

Experts by Experience



UNIVERSITY of
BRADFORD

Centre for Applied
Dementia Studies

Newsletter – Autumn 2021

Experts by Experience

At the Centre for Applied Dementia Studies, we work together with people with dementia and their families and carers in all areas, in research, education and training. At the moment, we have over 83 people who work with us either through co-presenting, teaching, developing training materials or through sharing their experiences of what it's like to live with dementia. We want to ensure that the real voices of people affected by dementia are not just at the heart of all we do but that those people are part of our team. In this newsletter, we share some of the things we've been working on together as well as opportunities for people to join us.

Come and join us at our Winter Social

*You're
Invited*

We would like to invite all our Experts by Experience, students, staff, and all those interested in dementia to our Winter Social.

Norcroft Centre, University of Bradford, **Wednesday 15th December - 10.30 – 12.30**



Come and join us for a cuppa and cake. We will have various stalls at the event, including dementia information and fundraising stalls where you can buy Christmas gifts, books and support local dementia charities.

For more information, email c.mason3@bradford.ac.uk

Cakes needed – if you can bake and donate a cake to share, let us know!

Update at the Centre

At the Centre for Applied Dementia Studies here at the University of Bradford, we've had a number of new staff join our team.

- ❖ Natasha Wilson has joined us as Dementia Care Training Programme Manager, and you can read her introduction on the next page.
- ❖ Dr Anas Shehadeh who is a Research Associate has joined us to work on a study looking at delirium.
- ❖ Amirah Akhtar who has joined us as a research assistant to work on the NIDUS study which is the New Interventions for Independence in Dementia Study.

We warmly welcome our new team members and hope you will meet them sometime soon.



New dementia website

A new website has been set up for people living with dementia, carers, and professionals. This is an international website and full of useful information

You can look at the new website [here](#) and we'd be interested to know what you think.



Forward with Dementia is a partnership run together with Dementia Alliance International, Alzheimer's Disease International and several UK and International Universities. It is registered internationally and in the United Kingdom.

Welcome Natasha!

Our new team member, Natasha Wilson introduces herself.

I'm Natasha and I started my new role as Dementia Care Training Programme Manager at the Centre, just last week! I'm already so excited for the opportunities which lay ahead, projects to work on and new people to meet.

I have always known it is somewhat my vocation to try and improve the lives of people living with dementia. My Great Grandad had quite frankly a horrendous time for lots of reasons during his dementia journey, and I made a conscious decision from then that I would do all in my power to ensure things changed for the better in my lifetime.

I graduated with an MA in Dementia Studies from The University of Sheffield in 2017 and have worked with people living with dementia in lots of different situations before, during and since that. One of my biggest aspirations is to open and manage a supported living alternative for people with dementia and prove that a traditional style 'care home' is not what people should have to settle for.

The favourite part of my previous roles has been meeting some truly wonderful people, most of whom I now consider to be my closest friends and extended family members. I'm famously known for my Sunday dinner efforts feeding (almost) the 5,000 around my dining table! I've attached some photos I've been allowed to share with you all of me and some of the friends I've made over the years. As you can tell, I'm known for my very serious nature... not!



I was born with a condition called Arthrogyrosis which means I use an electric wheelchair and have a team of PA's (other best friends!) who help me at home 24 hours a day. I think my own personal experiences of needing support have made me resourceful, creative and I would argue possessing a good sense of humour and thirst for adventure to prove people's assumptions wrong! Last year I did a charity wheelchair abseil, learned to drive a car I control with solely my hands & head and adopted a rescue Cocker Spaniel called Bette!

An update from Wendy

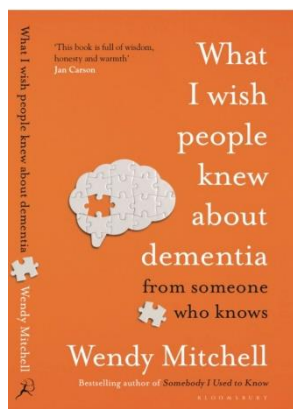
Wendy Mitchell, one of our Experts by Experience and an honorary graduate of the University of Bradford writes:

Hello everyone.

Well winter is almost upon us or may even have arrived by the time you read this! It's certainly been a strange year but hopefully still filled with magic moments we all crave. I can't wait to be at Bradford face to face again, seems like a lifetime ago. I loved seeing all your photos of your recent trip to Wales. Looks like you had a wonderful time.

As for me, well I have a new book coming out on January 20th - "What I wish people knew about Dementia, *from someone who knows...*"

So I'm busy doing interviews and articles ready for its release. I'll also be promoting it on Twitter from 1st December, so watch out for it all you Twitteroos...



Wendy's book is pictured above, along with a picture of Wendy

In between all that I was asked to produce our village calendar and I'd sold out on 1st November. It was lovely to hear stories of it being sent all over the world to children brought up in the village who now live abroad. I raised the lovely sum of just over £1600, which will be shared between my support group, Minds and Voices and several of the village clubs. The first £100 went to our local hedgehog rescue team



I'm still involved in lots of research but also enjoying more 'me time' in my paradise of Keswick. It's where I go to simply relax and enjoy long walks along with taking photos. Hope you're all remembering to enjoy some me time too

You can read Wendy's blog [here](#) and her latest book is available [here](#)

Media Club

Recently there have been a number of TV programmes and films featuring dementia, including the BBC documentaries 'Dementia and Us' and 'Inside the Care Crisis with Ed Balls', the Channel 4 drama 'Help' and the cinema film 'The Father' with Anthony Hopkins.

We have started an Experts by Experience Media Club to discuss the ways dementia is represented on TV and at the cinema. Our first meeting will take place on zoom from 2-3pm on 18th January 2022 and we are hoping to write about our group discussions to let producers and the public know what we think. If you would like to get involved, please let Clare know by emailing c.mason3@bradford.ac.uk



Inter-professional Education (IPE)

Several of our Experts by Experience take part in our inter-professional education days which happen twice a year in the Faculty of Health Studies at University of Bradford.

Twice a year, members of our Experts by Experience group join the Faculty of Health Studies Service User Involvement Group (SUIG) members at our interprofessional-education day for students.

This year two members of our group will present at the day, where students from across the faculty will come together to learn about the importance of working together with other professionals to improve patient care.

The students include those from a number of professions including nursing, midwifery, pharmacy, radiography, paramedics, social work and more.

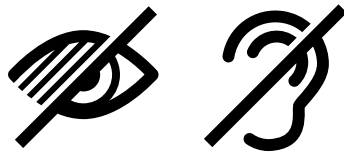
Students will also watch a dementia related video and discuss how the situation in the video could have been improved by professionals involved working together.

If you are interested in working with Faculty of Health students at our IPE days, email Clare at c.mason3@bradford.ac.uk

Vision and Hearing Loss and Dementia

Ana Barbosa and Wendy Andrusiak would like your views on living with dementia and sight or hearing difficulties. Ana writes:

We are keen to hear from any Experts by Experience living with vision or hearing difficulties (sensory impairments). We would like to know about the needs and challenges of living with sensory impairment and how people adapt and cope with the challenges.



Below are some of the questions we would like help with. You can email us your answers, or if you prefer, we can arrange a time to talk to you by telephone or on Zoom.

- What challenges do you face in your daily life because of living with a hearing or vision impairment? (Think about specific daily tasks such as cooking, leisure activities, getting dressed or undressed, personal hygiene, etc).
- How do you cope with the above challenges? You can think about:
 - Environment (for example, lighting, signage, etc)
 - Devices/ tools (for example, glasses, hearing aids, etc)
 - Help from others
- What other support would you like to receive to improve your hearing and vision capabilities?
- What advice would you give to other people affected by hearing or vision difficulties?
- How has your memory affected your ability to care for your own hearing and vision, including any devices you may use (i.e. hearing aids and glasses)?

Your feedback will be part of a book being written by Ana and Wendy and they are interested in hearing from both people living with dementia and those who care for and support them.



You can email your feedback to a.barbosa@bradford.ac.uk

Coronavirus Dementia and Care Homes (CoDeC)

***A Year on the Front Line* is a theatre performance based on our research study, Coronavirus and Dementia in Care Homes.**

It will be staged at the University's Theatre in the Mill during next year's UNIfy festival which aims to celebrate links between the University and the local community. The festival is taking place between 28th and 31st March 2022.



University of Bradford's Theatre in the Mill where the performance will take place in the theatre performance, actors will speak the words of real dementia care workers about their experiences of the Covid-19 pandemic in care homes for people living with dementia. The care workers who took part in our research told us about very traumatic conditions, but they also told us about many creative adaptations they made to cope during the lockdown. We want to share our findings through the theatre to promote discussion about what is needed in the aftermath of the pandemic.

We will let everyone know nearer the time about how to attend if you would like to come along. We are also hoping the performance will be filmed so that anyone who can't get here can watch it later at home.

In the meantime, we are looking for volunteer actors to play the parts of care home staff. Rehearsals will take place in the New Year. If you think you might be interested in taking part, please contact Clare for further information by emailing c.mason3@bradford.ac.uk

Andrea, Ana, Giorgia and Clare (the research team)

Opportunity to work with our students

Would you be interested in being involved in our Advanced Dementia Studies Master's Degree (MSc) course?

Many of our Experts by Experience work with our students who are working towards their master's degree in Advanced Dementia Studies. People living with dementia and those who care for and support them can get involved in lots of different ways, such as reading parts of student essays and dissertation assignments and giving feedback. There are also opportunities to listen to presentations given by students and comment on them.

If you are interested in taking part in our education programmes and work with our students, please get in touch.

You don't need to have any experience in this type of work, and we can support you to be involved.

For further information, or to put your name on the list, email Clare at c.mason3@bradford.ac.uk



Dementia & Us

Two of our Experts by Experience recently featured in the BBC2 documentary series Dementia & Us.

Chris and Allan Gilliver (Gilly) were filmed over a two-year period giving viewers an insight of what life is like when a person is diagnosed with dementia.



You can watch the two-part documentary [here](#) on BBC iplayer

Some useful links

Alzheimer's Society Helpline - 0300 222 11 22 www.alzheimer's.org.uk

Carers UK - 0800 055 6112 advice@carersuk.org

Find out about caring for someone with dementia at Age UK [here](#)

Dementia UK 0800 888 6678 or email helpline@dementiauk.org

Advice for people with dementia and their families – Corona Virus

<https://www.dementiauk.org/dementia-uk-coronavirus-advice/>

Occupation Matters – find activities for people with dementia online or to print [here](#)

Our Experts by Experience Group is a member of the DEEP Network

Innovations in Dementia click [here](#)

Find out about Rare Dementia Support [here](#)

Dementia and sight loss - top tips at [RNIB](#)

Some useful products and gift ideas [here at RNIB online shop](#)



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