



Online Aphasia Café: A springboard for creating stroke survivor-led aphasia communities?

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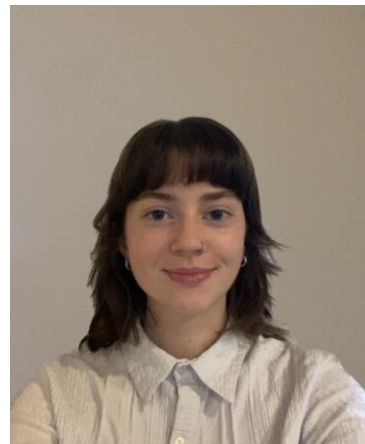


Conflict of Interest Declaration

We do not have any conflicts of interests.



Dr Helen Kelly



Hollie Burke



Aine Curtin

Today I will talk about.....

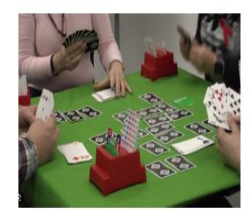
- Aphasia
- Role of Aphasia Cafés in raising awareness of aphasia
- Stroke Survivors raising awareness of aphasia
- Stroke Survivors setting up aphasia communities/groups

Aphasia

- At least 1/3 of people who have a stroke experience aphasia
- Aphasia is a communication difficulty affecting language (words and/or sentences)
- It can affect a person's ability:
 - to understand what they read and hear
 - to express themselves when speaking and writing
- It affects everyone differently
 - Different presentation
 - Different severity
- Aphasia does not affect intelligence!

How does aphasia affect people's lives?

- Daily communication challenges
- Limited opportunities for social engagement
- Reduced self-confidence
- Social isolation and loneliness
- Benefits of aphasia groups – friendship, peer support.



Raising Awareness of Aphasia

- Poor awareness of aphasia across the world!
- Raising awareness requires:
 - Spoken and written communication
 - Energy (often post-stroke fatigue)
 - Self-Confidence
 - Support – financial and other
 - Knowing how to access ways to raise public awareness e.g. newspapers, TV...
 - Knowing where to start!
- Aphasia can mean stroke survivors' voices are not heard
- Can Aphasia Cafés help? If so, how?

4 Embracing technology with aphasia

Helen Kelly, Larry Masterson, Eileen O’Riordan and Philip Scott

Technology, or more specifically Information and Communication Technology (ICT), relates to all technological methods used to manage information and aid communication technologies. It includes both computer and network hardware as well as their associated software. ICT is therefore a broad subject area which continues to advance and evolve at a fast pace, and so cannot be fully contained within the pages of this chapter. To harness the voice and perspectives of people living with aphasia, Helen (first author) explored with authors Larry, Eileen and Philip the impact that aphasia has on their use of technology in their daily lives. From the perspectives of the authors living with aphasia, *Health and Wellbeing* captures pertinent priorities around ICT for people with aphasia, more specifically, *Social Connection*, engaging in aphasia rehabilitation through *Telepractice*, and the accessibility of ICT for people with aphasia, i.e., *Digital Inclusion*. As one aim of this chapter is to educate speech and language therapy (SLT) students, 30 SLT students at University College Cork identified topics they would like to learn about in relation to technology and aphasia. Interestingly, many of their topic areas mirrored the priorities of our authors. First, we will provide a brief overview of ICT and how it may be used to enhance communication for people with aphasia. We will then explore ICT in relation to Social Connection, Telepractice, and Digital Inclusion.

Information and Communication Technology (ICT) and aphasia

ICT has become embedded in and permeates everyday society with 4.66 billion (59.5% of the global population) active Internet users worldwide and 79% of EU individuals using the Internet daily (Johnson, 2021). Although



Dr Helen Kelly



Phil Scott



Liam Kelleher



Larry Masterson



Martin Quinn



Dan Clancy

Raising awareness of aphasia through a co-designed website

Aphasia Café - a potential springboard for creating stroke-survivor led aphasia communities?

- Aphasia Cafés offer peer support and communication skills practice.
- Are there other benefits from attending aphasia groups?
- Do Aphasia Cafés support stroke survivors with aphasia to:
 - raise awareness of aphasia?
 - create their own aphasia communities?
- If not, what motivates and supports them to carry out this work?

- PPI Involvement - Two stroke survivors with aphasia provided advice at the planning stages. Both attended the Aphasia Home Café and had set up their own aphasia support groups in their local areas.
- Meeting 1 – Individual interview
 - Background and communication information
 - Discussion about their experience of stroke and aphasia
 - Involvement in stroke support groups
- Meeting 2 – focus groups
 - Experience of raising awareness of aphasia or other similar activities
 - Motivation for doing this
 - Benefits and challenges
 - Advice to others who want to do similar activities.

P	Gender	Age	TPS (yr)	WAB-R (Beside)	COAST %	Post-stroke challenges	Employment & Homelife	Stroke support groups attended
SS1	M	63	10	Anomic (Not det)	66	Aphasia; Mobility; Mental Health	Unemployed Family	Aphasia Café; Choir
SS2	M	68	5	Anomic (Mild)	51	Aphasia; Memory; Social Isolation; Mental Health	Retired Spouse	Aphasia Café; Headway
SS4	M	56	4	Conduction (Mild)	74	Aphasia; Mobility	Unemployed Spouse	Aphasia Café; Talking Heads; Online Café (UK)
SS5	M	66	13	Anomic Mild	64	Aphasia; Mobility; Dysphagia	Self-employed (part-time) Family	South Tipp Conversation Group
SS6	F	43	6	Anomic (Mod)	69	Aphasia; Hemiparesis	Unemployed Family	Aphasia Café; Irish Heart Foundation; Acquired Brain Injury Ireland; Online Café (USA)
SS7	M	63	6	Conduction (Severe)	71	Aphasia; Mobility; Managing finances	Self-employed (part-time) Lives alone	Aphasia Café; Acquired Brain Injury Ireland; SLT Communication Partner Programme
SS8	F	52	42	Anomic (Not det)	86	Aphasia; Paralysis	Unemployed Family	Aphasia Café; Cork Stroke Support; Bandon Stroke Group
SS9	M	57	11	Broca's (Mod)	74	Aphasia; Hemiparesis	Unemployed Lives alone	Aphasia Café; Cork Stroke Support; Talking groups
SS10	M	74	13	Anomic (Not det)	78	Aphasia; Mobility; Vision	Retired Spouse	Stroke Association NI Conversation group Aphasia Café

Activities to Raise Aphasia Awareness

- Involvement in Research as **PPI Consultants** and **research participants**
- Attending **Advocacy** Courses. Role as **Patient Advocate** on **charity** boards
- **Educating** healthcare students and professionals in local area
- **Sharing personal stories** and experiences about Aphasia on **social media** and **Aphasia Website**
- **Guest Speakers** on Podcasts, YouTube Channels, conference panels etc
- **Encouraging others** to join Aphasia café
- Daily awareness through **conversations with family, friends** and members of the **public**.

Activities to Raise Aphasia Awareness: Daily Conversations

“Yeah, it's... that's... come on, we need to... we need to... Awareness. You know? Maybe... You know... the street, you know, or... you know what people often, I walk every day down at the coast And... People ask me, oh, oh, are you, eh- your leg... And I was like... No, actually, I have aphasia. And they were like, what's that? And then we... You know... Again, it's aware. It's awareness.” (Mary)

“Well, I suppose... The most obvious and constant one is if I'm... meeting friends or or people I haven't met, I'll I'll I'll say I have aphasia, which I think is, you know. The most important sentence and then say.” (Jonas)

- Note: these are not the real names of our participants

Activities to Raise Aphasia Awareness: National

- Establishing a **National Stroke Conference**
- Creating aphasia awareness **documentary**
- Writing **newspaper articles** and **book chapters**
- Campaigning and **canvassing county councils** and **national government**
- **Patient advocate** for the **Irish National Audit of Stroke** committee
- **Co-designing the Aphasia Home Cafe website**
- **National Television** - stroke recovery & Aphasia Café



Aphasia Cafés – Develop Confidence

- “Yeah, like, um, eh, We all know that where we go, for Talking Heads. Is a safe place. For us to, check each ... to ... say, when we're together” (Tom)
- “It was through the, um aphasia group. um that, my confidence... the group, being in the group, give me the confidence to do other things, and particularly to do the conference.” (Peter)
- “And that's the holy all of these aphasia cafes... and the confidence, the confidence building from the cafe. It's, em you couldn't, you couldn't buy it” (Alex)
- Note: these are not the real names of our participants

Aphasia Cafés – Peer Support and Inspiration

- “And then I think it just broadens your view of what it is...it does, yes, clearly, being part of other groups is... is the important part of it. (Jonas)
- “Eh- I went up to Donegal four years ago, to set up a few cafes, aphasia cafes, with L helped him with it, and I went down to Carlow, to Tom, eh who's doing another Talking Heads. And he's in the cafe as well. Eh When he was launching his, eh I've been with Peter.” (Alex)
- “this, uh February, me and SS are coming down to, eh Talking Heads, and we're going to...get involved.” (Mary)
- Like, I’ll do, do this now. For Patrick. He has given us inspiration. Thank you Patrick, Thank you (claps) (Tom)
- Note: these are not the real names of our participants

Aphasia Cafés – Wanting to Give Back

- It's, um eh eh It's humbling, in a way, to be able to... Help others, and, eh help them because, eh w- when you were going through it, I didn't know (Alex)
- “I’m... so passionate about stroke and aphasia, I just want to see better outcomes for people, and I want to ensure that people don't have the same, uh experience that I had while I was in hospital.” (Peter)
- “I feel I want to be involved. And, uh it... stroke, and other things as well...um it gives me... a feeling of contribution...So, I feel my...involvement eh I I enjoy that, because I feel I'm putting something back” (Jonas)
- “So... the setting up of the website on the Aphasia Cafe was a big thing. Aphasia....it can... it can wreck your self-confidence, so the website was something that we saw as vital, that people could peruse it at their leisure, in their own time, in their own home.” (Alex)
- Note: these are not the real names of our participants

Conclusion

- Attending an Aphasia Café in person or online can be foundational for further advocacy activities.
- Opportunities to be involved in activities to raise awareness of aphasia.
- Desire to ‘give back’ to other stroke survivors living with aphasia.
- Developed confidence so they could also:
 - Raise awareness of aphasia
 - Establish their own aphasia support groups.
- Got support and inspiration from their peers in the Aphasia Café to develop aphasia communities.

'I thought I was dreaming' – Tipperary activist chosen as New York St Patrick's Day Grand Marshal

Volunteer, author and peace award organiser Martin Quinn will bridge the Atlantic this March after a surprise selection by the County Tipperary Association of New York

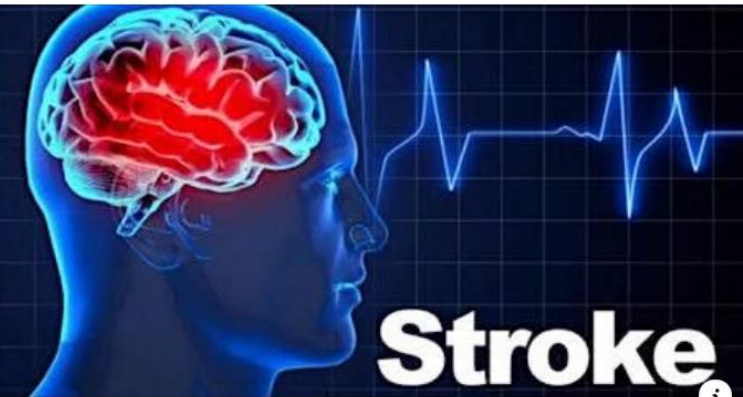


Martin Quinn. Picture by Derek Fanning



South Tipperary Stroke Communication Group
 23 February at 09:21 · 🌐

The 2026 National Conference on Stroke, will take place at the Cashel Palace Hotel, Cashel, Co. Tipperary, commencing at 9:30am.
 To attend you must register for the Conference on Eventbrite.
 The link to register is as follows;



EVENTBRITE.IE
 National Conference on Stroke 2026



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