

How questions posed by clients have informed, impacted and evolved an Occupational Therapy service from inception to now, 5 years on

Renae Knight

Chronic Disease Service Brisbane South

Metro South Health Service

Queensland Health

Background

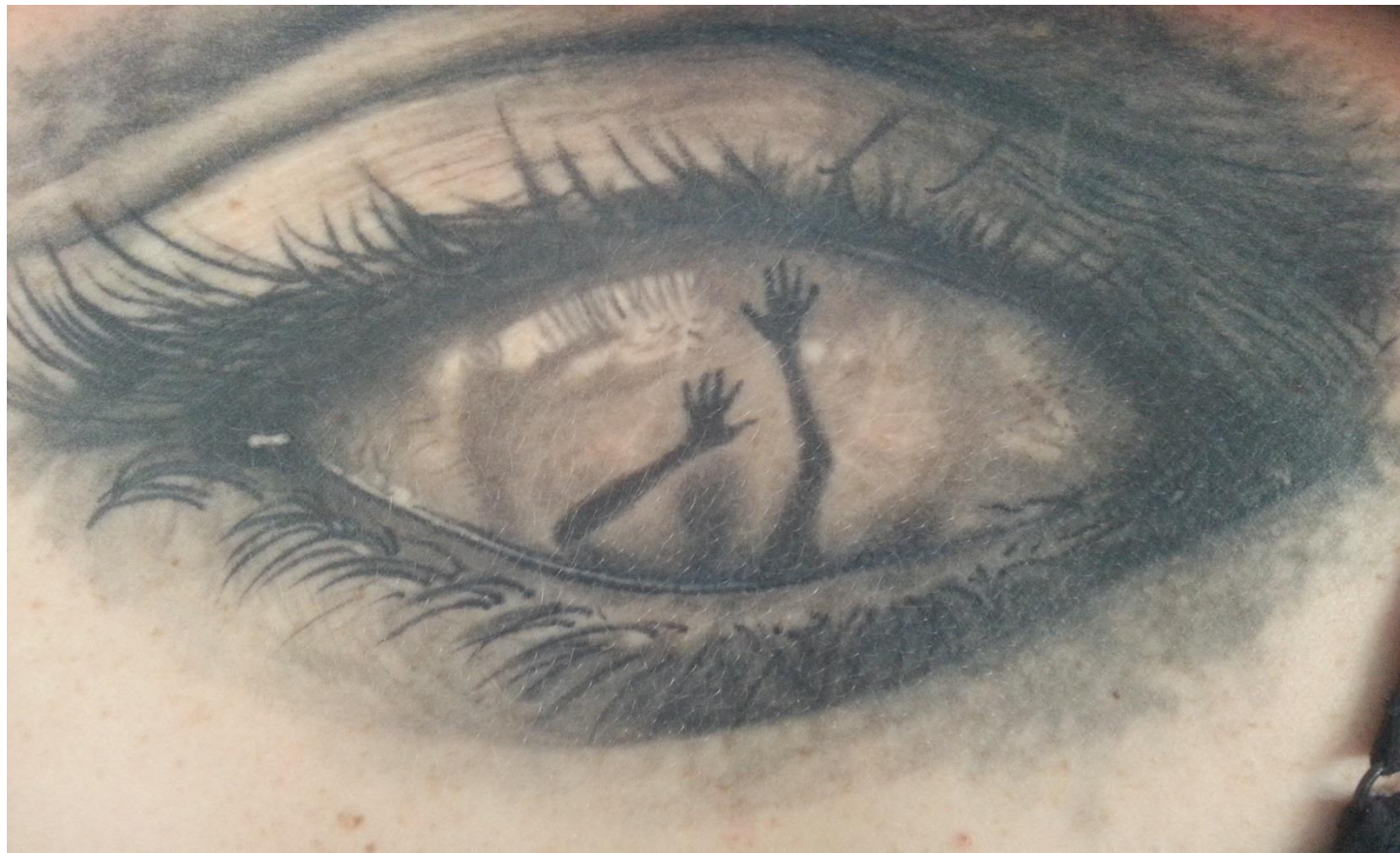
- Phenotypes
- OT role
- Level of distress
- Planetree
- Vignettes
- Take home message



Phenotypes

- Global MND/ALS
- Familial MND
- Flail Limb Variant/Progressive muscular atrophy
- Primary Lateral Sclerosis (PLS)
- Progressive Bulbar Palsy

<http://www.mndcare.net.au/Overview/MNDcare-approach/Information-and-discussion/ALS-MND-conference-presentations/8th-National-MND-Conference,-Melbourne-12-September/Solomon-Sarah-OT-and-MND-Poster-2015-final.aspx>



OT role



- Reduction in engagement in activities
- Doing = Living Vrklijan B.H., Miller-Polgar J
- Occupational deprivation Whiteford, 2000

Level of distress

- Most prevalent symptoms
 - Pain, nausea, fatigue, weight loss and poor appetite
- Most severe symptoms
 - Difficulties with sitting, standing and mobility

Planetree Philosophy of Care



- Care giving is best achieved through kindness and compassion
- Safe, accessible, high quality care is fundamental to person-centred care
- Access to understandable health information can empower individuals to participate in their health care
- It is essential to give individuals the opportunity to make personal choices related to their care
- Illness can be a transformational experience for patients, family and caregivers

Vignette:

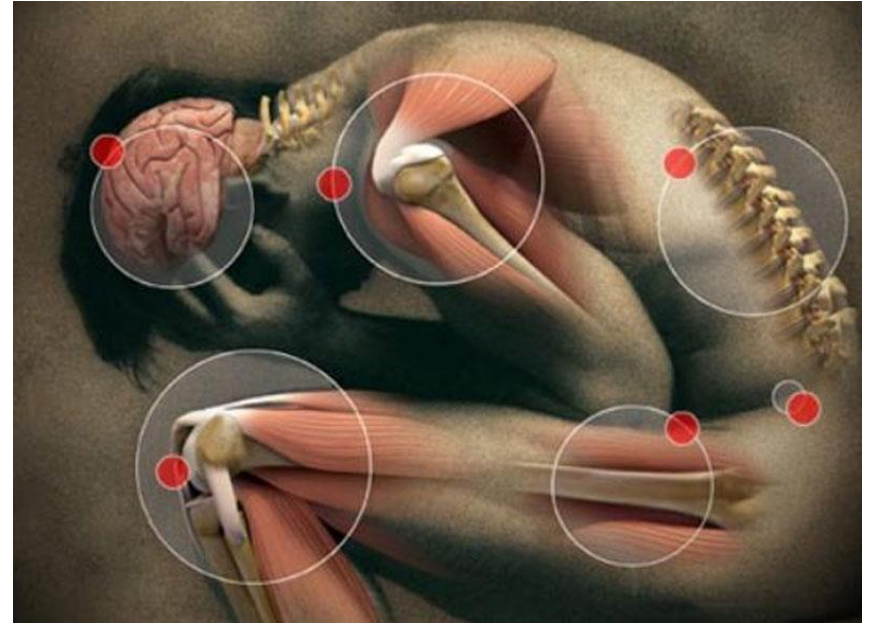


<http://hugme.co.nz>

“I was diagnosed when my baby was 4 weeks old, I still want to be an active engaged parent, how can we facilitate this?”

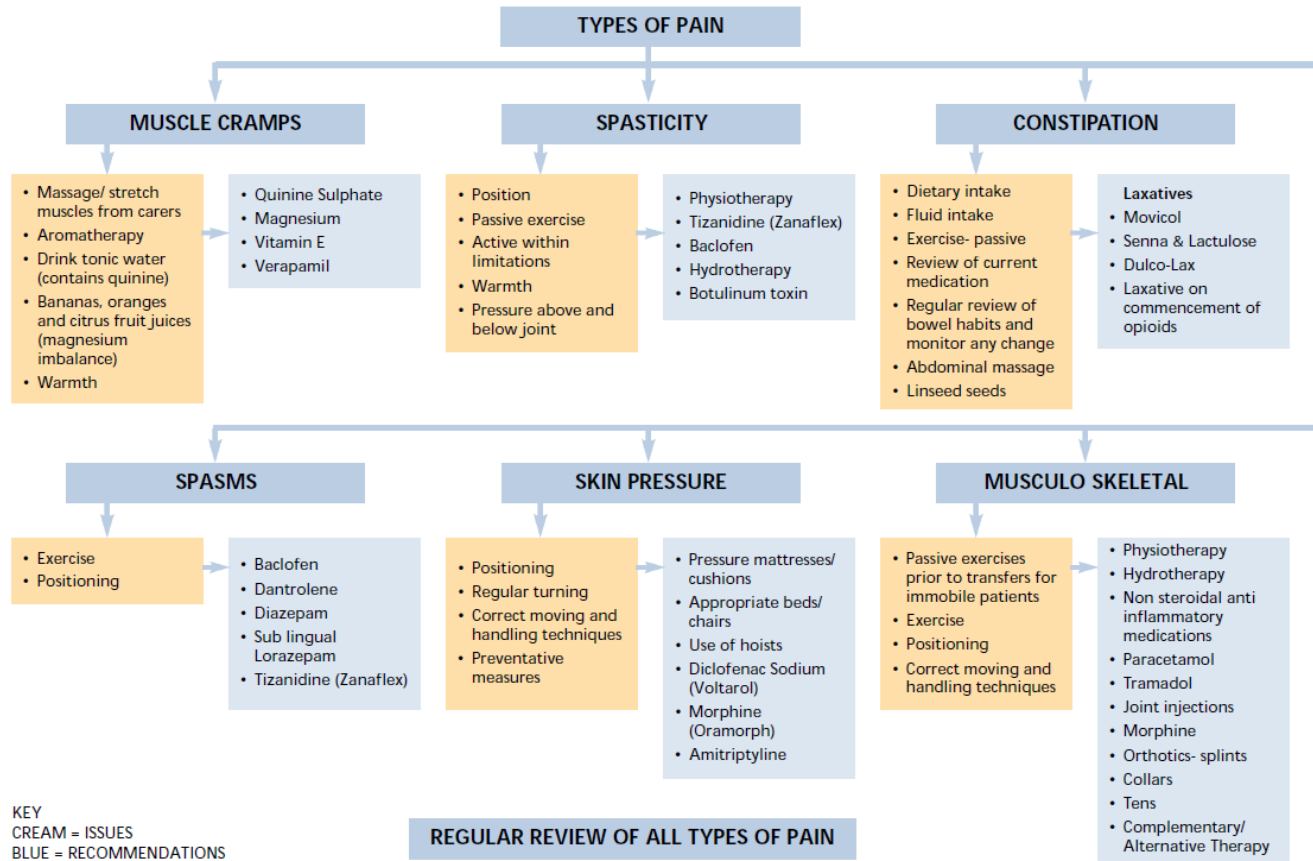
Vignette:

“The pain is at its worst at 2 to 3 am in the morning, when it is dark and quiet, surely there must be another mattress that will be more comfortable?”



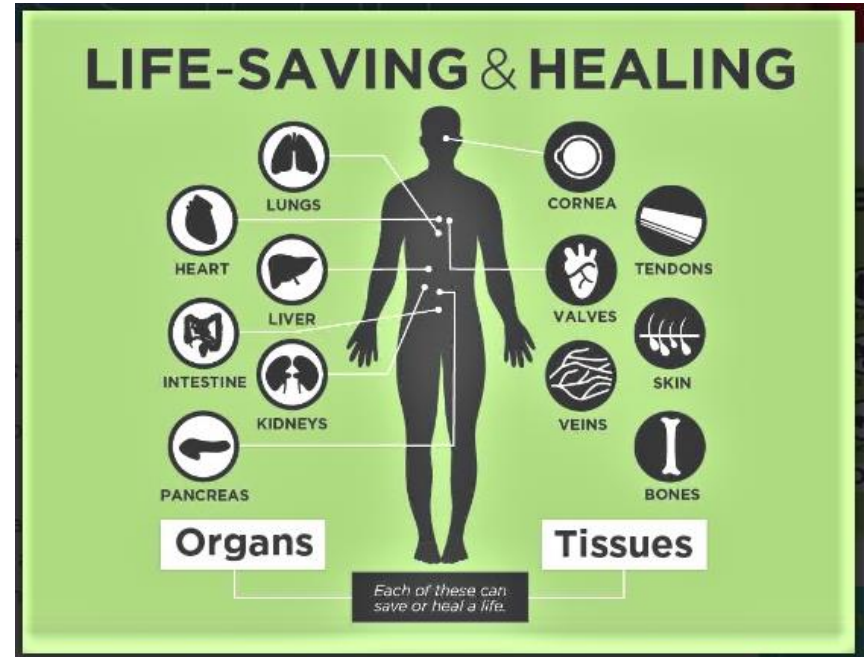
<http://www.refiningtruth.com/wp-content/uploads/2014/02/pain.jpg>

Motor Neurone Disease Pain Pathway - Physical Pain



Vignette:

“MND is robbing me of everything, and even when I am dead, it will rob me of the chance to donate my organs. This was something I had always wanted to do. Yes, I may have lived hard and fast for my 38 years and did smoke for a while, but there would still be a lot more years left in them.”



Vignette:



<https://www.microsoft.com/en-us/research/wp-content/uploads/2016/02/hackathon-eye-gaze-wheelchair-1.png>

“What constitutes communication, it is just voice replication, or it is now broader to include email, SMS text, twitter, Facebook?”



<http://linkassistive.com/wp-content/uploads/2012/07/eyeMobile-slideshow-1.jpg>

Vignette:

“Yes I am happy to accept equipment from MNDA, like a recliner, wheelchair or mobile shower chair, but not a hospital bed. Why is this?”



Vignette:

“So when I lose strength in my ankles, we can brace/support them, but what do we do when I lose strength in my knees?”



<https://www.alliedmedical.co.nz/media/2019/al28415001x-allard-navigate-4-foot-unlabelled.jpg.product.ashx>

You can and do make a difference for people with MND

An expert multidisciplinary team
has the greatest effect on
improving survival, better than
any drug, machine or surgical
intervention available



Rooney, J., Byrne, S., Heverin, M., et al. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg Psychiatry* 2015; 86: 496-501

