

## What is Primary Progressive Aphasia? (PPA) and how can Dyscover help?

PPA is a brain condition which begins with subtle speech and language changes. It gradually progresses, making everyday communication more difficult. In time, it affects other aspects of thinking. PPA is classed as a rare, 'language-led' dementia; about 3 people in 100 000 have the condition.

Speech and Language Therapy is the main treatment for PPA, but few NHS services are commissioned to provide this support. The route to diagnosis can also be slow.

To our knowledge, Dyscover is the only UK charity offering SLT-led specialist assessment, advice, therapy and long term support for people diagnosed with PPA, and their families.



PPA service lead Rosemary Townsend with SLT Barbara Greenwood

## How is Dyscover's PPA service funded?



Dyscover's PPA service depends on grants and donations. We charge subsidised fees for direct 1:1 SLT and operate a discretionary bursary fund for people in financial hardship. We are grateful to Awards for All who have supported our PPA service in 2023/24.

## How are people referred ?

Dyscover accepts referrals from across the UK. This year 80% of our referrals lived in Surrey or the South East 70% saw us in person at Dyscover's offices in Leatherhead 30% worked with us online, or a mix of online and in person .

In the past 12 months, 43% of people have referred themselves. 57% were referred by their neurologist or SLT. We have improved our website to help people with PPA and their families find us, and the information they need.





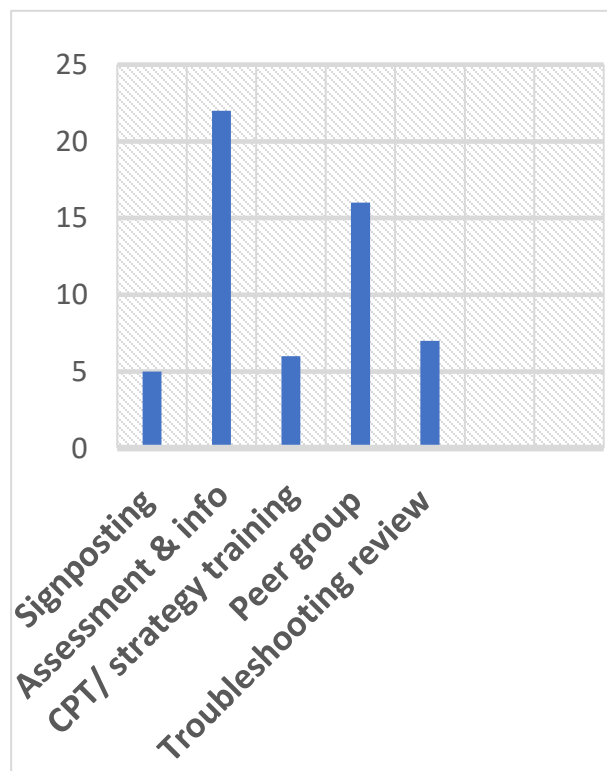
## What does our support look like?

- The research evidence supports a variety of Speech and Language therapy interventions for all types of PPA.
- At Dyscover we almost always work with couples and often include other family members. We help them to understand their difficulties and to develop tactics and strategies to manage their everyday conversations.
- We can introduce people with PPA and their partners to others with similar difficulties. People feel encouraged and less alone.
- We help people build a network of support and often work in partnership other NHS, independent and third sector organisations.
- Dyscover's support is long term and we encourage people to use us as a review and troubleshooting service for their communication problems.

This year we helped 34 newly referred people with PPA and offered ongoing support to 18 additional people.

**The chart shows the type of support people received, according to their needs.**

We delivered a total of **71 individual SLT sessions** and ran **16 small group sessions** this year.



## Our satisfaction survey – what did people say? (June 24)



**22 people replied** – 5 people with PPA and 17 relatives  
**82% rated our support as good or very good.**

### How did people benefit ?

**68%** said they understood more about PPA  
**68%** had learned tactics to manage their conversations  
**59%** felt less isolated,  
**59%** said Dyscover had introduced them to others living with similar difficulties.

### What are the key ingredients of Dyscover's support?

The following aspects were rated as 'very important'

Led by a specialist SLT – **74%**  
Practical and focussed on everyday conversation – **75%**  
Personalised – **80%**  
Long term – **72%**  
Option of in-person and online meeting - **75%**

### How would you describe Dyscover's support?

Empathetic,  
enabling, non-  
patronising,  
inclusive

Expert,  
knowledgeable,  
caring, inclusive  
empathetic,  
resourceful

It's good  
to know  
that we  
are being  
helped  
by  
experts  
in the  
field

Invaluable  
practical and  
emotional  
support

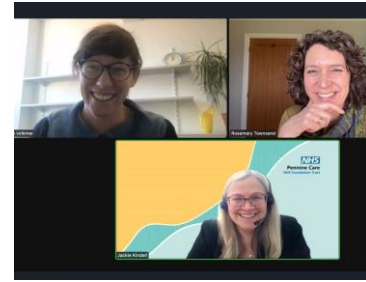
Kind, positive, understanding,  
listening, informed, caring,  
looks at the bigger picture.

# Other achievements this year – networking and learning



## The 10<sup>th</sup> session of the UK SLTs in PPA network

This group now comprises more than 120 SLTs, mostly working in the NHS. Since we started the group in 2022, Dr Anna Volkmer, Dr Jackie Kindell and Rosemary Townsend have run 10 themed meetings, aimed at growing skills and confidence in therapy for PPA. We have also created a resource bank for SLTs



## For the second year, a UCL – Dyscover PPA mini conference

Our theme this year was PPA and wellbeing. 35 people living with PPA attended. One of the outcomes was a plan to launch the first ever PPA Awareness Day in 2025



## An experimental Intensive Conversation Camp for couples

We contributed to this research project at UCL, which investigated whether people would benefit from a more intensive 'dose' of the Better Conversations with PPA programme (BCPPA – UCL). Rosemary delivered 3 of the group sessions for couples. People reported positive outcomes in goal attainment.

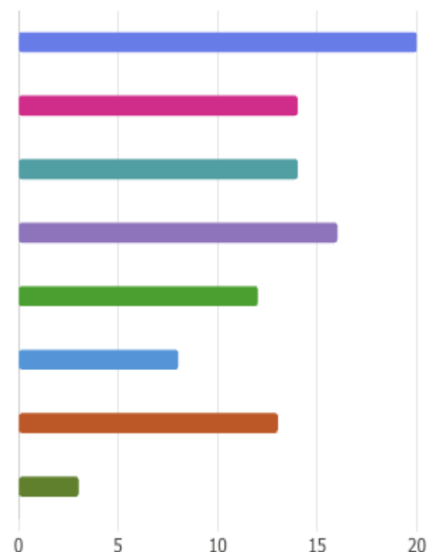


## Next steps? – our survey showed people want a range of support, long term

10. We want to develop our services for people with PPA at Dyscover. What should we include?

22 Responses

- **Advice and guidance sessions for the person with PPA and their partner** 20
- Information sessions for **other members of your family or friends** 14
- Opportunity to **meet relatives of other people with PPA** 14
- **Small conversation groups** for people who have a similar type of PPA 16
- Opportunity to **book a review and troubleshooting session** when you feel you need it 12
- **Training sessions for other healthcare staff** - to make appointments more aphasia friendly 8
- **Therapy sessions focussing on word finding** 13
- Other 3



We are grateful to our major funder Awards for All and also Surrey Carer Support for supporting the delivery and development of our services for people with Primary Progressive Aphasia