Submission to Members, Joint Select Committee on Preventative Health Care

Dear Joint Select Committees Members

Thank you for raising this Joint Select Committee on Preventative Health Care. I am a consumer of public health services, and in this capacity, make this submission.

My husband and I collectively suffer from osteoarthritis, osteoporosis and diabetes type 1. At age 61 and 62 respectively, these conditions have put increased strain on each other over recent years where we constantly have to change from care to care giver roles in the home. We both are able to volunteer away from home, allowing each other 'respite' from the other. We have grown family both here and interstate, our siblings and their families live interstate.

Both the hospital system and HACC services don't recognise our combined needs in both instances when a medical crisis arises with one of us, or when more than basic home help is needed on an ongoing basis. While we don't require access to specialised programs as some younger HACC clients with disabilities do, because osteoarthritis and osteoporosis are sometimes seen as aged related, no suitable ongoing 'package' exists that would help us in practical terms. Couples with conditions and age similar to us fall, to some extent, through the HACC cracks and a hospital perspective doesn't take into account an equally mobile restricted and potentially vulnerable 'carer', who has recognised aged related painful and restrictive mobility issues.

I would advocate a system whereby both our medical files would be viewed in tandem prior to whenever either my husband or I would be discharged from hospital into the care of the other, as it would become obvious a combined indivdualised service for us as a couple, along the lines of a short to medium package incorporating what is available now for the elderly over 75, would help, in preventative terms when a couple still has the potential to resume their normal lifestyle. A package would reduce the risk of one or both members of a couple sustaining increased physical 'burnout' or injury.

I was diagnosed with lumbar spine degeneration when I was 42, my husband has had type 1 diabetes since he was 28 and in later years he had developed osteoporosis. I actively participate in group hydrotherapy exercise class through Arthritis Tasmania at the St Giles pool in New Town, the former State Government owned Douglas Parker Rehabilitation Pool.

In May 2004, I was, I believe, a Category 2 elective neurosurgery patient having completed the Programme for Rehabilitation of Persistent Pain Patients at the Royal Hobart Hospital while awaiting surgery. The wait after completing this Programme was nearly three years; surgery was performed in January or February 2007. About nine months after my surgery, my husband fractured his hip, which was pinned while on holidays in Sydney, he had to have additional surgery at the Royal about three months later. Both operations may have contributed to a 4 cm leg length difference, not pick up until 2011 when he was hospitalized again, this time with a crush fracture to his upper dominant arm and a dislocated shoulder. My surgery resolved the chronic pain issue, but I believe my having to take on the demanding physical role of caring for my husband after his operation, resulted in my own long term recovery from my operation limited, as a weakened leg did not improve to a great extent, or the altered sensation in my foot. The original long wait for neurosurgery, I believe also, contributed to this outcome. Apart for short term home help, no other services were identified or offered by HACC providers apart from a toilet seat. A 'Bridge' chair was hired from Red Cross as one could not be sourced from the Government aids scheme.

Prior to my husbands discharge from hospital in 2011, it was discussed he would spend time in transitional care, but instead he was discharged into my care as a falls risk needing my supervision showering and using our front steps, as his dominant arm was in a halter and he had to use a crutch on the other side to compensate for the 4cm leg difference. No showering help was forthcoming and after a two or three month wait, an additional rail was installed on our front steps that a Hospital OT had previously insisted needed installing before my husband could return home. As our lawns were in full summer growth and both of us had been having problems mowing, we asked if our lawns could be mowed in the short to medium term as I thought the length was a potential trip hazard for my husband and I wasn't capable of holding his weight if he started falling. We were told HACC does not provide regular lawn mowing; they would mow lawns if access to a clients premise was deemed an OH&S issue for department staff. We now pay a company to do this task every 3 weeks.

In March 2011 I had my toe nails cut by a local private podiatrist for the first time, as my back was becoming painful again and now have hip bursitis. I found the experience unpleasant. I had been mentioning my symptoms to my GP for some time previous that wasn't investigated. In the last half of 2012 a specialty shoe retailer measured my feet and drew an outline, I experienced the same unpleasant feeling as I did previously at the podiatry appointment. This second experience convinced me I may have neuropathy and made an appointment with another podiatrist who conducted the test confirming the fact as well as a wasted muscle in an ankle. As a diabetic, my husband has these tests done regularly within the public system. This test doesn't seem as automatic for a non diabetic who may have neuropathy cause by spinal nerve impingement.

On the 1st February I made a double appointment with my GP to discuss this, he did his own basic neuropathy test, ordered plain x-rays and a CT scan, I was able to have them done the same day. That evening my GP rang to tell me I had "...many, many, many areas of degeneration..." he wants a neurologist to see me "...soon..." as the CT scan report mentions the possibility of cauda equina, a potentially serious neurological condition that can affect the lower limbs and internal organs. I am aware there is a long wait to see a neurologist, I do not know if the faxed/emailed referral has been 'acted upon' yet or what officially denotes the start of a waiting list for a patient, but most probably after I see the neurologist which could be months or years hence. This wait could be shortened some what in the event my internal organs stopped functioning, in which case I would be an emergency patient.

The 2007 surgery was performed for lumbar denegation; a chance chest x-ray last year picked up similar degeneration in my thoracic spine, the recent CT scan renders my sacral spine degenerated. All movements contribute to this degeneration and neuropathy on a daily basis and the slightest wrong movement can bring on bursitis. Bus travel ceased to be an option for me many years ago because to the stresses on my spine and locally, when I have appointments on days when my husband has the car for his volunteering, I catch taxis. We have both shared cooking meals, but my husband is sharing more of that load along with minor grocery shopping. For the main fortnightly shopping, we doing it together now, as it is becoming increasingly painful for me to do so.

On another matter, I accessed Oral Services on 29th January, with tooth ache and lower jaw pain, where the invoice states I had a limited oral examination in addition to a drilling and capped tooth. The drilling was inexplicably very painful even after local pain relief was administered, the pain was said to be referred and if it hadn't settled down in 3 weeks, (19th February), the tooth would probably need extracting. By the 5th March my jaw was so sore and painful I had trouble opening it wide enough to eat and the side of my tongue hurt when swallowing, that evening I attended E&R at the Royal, hoping for an x-ray, but came away with a codeine based

script, filled at a North Hobart Chemist. At an appointment on the 6th, my mouth was so sore, pain injections were given so I could open my mouth wide enough to be examined an x-ray plate positioned. The tooth was abscessed and extracted, the Dentist commenting there wasn't a lot of tooth to grip. After the extraction, an original presenting pain persisted; I went to a local GP on Saturday 9th February where she prescribed antibiotics. From symptoms, I know my tooth was already abscessed on the day it was drilled and capped. Unfortunately, I will have to continue to access Oral Services in the future as the Federal Government has pulled funding from the chronic disease dental scheme which would have allowed me to access people more professional in their field.

Many people like us, are trying to do the right thing for themselves in preventative health terms, wellbeing and appropriate exercise. For me, and the heath care system, an earlier, rather than a later appointment with a specialist may produce a better outcome for both, because if I present as an emergency patient it means others before me have a longer wait themselves and a sooner outcome for me may have a window for targeted rehabilitative and less expensive health care costs overall in my own case.

An individualised in home care package for a couple would be far cheaper than long stays in hospital because essentially medically speaking, the longer the delay, the worse the outcome, which in my case has been previously proven.

Yours sincerely

Mrs Julie Taylor

16th February 2013