

Targeting the under recognised sedentary behaviour epidemic in neurological disease
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Physical inactivity (lack of physical activity) is a major risk factor in non-communicable diseases, increasing all-cause mortality risk by 20-30% alongside being a central risk factor for dementia development. Although the relevant contribution of lifestyle factors in any individual can be difficult to ascertain with certainty, interventions targeting physical activity behaviours are critical in terms of primary and secondary prevention. It is undeniable that public health approaches in the general population to increase physical activity are needed, but we argue that a specific focus on higher risk groups, for example due to disability are warranted.

People with disabilities are half as likely as non-disabled people to be physically active [1]. People living with neurological conditions such as stroke, Parkinson's disease and multiple sclerosis and the rarer neurological disorders such as neuromuscular diseases, Motor Neurone Disease, Huntington's disease, Progressive Supranuclear Palsy, Multiple System Atrophy, inherited Ataxias and Hereditary Spastic Paraplegia generally are even more sedentary. This is despite general acceptance that regular physical activity has the potential to drive physiological, psychological, functional and quality of life improvements in people with neurological conditions.

There is emerging evidence from randomised efficacy trials and trials of real world tailored preventive interventions. Where physical intervention is one component of multi-domain interventions, there are improvements or at the very least maintenance of cognitive function in those at risk for dementia [2;3]. Early intervention (either primary or secondary) is required to achieve ongoing lifestyle modification and consideration of barriers and facilitators to regular physical activity is required, so promoting uptake and ongoing participation. Critical to the aim of facilitating long term engagement in regular physical activity (including exercise) is the need to embed flexibility, personal preferences and robust self-management principles in any interventions.

In this issue of *Practical Neurology*, *Alty and colleagues* present the important concept of "Preventative Neurology" in their *How to Understand it paper: Exercise and Dementia*. They appropriately point out that despite multiple constraints, clinicians working in neurology clinics and wards are vital in the ongoing efforts required in delivery of effective evidenced based primary and secondary risk reduction interventions. Supporting ongoing physical activity and exercise in an environment of changing physical and cognitive function has the potential to enhance meaningful participation in usual life activities with important public health benefits for these populations.

Limited knowledge of appropriate tailored physical activity interventions for people with neurological conditions are however compounded by a lack of a nationwide system to support participation in physical activity. People identify problems with access, cost, knowledge of professionals and concerns around the impact of disease specific symptoms, not only physical (e.g. fatigue, poor balance), but also cognitive and psychological (e.g. low mood or motivation), which in turn can lead to a great reduction in physical activity and associated secondary deconditioning. All of this may also be influenced through the bi-directional relationship between physical activity and sleep [4]. Signposting to health professionals who have the relevant skills and knowledge to support people living with neurological diseases to start and stay active is a first important starting point.

Further steps are needed to address the burgeoning epidemic of sedentary behaviour in people with neurological disease by developing novel evidenced based approaches to support physical activity for people with neurological diseases. Secondary prevention

physical activity strategies including common modalities of aerobic exercise, strength, balance and flexibility training and endurance or combined interventions have been examined in many of the more common neurological conditions such as Stroke, Parkinson's Disease and Multiple Sclerosis. These interventions range from technology-based rehabilitation to behaviour change interventions, focussing on increasing participation in physical activity. The success of these interventions in common neurological conditions have provided a platform for applying and modifying this evidence for application in rarer diseases, although to date the weight of evidence is much less, with fewer and smaller studies. Arguably, these rarer diseases often have a clear genetic underpinning facilitating opportunities to explore modifiable lifestyle factors and mechanisms of action.

In order to truly move the field forward, we need to consider new ways of designing physical activity trials so that they can truly inform neurology practice. Current practice typically involves interventions delivered and evaluated at the specific disease level. We suggest that a condition informed framework (see Figure 1) would have great utility in evaluating physical interventions in rare diseases. Such an approach would entail inclusion into a trial or intervention based on impairments such as fatigue, muscle weakness and balance problems rather than on a diagnosis such as Huntington's Disease or muscular Dystrophy (amongst a range of rare neurological conditions). Interventions for people with neurological disease delivered within such a framework would promote an active lifestyle through targeting specific physical, cognitive or psychological impairments at the body structure and function level to influence participation outcomes. Critical to this would be an individualised intervention approach that considers disease, co-morbidities and targets symptoms. Such an approach will require novel trial and statistical methodologies, but should they prove achievable would have the potential to lead to fully powered effectiveness trials that in turn could provide the evidence to achieve the urgently needed step change in thinking and practice.

References

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Figure Legends:

Figure 1: The Physical Activity in Rare Neurological Conditions Condition Informed framework [RP-DG-0517-10002]