

Socialising from home:
Peer support and communication practice at the
Aphasia Café

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Conflict of Interest Declaration

We do not have any conflicts of interests



What is 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
- It does not affect intelligence



How does aphasia affect people's lives?

- Daily communication challenges
- Limited opportunities for social engagement
- Social isolation and loneliness
- The rate of depression is higher for people with post-stroke aphasia than people who don't have aphasia following a stroke
- A lack of peer support and conversation practice services nationally



The Aphasia Café

- Initiated by Rachel Boland, UCC Clinical Therapies Society
- Local community café in Cork City – The Haven Café
 - Very supportive manager & staff
 - Low-noise environment
 - Wheelchair accessible
 - Accessible car parking outside
- Launched in 2017
 - Monthly meetings



The Aphasia Café

- Safe space for:
 - Communication practice
 - Develop skills & confidence
 - Peer support
- Accessible for people with aphasia
 - SLT student volunteers
 - Accessible menus
 - Materials to aid communication, e.g. pen & paper, picture boards etc.
 - Café staff were trained by people with aphasia

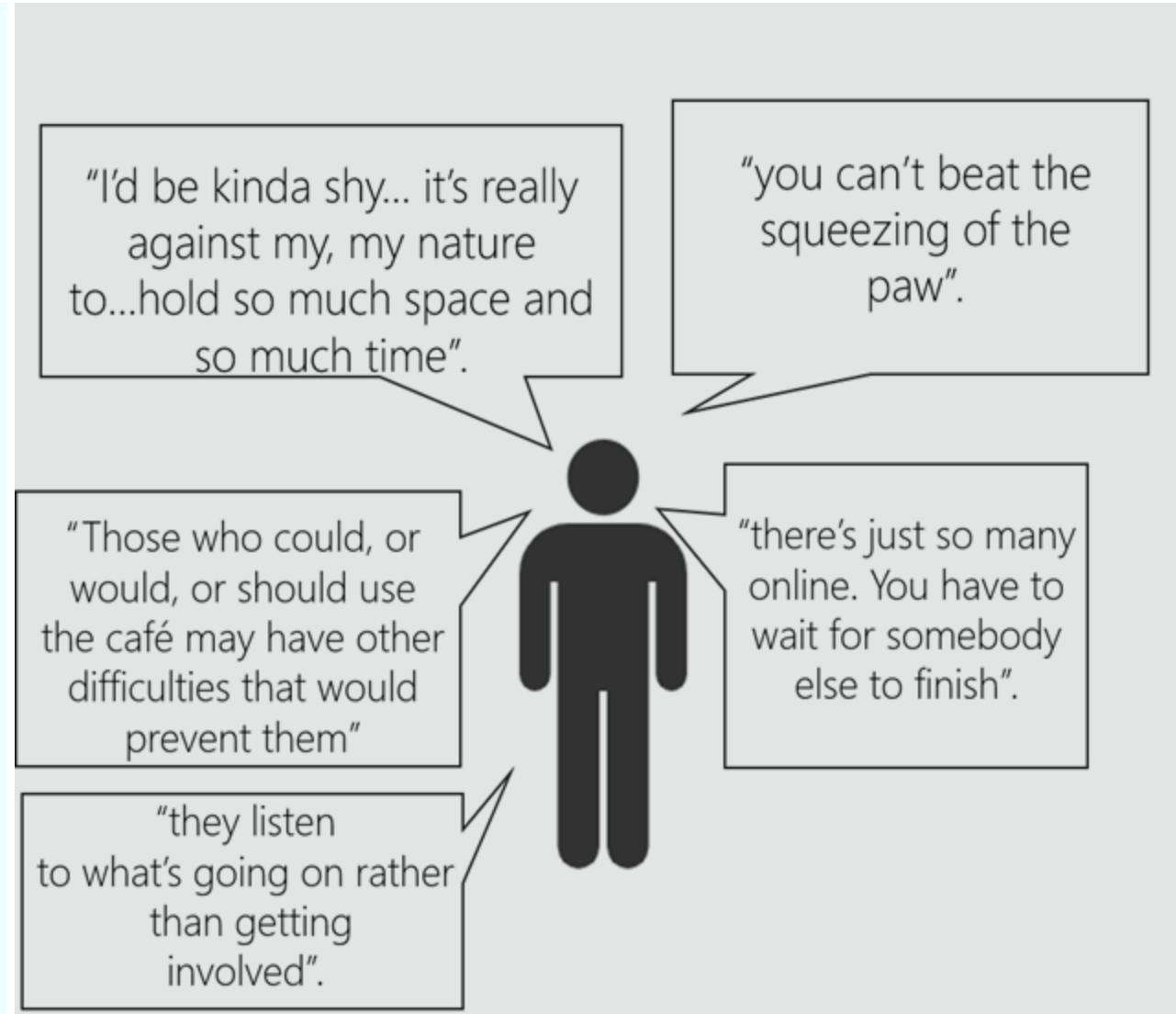
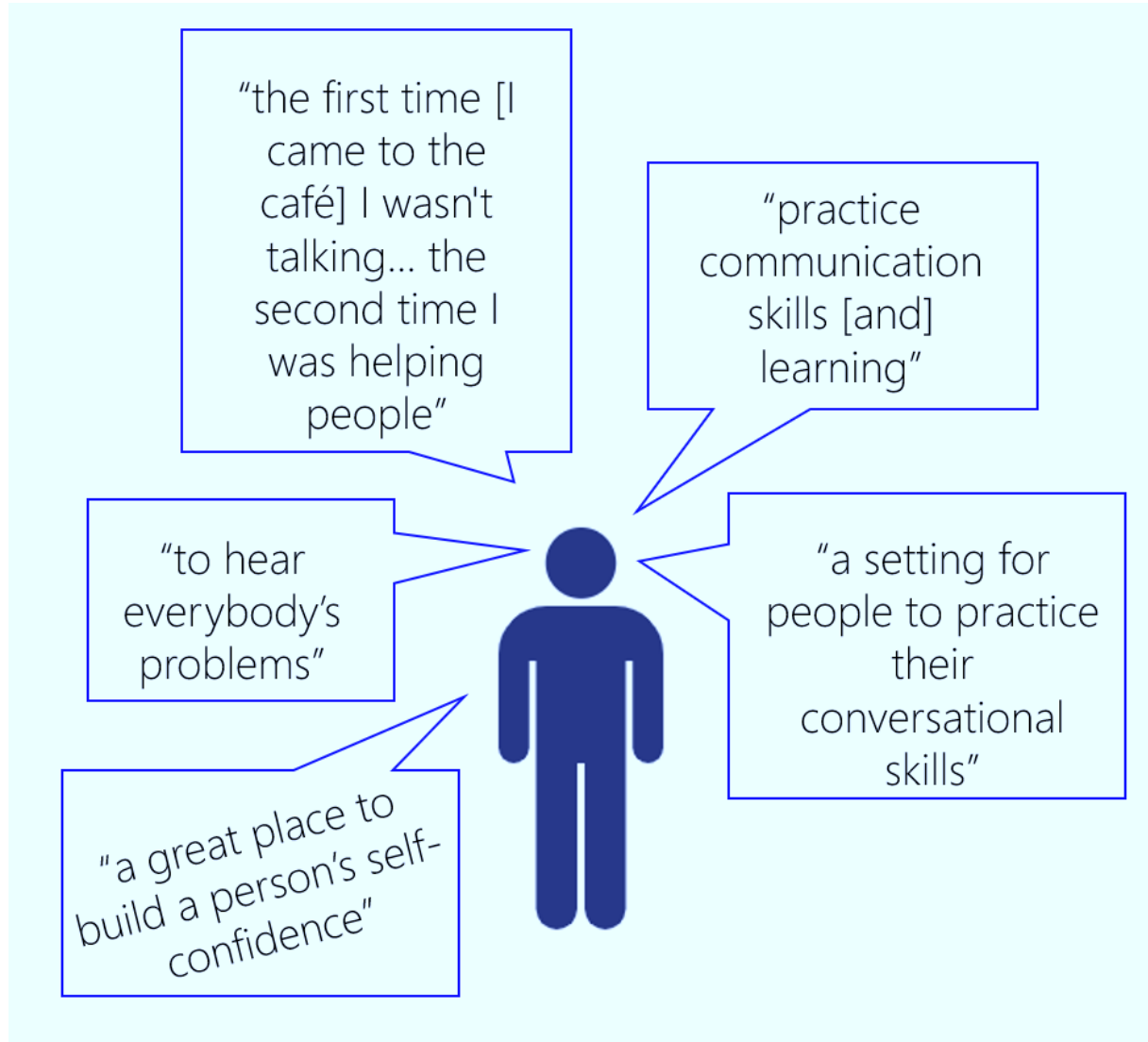




Lemons to Lemonade

- Aphasia Café closed - pandemic-related social restrictions
- Established our **Aphasia Home Café**
 - First online conversational space for people with aphasia in Ireland (*May 2020*)
 - Conversations from pets to politics!
 - Every fortnight on Zoom
 - >80 members from diverse geographical locations
 - urban and rural areas
 - across the island of Ireland
 - UK, Europe and even USA





Bell, S., Horgan, A., & Kelly, H. (in press) “You'll find most people who got involved with the Café couldn't do without it now” – socialising in an online versus in-person Aphasia Café. *Advances in Communication and Swallowing*.





Eileen O'Riordan



If you want to know more
about the Aphasia Home Café

Email helen.kelly@ucc.ie

or

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References

- Brown, K., Davidson, B., Worrall, L.E. & Howe, T. 2013, "'Making a good time': The role of friendship in living successfully with aphasia", *International journal of speech language pathology*, vol. 15, no. 2, pp. 165-175.
- Croteau, C., McMahon-Morin, P., Le Dorze, G. & Baril, G. 2020, "Impact of aphasia on communication in couples", *International journal of language & communication disorders*, vol. 55, no. 4, pp. 547-557.
- Cruice, M., Worrall, L. & Hickson, L. 2006, "Perspectives of Quality of Life by People with Aphasia and Their Family: Suggestions for Successful Living", *Topics in stroke rehabilitation*, vol. 13, no. 1, pp. 14-24.
- Cruice, M., Woolf, C., Cauter, A., Monnelly, K., Wilson, S. & Marshall, J. 2021, "Preliminary outcomes from a pilot study of personalised online supported conversation for participation intervention for people with Aphasia", *Aphasiology*, vol. 35, no. 10, pp. 1293-1317
- Ford, A., Douglas, J. & O'Halloran, R. 2018, "The experience of close personal relationships from the perspective of people with aphasia: thematic analysis of the literature", *Aphasiology*, vol. 32, no. 4, pp. 367-393.
- Hilari, K., Behn, N., James, K., Northcott, S., Marshall, J., Thomas, S., Simpson, A., Moss, B., Flood, C., McVicker, S. & Goldsmith, K. 2021, "Supporting wellbeing through peer-befriending (SUPERB) for people with aphasia: A feasibility randomised controlled trial", *Clinical rehabilitation*, vol. 35, no. 8, pp. 1151-1163.
- Kelly, H., Kennedy, F., Britton, H., McGuire, G. & Law, J. 2016, "Narrowing the 'digital divide'-facilitating access to computer technology to enhance the lives of those with aphasia: a feasibility study", *Aphasiology*, vol. 30, no. 2-3, pp. 133-163.

References

- Kelly, H., Masterson, L., O’Riordan, E. & Scott, P. 2022. Embracing Technology with Aphasia, Clinical Practice in Aphasia, 1st ed, J&R Press, Havant, UK.
- Kristo, I. & Mowll, J. 2022, "Voicing the perspectives of stroke survivors with aphasia: A rapid evidence review of post-stroke mental health, screening practices and lived experiences", Health & social care in the community, vol. 30, no. 4, pp. e898-e908.
- Menger, F., Morris, J. & Salis, C. 2020, "The impact of aphasia on Internet and technology use", Disability and rehabilitation, vol. 42, no. 21, pp. 2986-2996.
- Moss, B., Behn, N., Northcott, S., Monnelly, K., Marshall, J., Simpson, A., Thomas, S., McVicker, S., Goldsmith, K., Flood, C. & Hilari, K. 2022, "'Loneliness can also kill:' a qualitative exploration of outcomes and experiences of the SUPERB peer-befriending scheme for people with aphasia and their significant others", Disability and rehabilitation, vol. 44, no. 18, pp. 5015-5024.
- Northcott, S., Behn, N., Monnelly, K., Moss, B., Marshall, J., Thomas, S., Simpson, A., McVicker, S., Flood, C., Goldsmith, K. & Hilari, K. 2022, "'For them and for me': a qualitative exploration of peer befrienders' experiences supporting people with aphasia in the SUPERB feasibility trial", Disability and rehabilitation, vol. 44, no. 18, pp. 5025-5037.
- Ross, A., Winslow, I., Marchant, P. & Brumfitt, S. 2006, "Evaluation of communication, life participation and psychological well-being in chronic aphasia: The influence of group intervention", Aphasiology, vol. 20, no. 5, pp. 427-448.
- Tregea, S. & Brown, K. 2013, "What makes a successful peer-led aphasia support group?", Aphasiology, vol. 27, no. 5, pp. 581-598.