

Novel personal narrative therapy to help people with aphasia tell their story

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Researchers from City have launched a new project aimed at helping people with aphasia tell their story, and improve their ability to carry out everyday conversation following a stroke.

Involving researchers from USA and Australia, and funded by the Stroke Association, the [Linguistic Underpinnings of Narrative in Aphasia \(LUNA\)](#) project also involves people with chronic aphasia in the co-design process, as well as NHS Speech and Language Therapists.

Celebrated at a special event in early July, the international research team were joined by three people with aphasia who previously took part in the pilot study and have also volunteered to help at regular advisory group meetings, which will help shape the direction of the study.

There are more than 100,000 strokes in the UK each year, and it's estimated that about a third of [stroke survivors](#) will have some degree of aphasia, a language disability which affects language skills and conversation. There are also over 1.2 million [stroke](#) survivors in the UK and almost two thirds of stroke survivors leave hospital with a disability. Chronic aphasia can have substantial psychological and social consequences for a person, lowering their mood and quality of life.

Although speech and language therapists (SLTs) support the rehabilitation of people living with aphasia, there remains a clear lack of evidence-based treatments available for them to help people with problems related to everyday talking, known as discourse. In addition,

published research has shown that many SLTs lack the expertise and confidence to effectively use the tools that do exist to help patients with discourse problems. These barriers prevent people receiving the therapy that could maximise their everyday communication skills and lead to a better recovery.

To help address these issues, LUNA aims to develop a person-centred discourse treatment based on rigorous review of aphasia theories and intervention research. All the treatment materials will be subsequently co-designed by the researchers with a small group of NHS SLTs and people with chronic aphasia, so that they are easily understood by service providers and recipients.

One of the participants with aphasia, known as Varinder, who is a current co-designer spoke about her experience of LUNA.

"Confidence when you have a stroke is the hardest thing to build up, but LUNA is a partnership and a whole team thing, and that's so exciting."

Jan, another participant who has aphasia, also spoke about how the previous pilot study had helped him structure his LUNA story and address his previous issues with prepositions and story structure.

The study will also include a UK-wide online survey of practising SLTs to obtain information about their discourse knowledge and skills, and what helps and hinders them in delivering discourse assessments and treatment to their patients in practice. This information will be used to develop a training programme to enhance the knowledge and skills of SLTs, and be trialled with 60 SLT volunteers. The training programme should ensure that any newly developed tools from LUNA can be accurately and efficiently used in regular clinical practice.

In the final stage of the study, treatment with LUNA plus usual care

(community support groups) will be compared to treatment with usual care only in 24 people with chronic aphasia (more than 12 months). This will explore whether LUNA is a feasible and acceptable treatment for its users; whether it can lead to an improvement in patient discourse ability, their psychological state and social interaction; and whether it can be delivered as intended in the manual.

The full LUNA team includes Dr. Madeline Cruice, Dr. Lucy Dipper, Professor Jane Marshall, Professor Nikki Botting, and Dr. Madeleine Pritchard, from City, as well as Professor Mary Boyle from Montclair State University, USA, and Associate Professor Deborah Hersh from Edith Cowan University, Australia. The advisory team includes 4 people with aphasia and 4 SLTs from local NHS trusts.

Dr. Madeline Cruice, Joint Principal investigator of the LUNA project and a Reader in the Division of Language and Communication Science at City, University of London, said:

"We're thrilled to be moving forward with LUNA. The international evidence base for both aphasia treatments and clinical expertise signals that this project is much needed and timely. We're excited to be working closely with our clinical partners and people with aphasia, so that what we develop in LUNA can be implemented in the NHS in the future and also easily understood by people with aphasia and their family members".

Dr. Lucy Dipper, Joint Principal investigator of the LUNA project and a Senior Lecturer in the Division of Language and Communication Science at City, University of London, said:

"Through LUNA we hope to develop a therapeutic outcome framework which can help inform personal narrative, and we also hope to get more information about how clinicians across the UK in the NHS help people

with [aphasia](#) tell good stories, including the challenges and what would help them to do this better."

Hilary Reynolds, Executive Director of Strategy and Research at the Stroke Association, said:

"Having problems with using everyday language after stroke affects a person's confidence, mood and can leave them socially isolated. We're therefore delighted to be funding LUNA. It's a really exciting new study that we hope could lead to a real difference for those stroke survivors affected. We know that with the right support, stroke survivors can and do regain their independence and rebuild their lives."

Provided by City University London

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