

My name is Gary Samuels. My wife is afflicted with disease called Multiple Sclerosis, diagnosed in the mid 1990's. I have 2 adult children who are now living independently. I am currently receiving carer payment and carer allowance and my wife receives a Disability Allowance. I am writing to support the National Disability Insurance Scheme and would like to raise some of the issues that I believe are relevant to this debate.

As a brief background I have over 30 years experience as a health clinician/administrator. I have been both a union shop steward and manager in the health system and have both experience and good communication skills. I had no idea at the outset how difficult the health and welfare systems would be to negotiate and I feel completely abandoned. I regret that I did not heed the warnings provided by my wife's Neurologist when he informed me how hopeless the health and welfare systems were in Australia.

1. Since my wife became ill I have not had a holiday with my family and have on maybe 2 occasions been away from her for over 24 hours.
2. As a result of my requirement to provide full time care my employment was terminated by the Health Network that employed me.
3. I will probably lose my Nursing Registration this year
4. My wife's condition continues to deteriorate yet what services I can find to assist us are short term or being withdrawn. Family supports are negligible.
5. The focus of support is to the carer. I can have counselling. Respite is never available.
6. My wife has never had a health assessment and therefore there is no proper plan for her
7. My wife has a care plan with her General Practitioner that has been helpful to relieve some of the financial burden.
8. Superannuation offered no disability assistance
9. The financial and social impact upon my family has been devastating
10. If we had access to a Disability Insurance Scheme my family would not have been forced to endure the humiliation and isolation that resulted from this terrible disease.
11. If I began to earn an income I would lose all access to the support services I currently receive.
12. If you have ever read the novel "Catch 22" it describes our Health and Welfare systems perfectly.

Regards
Gary Samuels