

# Motoring On

– improving QOL  
for MND patients  
& caregivers



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# Palliative Care Gym Program



Continuing the Mission of the Sisters of the Little Company of Mary

# MND Occasions of service

## Jan – March

2012 : 2

2013 : 87

2014 : 172

2.8 MND patients/ session



# Observations

- Seeking opportunities for physical interventions and participation
- Gym was a setting for meeting education & psychosocial needs.

Unsustainable physical & emotional load



# Alternative model of care

## Patient & care giver survey

- 7/30 (23%) replied
- 6/7 (86%) seeking
  - shared illness experience
  - increased education
  - increased psychological support

- a) Share Space –  
meditation, massage,  
education & sharing
- a) Aquatic Physiotherapy  
Program

# Results: Share Space

2014

4 sessions held

Average attendance:

12 patients & 15 caregivers



**Staff valued:**

- Opportunity to meet education & complex needs in one setting
- Team approach

# Evaluation :Share Space

## Patients valued:

- Shared illness experience
- Access to MDT
- Seeing caregivers receive attention
- Enjoyed massage & meditation

## Caregivers valued:

- Education
- Felt supported and less isolated
- Enjoyed socialisation, massage & meditation

***“Good to talk and learn from the experience of others”***



# Results: Aquatic Physiotherapy

## Snapshot of 4 patients over 6 weeks

- 2 therapists
- Caregiver participation



## **Caregivers:**

- Not a burden to be involved
- Personal benefits
- Relished patients' joy

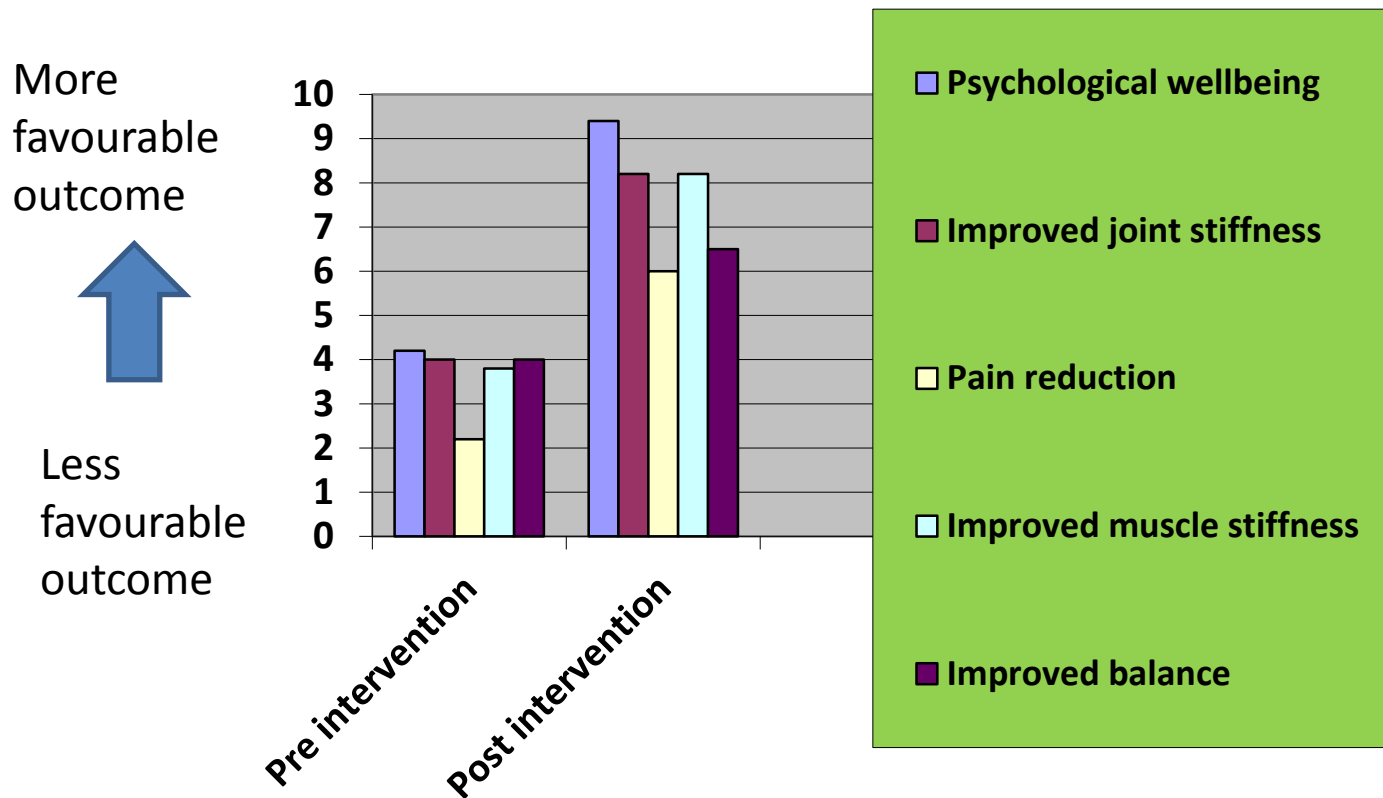
## **Patients:**

- Freedom of movement
- Reconditioning



# Results: Aquatic Physiotherapy

## Patient Reported Outcome Measures



# Conclusion

Transforming the therapeutic environment created an integrated model of care to address the diverse and complex needs of MND patients & caregivers within existing resources.



**“Let me start by saying it's no ones fault,  
but MND can be very lonely. In a full room of people  
you can be lonely...”**

## **Lonely**

Peter

(Via Eye gaze:27/07/15)

**Your family and friends are there for you but you are  
not for them. Slowly being stripped of your ability to  
interact, the loneliness starts to set in. When I say you  
are not there for them, you are there filling space in the  
room, but it, or you become a conversational Black  
Hole...**

**You cut a lonely figure, and you are.”**

