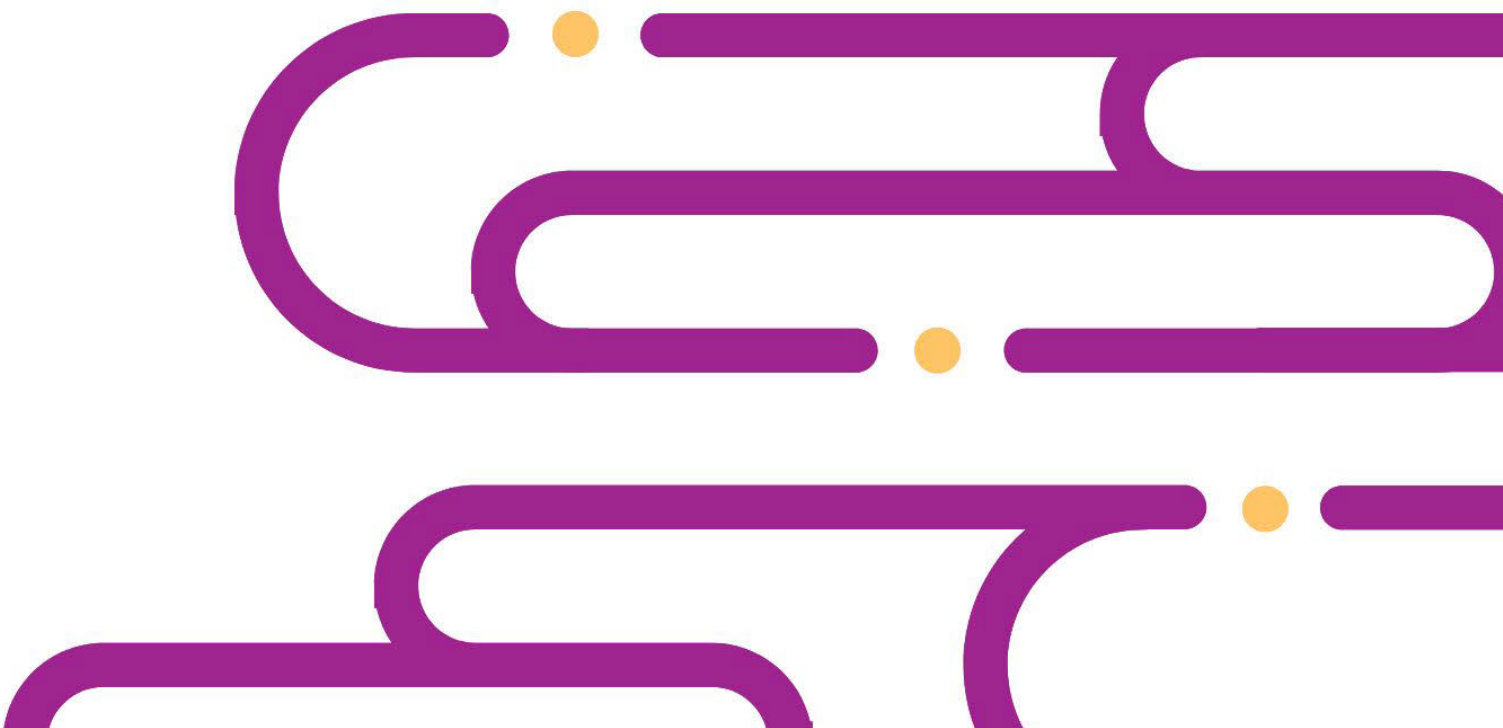




Parkinson's Australia's Submission

August 16, 2024

Consultation on draft lists
of NDIS supports



Parkinson's Australia is the national advocacy body representing people living with Parkinson's (and Parkinson's plus conditions), their families and carers, as well as researchers and health professionals in the Parkinson's community. National Advocacy. Connection. Awareness. We promote the best possible quality of life for people with Parkinson's. We advocate for the Parkinson's community on issues of national significance. We work to reduce the impact of Parkinson's by promoting best practice care to ensure that people can maximise their opportunities to live well and maintain their independence.

Parkinson's Australia supports Labor's proposed amendment (below) to the NDIS Bill, which gives a participant a chance to request funding for a support for something on the "out list". The NDIA might agree that a participant can access one of these supports, if it meets all of these criteria:

- *The support would replace one or more NDIS-funded support for that participant, and;*
- *It is the same cost or less than the total cost of supports it is replacing for the participant, and;*
- *It would provide the same or better outcomes for the participant than the support it is replacing, and;*
- *It meets any other conditions specified in the (currently unwritten) NDIS Rules.*


Parkinson's Australia objects to the very short timeline for this consultation. The very late issue of Easy English and Auslan versions or translations into other languages ostracises people in regional, rural and remote areas and people from CALD backgrounds thereby excluding these groups from meaningful contributions.

Parkinson's Australia is a member of the Neurodegenerative Palliative Care and Rare Diseases Advisory Group (NPRAG) for the NDIA. At the meeting of the working party on the 23rd of July, NDIA representatives asked if working party members would be interested in a separate session on this list, which was overwhelmingly met with a positive response. It wasn't until 14th of August that the working party members received a meeting invite for Friday 16th of August. Given that the consultation period closed on the 18th of August and there was only 2 days' notice for the meeting, it is felt that the NDIA wasn't seeking meaningful consultation. We are pleased that this consultation has been extended.

Parkinson's Australia also queries why "Early Intervention Supports for Adults" has not been included on the draft list of NDIS Supports when "Early Intervention Supports for Early Childhood" is on the list and strongly recommends that it be included as its own category.

Some Australians living with Young Onset Parkinson have responded to the list below using themselves and their stories as case studies. Parkinson's Australia appreciates their honesty and candour.

Regards,



Olivia Nassaris CEO, Parkinson's Australia

NDIS supports list

Supports that are 'NDIS supports'

The below contains 36 categories of NDIS supports, a description of the category, and any carve outs to the description that are not 'NDIS supports'.

Woman living with Young Onset Parkinson's in

As a current NDIS participant and a person who was diagnosed with Young Onset Parkinson's Disease (YOPD) at the age of 32, it is extremely disheartening to read the proposed lists of supports that, should the list be approved, not be considered as NDIS supports. While I appreciate that I am lucky to live in a time and space where I have access to any financial support, if this list is approved, it will only make it more difficult for participants to receive the help and support that they need and undermine the principles upon which the NDIS is built on; that people with disabilities have the same rights and value to society, and 'should be supported to realise their potential for physical, social, emotional and intellectual development', should be supported to provide people with disabilities the capacity to determine, for themselves, what they need in order to 'participate in, and contribute to, social and economic life' (Section 4 and 17A, National Disability Insurance Scheme Act 2013).

Assistance to Access and Maintain Employment or higher education

Description

Workplace assistance that enables a participant to successfully obtain and/or retain employment in the open or supported labour market, including individual employment support, employment preparation and support in a group and school leaver employment supports to assist students transitioning from school to employment.

Carve outs that are not 'NDIS supports'

Does not include:

- learning and support needs of students that primarily relate to their education and training attainment,
- work-specific support related to recruitment processes, work arrangements or the working environment,

Woman age [REDACTED] living with Young Onset Parkinson's, [REDACTED]

NDIS is designed around disabilities, so to go to another governing institution such as Centrelink would be counterintuitive, as they not equipped to support individuals with a disability. People with disabilities are more vulnerable, so there needs to be adequate support to enable somebody to be empowered to get back into the workforce and to support them in their morale and motivation, rather than being discriminated against due to having to try and cope with a system that is unable to provide adequate support.

To achieve inclusivity for all children/people with disabilities, it is essential that they are given additional support within mainstream facilities, or how are 'normal' children supposed to learn how to interact, accept and embrace children with disabilities? All children have the right to an education, and teachers should not suffer because they are required to provide extra assistance for children with disabilities; they should have their own support assistance to help otherwise everyone in the classroom suffers.

Woman age [REDACTED], living with Young Onset Parkinson's, [REDACTED]

At the age of fourteen, I had started hairdressing and went into full time work at the age of fifteen, into my career that was my first love. I have travelled Australia, working in high-end hairdressing salons and managing staff. Whilst owning my own salon on the Sunshine Coast over a couple of years, I started noticing a massive decline in my hands. Thinking that hairdressing was affecting my body already, at a young age in my late thirties. My hands were doing weird things; my thumb was not able to move and use of scissors was becoming difficult. I would write with pen and paper and it would hurt my brain. By the age of forty-five, being diagnosed with YOPD and being forced to give up my 30-year career of hairdressing, I was faced with a gut-wrenching situation. Financially, the burden of being, a single parent of three children and not being able to provide weighed on me heavily.

Due to all the changes going on in my body, I have been unable to work in any normal capacity at all. As time has progressed, there have been more symptoms and I have deteriorated. As someone that had a career and used to think I had all the time and possibilities in the world, I still grieve for the work and life that I was so passionate about. This disease does not discriminate.

- funding or provision of employment services and programs

Woman age [REDACTED], living with Young Onset Parkinson's, [REDACTED]

In 2019, I had an appointment with a Geriatrician who specialises in aged care, who kindly diagnosed me with young onset Parkinson's Disease. It was brought to his attention within the consultation that I had four MRIs and a lot of exploratory tests to find out what was going on. Unfortunately, until you go to a specialist, there are certain tests and MRIs only a specialist can refer you to. My GP was shocked to hear and had never ever considered that at my age, at 45 years old, I would have PD. My world had turned upside down, but finally somebody believed me.

The majority of people with a disability are often disadvantaged to the point of being under the poverty line. It is unrealistic to expect people in these circumstances to be able to pay or outsource things such as providing employment services and programs, etc.

Centrelink does not provide adequate support and training to prepare all people with disabilities for the workforce. The range of assistance required for varying disabilities is far too wide to cater to everyone. A bad initial experience into the workforce for someone with a disability could have devastating effects and would certainly deter them from trying again.

Woman with Young Onset Parkinson's in [REDACTED]

Often people with Young Onset Parkinson's are not able to stay in their profession after diagnosis. I know two people with Young Onset Parkinson's who were unable to continue their careers as a hairdresser and a linesman – both lost their incomes.

I believe that being younger and coping with life and Parkinson's, it's very important to have an inclusion where we can re-skill or retrain. Many people are scared to talk to their bosses about life with Parkinson's. I feel it's important that we are able to retain our independence, and this would be applicable especially.

Woman living with Young Onset Parkinson's [REDACTED]

I was 48 when I was diagnosed with Parkinson's. I am now 58. I work in law enforcement as a federal public servant. A job I have dedicated 24yrs to. As a single woman my independence and financial security is important to me. Also maintaining my work reputation that I had built over the past 24yrs is important. Parkinson's is degenerative and progression is certain. How fast we never know. What we do know is there are therapies that help. Everyone is different. Parkinson's is not an illness that one size fits all, therefore therapies and supports are different and change with progression.

Woman living with Young Onset Parkinson's [REDACTED]

There is a big assumption that services listed under mainstream supports are actually available and this could be an issue for some people especially given most people with YOPD are on lower incomes because they have to cut back or stop work.

Early Intervention Supports For Early Childhood

Description

Provision of a mix of therapies, and a key worker for the family. Supports for all children 0-9 years with developmental delay or disability and their families to achieve better long-term outcomes, regardless of diagnosis.

Carve outs that are not 'NDIS supports'

N/A

Parkinson's Australia queries why - "Early Intervention Supports For Adults" has not been included on the draft list of NDIS Supports when Early Childhood has been (above) and recommends that it be a category included in the list.

Supports that are not 'NDIS supports'

The below contains 15 categories of goods and services that are not an 'NDIS support', a description of the category, and any carve outs to the description that are considered an 'NDIS support'.

Day-to-day living costs

Description

Accommodation and household related:

- Rent, rental bonds, home deposits, mortgage deposits, strata fees, rental bonds and home deposits.
- Standard home security and maintenance costs, fencing, gates and building repairs

Woman age [REDACTED] living with Young Onset Parkinson's, [REDACTED]

When it becomes as safety issue for not just the participant but also the support workers or anyone coming into the home, maintenance should be covered by NDIS.

- General furniture removal and services, unwanted furniture pick up
- Pools, pool heating and maintenance, spa baths, saunas, steam rooms
- General home repairs, general renovations and maintenance.
- Water, gas, and electricity bills, council rates
- Water filters, purifiers, or aerators.
- Electricity generators, solar panels, and batteries

- Standard household items (dishwasher, fridge, washing machine, non-modified kitchen utensils and crockery, fire alarms, floor rugs, beanbags, lounges, standard mattresses, and bedding), replacement of appliances, including hot water services, solar panels, etc.

Woman age [REDACTED], diagnosed at 27 with Young Onset Parkinson's in [REDACTED]

With YOPD, I experience severe temperature thermal dysregulation causing temperature spikes, hot flashes, sweaty, and feeling cold easily, thus being permanently uncomfortable in body temperature.

Man, age [REDACTED], living with Young Onset Parkinson's in [REDACTED]

One thing that uses up most of my teaspoons for the day is washing dishes. My brain no longer can efficiently tell my hands what to do and it is an excruciatingly slow and draining process to manually wash anything anymore. I rely on my wife and support worker to pick up the slack where this is concerned. It saddens me, that a simple task like this takes so much effort with YOPD and that it leaves me unable to interact with my kids after dinner, especially if my wife is away for work.

Woman age [REDACTED], living with Young Onset Parkinson's, [REDACTED]

Some of my symptoms included a limp that would show up unexpectedly and randomly; my right foot would turn inwards; my big toe would raise up whilst my little toes would curl under; restless legs; sleep deprivation; anxiety (that I was unaware of at the time, which I had never experienced in my life before); PD off periods (freezing such as when there is a lack of dopamine being released); twitching of the eye; and due to my right-side being affected, I was even struggling to wipe myself whilst using the toilet and could not manage it at times with my usual dominant right hand.

Critical issue: exclusion does not represent value for money, a once-off purchase of a washing machine is better value for money rather than years of paying for a laundry service or support worker to do the laundry. It also improves independence.

People living with Parkinson's may no longer be able to hang clothes on the line due to stiffness in their muscles due to the disease so a dryer or a support worker would also need to do this for them.

It may be the same for people losing dexterity and a safety issue when washing dishes manually or having increased costs of support workers doing this for you while a dishwasher would be a low-cost investment that you would not have made otherwise until your disability stopped your ability to safely and manually wash your dishes.

We also consider heating/cooling a necessary wellbeing support due to Parkinson's effects on thermoregulation. And a bidet or similar for those that lose dexterity due to PD symptoms and can no longer wipe themselves, to maintain independence

Finance and payments related:

- Donations, tithes, gifts, and political contributions,
- Fines penalties, and court-ordered amounts
- Travel insurance, life insurance, home and contents insurance, car insurance and excess insurance for Novated vehicles (Salary Sacrifice).
- Superannuation for participants or related parties (exceptions apply for arm's length Employment arrangements)
- School / education fees including TAFE and university.
- Legal costs
- Child support fees, debt repayments, gift cards
- Business development costs, business skills development costs
- Debts, liabilities, and taxes, other than those necessarily incurred in the receipt of supports

Food, Beverage related:

- Groceries (except for modified foods required as a result of a person's your disability e.g. PEG feeding),
- Fast food services and takeaway food
- Alcohol

Lifestyle related:

- Cigarettes, vapes and smoking paraphernalia, legal cannabis
- Gambling
- Internet services, land line phone, mobile phones, mobile phone accessories, and mobile phone plans and smart phones.
- Gaming PCs, consoles and games, subscriptions for streaming services
- Standard toys, balls, racquets, uniforms, membership costs and other costs associated with recreational sports
- Wedding, honeymoon, funeral, other events.
- Musical instruments, music production, social media production
- Tickets to music, theatre, cinema or sporting events, and general conference fees
- Sex work

Woman age [REDACTED], diagnosed at 27 with Young Onset Parkinson's in [REDACTED]

Due to having YOPD and experiencing significant disabling symptoms of dyskinesia, dystonia, tremor, extreme pain and the psychological and physical impact YOPD has had on me and my failing love and intimacy area. Having only two sexual relationships in my entire life and the problematical relationship some people particularly with disabilities, have using dating sites where the act of getting hooked on the dopamine hit of the stream of contacts messages, rifling through pages and pages of disrepute, people on these sites and being used and terribly abused physical mental and financial and risk of domestic violence, infidelity and risk of sexually transmitted diseases harming the health of the immune suppressed system of a person with Parkinson's disease and stress and anxiety it poses on someone with a chronic illness with mental health instability. All of the above situations I have experienced in my two relationships with men. One I was married to for 15 years! - I strongly support the belief that NDIS should provide a safe environment for engaging in sexual activity by way of allowing the YOPD community the ability to buy sex toys and the use of sex support workers. We are young, viable, attractive and still have needs and desires that need to be met. It's human nature right and completely hideous that people you are in a romantic relationship with feel that they can get away with and exploited and exposed to these types of behaviours with a person who is most vulnerable, has no self-esteem due to impacts of their physical disability and who hasn't the mental capacity or physical health or capacity to deal with the hideous consequences of a destructive physical relationship.

- Sex toys

Man, age [REDACTED], living with Young Onset Parkinson's in [REDACTED]

Parkinson's is already impacting our intimate relationship from my slowness and muscle stiffness, resulting in limited movement on one side of my body with a pronounced loss of dexterity in my dominant hand. Over time, the level of care and support by my wife as a partner will increase and the fear is that some level of intimacy will be lost. We hope to maintain our intimacy and can see sex toys as an aid playing a bigger role in our sex life as it is an essential goal for our relationship and maintaining intimacy, so to me to be still able to give my wife pleasure as my symptoms progress, which may result in erectile dysfunction and further loss of mobility.

- Surrogacy, Menstrual products, IVF
- Trampolines
- General play equipment, indoor or outdoor.

- Membership of a recreational club

Clothing related:

- Jewellery, watches (including smart watches)

Man, age [REDACTED], living with Young Onset Parkinson's in [REDACTED]

As my disease progresses, balance issues will occur due to the rigidity in my trunk and loss of ability to pick up my feet while walking. In the usual Parkinson's (60+) population you may get a falls pendant for someone, but with young onset, an Apple Watch can do the same thing and still be worn in public without increasing the stigma around my condition. It would give falls alerts and allow calls if I couldn't get to my mobile phone. I think this technology is imperative for someone with young onset Parkinson's with a quick response by a partner, family member or emergency services if a fall does occur. For me it has the added benefit of monitoring my heart rate as I was diagnosed with an SVT and am an avid cyclist, should a crash occur. I also manage all my pill alarms, appointments and medications on apps on my Smart Phone (which is a work phone currently). If people with PD are purchasing separate tab timers, pill boxes with timers and other supports to help with medications/ reminders/ appointments, with the pairing of the Smart Watch and Smart Phone I think this is great value for money and would advocate the benefits of having both funded through NDIS outweighing the additional costs and burden of managing multiple devices. The watch can also have reminders pop up on them to remind me to stay hydrated as my thirst mechanism is compromised due to the PD and prompts me to move (do some steps every hour).

Man living with Young Onset Parkinson's & care partner in [REDACTED]

One of the items marked for removal was 'watches (including smart watches)'. He has in the past received funding for an Apple Watch (smart watch). The reason is that it has functionality to alert either myself, then if I don't answer, emergency services if he has a hard fall. As his balance deteriorates, his watch is going to be a very important part of him being able to maintain his independence. It has already been tested in a situation and works perfectly, thankfully he was ok but next time it may save his life. it has the ability to recognise a sharp drop or impact.

We don't think this item should be removed from funding, or at the very least, consideration should be made for people suffering from Parkinson's Disease or Neuro/balance-related disabilities. It would even be helpful in locating a wearer with diminished cognitive function who may have wandered off (using satellite pinpoint location technology).

Woman age [REDACTED], diagnosed at 27 with Young Onset Parkinson's in [REDACTED]

Due to having YOPD and therefore experiencing significant disabling symptoms, it's important for me that NDIA keep supporting funding for an Apple Watch; this is of significant concern as it tracks me, as this year I have had four significant falls, one where I fractured my sacrum right throughout and a wedge fracture on my L3 vertebrae prevention, allows me specific exercise health updates tracking such as my blood pressure and amount of exercise I do, tracks records the stability of my gait and walking, calls and contacts my emergency contacts including 000 emergencies due to a very good falls detection capability and all data information being backed up and stored on my Apple iPhone. Being able to receive calls on the watch without having to carry a cumbersome phone as well whilst exercising. The less you carry, the less of a fall risk you are with people like myself with Parkinson's disease. The number one cause of death with people with PD is falls risk. The Only pairing Apple Phone and Apple Watch technology has the capacity and capability to do that so well.

Apple Watches have the function to track your health and heart rate. Along with a detector, the watch has been vital to track my heart rate given the last 6 months I was also diagnosed with pericarditis inflammation and fluid on my heart also a spiking dangerous blood pressure due to a virus attacking my heart and comes on with high-intensity blood pressure high heart rate exercises which I can monitor and keep an eye on through my APPLE WATCH and subsequently paired APPLE phone and Health APP to monitor and share with my healthcare team.

Woman [REDACTED] with YOP in [REDACTED]

My concern with these lists is that they are too prescriptive. They appear to be put together without the consultation of medical professionals or disability advocates and undermine the lived experience of NDIS participants. For example, my experience with YOPD is completely different to the next person's and as such the support's that I need right now are very different to anyone else's. While I might not, currently need to access support for technologies such as a smart watch, there are those who are at risk of falls, for which a smart watch might mean the difference between life and death. It should come down to the word of the expert in this situation, the person living with the disability (or their carer), to determine what supports they need and why. It is already built into the NDIS Act that participants must provide evidence that a support is reasonable and necessary to 'assist the participant to undertake activities so as to facilitate the participants social and economic participation' and 'will be, or is likely to be effective and beneficial for the participant' (Section 34, National Disability Insurance Scheme Act 2013). Shouldn't that be enough?

- Makeup, cosmetic treatments, wigs, and cosmetics
- Standard clothing and footwear

Travel related:

- Cruises, holiday packages, holiday accommodation, including overseas travel, Airfares, passports, visa, meals and activities.
- Tickets to theme parks, tourism and entertainment operators.
- Motor vehicles, motorbikes, watercraft, all-terrain vehicles and other recreational vehicles, mechanical repairs, tools, vehicle registration.
- Petrol

Pet Related:

- Animals (other than approved NDIS funded assistance animals),
- pet food for animals other than for approved NDIS assistance animals,
- veterinarian costs, pet boarding, pet grooming, taxidermy, pet cremations/funeral

Carve outs that may be considered 'NDIS supports' for certain participants

The following day to day living costs may be funded under the NDIS if they relate to reasonable and necessary supports:

- Additional living costs that are incurred by a participant solely and directly as a result of their disability support needs
- Services delivered in a gym or recreational club related to the participant's disability support needs (excluding the cost of membership, entry, or basic equipment).

Woman with Young Onset Parkinson's in [REDACTED].

What I generally struggle with is the access to utilise the benefits provided. I am still working, albeit part-time, but still working to maintain independence. In order for me to receive a regimented exercise facility, I can't just join a regular gym or exercise centre in order to obtain benefits to exercise, e.g. 24/hr gym would be better than a 9am-5pm booked appointment session especially if struggling on an 'off day' have access to alternative health facilities such as wellness retreats or spa, so as to alleviate stress and anxiety to be able to use a local massage centre, not a physio for ongoing massages to assist with being able to remain physically active.

Woman [REDACTED] living with Young Onset Parkinson's Dx 10 years, [REDACTED]

I attended a regular gym doing 4 days a week of Pilates with a friend. I could no longer afford that and NDIS don't fund it so I had to stop. For the last two years I have been unable to find something suitable that was available after work hours. The gym's flexibility was perfect to allow me to move classes around without the financial impact of cancelling an appointment. I am currently reducing my hrs at work from 40hrs to 18hrs to be able to undertake exercise that is proven to work. Pilates worked at the gym but it's not doable.

Man, age [REDACTED], living with Young Onset Parkinson's in [REDACTED] & care partner

Exercise is prescribed for a neurodegenerative disorder like Parkinson's as it is the only thing shown to slow the progression of this incurable condition and a proven way to deal with both motor and non-motor symptoms as well as helping medication uptake and slowed GI issues. You should be able to spend money on a gym membership or group/community classes of your choice that have the added benefits of socialisation and lower costs than specialists. The increased costs when living regionally to get to a specialist gym not only take petrol and time, when he could check in monthly with the specialist exercise physiologist and run his tailored program at the local gym that's just 10 minutes down the road (BTW he would never have joined a gym if he was a mainstream non PD person, but now it is a necessity to slowing the progression of PD through exercise and this is a resources that can help him achieve his goal of staying in the workforce longer and being fit and able to interact with our kids). This also removes the barrier to daily exercise, being so close. He can't afford ½ day everyday to get to town and back to the EP. Maintaining employment is one of his main goals, not only for our livelihood but also his mental wellbeing. Any movement is better than no movement and it's only in doing the exercises that people like and are used to or have a friend that accompanies them somewhere close and accessible that keeps PwP active before the apathy sets in.

Woman age [REDACTED], diagnosed at 27 with Young Onset Parkinson's in [REDACTED]

Due to having YOPD and therefore experiencing significant disabling symptoms, being able to access the Alternative Supports of affordable gym memberships offering group classes and long-term social benefits will affect my physical health and wellbeing, and social connections are so important to my general lifestyle and mental wellbeing.

Critical issue: access to specialist treatment in regional, rural and remote areas is limited, so mainstream support may be their only feasible option.

Critical issue: does not represent value for money. Someone with young onset Parkinson's could have an exercise protocol prescribed to them by an Exercise Physiologist but pay much less for a gym membership to do the exercise close to home and possibly with friends who attend the same gym, thus increasing social interaction, combatting apathy (another symptom of PD) and inclusion in mainstream supports.

Critical issue: cosmetic procedures like tattoo eyeliner, lipliner or eyebrows can be a cost-effective way to help maintain dignity for those women living with PD that have tremor and stiffness. As they can no longer put on their make-up to the standard that they used to, these simple and low-cost procedures can make a world of difference to their self-esteem, mental health and maintain their participation in social activities.

- Play equipment where it is specialist sensory equipment could be funded under Assisted Technology
- Additional insurance costs that arise from modified vehicles
- Additional costs to upgrade standard household items to household items that include accessibility features

Not value for money/not effective or beneficial

Description

Alternative and complementary therapies:

- Crystal therapy
- Tarot card reading, Clairvoyants
- Cuddle therapy
- Reflexology
- Aromatherapy
- Sound therapy

- Yoga Therapy

Man, age [REDACTED], living with Young Onset Parkinson's in [REDACTED] & care partner

Yoga should be reconsidered, especially where geographical location or market deficiencies limit participants' access to supervised EP services that essentially translate to this activity if there can be periodical in-person or remotely provided EP supervision and instruction. Much of the exercises in the EP program designed to address my movement goals and symptoms are yoga-based poses to combat my muscle rigidity. If I can do these locally and more regularly, I will have greater benefits in terms of stress management, mood, and movement. This is another example of where an EP can prescribe a set of exercises and participants can get the same therapeutic value at a lower cost and closer to home.

Woman age [REDACTED], diagnosed at 27 with Young Onset Parkinson's in [REDACTED]

Due to having YOPD and therefore experiencing significant disabling symptoms and also side effects of some Parkinson's medication, I suffer from chronic stress, anxiety, pain, muscle spasms, obsessive rumination, depression, apathy and fatigue. I have been recommended by every medical healthcare professional, and it's scientifically proven that Yoga and Tai Chi, especially yoga, help reduce stress and anxiety and allow you to mediate the busy ruminating mind that sinks you deeper into depression.

Critical issue: access to specialist treatment in regional, rural and remote areas is limited, so mainstream support may be their only feasible option.

Critical issue: does not represent value for money. Someone with young onset Parkinson's could have an exercise protocol prescribed to them by an Exercise Physiologist but pay much less for yoga classes and possibly attend with friends who attend the same class, thus increasing social interaction, combatting apathy (another symptom of PD) and inclusion in mainstream supports.

Critical issue: Yoga is important for maintaining and improving mobility, joint flexibility, and posture and can also provide a great source of relaxation. As primary symptoms of YOP include stiffness, reduced range of movement, kyphosis, anxiety etc, yoga provides a deep, active stretch putting their bodies in varying postures, which is more beneficial than simple static stretching alone. Another benefit of attending a yoga class is that the sessions are always changing and provide a new challenge – and the social interaction, thus decreasing social isolation.

Evidence base: Yoga, as a mind-body therapy, used in PD rehabilitation as a simple, adaptable and effective complementary alternative therapy. Yoga training has been shown to be effective in improving motor symptoms, balance function and mood disturbances such as anxiety and fatigue.

Zhang T, Liu W, Bai Q, Gao S. The therapeutic effects of yoga in people with Parkinson's disease: a mini-review. *Ann Med.* 2023;55(2):2294935. doi: 10.1080/07853890.2023.2294935. Epub 2023 Dec 18. PMID: 38109929; PMCID: PMC10732191.

- Wilderness Therapy
- Alternative or complementary medicine

Wellness and coaching related:

- General massage

Woman living with Young Onset Parkinson's Dx 10 years,

Other therapies I have tried that work for me and have kept me working for ten years are massage, which helps manage my rigidity, stiffness and pain.

Care partner of man with Young Onset Parkinson's in [REDACTED] “Therapeutic massage that is directly related to a participant's disability support needs” is on the list as a carve out, but this is very hard to get. Not only does he use massage for pain management, reducing the disease's impacts around rigidity/muscle stiffness, stress, and dystonia; he has been seeing his therapist for over a dozen years. Massage through a PT is covered but costs twice as much and takes twice as much time due to the location of nearest services. We want to maximise his time for family, his other therapies and exercises to keep him well for longer. It also goes against choice and control for his preferred services providers.

Woman with Young Onset Parkinson's in [REDACTED]

What I generally struggle with is the access to utilise the benefits provided. I am still working, albeit part-time, but still working to maintain independence... especially if struggling on an 'off day' have access to alternative health facilities such as wellness retreats or spa, so as to alleviate stress and anxiety to be able to use a local massage centre, not a physio for ongoing massages to assist with being able to remain physically active.

Woman age [REDACTED], living with Young Onset Parkinson's, [REDACTED]

Prior to my diagnosis, I was seeing a physiotherapist and remedial massage therapist weekly over about two years to release the muscle spasms and help with pain relief. Getting a diagnosis was a long and painful road but was a huge relief to have done. Five years on, even though the medication has helped some of the symptoms, I still maintain fortnightly (I would go weekly if I could afford this) appointments for massage and physio to manage pain, muscle spasms and stress. Remedial massage is definitely a more cost-effective therapy; however, living off a disability pension makes it extremely difficult to fund these treatments.

Now, I not only have formed a great bond with my massage therapist, but the outcomes of my treatment have also been extremely beneficial. The importance of remedial massage therapy and physiotherapy in helping my condition cannot be understated, and they have been equally valued. Due to Parkinson's symptoms worsening from stress and anxiety, being able to maintain the same practitioners has been vital for my wellbeing, as it is stressful to have to repeat to various professionals the trauma my disability has caused me. Therefore, maintaining relationships with the same practitioners has been extremely important. I have experienced positive outcomes, such as my muscle and nervous system becoming less tense and more flexible, resulting in fewer injuries and improving my ability to do day-to-day activities with more ease. It has also improved my brain-to-body communication in that when the muscles and nervous system is more relaxed, the brain doesn't need to work as hard to tell my body to do simple things, such as “move this foot in front of the other”, after physio and remedial massage, it will actually compute and work together more seamlessly and does so for a prolonged time (over at least a few days).

Critical issue: access to specialist treatment in regional, rural and remote areas is limited, so mainstream support may be their only feasible option.

Critical issue: does not represent value for money. Someone with young onset Parkinson's could have a PT conduct massage but pay much less for massage from their preferred supplier.

Evidence base:

- Therapeutic massage was effective in improving motor symptoms in PD. It is suggested to be an appropriate form of CAM in treating PD. Kang, Zhiran, et al. "Effectiveness of therapeutic massage for improving motor symptoms in Parkinson's disease: A systematic review and meta-analysis." *Frontiers in Neurology* 13 (2022): 915232.
<https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2022.915232>
- All the articles had positive physical therapy results in treating pain in people with PD. It is concluded that land and aquatic physical therapy methods improve the levels of pain in PD patients. Henemann, Thays Tanner, et al. "Physical therapy interventions to manage pain in Parkinson's disease: A systematic review." *Human Movement* 24.3 (2023): 31-43.
- Massage therapy can be considered as an effective therapy for improving sleep quality in patients with PD. Tang, Rongzhu, et al. "Efficacy of non-pharmacological interventions for sleep quality in Parkinson's disease: a systematic review and network meta-analysis." *Frontiers in Neuroscience* 18 (2024): 1337616.
- There is a wide range of safe massage techniques with beneficial effects on both motor and non-motor symptoms of PD. Efthalia Angelopoulou, Maria Anagnostouli, George P. Chrousos, Anastasia Bougea, Massage therapy as a complementary treatment for Parkinson's disease: A Systematic Literature Review, *Complementary Therapies in Medicine*, Volume 49, (2020), 102340, ISSN 0965-2299, <https://doi.org/10.1016/j.ctim.2020.102340>.
(<https://www.sciencedirect.com/science/article/pii/S0965229919319272>)

- Sports or athletic supplements
- Life/wellness/career coach/cultural coach

Woman ■ living with Young Onset Parkinson's Dx 10 years, ■

I have previously engaged a life coach to help me continue to set goals and priorities. Living alone makes decision-making hard when Parkinson's has taken some of my cognitive ability. I don't need a psychologist; I need a coach.

- Hypnotherapy
- Neurofeedback
- Gaming therapy
- Mastermind coaching
- Somatic therapy
- Kinesiology

Energy and Healing Practices related:

- Reiki (including intuitive reiki), Scalar Lounge, Frequency Healing and Energy balanced massage, Deep Energy Clearing, Spinal Flow Technique, Shamanic Healing

Beauty Services related:

- Hair therapy, hair and beauty services including nail salons

Woman age [REDACTED] diagnosed at 27 with Young Onset Parkinson's in [REDACTED]

Due to having YOPD and therefore experiencing significant disabling symptoms of dyskinesia/ dystonia and tremor and extreme pain, I am no longer able to manage my own removal of hair and nails having to use a nail salon service and hair removal technician for this ongoing care. This is important to me particularly vital for such aspects such as self-esteem, social isolation, and self-care challenges. The need for loss of these services will impact my day-to-day life, making me isolated and embarrassed to be out in public, especially given that YOPD makes it difficult to manage your own hair and nails.

Due to having YOPD and therefore experiencing significant disabling symptoms of dyskinesia/ dystonia and tremor and extreme pain, I am no longer able to manage my own hair washing and styling as I have very long thick coloured hair which is messy and looks unkept and out of control if I don't blow dry straight or curly. I think it is vital to be able to access funding for a weekly wash at the hairdressers. This is important to me particularly vital for such aspects such as self-esteem, social isolation, and self-care challenges. The need and loss of these services will impact my day-to-day life, making me isolate being Embarrassed to be out in public especially given YOPD makes it difficult to manage your own uncontrollable hair. Also keeping it well-groomed and controlled makes it less voluminous and hot on your neck.

Care partner of man with Young Onset Parkinson's in [REDACTED]

He has not been able to cut his own toenails for years due to Parkinson's. He now sees a podiatrist for a medical pedicure regularly, but even more cost-efficient would be to see a nail technician if no other medical foot issues exist. He does not want me to have to cut his nails to maintain his dignity and a level of intimacy.

Critical issue: access to specialist treatment in regional, rural and remote areas is limited, so mainstream support may be their only feasible option.

Critical issue: exclusion does not represent value for money, a support worker would cost more to perform this function rather than services at a hairdresser which also represents independence for the participant and improves dignity.

Critical issue: does not represent value for money. Someone with young onset Parkinson's could have a nail salon cut their toenails but pay much more from a podiatrist or support worker.

Carve outs that may be considered 'NDIS supports' for certain participants

- Therapeutic massage that is directly related to a participant's disability support needs

Mainstream – Health

Description

- The diagnosis and clinical treatment of health conditions, including ongoing or chronic health conditions

Woman with Young Onset Parkinson's in [REDACTED]

We need to be able to seek assistance for younger women going through menopause as it is a very difficult time to cope with mentally and physically, on top of my PD symptoms.

- Diagnostic assessments and screening services.
- Time-limited, goal-oriented services and therapies:

- where the predominant purpose is treatment directly related to the person's health status, or
- provided after a recent medical or surgical event, with the aim of improving the person's functional status, including post-acute rehabilitation or post-acute care
- Any pharmaceutical
- Any equipment or assistive technology prescribed as a result of clinical care, treatment or management from a medical practitioner delivered in the context of clinical care.
- Acute, subacute, emergency and outpatient clinical services delivered through public or private hospitals.
- Prescription medicines, non-prescription medicines, biological medicines, vaccines, sunscreens, weight loss products, vitamins, sport and athletic supplements, homeopathic medicines, prescription glasses
- Nursing services (where related to treatment of a health event)
- Ambulance services or membership
- Health transport services
- Hospital in the home services
- Sleep consultant services.
- Health retreats
- New-born follow-up provided in the health system, including child and maternal health services
- Specialist clinical palliative care

Carve outs that may be considered 'NDIS supports' for certain participants

- Disability-related health supports where the supports are a regular part of the participant's daily life, and result from the participant's disability. This includes continence, dysphagia, respiratory, nutrition, diabetic management, epilepsy, podiatry and foot care, and wound and pressure care supports.
- Jointly with other parties, provision of specialist allied health, rehabilitation and other therapy, jointly with health services, to facilitate enhanced functioning and community re-integration of people with recently acquired severe conditions such as newly acquired spinal cord and severe acquired brain injury.
- Thickeners and nutritional supplements related to disability-related nutrition supports.

Mainstream – Mental Health

Description

- Any pharmaceutical
- Treatment for drug and alcohol dependency, eating disorders, gambling and other addictions.

Care partner of man, age [REDACTED], living with Young Onset Parkinson's in [REDACTED]

Some of these Impulse Control Disorders (ICDs) can be a direct side effect of Parkinson's medications, and though my husband has not been affected thus far, it is a possibility, and he would require intervention through no fault of his own but directly due to the Parkinson's. This help for treating ICDs and Parkinson's should come from the NDIS.

- Acute, subacute emergency and outpatient clinical services delivered through public and private hospital mental health services.
- Supports related to mental health that are clinical in nature, including acute, ambulatory and continuing care, rehabilitation
- Any residential care where the primary purpose is for inpatient treatment or clinical rehabilitation, or where the services model primarily employs clinical staff

Carve outs that may be considered 'NDIS supports' for certain participants

- Ongoing psychosocial recovery supports

Mainstream – Higher Education and Vocational Education and Training

Description

- School fees
- Any supports for students that primarily relate to their education and training attainment
- Building modifications to TAFEs and university campuses
- Services from a person employed at the participant's higher education facility
- Learning assistance and aids
- Teaching assistance and aids
- Textbooks and teaching aids (including alternative formats)
- Transport between education or training activities

- General education to employment transition supports

Carve outs that may be considered 'NDIS supports' for certain participants

N/A

Woman with Young Onset Parkinson's in [REDACTED]

I believe that being younger and coping with life and Parkinson's, it's very important to have an inclusion where we can re-skill or retrain. Many people are scared to talk to their bosses about life with Parkinson's. I feel it's important that we can retain our independence and this would be especially applicable.

- Work-specific aids and equipment required to perform a job (including modified hardware and software)
- Reasonable adjustments to access a workplace
- Work-specific support related to:
 - recruitment processes,
 - work arrangements or the working environment, including workplace modifications, work-specific aids and equipment,
 - transport within work activities and
 - work-specific support required in order to comply with laws dealing with discrimination on the basis of disability
- Employment services and programs, including both disability-targeted and open employment services, to provide advice and support to:
 - people with disability to prepare for, find and maintain jobs
 - employers to encourage and assist them to hire and be inclusive of people with disability in the workplace (i.e. support, training and resources, funding assistance to help employers make reasonable adjustments, and incentives for hiring people with disability, e.g. wage subsidies)

Carve outs that may be considered 'NDIS supports' for certain participants

N/A

Man living with Young Onset Parkinson's & care partner [REDACTED]

In 2016, I found myself attending my first-ever neurology appointment.

My parents had made it a priority to accompany me on the five-hour drive, from regional South Australia to suburban Adelaide.

It was the culmination of a journey that had taken five years and thousands of kilometres around the western portion of our continent.

Starting with small but very noticeable stuff; the odd tremor in my right hand and occasional facial fasciculations to full-on random runs along my right calf muscle* early in my adult apprenticeship, commencing February 2011.

By the time I had completed my FIFO apprenticeship, at an isolated copper mine in northern S.A., my balance, posture and movement were significant concerns for me, as well as overwhelming bouts of anxiety, clouding my cognitive ability* in situations at work.

I had also been embarrassed on occasions, as a deputy safety representative for my work group, when I had to step up and take our monthly meetings, being told that I could act as though I was interested by management; my voice was monotonal and often inaudible, delivered with a deadpan face.*

*With many of these classic Parkinson's Disease symptoms, and others, openly on display, I believe my chances of a much earlier diagnosis would have significantly increased had I not lived and worked in regional Australia. As it was, the first practitioner to recognise the condition was a physiotherapist in Karratha, W.A., where I was working and living at the time. It would be another three months before I found myself at the neurology appointment above in a suburban Adelaide practice.

As with any condition early intervention is essential to give sufferers the best quality of life outcomes.

It seems ridiculous to me that I can go from a situation where I was earning good money, paying tax, making contributions to my superannuation, and paying mortgages on two properties, whilst contributing support to my two children to the situation I now find myself in.

Where is my safety net? Is it my fault I now find myself here? Where was the medical expertise I needed four or five years earlier? The GP's and allied health workers with the experience and expertise?

Later in 2016, I attended a 50th birthday party. Mine.

My beautiful daughter had organised a get-together at a local hotel.

Far from being a celebration of the next phase of my life, setting myself up for a nice retirement and being able to help my kids out, I found myself in a situation where tough decisions had to be made.

Now I am being asked to make a submission to our federal representatives about proposed changes to the NDIS.

I cannot believe that they are serious.

Until recently I had private health insurance, which I called upon whilst I was employed and prior to being accepted by the NDIS.

I was covered for seven physiotherapy appointments a year and still had to pay out of pocket expenses!

I now hear that there are proposed 'carve-outs' for early intervention!

After the experiences I have alluded to above, our government representatives must be living in an alternate universe.

Do they seriously expect our health system to pick up the slack?

In this life, I am expected to take responsibility for myself. This was the mantra drummed into me as I grew up and this was the mantra I believed best an employed adult.

When I was diagnosed with Parkinson's I decided the best option for me was to relocate to Adelaide. Better for treatment and better for employment, however, to achieve these goals, I had to leave my home and my family.

Thanks to family, I found work as a labourer whilst undergoing treatment.

I then found better paying employment, in the field of electrical distribution, in my old trade, as a linesman.

I signed with an employment agency, for support in continuing my employment as a linesman. The agency encouraged me to disclose my condition to my employer, the reasoning being I could be held liable for damages as a result of a workplace accident, had I not given my employer the opportunity to mitigate risk due to my condition.

The result: stood down with pay, pending an 'independent' assessment, and an eventual agreement to be reassigned as a 'depot assistant', along with an accompanying pay-cut, from \$70,000 p.a. as linesman, to \$50,000 p.a.

Shortly after I needed a hip replacement, with insufficient leave, whilst paying mortgages on two properties and my share of the rent on my 'new' Adelaide dwelling. I was surviving on credit cards and eventually sold one of my properties at the bottom of the market for a loss of approx. \$90,000.

In mid-2018, via an interstate labour-hire firm, I was a linesman again and managed to stay with this until mid-2019; when undergoing medical assessment for a full-time position, medications for my condition raised concerns, and I was let go.

(During this period, I sold my remaining property at a loss of \$200,000.)

My employment agency signed me to the job-seeker side of their business. I received interest from a training company and also expressed interest in electrical drafting, which I had previous experience in at Roy Hill, during construction.

However, once the training company's HR became involved, interest fell away and as far as retraining, my agency reserved their budget for younger jobseekers, and I was advised to apply for HECS.

Retraining in electrical drafting may have led to an extended period in employment, and the possibility of managing my workload with treatment and therapy.

Fortunately, my wife has been supportive, although this has not been a great outcome for her in terms of finances. She has had to draw down significantly on her mortgage, something I feel ashamed of, as she shouldn't have to be responsible for that. She bears enough of a burden caring for me.

I paid my taxes, where's my safety net?

I don't want to be a drain on resources.

I don't want to be a burden, but I feel like I am being punished when I see the news cycle spin about the NDIS.

Egalitarian Australia?

Mainstream – Housing and Community Infrastructure

Description

- The provision of accommodation for people in need of housing assistance, including routine tenancy support
- Ensuring that appropriate and accessible housing is provided for people with disability, other than participants eligible for specialist disability accommodation (SDA)
- Ensuring that new publicly-funded housing stock, where the site allows, incorporates Liveable Housing Design features
- Homelessness-specific services including homelessness outreach and emergency accommodation.

Woman age [REDACTED], living with Young Onset Parkinson's, [REDACTED]

NDIS has an understanding of disabilities; no other services understand the complexities that come with facing homelessness while dealing with a disability. It is important to support somebody with a disability and keep them away from homelessness as much as possible. Otherwise, the compounding impact it will have on the individual could end up putting them in a compromising position, worsening their disability symptoms and putting more pressure on the system- therefore creating a bigger problem. Majority of people with a disability are often disadvantaged to the point of being under the poverty line. It is unrealistic to expect people in these circumstances to be able to outsource things such as homelessness-specific services and programs, etc.

- The improvement of community infrastructure, i.e. accessibility of the built and natural environment, where this is managed through other planning and regulatory systems and through building modifications and reasonable adjustment where required
- Postal services
- Housing subsidies (e.g. rental bonds, mortgage relief and assistance with buying a home)
- Crisis housing (excluding discharge from hospital, aged care)
- Mortgage payments.
- Rental payments
- Mobile homes, caravans, campervans, tents
- Purchase of land, or house and land packages

- Land taxes and levies
- Council rates and taxes

Carve outs that may be considered ‘NDIS supports’ for certain participants

- Medium term accommodation if you have a long-term home you will move into after MTA but you can’t move into your long term home yet because your disability supports aren’t ready and you can’t stay in your current accommodation while you wait for your long term home.
- Delivery fees for NDIS supports (e.g. delivery of assistive technology)

Mainstream – Transport

Description

- Accessible public transport
- Public transport fares
- Concessions to facilitate use of public transport
- Airline lounge memberships
- Transport costs for pets and companion animals.
- Transport infrastructure, including road and footpath infrastructure
- Community transport services
- Modifications to public transport and taxis

Carve outs that may be considered ‘NDIS supports’ for certain participants

N/A

Woman with Young Onset Parkinson’s in [REDACTED]

As for living in a regional area, access to Parkinson’s support group meetings are a minimum 2 hours away, so impossible to join in and prohibitive in costs to travel as I am not able to receive any travel assistance. This places undue financial strain.

Critical issue: Options for people in RRR to connect with others living with the same condition should be considered. Social isolation is as bad for people living with Parkinson’s as not doing exercise is for them and may lead to further deterioration of mental health and exacerbate the existing anxiety, apathy and depression that comes with PD..

Mainstream – Justice

Description

- Supports in secure mental health facilities which are primarily treatment focused (clinical in nature)
- Supervision and monitoring of offenders
- The day-to-day care and support needs of a person in custody, including supervision, personal care and general supports
- Pre-sentence psychological and psychiatric reports
- Secure accommodation facilities where the purpose of this accommodation is to safeguard the community or prevent reoffending, including secure mental health facilities.

Carve outs that may be considered 'NDIS supports' for certain participants

N/A

Mainstream – Aged Care

Description

- Aged care services

Carve outs that may be considered 'NDIS supports' for certain participants

- Supports for an NDIS participant under the age of 65 who chooses to live in residential aged care and purchase support from an aged care provider

Woman with Young Onset Parkinson's in [REDACTED]

None of the YOPD would want to be in an aged care facility, but to my knowledge, there are no specialist facilities for YOPD patients who need assistance, who perhaps struggle to undertake daily activities, and who want to live independently.

Critical issue: Options are needed for people under the age of 65 who require higher needs and are otherwise forced to enter into age care.

Unlawful goods and services

Description

- A support the provision of which would be contrary to:

- a law of the Commonwealth
- a law of the State or Territory in which the support would be provided.
- Assistive technology, vehicle modifications or home modifications that do not meet state and territory laws, the National Construction Code or relevant Australian standards
- Supports involving restrictive practices that are not authorised in the participant's state or territory of residence
- Illicit drugs or other consumable products that are against the law
- Firearms and weapons
- Seclusion rooms

Carve outs that may be considered 'NDIS supports' for certain participants

N/A

Income replacement

Description

- Income support payments
- Rent subsidy
- Loan repayments or buy now pay later payments.
- Income protection insurance
- Fringe Benefits for staff or contractors
- Cryptocurrency, shares, investment products

Carve outs that may be considered 'NDIS supports' for certain participants

N/A

Parkinson's Australia Submission Summary

Parkinson's Australia wants to ask further questions about this INs list, including how things that have an evidence base developed around them into the future, so that emerging therapies/interventions are included, can be added to the list?

We also want to emphasise these critical points, if the NDIS is all about choice and control and people are funded a certain amount for e.g. core supports or capacity building, they should have the choice to use mainstreams supports when that option costs less and keeps them engaged in their community than specialist services (often costly and inaccessible for regional people):

1. **Flexibility in Support:** We highlight the importance of flexible support options that can be tailored to the unique needs of individuals with Parkinson's.
2. **Cost-Effectiveness:** We stress that the proposed supports should be cost-effective, replacing or supplementing existing specialist supports with mainstream options without increasing the overall budget. This also goes for technologies like smart phones and smart watches that replace a myriad of other devices to help manage symptoms and has a falls alert and location services function. We also argue for the common sense approach to funding dishwashers/ washing machines/ dryers / hair dressing / nails as a lower cost option over time of having a support worker do the same things for you and maintains more independence for the person living with disability.
3. **Outcome-Based Support:** NDIS should ensure that any new supports provide equal or better outcomes for participants in terms of ability to use the plan, access to services (be it mainstream or specialist), increase in attendance to needed therapies and exercise facilities.
4. **Inclusive Consultation:** DSS/NDIS needs to address the need for more inclusive consultation processes, especially for those in regional, rural, and remote areas, and those from culturally and linguistically diverse (CALD) backgrounds. The timeline for people with disability to be contribution should be a standard month-long period as they need time to digest the complexities of the list and prepare their thoughts and get help to respond if necessary.
5. **Comprehensive Support for Daily Living:** People with young onset Parkinson's and Parkinson's Plus conditions often face unique challenges that require comprehensive support. It is crucial that the NDIS provides adequate assistance with daily living tasks, including age-appropriate personal care, mobility support, and assistance with household activities. This support should be tailored to the progressive nature of these conditions, ensuring that participants can maintain their independence and quality of life for as long as possible.

6. Access to Specialised Therapies: Access to specialised therapies, such as physiotherapy, occupational therapy, speech pathology, and psychological support, is essential for managing the symptoms of Parkinson's and Parkinson's Plus conditions. These therapies can significantly improve the physical and mental well-being of individuals, helping them to manage symptoms and maintain their functional abilities. The NDIS should ensure that funding for these therapies is readily available and accessible to all participants who need them. When they are not available, e.g. RRR participants should have choice and control as to how they can best use their capacity supports within the mainstream options available to them.

7. Support for Employment and Education: Many individuals with young onset Parkinson's and Parkinson's Plus conditions are of working age and may wish to continue their employment or pursue further education. The NDIS should provide robust support for employment and education, including workplace modifications, assistive technologies, and job coaching. This support is vital for enabling individuals to remain active and engaged in their professional and educational pursuits.

8. Assistance with Mobility and Transportation: Mobility challenges are a significant concern for people with Parkinson's and Parkinson's Plus conditions. The NDIS should offer comprehensive support for mobility aids, such as wheelchairs, walkers, and other assistive devices. Additionally, transportation assistance, including funding for accessible transport options, is essential to ensure that participants can attend medical appointments, therapy sessions, and community activities.

9. Flexibility and Individualised Planning: Given the progressive and variable nature of Parkinson's and Parkinson's Plus conditions, it is essential that the NDIS adopts a flexible and individualised approach to planning and support. Participants should have the ability to adjust their plans as their needs change over time, ensuring that they receive the most appropriate and effective support throughout their journey.

In conclusion, I urge the Department of Social Services to consider these recommendations to ensure that the NDIS provides comprehensive, accessible, and flexible support for individuals living with young onset Parkinson's and Parkinson's Plus conditions under the age of 65. Thank you for the opportunity to provide feedback on this important matter.



Parkinson's Australia Ltd
info@parkinsons.org.au
0407 703 328

ACN 671 516 822
ABN 46 011 714 078
parkinsons.org.au

