

Submission to the Arts and Disability Consultative Committee

Submission by a person with late-stage, young-onset Parkinson's disease (PD)

As invited, I am telling my story in this submission. Whilst I am disabled by Parkinson's disease, and advocating for those with PD, I believe that the issues I raise are relevant to people with a broad range of disabilities.

In telling my story, I have kept in mind the four priority areas identified by the Commonwealth Government's Cultural Ministers in the National Arts and Disability Strategy. Those priority areas are:

1. Addressing barriers to access and participation
2. Supporting arts and cultural practice amongst people with a disability
3. Developing audiences for disability arts companies and individual artists, and
4. Improving policy development and planning within governments

I have provided my own headings to tell my story. These intersect with the priority areas identified above. At the conclusion of this submission, I have made suggestions for improvement under the four priority area headings.

1.0 The Importance of the Arts: How to Access, Enjoy and Benefit from them when Living with Parkinson's Disease

1.1 Access and Barriers to Participation

I still find it difficult to identify as disabled although I'm frequently reminded by the things that I can no longer do for myself. After many years with young onset Parkinson's, thanks to physical therapy, modern technology and modern drugs, I am still able to live alone and be independent. However, I am often constrained by the difficulty of getting to places on my own, especially by public transport. I was unable to get to the face-to-face consultations in Victoria as they were in places I couldn't easily access on my own by public transport. I can drive locally and use public transport where I can. I use taxis for longer distances, but even with a half price taxi card, and some support from NDIS, the costs can become prohibitive.

I live in [redacted], and while I welcome the new trams on our route, along with many other ambulatory disabled people I can find them terrifying. The seats reserved for disabled, pregnant, or injured people are orange in the big new trams. They are often on the opposite side of the tram to the doors, and they are very thinly spread. I know I'm not alone in being unable to cross the cavernous tram to reach one safely, before the tram starts moving. If it starts moving while I'm standing, I will fall. The tram probably starts moving about 75% of the time before I reach a seat. I have not yet fallen flat on my face and this is entirely due to the kindness of strangers who either hold onto me, or catch me. Fortunately I am a small person. This whole scenario could be avoided if all the seats next to an entry door were orange. This would not make fewer seats available to able bodied people as they could still sit on them when no disabled person needs them. It would make the tram journey to any arts precinct less alarming to disabled people as well as causing less anxiety to the kind strangers who rescue them.

Generally, I find trains easier to access than trams (once I've reached the station) because they do have adequate disabled seating on either side of the doors, on both sides of the train.

- **This seating arrangement should be adopted by trams.**

I never travel in the rush hour or to anywhere that I know is crowded because there is a very high chance I'll fall or be knocked over. There is no simple solution to this problem. It's part of big-city life. Perhaps some performances or showings could be held at time, or in places, more amenable to disabled access.

I am fortunate that I have friends and family who companion me on outings so that I can enjoy theatres, cinemas, galleries and other places where the arts are displayed in all their forms. Crowding is probably the one problematic constant in such places where I never venture alone.

I have a companion card which I find incredibly useful for visiting venues that accept it. It is probably my best support in terms of being able to access galleries, cinemas, museums and other places where I'm a passive participant in enjoying other people's creative productions. The companion card allows my companion in for free.

- The companion card could be extended with government funding to increase the number of participating venues.

Disabled access to facilities such as toilets and parking spaces is not adequately policed. The same goes for disabled parking. It is no fun to arrive at a venue with one's companion and to find some disabled spaces taken by the able-bodied ("there was nowhere else to park"). This is also an issue for disabled toilets.

- A solution to this problem might be to make signs more forceful. The addition of ONLY or STRICTLY might make people think twice about using disabled facilities. Fines for unauthorised parking in disabled spaces should also be increased.

Aside from the frustrations or worse (I cannot stand in a queue for more than a few minutes before my whole body becomes dystonic, which can lead me to be unable to speak or walk without assistance) the kindness of strangers is a gift that keeps on giving.

- All venues should have seats (identified for preferential use like those on trams, trains and stations) close to where queues form, but also in foyers, and open spaces, so that seating is always available for those who cannot stand for long (there are many conditions that are associated with this including postural hypotension – common in PD, spinal canal stenosis, arthritis, dystonia);

One of the things that makes accessing art more difficult for people with PD is that there is very limited understanding in the wider community that Parkinson's is a progressive disease that doesn't necessarily follow a desultory pathway. Not only can severe stress cause a jump in disease progression, but it can also cause an immediate and rapid deterioration in motor function. In addition, people with PD, especially with later stage disease, are extremely susceptible to 'on' 'off' cycles that depend on the amount of dopaminergic drugs in their system. When they go 'off' their motor symptoms (and anxiety levels) increase markedly so the timing of drug doses is important.

- To minimise being forced to stand and wait, reliable timetables, and supported seating at all tram stops, as well as at arts events is vital.

1.2 The impact of creating art on my disability (PD): My story

I have always loved drawing and painting and even when young used writing and drawing as a way of dealing with stress. [redacted] I vowed that if I ever had the chance I would study [redacted] art. The chance came earlier than I wanted or expected when I developed young onset Parkinson's disease. I struggled for nearly ten years without a diagnosis, [redacted]. Ultimately I could no longer work at my hard-won career as a [redacted] and I was forced to return to my home town in the hope that could get appropriate medical care. Like many people with PD I had a co-existing disease, that had apparently confused the diagnostic picture.

Once under the care of a skilled movement disorder specialist my condition improved somewhat and I discovered that [redacted] art classes were held nearby. I enrolled under the tutelage of a well-known artist who noticed at once that I couldn't do the fine brushwork required [redacted]. I've never had obvious resting tremors in my hands but would develop them if I attempted to use my fine motor skills, I had lost my lightness of touch. She saw that my drawings were very bold and realised that I could only draw without a tremor if I applied quite a lot of pressure. I could thus never be a [redacted] artist using the classical water colour approach. She then suggested something that would change my life. She proposed that I try using water colour pencils instead of watercolour paints. This was a wonderful idea because I could press quite hard with a finely sharpened pencil. I break the tip off all the time and close inspection of any of my pictures would reveal this.

Over time I developed my own Parkinson's approach to drawing. I start my drawing by using a graphite propelling pencil and apply as light a touch as I can to get the outline or form of what I'm drawing. I never let people see my drawing at this early stage of a picture because the outline is composed of wavy jittery lines that look as though a daddy longlegs dipped in soot has wandered over the page. Next I use my electric eraser to rub out most of my wavy outline. My drawing now looks like something from a children's join-the-dots book. Then using an undercoat watercolour pencil for whatever I'm drawing (eg using the colour May Green for a leaf) I fill in the outline with firm lines. This is how I make my art [redacted].

[redacted] By 2014 I was unable to sustain drawing because of the pain in my shoulder from holding down my work.

I wanted to make a contribution to society. Art made me feel so good and as I thought that I could help others through art. [redacted] I began studying Creative Arts Therapy at [redacted]. Because I had been trained in [redacted], this opened up a whole new sphere of learning for me. My hopes were to complete the Masters, but the overwhelming fatigue of PD felled me in the end, and I had to be content with earning a Graduate Certificate. I'm still hoping that I can use the qualification to help others with PD and other progressive illnesses.

By early 2016 I was still having trouble drawing because of the pain from holding up my left arm. I was then fortunate to be treated by an OT and a physiotherapist specialising in PD. [redacted] This helped me to develop strategies to avoid freezing, which had blighted my life and was making me somewhat reclusive. The OT set me up with a 'work station' with a tilt-top table on wheels, and a chair of the right height that gave me postural support. After two years in which I'd agonisingly completed one drawing, I was able to draw freely again. Like many other people with PD, fatigue was a major problem for me, so the OT asked me to record how long it took me to fatigue for every physical and intellectual task I did. To my astonishment, while I could only do some tasks for 5 or 10 minutes, once set up, I could draw all day. I was astonished.

By good fortune I am able to access academic journals. I read a number of art therapy papers, though those that seemed most relevant were about dementia. I was delighted when I discovered the concept of 'flow'.

'Flow refers to a state of intense concentration, satisfaction, and enjoyment that is experienced when one is engaged in an intrinsically rewarding activity'¹. Flow can be felt in any of the arts, whether creating them or being lost in the creations of others. Engaging in drawing, writing, painting, music, dance and drama can all lead participants, whether active or passive, to experience flow.

When I am drawing, the world and all its worries disappear. I escape from my illness and the heightened anxiety that is a symptom as well as a consequence of it.

*I must point out that my recognition of art as a therapy for Parkinson's disease was well behind that of Parkinson's Victoria which has had a Painting with Parkinson's peer support group meeting weekly in Berwick for 10 years. There is a successful group in Torquay, and there are proposals to establish new groups in Geelong and the Bellarine Peninsula.

1.3 The Importance of vision to people with Parkinson's disease

There are many things that I have come to know about Parkinson's disease. I have come to know some things from my lived experience of PD, and I have come to know other things in my quest for knowledge about PD. This quest for knowledge stems from an intuitive response to the old adage 'Know thine enemy'.

Again, accessing the journals in my university's library (I am engaging in research, just not in my usual discipline) I have been able to read the latest articles about Parkinson's disease. One of my lived experiences of PD concerns my vision, which seems to have been affected in a myriad of ways. Long before I was diagnosed, my optometrist noticed that my pupils did not react to light symmetrically. He also noticed that I had 'measurable fatigability of the ciliary muscles'. I noticed that my eyesight was rapidly deteriorating, that outlines were not as 'bold' and that I had as

¹ Chancellor, B, Duncan, A and Chatterjee, A (2014), 'Art therapy for Alzheimer's disease and other dementias', *Journal of Alzheimers's Disease*, 39: 1-11; (p.5)

much trouble with distance vision as I did with age-related visual deficits. I, who had always had 20/20 vision became short and long sighted at the same time.

I also noticed that I had strange reactions to certain shapes or colours. Once I went to see a pain specialist physiotherapist. He had a gorgeous modern rug on the floor. It was of abstract design and very brightly coloured. Once I set foot on it I froze. I couldn't lift my feet. I have a similar problem with walking on dots or spots, which causes some difficulty because they border every pedestrian crossing, and block the path to every stairway. At first I thought the problem was because they are bumpy, walking on them does cause some difficulty, but then I realised just looking at them was enough to freeze me. I now step over them while trying not to look at them. It is clear that these dots are vital for blind people to be able to identify the borders of roads, stairs and escalators. However, it is important to recognise that they do present a barrier to access for many of the ambulatory disabled.

I also used to trip over shadows, or freeze at the sight of something crossing my path. Things rushing past me, like trains at a station, could topple me.

I thus came to know that there is something very visual about PD, but what I did not know.

Lest it be thought that I'm negative about everything I'd like to add that my vision loves lines. I can follow them with ease. Give me lines to follow on the footpath, road or swimming pool and I'm as happy as can be.

- **In order to improve them for everyone, including the blind and visually impaired, research and redesign the areas of dots, near roads, stairs, escalators, railway platforms etc, in consultation with advocates for the blind, PD advocates, advocates for the aged, disability advocates, physiotherapists and OTs**

I began to realise that there were numerous different changes that affect vision in PD, but also that things I was seeing could act as blocks or pathways to movement. I suspected that my focus on the very visual nature of drawing, and the relief from fatigue while engaged in it might not be a coincidence. I'm aware that there are painting groups for people with PD, and though the tyranny of distance has prevented me from engaging with them, I know I'm not alone in experiencing and noticing the importance of the visual arts in particular to some people with PD.

- **Provide funding to Painting with Parkinson's so that it is accessible to all PD people**

In my quest to understand why, or how this might be so, I came upon a very recent journal article with the rather forbidding title; 'Visuospatial exploration and art therapy intervention in patients with Parkinson's disease: an exploratory therapeutic protocol'².

The basic premise of the paper seems to be that people with PD suffer from visuospatial dysfunction which, among other things, has been linked to gait impairment. Further, the authors argue that 'art creation relies on sophisticated neurologic mechanisms including shape recognition, motor perception, sensory-motor integration, abstraction and eye-hand coordination'³. As well as the motor impact of creating art, a range of non-motor benefits are identified. These include 'self-awareness, relaxation, confidence and self-efficacy'.

In short, the authors' belief in the benefits of art to people with PD is so strong that they are proposing a protocol to use art therapy as a means of improving a large number of motor and non-motor functions that cause significant morbidity and misery to PD patients and impose a large and growing cost on society.

- **Governments should fund more research into the visuospatial aspects of PD. More knowledge in this area could alleviate some of the motor and non-motor symptoms which impose a large and growing costs on PD sufferers, and on society**

² Cucca, A, Acosta, I, Berberian, M, Lemen, AC, Rizzo, JR, Ghilardi, MF, Quartarone, Feigin, AS, Di Rocco, A, and Biagioni, MC (2018), 'Visuospatial exploration and art therapy intervention in patients with Parkinson's disease: an exploratory therapeutic protocol', *Complementary Therapies in Medicine*, 40: 70-76; p.70

³ (Cucca et al, 2018, p. 70)

1.4 Art as therapy

I have little doubt that much of what applies to people with PD in regard to the benefits of participating in the arts, and particularly in art, can be extrapolated to others with physical, cognitive and emotional disabilities. I consider engagement in creating art as a therapy.

In the paper mentioned above the authors refer to Art Therapy as a 'modality of neurorehabilitation'⁴. Art therapy has been recognised for quite some time as being an effective therapy for people with dementia⁵ as well as being helpful for cancer patients suffering from depression and fatigue⁶

Music and dance therapy are among other arts therapies that have been shown to help people with PD⁷

I feel that art therapy for various abilities and disabilities should be made more widely available, especially in a community setting, where people feel reassured that they belong, rather than being isolated in a medical setting. This would probably require additional financial support from local, state and Commonwealth governments but would likely provide significant social benefits that would offset additional costs.

- **Community arts based arts courses, accessible to all, should be widely promoted within the community (eg libraries, local government headquarters, local papers)) as well as on the internet.**

1.5 Recognition, quality and visibility of work by disabled artists

There is a number of organisations that promote and assist disabled artists. Arts Access Victoria (AAV), to whom my local Brotherhood of St Laurence/NDIS linkage coordinator referred me, has been very supportive and organised a solo exhibition for me at the Skin Gallery in Carlton. The Skin Galley is located on the premises of the Skin and Cancer Foundation and is an ongoing joint venture with AAV. AAV is very active in supporting and promoting the work of disabled artists.

AAV states that it: "is dedicated to an ambitious agenda of social and artistic transformation for people with disability, the communities in which they live and the arts sector in which they aspire to participate without barriers⁸".

AAV works with numerous organisations to this end and I'm only just becoming aware of the scope of its collaborations. AAC works with Rotary to produce the Ignite catalogue which showcases, leases and sells the work of disabled artists. It also runs a disability film festival in collaboration with Screen Australia and the City of Melbourne, with financial support from the Commonwealth Government, The Australia Council and the Government of Victoria. The festival supports the work of deaf and disabled artists.

I have only recently become aware of the extensive involvement of AAC and I believe that the wider community should also be made aware of its far-reaching programs, the full range of which can only be appreciated only by referring to its website⁹. I suspect that AAC's work is currently only broadly known through friends, relations and

⁴ (Cucca et al, 2018,

⁵ See, for example, Chancellor et al 2014, and Stewart, EG (2004), 'Art therapy and neuroscience blend: Working with patients who have dementia', *Art Therapy: Journal of the American Art Therapy Association* 21 (3): 148-155;

⁶ See, for example, Bar-Sela G, Atid, L, Gabay, N, and Epelbaum, R (2007) 'Art therapy improved depression and influenced fatigue levels in cancer patients on chemotherapy', *Psychooncology* 16 (11): 980-4;

Joly, F, Pasquier, D, Hanzen, C, Heutte, N, Levy, C, Le Tinier, F, Mousseau, M, Ciais, C, Murariu, C, D'almeida, M-C, (2016), 'Impact of at therapy (AT) on fatigue and quality of life (QoL) during external beam irradiation (EBI) in breast cancer patients (pts): a randomise trial (2016), *Ann Oncol* 27 (suppl_6): 1439PD, DOI: <https://doi.org/10.1093/annonc/mdw390.07> ;

Koom WS, Choi, MY, Lee, J, Park, EJ, Kim, JH, Kim, S-H and Kim, YB (2016), *Radiat Oncol* 34 (2): 135-144

⁷ Paccheit, C, Mancini, F, Aglieri, R, Fundaro, C, Martignoni, E and Nappi G (2000), 'Active musictherapy in Parkinson's disease: an integrative methodfor motor and emotional rehabilitation', *Psychomatic Medicine*, 62, (3): 386-393

Westbrook, B.K. & McKibben, H. *Am J Dance Ther* (1989) 11 (1): 27-28

⁸ <https://www.artsaccess.com.au/about-arts-access-victoria/>

⁹ <https://www.artsaccess.com.au/about-arts-access-victoria/>

colleagues of disabled artists. The quality of the work of many disabled artists is exceptional but I don't believe it is recognised sufficiently. This is probably also true of able-bodied artists, and I believe that society would be enriched if Australian culture gave more recognition to the value of the arts.

Arts Access Australia is the peak body for arts and disability the national level. Its stated goals are: 'to increase national and international opportunities and access to the arts for people with disability as artists, arts-workers, participants and audiences'.¹⁰

- Promote awareness of AAC's programs through billboards, television advertising etc

2.0 Addressing the National Arts and Disability Strategy's Four Priorities

During this discourse I have identified a number of issues within the four priority areas outlined at the start of this submission. I believe that in order for the strategy to be truly effective these issues need to be addressed. Some of them fall under the ambit of the Victorian State Government, and some are the responsibility of the Federal Government.

2.1 Addressing Barriers to access and participation

2.1.1 There should be stricter identification and policing of facilities provided for people with disabilities. Such facilities include toilets, changing rooms and parking bays. Perhaps mandatory wording could state that the facilities are ONLY for the use of disabled people;

2.1.2 There should be more orange seats on Melbourne's trams. There should be sufficient orange seats so that whichever direction the tram is going there are at least two next to each entry door. This will not limit seating for able bodied people, especially since most disabled people will avoid travelling in the rush hour. People with PD in particular may have significant postural instability with very poor balance and have a high chance of falling on a moving tram, bus or train.

2.1.3 All venues should have seats (identified for preferential use like those on trams, trains and stations) close to where queues form, but also in foyers, and open spaces, so that seating is always available for those who cannot stand for long (there are many conditions that are associated with this including postural hypotension – common in PD, spinal canal stenosis, arthritis, dystonia);

Some sessions of important artistic/cultural events should be held outside of rush hour during the day so that disabled people are not faced with crowds at the venue (like many people with PD I will fall if jostled or knocked) or on public transport;

2.1.4 To improve them for everyone including blind people and those with visual impairment, research and redesign the areas of dots near roads, stairs, escalators, railway platforms etc, in consultation with advocates for the blind, PD advocates, advocates for the aged, disability advocates, physiotherapists and OTs, so that they are easier for ambulatory disabled people, like those with PD to walk on, and to step over, as well as improving their functionality for blind people. Also assess if and how the colour of the dots makes a difference to PD people and others. Experiment with clearly marked linear boundaries. I suspect that delineating them will make them easier for PD people to negotiate. I believe it will be possible to improve the areas of dots for everyone, including blind people.

2.2 Supporting arts and cultural practice amongst people with a disability

2.2.1 The federal government should fund and promote widely competitive awards and residencies for disabled artists. It could do this in association with mainstream and disabled arts advocacy groups such as Arts Access Victoria and Arts Access Australia.

¹⁰ <https://artsaccessaustralia.org/>

2.2.2 The federal government should provide additional funding to advocacy groups like Parkinson's Victoria and Parkinson's Australia to promote and support creative arts therapies within communities. Parkinson's Australia's Painting with Parkinson's program should be expanded to permit everyone with PD in Victoria to participate.

They might also, in collaboration with state and local governments, support art residencies for therapeutic and creative arts practices at neighbourhood and community houses, such as SPAN Community House in Thornbury

2.2.3 Provide funding for specialist, inclusive art teaching at state primary and second schools where disabled children are enrolled.

2.3 Developing audiences for disability arts companies and individual artists

2.3.1 Provide extra funding to organisations like Arts Access Victoria to promote disabled artists' exhibitions and performances to the wider community. Funding could be specifically applied to television and hoarding advertising like that by mainstream theatre, galleries etc.

2.3.2 Provide funding to advertise awards, residencies and competitive exhibitions for disabled artists in all arts media

2.4 Improving policy development and planning within government

2.4.1 Establish a central socio- economic policy unit with a focus on identifying the non-financial (intangible) and financial benefits and costs of all aspects of all the arts, with the goal of maximising social benefits (*see 3.0, below*). This would necessarily be a large unit, grounded in the economic theory the government purports to implement. The unit will have a strong focus on intangible values, and will be able to advise on policy for the arts. It will not use economic modelling or plug in values from spreadsheets. This approach to policy necessarily requires a very good understanding of economic theory, including its ethical underpinnings (recalling that Adam Smith was a moral philosopher);

2.4.2 Establish a central unit specialising in health and population statistics and the arts, that will directly advise (or even be part of) the economics unit. It will have a focus on the statistics of disablement and disabling diseases in the Australian population (Parkinson's, muscular dystrophy, Alzheimer's, and many more) and their relationship with the arts (eg participation rates in active and passive engagement with the arts, including arts therapies). This unit will also be able to advise policy directly (eg health and transport planning for disablement) as well as indirectly (to the economics unit);

2.4.3 Establish arts specific data gathering units in the relevant Arts, Health, Transport, Planning etc agencies that will provide accurate and timely data to the economics and statistics units, and appropriate linkages with agencies that are already involved in data gathering and analysis (eg Australian Bureau of Statistics, Productivity Commission)

3.0 The Total Tangible and Intangible Value of the Arts to Society

It is impossible to quantify exactly the value of the arts to society in financial terms. However, if we make the effort, we are able to identify every possible benefit or cost associated with the arts, including the benefits of participating in arts and cultural events, and the value of arts therapies to disabled people. Once these have been identified (by the people employed in the units proposed in 2.4 above) it would be possible to infer dollar values using the various shadow pricing techniques available to economists (especially those who specialise in health and environmental economics).

I have little doubt that when a comprehensive benefit-cost analysis, in which all the conceivable benefits of the arts to disabled people in society are accommodated, the benefits (mostly with high intangible values) will far outweigh the (mostly financial) costs. Recalling that the benefits, while intangible, will prevent, reduce or delay the financial costs. That is, while the benefits are mostly intangible, the costs of forgoing them are not.

If just the two most common neuro-degenerative diseases, Parkinson's disease¹¹ and Alzheimer's disease (statistics often cited to include Alzheimer's and dementia), which affect a significant and growing proportion of the population, were to be considered, the results would be staggering¹²

¹¹ For more information see about Parkinson's in Victoria see the Parkinson's Vic website <https://www.parkinsonsvic.org.au/>

¹² There are currently 2,7000 Victorians living with PD, with up to 5,400 being young onset (personal communication, Kate Madden, Parkinson's Vic). In Australia about 81000 people, or 1/308 currently live with Parkinson's. The incidence of PD is three times higher in people over 65, compared with the general population. According to Parkinson's Australia this means that while Australia's population is forecast to increase by 1% in the next 20 years, the number of PD cases will grow by 4% (<https://www.parkinsons.org.au/statistics>). The statistics for dementia are even more grim. Currently, 436,366 Australians live with dementia with this is expected to increase to 589,807 in the next ten years (<https://www.dementia.org.au/statistics>)