

The development of the lipoma when Sean was an adult was seen as a trigger to reinstating the dysfunctional neck schema, which was strengthened by unusual and uncomfortable sensations in the neck/trapezius from the lipoma. Developing abnormal movement patterns as a consequence further strengthened the dysfunctional schema of neck functioning. Through discussion and demonstration of Bayesian Brain principles and how they manifest in normal and abnormal patterns of physical functioning, Sean could see the rationale of the model, and subsequently, the rationale for treatment via hypnosis. The aim of the hypnosis was to directly 'tap' into subconscious attentional systems to help Sean defocus from sensations from his neck, whilst attempting to perform normal movement patterns (including 'mirror' work), and allowing muscle groups to relax to prevent abnormal volitional tension (thus, strengthening the 'normal' schema of neck function). A self-hypnosis CD was made with the movement exercises, for Sean to practice at home. The intention was to get Sean to a stage where he could engage with physiotherapy to complete his physical rehabilitation. In only five sessions, over a period of two months, Sean had made sufficient progress via clinical hypnosis to be referred back to physiotherapy for further treatment. In collaboration with the physiotherapist, Sean continued to have periodic review in neuropsychology to consolidate his progress. He continued to use his self-hypnosis CD at home. After only four physiotherapy sessions over the next eight months, Sean had made a substantial recovery. He no longer had to support his head and had no observable abnormal movement patterns. At the time of writing, he still experiences some stiffness in his neck, which can become exacerbated at times with stress and muscle fatigue, but the impact on his life was minimal. He was back at work full time, gained a promotion and was back to driving. His confidence (which had previously hit a very low point) had returned, he felt more able to socialise, and he was hopeful that the remaining two planned sessions of physiotherapy and neuropsychology would see him return to his pre-morbid level of functioning. In summary, after a period of over two years of severely debilitating functional motor/movement symptoms (following

failed surgical, medication and standard physiotherapy interventions) which were eventually seen as untreatable, clinical hypnosis facilitated physical rehabilitation so that Sean could engage fully in FND informed physiotherapy to improve his symptoms to near complete recovery.

Resources

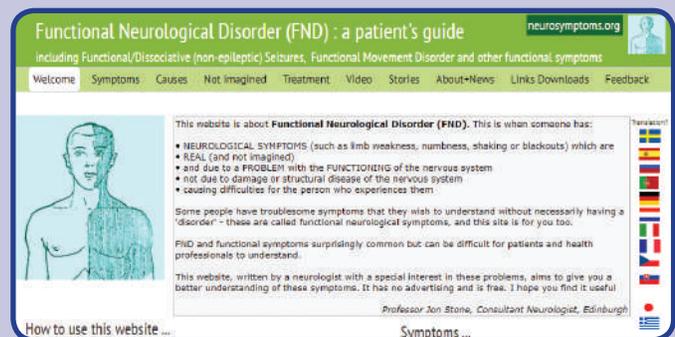
FND Information websites:

- www.neurosymptoms.org
- www.nonepilepticattacks.info



FND patient support organisations:

- FND Hope (<https://fndhope.org>)
- FND Action (www.fndaction.org.uk)



Exercise and physical activity: Physiotherapists' perspective

The benefits of exercise and physical activity in people with Multiple Sclerosis (MS) are widely documented. These include improved muscle strength, fitness and quality of life^{1,2}; yet uptake is poor placing people with MS at an increased risk of developing the secondary complications associated with inactivity, such as stroke, type 2 diabetes and cardiovascular disease^{3,4}. Indeed, there is evidence to suggest that only 20% of people with MS meet the recommended levels of physical activity³. It is therefore crucial that health professionals develop strategies to help change this trajectory as it is a public health concern.

But how do we engage people with MS, a progressive neurological condition, to sustain physical activity overtime? Many attempts have been made to address this issue but with limited success. Perhaps there is a need to examine this topic from another perspective. That is, understanding the prioritisation and meaning of exercise and physical activity both from the perspective of people with MS and health professionals such as physiotherapists.

Physiotherapists, the third most contacted healthcare professionals by people with MS in the United Kingdom⁵, play an important role in improving health and wellbeing through the promotion of exercise and physical activity⁶⁻⁸.

A recent study, using focus groups underpinned by the principles of framework analysis, explored physiotherapists' interpretation of exercise and physical activity; examined physiotherapists' views and opinions about the meanings and prioritised physical activity as reported by people with MS; and discussed the implications for clinical practice. Here physical activity was defined as "any bodily movement produced by skeletal muscles that result in energy expenditure"⁹ and would include domestic, occupational and sports related activities. Exercise on the other hand was defined as "a subset of physical activity that is planned, structured and repetitive"⁹ and aims to either improve or maintain physical fitness.

Physiotherapists were asked to reflect on the prioritised

exercise and physical activity practices of people with MS in the community (see table below). The full description of the study along with participants' quotes can be found here: <https://doi.org/10.1080/09638288.2019.1585969>

Overall four themes were developed from the analysis namely, "Blurred terminologies", "Influencing factors for the meaning of exercise and physical activity", "When professional expertise meets experiential expertise" and "The resolve: resolving professional and experiential tensions".

The study highlights that physiotherapists drew on the underlying physiological attributes of exercise (intensive) and physical activity (less intensive) as a way to differentiate the two terms. Interestingly, the findings highlight that whilst the use of exercise is embedded into clinical practice, physical activity, while considered, was less routine in application. This tendency to focus predominantly on exercise that led to fitness might be limiting the scope of physiotherapists in clinical practice and risks excluding other types of activities used by people with MS, that might be meaningful and necessary for sustaining physical activity in the longer term.

The professionals' perspective provided some insight into the attitudes of physiotherapists. It highlighted the gap that exists between professional expertise and experiential expertise. Whilst physiotherapists considered their views and opinions within the context of activities done to and for the body, people with MS did not limit their responses to expressions about activities to the body but reflected a broader and more holistic view of exercise and physical activity. People with MS expounded the concept of exercise and physical activity within the context of their lives¹⁰. This supports previous findings where health professionals by nature seek to prioritise health whereas the complexity of the lived experiences of the patient might prioritise other areas of life, such as family roles¹¹. Therefore, understanding both perspectives might facilitate greater collaboration between physiotherapists and people with MS.

The study highlights the need for greater clarity about key benefits of physical activity for people with MS. Physiotherapists were found to be confident with the effects of exercise and fitness but less confident about the impact of physical activity. This could be a reflection of the evidence base as the majority of studies in people with MS are reflective of those mildly or moderately affected with the condition. Also, it calls for written

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physical activity clinical guidance for people with MS which can provide a frame of reference for physiotherapists working in the community.

In summary, physiotherapists value exercise and physical activity as a method to manage the symptoms associated with MS. Physiotherapists are strategically placed in the community to initiate discussions, assess, and create opportunities to enhance the physical activity practices of people with MS. This study demonstrates that for this to happen, greater clarity of the message around the benefits of physical activity to people with MS is required and the importance of priority goal setting, as these might be key drivers for engaging and motivating people with MS in physical activity.

For more information about this study please find link below: <https://doi.org/10.1080/09638288.2019.1585969>

Key messages for clinical practice:

- Health professionals should be aware of and understand the individuals' priorities as these are key drivers to sustain physical activity in community dwelling people with MS.
- Physiotherapists should design flexible physical activity programmes which are meaningful, engaging and foster the necessary environment to sustain physical activity participation in people with multiple sclerosis.

For more information about this study please find link below: <https://doi.org/10.1080/09638288.2019.1585969>

Table: Showing the top 10 exercise and physical activity priorities and the reasons people with MS engage in exercise and physical activity.

	The prioritised exercise and physical activity practices of people with MS	The prioritised reasons why people with MS engage in exercise and physical activity
1	Self-care activities (e.g. shaving, shower, washing and dressing, cleaning teeth)	To improve MS symptoms (e.g. to improve or maintain strength, reduce pain and reduce spasms)
2	Everyday life activities (e.g. transferring, standing, pushing wheelchair or walking, climbing stairs)	Out of necessity (e.g. part of daily activities, activities that must be done)
3	Domestic activities (e.g. cooking, shopping, housework, laundry)	To keep active (e.g. to keep mind and body active, to maintain function and keep transferring)
4	Transportation (e.g. using public (bus/taxi) or personal transportation)	For mobility (e.g. to keep walking)
5	Leisure activities (e.g. gardening, dancing, sport, visiting friends)	Living with MS now and in the future (e.g. fear of deterioration, to combat MS)
6	Activities due to family roles (e.g. spending time with family, looking after children/grandchildren)	For self-reliance (e.g. to maintain ones' independence and choice)
7	Stretches (e.g. activities done to stretch the upper and lower limbs)	Emotional wellbeing (e.g. pleasure, improve mood, reduce stress)
8	Physiotherapy (e.g. activities done with or by a physiotherapist)	For self-esteem (e.g. to manage weight, sense of achievement, self-worth)
9	Activities without weights (e.g. upper and lower limb exercises, abdominal, bed and chair exercises)	Flexibility (e.g. to maintain or improve flexibility)
10	Activities with technology (e.g. computer, move it for MS DVD, phone, Wii)	For social reasons (e.g. social, feel connected, be part of community)

The full study can be found here: <https://doi.org/10.1080/09638288.2017.1309464>

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Acknowledgement: This research was funded by the Clinical Sciences Department, Brunel University London as part of the PhD Scholarship award scheme.

The brain tumour patient experience of ketogenic diet therapy

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ABSTRACT:

Background

Ketogenic diet therapy (KDT) is creating immense interest across the brain tumour community, but it is currently unsupported and poorly understood in standard neuro-oncology care due to a lack of clinical trial evidence endorsing safety, acceptability and therapeutic value. We report the experiences of twenty-five adult brain tumour patients on KDT for 4-51 months, with access to the services of a dietetic team specialising in KDT for epilepsy management.

Methods

A survey was conducted to gather information on reasons for pursuing KDT, the practical issues encountered and perceptions of the impact of KDT on tumour related symptoms, gastrointestinal function, weight management and psychosocial aspects of daily life.

Results

Twenty-five patients (71%), aged 30-71 years (median 46 years), on KDT for 4-51 months (median 11 months) completed and returned the survey. Nineteen (76%) had sustained KDT through episodes of surgery, chemotherapy, radiotherapy or combinations of these. All eight patients (100%) experiencing regular seizures and eleven of fourteen (79%) with fatigue reported improvements in these symptoms. Twenty patients (80%) reported weight-loss, particularly in the early weeks; for thirteen (65%), this was a positive side-effect. The most common adverse effect was constipation, reported by ten patients (40%). In both symptomatic and asymptomatic brain tumour patients, support for their choice to pursue KDT was readily reported to underpin their sense of empowerment and control.

Conclusions

Notwithstanding that the primary reasons for over 50% of the patients to commence KDT was to prolong survival, this study is unable to make any observations in this area. However, the patient experience would appear to show that refractory seizures and chronic fatigue may be alleviated by KDT. Furthermore, amongst the group, the survey shows KDT to be sustainable and tolerable. It would appear that KDT is worthy of further clinical exploration for its symptom management benefits alone.

Key words: Brain tumours, ketogenic diet, seizures, fatigue, quality of life.

INTRODUCTION:

Primary tumours of the brain and central nervous system (CNS) are a group of rare, heterogenous diseases, with widely varying outcomes. However, they are the leading cause of cancer death in the under-40s, and account for the highest average years of life lost, of any tumour type^{1,2}.

Many patients with brain tumours also have significant symptoms impairing their quality of life, including, physical problems (weakness, poor co-ordination), functional problems, seizures, fatigue, depression and cognitive impairment³. These may be

due to the disease, its progression, treatment side effects, or a combination of these. In addition, uncertainty around prognosis contributes to patients' anxieties and concerns^{4,5}. For many patients and their families, the need to actively contribute to the management of their brain tumour with its associated physical and emotional symptoms is a powerful motivator and 32-41% of glioma patients are reported to explore complementary therapies and consider lifestyle change to manage symptoms and prolong survival⁶.

The low carbohydrate, high fat, adequate protein ketogenic