

## **NDIA Consultation on Independent Assessment and Access**

### **Submission in response to the special session for PACT held on 16.02.2021**

As an Occupational Therapist specialising in supporting individuals living with Parkinson's, I would like to thank NDIA for providing the opportunity to provide feedback on the proposed changes to the Scheme. Many of our membership wishing to access the Scheme have experienced the problems as highlighted within the consultative documents. It is encouraging that NDIA have recognised these problems and are intending to resolve them as part of the proposed changes. This will go a long way in improving the transparency around how NDIA decisions are made and improve the perceptions around fairness in access to the scheme, which will remove much of our membership's anxiety around these issues.

People diagnosed with Parkinson's face significant challenges through the progression of their condition, which impacts individuals in very different ways, some experience rapid deterioration in function while others more slowly. This is complicated by on/off periods and the medication itself can impact functioning. As you can appreciate, it is not a case of you are either on or off, it ranges on a continuum. Promisingly, there is a growing body of evidence (e.g., Murman, 2012; Sellbach & Silburn, 2012; UK National Institute for Health and Care Excellence, 2017; Ahn, Chen, Bredow, Cheung & Yu, 2017; Spencer, Haub, & Rockers, 2020) that supports the application of early interventions, both pharmaceutical and non-pharmaceutical, to assist with the management of the condition for those living with Parkinson's during these periods. The relevance of this research for the Scheme is on the positive impacts of the non-pharmaceutical interventions to improve function and delay the effects of the progression of Parkinson's, which aligns completely with the insurance aim of the NDIS to provide early intervention support to potentially avoid or to delay "substantially reduced functional capacity", not to wait for it to occur.

The nature of the Parkinson's condition, its progression, and how best quality of life can be maintained for those living with Parkinson's raises three main areas of concern with the proposed Scheme that should be clarified, if it is to be successful: -

- On first diagnosis of Parkinson's, individuals are unlikely to show evidence of significant loss of functioning, but it is imperative for these individuals to immediately start their programme to manage the condition if they are to maintain functioning for longer periods of time. An initial assessment of functioning for individuals that are recently diagnosed with Parkinson's will NOT always identify significant decline at this point, and therefore requests would need to follow the exception track. Although the proposed scheme sets out CEO discretion to deal with early intervention requests it does not provide any detail of the basis on which that discretion will be handled, or how the exception request needs to be raised. By the assessor or the person being assessed? It is suggested that if early intervention

request is supported by professional allied healthcare providers then the CEO discretion should be automatically executed. Early intervention for someone living with Parkinson's can be the difference between being able to continue to contribute to society or be totally beholden on society. Clarification of the scale and nature of the CEO discretion would provide the much-needed transparency and consistency on how these exceptions are handled - the lack of which is a major critique of the current scheme.

- For those applicants living with Parkinson's with established functional decline, the scheme proposes a single independent initial assessment process, without an option to request a second assessment. However, in the case of someone living with Parkinson's their functional capacity can vary significantly on the day of assessment depending on the environment in which the assessment is conducted, levels of stress or anxiety of the individual, time of day, where they are on the on/off periods (which can be within 30 minutes of each other). This situation can be compounded by the associated periods of depression, denial, and isolation that people living with Parkinson's can be affected by, particularly in the early phases of diagnosis. It is suggested that consideration be given to situations that fall within these circumstances.
- The use of standardised tools across all applicants is the ultimate goal, but this should be balanced with appropriateness. Parkinson's is a complex, multi-system degenerative condition that presents with significant motor and non-motor symptoms that impact functioning. Several of the proposed tools appear more suited for testing functional capacity for those with an intellectual or developmental disability, rather than functional impairment linked to cognitive decline. It is suggested that there should be further consideration of how the tools are selected and used to measure functioning for specific conditions. Furthermore, the administration of the standardised tools should, for those living with Parkinson's, be administered by someone with an understanding of the impact of Parkinson's on an individual's functioning.

On behalf of our membership, I would offer to continue to work with the NDIA during this consultative period to ensure that those people living with Parkinson's are not further disadvantaged.

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