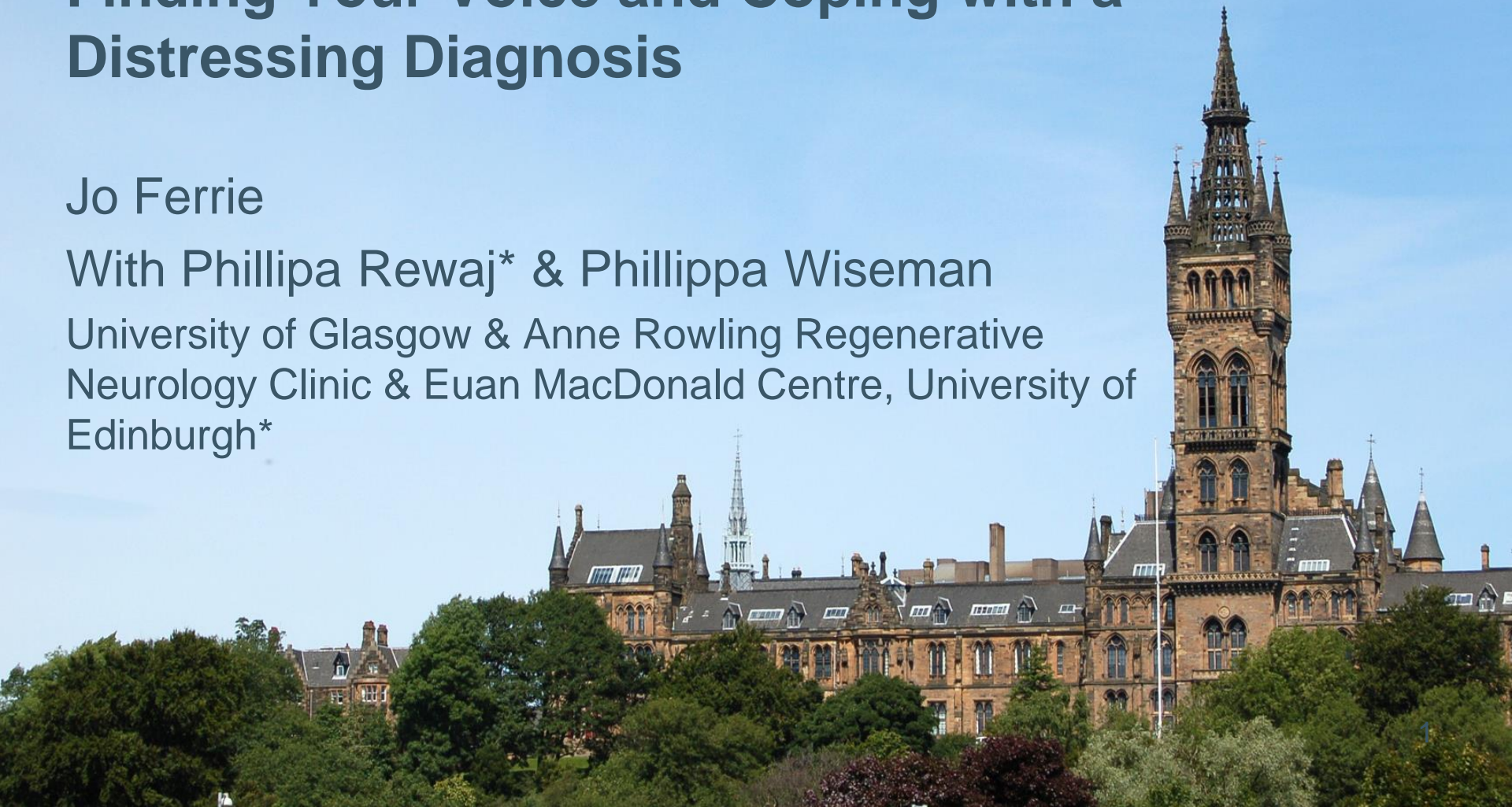**Finding Your Voice and Coping with a Distressing Diagnosis**

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- Overview of the project, and the research
- Theoretical framework and methodological approach
- Findings:
  - (re)gaining control
  - Identity & belonging
  - Identity & family
  - Identity & intimacy
  - Limitations of the 'product'
- Concluding Thoughts

- Loss of voice

- Context of conditions such as Parkinson's, dementia, MS and MND (ALS) – extends to stroke, some cancers etc.

- 50-80% MND patients experience dysarthria (Tomik & Guiloff, 2010)

- One of the most difficult symptoms to manage

- Use of Augmentative and Alternative Communication (AAC) together with Voice Output Communication Aids (VOCAs)

- To date, either
  - Your own voice, but very limited number of statements available
  - A synthetic voice, difficult to assimilate to (Murphy, 2004)

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- Speak Unique originated in computer science and the University of Edinburgh's School of Informatics (Veaux, Yamagishi, & King, 2011) .

- It became a clinical tool in partnership with Speech and Language Therapists, notably Dr. Phillipa Rewaj, now based at the Anne Rowling Regenerative Neurology Clinic (ARRNC).

- Speech is captured as early as possible, preferably before speech deterioration

- 100-400 sentences to capture phonemes and accent

- Any damage is 'repaired' by 'donor' voices, which can include family members: average voice model (AVM)

- Voices have been produced and given to families, but limitations with software have meant families have had limited, short-term access

- Early feedback (15 of 40 families trialed so far) has been positive.

- Similarity of synthetic to original voice: 3.3/5

- Intelligibility of their synthetic voice: 4.2/5

- The Speak Unique project is ran through 2016/17 to determine if VOCAs can be 'rolled out' to community SLT teams

- The evaluation occurred in 2017/18: 10 families plus 6 SLTs

- This paper focuses on the early engagement with the project from Lead SLTs, SLTs, and expert families.

- Social model – seek the views of experts (disappearing 'hidden voices'), and emphasizes social barrier to being and doing – at the expense of 'deficit of the body' approaches.
- Three main areas:
  - Paterson (2012) & Speech/time including Leder's (2010) dys-appearance
  - Blume (2012) & Technology
  - Shakespeare (2006) & Intimacy

  - Further: builds on earlier work
  - Ferrie, Robertson-Reick & Watson (2013) Living with MND
  - Ferrie & Watson (2015) MND & Corporeality
  - Ferrie & Wiseman (2016) MND & Waiting
  - Ferrie & Wiseman (2019 hopefully) MND, illness narrative and diagnosis

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- Phenomenological approach involved long interviews with families and SLTs

- Giving holistic (Fontana & Frey, 2008), thick and deep accounts, with subtle and nuanced meaning (Fine, 1994).

- Excellent approach for 'hearing hidden voices' particularly those who have experienced socio-political oppression which the social model argues is experienced by all disabled people (Abberley, 1992), as the approach can be emancipatory (Stone & Priestley, 1996) where participants are given time and scope to define the parameters of the interview – to talk about what is important to them.

- The phenomenological sociology approach (e.g. Allen-Colinson & Pavey, 2013) is particularly useful form of analysis as it examines the body as a site for understanding social barriers

- Embodiment, along with inter-subjectivity, temporality and spatiality is a central analytical pillar within the phenomenological research approach

- *Lieb* – the focus on the body, as it delivers experience, a subjective link between mind and body and world. This is understood as a dynamic relationship, and stands in contrast to:

- *Körper* – the body is an object, a medical model perspective

- Not to suggest that clinicians only see *Körper*, but in the short time they see patients, and given their role in diagnosing, treating, giving a prognosis, *Körper* traditionally dominates in the UK health system, and structured health systems globally.

- As receiving a diagnosis of MND is brutal, so giving it, is brutal.
- Christakis (1999) argued that medical professionals can delay diagnosis, and avoid giving a clear prognosis, particularly when the prognosis is bad and short-lived.
- The diagnosis is required to allow legitimation to the family
- And to access key services including occupational therapy, home adaptations, specialist equipment, social welfare and physiotherapy
- There is a clear detrimental consequence on families who wait for their diagnosis.
- While medical professionals may feel that '**waiting**' is '**hopeful**', most participants found that hoped turned to fear and frustration as their condition progressed (Ferrie & Wiseman, 2016)
- Thus in this pre-diagnosis stage, avoidance of the *Körper* or *corporeality* (Ferrie & Watson, 2015) is a disruption to the Lieb – to the dynamic interplay between the body and world required for biographical repair to begin

The illness narrative is:

'… a story the patient tells … to give coherence to the distinctive events re long-term course of suffering. The plot lines, core metaphors and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways' Kleinman (1988:49)

So, if a person with MND has not been diagnosed, or given a clear prognosis, and they are waiting in excess of 6 months for (often unexplained) tests to be completed

And with no narrative from medical professionals to explain the wait, or 'the pause'

No narrative that they can then adopt and adapt into an illness narrative and it is argued elsewhere (Ferrie & Wiseman 2016; Ferrie & Wiseman, forthcoming) that the lack of narrative impacts on biographical repair (Bury, 1982).

But what if losing your voice is a major symptom? Diagnosis may come after your ability to 'talk through' acceptance, has diminished.

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- The more I listened to [my personalized voice] the more I think it's ok. In the beginning, I thought it was a bit synthetic, but then when we started playing about with it … it started to get a bit better.

  – Carole

- This is about giving them back a bit of control. It's about giving them a choice. Whether they want our voice or a different voice, it's something that they can choose, they can listen to lots of options and they can decide what they sound like. I that's crucial. It gives them back a bit of dignity. Instead of sending them away with that awful clinical voice.

  – Lead SLT

- Having control is a strong theme in qualitative MND literature, where medical advice that reduces the body to medicalized object – *Körper* – is resisted.

- This is one field where participants felt they did have control, they were actively 'fighting'

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- I mean, you are your voice, aren't you? When I was young, we lived in [suburban area of city associated with socio-economic deprivation] … there was still a bit of a stigma attached to it even then, and my Mum sent me to elocution lessons to make sure I didn't start to talk like everybody else that was round about us … So I think even now when I'm speaking, I think back to what she sacrificed to let me do that.
  - Carole

- I didn't appreciate how important [my voice] was, until it started to change … it was no longer the faithful friend that it had been.
  - Michael

- I don't even like my [northern Irish] accent but if I had to talk through a communication aid with an English, Scottish, or Welsh accent, I'd be really upset, cos it's mine. I have a recognizable accent. It's more important to hold onto it.
  - Ann

- Here the importance of Lieb appears, the body, and by extension the voice, is representative and communicative of our historical legacy. Families talked of socio-economic status, or moving around the country, or nuanced differences between types of very localized accent: of being captured by their voices, and this requiring preservation in order to maintain their identity & personhood.

- Lieb and voice, were not just understood as 'place in the world' but also more intimately, as a connection to loved ones.

- Voice is such an important part of identity. It's not something I thought about, until I faced it. Do you ever phone your Mum and you say 'it's me' and she knows? From that one thing.
  - Bill

- What I said was 'minimise the sound of my brother's voice, I don't want my kids to remember me by my brother'. When they hear him, I don't want them to think of me.
  - Alan

- Other's ask to use their siblings.

- Intimacy continues to be something of a taboo in disability studies, with a few exceptions (e.g. Shakespeare, 2006)

- It should be considered in order to fully understand how Lieb is 'threatened' by loss of voice

- That's the hardest thing to deal with. To deal with not hearing that voice anymore … It was lovely, very gravelly. I've always been attracted to his voice and it's hard not hearing it. It's sad.
  - Pam

- The synthetic features of our voices do masque the individuality of some voices. We can't capture it all.
  - Lead SLT

- Where someone has lost their voice through a degenerative condition, it [the personalised voice] has got to create a more powerful link if it sounds something like the person. Because the emotional bond you have swith someone, you know, is their voice. It feels different to somebody else's voice.

- JF: That's right, it feels different, it doesn't just sound different.

- It feels different. It's partly pattern recognition. And it's partly an emotional response to the sound.
  - Micheal

- A fairly existential question emerges: who is the voice for?

- For the person with dysarthria, the voice is their expression of Lieb – it is their device to connect, dynamically, their body with the social world. For maximum preservation of Lieb, the voice created should sound like the voice in their head

- For their families, a different voice is required. To maintain their inter-subjective bonds optimally, the voice should sound like the one they hear

- Both are compromised by the synthetic properties of the voice, by it's lack of intonation and volume modulation.

- Paradox: wanting your own voice when you don't like how you sound

- I remember playing the voice for someone and they cringed and I thought, 'you think that sounds like you'
  - Lead SLT

- It ranges, so some people are like 'oh yes! I can hear myself!' and some people are like 'oh that sounds awful' and that's really the link to personality, and self-esteem and self confidence'
  - Chris, SLT

- Where voices have degraded, there's a risk that people are already withdrawing. So one came in with her Mum and when I asked her what she thought, her Mum would listen, and then repeat. Except she'd start by saying what she thought, and then told us what her daughter had said.
  - SLT

- Still a small study (respectable size in qualitative research). Plan to revisit participants to see how they've integrated their synthesised voice in to activities of being and doing.

- Critical voices are recorded as early as possible, probably before dysarthria is experienced. For those who have sudden vocal loss, perhaps through stroke, there is always going be a barrier.

- More voices banked = more likely to find a match.

- The value of this innovation to families is massive, but still fraught with emotional challenges
  - Personal – accepting a 'new' voice
  - Social – maintaining access to it
- In terms of well-being, the more a voice can be preserved and used, the better
- It seems evident that the voice is integral to Lieb and therefore useful in resisting the over-medicalization and reductionist power of *Körper*

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Thank you.

Time for questions?