

North East Trust for Aphasia

Final Report on the Support Group for Families of People with Primary Progressive Aphasia (PPA)

Aphasia Friendly Summary

Aims of Project

The North East Trust for Aphasia with Newcastle University ran a **support service** for families of people with **Primary Progressive Aphasia (PPA)**, a rare dementia.

The project set up **coffee mornings every 2 months for a year**, to

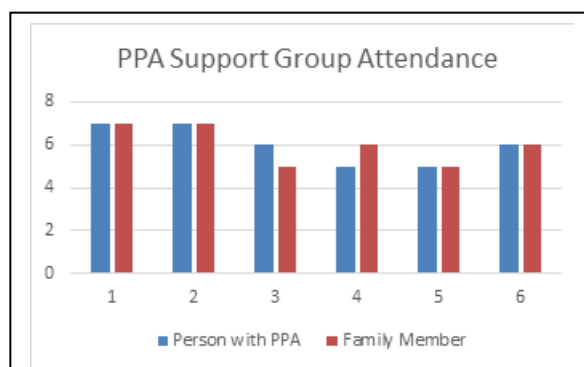
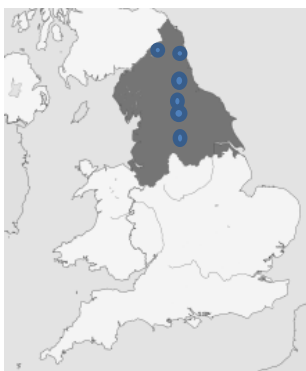
- help people to **support each other**
- **assess the needs** of people
- show **how communication can be supported**.

Participants

10 families registered from across **the North of England**.

The people with PPA were at **different stages** of the illness with **different communication patterns**.

10 or more people came to **each meeting** from across **Northern England**



Sessions

We had **6 meetings over 1 year**.

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2012 Giving Voice Award from the Royal College of Speech and Language Therapists

Participants suggested contents of the sessions.

We focussed on the family member.

Family members shared information and their experience.

They made a **WhatsApp group**.

We had **speakers** who talked about **communication aids** and **dementia carer support**.

Evaluation

All service users, both those with PPA and their family members, **valued:**

- **Meeting others**
- **Access to experts**
- **Exchanging information**
- They wanted **the service to continue**
- They wanted **more help** with **communication support**, focusing on **communication with their relative**

We asked **non-attenders** about **barriers** to attending, but got **no replies**.

Conclusion

This was the **first** such support service **in the North of England**.

There was a clear **unmet need**.

We identified the **best way** of meeting **differing needs**.

The project **linked speech and language therapy services** in North East of England with **national and local dementia services**.

Future

We will apply for **further funding** to:

- Continue **support group meetings**
- Support **specific communication training** for individual families

Rose Hilton, Janet Webster and Julie Morris

February 2020

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