

October 22-23, 2018  
Athens, GreeceJo Ferrie et al., J Neurol Neurosci 2018, Volume: 9  
DOI: 10.21767/2171-6625-C3-013

## FINDING YOUR VOICE AND COPING WITH A DISTRESSING DIAGNOSIS

**Jo Ferrie<sup>1</sup> and P Rewaj<sup>2</sup>**<sup>1</sup>University of Glasgow, UK<sup>2</sup>University of Edinburgh, UK

Adults diagnosed with neurological conditions can face a time limited future with few treatment options. Their experience of receiving a diagnosis is distressing, even when given well. Distress is exacerbated by waiting times, notions of illegitimacy, progressive and frightening symptoms. This paper draws on a number of studies, using phenomenological qualitative interviews of over 65 families across Scotland (around 15% of families who live with MND in Scotland) in between 2011-2018. The research focusses on the social model of disability, to determine where barriers to being and doing are constructed for participants, and what can be done to remove them. It will reflect particularly on the added value to adults who face dysarthria: voice degradation through impairment (for example through Motor Neurone Disease (Also known as ALS/MND)), -by using a voice recording of their own voice, to generate speech. Many rely on augmentative and alternative communication (AAC) to express themselves. However, the use of voice output communication aids (VOCAs) while facilitating communication, cannot currently preserve the identity of the individual, as users are restricted to a limited set of impersonal synthetic voices. The Speak Unique project (Led by Dr Rewaj, Euan MacDonald Centre) has explored the value of producing a synthesized voice, built around a person's own voice, (after recording of a finite number of sentences chosen for their ability to be deconstructed phonetically, for those phonetic building blocks to be reconstructed to produce infinite sentences). This paper presents an evaluation of this work, amongst other studies into the lived experience of neurological conditions. A diagnosis of a neurological condition is sufficient to trigger a biographical disruption (Bury, 1982) but there are services that enable feelings of control and hope. The impact of recovering their own voice was significant for families, impacting positively on wellbeing, social identity and intimacy



### Biography

Jo Ferrie is a Sociologist based at the University of Glasgow. She has worked within the disability studies field for 15 years, examining the socially constructed barriers that turn impairment into disability, with the aim of removing these barriers. In 2013, she has published the largest global qualitative study of the experience of living with motor neurone disease. She joined the Euan MacDonald Centre as a PI in 2012, and worked on a number of projects with them. She has worked with MND Scotland and Anne Rowling Clinic to further understand the impact of neurological conditions on people and their families. She is also Director of Glasgow Q-Step (a £3 million Centre to create a step change in how social science graduates use and understand quantitative data) and is seconded to the University of Edinburgh as Deputy Director – Training of the Scottish Graduate School of Social Sciences..

[Jo.Ferrie@glasgow.ac.uk](mailto:Jo.Ferrie@glasgow.ac.uk)