

# HUNTINGTON'S DISEASE EDUCATIONAL RESOURCE



**Super Rehab Sydney Quality Improvement Project:** Led by Trisha Purvis (Physiotherapist)

## HUNTINGTON'S DISEASE AND EDUCATION

Huntington's Disease is a progressive genetic neurological condition, resulting in involuntary movements, changes in mood, judgement and cognition and impaired physical function.

Clinical guidelines regarding physical therapy for Huntington's Disease recommend care plans to include education for individuals with the condition; as well as families and care-givers<sup>(1)</sup>.

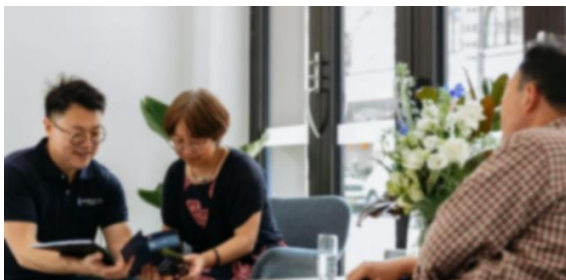
## WHAT IS THE GAP?

Physiotherapists often utilize patient education as a therapy modality when treating clients with Huntington's Disease. Currently, Super Rehab Sydney does not have an education resource for their physiotherapists to utilize in facilitating client education.

## HOW WILL THIS HELP?

This project aims to develop a resource that:

- Assists physiotherapists in efficiently providing client-orientated collated information regarding the condition.
- Facilitate the education component of therapy by allowing physiotherapists to deliver education to clients in client-friendly language.
- Helps clients/carers/family to develop a stronger understanding of the condition with a resource they can refer to (especially clients with poor memory who find retaining information difficult).



## METHODOLOGY

1. Physiotherapists will offer clients with Huntington's Disease and their family/carers an opportunity to participate.
2. A pre-survey will be conducted by physiotherapists with clients and their families/carers OR by the clients and their families/carers independently, as appropriate, using a link.
3. A resource will be developed based upon pre-survey findings and distributed by the physiotherapists.
4. A post-survey will be conducted by physiotherapists with clients and their families/carers OR by the clients and their families/carers independently as appropriate using a link.
5. An evaluation of the project based upon the post-survey to refine the resource.

## OUTCOMES

A pre-survey will be conducted to identify areas clients and their family/carers are interested in improving their knowledge about regarding Huntington's Disease. This will assist in the design of the resource to be client orientated.

A post-survey to gain feedback on what was beneficial and what could be improved for future for the education resource.

## FUTURE IMPLICATIONS

Once the resource has been evaluated and refined, the resource will be made available for physiotherapists to provide as a print-out or emailed PDF for the education component of their therapy.

A similar methodology may be applied for future quality improvement projects for other common conditions often presented at Super Rehab Sydney; for example, Multiple Sclerosis, Parkinson's Disease, Falls Prevention.

(1) Quinn, L., Kegelmeyer, D., Kloos, A., Rao, A. K., Busse, M., & Fritz, N. E. (2020). Clinical recommendations to guide physical therapy practice for Huntington disease. *Neurology*, 94(5), 217-228.