Greengross A4D Global Arts for Brain Health Changemakers
RARE DEMENTIAS Conversation
Thursday 18 January 2024, 3-5 pm GMT (4-6 pm in Italy)

Online by Zoom

More than 55 million people worldwide, 944,000 in the UK, of whom between 5% and 15% receive a diagnosis of a rare, inherited or young onset dementia. These conditions tend to occur at a younger age than Alzheimer's disease, the most common cause of dementia, and can cause symptoms that are not only memory-related, and include difficulties with vision, language, movement and behavioural changes.

Rare Dementia Support UK provides support for seven rare dementias: Posterior cortical atrophy (PCA), Primary progressive aphasia (PPA), Frontotemporal dementia (FDT), Familial frontotemporal dementia (FFTD), Familial Alzheimer’s disease (FAD), Lewy body dementia (LBD), Young-onset Alzheimer’s disease (YAD).

Personal expression through creative activities, whether reviving or learning afresh, spending time in nature and with others, enables enduring sense of achievement, or hope, of connection.

This Conversation, chaired by Professor Sebastian Crutch, Professor of Neuropsychology at the Dementia Research Centre, UCL Institute of Neurology, will explain the neuroscience and present a range of research, lived experience and practice in the UK members of Rare Dementias Support UK speaking on the impact of their chosen arts, Sweet Patootee Arts giving the Caribbean perspective and Eloisa Stella and Cristian Leorin of Novilunio in Padua, Italy discussing their rare dementias arts programme and their members discussing and campaigning for arts support for rare dementias in Italy

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THE CONVERSATION

Veronica Franklin Gould, President, Arts 4 Dementia

Good morning and welcome to our speakers and delegates from around the UK – from Australia, Austria, India, Italy, the Netherlands, Portugal, Taiwan, and from the United States of America.

More than 55 million people worldwide, 944,000 in the UK live with a rare, inherited or young onset dementia, of whom between 5% and 15% receive a diagnosis. These conditions tend to occur at a younger age than the more common form of Alzheimer's disease and can cause symptoms that are not only memory-related, for example, difficulties with vision, language, movement and behavioural changes.

Today's Conversation will be chaired by Professor Sebastian Crutch, Professor of Neuropsychology at UCL and will be co-chaired by his Rare Dementia Support RDS Creative Consultant Charles Harrison and for the Italian perspective, Eloisa Stella and Dr Cristian Leorin of Novilunio in Padua Italy.

Rare Dementia Support provides for seven rare dementias: Posterior Cortical Atrophy (PCA) Primary Progressive Aphasia (PPA), Frontotemporal dementia (FTD), Familial frontotemporal dementia (FFTD), Familial Alzheimer's disease (FAD), Lewy Body Dementia (LBD), Young-onset Alzheimer's Disease (YAD).

Personal expression through creative activities, whether reviving or learning afresh, spending time in nature and with others, enables enduring sense of achievement, or hope, of connection, as case studies on their inspirational Rare Space website illustrate - and indeed our Italian team. Their members each living with a different type of dementia are going to give us insight into how engaging with their chosen creative and cultural activities enhance their lives

We shall also hear from Tony and Becs, Co-Directors of Sweet Patootee Arts, whose film *The Turning Point* gives the Caribbean perspective, the importance of heritage and arts-based support.

On the question of access, participants can join arts programmes for their rare dementias at any stage in their diagnostic journey, chiefly through neurological referral and the marvels of Googling Rare Dementia – But on a personal level, the growing availability of social prescribing link workers through an individual's GP to address a person's wider, social and cultural needs can ease access to these arts to preserve brain health, from the outset of symptoms, but at any stage. Monica Boulton of the National Academy for Social Prescribing will explain.

Before handing over to Seb, I should explain that the instigator of this Changemaker Conversation series, Baroness Greengross, was passionate about the need for music and the arts 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.

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.

Now, I should like to introduce Professor Sebastian Crutch. Seb **i**s Professor of Neuropsychology at the Dementia Research Centre, UCL Institute of Neurology and is the RDS Clinical Lead. His research focuses on rare and young onset dementias, especially PCA, the 'visual variant' of Alzheimer's disease. The work has led to improved understanding of dementia-related visual impairment and the causes and consequences of atypical Alzheimer's more generally. From 2016-18, Seb directed the Created Out of Mind residency at Wellcome Collection Hub, bringing together artists, scientists and people living with dementia in a collaboration of over 60 individuals, institutions and charities aiming to shape and enrich public and professional perceptions of the dementias, and to explore the opportunities afforded by collaborative, interdisciplinary, publicly situated research.

Seb, it is an honour to welcome you as chair.

Professor Sebastian Crutch, Chair **Charlie Harrison, Co-Chair**

Professor Sebastian Crutch, Professor of Neuropsychology at the Dementia Research Centre, Institute of Neurology, University College London.

Thank you ever so much and thank you to you all for being here and to Veronica for inviting us. And yes, it's an honour to do anything in Dame Sally's name. So a real pleasure to contribute to this. I hope you can see on screen with me my dear friend and colleague, Charlie Harrison.

Just to explain the format for this afternoon. The idea is to keep this very informal and discursive. We will be sharing ideas, inspirations, anecdotes, a few facts along the way and generally talking a little bit about how our work in dementia and the arts has come together and conjoined. And most importantly, hearing from people living with or supporting someone and caring with and for and about someone who's living with a diagnosis of one of these rarer dementia conditions, to understand a little bit more about what it really means to engage in the arts and what some of the benefits and the impacts can be. So Charlie and I will just kick this off a little bit.

Charlie, I wondered if you might introduce yourself to everybody. Then we're going to ask each other a few questions for the first 15-20 minutes or so.

Charles Harrison, Co-Chair, RDS Creative Consultant, 'Rare Space: Celebrating the creative and cultural lives of people affected by rare dementias'

I'm Charlie Harrison. Thanks very much for inviting us to bring this together today. We're really looking forward to opening up these conversations. Seb and I don't get loads of opportunities to share some of this work and it's really nice to be able to hear from our members and to talk about arty things. I'm a visual artist by background and got involved in this area of work about ten years ago. I currently coordinate Rare Space: which is a new part of the RDS service. We're particularly interested in the creative and cultural lives. of our members and thinking about how these things impact on people's everyday life, bring about positivity and change as people adapt to their changing circumstances.

‘Rare’ Dementia

So, Seb, I was going to ask you a few questions to start off with, and I suppose the obvious one to start with is, what do we mean when we say ‘rare’ dementia?

SC Thank you. We often get asked why we use the word ‘rare’, because it seems to suggest that this is a niche interest. By ‘rare’ we mean atypical, ie, non-memory-led dementias, young onset dementias. So people living with conditions where the symptoms or the diagnosis happen before they're 65 and also inherited forms of dementia. Obviously, all of us are at some degree of genetic risk or greater likelihood of developing a dementia at some point in our lives.

Inherited forms of dementia

But there are some, relatively, mercifully relatively few, but still some families who live with a specific mutation in their family that gets passed from generation to generation, with 50% of all siblings in any generation being likely to get the condition if one of their parents has carried the gene. So directly inherited forms of dementia and rare dementias are those which don't typically fit with most people's stereotypes or assumptions about dementia.

I think despite great awareness building, there still resides the temptation to think, or to associate dementia with much older people and with memory. Many of the people we work with buck one or both of those assumptions. But by rare, we actually often don't mean it's not necessarily that numerically infrequent.

15% of all dementias in UK, 145,000 people – rare, but not that rare

We're probably talking about 15% of all dementia not being so-called typical late-onset Alzheimer's disease or vascular dementia, which are the two dementias which most people have heard of. 15% in the UK, that's about 145,000 people. So they're rarer, but not actually that rare. But sadly, many people don't ever get that diagnosis. Still, many people are told you've got dementia. No more information than that, or a diagnosis would be given of Alzheimer's disease, perhaps not recognizing some of the more specific early features.

CH, co-chair Thank you. That's really clear. I remember when I first started being involved with this, never really having any awareness around it at all. I feel it's a really important part of our message to share this information. We hear a lot about very particular challenges that people face because of some of the issues you're talking about, about how difficult it can be to get a diagnosis, for example, and also because of some of the quite particular symptoms that people have. Could you tell us a little bit about some of those challenges that are quite specific to this area.

SC, chair As Veronica mentioned in the introduction, we work with lots of people whose dementia presents not with difficulties with memory, but difficulties with vision, with seeing what and where things are, with problems with language that might be understanding what is being said to them or what they're reading, or being able to produce language and convey messages in the way they want to. Some dementias, particularly when attacking the front of the brain, cause distinct changes in people's personality and behaviour. People, perhaps, who might be more socially disinhibited, unable to follow the social rules or norms in the way that they normally would, and so do or say things or don't do or say things that they would otherwise have done.

Rare – meaning precious

So I think when we're thinking about challenges and going back to your first question about what do we mean by ‘rare’, we also intentionally use the word to mean precious, because I think many people, most importantly, including some of the people you'll hear from directly in a few moments, are able, because their dementia starts with something other than memory, to give us very generous and informative insights into what many people with any kind of dementia at any age may experience, perhaps a little bit later in the course of their dementia. For example, the majority of people with late-onset memory-led Alzheimer's, will also develop problems with vision and with language at a later stage, but perhaps at a stage when they can't necessarily explain or communicate that to other people or have insight into it themselves.

Educational message

So I think what we're hearing about today is not just stories of a personal nature, but stories with a really important educational and public awareness-raising message that we can't just think of dementia as presenting the challenges that it does initially.

Sadly, all of these are progressive diseases. So the challenges people were facing and the adaptations, therefore, when engaging people in different artistic and other opportunities, will need to constantly be on our toes to adapt to those challenges.

CH, co-chair I think that's been such a clear part of being involved in this area of work, that creativity is involved and threaded through so many different aspects of how we meet those. You're not just a psychologist, you spearheaded this two-year residency at the Wellcome Collection, Created Out of Mind (2016-18), and had a previous research interests and background with artistic work and creativity.

SC, chair As you say, I'm by no stretch an artist, but very early, you said that you fell into this area a little bit by chance. I feel the same, that I had the great privilege, within months of starting work at the Dementia Research Centre in Queens Square back in 1999, of meeting the visual artist William Utermohlen (1933-2007), who had recently been diagnosed with Alzheimer's disease and was very generously taking part in a number of research programme. To get to know him and his wonderful wife, Pat (art historian), and to understand a little bit about their story and how his experience of that condition were expressed through quite a now famous series of self-portraits that he painted and drew in the subsequent years. So that was my introduction.

Insights from people living with rare dementias

But thinking about creativity more broadly, almost all the research that I've been privileged to take part in or to lead, has been in some way inspired by or shaped by the experiences of people doing what you're about to do, of talking to people who actually know really what they're talking about. People would very generously refer to me as an expert in dementia, but that's an expertise which is derived almost entirely from the great privilege of speaking to hundreds of people with these so-called rare conditions and therefore, being able to build up a picture, a blended picture, from all those different experiences and all those individual differences of what the common features of these conditions are. So often it's people describing something that we've never heard of before, a difficulty with balance or perceiving where something is, or understanding a particular category of words or knowledge that has inspired us, sparked us to think of a new question or a new technique.

Creative approaches for dementia – a logical tool, not niche interest

As you know so well, Charlie, the dementias affect every aspect of life – personal, social, thought-based, emotional based. Our sensations can also be altered or the way we interpret them. So, I think the drive to involve creative approaches is not a choice or a niche interest, it's just a logical move that when you've got a set of conditions that can affect any aspect of human experience, why would we close off any tools at our disposal in order to try and understand what it means to live with that condition or to care for and about someone who does?

It would be good if I asked you a few questions, Charlie, if you don't mind. Obviously, you've said that you're an artist. I wonder, in particular, if you could just explain to people a little bit about what got you involved in this area. But most importantly, given it's been a few years now. What's kept your passion and your drive and your resilience to work in this area?

CH, co-chair As I mentioned, it happened by chance that you and I were paired up for this project ten years ago called Art Neuro, which was a project that just paired up artists and neuroscientists to see what might come out of that. I remember one of the first things you showed me was some of the visual processing tests that are used for assessment in the diagnosis of some of these rarer dementias. I found them quite fascinating because they seemed to have a lot of links to artworks as well. That first project, although it was quite small, wasn't just an artistic interpretation, some paintings made based off some of those visualizations.

I have to say I didn't have a personal relationship to dementia, as so many people do who come to be involved in this area. It's often you've had a family member and that's a real driving force for it. I actually think that's important as well, that people who don't necessarily have that personal connection also don't feel that they're excluded from being involved in this area. I think at some point everyone's going to be touched by it and it's important that people do engage with it. Also, over the years I have developed a bit of a personal relationship with it because I've come to know and love so many amazing people who we work with.

Building relationships to build resilience through arts

Just to answer what's keeping me involved in it. Well, it's lots of things, really, partly that developing and building relationships with people, like seeing how important it can be to share their own creativity and how that helping people adapt and things like that, can really build resilience. It's very inspiring to work with people and see how they meet the challenges head on. That's an amazing thing to see every day.

Also, all of our colleagues, such as yourself and others at the Dementia Research Centre and RDS, they're just so amazing and far more difficult tasks in our support team than I have. It's really amazing to work as part of that team. Everyone's heart is really in the right place and people work really hard and also it's very supportive environment. Whilst we provide support for others as well, we provide support for each other and that's an amazing way to work.

From a more personal perspective, it's a real opportunity to use my own imagination as well. Creative health, when we were first starting wasn't so in the public domain, and now it feels like a lot of people are engaging with creative health and how important creativity and the arts can be for people's brains, brain health. So there's a lot of opportunity out there, in terms of unexplored ideas and a lot of people coming into this area. It is interesting to work in an area where there is so much potential.

Interdisciplinary nature of dementia and the arts

SC, chair Absolutely. and Charlie, I just wanted to put one word you use which maybe helps people to understand a bit about the of interdisciplinary nature of dementia and the arts work, in that we don't just sit in our camps with me only thinking about science. And you use the word ‘assessment’, which I think most people would assume would be a me kind of word that I'm constantly doing, conducting cognitive tests or brain scans with people. Whilst you might pooh-pooh that and want them to express themselves. Can you just say a little bit more about where that intrigue or that interest in the notion of ‘assessment’ came from or parallels that you drew with your own work?

CH, co-chair I suppose for me it was just what I particularly found interesting from my own artistic perspective. But over the period that we've been working it, I also became very aware of two things. Assessments are, I feel, a really important way of how neuropsychologists, how the human race has come to understand how the brain works, but it's a very blunt tool as well. And over the time I've spoken to people, whenever I say to people living with rare dementia is, *Oh, I'm interested in assessment*, or that's been part of my work in this area.

People have so much to say and the vast majority of it isn't that positive, as everyone knows. It's an experience that so many people are familiar with, being in that situation where it's quite stressful and you feel quite put on. And whilst the assessments often give us a quite clear picture about some of the things that people might be finding challenging, they also don't necessarily give us a really clear picture of how that applies to people's everyday lives and the sorts of things they might want to be doing, like painting or going out in the garden or like seeing family members and things. And because there is this relationship between assessment and art, I feel, I think, that for me, that was a particular area where we might be able to find some real interdisciplinary ways forward, and we don't have time today. But the research side of my role has developed quite a lot with that area in particular, thinking about how painting and drawing can offer ways of understanding people's experience that also don't shy away from how unique everybody is and how we can express that variability in a way that also builds a clearer picture of the experiences that people are going through. So, yeah, if I start talking about any of those projects I'll be going for, I should probably leave.

SC, chair Well, that's fine. With this transcript, we can circulate a link to information your Talking Lines as an example of that - a project in which is really using drawing to complement other forms of interview by which researchers like me would typically try to get at people's experience of what works and doesn't work and is challenging living with or caring for in this situation. But that's great. Thank you, Charlie.

Rare Space

Veronica mentioned at the beginning about rare space, which is part of the rare dementia support service. Could you just say briefly what that is, just a little bit of context?

CH, co-chair Having done work for a few years in this area as an artist who's finding ways to represent and work with and collaborate with researchers and people with lived experience, I became increasingly uncomfortable that, as you say, the most important thing is to hear from those people. And through working with people, I realized that there's so many creative people in our membership out there who are doing amazing things and finding ways to meet their challenges. So, we wanted to prioritize that a little bit. I think in some ways that came out of lockdown.

Creativity Club During COVID we ran a creativity club where a group of people came together to meet online. It was incredible to see how much it meant people, and that they were learning new things and finding new skills and meeting new people. There were a lot of things, like building social connections and peer support and sharing their stories with others as well.

Social Prescribing Partnerships

We wanted to find ways to share those stories with wider audiences and also look for new partnerships with other organizations, in line with social prescribing. So we've had partnerships with places like the Wildfowl and Wetlands Trust. Last year, there was a Garden at Chelsea Flower Show, which co designed with people living with PCA, which we're going to hear a bit more about. There's also a project with Wigmore Hall, 'Out of the Ordinary', which has been an ongoing project based, about providing opportunities and linking people up with opportunities that might be appropriate for them, encouraging people to try new things and to think about new areas of research as well.

SC, chair Great, thank you, Charlie. That's really helpful. We'll return to a few of those themes in a moment, but I think before you're going to be interviewing Helena and David about their experience of living with PCA,and particularly their involvement in different artistic and creative activities.

Ask not what disease the person has, but rather what person the disease has – both

We just wanted to show you all a short film, or just a segment of a short film. The reason for showing you this is, I guess, one tension in the dementia and arts field sometimes is between the sciency bits and the artsy bits. And I don't really buy that as a real tension sometimes. Certainly, when I'm reading dementia and arts literature, I feel a little bit scolded. Sometimes people talk about the biomedical model, and I think that probably applies to people like me working in a neurological institute. I often use a quote by the Canadian physician Sir William Osler (1849-1919) 'Ask not what disease the person has, but rather what person the disease has' We tend to try, and whilst I agree with that, also try and modify it a little bit to say, well, why don't we ask both who the person is and what the disease is? Simply as a way of not anticipating who the individual is or what's important to them, but just understanding a little bit of the context in which they live and some of the challenges that they might be facing, and therefore some of the ways in which we might want or need to adapt some of the offerings that we make and creative opportunities that we provide.

Do I See What You See?

This is a short film. So, case in point is, as Helena will say for herself in a moment, she lives with this condition, Posterior Cortical Atrophy, which literally means back of the brain shrinkage. But rather than having me lecture you about what PCA is, I will tell you briefly that it is literally, as it suggests, it's most commonly a form of Alzheimer's disease, where those proteins affect not the memory centres in the middle of the brain, but the visual centres at the back of the brain. To start with. But, as I say, much better than me talking about it is to show you a few moments of a short film by the filmmaker and animator Simon Ball, in which he has responded to people's lived experience, descriptions of the condition. And that's what you'll hear a little bit of just now.

An ordinary eye test won't necessarily show much. Iso if you're looking at A B D E F that's not a problem. But if you're trying to read a line,

- *I get the first word, and when I go on to the second word, first word's gone.*
  Some from this sentence and some from this sentence, and then coming back up to this sentence, blobs on a piece of paper.
- *Everything does dance around all the letters and eventually just becomes one big blur. I've read extensively all my life and I can barely read.*
- *I'm writing . . .crowded page.*
  It's moving, it's mutating, it's everything in you. Ccc, H-U-R-C-H-F instead of five. B's instead of P's. P's instead of B's. There's a number of funny little things in my brain, and sometimes some do things and sometimes others do things.
  It's very frustrating to go to get something and it's not there, but it's there.
  I can often see things faster if they're moving.
- *And so if a bird flies across his vision, he's got it. He knows what that bird is. He can see it exactly as it was before, because it's somehow it's dragged his eye to it.*
  The glare when you're walking along, it's very, very bright.
- *And there's shadows and reflections or glistening puddles. Is it real? Is it solid ground? Is it something you're going to go down,*
- *going downstairs I can't see my feet.*
- *I always feel for the first step, so I can gauge the rhythm of the stairs.*
- *You do not know where to put your feet, so you get vertigo. It gives you vertigo.*
- *Well, it's like standing on the edge of something that you could just jump.*
  I can play all the notes, but not necessarily in the right order.
- *I can make a cup of tea, but if Graham talks to me in the middle of that, I will forget at what stage I was at.*
- *First of all, I've got to find a cup.*
  It's almost as though he must be able to see it.
  I can see it, but I can't see where it is. I still couldn't see it.
- *Where? There. Where there's a real one and there's an image. I can't distinguish between them.*
- *You have to dismiss the whole image. Somehow, and then get it to reassemble the whole thing. And then the kettle might be there again.*
- *Like, your reading glasses are in the midst of a load of other things. You can't spot them very easily.*
- *The whole thing, you do see it rather like a Breughel painting or crowded, surreal.*
- *My fingers were like bananas.*
- *I can't use the phone properly.*
- *You can Remember the code for your cash point? But you couldn't work the machine to put them in the right order.*
- *Oh, yeah, I can see the computer and something will come up on the screen. If I press the wrong key, then I'm stuck.*

SC, chair I hope that gives you a flavour, a little bit of an insight into some of the experiences and uncertainties of living with this condition, which affects not eyesight, but brain sight. So, on that topic, with that as a bit of background and context, I'll let Charlie introduce our first speakers, Helena and David.

CH, co-chair

Helena and David are really creative people who I've got to know a over the last year or so. They're involved in lots of things, like singing. They were involved in the Rare Space Garden that I mentioned briefly, in a previous Wigmore Hall project, Out of the Ordinary. They've also spoken to me about going for a swim in the sea and also rewilding their garden, and we often talk about our dogs as well – all valuable topics of conversation. I wondered if you could start off just telling us a little about yourself and when you started making art, Helena.

Helena I probably started doing art when I was a child because my parents both painted. But then after being a child, it became a thing where, well, that's what they do, and I'm a teenager and I'm not going to do that. So I didn't do any art at that point.

David The interesting thing was that it was when Helena's parents had died - going back seven or eight years – I suspected that Helena could have painted because our sons are both very good, partly because they were taught by Helena's parents. I'm thinking, well, it's probably in there. but there's been not wanting to be inferior to your parents, I suppose, from Helena’s point of view. After they died, Helena wanted to do some art.

Helena I studied art history, a lot of art history.

Visuo-spatial challenges

David You signed up for a course at the local college, where the artist taught drawing in a very conventional way – this was probably three or four years before we'd really understood that Helena was having visual problems. She had eye tests, glasses, but we had no idea that anything much was going on. You kept going for half a term, but they decided that as far as this art class was concerned, Helena couldn't draw, because already the PCA was giving her a distorted sense of space. That meant any attempt to try and be representational, learning to draw in the classic way just wasn't on. It wasn't there at all. It was deeply demoralizing, upsetting, wasn't it? It was very strange.

Helena But the interesting thing now I realize is that because one of the things that I have found from the beginning that's really strange, is the spatial stuff. I couldn't get into a car because of the spatial aspects of knowing which foot has to go here or there, not because I was going to drive, don't worry, but because it was just really complicated all of a sudden.

David Finding the door of the car became an impossibility and very bizarre situation with left and right. Helena would often not understand the left side of something – the car only had a right-hand side; and the right-hand side of the car only had a door was the driver's door. So whenever Helena approached a car, she would try and get in the driver's door. Really strange.

Helena Very odd and troubling situations as well.

CH Like the one with the original art class you went to as well which was really dismissive and terrible. I know now, having spoken to you quite recently, that you often refer to yourself as an artist, Helena.

Helena Yes, yes

CH, co-chair Would you like to give us a tour of some of your paintings, as you speak about that journey as well.

Helena Yes

David Very early after Helena's diagnosis, (through RDS we got involved with Wigmore Hall, 'Out of the Ordinary' music project. It was all online during lockdown and rapidly became a mix of music. There were music students who were improvising in response to stories that people with PCA and other conditions were telling. We were in the immediate post-diagnosis, grief phase, where everything was very difficult. But it became something where it was Helena's session. Out of it came tasks for the next week and challenges to go and observe outdoors.

Colouring silhouettes of seaweed

One of the first things was we found a piece of seaweed on the beach that Helena was particularly fond of.

Helena I liked the shape of it.

David This was a silhouette of the seaweed, duplicated many times that Helena then coloured in different colours to respond to the joy of suddenly seeing that seaweed was really pretty.

Helena It was really pretty.

David We'd lived next to the sea for ages and never got there. That was one of the first things, wasn't it? **Helena** It was.

Rare Space

"There were times early on when I was really cross and angry with everything, and I would make something and be able to say to David, "this is how I feel!""

Expressing Anger through art

David There are some other examples on the Rare Space site where Helena has a page of some things which expressed how she was feeling. The angry tunnel and things like that.

Finding a local sight-loss arts group

But the really big thing was finding an arts group that's run out of one of our local sight loss charities, run by a couple of art therapists. Could you talk about what that's like?

Helena Yes, I was looking for a group and I knew that I wanted to be in a group rather than just doing the art by myself. And luckily, I think, though, I went to the local museum and said to them, Do you know anybody who is doing some art and I've got a visual impairment, so it has to be of a particular nature. And they said, 'Yes, we know two people and we could give them a call.' It was a combination of the two things together that got me into art.

Masking areas of artwork to help focus

CH, co-chair You've mentioned in the past making artwork. I hope you've got a few more that you can show us. As there are particular challenges with PCA for making things, I've heard you speak before about taping off areas of the canvas, so that you can focus on particular areas.

Creating texture

You spoke in a lovely way about having a particular painting you had made where the sound of it was particularly nice because you had made it out of plaster and you could tap it.

Helena Yes.

David This is a very abstract thing, but if you go in close, it's got a lot of texture.

Helena A lot of texture.

CH, co-chair It's lovely. How does it make you feel, Helena, when you're making this work?

Helena I really enjoyed it. I liked the feel of it. I really felt like it was mine.

I did it just after I'd been up to London to see the Summer Exhibition at the Royal Academy. It inspired me. I think that's one of the things about art as well, isn't it? - you can go somewhere, see something and it'll give you an idea.

Vibrant colours with PCA

David One of the first things that Helena did with the art group is actually behind her on the wall.

If you lean over to me a bit, they'll see it, which is very abstract and quite drippy. But it's great. It's just got so much vibrant colour. PCA may lose shape, but colour is still really important.

Growing confidence as artist of quality, in social artistic milieu

CH, co-chair I think that's it. That growing confidence I've seen in you, Helena, as well, through making this art as well you've also mentioned. Because you go to a regular group where you speak with other people and you're inspired by their work, they're inspired by yours. I often find that those groups are quite helpful. Does that resonate with you?

Helena Yeah, absolutely. I am really glad that I'm in a group.

David I can see that the real quality, the expertise of the therapists who work there to facilitate Helena to do the art, but to be there very gently doing things to make it work, to make it not go wrong, this masking off thing, it's quite tactile. I see them getting a hold of her hands and putting them on the paper and say, look, put your hand here and then work in this space, within this frame. This is what you're doing now.

But you always have the ideas, don't you? And you get to the end of one piece of work, then you're always thinking, what am I going to do next? Often, it's very intangible, just about a colour or something. I'm going to do something in whatever colour, or it might be something to do with the beach or something like that.

Rare Space Garden at the Chelsea Flower Show

We had quite a lot of inspiration from our involvement with the Chelsea Flower Show.

Helena We went a bit flower bonkers.

David That's a nice flowery one.

CH, co-chair I think you said you made that almost the day you came back from visiting Chelsea after the garden had been shown.

Imagining the fragrance

Helena I just wish I could have the smell.

CH, co-chair I think we're all getting a sense of the smell there. Such a beautiful painting. Thank you so much for sharing some of your work and talking us through how that process has been. it's just so great to see you talk about your art and I'm a big fan.

Helena Thank you. It's really good. I love it.

David It's clearly a massively important part of Helena's wellbeing to be involved with this kind of thing.

Community Choir member

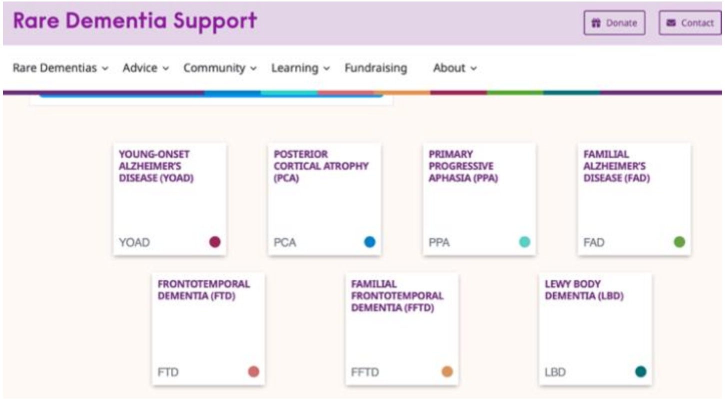
And she sings in a community choir. Not a dementia choir, just a local any ability group, and again, that expression is a key to dealing with these things. If you can't get out and do things

Helena I think doing things with other people.

CHAT kate white (Volunteer, Cambden Carers) So movingly represented - thank you.

SC, chair Thank you so much, Helena and David, for sharing that. I think you've been a fine advocate and I think we should all go a little bit flower bonkers or bonkers inspired by whatever we're engaging with at the moment, but that's great. Thank you. And I know you're staying on to join us in the panel discussion a little bit later on, so we shall hear some more soon.

Supporting Rare Dementias



Just before Charlie speaks with Chris and Andrea, I thought it would be helpful for me to mention that visual dementias are not the only types of conditions that we try to support through Rare Dementia Support, as you'll hear in a moment, much better from Chris and Andrea and via their work.

We also support people living with types of dementia which affect language.

- The broad category of conditions is called Primary Progressive Aphasias, or PPA, which really just means that language takes the prominent role earlier on and is a progressive change in those abilities.
- And there are at least three different types of language-led dementias, some, like Semantic dementias, which affect one's understanding and the type of memory that we have, not for day-to-day events, but for facts and knowledge about the world, including what words mean.
- Another type of PPA, Non-Fluent Progressive Aphasia, means that people understand perfectly well and know exactly the message they're trying to convey. But the fluency of their speech and their ability to use grammar and to articulate sounds and words in the way that they normally would have is progressively affected.
- Then a third type, which Chris and Andrea know much more about than me, called the Logopenic variant of Primary Progressive Aphasia, where things like word-finding, repetition and hesitancy when creating sentences ,are issues that come to the fore earlier on.

That's a bit of background, but the most important thing is not, as we've said, what disease the person has, but the person living with that condition. That's what Charlie and Chris and Andrea will be talking about a little bit in the next few minutes.

CH Fantastic. Thanks, Seb, and welcome, Chris and Andrea. Thanks so much for being with us today. Again, more very creative people who I've been getting to know over the last couple of years.

Chris and Andrea Chadburn

A very quick intro to say that you have interests in drawing and painting, poetry, cooking together, gardening and playing football with the grandkids - I know Chris is a big Burnley FC fan - and visiting museums.

You told me that this week you've been to see the Turner Prize at the Towner Gallery in Eastbourne, which is lovely to hear. You've been going out and about as well. Chris, would you like to introduce yourself.

Chris Sure. I live in Sussex. Andrea is my wife. 50 years - 50 years last year. It's now pretty much three years since I was diagnosed with Logopenic Aphasia - very debilitating. I know what I want to see, to say, but I can't say them. I have good medication, good speech therapy and both help. And I feel that from the three years I'm pretty much, that's where I still am, which is . . .

Andrea It is quite good. And it's having a sentence in your head. And he knows what he wants to say, but he hesitates, and he can't get the word out. It can be quite frustrating.

CH, co-chair That must be so frustrating. Also in social situations, we live in such a fast-paced world now, people aren't great at giving people space and time. That must be so difficult. Could you tell us more about that and whether you feel creativity helps at all.

Chris Well, I'm at the point now that I know what I can do and I know what I can't do. When I can't do things, I just walk along. I just want to keep going on until I can't do anything. We have a good life.

Enjoying art

Various things we enjoy, including art, but I don't do as much art as Helena does, by a long way. Drawing. painting, I always liked it at school, but I didn't go painting or drawing for a very long time. I was just thinking, it was when we were in Hungary and we had our boys there, and we had a day that we all had a painting, and it was really good. Then I never did anything for about thirty years. That was just because of work, we've got children and a lot of things to do, but it was when . . .

Andrea Lockdown.

Chris So when lockdown was there, we got a lot of stuff, painting, enjoying, and it seemed that we were quite good.

Starting to Paint

Andrea It was always something that we quite enjoyed doing, both of us, and drew with the children. We like going to art galleries, but it's a little bit like a lot of hobbies, you have to invest a lot of time in it. Then Lockdown brought that opportunity where we had hours in the day where we had not a lot to do. So we both started painting, and we discovered how much we enjoyed it. We discovered that we were not too bad at it, so we've carried on. We don't do as much as we did in Lockdown, but we still draw, we still paint. We're not good enough – not as good as Helena – to put a picture on the wall.

Creating cards for friends

We decided that rather than just keep them in a drawer, that we would draw pictures for our friends and our relatives. We've created birthday cards and anniversary cards, Christmas cards. Do you want to say a bit more about that, Chris? Do you want to show the latest one that you've done?

Chris The last thing I did was at the football ground.

Andrea This one has yet to be made into a card. Chris, do you want to talk about it?

Chris That's Brentford Football Club ground. I go there quite often, and I've got a friend who comes with me to the matches and sometime I don't know when he'll get a birthday card from me.

Andrea I think it's September.

Chris I've got another one which was 1997.

Andrea Only black and white, because we send the original ones to the recipients. But that was. That was West Ham.

Charlie's got a few pictures that Chris has done, but we don't keep the originals. We send them, make them into cards and send them to our friends. So the Brentford one, the guy at the front is Chris's friend, who he goes to football with. So he will enjoy receiving that in September.

Chris He doesn't know.

Andrea But we do other creative things.

Chris Well, I was thinking, we don't do art very much, really.

Andrea Normally in the winter we do more.

Chris But we do a lot of walking. Not when it's.

CH, chair And poetry as well. You had mentioned poetry as well. You had mentioned which poetry I think a lot of people might find counterintuitive for people living in this situation, but I love hearing you talk about poetry.

Poetry

Chris OK, the poetry. I'd always thought I should really get into poetry, and I had loads of poems that I'd got from charity shops. I must have had fifteen or twenty, but I never really did it until . . .. **Andrea** It was a speech therapist

Chris Yes, it was a speech therapist. The therapist told me about a patient who read the newspaper out loud every day. I thought this was too depressing. So I started reading Andrea a poem every day. And I do it every day, every morning.

Andrea We find that it helps his diction and his speech, and often we don't understand the poems, and so it creates a discussion which, again, helps Chris to have a conversation. He's got a very short poem that he's going to read. Which one is it?

Chris It's a funny one.

Bloody men

Bloody men are like bloody buses.
You wait for about a year,
And as soon as one approaches your stop,
Two or three others appear.

You look at them,flashing their indicators,
Offering you a ride.
You're trying to read the destinations.
You haven't much time to decide.

If you make a mistake, there is no turning back.
Jump off and you'll stand there and gaze
While the cars and the taxis and lorries go by.
And the minutes, the hours, the days. That's Wendy Cope..

CH, co-chair Beautiful.

Chris I think it's funny. **CH, co-chair** I love that. And very well read as well.

Chris I can read perfectly well, but it's getting what's in there.

CH, co-chair Thank you so much. It's really lovely to speak to you again and thanks so much for joining us today and look forward to hearing some more. I've seen lots of lovely comments coming in through the chat box as well. There's lots of interest in that = and there'll be more to talk about in the panel discussion, no doubt.

Chris Ok, that's good.

CHAT Anna Twells (Arts facilitator, Creative Minds) Such amazing art!! I love them all! Love the poem idea!
Jemma Saunders (Dementia Advisor, Andover Mind) They seem very Lowry inspired Chris - they are great
Bisakha Sarker MBE (Creative dance practitioner, founder Chaturangan Indian Dance) Much more than what I expected to learn. It's so entertaining.

SC, chair Thanks, Chris, Andrea, so much, really kind of you. Wonderful ideas there.

Tony T, Chief Executive, Artistic Director Rebecca Goldstone, Co-Director and Producer, Sweet Patootee Arts.

SC, chair So next we're going to be turning to a short conversation between Charlie, Tony and Rebecca. Lovely to see you. Thank you for coming.

Accessing appropriate support for rare dementias

A little bit of background: RDS, like many, if not hopefully, all organizations, is really conscious of how difficult sometimes it is for people with rarer dementias or other potential users of those support services to reach the services in the first place. That's partly because of the rarity of these diagnoses and people's general lack of familiarity, both in the public and the professional realm with some of these conditions, but also because of other factors that might limit people's access and inclusion in services, people's ethnicity, their socio-economic position, where they live, different types of stigma and misconceptions, particularly around what dementia is and assumptions people have made about them before they ever get their voice heard in the conversation.

Putting lived experience, inclusivity, front and centre

We're very interested in different approaches to work around equality, diversity and inclusion, as I hope is clear from Charlie's wonderful conversations so far, is very much wanting to put the lived experience and the voices of people who actually really know what it's like to live with these conditions front and centre. So, for example, with a lot of our outreach work, very generous members of our RDS community, whether with a diagnosis themselves or caring for someone who has, are out in the community, faith groups, community groups, professional organizations right around the country, essentially trying to get people to ask a really basic question:

Awareness of dementia type

Encourage them to say every time you hear the word ‘dementia’, to ask yourself, ‘What type?’ Just to try and raise and deepen. We've got very broad awareness of dementia, but now we need deeper awareness and understanding of how these different conditions can materially emotionally, spiritually, and in other ways socially affect people in so many different ways.

Rare Dementia Support partnership with Sweet Patootee Arts

It's with that interest, that set of values, that it's been really great to hear about the relationship Charlie has been building with Tony and Rebecca and their organization Sweet Patootee Arts over the last couple of years and through this partnership to understand how knowledge can be exchanged between different community groups and art venues, football clubs and dementia networks. And you guys will tell us all about learning from the experience of people in the black British Caribbean community and people with that heritage.

CH, co-chair Tony and Bec are creators of incredible heritage work that have been working this area for a long time. They're really experienced in working in the community and connecting with people in organizations. You're currently touring a film called *Turning Point*, which is such an amazing film. It's four short films, in fact, inspired by histories of black Caribbean experience after the First World War. Could tell us a bit more about that project and how it connects with your heritage work.

Rebecca We first started working together, working primarily on oral testimony, so a lot of work doing historical research, and because of Tony's Caribbean background, we ended up doing some TV museum interpretation. It was all factual work and connection with the community because of the type of stories that we wanted to tell. We were looking at that, Britain's colonial heritage. That's the context that we've built on since *Turning Point*. We wanted to revisit our art background.

Four stories set in Jamaica and Barbados to show in a gallery – and on a laptop

Tony had been writing, more dramatic writing. He started to use the information that people had told us about that period, the First World War and after. The *Turning Point* stories are set in Jamaica and Barbados in the 1920s, and an emergence of more Black Pride. There are four stories, two women, two men - some quite serious, also comedy and melodrama. Each one is ten minutes long, a theatrical performer giving a monologue, that performer responding to voices. We also wanted visual, quite immersive to work well in a gallery situation, where it could play on a loop, people could come and go. The sound would be important, but the visuals and the story. It has flexibility. It can be watched on a laptop as well.

Importance of sounds, hearing dialects, idioms evoking memory

The sound is important because there are lots of aspects, the Caribbean, the Jamaican and Barbados dialect, so we have subtitles. But for people from Caribbean communities, they fed back to us, actually being able to hear dialects and idioms and their connections with that, but also the sounds as well, whether it's birds or wind, there are lots of things that are very evocative. As Helena was saying about going to the Summer Exhibition and seeing other things, how it can spark ideas for yourself to be creative. Our idea is for people to be able to go and enjoy it as it is, but also, hopefully, going forward, we'll actually be able to work with partners to have workshops where people can watch *Turning Point*, or just one story from *Turning Point* and use that as a catalyst for their own creativity.

CH, co-chair You approached us because our interest is around rare dementias, and not just rare dementias, but more broadly as well. Some of the resources and services that are available for people from minoritized groups aren't particularly appropriate, and they don't serve the needs of these different communities. So another way that art can be powerful is that through artwork,such as a *Turning Point* film, that can be used as part of the resource toolkit that we might be able to share and connect with people.

The difference between someone like myself going into a community centre and talking about PCA or PPA, is not a very useful start to the conversation. Whereas entering into a situation where we're able to show aspects of your film, connect with people's heritage, really important parts of people's history, and then introduce the idea that every community centre that we've been to with this, people always say, 'Someone in our group's got challenges with language or challenges with vision.' It's building that trust and those connections through that work, it's so important.

Rare Dementia Support Connecting with Heritage

SC, chair Tony and Rebecca, one of the things that's been so helpful for us as Rare Dementia Support in our learning is that our premise is often that people feel quite isolated because they've been given a rare dementia diagnosis and they've never met anyone else in the similar situation. So, our role is to connect people, give them, help them find a sense of community. What we've learned so much about from your work is that the other pattern is also very much true, that if you can reach people by connecting them with a community they're already part of and keeping them connected, then out of that relationship, we might then meet people with these different forms of dementia where that supports, as Charlie says, not putting the diagnosis first, but putting the person first and building from an existing relationship. I wonder how easy or difficult you found it to work in that way, because it's certainly the opposite of our practice.

Tony T I think that it would be a complete lie to say that it was easy because we have to work with support networks. All of those things had to be put in place. On the other hand, ours has been a participatory practice for over twenty years, developing projects, identifying contributors, developing support networks, when we work with contributors, developing story and so on. *Turning Point* is in many ways an evolution of lessons we've learned. There are different examples. For example, the amazing day when we needed to know whether the humour was working.

Hackney Caribbean Elders,[1] We went to the lovely day centre, not far away from where we're based in Islington London, at Hackney Caribbean Elders. They just dropped us in the deep end. They said, *It's going to be lunch in twenty minutes, half an hour. Everyone is here at the moment in the day room, have at it.* We'd recorded little bits of our rehearsals on our phones and downloaded that onto the

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[1] For Hackney Caribbean Elders, see Cultural Diversity in Arts for Brain Health Webinar, July 2022, pp.18 ff.

computer, played back the computer to groups of people, some of whom we didn't know were living with dementias of one form or another. But there were people who came into the moment in a very big way. So much so that the support worker you met, Charlie, they were more than us because we didn't go in there with a methodology and an intent to try and provoke work with these people. It really came by accident. But we had a sense that there was the potential and the need to be sensitive to the ways we needed to enable people who might be living with dementias to work with us.

The upshot of our session at the Hackney Caribbean Elders from those people who worked with us on the sessions about the humour, that the humour did work, got thumbs up. They gave us fantastic crit about other aspects of the stories. They also participated in building the sound design that Bec was talking about they recorded for us as well. They all came into the moment. And the centre manager and the other staff saw ways that they could be developing work with us. We're going to be following that up. I believe that they want to follow that up with you as well, Charlie, as well. So these things are doable and possible, but the structures had to be put in place in order for them to work. Otherwise, it's not sustainable. You just make a flash and then it goes.

SC, chair Absolutely, thank you, Tony. That's really helpful. That theme of sustainability is one we'll come back to in the conversation in a minute. If you don't mind staying on screen, I'm just going to bring Monica Boulton in to join us.

Monica, thanks so much for being with us today. Could you briefly tell everybody about yourself and your role. And in particular, several people in the conversation so far have mentioned Social Prescribing. So maybe you could give us your personal definition of what that means to you.

Monica Boulton, National Academy for Social Prescribing

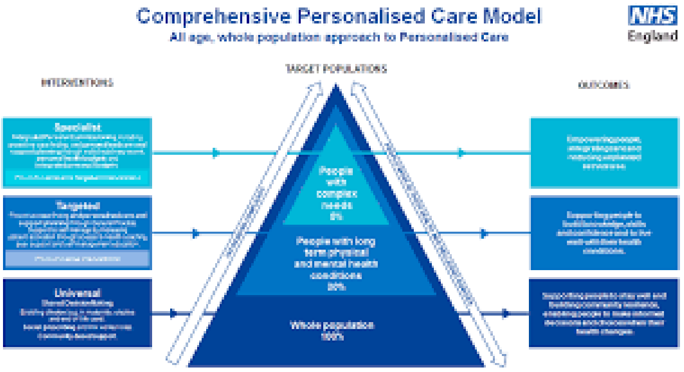
Thank you. It's really great to be here. I'm already feeling inspired, so looking forward to continuing this conversation.

I work for the National Academy for Social Prescribing (NASP), as their Healthcare Integration Lead. I've had a background in an interest in Creative Health, particularly around music supporting people with dementia.

I think the essence of Social Prescribing (SP) has already been beautifully captured throughout much of the conversation that we've been having. But just to put my spin on it, I SP is largely a holistic and very person-centred and community-based approach to health and wellbeing and bridges the gap between clinical and non-clinical support services.

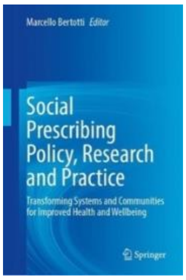
Connecting people to local activities, services and local community support

The essence of it is that it's a way of connecting people to services activities, support their local community, essentially that all have benefits and aid improvements in people's health and wellbeing. SP has, and similar approaches as well, have been practiced in the NHS



for years and years. But the NHS Long Term Plan 2019 marked a real shift because SP was incorporated into the Comprehensive Model of Personalized Care. Since then, around 3,500 SP link workers have been recruited directly into the NHS with commitment to recruit up to 9.000 by 2032 in the NHS Long-Term Workforce Plan and the SP movement has been explored, recognized, adopted all over the world, whilst continuing to gather momentum within research, academia.

In fact, Marcelo Barottti’s new resource *Social Prescribing Policy, Research and Practice: Transforming Systems and Communities for Improved Health and Wellbeing* demonstrates the multitude of ways in which patients can connect to varying SP services in across the world.


Marcello Bertotti *Editor*

Social Prescribing Policy, Research and Practice

Transforming Systems and Communities for Improved Health and Wellbeing

Springer

SC, chair That's brilliant. But it's really affirming to hear that many of the things you've heard already in the Conversation share the essence of SP for those of us, just to make things a bit more practical for those of us either with a lived experience or professional background who don't feel they've explicitly or knowingly connected with SP practice before. I wonder if you could just say about how that happens and also what people might expect from a conversation with one of the link workers that you refer to.

Monica I think it's probably important to highlight here that SP is not intended to ever replace or undermine medicine, but to complement and work alongside it. The main ethos of SP, as I say, is encouraging it to be person-centred and all built around this What Matters to Me conversation.

Locating and referral to local SP link worker

In England, SP link workers are predominantly embedded within primary care network. So your GP practice, meaning that healthcare professionals or other professionals in that Primary Care Network (PCN) who have identified perhaps a psychosocial issue, can make direct referrals into that SP service. There are some SP services that enable referrals from other professionals, such as fire service, social services care coordinators, people like that. But the first thing that I would suggest, if you're looking to find your local SP service, whether you're somebody in need of support or perhaps a creative organization looking to connect, would be to look on your GP or PCN website – hopefully, SP details are logged there.

Link worker identifies What Matters Most to the person - needs, skills, interests, aspirations

Once you've been referred into SP, to the link worker - in contrast to the GP’s ten-minute appointment - the link worker will spend up to an hour, sometimes more, using their expert skills and techniques, such as motivational interviewing, behaviour change techniques to get to really know what matters to that individual, what their interests are, what priorities they might have, what brings them that real sense of purpose and aspects of their wellbeing that they might want to improve.

Linking and empowering person to engage with chosen creative and cultural activity

Then through the connections that they've made with their local community, they can identify the services that are available to that person – including creative and cultural activities – and explore the barriers that there are to accessing those groups and services, and then be the bridge, if you like, empowering that person to engage with that onward referral.

The involvement can be anything from two weeks to six months. It's very client led and of course, health and wellbeing is ongoing and changeable, as we all know. And so sometimes link workers might see somebody more than once over a six-month period, or even longer.

Social prescribing pre- and post-diagnosis of dementia

Bringing it back to the dementia side of things. It's important to recognize that SP can be relevant at any stage of a condition, including dementia. So it could be pre diagnosis and also not just relevant for the patient, the person, I like to say, rather than patient, but also for the caregivers, the wider family too, as they navigate that world pre -and post-diagnosis.

SC, chair That's fantastic. Really brief and comprehensive summary. Thank you.

Monica Boulton happy to be contacted for further conversation: monica.boulton@nasp.info
Bisakha Sarker Veronica you have found a wonderful new format of webinar
Veronica: Thanks to Seb and Charlie – and shortly, Eloisa and Cristian – and artist members!

PANEL DISCUSSION

As we welcome Helena and David and Chris, Andrea back onto the screen for a few questions between us, do please feel free to ask questions of each other.

I just wanted to pick up on that final point you made, Monica, about the different stages which links in with Tony's point. I think about continuity as well, because there's continuity for the organizations, fantastic organizations like Sweet Patootee who are offering fantastic cultural opportunities, and the different arts organizations that Helena and David and Chris and Andrea were talking about. But there's also continuity for the person living with the condition or caring for and about that person as things change, because sadly, these are progressive conditions. I remember David mentioning that in describing one of the activities that they'd been part of, I think with Wigmore Hall, you said that was just at the stage where you're in that immediate post-diagnostic grief phase. So presumably, the link workers in directing people towards opportunities, but also Tony and Bec, you and Charlie and others, in responding to the people you're meeting, have to be operating, you have to be very nimble and on your toes in responding to people, not just different people and not just different diseases, but different people with different diseases at different stages or facing different challenges. How does that look? The link worker world sounds like a wonderful but very daunting role.

Need to embed SP referral at the onset of symptoms [2]

Monica Yes. Link workers cover a multitude of issues through their work and come from a variety of backgrounds with varied expertise. It is really about getting to know that local community and the time that they've got to get to know the person. I think that it's a really exciting way of embedding creativity at the start of somebody's journey. So, once symptoms first appear and it can contribute, that conversation to be right at the very beginning of somebody's journey. I think it would be great to see a world where referrals to SP become the norm as discussions are had around potentially life-changing conditions. Because then if it's embedded at that early stage, it's then more likely to be incorporated in the later stages as well, also for the family. I think it just starts that conversation of what non-medical interventions can also do. By embedding with that community, you've then got that more sustained care.

Need for sustainable arts prescription programmes

But obviously that then is reliant on the sustainability of organisations, which Tony touched on. That's why it's really important that SP is not just seen as the isolation of the role and why it really helps to bridge that gap between the community and healthcare to make sure that those two things are in sync with one another. Hopefully that answers your question.

CHAT: Veronica NASP's Thriving Communities programme centred around multidisciplinary partnerships that enable sustainable programmes - featured in our A.R.T.S. for Brain Health Social Prescribing report

SC, chair Yes, very comprehensive. I don't know if anyone else has any comments on that. So about either how you find the right thing at the right time, or, for Tony and Charlie, how you adapt to the different needs people are facing at different stages in their condition.

Tony T, Sweet Patootee Arts For me, in practical terms, it's about building trust, really, and relationships. We've essentially permanently got relationships with people who are gatekeepers in communities and also family and community social services. So some relationships they call, but we have a basic function of maintaining them all the time, and that's a huge drain on resources. But in terms of project delivery, it's because we have those relationships, we have the opportunities of being well informed. When we take an opportunity somewhere, we're not coming with an expectation that one strategy, one approach will fit everybody. It does become person-centred and the needs are understood and the sessions are structured basically, and then they become appropriate. But it's a crucial thing. There's no easy solution to the demands that it makes on us as an organization. It's the way that we choose to work, but it does take an awful lot of our time to maintain those relationships. On the other hand, the proof of the pudding, I think, is in the enjoyment of those sessions, because we all enjoy them. We all do, but also, the work that comes out of it

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[2] *A.R.T.S. for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia* (2021) calls for this specific amendment to NICE guideline [NG97] Dementia: assessment, management and support for people living with dementia and their carers. June 2018.

and then the opportunities to share the work with the public and the feedback that comes as well. Everybody seems to be having a good time and it's a model that really does work.

SC, chair That good time really seemed echoed in Helena, David and Chris, Andrea, and in your experiences of the groups and opportunities and activities you've been part of. Tony just there was stressing the importance of trust and also the challenge of sustainability, of maintaining those relationships. I was curious to know, in terms of trust and sustainability, how easy or difficult do you found it? Because presumably some of the activities and relationships you've built up have been for a fixed time, activities that have begun and had an end date. Is that right? And how does it feel when things come to an end or opportunities can't continue.

David Well, I think things like In the early days in lockdown, when there wasn't much going on, then there was a sense of loss at the end of something that had been good. And early on there was some Queen Square research into small groups that Rare Dementia Support were doing, that Helena was involved in. That was another thing which was a real high point of the week to have that contact and then it ends and it is a bit devastating. That was all exacerbated by it being in lockdown and there not being much else.

Social connection, trust, feeling safe

Now Helena's got a lot on. She just recently stopped volunteering as a befriender at the local food bank as another connection. I think all the things that in the end have worked for you are where you've found that connection with the people and the trust of the people and feeling safe. I mean, in the end, that's the key, isn't it? It's very difficult. If you were going into a situation where you were not feeling that the other people that you were with were looking out for you,

Sing Well

The choir works really well because such an embracing group of people who've just got lots of time and lots of willingness to accept everybody as they are and to make it work. That's the thing. I mean, it's a lovely set up, really. The lady who runs it - it's her calling almost, to do this. She was involved in schools and things previously, but I think that creating a community that is not just about singing, it's about the community as well, and to let anybody be part of that.

Helena It's called Sing Well.

Community singing less pressured that a chamber choir

David I sing in a chamber choir, which tries to do everything very properly, and it's all quite high pressure. The difference in the wellbeing that we get from our different choral activities is quite stark. I get lots of wellbeing from the music. For Helena singing with people is great, but there's so much more time in the community choir for it to be more than just music. That's a key thing.

And I think the same at your art group as well. You' talk about all sorts of things, and it's a very wide, general, safe environment for.

Helena Talking about life, the world and everything.

On Value of Dance

SC, chair We haven't talked about dance today, but people often talk about dance as being like the holy trinity. Its cognitive. You have to think about it. It's physical, but critically, it's also social as well. Rebecca was talking powerfully about the different components, these very immersive experiences, not just the vision, but the stories and the sound. That's something that we notice being offers that are particularly well received by broader members of our RDS community because people will have different access needs. Those really rich experiences mean that you have that element of something for everyone.

CHAT: VFG adds: Lyons S. et al, 2018. What research evidence is there that dance movement therapy improves the health and wellbeing of older adults with dementia? A systematic review and descriptive narrative summary, *The Arts in Psychotherapy.*

SP referral throughout healthcare journey for sustainable (arts) prescription programming

Monica, SP Can I just come in on the point? And I don't think it's just relative to SP but Creative Health more broadly. It is that we've still got quite a long way to go in terms of not boxing who fits the mould for who these creative activities can benefit. It goes right through the whole spectrum of someone's healthcare journey. Appreciation of that can perhaps lead to more sustainability in some of these things, which are often quite short term. We see it as relevant to and just as important in somebody's healthcare journey as the medicine itself. Therefore it needs to be sustained and more widely available. So I think there's more learning that we can do on those benefits to then encourage that sustainability - culture change.

CHAT

Jane Ward 16:44 I agree with Monica, we need a better system to enable linking between social prescribers and the organisations offering groups

Monica Boulton, **NASP** 16:42 On the topic of funding, we recently announced our Power of Music fund in collaboration with Universal Music, the Utley Foundation, Music for Dementia and others which will support grass routes organisations who provide opportunities for those with dementia to connect with music. Part of this project includes a "Centre of Excellence" which is a larger funded project which will hopefully provide valuable insight on the topic of integration with health as well as sustainability of funding. More info here: https://socialprescribingacademy.org.uk/the-power-of-music/the-power-of-music-fund/

CH, co-chair In relation to that sustainability point, Seb has been working very hard and others at RDS about bringing about the world's first RDS centre. So much of what we've been thinking about here today has been around how we can maintain and create a cultural space for people as well. Because I think when people are coming into clinic and doing those other things, you also want a space where people feel welcome and at home. As you know, London is a very busy place to come to. So lots of what we're thinking about is around having a base where we can express all this from our perspective. It's always been a question with our work, that you want to help everybody; and we have so many thousands of members, but the work of other groups, as we've heard today, is so important for people to connect within their own community. We can't run every group in every community, and so it's really important that people are talking to each other and different organizations are talking to each other.

SC, chair Completely agree, Charlie. And that's where those relationships you talk about are so complementary. I know that we've met lots of different people through our relationship with Tony and Bec as well around the UK, because we're trying to be a service for everyone.

CHAT
Jane Ward It's wonderful to hear about the provision of support over time by through the rare dementia support network. Continuity is of the essence being known and understood over time is crucial for us all but particularly when we are feeling vulnerable and needing support. The NICE guidelines do say there should be one point of contact over the lifetime of people living with dementia. I think there is a need for relationship over time attachment theory has a lot to say on our need for others. The finding of opportunities is so fragmented. I think fragmentation is very costly as not enough people attend than the funding is withdrawn. Things need time to grow and develop. Completely agree Kate. Huge issue for third sector is that we get funding for projects - but then, even if they are really successful, it can be tough to get continuing funding. We can spend a lot of time and effort trying to make enough changes to the project so it appears to be a new project so we can get funding for a 'new project'

Tim O'Brien 16:25 Question for Monica Bouton: Monica, while link workers have the opportunity to encourage people to try different creative activities to improve their wellbeing, how do they find appropriate activities? Is anything more needed to bridge the gap to providers that is not there at present? And are there enough providers out there? Is funding an issue?
Bisakha Sarker 16:26 There is definitely a need to train artists to deliver the work. It should become a part of art education
Veronica, Arts 4 Dementia 16:29 A4D provides early-stage dementia training for arts facilitiors
Tim OBrien 16:30 ...and A4D has been involved with Central St Martins running a programme with students there. We would love to be doing the same thing with drama, music and dance students!
Anne Stegmann Arts Therapists are perfectly placed to work in theses settings - art, music, dance therapists
Bisakha Sarker 16:30 Music to my ears
Anne Stegmann 16:33 Many Art Therapists work in museums and galleries

SC , chair One quick question that came in that Chris and Andrea may have a view on, but also a question for you, Monica, was about how easy it is to find activities. So the notion of a conversation with a link might be very encouraging and empowering, but that actual joining up. And the question from Tim O.Brien was about whether there's anything more needed to bridge the gap to providers that's not there at present. Just before you answer that, Monica, I just wanted to ask Chris and Andrea how easy or difficult you'd found it to find the kind of opportunities that you were talking about with Charlie earlier.

Difficulty of large groups with Logopenic variant PPA

Andrea Well, very difficult, really. It's hard work because of Chris's specific type of PPA. Being in groups of people is very difficult. Even on our social network, we stopped mixing with large groups of people. We tend to go out to dinner with just four of us rather than six or eight of us, because the more people there are around, then the more difficult it is for Chris to feel part of that organization. It's the same with going anywhere, really, whether it's an art group or any group activity because of that particular aphasia, then it's really difficult for him to become and feel part of a group.

West Sussex PPA group

We've recently set up a West Sussex PPA group. This has been done through UCL. We've got our second meeting next week. On our agenda is going to be: How can we make everybody with specific types of PPA to be part of a community that is going to work for them? At the moment, I think it's very difficult, which is why Chris enjoys doing art and poetry, walking, cooking. It's things that he can do on his own without having to talk, because that's his difficulty. But there must be a gap somewhere that we can fill.

SC, chair Thank you. That's really helpful. So, Monica, if it's okay to just come to you the final word.

Monica Yeah, I've read through the question in the chat, and I used to be a link worker, so remember the difficulties of there constantly being gaps out there in terms of provision and what's available. The simple answer is no, there's not enough funding, there are not enough groups out there.

<u>Call for Intersectoral infrastructure– and more sustainable arts prescription programmes</u>

Link workers have to work incredibly closely with the voluntary sector, and I think there is a real shift of healthcare and voluntary sector and local authorities working closely, more closely together. But I think we've still got a really long way to go, and I think that's why it's useful to see SP beyond the link worker role. The link worker role is at the heart of it, but actually in the context of a system and what is the infrastructure that's needed to actually enable that system to work smoothly? There's a lot more to say on that. But I think one thing to highlight is the data that can potentially be drawn down through the people that SP are seeing and what the needs actually are, rather than the reason why they're referred, can go a long way to then evidencing what's needed and then could hopefully bring down some funding. That's the blue sky world thinking, I guess. But that's the work that we're developing at NASP and we've got offers for integrated care systems (ICS) and PCNs to support that way of thinking a little bit more and really work in that very integrated way. So short answer is no, there's not enough, but I think we're on the journey to enabling a better, richer provision.[3]

SC, chair Great. Well, thank you so much for summarizing that. And let's hope in those ongoing conversations it can be not just, as you say, about fixing the funding gap, but also about seeing how things like what Tony mentioned, about trust being embedded at the heart of those systems and sustainable relationships. That'd be great to see over the next few years. Huge, huge thank you again to Helena, to David, to Chris, to Andrea, to Tony, to Rebecca, to Monica, and also very much so to Charlie for being such a big part of The Conversation this afternoon. We are incredibly grateful to you all. And I know if the audience were able to, they would be whooping, clapping, hollering and expressing their appreciation of all your contributions. Very much so. Thank you so much for your time.

Now we're going to hear from our wonderful Italian colleagues at Novilunio in Padua, Christian and Eloisa, and Frank and Fanny and Titzano. I shall now handover to Eloisa and Cristian to chair the rest of the session. I wonder whether you could introduce yourselves and say a little bit about your practice in Padua. It would be lovely to hear about that.

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[3] Since publication of *A.R.T.S. for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia* (2021), a proposal three-year Arts for Brain Health longitudinal study with UCL East has been agreed subject to funding.

Our Novilunio group photographed at Chioggia. (seaside town south of Venice)

Eloisa Stella, President, and Cristian Leorin, Co-Founder and Vice-President of Novilunio, of Padua, Italy, converse with rare dementia members, Tiziano and Francesco:

Eloisa Stella, President of Novilunio, Padua, Italy

We are a non-profit organization based in Padua, 23 miles west of Venice, in northern Italy. Novilunio, founded in 2014, is dedicated to inspiring a culture of positive change. This year we celebrate our tenth anniversary. From the very beginning, we have promoted the voices and perspectives of people living with dementia because we understood that most of the stigma and the prejudice that is around this condition is inked to the fact that people living with dementia, especially in Italy, are quite invisible - nobody sees them. We do our best to promote their point of view and to enable them to live a life as beautiful and full as possible. So, we organize peer to peer groups, both online and on site we also have a group for people living with communication impairments

Our group is part of a community working on activities, mostly associated with peer-to-peer support, which is core activity for most of whatever we design together with people living with dementia and their families. We organise peer-to-peer groups, both online and onsite and we have a group for people living with communication impairments.

Last year we started to organize activities focusing on social tourism, arts and culture, and social participation in order to give the opportunity not only to observe the beauty around us, but also to reappropriate our community. We shall be discussing this with Tiziano.

The right to a meaningful life, whatever our diagnosis - improving digital literacy

To fight against the invisibility that is common here in Italy for people living with dementia. we invest a lot of energies in advocacy, both inside our association. We also train other organizations here in Italy to take up advocacy for people living with dementia. Because we know that it is the way to promote their rights and point of view. Cristian also organizes courses and training opportunities to improve digital literacy for people living with dementia. He involves family caregivers so that they can work together and people living with dementia can keep working using their phones, their smartphones, Alexa and whatever digital technology is available, to enable them to maintain their full autonomy for as long as possible. And, of course, we have a helpline for people with dementia and their families.

I collected a few pictures of our tours last year. These places are mostly based in Padua, so we have Palazzo Bo, where Galileo Galilei used to teach. We went to see an exhibition of Frida Khalo, Giotto’s frescoes in the Scrovegni Chapel. We went to the tBotanical. Garden, a World Heritage Site founded in 1545.

Eloisa introduces

Tiziano Tracanzan

Tiziano used to be a biker. He lives in Grantorto, a small village near Padua. He was a sales manager, and used to take his bike all over Italy and abroad. Tiziano is part of our peer support group, actually, two peer support groups here in Padua. He was diagnosed with YAD when he was 62 years old and has long known about Alzheimer's because he was the primary caregiver for his mother.

As advocate for Novilunio

Tiziano does a lot of things for us. He's an advocate. We involve him in our training for professionals, so that these professionals who work in nursing homes or in the community, have the opportunity to talk with the person with dementia, like a peer, for a better understanding of their needs or their points of view, which they usually take for granted that they know everything – that's rarely the case because we're all so different. We asked Tiziano to talk with us today because he was part of our Art and Culture group. I asked him to tell us about his perspective, how he lived that experience.

Eloisa asks *Allora, Tiziano,* ci puuo parlare di che cosa e stato per te le esperiensi di veder un po le musei *a Chioggia.*

Tiziano *Per me e una cosa molto molto buona perche mi piace l'arte … vedere queste a fatto prima elodi*

Eloisa translates Tiziano's replies He has loved the activities because he loves arts and he had the opportunity to see beautiful arts venues in the city. There were particular places

Tiziano *Quello di cui abbiamo parlato prima sono le cose piu belle che abbiamo visto, ma quello che mi piace vedere che è attraverso gli altri . . . le persone con noi, queste viaggioano se vedi che quando vci esauriamo fuori, vedi questi colori, queste belleze. E la cosa molto molto bella quando ci svendiamo vedere cose bellissime. E questo è tutto quello che c'è da sorridere sul viso. Sono Felice*

He adds, *I actually like all* the activities, the cultural visits. He explained earlier how he especially liked the Scrovengi Chapel and the Botanical Garden and, of course, Palazzo Bo.

Eloisa asks *Tiziano, quindi ti piace vedere le persone che godono*

Tiziano *Quando facciamo l'uscite fuori la citta, quello, per esempio, andare alla piccola Venezia.*

Enjoying cultural activities together in the community

He also says that the part of these visits that he likes the most is seeing the faces of people living with dementia and the families – happy. He enjoys seeing them smiling and happy, and enjoying a good time together with our community. That's the best part of the experience.

Eloisa Every time we meet, every time we go for a visit, at the end we also include a time to have some food. Of course, we're Italian! - the stereotype is very real. A good time with a glass of wine or a coffee or some pasta.

Visiting Chioggia (See our headline picture on page 31)

At the end of the first part of the programme, which was at the beginning of July last year, we went to Chioggia, which is a very small village near Venice - they call it a small Venice because it looks similar, but is a little bit more rundown. It's basically, the underdog of Venice. But we had a fantastic time together because there was the sun and the sea and of course, we ate a lot of fish and fried fish and everything else. It was really good.
Thank you. *Graze Tiziano.*

CHAT

Veronica, Arts 4 Dementia: The charm of these weekly gatherings is that participants choose together on the day which museum, gallery or site of interest they wish to visit.

Claire Street Grazie mille Tiziano

Tim OBrien Grazie Mille Tiziano. Buona fortuna per il futuro.

Veronica Tiziano you are fantastic! Mille mille graze!

Eloisa introduces her colleague

Cristiano Leorin, Vice President of Novilunio.

Thank you very much. Firstly, I want to say a real thank you to Chris and Helena who we saw before, because I'm a speech and language therapist and I saw that they were participating and talking. I love it; and because it's nice to see if there are any communication problems that people are trying, what they are doing and saying what they need to say, and not only what their caregivers say, for example. That's something that I really like – thank you very much for participating today.

Empowerment

One of our keywords at Novilunio is empowerment. So the idea is that the people that are participating, this group, as Tiziano was saying, is nice because when they arrive, it's like a group of friends that are meeting, gathering, drinking coffee, laughing, meeting, usually to start at 10:30 and finish at twelve. In actual fact, we tend to start at ten and finish at 1pm because nobody wants to leave. And we are there talking, chatting, discussing and trying to find out solutions.

Improving quality of life, members free to speak their mind, inonn-judgmental and nclusive.

Our prime object is to improve quality of life for all of us. That's very nice because we are there and we are discussing and everybody can say what they need to say. You can say whatever you want. And that's very nice, because we are there altogether and we are not separate. Sorry for the caregivers, but we are separate from the caregivers. So in our group there are only people with diagnosed dementia, every kind of dementia, because it's very heterogeneous in our group. We are there discussing, laughing, crying sometime and sharing. So inclusivity is another word that I want to draw attention to.

But that's enough from me, because I want to introduce our special guest, that is Francesco.

CL introduces Francesco Parisotto 'Frank'

I will say a few words about him, because also Francesco is very young. He lives with Cadasil, a rare form of genetic vascular dementia, and is a really passionate advocate about Cadasil. Frank was a mechanic and sales consultant and worked for the Civil Protection Association for 25 years. So for a long time he was devoted to other people. As his mother also suffered with Cadasil, he had long known what it means. Frank lives an hour outside Padua. So every time that we meet, he and Fanny are traveling to Padua. They usually arrive with lots of coffee – our special coffee machine.

Frank’s poetry

Frank is here today because he really likes, loves to write poems. We have already heard about the importance of poetry. Frank has written sixty poems. So tonight, specially for you, we will have a reading from Frank about a choice of one, maybe, - Veronica translated these poems into English. I will ask Francesco to read the first one in Italian, so you can also listen to his voice. Then I will just have one question, (because time is short) and just to ask one thing to Frank. But before that, please, Frank, can you read Ascoltami

Frank recites in Italian.

Ascoltami	**Listen to Me**
Ascoltami	Listen to me
perché non senti	Because you don’t hear
lo grido il mio dolore	I cry out my pain
Nessuno ascolta	Nobody is listening
Ascoltami	Listen to me
Sento esplodere la mia vita	I feel my life is exploding
Mille pezzi vagheranno	A thousand pieces will drift away
Nessuno si poserà	Not one will settle
Nessuno si ricorderà	No one will remember
Ascoltami	Listen to me

CL Thank you, Francesco.

On the importance of listening to the person

As you can see from the translation, I think this is something that everybody, who is needing some help, is asking to all the world just to listen, but not just hearing. It's really listening to something. So I'm crying. I'm saying that there is something that is not going well. So please listen to me, please. Nobody is listening. And that's something we discuss in our groups: I have not somebody to talk really freely about what I feel inside. That's why the group, because in the group, nobody's paying any attention to the word you mean to say, if it's the right one. That's not important. The listening is very important.

So my question to you, Frank, is :

Cosa significa per TE scrivere POESIE. Cosa TI regala questa passione? What does it really mean to you to write poems, this passion you have.

Frank *Per me scrivere POESIE, e pesternare I miei sentimenti, cercare di guarire l’anima, communicare con le persone cercando un po’ di empatia*

For me, writing POEMS and expressing my feelings, trying to heal my soul, communicating with people looking for a bit of empathy.

Voglio scrivere e parlare per sentirmi vivo I want to write and speak to be alive

Voglio portare la mia esperienza e come affront le dofficolta. Non voglio arrendermi.
I want to share my experience and how I deal with difficulties. I don't want to give up

Voglio essere utile a chinque si trovi ad affrontare come me una DIAGNOSIi di DECADIMENTO COGNITIVO perche ‘DIAGNOSI non vuol dire FINE, ma CAMBIAMENTO’ e sparanzo nel futuro.

I want to be useful to anyone who finds themselves facing a DIAGNOSIS of COGNTIVE DECAY like me because ‘DIAGNOSIS does not mean END, but CHANGE’ and I am looking forward to the future.

Giornata	**The Day**
E' stata una bella giornata	It was a beautiful day
un po' dura, ma bella.	A little tough, but beautiful,
Il fato é stato clemente	Fate was kind
Il destino un po' irriverente	Its destiny somewhat irreverent
Il mio passo forte e sicuro	my step strong and sure
Guardando con occhi da bambino	Seeing with child’s eyes
il mio passato ormai lontano	my almost distant past
con il futuro in mano.	the future in my hand.
Futuro incerto	Uncertain future
Futuro da costruire	A future to build
Futuro da sostituire, con speranza,	A future to replace, with hope,
ed un po' di arroganza.	and a little arrogance.

Frank relates Cognitive Impairment to the art of piano playing

Come i tasti di un pianoforte BASTA TOCCARE QUELLI GIUSTI
Like the keys on the piano – you just touch the right ones

When one plays a piano, one can miss keys, or go out of tune because the keys are not in tune. Well, this also happens to us people with cognitive impairment, we just need to touch the right words, perhaps distant memories, those sometimes blurred moments, and everything returns to COLORS.

Colori	**Colours**
Ricordati di stendere i colori della vita	Remember to value the colours of life
non lasciare che il GRIGIO sovrasti	don’t let GREY dominate
Usa il ROSSO per amare	Use RED to love
Il ROSA per sognare	PINK to dream
il BLU per volare	BLUE to fly
il VERDE per giocare	GREEN to play
il BIANCO per viaggiare	WHITE to travel
Dolci, leggere pennellate sui tuoi sogni.	Sweet, light brushstrokes as you dream.

How empathy and emotion can reawaken memories

A volte la memoria fa cilecca, ma le emozioni rimangono, e facendo leva su quelle possiamo risvegliare ricordi che sembravano persi o dimenticati, ma erano solo addormentati in attesa dei “tasti giusti”.

Sometimes memory fails, but emotions remain, and by leveraging our emotions we can reawaken memories that seemed lost or forgotten, but were only asleep waiting for the "right buttons".

CHAT
Jane Ward Would love to hear more from Frank - brilliant
Veronica Frank, your poetry, the pieces drifting away - reminiscent of Seb's film Mille pizza vgheranno

CL, co chair Thank you very much, Frank. in a nutshell, what Frank was saying is that he's writing poems just to express the feelings. And this for him is like, heal the soul, communicate the people by seeking a bit of empathy. So he was talking about empathy a lot of time. His message for us all of us is: Never give up. Never give up because we have to fight.

ES, co-chair Actually, it's the motto of the two of them. The beautiful lady that you see right next to him, Fanny, is his wife. And her motto is always never, never give up.

Diagnosis does not mean the end. It is a beginning of … a new kind of life

CL, co-chair That's it. Another motto is: Diagnosis does not mean the end. It is a beginning of something else. It's a new kind of life. But it's something that you can also hope for a change. That's another thing that Frank was saying. I also have to say thank you to Frankie, because in our group, lots of the time, the other people are saying, *OK, you can do that, no worries*. *You can do that, no worries. We are together* We can do something together. That's something we really like in the group. But I think that sometimes, even if you do not have the right words, even if you are not saying exactly what you are thinking, but speaking from your soul, you really know what you want and you can see from the people how they look at you, how they listen to you, how they are taking care of you.

CL, co-chair We were discussing this also in the group with some doctors, psychologists who are sometimes not really s listening to you, but just hear things. So that's the perspective from our group. Thank you very much, Frankie, and thank you very much, Fanny and thank you very much, Tiziano, for your help and testimony to our president. Thank you to everybody. Thank you, Veronica, for inviting us. Tor sure., thank you, Veronica. I met her in Naples and was so nice.

Veronica, A4D, host Thank you so much. It's ever more wonderful to see and hear you and to see all your members. Actually, I was going to express it in Italian! *Grazie mille a Cristian, Eloisa, Tiziano e Frank, le vuoi poesie sono davvero audace e fonte di ispirazione per tutti noi.* – Thank you so much Cristian, Eloisa, Tiziano and Frank – your poetry is truly bold and inspirational.

I love to hear you say it empowers you to new adventures together. And I love all your smiles and your talking from your soul, as indeed everything that Seb and Charlie, Chris and Andrea, Helena and David, Monica, Tony and Bec - all our speakers been absolutely amazing, have given really valuable insights into how,, despite each diagnostic challenge, cultural and creative activity can make such a difference to life.

It was particularly moving when we were preparing for this Conversation today, to hear Helena spring up – David too - when she was telling us about RDS's music partnership, Out of the Ordinary, with the Wigmore, and how fantastic it was to be offered that when they were facing the dark trauma of diagnosis and to be immediately lifted by RDS offering the programme. Seb and his team made an enormous difference to her, as he and Charlie and Eloisa and Cristian do to all your members.

I should like to draw your attention too to this American study, How a rare dementia transforms patients into artists. This was research led by Adit Friedberg of the University of California in San Francisco., who was not able to join us, but their study explains the brain. changes that promote visual creativity.

Thank you all so much for joining us and mega thanks to our chairs, Seb and Charlie and Eloisa and Cristian, who is amazing to see. I do hope we won't lose touch. Frank and Tiziano, Helena and David, Chris and Andrea, you are inspirational!

Veronica adds: Our next Greengross A4D Global Arts for Brain Health Changemakers Conversation is going to involve International SP Student Champions, on Social Prescribing Day, Thursday 14 March. And then for World Refugee Day, we shall be discussion practice for refugees, including A.R.T. Art for Refugees in Transit of New York

CHAT

Tibbs Foundation, Bedford I will be taking all of this back to our group and it just resonates so much with us because we art based groups and music groups, **Veronica** It's so special intergenerational work that you do in Bedford.

Fernando José Carvalho Congratulation for this conference, and for all experiences shared, it was amazing. Additionally I want to make a question/tip, what do you think about Heat Shock Proteins Therapy in dementia, specially with targeting at HSP60, HSP70 and HSP90, thank you.
Fernando José Carvalho If you want to create a partnership with our **organization, High Performance Brain, let us know please, we are available to do it, thanks** **SEB – for you?**
Bisakha Sarjer The picture istruely shows what love of one's life nean
sumita chauhan Thanks everyone. It was very inspirational to hear about so many approaches and personal experiences. Made me aware of different perspectives, I would like to hear more about social prescribing if you arrange another meeting.
kate white Thank you ++++
Stephen Deazley Thanks everyone for sharing your practice, experience, stories and art today
debi miller Really interesting afternoon.
Anne Stegmann Thank you! Excellent !
Sarah Russell It has been so special to listen today. Very inspiring and uplifting. Thank you so much
sinead Devine Thank you .Great to see such wonderful work but unfortunately I must leave now.
Sarah Russell I would love to share your Poem with our groups Frank, if that is possible
Jemma S Thank you so much to you all for great Conversation, poems and arts, it has been really fascinating. However I do need to leav now.
Tim OBrien 👏👏 a Padua!
Claire Street Thank you so much. Fascinating work
Jemma S Thank you and Grazie!
Jane Ward Thanks for joining from Italy
Karen Murrell Thank you so much for this - look forward to having access to the transcript and edited video - and to the next one!!
Ian Witterick Thank you Veronica for arranging the event.
Claire Street Many thanks.
Monica Boulton Thank you everyone - feeling very inspired and encouraged!
Jacquie Nunn Thank you everyone.. A very inspiring afternoon.
Tim OBrien Thank you also to Veronica for making this inspiring event happen. **Veeronica –** much appreciated, Tim
Karen Murrell Thank you - hope to come to more
Jane Ward Thanks for a great session
anna twells Just a shout out for Creative Minds, lots of amazing artists across the UK doing work in care homes and for other groups 🙂 and one to one sessions
kate white Its' wonderful to hear about the provision of support over time by through the RDS network. Continuity is of the essence being known and understood over time is crucial for us all but particularly when we are feeling vulnerable and needing support. The NICE guidelines do say there should be one point of contact over the lifetime of people living with dementia. I think there is a need for relationship over time attachment theory has a lot to say on our need for others. The finding of opportunities is so fragmented. Fragmentation is very costly as not enough people attend than the funding is withdrawn. Things need time to grow and develop.
kate white assessment as a collaborative and interpersonal process. I recall a moment when my partner who had been diagnosed with Alzheimers so not a rare dementia - he was being taken through the usual memory assessment and he was asked about what season were we in? As language was more challenging at this point he started whistling the tune "Autumn Leaves" which being a jazz pianist came totally naturally to him. The assessors didn't get it and looked bewildered!! It was the end of October by the way.

kate white Love the international conversation …We at the Dementia Community invite you all to join us!!
https://journalofdementiacare.co.uk/dementia-community-membership
Dementia Community's vision is of a world where all people feel connected, informed, empowered and purposeful; actively engaged in co-producing changes that improve everyone's experience of dementia, both in care and in wider society.Dementia Community is the new name for the organisation that:Publishes the Journal of Dementia Care Produces the UK Dementia Congress Provides the National Dementia Care Awards Connects and empowers the Dementia Community

SPEAKER BIOGRAPHIES

PROFESSOR SEBASTIAN CRUTCH is Professor of Neuropsychology at the Dementia Research Centre, UCL Institute of Neurology and is the clinical lead for Rare Dementia Support (RDS). Seb studied Experimental Psychology at Oxford University, before completing his PhD part-time whilst working at UCL and qualifying as a Clinical Psychologist (CPsychol). His research focuses on rare and young onset dementias, especially posterior cortical atrophy, the so-called 'visual variant' of Alzheimer's disease (AD). The work has led to improved understanding of dementia-related visual impairment and the causes and consequences of atypical AD more generally.From 2016-18, he directed the Created Out of Mind residency at The Hub, Wellcome Collection, bringing together artists, scientists and people living with dementia in a collaboration of over 60 individuals, institutions and charities aiming to shape and enrich public and professional perceptions of the dementias, and explore the opportunities afforded by collaborative, interdisciplinary, publicly-situated research.

CHARLIE HARRISON As a visual artist and arts consultant, Charlie co-ordinates 'Rare Space' a new part of RDS which aims to bring together and celebrate the creative and cultural life of RDS members. Charlie has seen first-hand the huge part that cultural activities play in people's lives together and over the past decade he has devised and consulted on a series of research and engagement projects that foreground the creative strengths, celebrate the diverse experiences and highlight the expressive will of people living with these conditions.

HELENA & DAVID CLARKE Helena was diagnosed with Posterior Cortical Atrophy in 2020, after having originally been told she had a visual impairment. Over the past 3 years, Helena and David have engaged in a series of creative projects alongside RDS including being involved in the development of the Rare Space Garden designed by Charlie Hawkes, which achieved a gold award at RHS Chelsea Flower Show 2023. Helena is an artist in her own right, making drawings and paintings which reflect on and adapt to the challenges of life living with PCA. Helena and David incorporate creativity into their lives in several ways, whether it be rewilding their garden, cooking improvised soups, swimming in the sea or visiting cultural venues together.

CHRIS & ANDREA CHADBURN Since 2021 Chris has been living with a diagnosis of logopenic variant Primary Progressive Aphasia, a rare form of dementia which presents challenges with language and speech. Both Chris and Andrea include the arts into their daily lives through painting, drawing, sewing and poetry. Andrea has always been creative and often works with watercolours. Artmaking is a relatively recent endeavour for Chris but he particularly enjoys painting pictures of buildings and making cards for friends and family. They love gardening and cooking together and having just celebrated their 50thwedding anniversary, they are determined to continue living life to the full.

TONY THOMPSON & REBECCA GOLDSTONE, co directors of Sweet Patootee Arts, are producers of documentaries and heritage interpretation, bringing inspiring, compelling and diverse stories of real people to an international audience. Over the past 2 years they have been working alongside RDS for their touring exhibition TURNING POINT, a series of four short films inspired by oral histories about the Black Caribbean experience after the First World War. Together with Rare Space they are currently undertaking a knowledge exchange with community groups, arts venues, football clubs and dementia networks to learn more about Black British Caribbean Heritage, share information about rare dementias and generate new creative ideas.

MONICA BOULTON is the Healthcare Integration Lead for the National Academy for Social Prescribing and a Non-Executive Board Member for Musical Walkabout CIC. Monica has been involved in Social Prescribing for nearly 10 years after her Music degree confirmed her passion for how important the creative arts are for people with Dementia. Having worked as a Social Prescribing Link Worker and managed multiple social prescribing projects, and volunteered as both a SPLW Manager’s champion and national expert for the National Association of Link workers, Monica has a true sense for the difference Social Prescribing can make not only to people’s lives but to the health system and communities too. Monica is passionate about community development, and has extensive experience in the voluntary sector alongside providing some Social Prescribing System consultancy work.

CRISTIAN LEORIN is an adjunct Professor at the University of Padua and the University of Modena-Reggio Emilia where he teaches courses in Assistive Technology and Speech-Language Pathology' and Augmentative and Alternative Communication. He assists the European Commission as an external expert in the evaluation and monitoring of research projects focused on e-Health technologies for people with disability and dementia.
He collaborates with non-profit organizations and public health institutions (including the Italian Ministry of Health and the Veneto Region Health Department) in the co-design of services for individuals with chronic and degenerative conditions and disabilities.
He is the co-founder and Vice-President of Novilunio, a non-profit association dedicated to improving the quality of life and social inclusion of people with dementia and their families.

ELOISA STELLA is an applied anthropologist, a social communication specialist, and the current President of Novilunio. A graduate of University of Toronto, over the past years she has assisted a variety of for-profit and non-profit organizations in Italy and Canada in developing and promoting community building projects, engaging stakeholders, and establishing liaisons with private and institutional partners. She also assists in the development of innovative community-based public health and social care services aimed at improving the wellbeing and dignity of people with or at risk of dementia.

FRANCESCO PARISOTTO, also known as "Frank," is a passionate advocate living with Cadasil, a rare form of genetic vascular dementia. Born in Baden, Switzerland, in 1965, he returned to Italy at the age of six and settled in Bassano del Grappa, in the Veneto, in northern Italy. Frank has worked as a mechanic and a sales consultant for a medical cannabis store. He married his wife Fanny, who has multiple sclerosis since 2010. For over 25 years, Frank has volunteered at the local civil protection association and helped communities devastated by natural disasters. In 2015, after a series of ischemic strokes, he received his Cadasil diagnosis. His mother also suffered from the same condition and was assisted by Frank throughout her long illness. Frank and his wife have managed to maintain autonomy and wellbeing despite the limited resources offered by their community. In 2021, they joined Novilunio's peer support groups in Padua and participated in a local support group for people with early-onset dementia. Recently, Francesco has discovered the power of poetry to express hardships and hopes after diagnosis. He is currently working on his first collection of 60 poems, which will be published later this year.

TIZIANO TRACANZAN is an advocate with dementia who received a diagnosis of early-onset Alzheimer's two years ago, at the age of 62. Born and raised in Grantorto, a small village near Padua, Tiziano worked for several years as a Sales Account Manager for Italian, Swiss, and American companies. He has travelled extensively both in Italy and in other parts of the world, for work or pleasure, with his Harley Davidson bike. Tiziano was the primary caregiver for his mother, who died of Alzheimer's over 30 years ago. In 2022, he joined Novilunio's local peer support group for people living with dementia. Last year he also joined as a member and co-facilitator of a support group for people with aphasia. He also contributed to the design of the cultural activities programme for families associated with Novilunio.

VERONICA FRANKLIN GOULD, President, founded the charity Arts 4 Dementia in 2011 to develop weekly programmes at cultural venues, to re-energise and inspire people above early symptoms of dementia, with a website signposting arts opportunities for dementia nationwide. She worked with Dementia UK to devise training 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),Veronica was appointed A4D president. Her regional guide Reawakening Integrated: Arts & Heritage (2017) 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 trustee of The Amber Trust and Vice-President of Decibels (Music for the Deaf) on the advisory boards of the Global Arts in Medicine Fellowships and The British Society for Lifestyle Medicine.

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