## Response to Productivity Commission Draft Report:

# Disability Care and Support

Firstly, I would like to say that I am really pleased that Australia is now moving towards the introduction of a national disability insurance scheme; such a scheme is long overdue. The lack of social and economic support for people with disabilities in Australia has wreaked enormous, and ongoing, hardships on some of the most vulnerable families in Australia. While the Draft Report is detailed and comprehensive, there are nevertheless still some areas that I believe require closer attention. My major concern is with the vagueness relating to the intersection of the proposed insurance system with what is euphemistically called the palliative care sector on page 3.30 of the Draft Report (Volume 1). It is of critical importance that the Commission be aware of the huge shortcomings of the existing approach to palliative care in Australia. Related to this, the Commission needs to ensure that the significant and far-reaching disability-related needs of families dealing with terminal illnesses are acknowledged and explicitly catered for; these needs can sometimes span years. Until the deficiencies of the current approach to palliative care in Australia are clearly identified, it is impossible – and hence premature – for the Commission to consider (as it does on page 3.30), in any meaningful way, the nature of the articulation between the palliative care sector and the proposed disability insurance scheme.

It is the purpose of this brief submission to outline some of the problems emanating from Australia's rudimentary and exclusionary approach to palliative care and, in so doing, to foreground the existence of a vast reservoir of currently unmet disability-related needs amongst many families who struggle on a daily basis to cope with the multifaceted demands of terminal illnesses.

I write on the basis of my experiences as a caregiver of a spouse who was afflicted with a devastating neurodegenerative disease called Multiple System Atrophy (MSA). While my direct experiences and knowledge relate to MSA, the issues I raise have much broader applicability, most especially in terms of people and families dealing with a broad spectrum of neurodegenerative diseases, including conditions such as Huntington's Disease, Multiple Sclerosis, Progressive Supranuclear Palsy, Amyotrophic Lateral Sclerosis, and Parkinson's Disease. The key issues for consideration are outlined below.

**Problems with the definition of palliative care**

Definitions of palliative care in Australia (unlike in some other countries) tend to very narrow, focusing on the late stages of terminal diseases, most especially cancer. Patients with chronic life-threatening illnesses other than cancer tend to fall outside of the 'system' as it is currently constituted (this is certainly not meant to infer that families dealing with cancer get all of the help they need). The choice for such patients and their families, at the moment, is stark and dispiriting: they have the option for the disabled family member to be admitted to a totally inappropriate (especially if they are still young) aged-care nursing facility or to struggle on alone at home.

It is my understanding that in the countries comprising the UK, and in the Nordic countries, for instance, palliative is generally considered to refer to life-limiting illnesses and that appropriate services ‘kick in’ once such an illness (cancer, neurodegenerative disease, etc.) has been diagnosed (and the services available increase as the needs of the families intensify). Here is Australia, no such system of assistance exists for Australians with neurodegenerative diseases. In the case of my own family, my husband had multiple MSA-related disabilities and our needs were huge but we received no support at all until the last few years of his illness and then the support we did receive – which was not palliative care support – was woefully inadequate.

**Lack of hospices in Australia**

The luke-warm support for palliative care in Australia is also apparent in the dire lack of hospice accommodation. In the UK there is a very widespread network of hospices and these provide appropriate accommodation, respite, day care, and general support and services for people and families who are struggling with the demands of living with terminal illnesses. Hospices in Australia are few and far between; in a large city like Brisbane, for instance, there are no hospices at all. The nearest hospice is in Ipswich and this is a tiny, six-bed, hospice. So the lack of in-home services for the terminally ill (such as those dealing with neurological diseases) is compounded by the lack of hospice accommodation.

While it is possible to access general respite accommodation, for a few weeks a year, the respite is not geared towards the needs of high-care palliative patients. Moreover, because of the voluminous paperwork involved, there is a pressure to take respite for two- or three-week periods, when sometimes all that is required, and wanted, is a few days respite. The inappropriate care environment, in tandem with the lack of flexibility regarding length of stay, means that many individuals, carers and families baulk at using general respite accommodation. The only other type of respite available is in palliative care units, mostly attached to hospitals. There are not many of these units available and the prevailing shortages of beds means that they are almost impossible to access and, importantly, they are often hostile to the needs of patients who do not fit the stereotypical idea of a palliative patient (i.e. non-cancer patients are often regarded as ‘matter out of place’). I know this factor is acknowledged in the palliative care literature and this was certainly my experience on the one occasion that my husband was admitted to a hospital-based palliative care unit (just a few weeks before he died). I had come down with a severe case of ‘flu and was barely coping (plus there was the risk of me infecting my husband). I was desperate, and with the help of a charity-based palliative care outreach organisation, I was able to arrange for him to be admitted to the palliative care unit (significantly, the paperwork for admittance was based around symptom management, rather than carer exhaustion and illness). His admittance to the unit was an error of judgement on my part and one that I still grapple to come to terms with; I feel guilty at allowing him to be admitted to what turned out to be an inappropriate place. While some of the staff were lovely, other staff were openly hostile to his presence and his multiple disability-related needs. Added to this, we had a greater range of disability equipment at home than was available in the unit. For instance, no air-mattress was available – I had to lobby for this and the ten-hour period that he was without an appropriate mattress resulted in skin breakdown and ulceration – and another basic item, a hoist, was not available and when one was accessed it was old and only partially working. In addition to lack of basic equipment, many staff were not familiar with the fundamentals of looking after a late-stage neurological patient: for instance, they were not familiar with doing PEG feeds, with using hoists, and, unforgiveably, some staff didn’t even bother to ‘glove up’ when changing catheter bags, etc. (not surprisingly, within a few days of being in the unit, he had developed a severe urinary tract infection). In short, the palliative care unit was hostile to the needs of neurological patients with multiple disabilities; it was an entirely inappropriate environment. At the time, there was really no option other than to use the palliative care unit, but thoughts of that admittance still break my heart.

In short, it is imperative that the Commission acknowledge the specific needs of palliative care patients will disabilities. At the moment, the lack of appropriate assistance is simply cruel. In addition to acknowledging the needs, it is, of course, even more important to make sure that the acknowledged needs are appropriately catered for in the proposed National Disability Insurance Scheme (NDIS).

## The critical importance of acknowledging that many people with terminal diseases endure significant periods – in some cases years – of profound disability

I think it is important to reiterate and reinforce the fact that some people with terminal illnesses continue to live at home with their families and that their preferred place of death is their home. Other than emergency hospital admissions for symptom control, then, these people live at home with their families for the entire duration of their illnesses (which may last for years) and for much of this time may experience significant and profound disabilities. Bearing this in mind, there is a disturbing lack of clarity in the Commission’s suggestion, on page 3.30 of the Draft Report (Volume 1), that individuals in the ‘very final stages of their life…would be referred to the palliative care sector’. Firstly, it is important that the Commission be cognisant of the fact that in the case of many neurological patients, it is often not possible to pinpoint with any degree of accuracy when patients are in the final stages of life. This is why they are often effectively debarred from accessing the existing, limited, palliative care services. Secondly, neurological patients (and perhaps other categories of patients) have needs for intense nursing for years, not just in the final stages of their diseases (if the final stages can be discerned). And lastly, in the case of neurological patients, the suggestion that individuals be referred to a palliative care sector that, as it is currently constituted, does not cater for their needs, sounds like abandonment.

To labour the point, then, the special needs of individuals and families who are struggling to cope with neurological illnesses, often over significant spans of time, need to be acknowledged and catered for under the proposed new NDIS. Further, much more attention needs to be given to detailing the exact nature of the articulation between the NDIS and the palliative care system. Allied to this, the definition of palliative care being used needs to be clearly spelt out.

In order to provide insight into the total inadequacy and, indeed, barbarity of the current situation for people with terminal neurological illnesses, I outline below some of the issues our family had to contend with.

## A few background comments about Multiple System Atrophy (MSA)

MSA is a degenerative neurological disease. Once afflicted, the sufferer deteriorates very rapidly and within a few years is typically profoundly disabled (the average life expectancy on diagnosis is around six years). My husband had the disease for eight years, was disabled to the extent that he could no longer work after a few years, then endured a period of severe disability and, then, for the final four years of his life was profoundly disabled. One of the cruellest things about MSA is that while it systematically knocks out bodily systems, it does not affect cognition. Trapped within a rapidly deteriorating body, he remained as bright and cerebral as ever, perhaps even more so as, eventually, his mind was virtually all that he had left. In some countries, my husband would have been considered to be a palliative patient in the very early stages of his disease, and we would have received some assistance. But here in Australia we had no support at all until the last few years of his disease and then the support we did receive was woefully inadequate.

## Some key issues regarding the lack of appropriate support

Our family struggled to cope with the constantly expanding demands of living with MSA. The types of assistance available to MSA patients and their families in places such as the UK – including significant in-home support, access to hospice respite, and advocacy services – are non-existent in Australia. However, we did receive some limited support. Even though, age wise, we did not strictly qualify (i.e. my husband was not yet 65), our needs were clearly such that we were given an EACH package. The enormous relief on receiving the EACH package quickly evaporated, however, when we were told that no packages were available in our geographic area and that, literally, we would have to wait for someone to die in order for a package to become available for reallocation (plus the package would have to come from another area). After an eighteen month wait, we received a package. Our provider was generally very good but, of course, limited by budgetary constraints. We received around 16 hours per week of personal care assistance from our EACH package and this was often topped up by another 4 hours (and sometimes slightly more) from Commonwealth Carers. I realise that this is more help than many carers get, but my husband's needs were profound, and I was run ragged trying to cope (plus engage in paid work as well in order to keep the house running and to deal with the mounting disability-related financial costs). My sister-in-law came over from New Zealand to help out for certain periods of time and my daughter also helped, but, beyond this assistance, there was no other help.

My husband desperately wanted to stay at home and we loved him and did not want to abandon him to a totally inappropriate aged-care facility (which was the only other option available to us). In the last year of his life, he was totally bed-bound, and was only able to move his arms and, to a certain extent, his head; he was unable to speak (although, on a good day, he could make limited use of a Light Writer); he was no longer able to eat and was fed nutrients via a PEG; he was catheterised; his eyesight was failing; due to his inability to swallow, he required constant 'suctioning out'; and when the secretion-induced coughing or the distress became overpowering, I administered oral morphine or gave injections of drugs to control the secretions). He was, though, still able to smile and to communicate his appreciation at the things that were being done for him. He was a generous and loving man and it fills me with pain to now contemplate (there was no time back then) the pain he must have felt at seeing his family crumbling beneath the weight of his care. He wanted nothing more than to stay at home and at least we were able to give him that, but it was a shattering time of ongoing, and virtually unrelieved, work and nursing and very little sleep. The irony with our EACH package, though, was that as our needs became greater, our assistance was effectively reduced. As a hoist was now needed to move my husband, he became a 'two-assist', meaning that, from an occupational health and safety point of view, two personal care assistants were now required to move him using the hoist (for the bulk of the time, of course, I was moving him by myself). So rather than 16 hours of assistance from one personal carer, it now had to be eight hours of assistance from two personal carers (eventually, to avoid the loss of hours, I, or my daughter, and sometimes my sister in law, agreed to act as the second worker when the hoist was used by a personal carer for hygiene sessions or toileting, etc.).

Our difficulties were also exacerbated (and the value of the care undermined) by the fact that our provider was not willing to train any of the personal carers to do PEG feeds. This was compounded by the fact that as all of the drugs my husband required had to be dissolved in water prior to administration via the PEG, the alteration in their form meant that the personal care workers were legally proscribed from administering any drugs even if they were in a Webster pack (I would not have expected, or wanted, them to administer, for example, morphine, but many of the drugs were not in this category). As the protein in the nutrient feed interacted with the key drugs administered on a daily basis, this meant that the PEG feeds had to be distanced from the administration of drugs and ensured that something needed to be given via the PEG every few hours, and only the family could do this. Under these conditions, it was impossible to get a proper break even when personal care workers were in attendance. (On the positive side, though, in the last few months of my husband's life, we did get some sterling help – including a weekly visit from a nurse, access to a 24 hour nursing advice line, and two sessions a week from some outstanding volunteers – from a charitable palliative care organisation, Karuna. If only we had been able to access assistance of this nature earlier, it would have made a huge difference).

The incessant 24/7 nursing and caring demands, in addition to running a house, meant that there was never time for the things that we might imagine we want to do when someone we love is dying; things such as spending quality time together, reminiscing, and looking through old photographs, etc. These types of things were a luxury that was largely unavailable to us: our house was just a whirlwind of frenetic survival activity. It was a shockingly cruel period of time for all of us and one that still haunts me and always will. We had always been good, honest, hard-working citizens, but when we really needed help there was no effective government support available to us and we were simply abandoned to survive as best we could.

**Some additional points**

It seems that the key 'selling point' of the proposed NDIS is the fact that disability could strike any of us and therefore it makes sense to ensure that we are all covered for this eventuality. While I understand the pragmatics of the situation, I find it disappointing that the focus is squarely on self interest; I would much rather like to see the issues couched in terms of citizenship rights. For my husband, disablement involved not only a systematic process of dehumanisation but also an effective stripping away of citizenship. I, too, felt that, in taking on caring duties, I ceded rights to full citizenship and entered into some sort of netherworld of incessant struggle. In some countries, social welfare and caring is considered to be a core activity, a sort of social cement that binds the society together. Why not Australia? It would be good if the Commission's final document could at least give lip service to the idea that the right to both give and to receive care should be seen as a fundamental cornerstone of citizenship.

Just a couple of more minor points: the use of the word ‘customer’ when referring to potential beneficiaries of the NDIS is abhorrent; they are not customers, they are citizens. Equally distasteful is reference to people ‘blocking beds’ (for instance, on page 1.11 of the Draft Report, Volume 1): this is a variation of the abusive term ‘bed blocker’; it focuses negative attention on the hapless person who has been failed by an inadequate system rather than on the deficient system itself. This wording should not appear in a report of this nature.

Thank you for the opportunity to comment.

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