

Neuro-muscular Bridges: Outcome of the development phase of a self-management programme for people with neuro-muscular diseases

H Pöstges², F Jones^{2,3}, L Lee¹, S Holmes¹, N James¹, MM Reilly¹, M Hanna¹, G Ramdharry¹

1-Queen Square Centre for Neuromuscular Diseases, UCL/UCLH, London, UK

2- Bridges Self-management, London, UK

3- Faculty of Health, Social Care and Education, St George's University of London, UK

Neuromuscular diseases (NMDs) are a complex, multifarious and heterogeneous group of disorders, including peripheral nerve and muscle diseases. Many NMDs are lifelong conditions, and the varied, multi-system nature of NMDs 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 (SM) is a programme consisting of defined strategies used by clinical staff supported by SM tools and has been developed in other neurological conditions.

Project aims:

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

Methods

Co-design methods were used to develop a book, web site and digital app containing support materials for people with NMDs. This was in three stages: 1) Discovery stage: interviews with people living with NMDs and their families informed the team of digital preferences and content for the resources; 2) Content was developed using creative writing workshops, individual interviews and Q&A videos with health professionals; 3) editing and decisions on content by people with NMDs.

Results

Prototypes of the book digital tools have been approved by the people NMDs involved in the development, and independent users. The NM Bridges book, website and digital app were officially launched in January 2020 and are available through Bridges.

Conclusions

We have co-designed resources to support self-management contextualised to the needs of people with NMDs and their families. These resources were tailored to the day to day issues and challenges encountered by people living with NMDs. An evaluation of the feasibility of integrating this programme into a specialist NM service will be undertaken by therapy and nursing team at the Queen Square Centre for Neuromuscular Diseases, London.

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