

Helen's story

'Aphasia Support' is a registered charity who support people with aphasia. Aphasia is a language disorder which affects a person's ability to speak, read, write and understand language. They were invited by Locala's Speech and Language Therapy team to run a weekly session at Dewsbury Health Centre, where they use 'apps' to help people re-discover communication skills such as word finding, pronunciation and writing. They also run 'Aphasia Cafes' where people can meet and socialise. For more information <https://www.aphasiasupport.org/> Locala's Adult Therapy Service provides treatment, rehabilitation, advice and support to people living in Kirklees. The service includes physiotherapy, occupational therapy, speech and language therapy and dietetics.



Introducing Helen: Helen lived and worked in Australia for many years before returning home in 2019 to help her family care for her Dad, who had dementia. Her sister is called Lucy. Helen explains that last year, her own health suddenly deteriorated. She was admitted to hospital in September with suspected pneumonia. A week later, whilst still in hospital, Helen had a stroke.

What happened: Helen recalls, "One day I fell out of bed. One of the staff told me to 'get up' but I couldn't." Lucy explains, "Having messaged each other the evening before – she'd had many tests but didn't have Covid - suddenly she wasn't replying to messages. Her friends were contacting me, asking if she was alright, because they weren't receiving replies either." Lucy then had a phone call from the hospital telling her that Helen had had a stroke and had two cerebral aneurysms. Lucy was able to see Helen, "They couldn't tell me about Helen's prognosis. She was laid in bed, unable to speak, floppy on her right side, her face had dropped." Helen was moved to the Stroke Unit, but due to Covid restrictions, Lucy was stopped from going onto the ward with her. "We had no clue what the impact on Helen was." Adding to the stress of separation, and not being able to say goodbye, was the family's painful past experience. They had lost Ruth, another sister, in 1999, who died following a stroke.

Disappeared: The sisters explain how covid restrictions continued to shape Helen's experience during her early recovery. She had to 'isolate' for 2 weeks and then visiting was restricted to one hour twice a week. Video calls didn't work, as Helen couldn't talk and the device would fall to one side, so that Helen's face was no longer visible. Lucy says, "Helen is usually very active on social media – many of her friends are still in Australia – but she was unable to use her tablet or phone. It was like Helen just disappeared." Helen received many cards, but she says, "I just put them in my bag." Lucy explains "it was not until Helen came home, 2 months after the stroke, that we realised Helen couldn't read." Multiple cards and letters were found unopened in Helen's bag.

Discharge home: The sisters believe that the transition from hospital to home could have been smoother. The situation was unusual – a stroke survivor returning home to elderly parents, one of whom had advanced dementia. The home 'visit' had been done over video and not with Helen in person. Lucy says, "I didn't know what Helen was capable of." She continues, "We had a phone call from the Discharge Team who gave me information we hadn't known before and telling me Helen was coming home. She said we should have had a weekly Zoom call, to discuss Helen, but we hadn't. We didn't feel involved in planning for home at all." Lucy felt there were too many unanswered questions, including concerns that Helen couldn't see from her left eye – the stroke had inhibited the optic nerve – and ongoing respiratory problems. Following a meeting, a discharge date was agreed, and Helen came home early November, initially supported by the Reablement team, who at first visited three times each day. They helped Helen with her medication. Lucy says, "She came out with a selection box! We didn't know what any of them were." Helen explains that many of the adaptations made for her Dad, such as their shower room, helped her too. "I couldn't talk so well. But I was washing and dressing myself and I was walking with a stick."

Rehabilitation: Helen's memory of her time in hospital remains unclear. Lucy explains that Helen had to move between the Stroke Unit and the Respiratory ward, depending on her medical needs and that there were times she wasn't well enough for rehabilitation. Whilst on the Stroke Unit, however, Helen received daily physiotherapy, occupational therapy and speech and language therapy and was making good progress. Lucy was determined that Helen's recovery should continue once home and was concerned to be told that community rehabilitation would not be available on a daily basis, also that there was a waiting list. **"We weren't expecting that – we thought the guidelines were for daily rehab. And why had they only just got a referral? Surely someone knew Helen would need the referral weeks before?"** Lucy was worried that Helen's progress would falter, so arranged for private speech and language therapy. She continues, **"It was actually a week later, the day Helen started with private speech and language therapy, that we had a call from Lisa, the therapist from Locala."**

Helen describes Lisa, her Speech and Language Therapist, **"She was ace! Very good. She told me why I couldn't speak. She explained what part of my head wasn't working and how we had to get it going."** Helen says that Grace, Assistant Practitioner was hugely helpful too. **"I couldn't say anything. She brought a big book and said, 'we'll start at the beginning.'** Helen explains how her speech has gradually improved. **"At first, when I was in hospital, I didn't even know what a picture was – like an elephant. Then I could read things for a farm, and then a zoo, it all came back. Every time, Grace had a lots of things I had to say. Like, 'I can, he can, they can, I did...' I had to say things that were one syllable, then two, then three syllables."**

Helen says that Nic (physiotherapist) and Jan (occupational therapist), **"got me moving. At first, I thought my leg, arm and hand were going to be useless, but the therapists told me I would get them working again."** Lucy adds that Jan has been **"brilliant"** and has been approachable and supportive, **"when I need to ask someone, is this normal?"** The sisters feel it is often confusing who does what in rehab, such as, **"writing is occupational therapy, not speech and language."** Jan is helping Helen access a mobility car. Helen is looking forward to being independent and back on the road again!

Moving on: As Locala's therapists withdrew their care, they referred Helen to Kirklees Council's 'KAL' programme (Kirklees Active Leisure) for 12 weeks of supervised gym sessions. Helen feels the gym sessions have been very beneficial, but she didn't feel ready to be discharged from rehabilitation. Lucy says discharge left Helen feeling **"stranded. It wasn't her choice."**

Aphasia Support: The Stroke Association had suggested a couple of groups, but they weren't quite the right fit for Helen. Lucy found out about the 'Aphasia Support' charity by searching online. The sisters are now regulars at the charity's 'Aphasia Café' held in Halifax every 2 weeks. Helen says, **"It's great!" It's getting better every time we go."** The café is attended by those who are aphasic. Friends and family are welcome too. It's a caring, proactive mix of peer support and structured goal setting. Helen likes that everyone has a shared desire to get better. **"You have to think about other ways to say something."** Helen gives an example. **"If you get stuck with the word cup, say 'the thing I put coffee in'."** Lucy adds, **"They all help each other."**

It was James from 'Aphasia Support' who suggested Helen join their 'App Group' at Dewsbury Health Centre for a 12-week programme of one-to-one intervention. Working with Hannah, an **"amazing"** Speech and Language Therapy student, Helen used technology to improve her communication skills and was encouraged to use synonyms rather than struggling to find a specific word. The sessions also helped Helen practice writing by hand, something that she both enjoys and finds useful. Eventually she could write half a side of A4.

Helen and Lucy want as many people, especially Health Care professionals, to know about 'Aphasia Support'. They feel there needs to be a more effective way to tell stroke survivors about places and community groups that can help them, bearing in mind that many with aphasia cannot read or speak on the phone.