Greengross A4D Global Arts for Brain Health Changemakers
Young Onset Conversation
Thursday 26th October, 8.30-10 am GMT (6-7.30 pm) in Adelaide)

There are 3.9 million people worldwide - 70,000 in the UK – living with young-onset dementia (under the age of 65). Diagnosis takes on average 4.4 years to achieve, rather than two years for older people, causing greater challenge to those in employment with significant financial commitments such as a mortgage and they may also have families to support. There being at present no known cure, creativity is proving unexpectedly engaging for them, preserving cognitive function and wondrous sense of achievement, identity and wellbeing in the community, at our inspirational speakers will reveal in lively Conversation, chaired by Professor Jan Oyebode.

THE CONVERSATION

THE CONVERSATION

Veronica Franklin Gould, President, Arts 4 Dementia

Good morning and welcome to our speakers and delegates from around the UK – many from the NHS, which is good news! – from Australia, Austria, Ireland, Italy, New Zealand, Nigeria, Singapore, Taiwan, and from the United States of America.

Today's Greengross Arts for Brain Health – Changemakers - Young Onset Conversation will bring insights from inspirational people who since their diagnosis with a YOD have been living remarkable lives through creativity – for most, as never before. And Chris, having given up playing his tenor horn after heart attacks, when dementia struck he thought blow it – or rather, I'll blow the horn again – and a decade later he is still at it!

Our chair, Professor Jan Oyebode, a specialist in the field and Head of dementia care at the University of Bradford, will lead today's Conversation. We are honoured to be able to hear and share how, despite the challenges of dementia, Kate Swaffer of Australia, Keith Oliver, Wendy Mitchell, Chris Norris and Gail Gregory, advise, write, create poetry, photography, art and music - to live their best possible lives. In a fascinating Panel Conversation, they will exchange experiences of their creativity and its impact.

Then we look at Access: Hamaad Khan, Global Development Officer at the National Academy for Social Prescribing, explains how social prescribing provides the link between the patient, through the GP surgery, to arts and wellbeing programmes that can empower them to preserve their brain health. Hamaad will touch on global social prescribing approaches, and the champion scheme that encourages medical and neuroscience students to interact with these artists, to glean insight into their condition and material for dissertations.

Tessa Gutteridge is the driving force behind Young Dementia UK and Director of the Young Dementia Network.

Each person will talk for about five minutes and the resulting Conversation between them will open our eyes to the reality and impact of arts to preserve brain health in Young Onset.

Finally, in view of a tragic need, Professor Adam Ockleford, a specialist in music for children facing exceptional challenges, will explain how this helps children with Batten Disease, a symptom of which is dementia.

The instigator of this Changemaker Conversation series, Baroness Greengross, was passionate about the need for music to be embedded in the health and social care system for dementia. Sally, our dear friend, Arts 4 Dementia patron and Co-Chair of the All-Party Parliamentary Group on Dementia, worked indefatigably to advance arts for brain health strategy in Parliament. And after her death last year, many of us learned that she and her husband created the British Museum's Youth programme– how Sally would have valued our focus today on Young Onset!

We are truly grateful to our speakers whose guidance inspires best practice in arts for brain health the world over, to Nigel Franklin of A4D for technological wizardry and to uur colleague Amisha who will keep an eye on and preserve the Chat and help edit the recording for an online resource, together with this transcript. If you would like to upload your own resources, we shall add those too.

I should like to introduce our chair. Jan Oyebode, Professor of Dementia Care at Bradford, has spent most of her career as a clinical psychologist in the NHS. She now works in research, where her current focus is on relationships, coping with life with dementia, and family caring. Her recent work includes The Angela Project – improving diagnosis and post-diagnostic support for people with young onset and their supporters; The DYNAMIC project – on social care for people living with YOD and their families. She also leads the Young Dementia Network's research workstream.

Jan, it is an honour to welcome you as chair:

Jan Oyebode, Professor of Dementia Care at the Centre for Applied Dementia Studies, University of Bradford.

It's a real honour for me to be here. I think we're all going to have such an enriching time, getting this conversation together, with several people who are very inspiring figures in the young dementia world and the dementia world generally, and who are outspoken advocates for good support and services for people with dementia.

I think it's wonderful to have a focus today on Young Onset Dementia (YOD). It's catching more attention now than it used to. That is largely thanks to prominent voices who've been acting to draw attention to the needs of everyone with dementia, but especially for people with YOD because, as you see from our panel, these are people who are younger themselves. First of all, Veronica invited me to speak briefly about The Angela Project.

The Angela Project (2016-19)

This was a project funded by the Alzheimer's Society in the UK to run from 2016 -19. We are still producing outputs and resources. The project aimed to improve assessment and diagnosis and post diagnostic support for people living with YOD. It was led by Janet Carter, who is an old age psychiatrist working in North-East London Foundation Trust and at University College London. She led the work on diagnosis, along with Professor Jackie Parkes from the University of Northampton. We ran the post diagnostic work stream from the University of Bradford. Keith was also involved as a key member of our Involvement group. We surveyed people living with YOD in the post diagnostic work stream to ask people about the services and support they received. We had responses from 233 people living with YOD or their family carers. They were a mixed group of people aged from their 30s to their 60s, with an average age in the 50s.

Survey headlines – only one in five able to access specialist service

Just drawing your attention to some headlines that came from this survey. Only 20% of people received any specialist service. The Specialist services for YOD were associated with higher satisfaction and higher quality. They provided better care continuity, and there was better care planning, but only one in five people were able to access a specialist service.

About half those who responded to the survey accessed some dementia-related activities, but just under half hadn't attended any dementia related activities in the three months prior to completing our survey.

Care costs

The cost of care is very modest for people living with YOD. People were using Health and Social Care and Third Sector Services, which cost on average £394 per three months. But for Family Care if you totted up a total based on the pay a care assistant, families contributed care worth over £8,000 in that same three-month period. So we can see that families provide a lot of support. Official services aren't providing a lot of support. We knew that there were difficulties in accessing services, and we wanted to find out more about what was really helpful. We asked people to give us a brief description of any service they'd found helpful; and we analyzed these to understand what they were, how they were provided to be helpful, and why they were helpful. Our 233 respondents sent in over 850 examples of positive services. I think this makes us feel more hopeful to know that there are a lot of things that people living with YOD do find helpful.

How Services Helped

We tried to distil the essence of these from all the examples. There were three reasons why services were found to be helpful. Firstly, they helped the person living with YOD to maintain independence and autonomy. Secondly, they enabled the person to be themselves, to have their own identity; and thirdly, they enabled people to feel connected with others and the world.

Creativity and the Arts – the power of music as self-expression

Now we didn't ask people specifically about arts and creative activities. And because we asked about services and support, a lot of people told us about conventional health and care services. But people did also mention creativity and the arts, and I just want to finish my brief few words by giving you an example from someone who spoke about the place of music in his life. He said, ‘Once you've got a diagnosis of dementia, most people define you by the diagnosis and not based upon your potential and who you really are. And that makes you reluctant to engage with anything.’ He said, ‘What's been good for me has been music and situations where people allow me to play that music and express myself. People recognize what I do is relevant. I'm still full of the person who I used to be, who I am. I'm still full of the youngness, full of the energy and full of the enthusiasm. What's important for me is something that's compatible with who I am.’ He gives us an example of how music and creativity in his own life helps to contribute to him feeling that he is very much himself and valued as himself by the people around him.

In the transcript, you'll have links to the Young Dementia Network site – all the outputs from our project are there for anyone to access, with articles and other resources connected with The Angela Project.

Let's turn to our panel. Each person is going to have a few moments to say something about themselves and the part that creativity plays in their life.

THE CONVERSATION PANEL

Kate's such a well-known name I feel I'm in the presence of the royalty of the dementia care world here today. Kate is a researcher and a published author and poet, and a global campaigner for human rights and disability rights of older people and people living with dementia. We're delighted to have you with us today from Australia, Kate, and to hear about the place of the creative arts in your life.

Kate Swaffer, author, activist, academic, poet, photographer, Australia

Thank you so much, Jan, and welcome, everyone. I'll just start with a special thank you to Veronica for the invitation to be with you today and to join so many wonderful friends also living with dementia; and also thank you to everyone for making time to join all of us. I know some of you and know some of your names and your incredible work in dementia. So together, maybe one day we can change the world!

I thought rather than focus on my creativity, which I'll discuss very briefly, but I think that the reason that so many of us have turned to creativity is really what happened to me and what happened to many people before me, to people such as Christine Bryden and the late Dr. Richard Taylor and then has happened to so many people still.

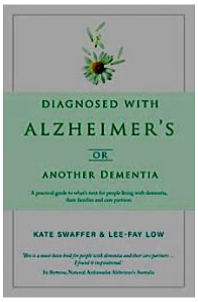
My diagnosis 'guidance'

Being diagnosed with a rare YOD as a 49-year-old married working mother with two teenage sons was truly pretty traumatic. Particularly because I'd been a nurse and I didn't know that young people could get dementia. But what was worse than the diagnosis, I felt, was that being told the only thing that I could do was to go home and prepare for the end. Get my end-of-life affairs in order and there's nothing we can do. So I think for me it was a spiralling downhill to start with. And for my husband and teenage kids, I thought that there was no hope for any sort of future together as a family. Thankfully, I had a couple of lucky breaks.

University response – Accommodating Acquired Disabilities

I was a mature age university student at the time. My lecturers were perplexed about why everybody else told me to give up everything – they just saw me as a person with acquired disabilities and referred me to the disability support Team. But my employment was terminated upon disclosure of the diagnosis. Although dementia causes disabilities, we all know that now and the World Health Organisation have been saying that for 15 years, in fact since before my diagnosis, not one healthcare professional or service provider has advised me ever until quite recently that I had rights under the Disability Discrimination Act in Australia and the CRPD to be supported to stay at work.

CHAT Veronica, A4D: In 2019 The All-Party Parliamentary Group on Dementia, co-chaired by Baroness Greengross and Debbie Abrahams MP launched the *Hidden No More: Dementia and Disability* report.



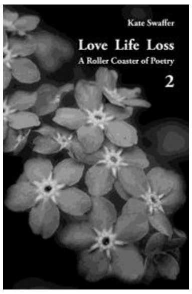
The other factor that impacts my more positive trajectory is that I soon realized and I'm a retired nurse also – there's some other retired nurses in the room. I believe. Wendy – I realized if I'd had a stroke, age 49, I'd have been offered rehabilitation and supported back to work with disability adjustments if needed. And the creativity part is really important. But we really have to question why the dementia and healthcare sector tells us to go home and prepare to die.

In my experience the education system supported me to keep living Kate Swaffer's life, as a person with acquired disabilities. I think being supported as a student enabled me to continue to live my own life, meaning I could continue with my studies and I still get support from a university today disability support.

No support from the Healthcare sector – Disability Rights issue

But I still don't get support from the healthcare sector. So it is a major rights issue facing people with dementia. I didn't want a new identity. I wanted support to maintain the one I had.

Dementia's gifts – new friends, maths replaced by creativity



That doesn't mean that having dementia has been all bad. Dementia has given me many gifts, and it's introduced me to loads of amazing people around the world, like many people on this webinar. It's given me a clarity about life and about people that I didn't have before, despite the increasing fog. And I wasn't a poet before dementia. I wasn't really interested in photography and design. And all of those things have taken over the parts of my brain that don't function like they used to, like my photographic memory, my high level of maths ability that's gone. I can't even use a calculator anymore. But these other creative gifts seem to have turned up to replace the things that have gone missing.

New Creative Thinking and Skills – Pictorial Vision

So, whilst there are progressive changes to my cognitive capacity and my memory and thinking, my memories change, my thinking. I see things in pictures now, which I believe is very much like people with autism. And I actually believe through continuing to study and to continue to be so active, as many other people here with dementia are living active lives. I think we are creating new neural pathways in our brain.

Focussed Rehabilitation – Need to Support and Encourage People to Live Well

The other thing because I had been a nurse and was able to fund it, was a really focused rehabilitation programme similar to someone post stroke. We need to support people to live their best life possible with dementia, not only to prescribe, giving up and preparing to die from it. And yet most of the people I meet newly diagnosed through Dementia Alliance International are still advised to prepare for the end, and there's nothing that they can do to live a positive life.

People who don’t believe we have dementia

There's a couple of things I just wanted to say about – and some of us here have faced this challenge – living more positively than an expected with dementia, particularly living more positively than people who are older and in a later stage of dementia. There's been a group of people around the world who quite publicly say they don't believe we have dementia. My own neurologist was quite insulted by that, is as if there's a group of people who don't believe he has the capacity to diagnose a person with dementia, even though that's half of his patient cohort.

Creative Gifts that Keep Giving – Poetry, Photography, Music, Gardening

But for me, the gifts that just keep giving are the poetry and photography, which I didn't have an eye for photography. A much stronger interest in gardening and a really changed and very different musical palette now. They've been incredible gifts of dementia. And I do think that the other really important gift is it puts everything in perspective. And you really do learn to just enjoy whatever you get today and not worry too much about what might happen tomorrow.

CHAT Kate Swaffer, Kaurna Country Here are links to my books *What the Hell Happened to my Brain: Living beyond dementia* and my poetry books –

J.O., chair Thank you. That was just such a rich five minutes. You've said so many things that I'm sure will strike a chord with lots of people listening; and you've packed so much in there in terms of words about our rights and the importance of hope, but also the opportunities to live our best life possible; and the gifts that you didn't expect that dementia has brought you. Thank you so much. We will hear more from you in a little while and let's now turn to Keith.

J.O., Chair Keith Oliver is a retired head teacher and we've known each other for a lot of years now. And Keith has written short stories, books, poems and now has started to produce watercolour paintings and artwork. He is going to tell us a little about his life and how it's going and the connections with creativity.

Keith Oliver, Alzheimer's Society Ambassador, human rights activist, author, 'Photography, Painting and Poetry'

It is wonderful to be here this morning and a real privilege to follow on and take the bat on from my dear friend Kate. Moving on then as part of maintaining my wellbeing, it is now not overstating the fact that creativity and stimulating leisure activities makes life for me worth living and has filled so many vacuums in my life which have been created by Alzheimer's.

Intergenerational collaboration

There are a number of threads through my talk, the value, first of all, of intergenerational collaboration in the arts, pursuing activities as an individual for my own satisfaction or in a group when sharing the learning and the results, which often includes encouraging and supporting one's peers. I've subtitled my little contribution today as the three Ps, 'Photography, painting, and poetry'. And we'll explain why as I go along.

Photography

Firstly, photography is the only creative pursuit amongst the three which I have enjoyed and practiced since well before my dementia diagnosis, which occurred on New Year's Eve 2010. I taught creative black and white photography as part of my art curriculum to primary school children; and then in liaison with a local secondary school, taught the children how to develop and print their images in a dark room. This was an exciting and adventurous activity for us all in more ways than was always anticipated with children collaborating and creating together in a dark environment.

Then since being diagnosed. I have become the photographic student – learning with others who have dementia how to make better use of cameras on my iPad and smartphone. This has been through two dementia projects here in Canterbury, one funded by the Arts Council and the Dementia Engagement and Empowerment Project (DEEP); and one by Kent County Council, the latter combining photography with poetry and music to enable people with dementia to express a creative narrative of their own.

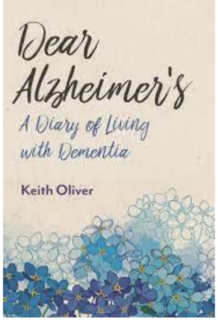
Painting

Between the ages of eleven and 64, my sole use of a paintbrush was to paint walls and ceilings with my wife in our home. After Lockdown, I joined an online art group led by Frances Isaacs and my dear friend Gail was part of that group as well. I was introduced to a skill and a passion which I never knew I had, which is watercolour painting. This has completely changed the way I look at the world in which I live. I don't copy when painting, but try to take a story in my head and transfer it onto paper using paint. This has encouraged me to be more resilient, patient to rework ideas and take risks and some happy accidents have been the result.

Similarly, it is only since being diagnosed that I have written poetry, some of which I have been very fortunate to publish. I'm going to finish mine a little bit with a poem, which I wrote some months ago and which seeks to turn stigma a negative stereotypes on their head and was recently the subject of an Arts Council funded film. Depend upon which where you put the emphasis on the words. Is called atrophy.

A - trophy

Re-reading the neurologists report
Nearly said my neurologist
But he doesn't belong to me
And I certainly don't belong to him
About a brain which does belong to me
Why does the word atrophy jump out
Puzzle me, concern me, cause me to self doubt
Surely atrophy should be reason to celebrate.
Who has given me atrophy
Shook my hand in exchange for a smile?
This is atrophy shared with family and friends
Whether they like it or not.
Picturing atrophy in my mind
Filling in the gaps
Atrophy maybe for my brain
For sporting achievement
For effort, for trying (very!)
For quizzing – a good memory test
Even for being ME.
I don't need atrophy to remind me
How hard it is to remember
But what some people say and do shines through
A trophy that many compete for
Are given
But few will want to win
Maybe around the base
We have names engraved
Past winners, past friends, past ...
In atrophy so we never forget them.
Fair to say sometimes
It feels my brain is shrinking
But then my heart gets bigger
Maybe that's what deserves atrophy!



J.O., Chair Thank you so much, Keith. That's such a beautiful poem, and beautifully delivered too, really lovely and you have achieved all this living with a brain that has some cognitive problems, but demonstrating to us just the sheer creativity that has arisen since that diagnosis, I think, is so inspiring.

CHAT **bisakha sarker** Beautiful poem **Keith** Poetry by Writers with Dementia What a great webinar.

J.O., Chair Next on our starcast is Wendy Mitchell. Lovely to see you, Wendy. Wendy has lived with dementia since I think 2014 and has a blog Which me am I today? where we can all read about the day to day adventures, trundles and visits to paradise, as well as other things. Wendy is also author of best-selling books, which if you haven't read them, I do highly recommend. Reading Wendy's books if you are working with people with dementia, you would learn so much. Wendy, over to you.

Wendy Mitchell, author, photographer, social media champion, blogger

Thank you. And as Keith said, it's so lovely to share the stage, if only online, with so many wonderful friends.

Throughout my life, I've had many artistic interests, but dementia has taught me the importance of Time – and how!

Time – Enjoy the moment!

This very moment is the only time any of us are guaranteed, as no one knows what's around the corner. I was as guilty of anyone in my working life of wishing for the weekend, wishing for the following day, wishing for the next holiday. But now I simply do my best to enjoy today. Enjoy this moment. Nature has taught me to enjoy the smallest moments during lockdown which everyone found difficult. I realized I needed to find a new routine.

Photographing Nature – Take Time to Stop and Look, Really Look!

As my old routine of traveling three or four times a week around the country, giving talks disappeared, by pure chance I bought a camera just before lockdown. One day I saw it staring at me from the bedroom carpet. Could this be the answer? Because I never had time to discover my village before – I was too busy traveling. But how the world had slowed down.

The Camera Lady – seeing dementia in a new light

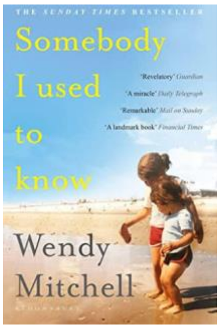
I went out each day taking photos along the way. Clicking those magical moments so often missed if you don't take time to stop and look. really look. I discovered we had a village Facebook page. So each teatime I'd post my photos and the comments that came back were so wonderful, so heartening. We were having to stay indoors. So it's lovely to see village life through photos. Another said, I never realized our village was so beautiful. You see things we all miss. This different means of socializing with the community around us is what got me through this strange period we all faced. Most villagers didn't know I had dementia at the time either.

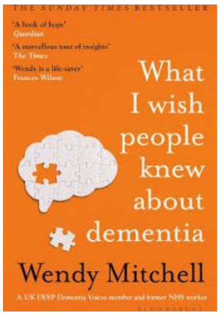
CHAT Berni God Wendy you inspire me with your camera ! ❤

Word began to get around that I did have dementia. But instead of calling me Wendy With Dementia, they started calling me ‘The Camera Lady’. They saw my talent with a camera before they saw my dementia. So now they saw dementia in a whole new light. I still post my photos every single day on the village Facebook page and the villagers even asked me to produce the village calendar for two years to raise funds for the village but also my support group. So my new hobby helped me as well as many others.

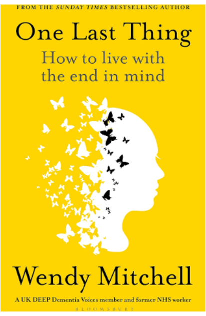
Which Me am I Today?

My other main therapeutic passion is writing. I can type words faster than I can think and speak them because that part of my brain hasn't luckily been affected yet. Typing is my escape from dementia. My blog *Which Me Am I Today?* is simply my memory. But it's so humbling to think that people all over the world read it. It was the blog that led to publishers asking me to write my first book. But I kept turning them down. I knew I couldn't write a book by myself because I’d never remember what was on each page as soon as I turned it over.





So when the lovely Anna Wharton, emailed me out of the blue and said ‘I think we could write a book together’ that I'd wished I'd had when my father was alive. Suddenly, the impossible was becoming a possibility. I didn't want Anna to write my book. After all, she's a ghost writer. I didn't want her to just interview me and write my book. It wouldn't be my book. So we found a way whereby it worked for both of us. She told me what we were writing about each day. I typed my words. Then Anna would work her magic and weave it into the storyline and keep it all in time order. That's how we wrote my first book, *Somebody I Used to know* and my second *What I wish people knew about dementia*. My publishers are Bloomsbury, the same publisher as Harry Potter. Where's the connection? you might ask. Well, I was diagnosed on Harry Potter's birthday, 31st July, so the partnership was simply meant to.



My last book

But Anna has taught me the art of writing, the importance of writing is the detail, just like the click of a camera, the detail that so often missed. That's why I know my last book. *One Last Thing* is my final book. As through writing that I discovered the balance was tipping in Anna's favour. And for me, a book isn't my book unless I've written it.

So they're my two creative pastimes. After all, we all had talents before a diagnosis of dementia. We don't suddenly lose those talents overnight when we're diagnosed and with help and patience we can learn new ones. Thank you.

J.O., Chair Thank you very much, Wendy. A lot of really interesting words of wisdom there. Your focus on time, the importance of time, and the time that the terrible pandemic gave you to observe and then allow your photography to flourish, that's really fascinating.

J.O., Chair Our next panel member is Chris Norris. Chris was diagnosed with frontotemporal dementia just over ten years ago now. We haven't really heard yet from someone who's a musician. But Chris blows the horn and is going to tell us a bit about the place of music in his life today. Over to you, Chris.

Chris Norris, tenor horn player in brass bands, Alzheimer's Society Ambassador, Kent Dementia Envoy

Thank you, Jan. And good morning, everybody. It's great to see everybody here. It occurred to me earlier on in the talks, people were saying that they see us as a person with dementia, and they don't see the person behind the dementia. It occurred to me when I looked at the picture of me blowing the horn and saw instead a picture of a light bulb in the ceiling – unfortunately, the rest of the picture of me actually playing my tenor horn had disappeared off the screen – it rang a bell with me. Well, there you go, that just goes to show – we're more than the dementia and I'm more than a light bulb.

Cornet player in the Mounted Band of the Lifeguards

So whizzing on, I started my music playing when I was eleven; and I went into the army at the age of 15 as a junior musician in the Mounted Band of the Lifeguards. I had to be able to play my instrument. My weapon of choice at the time was the cornet. I had to be able to play that riding on my horse, which is no mean feat, because of course horses have a mind of their own and they sometimes don't do what you want them to do. When I came out of the Mounted Band of the Lifeguards I joined the Kent Police. And about a year after I joined them, they started the Kent Police Band. So I was a founder a member of that and at the time. I decided to change my instrument.

I feel a bit like a ventriloquist now because I'm going down into my box of tricks, and there we are, that's what a tenor horn looks like. So a bit different to the cornet. Well, it's the same shape, but it's just, on its upright when you play it. So that's a tenor horn. And in brass bands, it replaces the French Horn that you see people playing in the orchestra, where they shove a hand up the bell and tootle. I played away nicely, then

Heart attacks stopped Chris playing the horn

Unfortunately, in 2008, over an 18-month period, I had three heart attacks. The consultant told me each time, Chris, 'You really should stop playing your music. You're putting too much pressure on your heart.' I didn't listen because music was a part of me and had been a part of me. But when I had my third heart attack, I thought, well. I just must listen to what I'm being told and give up playing. I stopped playing for five years.

FTD diagnosis, blow it! – Triumphant music for wellbeing

Then I got my diagnosis of frontal temperature dementia (FTD) and I thought, oh, well, blow it. As Jan said earlier on *Well, blow it*! If my heart doesn't get me, the brain's going to get me. So I went back to it. I'm happy to say I haven't had any heart attack since then. So there we are that's jolly dinkham.

A4D Music Reawakening

Then I was invited in 2015 by Veronica to take part in the Arts 4 Dementia programme for musicians with YOD; and this was joined together with the English Chamber Orchestra musicians and London College of Music students. And we all sat down and talked about the challenges that I had and that we found coping mechanisms and ways around the difficulties of doing things. I've lost a lot of things that I had learned when I was at the Royal Military School of Music at Kneller Hall in Twickenham. I'd forgotten those and I was losing some of my techniques. But between as we managed to find ways around it.

Transposition – mutual learning

They also learned things because they never had to transpose their music. They just played what was on the page. Whereas if I'm playing along with them because my instrument is in a different key, then I have to be able to transpose which I've lost the ability to do. The upshot of that was, we then put on a performance at the Wigmore Hall in London, which is a very grand place, we composed some music; and we put on the performance there – which just proves that people living with dementia still can and still do.

Welcome to Our World

Along the way I also joined Keith Oliver. In writing a chapter in one of his books. *Welcome to our world*. I'd never done any life writing before. In those chapters we talked about life before, life with the diagnosis and what you saw into the future. So that was all very exciting. That's the only time I've gone into that side of things.

DEEP *I've Got You!*

Then on the 10th anniversary of DEEP, which Keith mentioned earlier on, they put together a video called *I've Got You*, and if you go onto the DEEP (Dementia Voices) website, you can see *I've Got You* and they got me to do all the music background. So in places in the film there are nine pictures of me on the screen playing all the different parts which I thought was quite interesting and funny. It's a bit like

Celebrity Squares, really. It was really quite funny. I put on a different shirt and jumper for each picture on the screen. So it looked like there were nine of me.

Learning a new instrument

During lockdown, the group that I belonged to decided that we would do our own research about music. We looked into the idea. Is it possible for people with dementia to learn a new skill and we found that it was – we all learned the ukulele. We managed to put on a performance – none of the others were musicians. They all thought I'd be able to do it easy-peasy-lemon-squeezy. It wasn't the case. Learning a new instrument can be challenging, but we were all chuffed with what came out at the end.

Worries floating away with horny fiddle

You have to laugh sometimes with dementia. Recently I was sitting on a Q&A panel on stage in front of an audience, around the arts. I thought the audience knew that I was a musician. But as I found out, they didn't know what context it was. They didn't know I played the tenor horn. I was asked a question as to how music helped me. I replied that when I get tired and frustrated, I take out my horn and have a jolly good play and fiddle with it, and all my cares and worries float away. I noticed that I was sending the audience into hysterics because they didn't know that I played the tenor horn.

Laughter the best trip on words

I find these days when I start talking, the words just keep coming out. I know something's going wrong, but I can't stop them anyway. Everybody was in hysterics. I had to explain to them. Yeah, I'm a tenor horn player. So when you're living with dementia, I've learned to laugh when dementia sticks out its foot and trips us up. I think that's what living with dementia is looking at the things we can still do and not the things that we can no longer do because there's zillions of things we can still do. Thanks very much.

CHAT Kate Swaffer Laughing is also my way to cope with the changes! it sure beats crying

J.O., Chair Thank you, Chris. That made me smile. Probably made everyone listening to you smile as well and that message of the things that you can still do and you do do carry you forward, despite that advice you had not to carry on playing. So thank you very much.

Last, but not least on our panel of people living with YOD today is Gail. Gail Gregory was diagnosed three or four years ago. She lives in Lancashire. Gail received a diagnosis three or four years ago. Now in her early 50s, Gail writes a blog and has a talent for art. And you can see an art piece behind Gail now on the screen. And she's going to tell us a little bit about the place of art in her life.

Gail Gregory, artist and blogger


Remember, inspiration can go a long way. Thank you for listening to me.

Thank you so much for inviting me to join you all this morning. It's an honour to share with you how I keep my brain active while hopefully I'm inspiring others.

Difficulty of diagnosis

When I received my diagnosis of early onset Alzheimer's four years ago, I felt empty. I felt lost. Not only had I received my diagnosis, but I had the very difficult decision to give up my business. The business that I had worked so hard to create, so I felt like I'd lost everything. I felt like I'd lost all purpose in life.

Culture, Creativity and Writing Restores Sense of Purpose

It was arts, crafts, photography and my blog that brought a sense of purpose back into my life. I needed to find ways. That I could keep my brain engaged. Our brains are very remarkable and require regular exercise to stay sharp and function at their best. So I needed to ensure that my brain was staying active. Now, for me it was arts and crafts, nature and photography.

Challenging Myself to Promote Brain Health

I do like to challenge myself with new information and skills. And I believe by doing this I'm hopefully promoting my brain health and holding on a little longer to my cognitive function. By incorporating my arts and crafts into my daily life, I am hoping that I will keep my brain engaged much longer.

I always like to start my day with an early morning walk and that's joined with my four-legged friend Toby, who was a celebrity in his own right and poses regularly for photographs that are shown on our local weather TV station.

Camera as Memory Aid

I love being outdoors just to soak up the beauty of nature and capture my walks on camera because it just doesn't take photos. It's a wonderful memory aid and I can relive my walks on my photographs later. The sights and sounds of nature are just so calming. And I have indeed countered some very special moments with nature. I'd even had little Robins feeding from the palm of my hand. Such a great way to start the day.

After a good dose of fresh air, it's off into my craft room. Or I sit at the computer and write up my blog, depending what inspired me on that particular day.

Inspiration can be very powerful. It has the ability to ignite others and encourage others. An inspiration can come from many, many different sources. Lots of things inspire me to be creative. Other people, flowers, nature. The list is endless. We all have so much beauty around us. If only we would take the time to stop, to look, and to listen.

Dementia Inspired Me to Try New Things

A supposed dementia has inspired me because it's given me the opportunity to try new things, to be creative and to use my imagination. I do try to attempt a piece of art.

Art to Calm Me

Most days it helps to calm me as I immerse myself in a piece of art. Dementia seems to disappear. I have no confusion. I have no agitation. It's just me and my artwork. Arts, crafts, nature, and photography is my form of mindfulness.

Learning Art Post-Diagnosis – Great Comfort in Mastering New Creative Skills

I had never done any drawings or any paintings until after my diagnosis. That was all thanks to a wonderful lady called Frances (Isaacs), also living with dementia, who encouraged me to try drawing in watercolour. I was so surprised when I found out that I could actually draw and I could paint. But the biggest thing was that I was learning something new whilst living with dementia. Art became a way of bringing out a creative side in me that I didn't even know existed. I started to express myself on how dementia made me feel. It was becoming a way to release the feelings and emotions that I was carrying inside. My blog and poetry helps also. It's just a great comfort to let things go. There are so many benefits to arts and crafts, nature and photography. I believe by doing these that I'm keeping my brain active and it's beneficial to my wellbeing.

Health Benefits of Artistic Achievement

It reduces my stress levels. It alleviates my symptoms of anxiety. It helps me with the feeling of loneliness. And it keeps my brain active. The best thing of all is the feeling of achievement when I've actually completed a piece of artwork.

Art Brings Power to Motivate, Inspire Others

So let us embrace the power we have to inspire. Encourage and motivate others. Let us be a trigger for change and make a positive impact in the lives of those around us. Remember, inspiration can go a long way. Thank you for listening to me.

J.O., Chair Gail, thank you very much. And very appropriate to end on a type of call to action for us all to show how, living with dementia or not, we can inspire others, and we can help others to see some of the ways that we can enrich our lives. I think you've all spoken about having very rich lives. Thank you very much Amisha for showing Gail's wonderful drawings. Thank you.

THE PANEL CONVERSATION

We have just a few moments for everyone on the panel to talk to each other. Welcome back, everyone. You've all said things that connect with each other. And I'm sure you'll have been listening to each other and thought, 'Oh, yes, that resonates with me'.

Chris

Let people know we have dementia

Yes. I think sometimes when you're living with dementia, sometimes people are a bit shy to let other people know that. Dementia does exist in their life and in my banding. I now make sure that people on either side of me know that I'm living with dementia and they are very helpful. They will subtly lean forward. If we're told to go from a certain place on a piece of music, they will lean forward and count on the music as if they need to know where they are. I know *they* don't need to know but they are just subtly helping me. If I didn't tell them, they wouldn't do that and I would not be able to carry on as successfully as I am. So I think it's very important that we let people know of our conditions.

Giving Inspiration to Others

What Gail said about inspiration to other people is bang on the nail because it puts things in a totally different context, that we still can. When you look at the things that the people on the screen have done, you think: Wow, we're no different to everybody else. We achieve things. And we will carry on achieving things. And there's no stopping us because we've got the power to go on. Thank you. Thank you, Chris. Smiling broadly.

J.O., Chair Wendy?

Wendy

Friendships

To me through all this is the friendships, how we've encouraged one another. We've all had that dreadful experience of diagnosis.

Hope

We've not heard that tiny four-letter word that means so much to anybody - Hope. And yet all of us. *Kate was the first person to give me hope*. It's that if we were a company wed be succession planning. To keep that motivation and that knowledge of can-do attitude. And I think that's just shone through today.

J.O. Chair Yes - and Kate?

Kate Thank you. I didn't know that, Wendy. It's lovely to hear that, thank you. And I started blogging, maybe 2009, I think that was, before the book.

Tell People You Have Dementia

But I wanted to comment on something that you said, Chris, because I think it's really important. You said that we should tell people that we've got dementia and not be fearful of doing that. I had a lovely example of a close nursing friend and her husband come to visit me one day, maybe three or four years into the diagnosis. And they sat down and asked me how I was. And I did the typical *I'm fine*. Probably everyone says that down the street because we all think nobody really wants to know what it's like. My friend's husband said, ‘Now, Kate, I'm sure things aren't fine all of the time. They might be right now while we're visiting. But really, if you don't tell us what it's like for you, how can we actually support you?’ And I really took that to heart, and there's been some negatives to taking that to heart.

With Cancer, Parkinson’s Disease or Diabetes, We Wouldn’t be Fearful or Ashamed

But seriously, if we had cancer or if we had Parkinson's disease or if we had diabetes we wouldn't be fearful or ashamed of telling other people if it came up in conversation.

Be Upfront – Break Down the Stigma

I think that one of the ways that we can help break down the stigma is to be as upfront about having dementia as we would be about cancer. A very high profile media woman in Australia – she's currently Chair of the ABC Television Channel was quoted a few years ago ‘when Someone Gets Cancer, everyone swarms around you, promises to be with you’. - I don't know if anyone has had cancer - everyone promises to be with you and hold your hand till your last breath. But when you tell them you got dementia, a significant proportion of those same people quietly disappear. Is it that they're scared? Or is it this late-stage dementia that they think we're going to go straight to? Is it that they're fearful for their own potential to have to. There's too much fear attached to dementia, so we can't be open. We just need to be open about it like we would about anything else.

CHAT

Kate White: My partner and I emerged from feeling shame to being “out and proud with Alzheimers” that was through being part a group called Remembering Yesterday Caring Today where creativity was at its heart. We re kindled love and connection and hope. This conversation is so brilliant THANK YOU. **Kate Swaffer, Kaurna Country**: 🌻

Kate White: I have talked about an expanding sense of self with dementia rather than a shrinkage.

J.O., Chair I think you're all breaking the mould in being open about it. And I think this is the only way. To show people how living with dementia isn't the end of life. That lives continue. You go on growing, developing. And it gives everyone who receives that diagnosis hope, that they still might not get from a healthcare professional. And I think as healthcare professionals, we could do much, much better in giving that hope at the same time as knowing that a diagnosis isn't an easy thing to receive. Gail, is there anything you'd like to comment on before we move to the next section of our meetup?

Gail

Give us Time to Learn New Skills

I think the only thing for me is many people think that we can't learn new skills. But. They should just give us time and be more patient with us because if they give us more time, we would learn new skills and we still can learn new skills, and I proved that.

Kate I think with support, people can still do what they used to do, too.

Gail If that's what they want to do, right? I've proved that I've learned how to paint and how to draw, after diagnosis. And I'd never done that before. Give us a chance so we can learn something new.

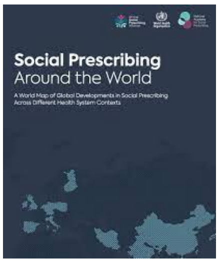
J.O., Chair Thank you. I think the brain is a wonderful, marvellous thing, isn't it. You've all spoken about ways that your brains work, knowing that you have this diagnosis. But you found new ways of seeing things, new channels, as well as continuing things that were already in your life, I do think it's very inspiring to hear. Thank you everyone, for contributing and giving your own angle. Everyone's different. You've all brought so much enrichment to this conversation. Thank you.

CHAT
Keith Oliver: What a great webinar.
Nigel Franklin, A4D: So inspiring!
Veronica, A4D:Thank you all for your profoundly inspirational and courageous sharing - thank you Kate for staying up late to talk from Australia, Wonderful Conversation
Berni God: Thank you so much ! Veronica ! Mostly for inviting me to this real and inspiring people who live with Dementia amazingly ! Makes me inspired to live in the moment and with Joy regardless of what news they have been given !
QJ: Thank to all who have contributed it was very powerful
Tibbs Dementia: such a helpful, hopeful and inspiring morning. Thank you.

ACCESS & SUPPORT

J.O., Chair At this point, we're going to move on to think about access because many people living with dementia may need some assistance to know how to make those connections to get into using the creative side of themselves.

We are going to start by hearing something about social prescribing from Hamaad Khan, who’s a medical student, but not just your average medical student Hamaad is Global Development Officer and he collaborated with the World Health Organisation to author a report on Social Prescribing Around the World. Really looking forward to hearing what you have to say.



Social Prescribing
Around the World

A World Map of Global Developments in Social Prescribing Across Different Health System Contexts

Hamaad Khan, Global Development Officer, National Academy for Social Prescribing ‘Social Prescribing: Its Place Purpose & Value: For Dementia Care and Patient Wellbeing’

Thank you so much, Jan. It's an absolute pleasure to be here this morning to talk to you all about social prescribing (SP) and galvanizing a student movement for the benefit of dementia care that is more holistic, complete, empathetic and patient-centred.

Paradox of Modern Medicine – More Medicines and More Illness

But first I would like, as a medical health professional to talk about the cultural clinical context that we're in. There's a gaping, huge, daring paradox of modern medicine, which I like to call it. And the paradox of modern medicine is that we live in an age with more medicines, more therapies more treatments and yet also more illness.

Now, if medical drugs are designed to revive, restore and renew good health, we should be experiencing an unprecedented level of good health across our societies. Yet at this time of the greatest scientific medical understanding, it seems ever harder to attain good health, good wellbeing and good nutrition. This goes across the board not even looking at the ageing population or dementia diagnosis.

UK’s System of Sick Care

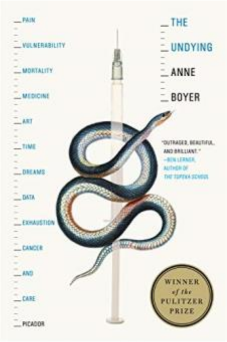
In this context, the UK has created an industrialized healthcare system of sick care, not healthcare. We admit the sick, we tend to the sick, we care for and heal the sick as health professionals. And when we're done laughably, ironically, horribly, we put our patients back out into the very same conditions, environments and lifestyles that exacerbated or perhaps even caused the very sickness in the first place. So a whole system is cyclical, fragmented, acute pep. Our health systems are designed to respond to crises, but they're not yet developed with a vision of health creation and disease prevention.

SP – A Model for Health-Care not Sick-Care

That's where SP comes in. It's about understanding what's the matter with the patient, but also what matters to the patient holding their hand, understanding what the problem is and seeing where we can make those vital social connections to improve a biopsychosocial understanding of their health.

Diagnosis

But in this context, in this horrible, industrialized context, the patient becomes a passive entity. We have heard much already about the burden of a dementia diagnosis and how, unfortunately, you can sometimes have your social networks collapse and you feel this passive sense. We see this a lot in our medical care. A brilliant writer called Anne Boyer talked on her cancer diagnosis and experience of medical care. I wanted to share this because I thought that this may even resonate with quite a few of the audience here today. She said in *The Undying*:



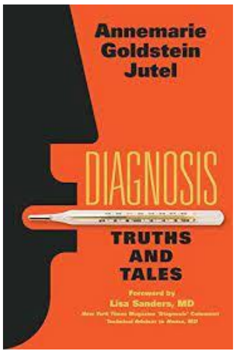
> We fall ill and our illness falls under the hard hand of science, falls onto slides under confident microscopes . . . then there is this body (my body) that has no feel for uncertainty, a life that breaks open under the alien terminology of medicine.

(Boyer, A., 2019, *The Undying*, 18)

She writes beautifully about how empirical science does little to invite respect and care for the patient voice in their journey to a long-term wellbeing and resilience. And that's the key. Because the patient voice is hushed under the hubris of modern medicine.

Listening to the Patient

There's a common phrase in medicine by William Osler, who is considered one of the grandfathers of evidence-based medicine. He said many years ago, ‘Listen to your patient. They are telling you their diagnosis.’ It seems we've stopped listening because now 44.6% of patients want more involvement in their healthcare. And yet at a record high, 10% of patients feel disregarded.



Again on what a diagnosis means and its effects on our patients. It changes how we think about our bodies. Annemarie Goldstein Jutel says our disorders are futures and even our identities. It brings into the foreground consciousness of a body that is sick, complains, creeks, and disobeys our intentions to do what we want to do.

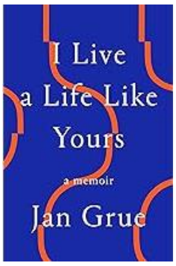
(Jutel, A.G., 2019, *Diagnosis: Truths and Tales*, 18)

But medicine and SP, as it were, can offer far more when we allow patients the dignity and autonomy to direct their own care, to understand how they want to move forward with their life. Because diagnosis is not a fate. It's not a burden.

SP Student Acting with Early-Stage Dementia Participants at Southwark Playhouse (2020)

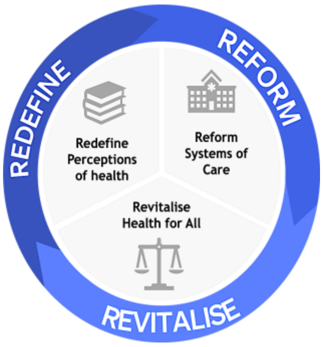
As a neuroscience student a few years ago, I had the absolute privilege of attending an early-stage dementia programme which Veronica organised for Arts 4 Dementia in partnership with the Southwark Playhouse. As a volunteer at these weekly SP drama workshops, I saw dementia beyond my clinical gaze of neurofibrillary tangles or amyloid plaques. I found vibrancy in many people, not just patients, but people who persisted through a disease that is so far easily marked by loss and deficit. I saw patients who weren't encouraged to submit to their symptoms but empowered to improve their own health and wellbeing in a way that makes sense to them. That's what SP is about. It's removing the unnecessary clinical gaze and connecting patients to their community services and resources so that they can also be incorporated and integrated into a wider sense of care.

Jan Grue, the Netherlands writer talks about his cerebral palsy. He mentioned the clinical gaze and says:



> What is this gaze, which is so sharp and penetrating but simultaneously dull and disinterested, that separates things that should not be separated and at the same time mistakes one thing for something very different?

(Grue, J. 2021, *I Live a Life Like Yours*, 30)



SP: Establishing Cultural Change

SP tries to remove a lot of that unnecessary clinical gaze. It's about establishing a cultural change. We want to redefine perceptions of health. As a student, my perception of health was determined by symptoms, diagnoses and biomedicine. But by understanding that patients can improve their sense of wellbeing with a biopsychosocial care,

Every GP has Linkworker to Connect Patients to Arts Programmes

By incorporating a linkworker who can connect them to the community, understanding what sort of hobbies are important, whether it may be playing instruments and improving your sense of wellbeing through different forms of art, as we've heard.

Redefining Perceptions of Health It's about redefining that perception of health, not just for current doctors and healthcare workers, but also for future doctors, current students.

Reforming Systems of Care And by doing so, we reform our systems of care. We make sure that every GP has a vital link worker as we now have in this country, where when patients come in with perhaps symptoms of dementia, not only are they given a biomedical care, but they're also connected to their communities so that they have a holistic sense of wellbeing.

Revitalising Health for All By doing so, we eventually revitalize health for all, by not just unnecessary medicalizing, but vitally socializing, people's connections too.

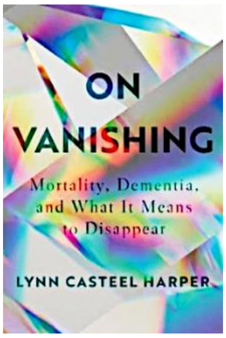
SP Student Champions

Here is our cohort of SP Student Champions. These are healthcare students and also leaders of Change of Tomorrow that is vitally needed understanding that actually clinical care isn't just in the biomedicine, but in the biopsychosocial care. We are excited and empowered to also empower our patients and to not just burden them with clinical diagnosis, as it were.

Mural – Looking Beyond the Pills

This is a beautiful mural that we all created and presented at the House of lords in 2022 on how we have to look beyond the pills, and incorporate a wider understanding of what health can mean and how we can actually invite that patient voice: *What matters to you? What does health and wellbeing mean to you?* And *How can I as your doctor, as your healthcare professional, not just medicalize, but help fulfil that vision of yours?* Because a diagnosis isn't a sealed fate or a burden for you to bear.

So that's SP, the axis of SP. I wanted to end on this note because I thought it reiterated the conversation before and again. A beautiful book by. Lynn Casteel Harper. She writes on Dementia. she said: ‘As the degree of neurological impairment increases, the person unfortunately, becomes increasingly neglected and isolated.’ She calls this the vanishing. ‘The vanishing at the vanishing point . . . is an illusion . . . The person with dementia exists beyond my capacity to keep her in my line of sight.’ And that's what SP is about. It's about keeping our patients in our line of sight and not losing them to unnecessary biomedicine. Thank you so much.



J.O., Chair Thank you very much. I think that will be very inspirational for people who work in health and social care. Where we have the weight of medical biomedical tradition on our shoulders. I think by working with other medical students to break out from those confines and be able to see the people that you work with, I think that that can make a real difference if you can shift that culture. So thank you very much for your words.

CHAT
QJ: Harmaad.what gaps do you think we need to bridge to improve the links between Art & Health and social prescribing? Thank you **Hamaad, @HamaadAKhan**: ."Thanks QJ. I think in part its (1) educating healthcare workers to recognise this now evidence-based pathway to wellbeing, (2) developing sustainable funding models to create capacity in communities to upscale their programmes - but the crucial link is already there with link workers. Every GP practice now has a LW, referred to by the GP if recognised that the patient can benefit from a social prescription
Jane Troughton: Brilliant!
Wendy:Refreshing to hear Harmaad 🙌 **Hamaad,** ❤️
Alison Canty: Thank you for a fantastic session.
bisakha sarker: Such clarity of thoughts from Hanaad **Hamaad** ❤️
Veronica, A4D:Thanks so much Hamaad - such an important widening of understanding to clinicians. It is truly wonderful that GPs can from the outset guide patients towards social prescribing link workers who can direct them to local empowering arts. Warmest thanks, **Hamaad**, ❤️

J.O., Chair And our next speaker in this part of the programme is Tessa Gutteridge. Tessa is the person who started the Young Dementia Network, which has been going for several years now in the UK. She worked to improve things for people living with YOD for many years before that, too. Tessa is going to talk a bit about how people can access the Network if they're living with YOD or working with people with YOD.

Tessa Gutteridge, Chair, Young Dementia Network and Programme Director for YOD, Dementia UK

Thank you. However many years I've worked with YOD. I'm realizing every day, this morning included, there's just so much to learn. So much to rethink.

I've just thoroughly loved this conversation so far, so thank you very much for including me. I think most of the contributors today. have played a part in the Network, either on the Steering Group, or take a part in our activities. So you know us well, but for those of you who don't know us, thank you very much for the opportunity to tell you a little bit more about the Network.

Young Dementia Network

We're a collaborative community of over 5,000 members now. We're united with a common purpose, that's around improving lives of people with YOD and their families. We want improvement now, of course; and we want to bring about significant change for the future.

Membership

The broad membership is an amazing blend of people. Just over 40% or so are people with lived experience; and then the rest are professionals from Health and Social Care – a range of roles, really, including Admiral Nurses, clinicians, service developers – and then academics and researchers and then people who are interested in YOD. The Network is steered by people with a passion for change – vocal activists with networks of their own, professionals from dementia organizations and academia. All volunteer their time and expertise. I don't know what we would do without them. There are just three staff who are very motivated. And to be honest, we're driven by personal experience ourselves too.

We set up, as Jan said, a few years ago, back in 2016. This was really because awareness of YOD and the information and support from pre-diagnosis onwards was nowhere near good enough then – and still nowhere near good enough now. And although I would say that there has been some progress made in some areas, there's such a lot of variability.

Current aims:

To Improve Diagnostic Experience

Our current aim as a network, and where we're most active this year, based on feedback from people with YOD, is around improving the experience of diagnosis, for the person and for the family. The route to diagnosis can be very challenging.

Increase YOD Profile and Lifestyle Support

Alongside that, we're really keen and we need to do it alongside, of course, to increase the profile of YOD amongst public and professionals. When something substantial has happened there, we want to increase access to lifestyle support. That's another part of our aim. That needs to change, of course, as you know, as needs and wishes alter along the way.

Working in Collaboration – does the Network have a part to play in Creativity?

In this and all our work, we work collaboratively. We don't feel that any one group or organization has all the answers. We definitely feel stronger if we work together, both nationally and internationally. But I did wonder when Veronica invited me to be part of this conversation, does the Network have a part to play?

Creativity in our lives

I especially feel that now after hearing the amazing creative contributions from people who live with YOD and who know what they're talking about in terms of what creativity means to them. I do understand intuitively the vital part creativity plays in all our lives, whether we have a disability or not. And the prospect of this conversation made me think about what part creativity plays in my life. We can get wrapped up in work and general everyday personal stuff, can't we? It gave me an opportunity to think about that. It’s a running joke in my family that the cross-stitch cushion cover with pretty rosebuds decorating it which I started in order to mark the birth of my only daughter Rose is still – 33 years on – not finished, it's nowhere near finished. In truth, that does not give me joy, so that made me think, well, where am I creative? Creating dishes for family and friends to share, creating a beautiful garden again for family and friends to share with me. This all gives me pure pleasure, and I feel it nurtures a very different aspect of me that needs to see the light more and more.

Turtle Key Arts music workshops

Closer to home, through the YOD Oxfordshire group, I've witnessed the blossoming of people with dementia who were previously very tightly buttoned up, especially in terms of their communication and connection with the world around them. They took part in the Turtle Key Arts Workshops over a number of years. That covered music and singing, dancing, poetry. and it was absolutely wonderful.

Arts participation for brain health to ease meandering peri-diagnostic stress

So thinking of the Network, I don't think that improving the diagnosis experience or improving the understanding and awareness of YOD is an essential precursor to a person accessing their creative spirit. But I do think that reducing the stress associated with the lengthy and sometimes meandering route to diagnosis matters. Knowing what you're dealing with, being able to have easy access to a professional who you can trust, and having sound information along the way, I do think is really important. And for those around you, family, friends, employers, community, to be able to recognize, accept and welcome you as yourself, with YOD and put up no barriers to participation in joining in or in pursuing your own life-enhancing, creative opportunities. I really feel that's important, too.

I think that aims that the Network pursues and the work it's doing should support the person with young onset and so contribute to enabling the mind space, time and energy for creativity to flourish. I think it's that work that the Network is involved with. I also feel that the photos, pictures, the sketchings, poems, music, the wonderful books that people with YOD create and share actually motivates and lifts the spirits of the people who work in the field as well – people like me and my colleagues. So don't underestimate the value of that. That's absolutely marvellous. Thank you. Thank you for giving me the opportunity to be involved in this.

CHAT: Tessa Gutteridge: Young Dementia Network website and Join up form: YDN YouTube animation (1 min 40s) explaining the Network from the perspective of a person with YOD.
Alison Watson-Shields: Thank you so much for sharing such interesting, engaging and thought provoking content.
Veronica, A4D:Tessa, it is so valuable to know of the support you give through the Network and of your openness to creativity - as you say, sharing nutrition and gardening brings such uplift. And reducing stress over the peri-diagnostic process is so important, especially in YOD which takes so much longer. We shall do our utmost through Arts 4 Dementia to signpost arts opportunities for dementia nationwide.

J.O., Chair Thank you very much. Tessa.

To Be, or Not to Be Open About Dementia

It's been inspirational to hear members of the panel; and that I think you're helping us break through you’re helping the people living with YOD to break through that catch 22 where if you're seen to talk about the things you can do, people then accuse you of not having dementia. But by being open about your dementia, you are showing both that you do live with this unwelcome guest but also that you find ways to flourish and you contribute a great deal to society.

So I think the work you're doing is really pioneering and trailblazing. And it's been just very enriching to hear about it.

Veronica, A4D, Host I want to thank you, Jan, for your expert chairing of our Young Onset Conversation. You yourself, and Tessa, enable so many people with young onset to flourish by the very powerful work that you do. We are all enormously grateful and privileged to have you as chair, generating rare and valuable insights from our courageous, talented and inspiring speakers today.

Tragically, I felt it significant now to raise awareness of how music helps children whose lives are curtailed by Batten Disease, of which dementia is a symptom, through the leading authority of our final speaker Professor Adam Ockleford.

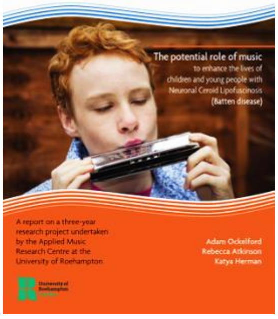
Adam is a music psychologist based at the University of Roehampton in London. His research interests include the impact of different neurological conditions on the development of musical abilities in childhood, and, conversely, the potential of music to mitigate the effects of neurodegeneration. He has worked extensively with children and young people with Neuronal Ceroid Lipofuscinosis (NCL) or Batten Disease. Symptoms include blindness, epilepsy, and the decline of speech, language, and dementia. Adam led a three-year project that examined the potential role of music in enhancing the lives of children and young people with NCL – it has been deeply moving to see the remarkable effect he has on such challenged children. It will be really interesting to hear from you, Adam.

Adam Ockelford, Professor of Music, University of Roehampton, 'The potential role of music to enhance the lives of children and young people with Neuronal Ceroid Lipofuscinosis (Batten disease)'

Thank you for inviting me to talk briefly about the potential role of music in children and young people with either juvenile or infantile dementia, which is very rare, but it does affect a few hundred children in the UK at any one time.

The Amber Trust
Music for Blind Children

One of the symptoms of juvenile dementia can quite often be blindness. And this is where my interests overlap because I run a charity called The Amber Trust, which supports children and young people who are visually impaired to make music. We studied twelve young people, very much with the support of their families and their teachers. They were across the age spectrum from early years to later teenage years and had a whole range of stages in their journey through Batten Disease.



The potential role of music
to enhance the lives of
children and young people with
Neuronal Ceroid Lipofuscinosis
(Batten disease)

A report on a three-year
research project undertaken
by the Applied Music
Research Centre at the
University of Roehampton

Adam Ockelford
Rebecca Atkinson
Katya Herman

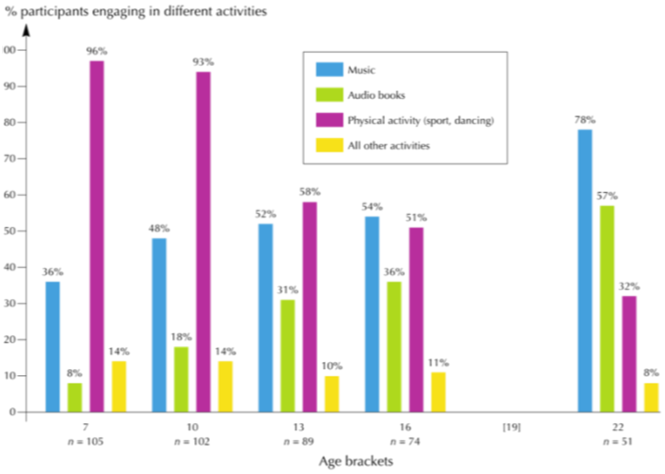
Musical stimulation - key findings

Brings pleasure even at end of life: The key findings were that the capacity to engage with music declined more slowly than their other abilities. Even at the end of their lives, it seemed that music could still bring them pleasure – as well as offering social opportunities for them to remain part of their families, which was terribly important.

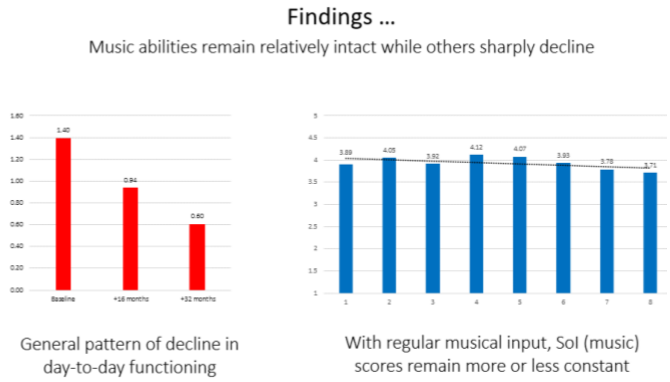
Can stimulate otherwise inaccessible memories As with older people with dementia, it seemed that music could stimulate memories that may otherwise be inaccessible.

Microsongs extending communication by up to four years We felt strongly that active encouragement to engage with music was important in the earlier stages of the disease. So adopting a pre-emptive approach. Almost universally, we found that children could continue singing when they could no longer speak. And we devised some special microsongs or short, functional songs that contained everyday language such as *No, thank you* and *Yes, please* which was a way of extending communication in some cases by three or four years.

Above all, music was a source of great pleasure to many of the young people. we worked with, promoting wellbeing and emotional regulation.



Here are some of the findings. What we found- this is from parental reports - was that while music was of average importance for seven-year-olds who are in the early stages of the disease. By the time the Juvenile Batten Disease



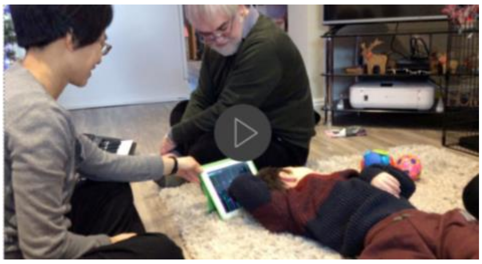
Findings ...

Music abilities remain relatively intact while others sharply decline

General pattern of decline in day-to-day functioning

With regular musical input, SoI (music) scores remain more or less constant

patients were older, music became incredibly important. In about 80% of cases music was the main source of leisure activities, along with audiobooks, slightly less so. There's a change in the kind of leisure activities that children and young people with Batten Disease go through as their journey progresses. And here's the evidence for the continuation of musical engagement. You can see over the three years of the study. The children's capacity to engage with music stayed more or less. constant while overall there's a general pattern of decline in day to day functioning. Then a couple of videos, just to show some of this in action.



Here is Ollie. Ollie has lost many of his abilities. In fact, he never got to be verbal. But music was very important to him. And here he is playing, interacting with me by using an app on an iPad, which he plays with his elbow. Here we go. Ollie lies on his back while Adam sings gently *'Ollie play that song / While we sing / Ollie play the song / All join in / Ollie play that song / While we sing.'* Ollie turns over, and at the end of each line, touches the iPad behind him with his elbow, making the screen sparkle and play trinkling electronic music.

In fact, technology was incredibly important. The Amber Trust is currently sponsoring. Technology in Music Education (TIME) to create a new sound beam, a sort of ultrasonic beam through which children who can perhaps just move a finger will be able to engage with music-making.

Here's Lily who I worked with for several years at the end of her life. Lily had lost the ability to speak when I knew her, but she could still sing. Here she is expressing first of all her preference for something to eat and drink. Both are seated at the piano, Adam plays and asks *What you like for breakfast, Lily?* As she answers, Lily claps merrily. *I would like some breakfast … I would like some … I would like some Weatabix*
What would you like for a snack Lily. I would like some fruit.
What would you like to drink Lily. I would like some squash.

Here's a song with Lily expressing her feelings which are very important.

How are you feeling? How are you feeling. How are you feeling today. Happy Happy Happy Happy Happy Asked to ask Adam, *How are you feeling?* He replies. *I'm feeling Happy Happy Happy!*

Lily was an extraordinarily happy person and a great inspiration to work with.

And finally, With Music in Mind working on the project helped us think of the place of music in the children's lives. The inner Circle is about listening. Playing and singing and making music with others. Then the Outer Circle was the broader effect of music in supporting, remembering. Understanding, moving. Communicating socializing and feeling. And indeed, I'm involved in a project with older people with dementia, now called Take Note that uses that framework.

Veronica, A4D host

Thank you, Adam. That was so incredibly moving. It's so important that we know about juvenile dementia and that involvement with music can extend communication by three to four years – oh so valuable with children. Thank you very much for opening our eyes. This is just a start for us. I hope that we shall have a special, dedicated event in the future. Thank you very much and thank you all for coming, to Jan our chair, to our inspirational speakers. We do look forward to welcoming you again to take forward action points raised today. For anyone on the call with YOD, you will find links for support through Tessa's Young Dementia Network – and do give the arts a go – Gail, I can't believe you have had no art training, only taking it up after your diagnosis. If you live in Kent, look out for Chris playing his tenor horn on bandstands at the weekend. As I write this transcript, Gail and Wendy's blogs fly in, Kate it was fantastic to hear Wendy say that your example gave her Hope. Keith you generously give guidance all over the world. Thank you to the Arts 4 Dementia team, my brother Nigel Franklin for overseeing the technology, and to our series Coordinator. Finally, to Jan, warmest thanks for your research strength and generosity in steering our Greengross A4D Global Arts for Brain Health Changemakers – Young Onset – Conversation today. Changemakers indeed.

*** Our next Greengross Conversation will focus on the impact of art – and a garden! - in Rare Dementias, to be chaired by Professor Sebastian Crutch of UCL, on Thursday 18th January 2024 – do Save the Date ***

If you know of anyone with a Rare Dementia who would like to tell us how art, dance, music, drama, poetry . . shines for them – wherever in the world – here's my email: veronica@arts4dementia.org.uk

CHAT
Jan Oyebode: It's been such a pleasure to meet you Kate - thanks for coming and contributing
Kate Swaffer, 😘
Wendy: Lovely to see and hear you again Kate 🤗xx **Kate Swaffer**, 🌻🌻🌻
Jan Oyebode: Thanks again Veronica for inviting me to chair - thanks to the star-studded inspirational panel members and to Hamaad, Tessa and Adam.
Kate Swaffer, Kaurna Country:I'll hang on to listen to Adam … juvenile dementia is such an important topic. thanks everyone, for such wonderful contributions too
Caroline Welsh: Thank you so much for a wonderful session..
bisakha sarker: Veronica you are Amazing **Kate Swaffer**, 👍 **Veronica, A4D** ❤️
QJ: Thank you so much for today's webinar has been very enlightening and I would like to thank all the speakers. **Lucy Szablewska**: Such an interesting session - many thanks!

Sabrina Ahmed: Really enjoyed this session, such great speakers, thank you!
Kate white: Thank you Veronica and colleagues especially those with lived experience sharing your moving stories.
Julie Allan: this has been so heartening, thank you all so much
Laura Cleverley: What a powerful webinar, thank you so much to you all for sharing! I feel very moved too Veronica
Tanya Duckworth: Thanks for the invitation to join today It’s been a wonderful session!
Kerry-Ann Stanton: thank you, moving and informative indeed
QJ: Thank you Veronica and all who have been involved
Kathryn.Sams: very interesting session, thanks to eveyone who has shared their story, or presented, as a health professional has certainly given me lots of inspiration, thank you
Carol Victoria: It's been incredibly informative - Thank you all!

SPEAKER BIOGRAPHIES

PROFESSOR JAN OYEBODE is Professor of Dementia Care at the Centre for Applied Dementia Studies, University of Bradford, where she is also Co-Director of a Doctoral Training Centre on Transitions in Dementia Care. She is also a registered clinical psychologist. Her current research interests focus on relationships, coping with life with dementia, and family caring, including how culture, age of onset and type of dementia impact on these. Her projects related to YOD include The Angela project (Improving Diagnosis and Post-diagnostic Support for People with YOD and their Supporters) and RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young). Jan has written both academic papers and more accessible briefings on young onset and frontotemporal dementia. Jan leads the Young Dementia Network Research workstream.

KATE SWAFFER is researcher and published author and poet, with a MSc in Dementia, Bachelor of Psychology, Bachelor of Arts, GradDip in grief counselling, and retired nurse. She is a global campaigner for the human rights and disability rights of older people and people with dementia, having won numerous awards, including the 2017 Australian Of The Year in SA. Kate has played a vital role as a catalyst for change in dementia globally, and co-founded the Dementia Alliance International, a global group for people with dementia. She lives with YOD and writes about her experiences on her website.

This presentation will discuss my experience of a diagnosis of a rare YOD as a working mother of two teenage sons, and a university student. My employment was terminated upon disclosure of the diagnosis, and although dementia causes disabilities, not one health care professional, or service provider including the national dementia charity advised me of this, nor that I had rights under the disability discrimination act and the CRPD to be supported to stay at work. I will then compare how being supported as a student with disabilities, enabled me to continue to live my own life, meaning, to continue with my studies, and on to my PhD with disability support. This is a major rights issue facing all people with dementia. I don’t want a new identity; I needed support to maintain the life I had prior to diagnosis. Dementia has also given me many gifts. It has given me a clarity about life despite the increasing fog, and a new creativity that includes poetry, photography and design. Whilst there are progressive changes to my cognitive capacity, and memory, my thinking has become visual, and I believe I’ve created new neural pathways through continuing tertiary studies. A proactive rehabilitation program has been the other key to my not having progressed as anticipated. It is time we support people to live their best life possible with dementia, not only to prescribe disengagement, and die from it!

KEITH OLIVER lives in Canterbury with his wife and until diagnosed aged 55 with Alzheimer’s in 2010 he was headteacher of a large primary school, studying for a Master’s degree and a primary schools adviser. In 2012 he created the first NHS Dementia Envoy based in Kent. An Alzheimer’s Society Ambassador, he has published or contributed to four books about his life since diagnosis and is currently co-editor on an Open University book series on dementia, inspired by Tom Kitwood. Keith’s passion for creativity, borne of his days as a teacher and head teacher of a school recognised by the Arts Council with Gold Artsmark, has remained undiminished since his diagnosis. Whilst frustrated not to continue to play his guitar he writes both poetry and short stories and for the past two years has taken up watercolour painting. In August 2018 he spoke at the United Nations in Geneva about the rights of people with dementia and has spoken previously at many dementia conferences in the UK and US and beyond, since the pandemic. His activism and vision in the world of dementia was recognised by Canterbury Christ Church University who awarded him an honorary doctorate in 2021.

WENDY MITCHELL I was diagnosed with YOD on the 31st July 2014 at the age of 58 years young. Post diagnosis, I was so shocked by the lack of awareness, both in the community and the clinical world, that I now spend all my time travelling around the country raising awareness and encouraging others to speak out in order to reduce the stigma associated with dementia. I am now proud to be the author of the not one but two *Sunday Times* best sellers, *Somebody I Used to Know*, and *What I wish people knew about dementia*, and two Honorary Doctorates. My third and final book, *One Last Thing, Living with the end in mind* has just been released. Who would have thought that possible nine years ago when I was diagnosed?

CHRIS NORRIS was diagnosed with frontotemporal dementia in December 2012 In the 1970's, he was a musician in the Mounted Band of HM Lifeguards. On leaving the Army, he continued his music and was a founder member of Kent Police Band in 1977.He still plays in Brass Bands and most weeks he can be found playing his tenor horn in concerts somewhere in Kent or further beyond. He was part of a project with Arts 4 Dementia in London where musicians who have a diagnosis of dementia were encouraged to become involved in music making. This was run alongside the English Chamber Orchestra and the London College of Music and proved to be very successful. Chris is an Alzheimer's Society Ambassador and a Kent Dementia Envoy.

GAIL GREGORY 2019 – I found myself in a new chapter of my life after i was diagnosed with early onset Alzheimer's at the age of 54. I now live as positively as i can, always looking for something to stimulate my brain. I start my day with an early morning walk with my Scottie dog Toby, enjoying our beautiful local surroundings, helping me create wonderful everlasting memories through the lens of my camera. I believe I need to keep my brain as active as possible. So I focus on the things I can do, like my art, my crafts, blogging, walking and photography. Live life, every moment is precious.

HAMAAD KHAN a medical student and Global Development Officer at NASP, is dedicated to advancing global health systems with a focus on health promotion and disease prevention. He holds a Neuroscience degree from King's College London and an MSc in Global Health and Development from University College London. Hamaad's research focuses on international social prescribing models. He collaborated with the WHO to author the first global report on social prescribing, highlighting healthcare policy advancements in 24 countries. His goal is to integrate this knowledge into clinical practice, driving broader systemic healthcare changes. Hamaad co-leads the Global Social Prescribing Student Council, collaborating with student leaders worldwide to enhance social prescribing education in health curricula. In 2022, his advocacy against overprescribing in medical education earned him the youngest-ever Hillary International Award for Health & Care Leadership.

TESSA GUTTERIDGE. Motivated by family experience of dementia, Tessa has focussed on YOD for more than two decades. As the driving force behind YoungDementia UK, the first national charity for YOD, Tessa led the creation of a range of award-winning services. Following a welcome merger, Tessa, as Dementia UK's Programme Director for YOD is encouraging the growth of a range of specialist nursing support and information. Tessa observed the inequity that exacerbates every aspect of the experience of YOD and recognised the different impact of dementia in mid-life. Hence in 2016 Tessa initiated, with highly motivated collaborators including Dementia UK, the **Young Dementia Network**. With Tessa as its chair, this online community's aim is to improve the lives of people with YOD now and in the future. Tessa believes everyone should be enabled to live as fully as they can, whatever their disability or circumstances. She continues with optimism and hope.

PROFESSOR ADAM OCKELFORD is a music psychologist based at the University of Roehampton in London. His research interests include the impact of different neurological conditions on the development of musical abilities in childhood and, conversely, the potential of music to mitigate the effects of neurodegeneration. He has worked extensively with children and young people with Neuronal Ceroid Lipofuscinosis (Batten disease). Symptoms include blindness, epilepsy and the decline of speech, language and swallowing abilities. Adam led a three-year project that examined the potential role of music in enhancing the lives of children and young people with NCL. The use of music in the form of 'micro-songs' was particularly effective in sustaining language when speech itself was no longer possible, and the capacity of music to enable children and young people can engage deeply and meaningfully with family members and friends, even in the most advanced stages of the disease. Sounds of Intent report

VERONICA FRANKLIN GOULD, President, founded the charity Arts 4 Dementia in 2011 to help develop weekly learning and participation programmes at cultural venues, to re-energise and inspire people above early symptoms of dementia, with a website to signpost arts opportunities for dementia nationwide. She worked with Dementia UK to devise training and insight for arts facilitators, and with universities to provide best-practice conferences and reports. Her inaugural A4D Reawakening the Mind programme (2012-13) won the London 2012 Inspire Mark and Positive Breakthrough in Mental Health Dementia Award 2013 and she was 2014 Sunday Times Changemaker finalist. On publication of Music Reawakening (2015), she was appointed A4D president. Her regional guide Reawakening Integrated: Arts & Heritage (2017) mapping arts opportunities for dementia aligns arts within NHS England's Well Pathway for Dementia. Her social prescribing campaign (2019-23) encourages professionals to empower people to access wide-ranging arts from the outset of symptoms, to preserve their Brain Health, with practice disseminated in A.R.T.S. for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia (2021). Her Global Social Prescribing: The A4D Arts for Brain Health Debates involved speakers and delegates from 40 countries around the world. Veronica is on the board of Arts in Medicine, The Amber Trust and the British Society of Lifestyle Medicine.