



# Stuart McNaughton

- Diagnosed profoundly deaf aged 4, HA from 5
- Mainstream schooled
- Bilateral cochlear implants (L: 2000; R: 2013)
- 12 years in Advocacy role with industry
- Qualified Psychotherapist [MBACP] / Teacher
- Currently in Private Practice (Feb 2019 >)
- Started The Cochlear Implant Coach (Feb '22)
- Launched the REDJ Programme (Apr '22)
- Currently supporting 2 adults and 6 families

# The Missing Piece of the [CI] Jigsaw



**Stuart McNaughton**

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SUPPORTING FAMILIES BEFORE, DURING, AFTER AND BEYOND

Instagram



①

What we already knew

②

What we know  
*(from this survey so far)*

③

What I see in my work

# Part 1: What we already knew....

- Hearing loss if unaddressed can negatively impact many aspects of life.....  
mental health.<sup>1</sup>
- A failure to act [by 2050 with the predicted extra burden of hearing loss in society] will be costly in terms of health and well-being of those affected.<sup>1</sup>
- 89% reported significant social and personal problems as most common impacts of hearing loss.<sup>2</sup>
- 58% reported that their relationship had suffered as a result of their hearing loss with many reporting their partners had left them.<sup>2</sup>
- General concerns - and sometimes fear - of cochlear implantation.

<sup>1</sup> World Report on Hearing, WHO, 2020

<sup>2</sup> The Impact of Hearing Loss on Mental Wellbeing & Lifestyle, ClearLiving, 2020

# Shifting focus to Part 2: What we know (from the survey)

## Cochlear Implants in Deaf and Deafened Adults: A Global Consultation on Lifelong Aftercare

Connie Mayer Sue Archbold Leo De Raeve  
Brian Lamb Ruth Warick Darja Pajk Imran Mulla  
HEAL, COMO, 2022



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## Rationale

- Current global guidelines (Buchman et al, 2020) do not address the lifelong care necessary for both rehabilitation and technical support to maximise benefits of cochlear implantation
- Goal to increase understanding of the requirements of adults who receive CIs from the perspective of the user
- No previous investigations focused on the user view
- Share knowledge globally with professionals, policy makers, funders, user and advocacy groups to improve practice and provision

## How often did you receive rehabilitation or therapy services?

Year of Implant Use	Most Common Number of Sessions	Range
1 <sup>st</sup> year	<b>12+ ....but...</b>	0 to 12+
2 <sup>nd</sup> – 5 <sup>th</sup> year	0	0 to 12+
After 5 <sup>th</sup> year	0	0 to 12 +

But .... second most common number of sessions was 0!

## Did you feel the service you received was sufficient?

Nature of Service	Yes	No
Fitting, Mapping, Programming	86%	14%
Rehabilitation, Therapy	68%	<b>32%</b>

## Which services are most important?

As reported in order of importance

Regular Programming, Fitting, Mapping

Funding for Ongoing Support

Access to Repairs

Rehabilitation

Access to Technology Support

Family Support

Peer Group Support

## Who funds the services?

Service	Public/Govt	Private Health	Charity/NGO	Personal
1st Implant	62%	35%	2%	9%
2nd Implant	48%	40%	1%	14%
Mapping	67%	24%	3%	10%
Rehabilitation	63%	20%	3%	16%
Repairs	50%	23%	2%	<b>29%</b>
Spare Parts	48%	21%	2%	<b>36%</b>
Replace Processor	39%	26%	1%	<b>26%</b>
Upgrade Processor	55%	31%	1%	16%
Streamers, Accessories	35%	16%	1%	<b>54%</b>
Batteries disposable	38%	13%	2%	<b>49%</b>
Batteries rechargeable	44%	20%	1%	<b>41%</b>

# Part 3: What I am seeing in my CI work

Desperation

Worry

Sleep deprivation

Humiliation

Burnout

Failure

**Suicidal**

Exasperation

**Shame**

*Low self esteem*

Confusion

Depression

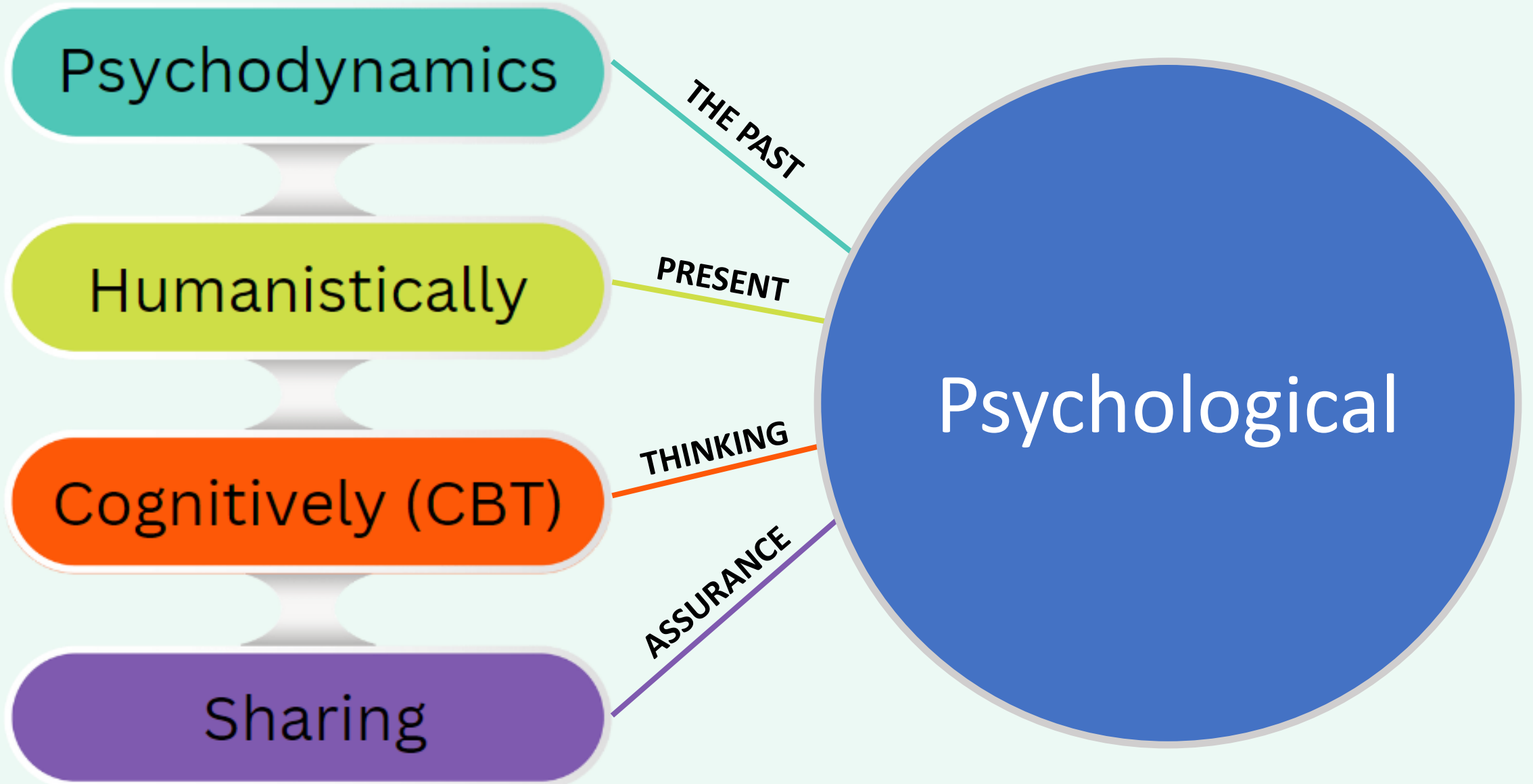
Withdrawal

Guilt

Fear

Denial

**Frustration**







## THE QUESTION REMAINS:

Who is supporting the families before, during, after and beyond?

### 1. More specialized support

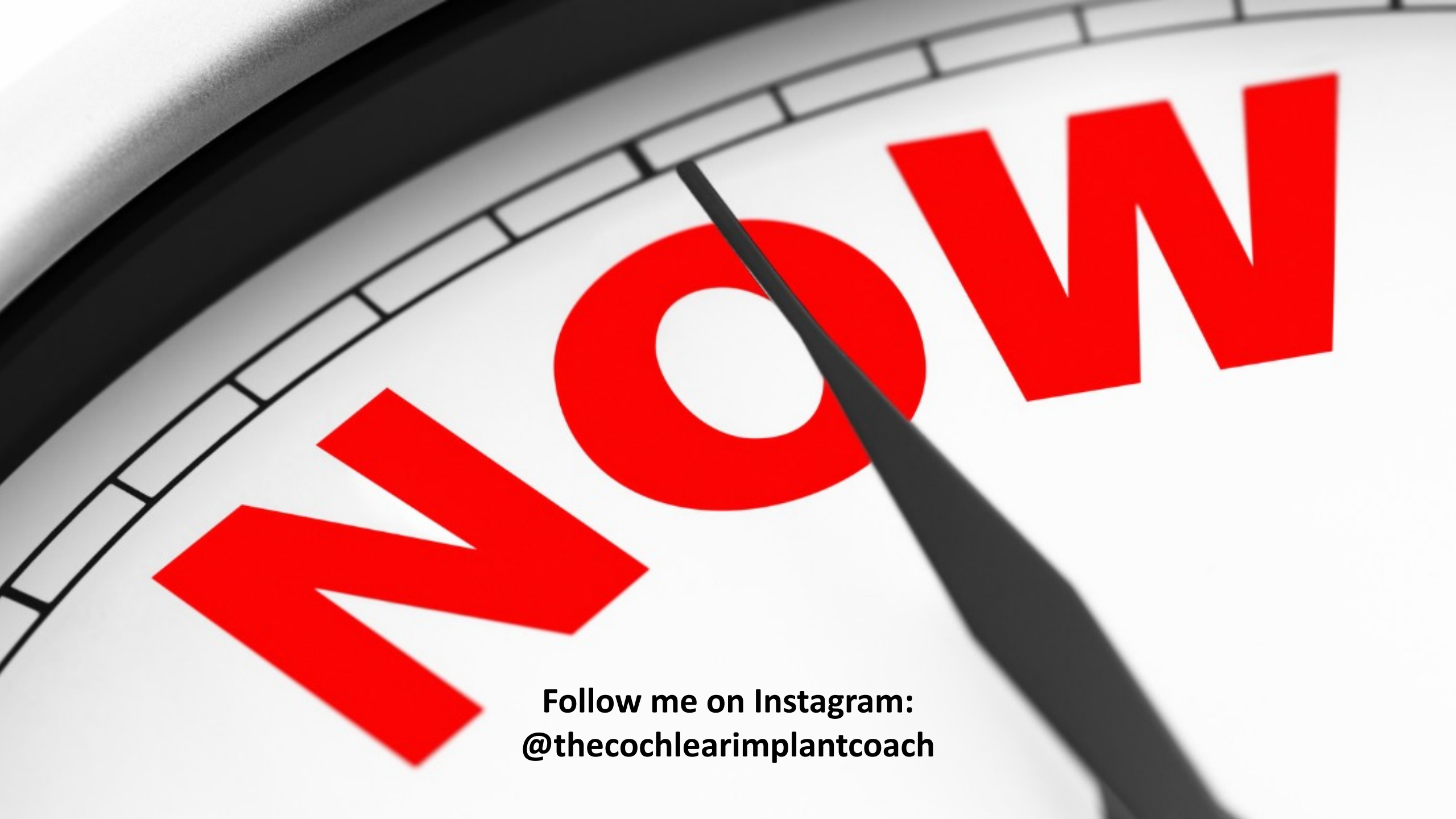
- CI field is mature in terms of development, but not support
- Result: 'Implant them and let them get on with it' mentality

### 2. Dedicated mental health therapists /specialists

- We know that the number of users is too large for CI Centres to manage
- qualified to deal with a range of themes
- Mentors and ambassadors play a vital role, but be aware of the emotional demands

### 3. Is this the opportunity to develop some of the CIICA group?

- Our combined lived experience + some training = gamechanger



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