North East Trust for Aphasia

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

Background

The North East Trust for Aphasia (NETA) was increasingly receiving enquiries from families with a diagnosis of Primary Progressive Aphasia (PPA). The remit of NETA is to raise awareness of aphasia and to offer support and on-going communication practice for people with acquired aphasia, but it does not include those with aphasia as a part of dementia. We wished to pilot a small service to scope out the needs of people with PPA in our region. We wanted to gather information about the likely number of participants in our region, the services they were linked in with and any gaps in provision or information, the type of communication support they might need and the best way of providing this.

Promotion and Recruitment process

We disseminated information about the project to Speech and Language Therapists (SLTs) and diagnosing clinicians across the region. We linked in with the Rare Dementias Support group delivered by University College London who posted information on their website. We forwarded registration forms to SLTs, relevant medical staff and related services, and to individual enquirers as well as one or two people we were already aware of through NETA. The criteria for acceptance were

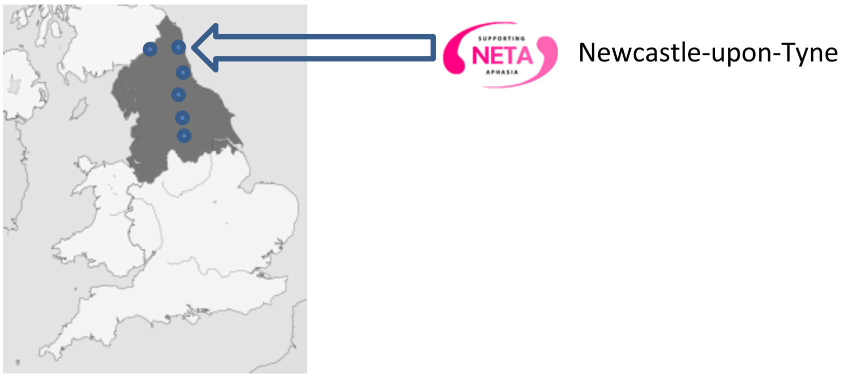
- that there was already a diagnosis of Primary Progressive Aphasia
- they were able to attend the Centre in Newcastle University
- they had a family member or friend to attend with them as the family members were to be the primary focus of the service.

Registered participants, geographical distribution and attendance

10 people with PPA and their family members registered. An additional family did not respond to the invitation. 3 further enquiries were received at the end of the project but

had yet to register. People heard about us via their SLT, the Rare Dementias Support website, other dementia services and from peers. Participants came from a wide geographical area including outside the North East region.

Geographical location of participants



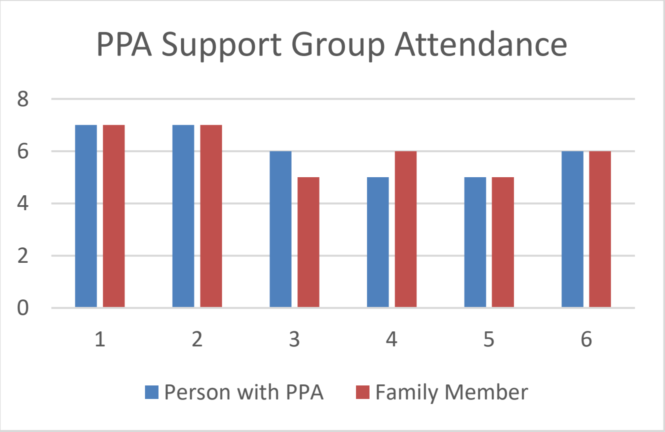
Type of primary progressive aphasia

Primary Non Fluent Aphasia (PNFA)	Logopenic Aphasia	Semantic Dementia
2 participants with PNFA were non-verbal with minimal alternative means of communication including minimal facial expression. 1 person did not attempt speech but was at an earlier stage, judging by non-verbal behaviour. This person only attended 1 session.	4 participants had logopenic aphasia with marked word finding difficulty and at times topic maintenance problems. One of these had a computer based communication aid but was not initiating using it.	3 people had a diagnosis of semantic dementia. At the end of the project, 1 was re-classified as having Alzheimer's disease by the neurologist. 1 person was using pictorial support effectively but frequently expressed anxiety at the steady loss of known words. One was at an early stage and verbal communication was relatively good.

Primary Non Fluent Aphasia (PNFA)	Logopenic Aphasia	Semantic Dementia
Observed communication support		
No attempts to elicit the person with aphasia’s opinion or wishes were observed although in all cases there was a general inclusion of the person with aphasia in the family members comments for example use of tag questions, first person plural pronouns and body language	The people with aphasia often initiated utterances including initiating new topics. One participant was able to get her meaning across with support from family members. One looked to a partner to talk for her when language broke down. 1 person’s partner would take over the conversation automatically.	2 people with semantic dementia needed support from family to understand at times and this was initiated by the family member, usually by repetition or re-phrasing.

Attendance

Average attendance was 6 people with PPA plus 6 family members. Most attended regularly or were in regular contact. The majority attended with their family member, but there were additional adult children at times, or a friend in place of a partner. 2 dropped out after 1 meeting: one for health reasons and one for unknown reasons. 1 dropped out after 2 meetings, with no reasons given.



Contents of sessions

We offered sessions every two months from April 2019 to February 2020. Apart from the initial meeting, the agenda followed the wishes of participants. Notes and related information were sent out to everyone registered after each meeting.

An early request was for information about research participation. Via our developing network of people working with PPA, we were able to create a list of researchers in the field in London, Oxford and Cambridge, although few were actively recruiting.

Most people were known to their SLT and had not been discharged. Some specific communication management advice was discussed such as using answer phone systems to best advantage, using Apps on standard iPads to enhance communication, ideas about maintaining some reading as an accessible leisure interest. We had a speaker from our Regional Communication Aid Service and that led indirectly to at least 1 couple being referred back into their SLT service. 1 person had a computer based communication aid. Others had tried one but rejected it. 1 person with semantic dementia used a standard iPad to support communication. She also used drawing for everyday tasks. No other low tech aids were in evidence.

Opportunities for modelling supported communication were limited. This was mainly due to the pressing need of the family member to talk and share information. A high percentage of session content was information exchange, signposting and general advice. In addition, the relatively large number of participants (10 or more at every session), the small number of meetings and the widely differing types of aphasia and the stages of the participants in the disease process, made any modelling somewhat perfunctory and less than effective.

The type of information emerging from peer to peer exchange concerned benefits, safety measures such as carer emergency cards, the Sunflower Hidden Disability lanyards, remote access to the Rare Dementia Support group. With the appropriate permissions, a WhatsApp group was set up at the second meeting for participants to exchange information directly. This was managed by the group themselves without our involvement and we were not in the WhatsApp group. All but one participant joined the group. The outstanding participant was invited to share his email address, instead, as he was not using WhatsApp compatible technology.

In our final session, staff from a dementia carers' support service came to speak to the group. As well as dementia focussed carer support, we were able to share resources developed for NETA to support carers and identify disability-friendly active leisure interests across our region. It was apparent during sessions, and from the feedback, that family members of people with PPA felt a need to have a separate space to be able to talk frankly about their roles and the impact of their partner's PPA diagnosis on their lives and their relationship.

Evaluation

We took part of the penultimate session to discuss, as a group, topics on a simple feedback form that had been sent out beforehand. Following this, dyads were invited to complete their own feedback. Both group and individual sources of feedback are in the attached document. We made repeated efforts to elicit feedback from those not amongst the regular attenders but without success.

The most important outcome was meeting other people in the same situation and being able to pool information and experience. Those who responded were all positive about the project and keen for the service to continue in some form. They found access to communication experts helpful but generally felt that any communication coaching for carers needed to be specific to each person with PPA, due to the differences in symptoms and the degenerative nature of the illness.

There were justified comments that the communication during and after meetings needed to be more aphasia friendly. As the carers were the main focus for the project, the decision had been made to present information and notes suitable for family members. During sessions every effort was made to ensure those with aphasia were following the discussion, but there was an element of family members taking over, and this will be taken into account in any future provision.

Networking

The project has enabled us to network with local neurology and psychiatric services as well as nationally with the Rare Dementias research and support groups. We have also linked with local dementia services both statutory and third sector. We have received enquiries from a Community Psychiatric Nurse (CPN) about who best to refer to for a medical opinion. The existence of NETA as a charity supporting aphasia in the North East has wider recognition as a result of this project.

Aims and Outcome

Stated aim	Outcome	Comment
Peer support and exchange of information	√	Feedback illustrates the importance for both carers and the person with aphasia of meeting others in a similar situation.
Informal observation of type of communication difficulty, stage and need including any strategies being tried by family members and their effectiveness	√	Observations of type of aphasia and severity are described above.
Modelling simple strategies to help support communication	Partial	This aim was not fully met for the reasons given above.
Explore the communicative needs of the people with PPA and their family members, and consider how these may be supported	√	It was clear that the widely differing communication difficulties both in terms of type of aphasia and stage of the disease process, would make any kind of group communication coaching less effective than a dyad approach. This is reflected also in the comments by participants.
Exploration of logistical factors affecting attendance; indication of likely numbers	√	Participants were willing to travel more than an hours' drive to attend. Feedback indicated that parking was a problem and

and possible groupings for further indirect intervention, gathering qualitative and quantitative information in order to apply for funding for a short course in supported conversation		this might need to be addressed for future support group sessions. Numbers were higher than expected and sufficient for a group approach in terms of ongoing support. Funding a group course in supported communication was not found to be appropriate.

<u>Impact</u>

Expected Impact	Outcome	Evidence
Give us information about unmet need	√	The geographical spread, and number of participants indicates the need for a northern service and that there is no other equivalent existing service.
The first such support service in the North East	√	
An ongoing informal peer support network for families with PPA	√	This has been achieved by use of the WhatsApp group of peers who have met each other at the PPA support group. One person could not join for technical reasons and has been invited to share an email address in lieu.
Identification of the numbers and needs of these families to form the basis for a funding application to provide more timely interventions in	√	There is clearly a population of families with PPA who feel a great need for support by professionals with a thorough understanding of aphasia. But it is evident that

supported communication techniques as appropriate.		communication support beyond very general advice requires a dyad specific approach.
Opportunities to develop a collaborative approach with SLTs across the North East region to enhance provision for this group with the beginning of a care pathway for families with PPA.	√	The majority of participants were already known to their SLT service which had suggested the PPA group to them. Some were encouraged to re-approach their service for further support after their awareness was raised about what they could request and how to do it.
Enhancing liaison between neurology, psychiatry and SLT to ensure early referral for communication advice and support.	√	The existence of the group and the networking has enhanced awareness of the potential value of SLT for people with PPA and aphasia in general.
A showcase for the value of supported conversation and peer support.	Partial	Peer support was a strong element of the project. Supported conversation work will hopefully follow.
With stronger links with diagnosing clinicians, we would be in a position to advise SLT colleagues who suspect PPA about appropriate routes for further investigation.	√	Although not specifically an SLT enquiry we did have this enquiry from a CPN.
Liaise with SLT colleagues to ensure they are aware of families with PPA in their area.	√	As information about the service spreads it seems likely that we will get more approaches that are not via our existing SLT links. None of the 3 enquiries received at the end of the project were from SLTs. Each was

		recommended to liaise with their local SLT service as well as registering with our group.

Conclusions

The project provided a new support service for people who are living with primary progressive aphasia. We demonstrated a clear unmet need in the northern region. Peer support between family members was a major outcome and opportunities have been established for ongoing contact. In addition, a wide range of information about access to carer support and entitlement has been discussed and distributed.

The project served to highlight the communicative needs of this group to diagnosing clinicians, dementia support groups, SLT services and other professionals in the dementia services who may have limited experience of aphasia. The project identified how ongoing supported conversation training might best be provided alongside a group approach to support for family members and people with PPA.

Future plans

Newcastle University Speech and Language Sciences section is in discussion about suitable applications for funding to continue offering a service to this group. It is hoped to hold occasional intermittent meetings as an interim measure until some longer term funding can be established. The purpose of this would be to retain the group identity and introduce new members.

Dissemination

The project will be reported back via BAS networking opportunities including submission of a poster presentation for the next BAS conference. The outcome will be disseminated to regional SLTs via presentation at the regional Clinical Excellence Network and Aphasia Study Group. An abstract will also be submitted to the North East SLT SLT Research Symposium 2020 this summer.

The written report will be shared with supporting medical departments and an outline of the project will be included in NETA communications such as the website and newsletter. A summary of the project has been included in the annual update from NETA to The Aphasia Alliance.

Acknowledgments

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Rosemary Townsend of Dyscover www.dyscover.org.uk was generous in sharing information about her experience with PPA and her networks in the Rare Dementias sector.

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