

Young Onset Parkinson's Exchange (YOP-X) App and Website

The Young Onset Parkinson's Exchange (YOP-X) App and website is an information portal and resource hub supporting people with young onset Parkinson's, and provides a valuable workforce tool for GPs and other health professionals. Developed as a living lab model, the experiences, ideas, knowledge and daily needs of people with young onset Parkinson's have underpinned all App and website content, with more than one hundred individual stories and experiences shaping tools and resources. YOP-X also provides a fast track for people with young onset Parkinson's to collect and collate information relevant to their NDIS applications.

Features of the YOP-X App and website include:

NDIS Wallet: Providing an efficient way to consolidate everything that the NDIS needs to know about someone with young onset Parkinson's to consider an NDIS application, utilising a streamlined process for people to describe their worst day, a key requirement of the NDIS application process.

Goal Setter: A tool allowing for the collection of short, medium and long term goals, a key requirement of accessing NDIS funding.

Employment Experiences Checklist: Providing an efficient way to capture past or present employment experiences including a reduced capacity to work or early retirement, and targeted support strategies for those still working.

Employer Letter: A personalised letter generator to quickly capture any symptom information and strategies to assist in the workplace that a person with young onset Parkinson's wishes to share with their employer.

Flexible Working Arrangements Form - A personalised application generator for flexible working arrangements covering changes to work schedules, how work is carried out and changes to the work space and environment.

Free Telephone Legal Advice - A national directory of free telephone legal services to answer legal questions associated with employment, health, finances, family and future planning.

Employer Fact Sheet - For proactive employers who wish to expand their knowledge of young onset Parkinson's and identify strategies for supporting their employees.

Be Well Videos - Providing scientifically supported mental health and wellbeing information and strategies to target key issues for people with young onset Parkinson's including anxiety, depression, apathy and chronic sleep deprivation.

Sex, Relationships and Intimacy Checklist – Providing an efficient way to identify key issues impacting on the couple relationship include grief, resentment, changes in sexual functioning and partner roles, and a lack of sleep for both the person with young onset Parkinson's and their partner, and offering strategies to overcome these.

Sex, Relationships and Intimacy Discussions - A series of 5 videos exploring issues around sex, relationships and intimacy for people with young onset Parkinson's and their partners, presented by a qualified Relationship Therapist.

Thought Switcher - A tool designed to interrupt negative thoughts and nurture positive thoughts in their place

Planning for the Future - A fact sheet of future planning considerations including medical retirement, superannuation and insurance.

Strength and Balance Exercise Videos - A series of 10 videos with exercises designed specifically for people with young onset Parkinson's, and with the option to create a personalised workout

Change Your Brain - Neuroplasticity tools and videos produced by Dr Fiona Kerr of the Neurotech Institute

Task Setter - Setting focused tasks for the week with daily reminders to undertake the task for 7 days to set up successful daily routines.

Push Notification - A personalised prompt tool with a countdown to assist with pushing past apathy

Sleep Check-in - Providing an efficient way to identify key issues impacting on sleep, and offering strategies to overcome these.

Maximising Energy - Tools and videos exploring sleep issues, fatigue and ways to maximise energy produced by Dr Fiona Kerr of the Neurotech Institute

Ask Maggie - A question and answer opportunity for the kids of people with young onset Parkinson's to post their questions to Senior Clinician, Maggie

Discussion Forum - Providing the opportunity for people with young onset Parkinson's to network and information share

For more information on the YOP-X project and to access tools and resources, please visit www.youngonsetparkinsons.org.au