

## National Alzheimer's Society Update July August September

### Our Impact Framework

In each newsletter I share the changes Alzheimer's Society wants to see and what it is doing to make a difference through one element of our impact framework. Our Impact framework highlights 6 pivotal areas people affected by dementia told us are critical to their support to allow them to keep control of their life. Our theme this time is - "Adjusting to life with dementia" and follows on from "Getting a diagnosis."

So, the following video links the two together!!

Our Wakefield Voices Together is a group of people living with Dementia who have produced a video.

**Voices Together** members wanted people going through a dementia diagnosis to understand that receiving a dementia diagnosis is not 'the end of life'. They recently launched their video called '**Dementia. Life goes on.**'



Please share this video with your contacts so the voices of people with dementia can be heard.

<https://www.youtube.com/watch?v=fog0rV7mv0E>

The video was launched at the Wakefield Dementia Road Show held at The National Mining Museum during Dementia Action Week.

In the video Ian, Joan, Ian and Phil explain how being in this group has helped them to adjust to life with dementia.

The video is a coproduction between Alzheimer's Society Creative Brand Engagement team, Wakefield Dementia Support Services and Voices Together (Wakefield Dementia Voice Group) members. The idea evolved from conversations in the group, followed by a focus group and planning discussions.

## **Let's collectively Make Dementia a Priority.**

On July 4 the country elected a Labour Government for the first time in 14 years.

Countless times Alzheimer's Society has shared the important message: the new Government must make dementia a priority. But now, with a party in post, it's vital we see this call made a commitment.

It's time to ensure the new Government's priorities are your priorities and that as the greatest health and social care challenge we face, dementia must be a top government priority.

The need to make dementia a priority has never been greater but nor has the opportunity, if those in power choose to grasp it.

Join over 15,000 voices saying that the new UK government must Make Dementia a Priority by visiting this link and making the pledge.

<https://action.alzheimers.org.uk/page/150423/petition/>



## Companionship Project – Developing Services to support those with Social Isolation and loneliness

Alzheimer's Society's Service Design team wants to understand people's experiences of social isolation and loneliness and explore what services might be needed to support those who are living with dementia, their carers and supporters.

We want to explore the topic of companionship with people with or without dementia, their carers and supporters. We want to hear from all communities but would particularly like to connect with members of Black African and Caribbean and South Asian communities.

If you know of any Black African and Caribbean or South Asian community members, leaders or groups who might be interested in working with the Service Design team on this project, please get in touch.

Contact: [servicedesign@alzheimers.org.uk](mailto:servicedesign@alzheimers.org.uk)



## Building Inclusive Dementia Services

Alzheimer's Society is working with a researcher- Dr Moise Roche from UCL on a project to co-produce a service model with the Black African and Black Caribbean community. Many Alzheimer's Society staff who deliver face to face or telephone support either in our local services or national services will be looking to recruit people who have accessed Dementia Support Services or our National Dementia Support Line. We are looking to contact current and former service users to participate in the consultations/workshops to co-produce the service model. We will also be recruiting people not using our services via external organisations.

- Help us build better services for dementia
- Are you affected by dementia?
- Are you caring for someone who is affected by dementia?
- Do you work with Black families affected by dementia?
- Are you Black African, Black Caribbean or Black British?

Come tell us the type of support and services you need.  
We will reimburse your travel cost and give you £30 for your time.

If you are interested in hearing more about this study, please contact Dr Moïse Roche at [m.roche@ucl.ac.uk](mailto:m.roche@ucl.ac.uk).

The contact number for Dr Moise Roche is 07757918995 for people who prefer calling over emailing. Closing date for interest December 2024.



## Updates on Disease Modifying Treatments

Two disease-modifying treatments for Alzheimer's disease, lecanemab and donanemab, are currently going through the UK regulatory approvals process to determine whether they will become available on the NHS. These are treatments that clinical trials have shown can slow the progression of the disease, slowing down the speed at which memory and thinking skills get worse by more than 20%. It is also important to recognise that both drugs were found to have side effects, some severe.

The National Institute for Health and Care Excellence (NICE) are currently appraising both drugs, assessing evidence of their cost and clinical effectiveness to make a recommendation on whether they should be used in the NHS. As part of the appraisal, NICE invited stakeholders to submit evidence. **Alzheimer's Society** submitted evidence which included drawing on our existing knowledge from our work and conducting new involvement work with people living with dementia, through focus groups and surveys. NICE have now held committee meetings for both drugs, with an expert committee reviewing and discussing the evidence. The meetings were held in private, and the results of the committee meetings will not be made public until the Medicines and Healthcare Products Regulatory Agency (MHRA) announce their decision on whether the drugs are deemed safe enough for use in the UK. We are currently awaiting these announcements, which are expected soon.

Thousands of people in the UK could potentially benefit from these new drugs if they are approved for use, however the healthcare system is not yet ready to deliver them. Currently a third of people with dementia in the UK do not receive a diagnosis at all, and only 2% of people that get a diagnosis receive one of the specialist diagnosis tests that would be needed to demonstrate eligibility for treatment. **Alzheimer's Society** is calling on the NHS to publish plans for how they intend to deliver new treatments, including through investment in diagnostic infrastructure and workforce expertise to improve access to an early and accurate diagnosis, inclusive of subtype. It's also important to recognise that there are over 100 Alzheimer's disease drugs in clinical trials now and we can expect to see more drugs making applications to UK regulators in the future.

## Research and the Alzheimer's Society ...did you know?

Alzheimer's Society funds cutting-edge research into the cause, care, cure and prevention of dementia, thanks to our incredible supporters. Here are some important highlights of how donations to Alzheimer's Society make a difference to dementia research.

Since 1990, our supporters' donations have allowed us to invest over £80 million into dementia research.

This includes funding over 400 research projects, which have made a real impact to both the dementia research field and people affected by dementia.



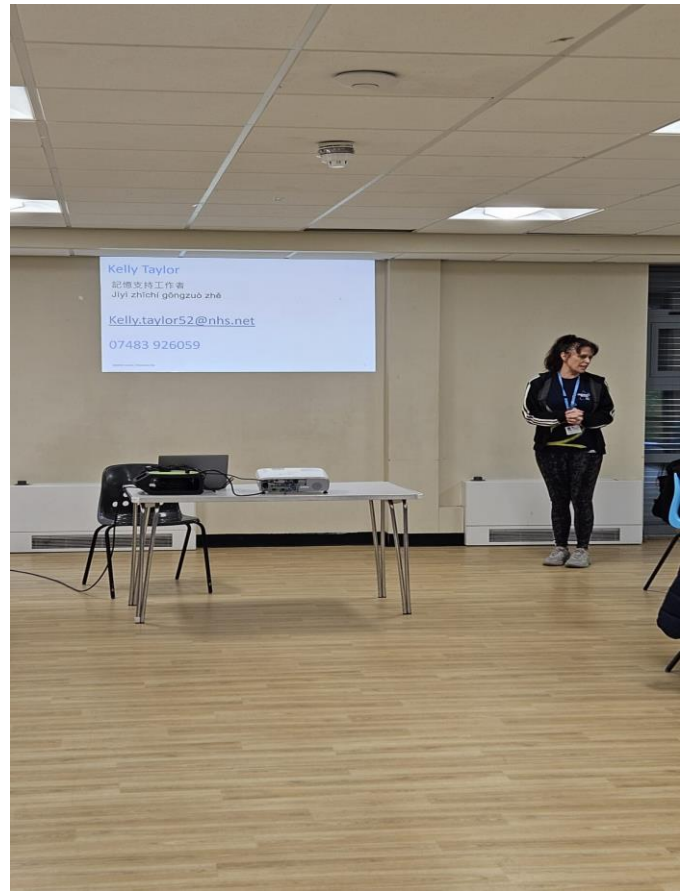
## Spotlight on work in Leeds

In Leeds one of our Memory Support Workers - Kelly has been working with the Chinese elders' groups. She worked with a group facilitator to produce a bilingual PowerPoint presentation. During the sessions translation took place. Through this work she has been asked to present to other groups at other community centres.

Other Memory Support workers are looking to increase their reach into the Farming and rural communities, ones that can be underserved by services.

**'Kelly worked with Natalie from the Chinese community in Leeds to produce a Bilingual PowerPoint.**

**Natalie translated the sessions which have been well received'.**



If you know of a group in Leeds or Wakefield who may benefit from information about our services, contact the Leeds Duty Line or Wakefield duty line - details on page 9.

## Is your organisation or group predominantly for people affected by Dementia?

Do you know about our **dementia directory** which you can use to find local support services for people with dementia and their carers in England, Wales, and Northern Ireland? If you are an organisation that offers a service for people with dementia you can list your organisation on our directory.

## Dementia Support Forum.

This is a helpful online community where anyone who is affected by dementia can receive valuable support. It's free, open day or night, and can be accessed online Visit [Alzheimers.org.uk](http://Alzheimers.org.uk).

On our **Dementia Support Forum**, you can:

- ask for advice
- read other people's stories
- offload your concerns about dementia
- share helpful information

## Dementia Together Magazine

[www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together)

Alzheimer's Society's magazine is produced six times a year for all our supporters, and anyone affected by dementia.

All libraries in Wakefield and Bradford are currently piloting having free copies of our magazine which library users can read in the library or take away and keep. Initial feedback suggests that the magazines are being well received.

## For dementia professionals

We provide a range of information services, resources and specialist training for health and social care professionals working with people who have dementia.

<https://www.alzheimers.org.uk/dementia-professionals>

## Volunteering for Alzheimer's Society

Each edition of this newsletter will feature one way people can be involved with Alzheimer's Society as a volunteer.

This time I ask **Do you have first-hand experience of dementia?** Help shape our work through Involvement and use your experience to ensure everything we do reflects the needs of people affected by dementia.



if you click the link below, you can subscribe to the Bulletin and will start receiving them going forward:

[https://r1.dotdigital-pages.com/p/7OMR-1V9/subscribe-to-the-involvement-bulletin?dm\\_t=0,0,0,0,0](https://r1.dotdigital-pages.com/p/7OMR-1V9/subscribe-to-the-involvement-bulletin?dm_t=0,0,0,0,0)

This Bulletin, sent by email, provides information about opportunities for people with lived experience of dementia to share their views and influence projects. It will give information on some involvement work taking place across the Alzheimer's Society. and ways that you may like to support Society in its work.

## Entertainment and exercise opportunities

### Free cinema tickets (see criteria below)

Creative Minds presents 'Up North' a triple bill film screening with The British Urban Film Festival (BUFF).

Free tickets available (on a first come first served basis) for people who use Southwest Yorkshire Partnership NHS Trust services/carers/the unemployed/Halifax residents.

The screening features 2 short films created locally:

'Lavender' (UK, 27 mins) - an emotional drama that delves into the memories of a person living with dementia, built around an interpretation of some of the difficulties they may face.

'Taxi' (UK, 24 mins) is a gentle, funny and touching insight into the lives of a group of people we often take for granted.

Headline feature film: Absolutely Marvelous (UK, 84 mins) a fly-on-the-wall boxing documentary which centres around a visually impaired mother and her day-to-day life.

Time and date: 6.15pm-10pm, Friday 26th July 2024

Venue: Crossley Gallery, D Mill Reception, Dean Clough Mills, Halifax HX3 5AX

Tickets booking: Up North, Down South (July Edition) - presented by Creative Minds

Tickets, Fri 26 Jul 2024 at 18:15 | Eventbrite

<https://www.eventbrite.co.uk/e/up-north-down-south-july-edition-presented-by-creative-minds-tickets-916120219237>

## Tai Chi classes in Keighley BD21

There are no geographical restrictions so anyone who meets the referral criteria and can get to Keighley is welcome to join the class.

**GENTLE EXERCISE FOR PEOPLE WITH DEMENTIA & THEIR CARERS:** adapted from Tai Chi by experienced Tai Chi practitioner, Helen Parsons. Easy and enjoyable movement routines that can be done seated or standing. The class will be run in a safe and welcoming environment and there will also be plenty of time for refreshments and making new friends.

**WHEN:** 3rd Friday of every month from 1.30 pm to 2.45 pm

19 July, 16 August, 20 September, 18 October, 15 November, 20 December

**WHERE:** Keighley Shared Church Hall, Market Street, Keighley, BD21 5AD (in St Andrew's Churchyard between Morrisons and the Markets)

**COST:** FREE! donations to help with running costs are welcome

**BOOKINGS & ENQUIRIES:** Elizabeth Anderson, 01274 583364: 07766 220725:

elizabeth@thememorytree.org.uk

**REFERRAL GUIDELINES:**

- Designed for people with dementia living at home to attend with their main carer.
- If the main carer can't come, or the person lives alone, the person with dementia can come with someone else (friend, neighbour, relative or a paid companion).
- Booking is helpful but not essential.

## Leeds Up & Go Dementia Engagement and Empowerment Project (DEEP) group

### Vibrant new Headingley mural highlights friendship and support after dementia diagnosis

A new mural created by people living with dementia was officially launched on Thursday 11th July at the AMT Headingley Rugby Stadium. The Leeds Up & Go Dementia Engagement and Empowerment Project (DEEP) group created the Keeping In Touch mural to highlight the importance of making connections and taking new opportunities after a life-changing dementia diagnosis. Members draw on the support they have found in the group to rebuild their confidence and social connections and are keen for other people affected by dementia to know that help is available. The mural shows the importance of activities such as watching sport and spending time with animals, and the friendships that help people navigate the challenges of life with dementia.

The mural is on the ginnel between Kirkstall Lane and St Michael's Lane (between Car Parks E and F on St Michael's Lane). It is accessible on foot or by wheelchair, but it is not possible to drive directly up to the mural due to its location on a pedestrian route.

DEEP group member Warren said: "Our intention is to show that dementia is not the end, it can be a beginning of a new chapter. We wanted the mural to celebrate things like friendship and support, getting out and about, doing things completely new to what we've done in the past, the power of sport to connect and help people overcome social isolation. All these things may have a positive effect on people's dementia symptoms. Hopefully when people see the mural, it may help them, or their carers or friends, to say 'Look at what people with dementia have done, and maybe I could do something similar.'"

**Leeds Up & Go DEEP group is facilitated by Leeds Playhouse and Dementia Friendly Leeds, which is part of Leeds Older People's Forum.** Both organisations are committed to finding creative ways of engaging people living with dementia in the community. Established in 2016, the group meets fortnightly at Leeds Playhouse or on Zoom to help Leeds become a more dementia friendly city. Group members share their experiences of life with dementia, guide businesses and services to include people affected by dementia and get involved in dementia research.

## **Alzheimer's Society National Dementia Support Line available for people across West Yorkshire 0333 150 3456**

### **Information on a wide range of topics**

Monday to Wednesday: 9am – 8pm

Thursday and Friday: 9am – 5pm 0333 150 3456

Saturday and Sunday: 10am – 4pm 8pm 0333 150 3456

If you are supporting people who use a language other than English, please explain to them that they can ring the support line and say the English word for their preferred language and they will be phoned back by a person using that language.

Have a look at items to support independent living.

Shop online or call 0333 366 0035.

Website [www.alzheimers.org.uk](http://www.alzheimers.org.uk) a range of factsheets, blogs, access to our Dementia Support Forum - our online community and much more.

## Across West Yorkshire locally

Leeds Memory Support Workers can be contacted via our duty phone on 0113 231 1727 or by email [memorysupport.lypft@nhs.net](mailto:memorysupport.lypft@nhs.net)

Wakefield Dementia Advisors can be contacted via our duty line on 01924 373264 or by email [Wakefield.Team@alzheimers.org.uk](mailto:Wakefield.Team@alzheimers.org.uk)

If you do not live in one of the above areas search on our website for support locally and this will direct you to services such as **Bradford Dementia Hub, Calderdale Dementia hub, Kirklees Dementia hub and Dementia Friendly Keighley,**

Thank you for reading this newsletter.

Ben Johnson

My contact details are.

E: [ben.johnson@alzheimers.org.uk](mailto:ben.johnson@alzheimers.org.uk)

T: 07354 165663

### Social media links

Facebook: [@alzheimerssocietyuk](#)

Instagram: [@alzheimerssoc](#)

Twitter: [@alzheimerssoc](#)

LinkedIn: [Alzheimer's Society](#)