Can you help The Angela Project team with ideas for new young onset resources?

The Angela Project was a three-year research study carried out by the universities of Bradford, Northampton, Surrey and UCL, funded by the Alzheimer’s Society, and in partnership with Dementia UK and YoungDementia UK. It was designed to look at how post-diagnostic support for people living with young onset dementia and the accuracy of diagnosis can be improved.

During the study, views were gathered from professionals and over 230 people living with, or caring for, someone with young onset dementia making it the largest study of its kind. 500 sets of case notes were audited and the team talked to commissioners and service providers to understand more about what helped and hindered them in providing young onset dementia services.

The survey also looked at good practice and what needs services that provided good services met, as well as the barriers and facilitators to good practice in post-diagnostic support for younger people.

Now the research is complete, and their key findings and recommendations are known, they want their findings to be put into everyday practice by creating accessible resources for different audiences and uses. Perhaps a care / support plan for the person with young onset dementia to agree with their supporting professionals, or a clinic checklist to ensure your clinic is meeting the best standards in young onset care. What resources or tools would you find useful?

Please send any comments, views or ideas to Clare Mason at c.mason3@bradford.ac.uk or if you prefer, telephone Clare on 07917 751478.
Exciting Sheffield-based gardening group coming soon!

Gina O'Connor decided to start Roots & Bloom after her step-father was diagnosed with Alzheimer's disease at a young age. He struggled with regular dementia groups / activities and so wouldn’t go to them. Realising there must be other families in the same situation, Gina has set about creating something she hopes that younger people will find enjoyable and interesting!

Her plan is to build a flower farm producing locally grown, sustainable bouquets that she will sell to the public. She is gearing up for her first growing season and is hoping to move to a bigger plot of land in Sheffield soon. Once established she will set up sessions where people with young onset dementia can go and get stuck in, helping her to grow and sell the flowers. She is keen to keep the groups to under 65s, so that younger people have something that is tailored specifically for their age.

If you'd like to find out more about Gina’s plans or would like to express an interest in attending her group sessions, you can email Gina or sign up to her newsletter here. You can follow Roots & Bloom on social media here Facebook | Twitter | Instagram.

'It's not a bad life,' says Jane

In our last two newsletters, Jane has written articles for us, sharing her personal experience of young onset dementia following her husband Ash's diagnosis two years ago aged 58.

Jane always writes about her life and feelings with incredible honesty. She admits she sank into despair after Ash was diagnosed but decided in time that she had to create a new life for herself. She reached out to her friends and now finds regular country walks, meals out and being active in her village community have helped her to regain her sense of self. You can read ‘It's not a bad life’ by Jane here.
A Way With The Fairies - a new Kindle book for children

Raja Badrakalimuthu has worked as a consultant in old age psychiatry since 2012. He has led his liaison team and dementia unit in Basingstoke to national recognition and has a particular interest in the care of younger adults with dementia.

Raja has written a book which tells the story of eight year-old Sachin's experience as his mathematical genius of a father fights dementia. Sachin narrates through play, puzzles and poems a poignant yet powerful and positive life of his Appa.

Raja has generously donated three signed copies of his book to us. If you would like to be entered into a draw to win a FREE copy, please email us with your full postal address by 29 February.

A Way with the Fairies is available on Amazon as a Kindle download, click here.

Dementia and me - podcasts

Dementia and me is a recently launched weekly podcast, created by the team at BBC Radio Sheffield. It shares interviews and discussions on a range of issues relating to dementia.

Their podcast on 20 January featured an excellent interview with Wendy Mitchell, who is living with young onset dementia. You can listen to the podcast with Wendy here, or catch up with all their podcasts so far here.

Have you experienced changes in your memory, words or other parts of your thinking?

Wonder TV is currently making a series for the BBC called Living with Dementia (working title) which will be an honest and sensitive exploration of life with dementia.

As part of the series, they want to capture the experiences of people seeking a diagnosis after noticing changes with their memory, words or other parts of their thinking.
The production team would be delighted to hear from anybody currently visiting their GP or memory clinic about changes they have noticed.

Get in touch on 0207 013 4283 or dementia@wondertv.co.uk

---

**Moving Kinship Hubs**

The London-based Moving Kinship Hubs offer a new creative psychosocial service, supporting people living with young onset dementia and their family carers. The hubs support ways of ‘listening with movement’ which impact positively on family communication and relationships. Led by arts and health professional, Dr Beatrice Allegranti, the hubs involve the creation of personalised dance and musical performances based on experiences of living with dementia.

This is free service is supported by Arts Council England and Public Health and is part of the social prescribing portfolio in GP surgeries and NHS Trusts across the UK. Hubs run every 4-6 weeks at Alexandra Palace and Merton Arts Space. Book to attend via email or telephone.

Contact beatriceallegrantidancetheatre@gmail.com | Tel 07714 196810 | Download a flyer here | See www.beatriceallegranti.com/blog for short videos and testimonials about the participatory hubs.

---

**Young onset dementia news in brief**

**The Frontotemporal Dementia Annual Seminar** will take place at the Wellcome Trust, London, NW1 2BE on Friday 27 March, between 9.00am-4.00pm. To view the programme click here. Tickets are £80 but for non-professionals such as family carers and people affected by FTD they are free of charge. Free places can be booked here.

A new group for people aged under 65 and their family members has launched in Plymouth called the Memory Matters Young Onset Group. It meets on the 2nd Saturday of each month from 10.00am-1.00pm at Memory Matters (upstairs from the Moments Café), 69a New George Street, Plymouth, PL1 1RJ. The group enjoys peer support, information exchange, fun, learning opportunities and sometimes social activities and provides a relevant voice to shape local services. Telephone Anne Smith on 01752 243 333 or email anne.memorymatters@gmail.com to find out more.

Living with young onset dementia and actively shaping dementia research - The Angela Project is a newly published article co-authored by Keith Oliver, who is living with young onset dementia. Read the paper here.

The next meeting of the Alzheimer’s PCA Support Group in Wokingham is taking place on Friday 19 June, 2.00-4.00pm. For more information please contact Helen via email.
If you live in the Hartlepool area, are you aware of the Hartlepool Young Onset Dementia Group? They have approximately 20 members and meet each Thursday in the Centenary Lounge at Hartlepool Football Ground. They also have a calendar of days out playing bowls, badminton, table tennis and botcha, all funded by local charities and Hartlepool Borough Council. To find out more, please email Lynn.

Dementia Forward has just set up a group for younger people in York and will soon be starting another in Scarborough. To find out more please contact Amanda via email.

In addition to their popular Kaleidoscope Cafe based in Blackheath, Age Exchange will soon be launching two new groups for younger people living with dementia and family members and friends. Cafe Connect in Blackheath starts on 12 March and Cafe Create will meet on 3 March in West Norwood. Click on the links to download flyers for each group.

Once Lost is a powerful new musical about living with dementia. Told through memories and original music, this story challenges expectations and sheds light on what dementia cannot steal from us. The show was inspired by the writer's family experience with the illness and their passion to raise awareness for it. It encompasses comedy, drama and happiness amongst the reality of the illness. Watch Once Lost: A New Musical at the Edinburgh Festival Fringe, 17-23 August 2020, for tickets and information click here.

Nikki Demajo Albanese is a BA (Hons) student in her final year at The Guildhall School of Music and Drama. She is hoping to interview someone (under supervision) who has young onset dementia, and their partner / relative / carer. She would like to create a performance which focuses on a person who is losing their memory and tries to cling on to the memories. Ideally, the person should be comfortable being recorded and sharing their story. If you would like to find out more, please email ndemajo@gmail.com

If you would like us to share details of a new young onset dementia related group, service or event, or anything of interest to the young onset community, please email katefallows@youngdementiauk.org

Book giveaway winners - 'Dementia - Support for Family and Friends'

Congratulations to Christine Turner, Linda Hodson and Sarah Cox who were the three lucky winners in our December book giveaway. They have each won a copy of Dementia - Support for Family and Friends, a book aimed at anyone with a friend or relative with dementia.

If you weren't one of the winners but would like to purchase a copy of the book, Jessica Kingsley Publishers has kindly offered a 20% discount to our newsletter readers, valid until the end of March. Click here to visit their website and use the code PULS20 at checkout to apply the discount.