

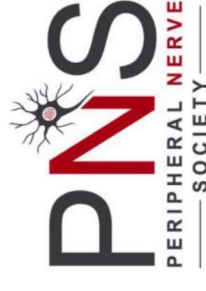


## Neuro-muscular Bridges: outcome of the development phase of a self-management programme for people with neuromuscular diseases

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# Background



Many NMDs are lifelong conditions, and the varied nature of NMDs often leads to considerable physical disability

Strategies to manage the individual and societal impact of chronic diseases includes increased emphasis on the promotion of adaptive behaviour change through strategies such as collaborative self-management

Bridges Self-Management is a programme consisting of defined strategies delivered by trained clinical staff, supported by self-management tools

## **Project aim:**

Co-design a unique digital and paper-based self-management support package for people living with NMD and their families, using Bridges methodology

# Methods

## Discovery stage:

Interviews with people living with NMDs and their families informed the team of digital preferences and content for the resources



14 semi-structured interviews with patients & family



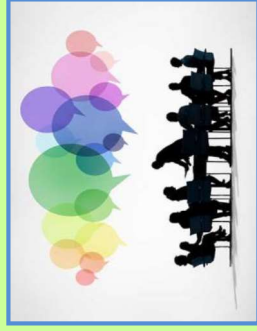
6 semi-structured interviews with health professionals



Patient and family survey

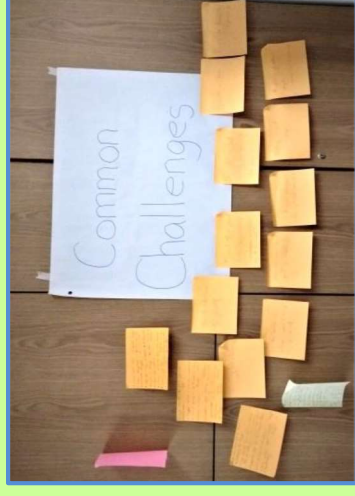


Scoping of other digital resources



## Co-design of content:

Content was developed using creative writing workshops with people with NMDs, individual interviews and Q&A videos with health professionals. Content selected and edited by people with NMDs

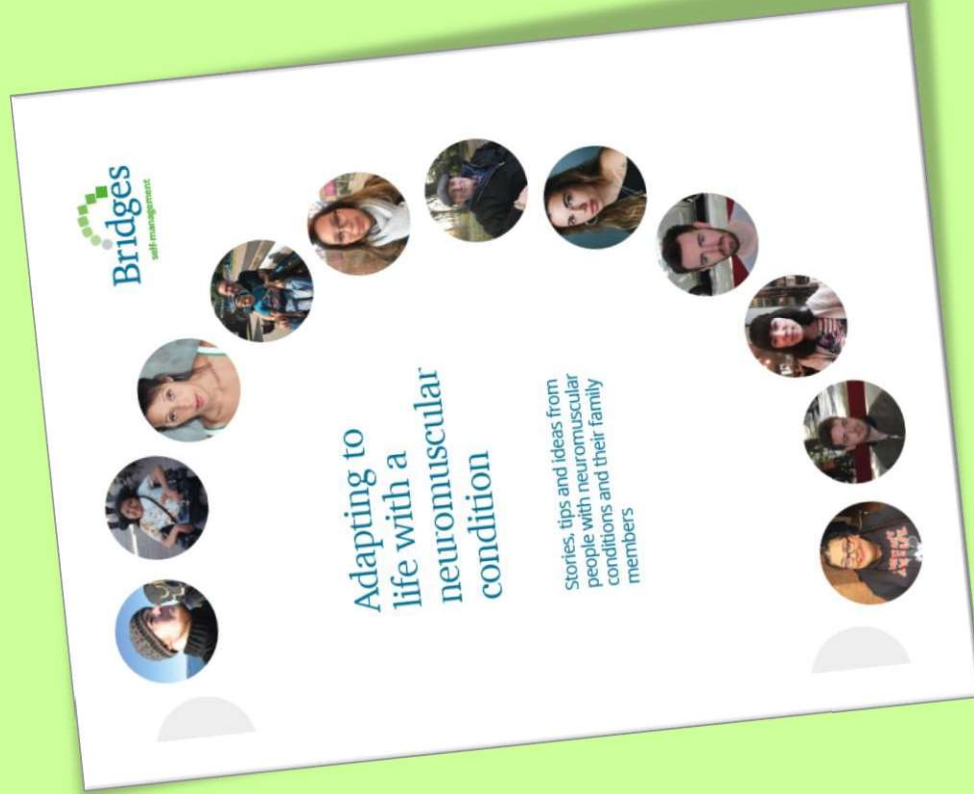


## User testing:


Panel review of book and initial usability/accessibility testing of digital tools with people with NMDs

## NM Bridges book

- Patient & family stories
- Advice
- Reflection & planning tools



**Richard's example 1**



**Richard's example 2**

**Things to do:**

Go to a local pub/shop that doesn't have a ramp

*Step 1: Friendly conversation with the owner, book table for a specific date, let them know you definitely need it for then.*

*Step 2: (if no ramp) Remind owner they have a legal obligation to provide access, send an email so I have evidence.*

*Step 3: (if no ramp) Email a discrimination complaint, cite the equality act, say they have 14 days to respond.*

*Step 4: (if no ramp) Wait 14 days, send email to say they are in violation of the equality act and you can now sue them.*

*Step 5: (if no ramp) Offer one last chance before legal action, no matter how reasonable you are it usually comes to this.*

*Step 6: (Ramp hopefully installed now but if not) Contact law firm, give them the emails.*

**Things to do:**

Increase mental resilience to better deal with a difficult situation

*Step 1: Reach out to family and friends: Hosting things at my house like board games.*

*Step 2: Do as much exercise as you can do, no matter how little, especially breathing exercises.*

*Step 3: Read as much as you can about resilience, the Happiness trap is a good start.*

*Step 4: Volunteer and find a project that is meaningful to you for a sense of purpose.*

*Step 5: Try to focus on the present moment, don't get lost in memory or hopes for the future.*

*Step 6: Try to make sure you are getting nutritious food and good sleep.*

Action Plan



Home Patient stories Family stories Family advice Professional advice Useful links


**Adapting to life with a neuromuscular condition**

## NM Bridges Website


- Stories, videos & audio
- Top tips from people with NMD & families
- Q&A with health professionals
- Sign-posting to helpful resources

### Patient stories

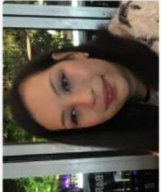
Read and listen to stories from people who live with different neuromuscular conditions. They follow the path from their initial reactions after diagnosis, to adapting their lives, and moving forward with new dreams and ambitions.



**Tatum, 25 years old**




**Andrew**




**Victoria**

### Family stories




**Mother - Hazel**  
My son Will lives with Becker Muscular Dystrophy.

[READ STORY >](#)



**Husband - Harry**  
My wife Hannah lives with Congenital Muscular Dystrophy (SEPN1).

[READ STORY >](#)



**Sister - Annabelle**  
My younger sister Donna was diagnosed with Myotonic Dystrophy Type 1, in 2015.

[READ STORY >](#)



**Question 3: What are Top Tips for managing fatigue?**

[WATCH A VIDEO](#)


Rebecca Jeffcott, Occupational Therapist at the National Hospital for Neurology & Neurosurgery (UCLH), talks about the following six areas that are critical to manage fatigue: Sleep, rest, diet, exercise, thoughts and mood, and managing activity.



**Question 9: What type of shoes should I wear with splints?**

[WATCH A VIDEO](#)

Andrew Frame, Orthotist at the National Hospital for Neurology & Neurosurgery (UCLH), explains that the type of shoes to wear can be best recommended by your therapist depending on which type of splints

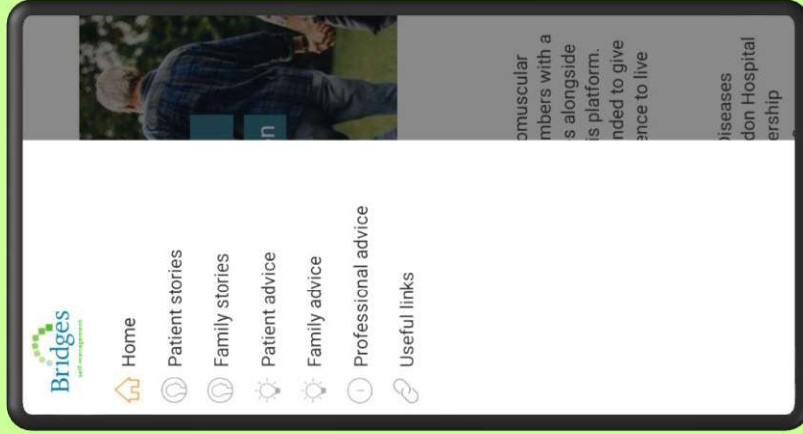


**Question 8: What are Top Tips for exercising?**

[WATCH A VIDEO](#)

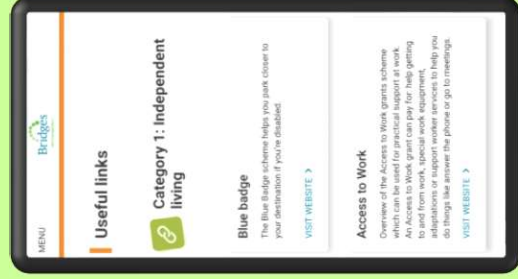
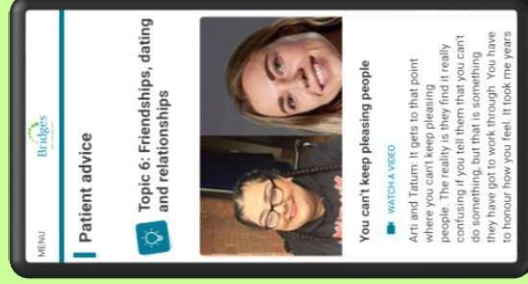
Charlotte Massey, Physiotherapist at the National Hospital for Neurology & Neurosurgery (UCLH), shares her Top Tips for exercising with a neuromuscular condition including how hard you should be working and precautions.

[READ TRANSCRIPT OF THE VIDEO >](#)



## NMD Support app

- Same content as website
- iOS and Android compatible



# Next steps

## Development of training:

- Co-design of health professional training to deliver self-management interventions using the tools
- Co-designed with people with NMDs, health professionals specialised in NMDs & self-management experts

## Evaluation of NM Bridges

### intervention:

- Feasibility hybrid cohort study of effect and implementation
- Outcome domains will be based on a current qualitative study
- Using Normalisation Process Theory to explore imbedding NM Bridges into practice



## Resources & acknowledgements



### Neuromuscular Bridges:

Webpage

<https://nmd.bridgesselfmanagement.org.uk/>

### NMD Support digital app:

Apple store and Google Play



**NMD Support** 12+  
NMD Stories and advice  
Bit Zesty  
Free

This work is dedicated to the memory of Pooja, a committed and valued member of our co-design group

