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Stroke and Neurological Physiotherapy
Facilitating movement

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Productivity Commission Public inquiry

Disability Care and Support

Submission: **Carolyn Luke B. Physio (Hons) MSc (UK), Neurological Physiotherapist**

Thank you for the opportunity to submit suggestions on a revised scheme to provide Disability Care and Support to people with severe and profound disability. Conducting a public inquiry into a long-term disability care and support scheme is a commendable undertaking to which I believe I can make a meaningful and informed contribution.

I am a neurological physiotherapist of 14 years. In this time I have worked in the public hospital rehabilitation system and also in private practice. I have predominantly worked with people who have experienced stroke or have a diagnosis of Multiple Sclerosis. Both populations have a chronic, often severe and profound, disabling condition requiring long-term essential care and support. The treatment I provide contributes to the package of care services accessed by the person with a disability. The treatment I provide improves functionality, enhances quality of life and increases economic and social participation of the person with the disability.

My document will outline improvements to enable people with severe and profound disability to access sufficient specialized physiotherapy treatment. The purpose of the suggested improvements is to facilitate access to required long-term essential care, which will result in enhancing the quality of life and increasing economic and social participation for people with disability. The document will address:

- Access to specialized physiotherapy treatment
- Access to specialized physiotherapy treatment – stroke
- Access to specialized physiotherapy treatment – Multiple Sclerosis
- Suggestions for National Disability Care and Support Scheme
- Case Studies

Accessing specialized physiotherapy treatment

Currently the public hospital system is overloaded with acute rehabilitation patients and my experience has indicated that there is little time to follow people up for a duration greater than 3 – 6 months after their initial rehabilitation admission. There are community rehabilitation centers which the disabled person may access, however the physiotherapy treatment these centers offer is often conducted via group programs, with limited one on one time or expertise. Thanks to the initiative of the Enhanced Primary Care (EPC) Program people with a chronic condition can receive $47 back for 5 physiotherapy sessions per year. This does help people with severe and profound disability, such as those with chronic disabling conditions as stroke or MS. However, such patients must 'top up' this EPC refund from other sources (e.g. personal funds, family resources and charitable donations) to facilitate access to specialist private physiotherapy. Such specialist services cost $110 for a one hour session. Regular one hour sessions are necessary in order to make changes to the person's musculoskeletal system and then central nervous system. The sessions must also integrate these changes into the person's functional movement, and a home exercise regime must be developed and instructed...

- Treatment specialization – stroke

In my experience, it is very evident that people following stroke need on going specialist physiotherapy in order to continue to improve and achieve functional goals. In addition, and of equal importance, it is necessary for people following chronic stroke who, with the on-going inactivity, and natural effects of ageing, are at a high risk of loosing their mobility within a 5 year period. This can be explained in Figure 1 which shows how decreased balance, fear of falling, causing increased fixation, decreased movement patterns, causing muscle length changes; further decreasing balance options can form a downward spiral in mobility. This inevitably occurs once the patient returns home and is discharged from the hospital system and snow balls over months or years. On going input is needed to ensure this vicious cycle does not occur and can in fact be reversed. Decreasing fixation, allows increased balance reactions, improved muscle activation and movement patterns, increased muscle length, and further increased balance.

- Treatment specialization – Multiple Sclerosis

It is very common for me to start with an MS patient who has deteriorated to a wheel chair, thinking their MS has progressed and yet discover that it was not the MS progressing at all but the secondary effects snowballing. "I just thought that was the MS getting worse" is the common statement I hear. People are amazed at the recovery and functional restoration they can achieve with regular individualized treatment. Sensation, movement and balance reactions often return.

Suggestions for National Disability Care and Support Scheme

I would like to propose on the basis of my extensive experience and noted outcomes from the specialist treatment I provide, that people with stroke or MS be provided access to a minimum of 12 sessions of physiotherapy funded by a Long-term Disability Care and Support Scheme each year. This allows access to a minimum of one specialist physiotherapy session per month which would be enough to maintain mobility. This would maintain people in their home, reduce nursing home admissions, reduced carer burden, reduced community help, home help and home modifications required. In addition this would have a significant impact on well being and depression. I am aware that under the Better Access to Mental Health Care Initiative, people with depression can be funded for 12 sessions of psychological treatment per year. Under this initiative the treatment may be provided by Psychologists or Occupational Therapists or Social Workers. It is apparent to me, and is noted in evidence based research, that people living with a severe and profound disability and diagnosis such as MS have to deal with depression as well as physical disability.

This noted need for increased access to specialized physiotherapy treatment, (in line with the access currently provided to other allied health treatments) has been observed and subsequently articulated resulting from my experience in the public health system, and private health system. My experience has enabled me to follow patient's progress for up to 10 years. As a result I am aware that continuing specialist physiotherapy input would not only contribute significantly to enhancing the quality of life and increasing economic and social participation of the patient, but also contributes to an overall reduction of costs to the health system. I outline this with 3 cases below of which I have known for 10 years.

Case Studies
Case 1 Monica:

Monica had a stroke 10 years ago. She was admitted to a private hospital. The private hospital referred her to an interim care facility to await nursing home placement. I met Monica at this placement as the physiotherapist for a government trial of an extended Rehabilitation program in 12 interim care facilities Australia wide, where people receive intensive physio while awaiting nursing home placement. From there I referred Monica to the rehabilitation unit. She received physiotherapy for a few months, got walking with a four point stick and returned home with her husband who has cared for her for the past 10 years. Monica then came to me 3 years ago to have private physio. She is still walking with a four point stick and transferring however her body has become more contracted with inappropriate fixation in order to hold herself up against gravity. Monica's bed mobility has become worse and she is beginning to find it difficult to stand up. This is because she has reduced muscle length, increased fear of falling, therefore decreased forward weight shift, therefore reduced muscle length and hypersensitive feet which limit her ability to push through her heels to extend her hips and therefore decreased hip strength. If she did not have regular physio she would quickly loose her ability to stand and become a heavy person to care for and would require hoist and/or nursing home placement very soon. With regular physio Monica has been able to stay at home for a further 3 years and continues to do so. The savings to the health system, by avoiding the daily cost of nursing home placement for the past 10 years is considerable and the improved quality of life being able to life at home with her husband is priceless. I have many patients at this borderline level of mobility who have been able to stay at home, some independently, with regular physio to ensure their bodies to not tighten up, fixate and loose their balance reactions.

Case 2 Warrick

There is currently no research supporting a standard physiotherapy treatment protocol for how best to manage MS. However in my experience a fortnightly session to achieve, maintain and build on postural control stability and improve the person's mobility is most beneficial.
Warrick is a very good case example. He is 57 years old and was diagnosed with Multiple Sclerosis 10 years ago. I met Warrick in the public system where he received two bursts of two week in patient rehabilitation per year. When I first met Warrick his marriage had dissolved due to his disability, he lived at home alone, and had just been discharged from a psychiatric hospital due to suicidal thoughts. Each time Warrick would come into the rehabilitation unit dragging his left leg behind him and stumbling down the corridor falling onto the walls in a manner that was very unsafe or uncomfortable to look at. At the end of the two weeks of daily physiotherapy we would have Warrick walking (taking steps with left and right feet) laps around the gym throwing a basket ball. Warrick would then go home and be able to walk for a month before having to stumble around and try to cope with life independently for the next 5 months. As Warrick put into words "It is hard to stay positive when the first thing you see in the morning is the floor coming towards your face". Warrick encouraged me to go out and start a business on my own privately. He then had his local Christian motor cycle club to a fund raiser, which they since do every year, to raise $5000 so he can have weekly physiotherapy. For the past 4 years Warrick has had weekly physiotherapy sessions and walked unaided without a stick or splint, over 500 m. He recently achieved the goal of 380 steps up and down a flight of stairs without any rest and we are forming a goal for running. The weekly physiotherapy has allowed him to maintain his stability, mobility and balance and build on this. It has kept him managing at home, functioning in the community, and in good spirits for the future. If each person with MS could have $2500 in order to have fortnightly physiotherapy session, the burden of costs on community supports would reduce and their well being greatly improved.

Another suggestion I would like to bring to how health care can be improved for people with neurological conditions in particular, stroke and MS is the expertise of physiotherapists in the public system. The significant improvement in a person's response to physiotherapy is due to experience and expertise of the physio. The difference between a junior Grade 1 physiotherapist and a specialized trained physio is akin to that of a footballer in the little league verses the AFL. So I ask you, which one would you like to work on your mother or father? However, most consumers, the patients, are not aware of this difference and many people to reach their full potential and are placed in nursing homes unnecessarily. When Warrick attended local inpatient rehabilitation on two occasions the last 4 years, the junior physiotherapists would not let him exercise without holding onto a rail due to safety. Warricks reply was "but I already know how to hold onto a rail". Another physiotherapist spent her session time teaching him how to put on his shoes, which 57 year old Warrick patiently listened to, even though he had been doing this successfully for 50 years. Currently even though senior physiotherapists exist in the hospital to up skill the junior physiotherapists, the fact is a lot of their time is taken up sitting at desks signing time sheets, finding locums and doing other administrative assistant tasks. Due to case mix funding the patients are moved on with little consult from the senior physiotherapists. In order to climb the ladder and increase in salary a physio must become a manager. Therefore the skill is taken out of the treatment rooms. I see this in private practice daily as the people eventually come to me one to two years later with unfulfilled potential. It then takes longer, more time and money, to “undo” the compensatory fixation patterns that their central nervous system had to learn and they have then been left with after rehab and retrain the natural balance mechanisms again. The following case study is an example of this.

Case 3 Bert:

I have recently started with Bert who had a stroke twelve months ago. He was discharged from the rehab centre to home where he transfers from bed to wheel chair and uses a wheel chair around the home. His arm had “no movement” and was in a “spastic” flexed posture and he had significant pain in his shoulder when it was moved and when he sleeps. There is very common for stroke patients in the community who cannot move their arm or sleep due to shoulder pain for the rest of their lives which is a serious factor in well being and can be avoided with experienced treatment. Bert’s wrist was completely flexed and in a painful “gross” alignment which was at risk of limiting hygiene of the palm. He was about to have a botox injection. An injection which “paralyses” muscle fibers in order to reduce the spasticity in the hand and wrist. The spasticity is flexor activity of his central nervous system which is attempting to hold itself up against gravity. So his system has learnt this. This activity then changes his body alignment and limits him gaining appropriate extension in his trunk and leg. I have been working with him for 2 months once a week. In this time I have had to work hard to release the flexion and then immediately stimulate other more appropriate postural activity in his trunk and leg. He is now walking around the house, to the toilet, to the car, into restaurants and appointments with his wife, his arm is nice and loose, his wife can help him dress much easier and his hand can rest flat. We are now looking at holding objects with 2 hands. We are aiming for Bert to be able to walk around the house on his own. What a release of burden for his wife and an improvement in well being for him that will be.

Had Bert had specialized experience physio in the inpatient rehab system, he would not have needed to have this 2 months of physiotherapy. Bert was receiving physiotherapy from a community rehabilitation centre. In these sessions his arm was tied to a pull and wrenched up. Bert mentioned to me that it was extremely painful and asked me if he should let them do this? This physiotherapy was common 40 years ago and I consider it to be barbaric with the knowledge we have today of the biomechanical complexity of the shoulder and sensorimotor control. There was very little analysis, or thought in this treatment and unfortunately such treatment is not uncommon to my ears. I propose that each rehabilitation unit has a Grade 4 physiotherapist that job description only involves clinical patient treatment consulting with junior physiotherapists, and nurses to ensure that each patient gets access to a the quality of treatment they deserve. I would like to suggest a system that currently exists in the UK health system. Physiotherapists can progress from a Grade 2 equivalent position to either a Super intendent (Manager of a department) or a clinical consultant (training and improving the skill of junior staff and helping them clinically, running in-services). The clinical consultant must have significant post graduate clinical training and specialization in order to attain the position. Currently I am aware of only one Grade 4 neurological physiotherapist in Victoria that is at St Vincent's hospital. Some rehabilitation units in Victoria have developed a Gr 4 position however this have been advertised as orthopedic physiotherapy positions and are in essence management roles. I feel this is a great shame as orthopedic physiotherapy is less complex and more "recipe" type treatment for each condition. Whereas retraining the central nervous system is very individual to each person depending on their previous posture, activities and how their postural system has adapted pre injury, how the musculoskeletal system has adapted, the site of the lesion, their learning style, body awareness and inter-relation of body parts in postural control. It therefore involves a lot of detailed analysis and problem solving to determine what handling skills best stimulate the postural control and motor control system to which experience is essential and is the difference between someone walking and not walking again. I therefore plea for a senior Grade 4 clinical consultant in each major rehab centre.

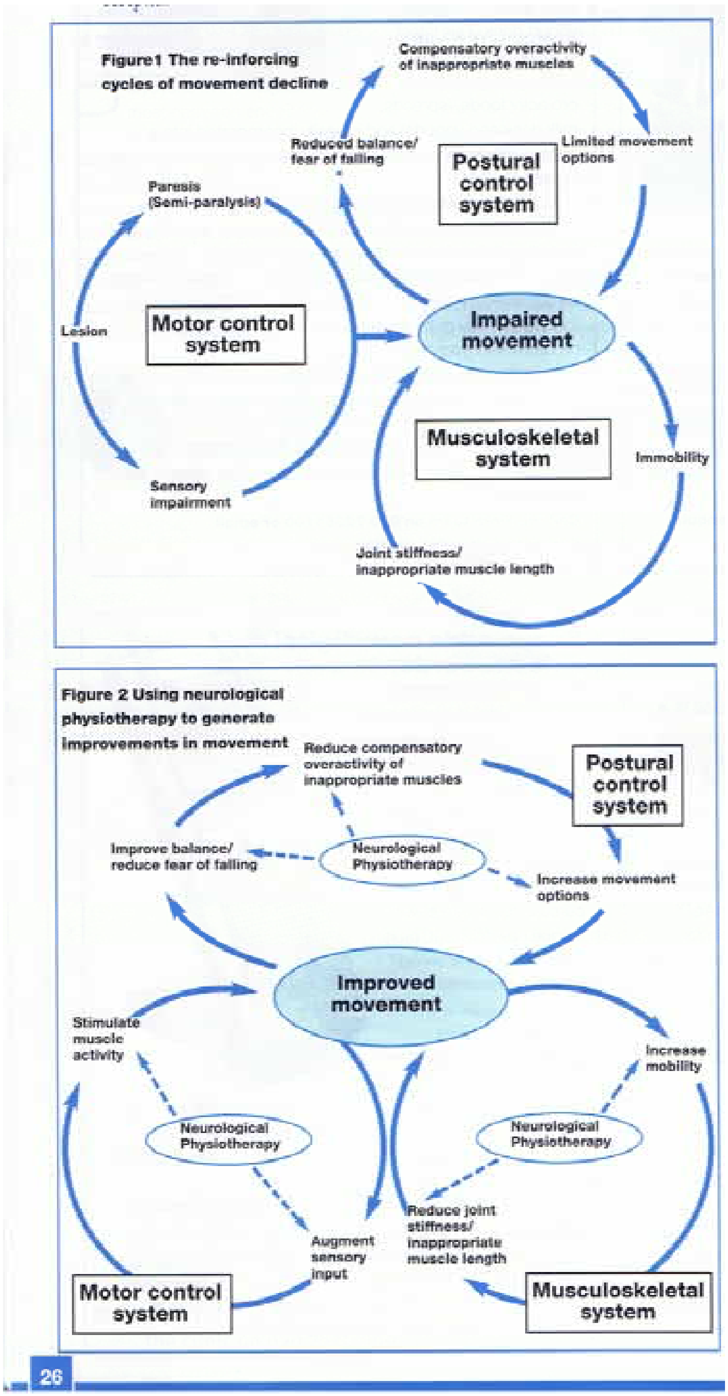
Summary of suggestions:

In summary, people following stroke and with a diagnosis of MS in the community struggle with reduced mobility and well being. This is likely to worsen with the natural progression of physical impairment and ageing. In addition, the standard of neurological physiotherapy in the public health system is very low, due to lack of specialized supervision, and the overloaded public rehabilitation system. Consequently people currently have very limited access to specialized experienced physiotherapists that can make a significant difference to their life.

I therefore recommend:

- A minimum of 12 physiotherapy sessions per year funded in full by a Long-term Disability Care and Support Scheme for people who have experienced stroke and have a diagnosis of Multiple sclerosis.
- A Grade 4 neurological clinical consultant physiotherapist appointed to each major rehabilitation hospital

Figure 1 – Cycles of movement decline and recovery



Ref Luke C, Hamer, A Neurological Physiotherapy… never assume. Capital Doctor. 36: 26-27; 2004.