

# Better Conversations with Primary Progressive Aphasia (BCPPA): Communication training to keep families together.

<https://neurodegenerationresearch.eu/survey/better-conversations-with-primary-progressive-aphasia-bcppa-communication-training-to-keep-families-together/>

## **Name of Fellow**

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## **Institution**

## **Funder**

NIHR

## **Contact information of fellow**

## **Country**

United Kingdom

## **Title of project/programme**

Better Conversations with Primary Progressive Aphasia (BCPPA): Communication training to keep families together.

## **Source of funding information**

NIHR

## **Total sum awarded (Euro)**

€ 430,876

## **Start date of award**

01/10/15

## **Total duration of award in years**

4.0

## **The project/programme is most relevant to:**

Alzheimer's disease & other dementias

## **Keywords**

## Research Abstract

There are certain types of dementia where people have difficulties with communication, for example difficulties thinking of words, understanding words or using the right sounds, but their memory and thinking skills remain good. This is called primary progressive aphasia (PPA). People with PPA often describe a number of years during which communication becomes slowly worse, yet they try to cope at work and socialise with family and friends without telling anyone about their difficulties. This can cause a lot of distress and frustration for these people and their families, but they often have a lot of difficulties getting the help that they need. There are speech and language therapy exercises that have been shown to help people with PPA use their words for longer. These include repeating words, matching words to pictures and descriptions, and practising sounds that make up a word, and have to be done every day. People with PPA often find these exercises frustrating. So a lot of speech and language therapists (SLTs) work on “communication training” instead. This involves SLTs, people with PPA and family members discussing how to make day-to-day conversation at home easier. Giving advice to a family member is important because the person with PPA will get worse over time. I recently did a small survey of 23 SLTs who work in London and the South of England. I found that they use programs like this that are for people who have stroke-related communication difficulties (‘aphasia’). These programs have not yet been proven to work for people with PPA. But they can be successful for stroke survivors. This lack of clinical evidence inspired me to apply for funding to start some research. I was awarded money from the Guys and St Thomas’ Charity, and in April 2014 I started to develop a new communication training program for people with PPA and their families. It is called Better Conversations with PPA (BCPPA), and it is based on one of the programs for stroke-related aphasia, called Better Conversations with Aphasia. I chose to base it on this program because it comes with growing evidence that it works well for people with stroke, and some of the SLTs in my survey reported using it. Also it is free on the internet, so it is easy to access. However, it does not include information on dementia and the brain, nor on how communication will get worse. This means I need to adapt the program. With the Guys and St Thomas’ Charity funding, I am starting to gather evidence about whether people find it useful, and whether it works. But I need to do a bigger study to be sure. I will do this in three stages: 1. A large survey of SLTs in the UK I will ask them in detail about what therapy they offer to people with PPA. I also want to examine all the published information on speech and language therapy for people with PPA. This will help me work out what the current therapies have in common, and what works and what doesn’t. 2. Adapting BCPPA into a therapy program on the internet, plus a manual, to help SLTs to use it. To do this I will ask SLTs and people with PPA and their families from South London and the Maudsley NHS Trust where I currently work to help me test it and agree on what it should include. 3. Testing the program with a small group of people with PPA, and comparing the results to ordinary SLT treatment (given to another small group of people with PPA). This will help me prepare for a bigger trial by allowing me to test out ways of measuring improvements. I will be able to work out how much help I need to give the SLTs to make sure they are all doing the program the same way. It will also allow me to measure how many people are needed for a bigger trial i.e. how many people I need to make sure the measurements are strong enough to show a real improvement, not just a coincidence. If BCPPA is a success after this study, I will go on to run a larger trial of the BCPPA program with more people and more SLTs. If there is good

evidence that BCPPA helps communication, I will spread the word to SLTs across the UK and the world, and they will be able to train themselves using the internet and use it with their patients.

**Types:**

Fellowships

**Member States:**

United Kingdom

**Diseases:**

Alzheimer's disease & other dementias

**Years:**

2016

**Database Categories:**

N/A

**Database Tags:**

N/A