

Holistic Support



RARE
DEMENTIA
SUPPORT

Nikki Zimmermann



I am delighted to be here speaking to you all today and I am really honoured to be part of the Rare Dementia Support Team.

It is a fantastic team, but we are still formulating my role at present as there are so many avenues to explore.

I have spoken with some of you before, but for those I haven't we thought today would be a great opportunity to introduce myself and tell you a little bit about my background and experience.

It is a little different from the normal 'Research' background which most of the team have here but hoping it will bring some benefits.

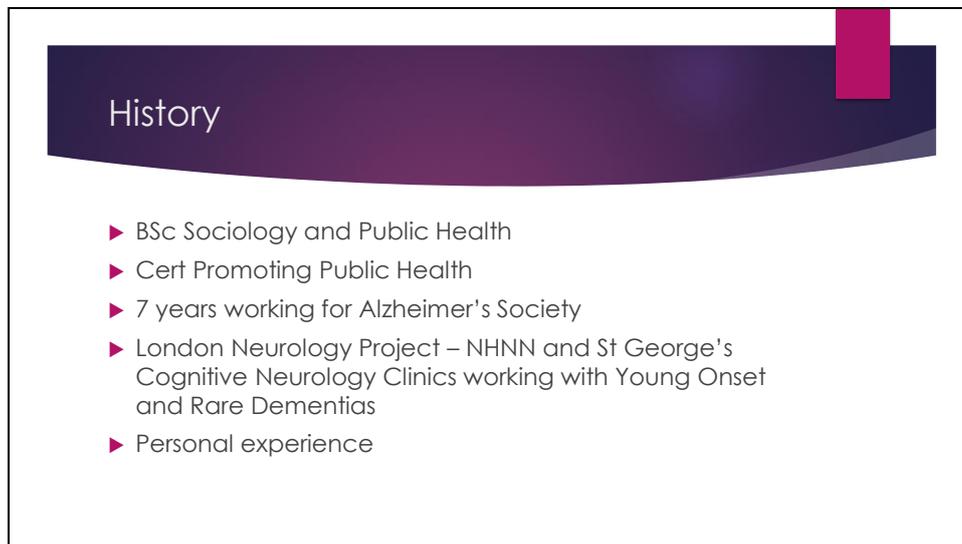
A bit of Background for Context



So here is a little bit of context of who I am, just to make me seem a little more human.

As well as working at RDS, I am a wife, a mother and owner of a crazy dog. Which basically means I cook a lot of food, I do mountains loads of washing and I'm often found running around Streatham Common with my dog as she chases squirrels.

For those dog owners who I have already spoken with, there is a popular belief that dogs really are great for your mental and physical health. I totally endorse this. If you haven't got a dog and you like dogs but can't commit to being an owner. Borrow my Doggy is a great website where you can get a matched up with a local pooch and have a weekly dose of walking, cuddles and companionship – top tip for the day!



History

- ▶ BSc Sociology and Public Health
- ▶ Cert Promoting Public Health
- ▶ 7 years working for Alzheimer's Society
- ▶ London Neurology Project – NHNN and St George's Cognitive Neurology Clinics working with Young Onset and Rare Dementias
- ▶ Personal experience

So, for my academics, I have a BSc in Sociology and Public Health, gained through mixed disciplines of University of Abertay and the Open University, spanning over many years. At my graduation ceremony, the Dean politely commented on this, as she was so impressed of the almost 20 years, 2 Children, 2 Dogs, 6 house moves it took for me to finally complete it.

However, it all adds up to great practical experience.

I then went on to do further studies in Public Health, after I finally discovered I actually enjoyed studying.

What I really enjoyed is looking at the provision of services that people wanted and needed, by working with people and really **listening** to people.

I worked for the Alzheimer's Society for 7 years in a variety of roles which I will talk further about shortly

My last role for the Society was very special to me as it was something that I was really passionate about and identified a real gap in services.

Here, I was lucky enough to work with some amazing Clinical and Research Staff in the Cognitive Disorders Clinic at Queen Square and the Cognitive Neurology Clinic at St George's. In the last 3 years, I have learned so much from staff patients and carers.

I have added in my personal experience, as my father developed early onset Alzheimer's disease at age 62, so I have seen first-hand the impact neurodegenerative diseases have on a family.

Hopefully, some of my 'mixed' experience will be a help in my new role.

Personal Experience

- ▶ Symptoms and Signs
- ▶ Going to the GP
- ▶ Referral to MAS
- ▶ Medication



I don't want to dwell on my personal experience, but I do feel 'learning from experience' is vital for helping others.

To add a bit of geographical context now, I was living in Scotland with my young family and my parents were in the South West of England when the signs first started appearing.

My father decided to retire, and we put his 'symptoms' down to being restless after working for so many years – he didn't know what to do with himself.

In fact, he had retired because he could no longer do his job to the very high standard he was used to.

After a good while we finally persuaded him to go to the GP.

It's never a good idea when the GP is a very good longstanding family friend, who didn't want to upset my Dad. So nothing happened.

My brother then went with him and the GP said to my brother I really think we need to go carefully and take this very slow??

Finally, we got a referral to the Memory Assessment Clinic, who delighted my father by stated how 'young and fit' he was. This only reinforced the idea that he was fine.

After months of tests and scans etc he was diagnosed with Alzheimer's disease.

No support was offered, and because he had a slow heartrate, he was not suitable for Donepezil. (This was before NICE Guidelines changed and Memantine was supposed to be only offered to those at moderate to severe stages).

However, I was informed that we could pay for the medication, which as we live in the UK not the USA, I refused on principle.

Not to be defeated I immediately wrote to my father's MP who was very supportive and wrote several letters and lo and behold, he received the appropriate medication courtesy of the NHS.

Personal Experience Cont.

- ▶ Problems and Barriers
- ▶ Support and Care Options



As time went by, we were beginning to notice barriers popping up at regular intervals. I really don't wish for this to sound a depressing story, as my father lived for 13 years with Alzheimer's disease. Many of them were extremely full, happy years with the odd hiccup now and again.

We did struggle with finding age appropriate activities, as he was relatively young and fit. Unlike many of you here 'language' was not a problem for him, it was often rather colourful, but it wasn't affected until the later stages.

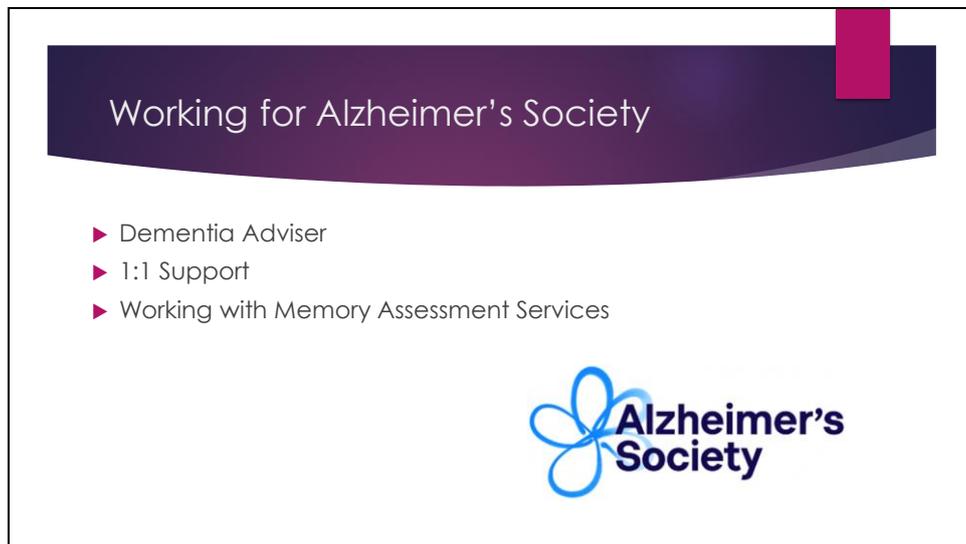
Frustration was a big problem though, and in the very end we added up he had been banned from 4 Day Centres and 3 different Care Homes. This was ultimately due to his needs not being met, as he was younger and fitter than their average cohort.

So, over those 13 years I really did learn a lot about GPs, Memory Services, CMHTs, Social Services etc.

There were constant barriers and I really had to question things many times – but experience gave me confidence to do so and now when supporting people, I advise them not take the first knock back, as quite often with applications they can be rejected the first time, but often accepted on appeal.

The photo here is of my father aged 20.

I always used it with day centres, hospitals, care homes etc as seeing him like this he was viewed a little differently than the 'challenging' man they now encountered.



Working for Alzheimer's Society

- ▶ Dementia Adviser
- ▶ 1:1 Support
- ▶ Working with Memory Assessment Services



I moved with my family to London in 2011 and I approached the Alzheimer's Society to volunteer

Fortunately, they were looking to cover a staff members sabbatical so I was offered a paid job.

I started off as a Dementia Adviser working in Southwark Memory Service, South London. The team consisted of a Psychiatrist, Psychologist and two Nurses. They assessed and diagnosed people, and we provided support.

Local authority cuts meant less options resulting in inadequate provision. I was seeing the problems people were facing, but with some knowledge I could at least navigate the maze of the health and social care system.

From there I moved on to Wandsworth where they had just reconfigured services joining teams and this was a new part of the Dementia Pathway.

After a few years of working with Memory Assessment Services I wanted to have more of an input on service design. I'd spent several years listening to people affected and felt limited with existing resources. I wanted to use the information I had gathered to change things and make things better.



Partnership working

- ▶ Service Manager
- ▶ Service Development
- ▶ Partnership Working
- ▶ Creating Dementia Friendly Communities



I took the role of Service Manager for the London borough of Sutton, a leafy suburb with huge potential for partnership working.

Alzheimer's Society had several services here, but they worked very solo and not as part of the community.

Sutton had a fantastic Health and Social Care Commissioner who was very passionate about dementia and a very active local Mayor too. Before long we had set up a Dementia Action Alliance and had many organisations signed up to become Dementia Friendly. Age UK set up an abundance of services, the libraries set up Dementia Cafes. Gyms took up training and adapted classes to suit needs, Cinemas ran special screenings. Lots of dementia friendly activities were happening.

I was also heavily involved in the Sutton NHS Vanguard project to improve Care Homes. It changed the experience in care homes for both residents and staff. Resident wellbeing was reported to be improved and hospital admissions had decreased. Staff morale was boosted resulting in more consistency for residents and staff staying in their roles for longer.

It was nice to work on a project that viewed the Care Home as a pleasant way to live out your days, rather than the image of a Work house, which is often portrayed by the media.

London Neurology Project

- ▶ Pre, Peri and Post Diagnostic Support
- ▶ Embedded in the team
- ▶ Immediate Individually Tailored Support



So, my previous role was very different to normal Alzheimer's Society practice.

The idea came about with talking to Prof Nick Fox and Dr Cath Mummery at Queen Square and Dr Jeremy Isaacs at St George's.

Both hospitals wanted slightly different things, but that was fine as we could easily adapt. I took my thoughts back to the Alzheimer's Society and eventually we got funded a pilot project.

At Queen Square, I supplied personalised post diagnostic support for all types of dementia, from all over the country, occasionally spreading overseas.

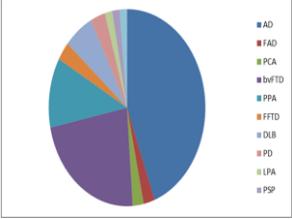
At St George's, where they have considerably less staff, we introduced 'wrap around' support from the point of clinic referral.

This involved contacting potential patients and supporting them through the whole process, sometimes waving good bye as they had no diagnosis, but ultimately being there at the crucial point of diagnosis and offering post diagnostic support.

I learned so much from sitting in the clinic rooms and became an important part of the team.

Evaluation

- ▶ Statistics and Demographics
- ▶ Feedback
- ▶ Service User Involvement
- ▶ Young Onset Support Group



Diagnosis	Color
AD	Blue
FAD	Red
PCA	Green
bvFTD	Yellow
PPA	Purple
FFTD	Orange
DLB	Light Blue
PD	Dark Blue
LPA	Light Green
PSP	Light Purple

We collected so much data from this project – different diagnosis (as seen on the pie chart), sets of demographics, support options available up and down the country etc.

We collected a lot of rich feedback from patients; all stating the lack of services for younger people, the need for separate services for carers who are still working, the need for support for families with dependent children, and the need for empowerment for people that now have a diagnosis.

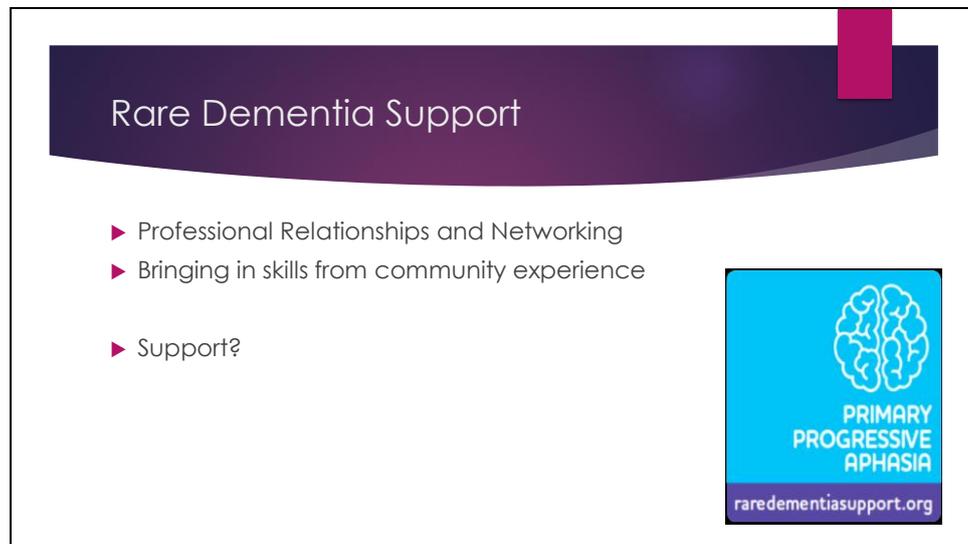
I was very fortunate to have a trusted colleague at the Alzheimer's Society who helped to find some roles for those who wanted to speak out on these issues. I accompanied one such to City Hall as she addressed the Assembly and the Mayor on issues faced by younger people with dementia, and what needs to be in place to make London a dementia friendly city. Although nervous she was very empowered afterwards, and congratulated by many as being a true inspiration.

Another couple I have took to do some teaching for the paramedic students at St George's University.

It is an amazing turnout when 140 students show up on a Friday afternoon to learn about young onset dementia. Interestingly, both participants had word finding difficulties, so we adapted the talk so it was more like a Graham Norton Interview on a sofa with lots of short prompting questions. After a standing ovation, the students claimed it was the most useful part of their training and will never again assume a middle-aged man with word finding difficulties is the result of an afternoon of irresponsible alcohol consumption.

St George's hold a monthly Young Onset Support Group which I still continue to run.

It's very different to this but it's a space where they can meet, give peer support, swap strategies and feel less isolated.



Rare Dementia Support

- ▶ Professional Relationships and Networking
- ▶ Bringing in skills from community experience
- ▶ Support?



So now I am here in my new role and it's all a bit different, but it's really important to find a way effectively to bring my Community skills into the group.

I've spent a lot of time building relationships and networking and learning from this so I think I can bring a very realistic view of what happens in the community.

namely no one knows what PPA is?

GP doesn't often know what to do?

Social Services have never heard of such a thing? – so they can't find the box to tick for assessment

What I really want to look at and develop is the whole concept of 'SUPPORT'.

It is a very ambiguous term, but I want to explore what it means to all of us?



Person Centred Approach

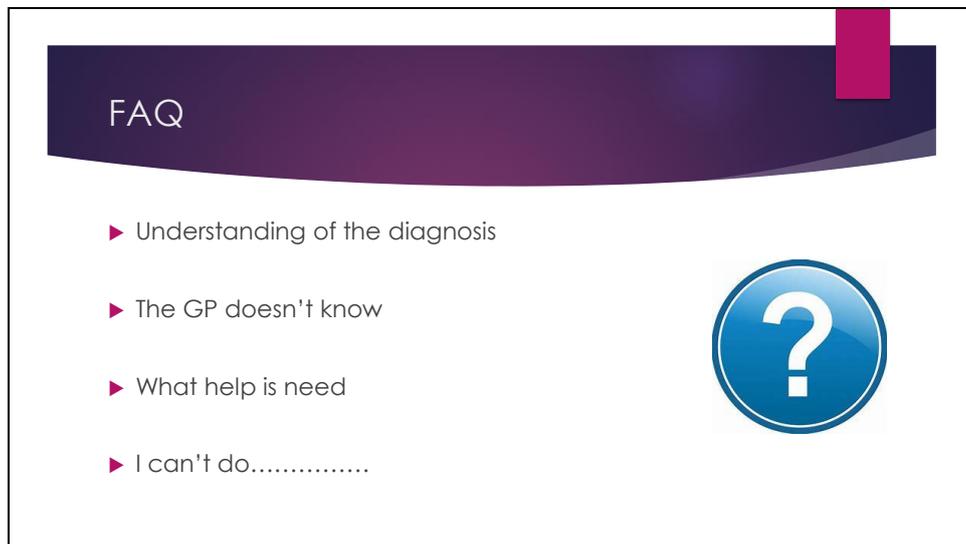
- ▶ Signing up as a New Member
- ▶ Telephone support
- ▶ Information and Resources



Most people come to us through the website and sign up as member.

We have now introduced the offer of an initial telephone call. This way I can find out a bit more about you and your situation and we can meet your individual needs, rather than just emailing lots of information over to you may or may not read. I'm hoping to develop this further.

We also get membership requests from many professionals too, from all over the world. Often, they don't tell us they are professionals, and I really wish they would so we can equip them as effectively as possible to be able to support you. We don't want to keep this knowledge a secret, we want to share it so it is helpful to people like you. So we are developing some Professional Resources, that way we can help them to help you.



The slide features a dark purple header with the text 'FAQ' in white. Below the header, there is a list of four frequently asked questions, each preceded by a red right-pointing triangle. To the right of the list is a blue circular icon containing a white question mark. The entire slide content is enclosed in a thin black border.

FAQ

- ▶ Understanding of the diagnosis
- ▶ The GP doesn't know
- ▶ What help is need
- ▶ I can't do.....

Here are a few frequently asked questions we receive:

My wife/husband has just had a diagnosis of PPA, I don't really understand what it means? This is often best as a telephone conversation with resources sent on. I can then ask questions on more precise details of diagnosis and talk through the different types and common symptoms. Sending information on is then really helpful to reaffirm, explain to family and friends and give copies to any health professionals they come into contact with.

The GP doesn't know? It is a rare condition and we need more awareness and training. We are developing some professional packs to send out. I always tell people to keep copies of the factsheets. With a bit of luck, it will be the start of further education in the condition.

What help is needed – will depend on the person, the symptoms, their family and social environment, lots of things as everyone is different. We have some generic information that we send on as a 'guide' to use at times when needed. Forward planning is always a good thing and sorting out financial and legal matters early is always recommended. Fortunately, we have our Legal Advice Service to help

Finally, people often find it frustrating struggling to be able to do things they have always done. Unfortunately, this is the impact of the disease. It can sometimes be the case of trying to adapt or needing extra support. Sometimes that just can't happen, so look at the things you can still do and change the focus.

For one thing you can't do, think positively about two things you can do!

A presentation slide titled "Service Development" with a dark purple header. Below the header is a bulleted list of five items: Membership, Holistic Support, Professionals, Feedback, and Empowerment. To the right of the list is a graphic of several hands of different colors (purple, red, yellow, blue, green, orange) stacked on top of each other, symbolizing teamwork and support.

Service Development

- ▶ Membership
- ▶ Holistic Support
- ▶ Professionals
- ▶ Feedback
- ▶ Empowerment

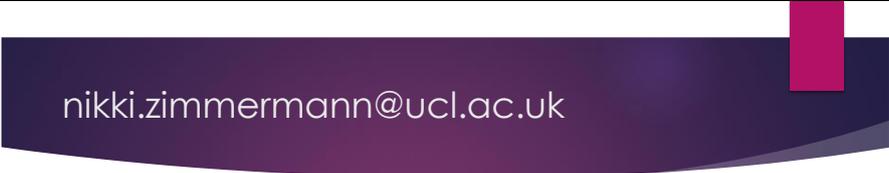
So, going forward I will be looking how to develop the different strands of the membership. Professionals, People with a diagnosis, Carers, International contacts etc.

We will define 'holistic support' and look at individuals needs

Plan to reach out and assist more professionals with a variety of resources.

And finally, we want to help empower our members.

As always, your feedback is crucial for development.



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- ▶ Thank you for listening
- ▶ My job is to listen to you and try and answer your questions, so please do get in touch