quick pick-me-up. During busy or difficult periods, a cup of coffee stands in for a complete breakfast and fresh fruits and vegetables are replaced with high-fat, high-calorie fast food. When feeling down, a pint of ice cream becomes dinner (or you skip dinner altogether).

To boost our mental health, we should focus on eating plenty of fruits and vegetables along with foods rich in omega-3 fatty acids. Dark green leafy vegetables in particular are brain protective. Nuts, seeds and legumes, such as beans and lentils, are also excellent brain foods. For healthy and traditional Baisakhi dishes.





Visit this site ‘Super Healthy Dishes You Can Prepare at Home This Baisakhi’.

[9 Healthy and Mouth-Watering Baisakhi Recipes to Try at Home \(kent.co.in\)](#)

Watch this interesting You-tube video on Vaisakhi (Punjabi: ਵੈਸਾਖੀ , vaisākhi).

Mike Cheung May 2024



**Finally, A Quote from the Sikh Mental & Wellbeing Website**

*“You can have “Good Mental Health,” “Somewhere in the middle” or “Poor Mental Health.” Just like our physical health, we need to take care of our mental health. Mental Health describes your mental state – how you are feeling and how well you can cope with day-to-day life. Sometimes we can cope really well, other times we can struggle. It can change from ‘moment to moment.’ We encourage you to learn and develop wellbeing techniques, so you can learn to stay in tune with your mental health and have ways to deal with it yourself. At the same time, having the knowledge that you can reach out for help whenever you need.”*

**In Punjabi**

ਤੁਸੀਂ "ਚੰਗੀ ਮਾਨਸਿਕ ਸਿਹਤ", "ਕਿਤੇ ਵਿਚਕਾਰ" ਜਾਂ "ਮਾੜੀ ਮਾਨਸਿਕ ਸਿਹਤ" ਲੈ ਸਕਦੇ ਹੋ। ਸਾਡੀ ਸਰੀਰਕ ਸਿਹਤ ਦੀ ਤਰ੍ਹਾਂ ਸਾਨੂੰ ਆਪਣੀ ਮਾਨਸਿਕ ਸਿਹਤ ਦਾ ਵੀ ਧਿਆਨ ਰੱਖਣਾ ਚਾਹੀਦਾ ਹੈ।

ਮਾਨਸਿਕ ਸਿਹਤ ਤੁਹਾਡੀ ਮਾਨਸਿਕ ਸਥਿਤੀ ਦਾ ਵਰਣਨ ਕਰਦੀ ਹੈ - ਤੁਸੀਂ ਕਿਵੇਂ ਮਹਿਸੂਸ ਕਰ ਰਹੇ ਹੋ ਅਤੇ ਤੁਸੀਂ ਰੋਜ਼ਾਨਾ ਜੀਵਨ ਨਾਲ ਕਿੰਨੀ ਚੰਗੀ ਤਰ੍ਹਾਂ ਸਿੱਝ ਸਕਦੇ ਹੋ। ਕਈ ਵਾਰ ਅਸੀਂ ਸੱਚਮੁੱਚ ਚੰਗੀ ਤਰ੍ਹਾਂ ਸਿੱਝ ਸਕਦੇ ਹਾਂ, ਕਈ ਵਾਰ ਅਸੀਂ ਸੰਘਰਸ਼ ਕਰ ਸਕਦੇ ਹਾਂ। ਇਹ 'ਪਲ ਤੋਂ ਪਲ' ਬਦਲ ਸਕਦਾ ਹੈ।

ਅਸੀਂ ਤੁਹਾਨੂੰ ਤੰਦਰੁਸਤੀ ਦੀਆਂ ਤਕਨੀਕਾਂ ਨੂੰ ਸਿੱਖਣ ਅਤੇ ਵਿਕਸਿਤ ਕਰਨ ਲਈ ਉਤਸ਼ਾਹਿਤ ਕਰਦੇ ਹਾਂ, ਤਾਂ ਜੋ ਤੁਸੀਂ ਆਪਣੀ ਮਾਨਸਿਕ ਸਿਹਤ ਨਾਲ ਤਾਲਮੇਲ ਰੱਖਣ ਅਤੇ ਇਸ ਨਾਲ ਖੁਦ ਨਜਿੱਠਣ ਦੇ ਤਰੀਕੇ ਸਿੱਖ ਸਕੋ। ਇਸ ਦੇ ਨਾਲ ਹੀ, ਇਹ ਗਿਆਨ ਹੋਣਾ ਕਿ ਤੁਸੀਂ ਜਦੋਂ ਵੀ ਲੋੜ ਹੋਵੇ ਮਦਦ ਲਈ ਪਹੁੰਚ ਸਕਦੇ ਹੋ।



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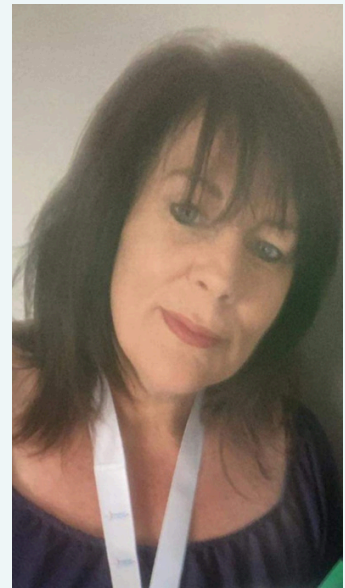
# Alexa Fund - Battle against Dementia...

## by Anne Scott

The 'Alexa Fund' has been launched by the Battle Against Dementia in recognition of the immense pressure that those suffering from dementia and their carers have to remain living in their own homes.

It is aimed at supporting the wellbeing of those living with dementia and their unpaid carers and focuses on the following:

- Improving/maintaining mental health.
- Improving/maintaining physical wellbeing and health.



### Am I eligible?

You are eligible to apply for this funding if you live in Scotland and living with dementia.

Please note that we reserve the right to close the fund early if, at any point it seems we will receive too many applications to process.

### Battle against Dementia charity funds Amazon Alexa for Glasgow residents

The charity Battle against Dementia is to fund hundreds of free Amazon Alexa devices for people with the illness.

People with dementia who live in Glasgow are being offered a free Amazon Alexa by a charity that support families affected by the disease.



Battle against Dementia is to fund hundreds of the devices for households across the city at a cost of £10,000.

The charity carried out a trial with the advocacy service Ceartas in East Dunbartonshire and families and carers reported positive benefits. Carers said it was useful for setting medication prompts.

The charity, which runs celebrity-backed golf tournaments, hopes to raise enough funds to roll out the technology across [Scotland](#)

Battle Against Dementia was founded by Douglas McCluskey after his father passed away with vascular dementia. He was originally an ambassador for Alzheimer's Scotland and through the organisation, held many events in his father's memory.

**READ MORE: [Billy McNeill Fund to be launched for former footballers affected by dementia](#)**

He said: "We did a test study last year with a group in East Dunbartonshire, we bought three or four and they were passed onto families to see what the effects would be.

"The test came back really positive.

"There's a man up in Skye who has dementia and has made his whole home voice activated. The charity has decided that investing this money would be a good way to help people with dementia directly.

"I think having something like that could help people who are struggling.

"You can activate it to tell jokes, or to play music, it's very therapeutic.

"There are no buttons to press, it's voice activated so you can ask for a song but carers can activate a time schedule to remind people to take their medication. All it needs is a wi-fi connection.

"We thought Glasgow would be a good starting point but we would hope to roll this out across Scotland".

#### ADVERTISING

The husband of one woman with dementia, who took part in the trial, said the technology had been a "great help".



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#### ADVERTISING

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**READ MORE: [Dementia sufferer put at risk after carers faked visits](#)**

He said: "Surprisingly she has taken to it like a duck to water, as she does not need to fiddle with buttons or switches but merely speaks to it.

"The like a nap in the afternoon and usually tells me when to wake her but, with Alexa she tells it to wake her in 2 hours and it does.

"She says it is more obedient than me!

"I have to say, every day I find something else it does and I do not know how I lived without it.

"You can set up full routines with the Alexa so that when come in and say Alexa I am home it will play preselected music or news etc. The list is endless."

Battle Against Dementia launched the Billy McNeill Fund two years ago to support former footballers affected by the disease. A major celebrity-backed fundraising event at Mar Hall has been postponed until 2022 due to the pandemic.

To apply for a device visit [www.battleagainstdementia.org](http://www.battleagainstdementia.org) or email [alexa@battleagainstdementia.org](mailto:alexa@battleagainstdementia.org)

**The Alexa Fund is an initiative launched by the Battle Against Dementia to support individuals living with dementia and their unpaid carers in Scotland.** It focuses on improving and maintaining the mental and physical wellbeing of those affected by dementia.

**The fund recognizes the challenges faced by individuals with dementia and their carers in remaining in their own homes and aims to provide assistance in this regard.**

The Battle Against Dementia organization, founded in 2018, also has the ambition to create a Dementia Hub in Glasgow and the west of Scotland. **This hub is envisioned as a safe and enjoyable place where people with dementia and their families can receive support, participate in activities, and get information, support, and advice.**



[In a past initiative, the charity funded hundreds of Amazon Alexa devices for households in Glasgow affected by dementia, with the goal of easing the lives of those dealing with the disease.](#) This reflects the organization's commitment to using technology to improve the quality of life for people with dementia and their carers.

[For more information or to get involved with supporting the Battle Against Dementia in Scotland, you can visit their official website.](#)

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## Clothing Transitions...by Teepa Snow

As summer approaches and the temperature climbs, it can sometimes be difficult to encourage people living with dementia to shift from winter to summer clothes. Why might this happen? One main reason is that, when people are living with dementia, their internal regulatory systems do not always function properly. This means that their brain might still be registering a sense of feeling cold, even if the environmental temperature is now warmer. How can we help individuals transition away from winter clothing so they don't become overheated?



When someone living with dementia is attached to certain clothing items, especially if the items help them feel warm and cozy, trying to get them to change abruptly into a full summer wardrobe may not work well. It is often best to transition in small steps or phases, changing out one clothing item at a time. It may help to find items that are very similar in colour and style to the warmer clothes they like, but are more lightweight. The individual will likely be more willing to switch out the item if it appears very similar to the one they favour. Once they have accepted the more lightweight item, then remove the warm item from their sight.

Another suggestion to consider is trying to transition some clothing items to those that are more temperature responsive. For instance, choose fabrics that wick moisture away from the skin. That way, even if they insist on wearing long sleeves and do perspire, the moisture will not sit on the skin and cause skin breakdown or other issues. Choosing warm-coloured clothing, such as oranges, reds, yellows, and browns, in lightweight fabrics is another possible strategy, as warm colours will often help send the brain a signal of being warmer. By contrast, cool clothing colours such as blues and greens can cause some people to feel colder.

Also, pay attention to the individual's extremities. Often, when people are older or are living with dementia, the circulatory system usually isn't as effective as it once was. So, their hands, feet, and head may not receive proper blood flow, and may be cold, even in a fairly warm environment. When one's extremities are cold, they are much more likely to feel cold all over. By keeping their hands, feet, and head warm, you can help them adjust to the temperature change more easily. Try using hats, thick socks, warm house shoes, or foot blankets to keep extremities warm.

Since it may be impractical and cumbersome to wear gloves or mittens when inside, try handing them a covered mug of warm liquid to hold. Also, do keep in mind that circulation issues can cause them to feel cold in general, so when others are wearing sleeveless shirts in the summer, they may feel more comfortable in lightweight long sleeves.



When an individual has just bathed or showered, they are likely to feel a bit chilled, so trying to get them to put on summer clothes at that time may be especially challenging. Keeping the bathing room as warm as possible and putting on an outer layer, such as a robe or cardigan, can help them feel less cold. Then, when they warm up, they may be willing to remove the outer layer.

Another strategy to help the individual transition out of winter clothing is to actually allow them to be in a warm environment with their winter clothing on. If it is hot outside, you could bring them outside - carefully monitored, of course. Or, if inside, you can purposely make the inside environment a bit warmer by turning up the heat or turning down the air conditioning or fans. You may wish to put on lighter clothes on yourself before doing this!

When the individual starts getting warmer, help them to recognize that the temperature is changing by saying something like, “Wow, it seems like it’s getting really warm – here, feel your head, you’re starting to perspire!”

Experiencing this significantly warmer temperature may help their brain recognize the temperature shift. Then they may be more likely to let you take off a layer of their clothing, or transition to a more lightweight garment. However, if they are getting warm and still do not wish to remove any clothing, then you will need to get them into a cooler environment so they can remain safe.



When clothing transitions are challenging, these strategies may help ease the shift to cooler clothing. Remember that patience with the process, and being willing to try different tactics, is essential for effective support of those living with dementia.

Teepa Snow



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## Poetry - Yes, I Cry...by Wendy White

### Yes, I cry

Yes, I cry when it gets too rough,  
when it feels like I have had enough.  
When all I want is to run and hide,  
please stop and let me off this ride.

No-one can help you prepare  
for how life changes once  
dementia is there.  
Taking each bit of a person away,  
little by little taking more every day.

Yes, I cry for you mum  
as you grow old, wishing  
dementia would release its hold.  
I cry for what was and what is now, I  
try to make sense of the why and how.

So enjoy what you have because  
it's only lent, everything in life  
is heaven sent.  
Borrowed for now but in the end  
it's the life you remember  
that will help you mend.

by Wendy White

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# Carers Training...by Age Scotland

More than 90,000 people in Scotland are living with dementia and this number is forecast to increase over the next decade. Early diagnosis of the condition is crucial and can help prolong the quality of life for people living with dementia.



We offer online and in-person training courses to raise awareness of dementia, help people learn how to be more inclusive of people living with the condition, and for carers to be better informed about their rights.

Workshops run regularly throughout the year and there are also self-study options, which allow you to complete courses in your own time.

Find out more about our free workshops.

## [Dementia Awareness](#)

This workshop will increase your awareness of dementia and how to be more inclusive of people living with the condition.

<https://www.agescotland.org.uk/information-advice/information-workshops/dementia-training/dementia-awareness>



## [Dementia Inclusion](#)

These workshops will help ensure your activities enable people living with dementia to be included and involved as fully as possible.

<https://www.agescotland.org.uk/information-advice/information-workshops/dementia-training/dementia-inclusion>



## [Carer's Training](#)

Our free, accessible training for unpaid carers of people with dementia helps to ensure they have a greater understanding of their rights, and how to access them.

<https://www.agescotland.org.uk/information-advice/information-workshops/dementia-training/carers-rights>



## [Dementia Friendly Communities Capacity Building](#)

These workshops are aimed at members of the Dementia Friendly Communities Network so they can grow their impact.

<https://www.agescotland.org.uk/information-advice/information-workshops/dementia-training/dementia-friendly-communities-capacity-building>



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## This Month's Recipe

### Yang-Yang Crispy Beef...by Michael Cheung

#### Ingredients

- Peanut oil, for frying.
- 1 sirloin steak, cut into 1.5 cm thick and finely sliced into strips.
- 2 tablespoons cornflour.
- Sea salt.
- 1 tablespoons light soy sauce.
- ½ tablespoon of sweet chili sauce.
- 1 small orange zested and juiced.
- ½ head cos lettuce, shredded.
- ¼ cucumber, sliced in half, seeds scooped out and thinly sliced into half-moons.
- 1 scallion, thinly sliced on the bias, for garnish.
- ½ tablespoons rice wine vinegar.

#### Method:

1. Marinate the beef strips in a l bowl and add cornflour Toss until the beef has absorbed the cornflour.
2. Heat a wok over high heat and fill halfway up with peanut oil. Heat the oil, for about 20 seconds.
3. Fry the beef in small batches until golden, 3 to 4 minutes. Drain on paper towels and season with sea salt.
4. For the sauce: Set another wok or sauté pan over high heat and add the soy sauce, chili sauce and orange juice. Bring to a simmer and cook until it becomes thickened and coats the back of a spoon, 1 to 2 minutes. Toss the beef in the sauce to coat thoroughly.
5. Serve over a bed of the shredded lettuce and sliced cucumber that has been sprinkled with rice vinegar. Then garnish with the scallions and orange zest.
6. Can also serve with boiled rice.



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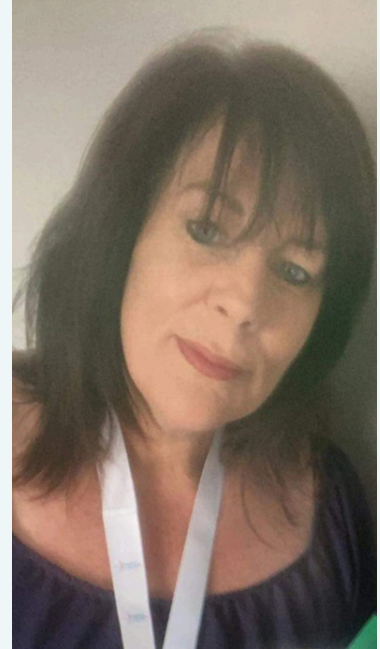
# End the “Persecution” of Unpaid Carers...

## by Anne Scott

The Government is facing calls to abandon cruel and nonsensical fines levied on tens of thousands of unpaid carers for unwittingly breaching earnings rules by just a few pounds a week.

Those who claim carer’s allowance, currently £81.90 per week, while working part-time are being forced by the Department for Work and Pensions (DWP) to pay back money that has been erroneously overpaid to them, in some cases running to more than £20,000, or risk going to prison.

**Carer’s allowance** is paid to those who provide at least 35 hours of unpaid care a week to look after, in the main, disabled relatives.



While those in receipt of the benefit are allowed to have a second income from a job, there are strict government limits on how much they can earn – currently £151.00 a week.

Overpayments can rapidly build up because even if the weekly earnings limit is exceeded by as little as £1.00, claimants become automatically ineligible for the entire carer’s allowance, resulting in a “cliff edge” repayment penalty.

Back in August 2019, the Work and Pensions Committee published a **highly critical report** on the DWP handling of carer’s allowance overpayments and accusing the DWP of “bullying and harassing” those who had unknowingly been overpaid the benefit.

The cross-party group of MPs called on the DWP to completely reassess its approach and consider writing off debts due to its own protracted administrative failures.

Although the DWP has IT systems that flag up when a carer’s income breaches the earnings threshold, it fails in many cases to act on the information.



Last week, news emerged of the shocking case of Vivienne Groom who was [prosecuted for failing to declare her minimum wage Co-op job while caring for her mother.](#)

She initially agreed to pay the DWP £16,800 in monthly instalments of £30, but when she stood to inherit £16,000 from her mother, the DWP sought to seize it using proceeds-of-crime laws.

Mrs. Groom had no legal representation and pleaded guilty over benefit fraud offences. She was sentenced to a community order with unpaid work requirements in November 2023.

This happened, despite the fact that she was told by her social worker that she did not have to tell the DWP about her job.

In addition, the DWP itself would have been told by HMRC that her carer's allowance entitlement had changed.

Mrs. Groom said: "I followed that lady's rules and I looked after my mum. I mean, if people look after their parents they should be paid more money so they don't have to go to work as well. I had to go to work. We had bills to pay."

Ken Butler, DR UK's Welfare Rights and Policy Adviser, said: The fundamental issue is that, despite her carer responsibilities to her mother, due to the low level of benefit she was receiving, Ms Groom needed to work on top of this because she had "bills to pay."

"Those in receipt of carer's allowance are more likely to be cutting back on food and heating (35%) compared to all carers (25%), according to [statistics from Carers UK.](#)

"Meanwhile, nearly 8% of unpaid carers in receipt of carer's allowance are using food banks to cope with the cost-of-living crisis, compared to 5% of all unpaid carers."

The persecution of unpaid carers like Mrs. Groom must end together with the harsh carers allowance earnings rules."



Helen Walker, Chief Executive of [Carers UK](#) said: “A wholesale reform and review of Carer’s Allowance and other carers’ benefits is needed to ensure these adequately support unpaid carers during the time they spend caring for someone so that the system does not punish them for misinterpreting complicated and harsh earnings rules.

“It’s shocking that there has been so little investment in the way that carer’s allowance is operated and the tight rules mean that many carers who need it, aren’t getting it. It’s even worse when you consider how much unpaid carers’ support is worth, which is billions every year.”

“We need the systems within the DWP to understand and tackle some of the challenges carers face in claiming benefits much better. We want to see the Department’s research, which they commissioned several years ago and, despite repeated requests, has not been published.

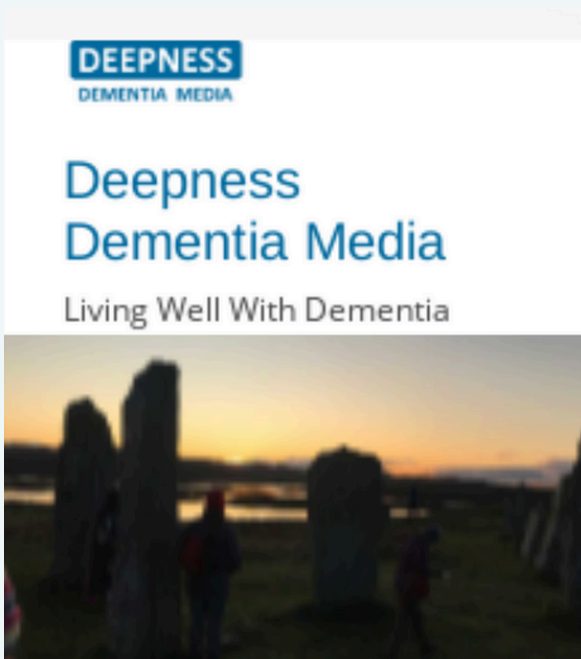
“Thousands of carers have told us that reforming carers’ finances is their top priority. Unpaid carers deserve better from our politicians and they must be a priority for investment.”

For more information see [‘DWP are the real criminals’: carer in tatters after ‘brutal’ fraud prosecution](#) available from [theguardian.com](http://theguardian.com).

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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/6pngYVybZ3qUf6XMhOOFuK>

**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>