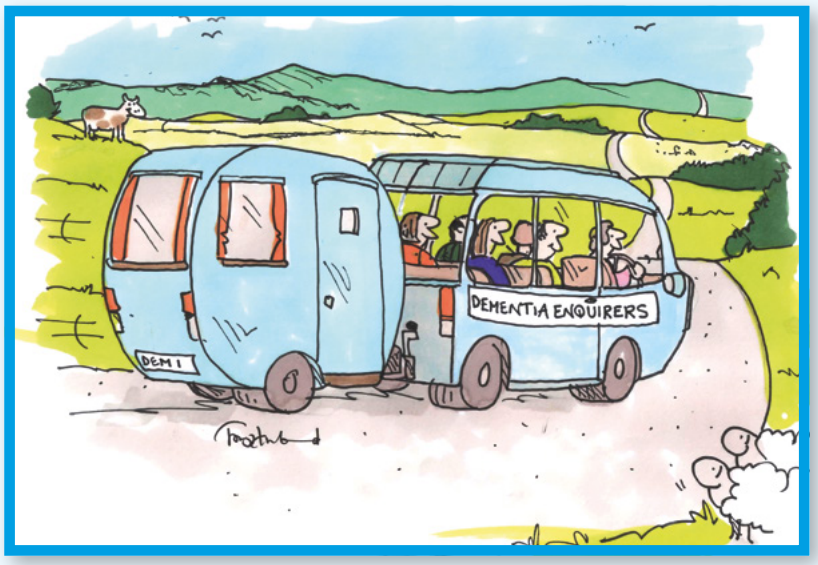
October/November 2024

Our deep News

The Newsletter from the UK Network of Dementia Voices

> **Power at its best is love implementing the demands of justice. Justice at its best is love correcting everything that stands against love** Martin Luther King Jr



In the DEEP network we talk about people with dementia being 'in the driving seat', being able to talk, be heard, listen, influence and change. It is co-operation of people with dementia, carers, professionals, and based on love.

We trust each other. And we hope that you trust Innovations in Dementia to provide the scaffolding to you and your group. We are trying our best to be here as point of contact and support, even though the large-scale funding has come to an end. But read on to hear some good news about funding for Our DEEP News - and how you can be more in the collective 'driving seat' of our DEEP magazine. As Trish says in News from DEEP groups: **"there is beauty and power in unity."**

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News from DEEP groups

Autumn on the allotment



Budding Friends is a social gardening and art group of people with dementia and carers in Exeter. We have a number of allotments and have been hard at work this year. These glorious photographs combine both our interests. Steph was particularly chuffed with her carrot growing expertise! The other photos are our attempt at vegetable art. Not quite Arcimboldo but we tried!

(For those who don't know (I didn't!) Giuseppe Arcimboldo was an Italian Renaissance painter best known for creating imaginative portrait heads made entirely of objects such as fruits, vegetables, flowers, fish and books).







A reminder to all DEEPers. We hold regular DEEP facilitator and co-facilitator Zoom meetings. These meetings give you the opportunity to share, learn and support each other.

Next Zoom meetings:

Wednesday 13th November 12.00-1.00pm

Thursday 12th December 10.30-11.30am

Email **DEEP@myid.org.uk** to find out more.

News from DEEP groups

Out in nature – in the wild weather!



Have you heard the expression “mad dogs and Englishmen”? Well, that was the Right Minders in October! We had a ‘research project walkabout’ of the nature reserve at RSPB Bempton. We wanted to look at accessibility needs for people with dementia, but also other conditions. On the day in question, 16 folks turned up and 9 of us did the walkabout. It included Lucy a health and social student who wanted to meet people in real life situations.

Our photos show how wild the weather was. It certainly blew off the cobwebs! We managed to walk down to Bartlett View point where we saw plenty of gannets – spectacular!

On our return to the café we collectively completed the “Outside Public Space” dementia-inclusive checklist. We will feed back our results to Dave, the site manager. We also offered the staff and volunteers some dementia awareness training, which Dave will organise. This was a “win win” for us and made the visit worthwhile.

The day was full of fun, plenty of giggles and gave us an opportunity to build relationships, ask questions and collaborate with each other. There is beauty and power in unity – and this is what Right Minds is all about.

15 months of funding for Our DEEP News

We were delighted to find out that Awards for All (at The National Lottery) are funding Our DEEP News for 15 months. This means that we can keep producing and printing our magazine, and sending physical copies in the post to DEEP groups. We know how important it is to hold a copy of Our DEEP News in your hands, to feel part of something bigger and read about each other’s stories and achievements.

We thought it was a good opportunity to do things a bit differently with this funding:

1) **Support a new editorial team of people with dementia to lead and shape the content of Our DEEP News**
2) **Share our messages from DEEP out to a wider audience of people beyond DEEP**

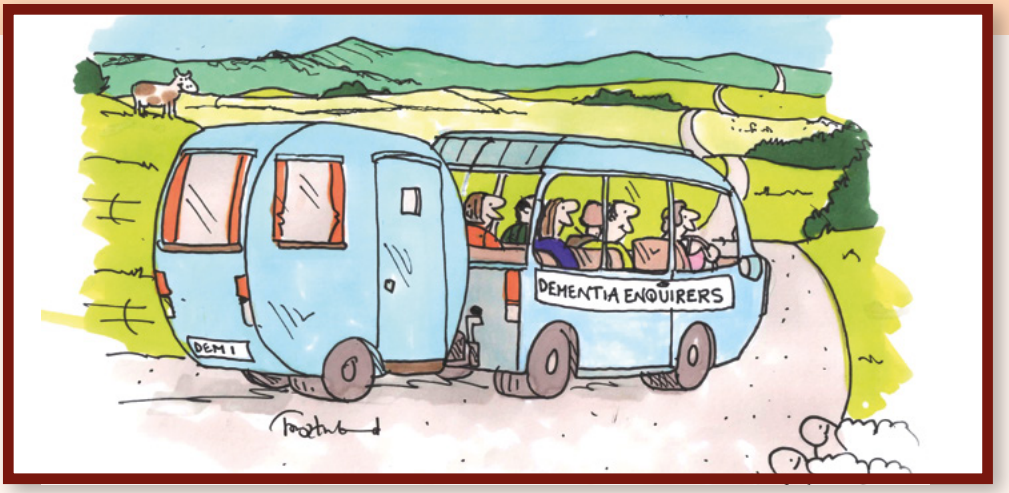
If you or your group are interested to get involved please contact **rachael@myid.org.uk**

Launching the DEEP "Tony Husband creative award"

Tony Husband, a dear friend of the DEEP network, died a year ago this month. You will know Tony's illustrations from a lot of DEEP publicity materials. We were so honoured to receive a donation from friends and family (and local pub!) of Tony after his funeral last year. More recently we were delighted to be contacted by David, the manager of the band Sea Power (formerly known as British Sea Power) with an extra donation.



Tony



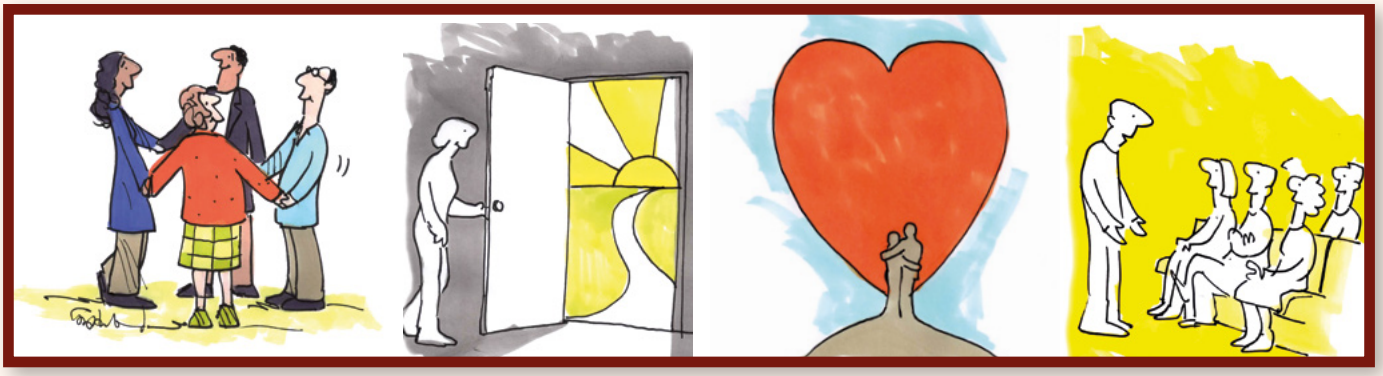








Photo of Sea Power courtesy of Paul Husband (Tony's son)

"Sea Power knew Tony for many years and he was always a very much welcomed and loved guest at dozens of their gigs, always there with a big smile, wonderful stories and good vibes - plus gifts of amazing spontaneously astute and wry cartoons.

He attended all of the Krankenhaus festivals where he did his very popular Cartoon Confessionals which touched a lot of our punters and many of them this year were full of sadness at his passing but equally had many funny and also inspiring stories to relate. Last year he did his reading about his father which had many in tears with his painfully accurate descriptions of how he and his father had dealt with his decline.

Last year is especially poignant as at one of the traditionally chaotic end of live gig sets by Sea Power, Tony grabbed a spare guitar, jumped on stage with the band and jammed pretending to play guitar (badly!) much to everyone's amusement. He said afterwards it was a dream come true and he felt like Neil Young!!

He was irreplaceable and will continue to be sorely missed.

So it was a no brainer for us to set up a little 'shrine' to him and ask for donations".

To remember Tony, we are setting up a Tony Husband creative award for the DEEP network. This will be an annual award. Do you have ideas for a name for the Award? What should/could be included? How should winners of the Award be decided?

Send us your ideas. We will provide more information about the Award in the New Year. Thank you Tony.

Books for people with dementia

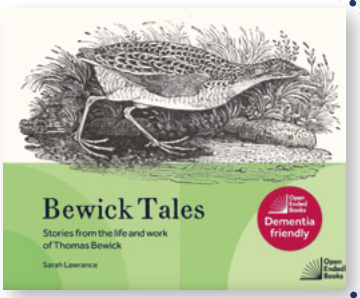
There are a few books around at the moment that are aimed at people living with dementia.



We have previously shared the Reading Well dementia list that some people with dementia from DEEP were involved in. The booklist provides reliable information, advice and support as well as personal stories and age-appropriate books for children.

We know a lot of people love reading, but can find it difficult with the changes that dementia brings. Some books aim to be more accessible to people with dementia.

Open Ended Books are based in the North East of England. They have created a 'dementia friendly' book and are hoping to develop more. Their first book is about an artist and engraver called Thomas Bewick. We have one free copy if a group from the North East would like it. Get in touch.



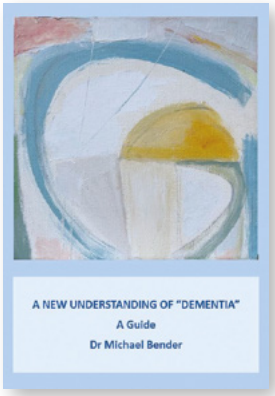
Cognitive Books explore well known themes and feature short passages of rhyming text and beautiful illustrations. The books include exercises and a free audio download. There are currently two books, one about the Beatles and one about the 1966 World Cup. The books are available to order here: **https://www.cognitivebooks.co.uk**

COGNITIVE BOOKS®

Dr Mike Bender writes:

A New Understanding of Dementia: A Guide is a step-by-step self-help guide by Dr Mike Bender. It is written for people living in the community and worried about the cognitive changes they are experiencing. Mike is keen that it be readily available to DEEP groups. He is offering the book at £12 (instead of the usual £18).

Get in touch if you would like to take up this offer. We will send you a special link to use to order the book.



What kind of books about dementia would you like to see more of? Should there be more 'dementia accessible' books? What could technology do to help people with dementia to continue engaging with books and reading? Let us know what you think.

Taking part opportunities

Are you from a LGBTQ+ community?

A researcher at University College London is interested in your views about using dementia services (and your contact with LGBTQ+ organisations). They also want to learn more about barriers and what other support that might be helpful. If you are interested please contact **Simran.Kainth.18@ucl.ac.uk** You would take part in an online interview for about 45 minutes. You would receive a £20 Love2Shop voucher for your help.

Dementia Carers Count survey

Dementia Carers Count is a national charity that supports carers of people with dementia.

They are keen for carers to complete their annual survey. The survey can be found here **https://dementiacarers.org.uk/blog/2024-carer-survey**/ Or they can send paper surveys or talk through it over the phone if people prefer. The survey is open until the end of 2024.

Last year, they heard from over 1,300 carers who described their caring roles, what they found hard and what would make the most difference to them. The findings informed their report "Invisible and our Dementia Carers Manifesto". This year, they are looking at carers' rights and what carers would like the government to prioritise.

Question: should DEEP do an annual people with dementia survey? What do you think?

There is a DEEP guide to help you decide whether you want to take part in an opportunity. Will you get the right support to contribute, and will it be the right fit for you? Visit the DEEP Website to find this and many other resources to help you make decisions right for you. https://www.dementiavoices.org.uk/deep-resources/

Closing thoughts



Dear Dementia,

I think it's time we sat down and had a bit of a natter…a heart to heart.

I did prefer my life when you weren't here, but now, not of my choice…I can't live without you …I really really wish I could.

There is one thing I would like to say to you…There is no need to be with me 24 hours a day!

I would really like some me time…some time with Gail!

You're in my thoughts, and I know you are always nearby, however, sometimes I would just like to forget about you.

I often think of my life without you, those wonderful days I took for granted, those sunny clear days before you'd entered my life and brought fog!

I now know we'll never part, and I know some days you'll be a real pain, making your presence and interrupting my days.

It would be so nice to be free again, to roam, to have endless long distance car journeys where I'm behind the wheel……To have conversations that doesn't involve that word dementia!

Some days you suffocate me. On these days I have to accept you are my sidekick and we will spend time together, for however long that may be. I must say…I do feel relief when you leave.

If you ever feel the need to find a happier place to be, please feel free to leave. I won't be hurt in anyway do what you need to do.

By Gail Gregory

Next month

Deadline for items for Our DEEP News December 2024 will be 29th November. Please email any items to DEEP@myid.org.uk

To be in touch with DEEP please email DEEP@myid.org.uk
Telephone: 01392 420076
Postal address: PO Box 616, Exeter EX1 9JB

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