

Telehealth Skills ECHO – Rachel’s perspective

Hello Everyone

Thank you for the opportunity to share my experience with Telehealth.

My name is Rachel. I live with severe Myalgic Encephalomyelitis or ME. It is a neurological disease. I assume you haven’t heard about it because it’s a neglected health condition and disability. I have founded ME Group Australia, an Australian charity to improve health for people with ME. (Some of my team calls me a crazy one with respect.)

Today happens to be the Severe ME Understanding & Remembrance Day. It’s affectionately known as Severe ME Day. This is the day to bring public attention to the disease and people who are currently living with it or those who are no longer with us.

I’m humbled to be able to mention Severe ME Day today with healthcare professionals who are interested in providing Telehealth service. It is an enabler of healthcare for us. I would love to have any opportunity to collaborate and create the way to care for the neglected group of Health Consumers.

I’m going to share my experience and thoughts on Telehealth.

The opportunities and potential with the model of care is massive. So, please use my talk as an ice breaker for a long-lasting conversation.

Telehealth is the Model of Care in Need

It is not only for remote and rural health professionals and their patients. But also for those who are homebound in urban communities and cannot access healthcare.

By limiting the service recipients to remote and rural, the opportunities for real innovation are not recognised. People who are homebound in urban communities are in desperate need for virtual healthcare. So, please include us to bring innovative ideas and possibilities to the discussion table.

My Telehealth Experience

It got better once I passed the initial uncertainty and nervousness.

GP

- I always had technical issues. But we always managed to have meaningful consultation.

Psychologist

Life with severe and disabling disease in isolation is never easy. I have episodes of trauma and distress that never seems to go away.

- Without access to telehealth service, I may have had serious nervous breakdowns with serious consequences.

Neurological Physiotherapist

As part of NDIS Capacity Building fund, I can access to allied health service.

I have an amazing neurological physiotherapist. She usually visits me for therapy and evidence gathering discussions for reports and assessment. She even co-created in-depth individualised support worker training module with support and care plans.

Nothing is impossible for her when it comes to my care. She's got an innovative mind like me. (But I say she is the smart one.)

- With one of Telehealth services with her, she went to a supplier's store and did equipment demonstration and had Q & A session with the supplier.
- It was a very uplifting experience. Seeing equals thousands of words. Interacting with the supplier and seeing his dedication to give me all the information I need was also a positive human interaction.

I prefer video than telephone

Video can overcome invisible impairments, such as:

- Slow information processing with cognitive challenge,
- Aphasia that gives me extra challenges to find the right word. For example, I say “right” when I was thinking “left”. Figure out the best way to articulately explain what I want to say on the spot, is very challenging.
- Dysphonia – challenges with low voice volume. So that my voice on the phone is just some sound or noise to you. No words... Usually they get frustrated and agitated, and it caused distress to me.
- Physical and cognitive exhaustion,
 - My speech starts slur, or I cannot talk anymore. It comes with muscle exhaustion. And my voice gets quieter without me noticing. Usually on the phone, other party has no idea about my extreme challenge at this stage.
 - Brain crash that I can no longer process and retain information. It’s like a thick metal barrier around my brain. So frustrating!

Video can minimise misunderstandings:

- Thanks to facial expression and hand gestures
- Effective communication is often not verbal. Posture, facial expression, hand gesture. → And you cannot role your eyes when I’m watching. *grin*
- It’s easier to develop rapport.
- I would like to acknowledge that different disability comes with different preferences and challenges. Be mindful that everyone has different communication needs and style.

Video gives an opportunity to form effective partnership between healthcare professionals and patients = Value

- Good team relationship between healthcare professional and their patient is the key for meaningful long term health benefit. Video helps to develop the trust easier. (The secret skill is smile.)
- Teamwork can make unforeseen technical problem less distressful.
 - I’m lucky to have a long-term GP whom we have good rapport, trust and mutual understanding of my complex health challenges. And there is no stigma and gaslight from him.
 - With this trust and comfort, I managed to have telephone consultation when the video access just didn’t work for us. It was still effective for me.

If you have questions about Myalgic Encephalomyelitis (ME) here is some information (see below). Please feel free to reach out to me. I may be slow in responding, but I will get back to you with relevant information possible.

ME International Consensus Primer for Medical Practitioners (ME-ICP)

<https://tinyurl.com/meicp2012>

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