Introductory remarks – setting a context for the debate / review

Citizenship in practice is basically about the right to belong (a sense of inclusiveness) and participate with dignity and respect within a society.

The present government has rightly shown a deal of concern about the issue of citizenship. Citizenship is perhaps best understood and addressed as an ongoing and evolving project that permeates a range of policy areas.

The understanding and practice of values such as tolerance, a fair go and respect have been rightly advanced as core (though of course not uniquely) Australian values.

Ill health can and does have a chilling effect on the ability of people to feel a sense of belonging and on their ability to participate with dignity in society as active citizens.

Living with a spinal cord disease – a personal account

In mid March 2005 following receipt of a flu vaccine at my work. I went onto develop flu vaccine-mediated transverse myelitis. My symptoms developed over a number of weeks and by June 2005, I had reached a point of profound numbness from the neck downwards.

This is the same neuro-inflammatory spinal disease which the Parliament of Australia received information about in 2002, in relation to the impact that it had on the life of a young boy by the name of Luke Alderton.

I feel it necessary to share my story in the hope that those who remain steadfastly opposed to supporting the findings of the Lockhart review and the proposed legislation, might at least be moved to use their professed concern for the integrity of human life (especially that which is vulnerable) to support an improvement in:

the management of access to and provision of resources for those human beings whose lives are challenged by neurological and autoimmune conditions.

a) **My symptoms**
b) **The reaction of my workplace**

My symptoms – in brief

My flu-vaccine mediated transverse myelitis developed over a number of weeks and by June 2005 I had reached a point of profound numbness from the neck downwards.

Among the symptoms I experienced were:

- A very tight girdle band-like feeling around my chest making it very difficult and painful to breath.
- Great difficulty in walking and an inability to climb stairs because of the weight of numbness in my legs and because of the difficulty in using my constrained lungs to breathe.
- Numbness and weakness in my hands resulting in an inability to hold onto/manage objects and a loss of fine motor skills. This is because I had lost my ability to touch, and touch is one of the main feedback mechanisms used by the brain to maintain grip and control of objects.
- Pain in my neck and an inability to sit for periods
- Fatigue

There are of course other symptoms and examples of the impact that transverse myelitis has had on my life.

After suffering these debilitating symptoms for several weeks, I was finally diagnosed with transverse myelitis and immediately given a course of Methyl Prednisone intravenously for 5 days at high dose (see below).

The reaction of the workplace

I immediately relayed my symptoms to the workplace in advance of being diagnosed with transverse myelitis. There was already an awareness that my condition was possibly related to the flu vaccine and thus a workplace injury.

As I could not initially type at all (not even with two fingers) I organised for voice recognition software to be installed. Given my lack of experience with it and the absence of any support or training, I failed to install it properly and struggled to make use of it.

My symptoms significantly slowed me down, but the amount of work I was given was not been reduced. Indeed, I was not given any reduction in my workload until February 2006. In response to this, a return to full work schedule was proposed, treating and assuming the trajectory of my condition to be as predictable and straightforward as a broken arm. This ignorance was confronting and most frustrating.

> **I began to realise that there was a significant lack of public awareness, not to mention misconceptions about conditions such as mine—indeed perhaps even a lack of legitimacy associated with such conditions. Because my condition did not manifest with any obviously graphic physical cuts, bruising, or scarring, I experienced what appeared to be either an inability or unwillingness on the part of the workplace to understand my**

> **condition and thereby accommodate it. I believe that this may have accounted for at least part of the attitude toward my condition.**

In September 2005, I had to have 5 days of Methyl Prednisone administered intravenously at high dose. I did not appreciate having a couple of days of this drip administered to me in my office at work, rather than in hospital or at home.

In late January 2006 it was accepted by the relevant insurer that my transverse myelitis was a workplace injury.

In May 2006, I finally received a workplace/office assessment.

My experience with the relevant insurer has been a mixed one. I was heartened by those staff who handled by case in good faith and in a timely and efficient manner. However, I have also been immensely frustrated by staff who seem to have displayed an incomprehension of spinal cord diseases and their effects. There appears to be a systemic refusal to understand and deal with such conditions in a timely, efficient and effective manner so as to give dignity and legitimacy to the injured individual. One example that illustrates this is; was being asked why someone whose life had been turned upside down by transverse myelitis symptoms[1], might need or might benefit from any form of counselling.

Conclusion

My message to the Senate Committee is clear, however: transverse myelitis has impacted not only on my ability to work, but also on my ability to participate in society and have a sense of belonging.

I have been relatively fortunate to have made improvements in my condition and in the management of my condition, though I still retain physical deficits which impact on my quality of life and sense of belonging and acceptance. Not all persons with such conditions have been or will be so fortunate. I believe that the challenge presented by conditions such as transverse myelitis are systemic and go to the heart of citizenship. These challenges are deserving of greater, more careful and sophisticated attention and redress.

Recommendations

The Committee might wish to consider establishing a compulsory reporting system for certain neurological and autoimmune diseases such as those listed below.

- Guillain Barre syndrome
- Motor neuron disease

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[1] where you cannot do what you used to take for granted, that you cannot work like you used to; that nothing feels the same and you're just fatigued and frustrated because your life is no-longer what it used to be.

- Transverse myelitis
- Lupus
- Sjogren's syndrome
- etc

The reporting system should naturally be subject to all of the privacy guidelines that apply to reporting to ADRAC.

The system would contain penalties for a failure to report.

Such a reporting system would assist with a more efficient and effective allocation of resources to those issues.

I understand that currently there is no compulsory reporting system, and it seems that an amount of under-reporting is occurring.[2] The significant variation in the reported odds of developing transverse myelitis reflect the problematic lack of effective monitoring and research around such diseases.

My adverse reaction to the flu vaccine in 2005 was not reported to ADRAC and did not appear in their statistics until I reported it recently on 2 October 2006.

Final comments

I do not seek to comment on the pros and cons of the embryonic Stem Cell research, as those arguments have been well-rehearsed elsewhere. However, I would like to make the following two submissions in relation to Senator Stott-Despoja's draft bill

(i) As the committee would be aware, there have been a number of concerns expressed about the embryonic stem cell research, and the nature of the regime under which it should operate. This is indeed a heavily value-laden issue and there is no one solution that can cater to the diversity of concerns and interests. However, I believe that the legislation proposed by Senator Stott-Despoja appropriately covers the range of concerns that have been raised in relation to abuse of a mandate to allow stem cell research. This has is achieved by the imposition of strong penalties, and the prescription of very clear guidelines and boundaries for such research.

(ii) If parliamentarians decide to reject the draft bill (based on a concern for the integrity and dignity of *all* human life) then I submit that they may wish to consider devoting some of their efforts to actively contributing to reforms which better guarantee that people who suffer from autoimmune and neurological diseases, receive the timely and effectively

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[2] I am aware of others that have also developed such diseases. On 23 September 2006, Chanel 7 news featured a story on a 21 year old woman who developed transverse myelitis –"the Spinal Girl". It is understood that the hospital at which the girl was a patient had strongly encouraged the woman to go public. It is understood that the hospital felt that public awareness of diseases such as transverse myelitis needed to be raised. I would encourage members of the committee to view that footage.

administered support (including workplace assistance, medical treatment and so forth) that they so desperately require in order to function as fully fledged Australian citizens.