

Age 4/8/05

Supp Submission No. 191.1  
(Inq into better support for carers)

*It has been said that the humanity of a country, its government and people can be seen in the way the old, the young and the vulnerable members of society are regarded and supported.*

### ACCESS

*Although legislation for the disabled has been in place for more than 15 years, there are still glaring examples of neglect with regard to access for disabled people and their carers eg few ramps into buildings, entry and exit from swimming pools. A notable exception is Collaroy ocean pool which has ramp and rails. Sydney CBD is all but inaccessible for the aged and disabled as traffic dominates. There is little time to cross roads and the general environment is unfriendly to all but the able-bodied and swift of foot.*

*Notable exceptions from our own experience are both the National Gallery of Australia and the Art Gallery of NSW which are most caring in their approach to the aged and those with disabilities. QANTAS ground staff are also very helpful.*

### ACCOMMODATION

*Wherever we have stayed in hotels or motels over the past eight years, rooms with disabled facilities are invariably the worst rooms in the house. I have spoken to managers everywhere we have stayed and explained that simple pleasures such as walking on the beach are not available to most with mobility disabilities. The least that could be provided is a view when this is available. There seems to be an assumption that the disabled are second class citizens.*

### ACTIVITIES

*Probably the greatest challenge for carers is trying to prevent their partners or those they care for to keep interested in life and not suffer boredom which is very destructive. Carers become responsible for entertaining and all activities.*

*When people become disabled it often requires a complete re-education and re-orientation. In our own case, my husband was very much an outdoors man, an Australian Rowing champion, Queen's Scout and sailor. He thrived on physical activities and challenge.*

*The stroke has changed all that, although he has been fortunate to sail with Sailability, a support organisation for disabled who want to sail. We went to Newport and for some time this was wonderful for my husband, but his lack of flexibility and inability to get up and down ladders and balance on a floating pontoon made this very challenging for the elderly men who volunteered to help. I have been able to encourage my husband to paint, which he has done with some enthusiasm, but the cost of classes and petrol to get to classes on a weekly basis makes it difficult as he was going to classes at North Sydney. I think twice before driving anywhere as it now costs around \$80 to fill the tank of our car.*

*My husband likes to do Crosswords, but even these are at least \$6.50 a book, which may seem a small amount, but everything mounts up.*

*My husband's involvement in OMNI (Older Men New Ideas) Art classes, varied support groups and all doctor's, podiatry, dental and other appointments require me to drive him there.*

## **ACUPUNCTURE and ALTERNATIVE THERAPIES**

*As my husband was given a very poor prognosis by conventional medical practitioners after his stroke, I organised Chinese massage and acupuncture on a daily basis until I learnt the massage techniques and applied these myself. I also purchased a range of very expensive glyconutritional supplements, which we believe made a very significant improvement for health and recovery.*

## **ADVOCACY**

*Carers find themselves in an advocacy role in a wide range of situations and this can be, at times, very repetitive and ongoing. Fortunately, I have been well educated and able to clearly articulate problems and seek positive solutions. Sometimes I just get discouraged because it is like whistling in the wind or whingeing. It has been very valuable to have the support of the NSW Carers Association and the Stroke Recovery Association as official spokespersons.*

## **ANGER**

*After the trauma of severe stroke suffered by a loved one, carers may feel very angry. It is a self-destructive but understandable emotion, but can lead to severe depression. A great depends on individual circumstances and how much immediate personal support the carer receives. Initially, I was in trauma also but had to keep functioning positively to support my husband and assist his recovery. Only one of my friends asked me "How are you?" It was somehow assumed that I was strong and capable, which I am. Few recognised the fear and isolation I was experiencing.*

*As a practising Christian, it was shocking for some to hear me say that I had shaken my fist at God and said "Why us?" until I realised "Why not us?"*

## **ASSUMPTIONS and ATTITUDES**

*Probably the most unhelpful assumptions are that those who have become disabled and their carers have become so from choice. Believe me, both my husband and I have strong work ethics and I would be extremely happy to be back in the full-time workforce earning the substantial salary I was earning before my husband's rehabilitation necessitated my resignation to take him home to our farm.*

*I believe the top-down attitude is that anyone who sinks to the unenviable reliance on Centrelink benefits is "rotting the system". It is pretty clear to me that there are many more ways within Government and within the community that are open to deeper questioning, but it is easy to blame the victims.*

*For both my husband and me, financial independence has been a high priority, but things started to go wrong for us when my husband was made redundant in 1992, aged 51, very badly handled by Telstra in the scramble to downsize and privatise. This was a huge blow to my hard-working husband's self-esteem. At the time his blood pressure started to become a problem and the stroke seven years later was the consequence.*

## **BENEFITS**

*Apart from my husband, who precisely is benefiting from my caring? I am certainly not benefiting financially as I have never been in such a precarious position in my life, and now at 63, have the daily frustration of having little opportunity to change the circumstances in which we find ourselves. In the past when I was younger, I was extremely resourceful and have had to study and retrain a number of times, but now, despite high level skills, I cannot even get to interview, and find that my own confidence and self-esteem is at an all time low.*

## **BENEVOLENCE**

*We have been the grateful recipients of tangible support from my husband's former Rotary Club members in Bathurst, who came and cut wood for us as our slow combustion fire had to be kept going 24 hours a day. Our farm was in a very cold region near Oberon, and I had to keep my husband warm. Normally, we cut wood for the winter during summer but as my husband had a stroke in December and we were in hospitals in Sydney and Bathurst for six months we were unable to prepare for winter.*

*Rockley Lions Club also helped me to mend fences and helped me in clearing our home and sheds when I sold the farm two years ago. I was unable to do the physical labour alone and having lived off our savings for six years our financial situation was rapidly deteriorating..*

*My heartfelt thanks to both these wonderful groups and to a few other individuals who watched over us during those years of challenge and isolation.*

## **BUREAUCRACY**

*It appears that as in many other areas of government, there is too much complexity in the assessment and delivery of services across Federal, State and Local Government jurisdictions. Some people become very expert at negotiating it all. I have found the whole scenario very frustrating and unsatisfactory. There is an observable tendency by bureaucrats to see people like us as mendicants, and a lower form of life. There is an entrenched patriarchal/matriarchal in the attitudes displayed by a number of service providers who at times are patronising in the extreme.*

## **CAREER**

*I used to have a life, a stimulating and interesting professional career and an income of my own. From 1999, I envisaged myself working at least another nine years, possible 14 in the paid workforce. I was 47 when my husband was made redundant and 54 when he had the stroke. I am now 63.*

*There seems to be an assumption that anyone who becomes a carer is incapable of other employment. I have always been a carer, of my parents and parents in law, my three children and husband, but until 2006, I did so with no "benefits" from Government.*

*At one point in our marriage when we were both in the workforce, and paying 49% tax, one of us was in reality working for the ATO, so we have paid our taxes and*

*never tried to shirk our responsibilities to our families, communities and workplaces.*

## **CENTRELINK**

*Singularly the most humiliating and convoluted organisation I have ever had the misfortune to deal with. I could write volumes. Perhaps the most threatening experience was last year, which was our 30<sup>th</sup> Wedding Anniversary.*

*My husband and I decided to revisit New Zealand where we had honeymooned in 1977. It is important to explain that after personal disability strikes a relationship, it changes your attitude to "The Future" because when one or both partners come close to death it seems increasingly irrelevant to harbour long-term plans for the future.*

*We had enough savings and so I decided that the trip to New Zealand was important and I am glad we had this time, which was, however, bittersweet as we had both been so young, healthy and hopeful in 1977.*

*I was advised to inform Centrelink of our departure and arrival dates, which I did. We returned to Sydney on a Sunday, and I rang Centrelink on Monday to let them know we were back. I was stunned to be told that they already knew because they had been informed by Australian Customs. Were we criminals under such tight surveillance?*

## **CHARACTER and TRIBULATION**

*The Bible states that tribulation breeds character, so by consequence, most carers must be people of considerable character including high levels of compassion and responsibility and from my observation of those in both Stroke Recovery groups and Carers Association I believe this is so. It may also be worth commenting that the caring role appears to fall unequally upon the shoulders of women. I dare say if the majority of men had to give up paid employment to look after others for minimal payment, we would probably see more government initiatives to support carers.*

## **CINEMAS AND THEATRES**

*I have always enjoyed good films and theatre. We are able to go occasionally to Roseville Cinema at "Golden Oldie" rates of \$8 per ticket. Theatre is largely beyond our means, but I do have a friend who occasionally has a spare ticket and she invites me to see a play, which I really enjoy.*

## **COMMUNICATION**

*For communication to be truly effective it must be interactive rather than one-way, and be sensitive to all potential personal, social and cultural barriers. There is a huge literature about the art and science of communication of which few are aware. Launching into campaigns to communicate with significant individuals or groups may be fraught with complexity, and there seems to be a tendency for politicians in particular to categorise and underestimate the intelligence of their audiences, especially the elderly who may be disadvantaged, but not ignorant.*

## **DENTAL CARE**

*Looking after our teeth has always been a priority but last year I was required to have \$1500 of Periodontal treatment which is the equivalent of six weeks Carer's payment. This treatment needs to be ongoing on an annual basis or I may lose my teeth. We both go every six months to a normal dentist for general care at around \$200 per session.*

## **DEPRESSION**

*Very common among carers and their families dealing with disability or chronic illness*

## **DETERMINATION**

*It requires ongoing determination to keep trying to improve the situation and there are some days when carers would just like to stay in bed or escape their caring responsibilities.*

## **DISAPPOINTMENT**

*Personal dreams and expectations tend to fall by the wayside.*

## **EDUCATION**

*Being well educated and not easily intimidated is essential for survival in the caring arena.*

## **EMOTION**

*Being a carer can at times be likened to riding an emotional roller coaster, especially in the early stages before one becomes resigned to the changed circumstances*

## **EMPLOYMENT**

*To be employed and earning a decent wage would be the best respite that most carers would appreciate. The way Centrelink assesses payment of benefits when a carer is attempting to return to work is not aware of the insecurity carers may be feeling and rather a Catch 22 situation.*

## **EMPOWERMENT**

*Becoming a carer has been a most disempowering experience.*

## **ESCAPE**

*In discussion with other carers, it is not unusual for them to express a desire to just escape their caring responsibilities, a feeling I have shared from time to time, but with little money, the destinations are pretty limited.*

## **FAMILY**

*We have three children and three grandchildren. It saddens me that our grandchildren will never know their grandfather in his prime, nor the fact that he was so active and he would have no doubt been taking the children on bush walks, sailing, camping and probably making wooden toys and kites for them as he did with our own children.*

*Our children have been supportive, but I have also been aware that they have lives of their own and I am reluctant to burden them with our situation.*

## **FAITH**

*We have been upheld in prayer and community involvement with our Church. I believe without Faith I would have found this all much more challenging.*

## **FITNESS**

*My own fitness and health has become a priority since I was hospitalised with heart failure earlier this year. I now try to get to a local gym for an hour at least three days a week, but there is little doubt that my husband's disability limited my own ability to exercise and be as active as I was previously.*

## **FRIENDSHIP**

*We have been blessed with some special friends who have been aware and keep connected, even if only by telephone. For these people I have been extremely grateful. There are others who simply disappeared from the scene, and that's OK. We certainly learnt who our true friends are.*

## **FRUSTRATION**

*Too many instances to catalogue, but my patience is also being well tested.*

## **FUN**

*Not enough but I actively seek out good comedy programs on television and always feel better after a good laugh.*

## **FUTURE**

*Try not to dwell on it too much as it just makes me sad.*

## **GOVERNMENT**

*Would just like to say that Hornsby Shire Council in which we reside has a wonderful coordinator for seniors and each year has an excellent program for Seniors Week of affordable events and outings/*

## **HAIRDRESSING**

*Having my hair well cut and coloured was always a matter of personal pride. At current costs this has become a luxury I can no longer afford so I have grown my hair and am rapidly greying and ageing. Would love to have a manicure or massage, but out of the question. Little luxuries are unaffordable for most carers.*

## **HOMELESSNESS and HOUSING**

*I have great concern for those carers who do not own their own homes. Really have no idea how they are surviving.*

## **HOUSEHOLD BUDGET**

*With ongoing and rapidly escalating costs for food, petrol, home and car maintenance (had a tap repaired yesterday in two minutes at a cost of \$55), gas, electricity, phone and Internet, it is impossible to budget as there are no constants and GST on everything.*

*Luckily, I have always bought good clothing to last and still manage to look neat and tidy, but haven't bought new clothes for some time. My husband's wardrobe changed dramatically, as he was initially a Fletcher Jones man, then an RM Williams and now I shop at Lowes. He could no longer wear his boots because of his inflexibility at the ankle and foot and his sedentary lifestyle meant that he has gained weight and gone from a 38 to a 44 inch waist. He has to wear slip on brogues and I bought him four good pairs of shoes, two for best and two for everyday wear. Each pair was around the \$150 at a sale.*

*He was always a careful dresser and liked good quality clothes.*

## **HUMOUR**

*My sense of humour has had some solid testing but is still in tact as I have always been able to see the ridiculous in any situation.*

## **IGNORANCE**

*There is certainly a lot of it.*

## **INITIATIVE**

*Probably the biggest adjustment for me has been to the change in my husband's personality. He always demonstrated great initiative and self-confidence. He now demonstrates very little initiative even though I encourage him but his comfort zone has really moved into a very tight little circle around his immediate needs.*

## **JUDGMENT**

*Dangerous to sit in judgment of others without walking in their shoes.*

## **KINDNESS**

*Random acts of kindness by strangers has such an uplifting effect, and it is usually something very small but shows one human being reaching out to another.*

## **MARGINALISATION**

*An unavoidable consequence it seems. The mainstream flows past and you find yourself sitting on the bank and watching the rest of the world go by.*

## **MAKING WAVES**

*Change only occurs when an individual or groups of like-minded individuals decide to become vocal about a situation, which they perceive to be inequitable or unjust. Sadly, many people who experience disempowerment and marginalisation may be too tired to actively engage in situations beyond their comfort zones to encourage and engender change. Being a catalyst for change can be a daunting role for many.*

## **MARTYRDOM**

*I am not impressed by martyrs and think their stoic acceptance of the unacceptable does no good to themselves or others. It is difficult at times to articulate one's needs, and, at times sense of desperation but I have discovered that few people are truly aware of the circumstances of others unless these are explained as clearly as possible, and even then some choose not to become involved beyond the limitations of their own comfort zones.*

## **MEDICAL INSURANCE**

*Who can afford medical insurance on Centrelink "benefits"?*

## **MEDICATION**

*Following my sudden and unexpected hospitalisation in February 2008 with atrial fibrillation and congestive heart failure, my husband and I are now on \$50 per month for medication. Prior to my hospitalisation I was relatively healthy, and I was on no medication, but since his stroke I have been periodically depressed and stressed.*

*The combined cost of our medication is now a substantial cost to the Government, which I believe could have been avoided in my case, at least with less stress. So the Government "saves" money by poverty level Centrelink payments and people get sick as a direct and indirect consequence. So where is the saving?*

## **MOTIVATION**

*It requires high levels of self-motivation and the ability to motivate someone else to continue in the caring role. This is relentless even when the carer may be feeling ill or downcast, and despite the rhetoric, respite services are inadequate, inflexible and most carers experience considerable guilt when considering putting their loved one into respite care.*

## **NUTRITION**

*Good nutrition depends on healthy options and these are not at bargain basement cost. Fortunately, I know quite a bit about nutrition and have managed to keep my husband well for the past eight years by judicious shopping and cooking, but given the escalating cost of fresh food, meat and fish in particular, there is a pretty basic bill of fare*



## **OVERWHELMED**

*The response to too much change happening too rapidly can leave one feeling completely overwhelmed and the danger is that important decisions may need to be made while still feeling overwhelmed. There are some decisions I made which I now realise I made out of fear and which were not wise.*

## **PARTICIPATION**

*Lack of money drastically limits participation. There are places I would like to go and things I would like to do, but they are just beyond possibility.*

## **PASSIVITY**

*Really destructive behaviour, but understandable in some instances of disempowerment.*

## **POLICY**

*Good policy requires compassion, imagination and understanding rather than blaming the victims which has become a common response to disadvantage.*

## **POSITIVITY**

*Really have to work hard at remaining positive and encouraging others to be so also.*

## **RECREATION**

*Carers tend to have little opportunity for their own recreation and regeneration.*

## **REFLECTION**

*Certainly now have time for plenty of reflection on the human condition, our own and others.*

## **REHABILITATION**

*Eternal gratitude to Royal Ryde Rehabilitation Hospital and especially the physiotherapists, speech pathologist and occupational therapists without whose patience and expertise I could not have found the way forward.*

## **RESPITE**

*Very difficult to organise. Seems like an act of abandonment and the ultimate guilt trip.*

## **RESPONSIBILITY**

*I have yet to meet an irresponsible carer, though most experience burnout, grieving and sadness.*

*Most carers from my observation have a strongly developed sense of personal and social responsibility, which I believe, is largely taken for granted. Throughout my career, I have had multiple involvements in not-for profit organisations and have always been able to mentor and support others. I find my current situation so much more difficult as a result because I have never been accustomed to asking for help.*

## **RETIREMENT**

*When can I expect to retire? Under what physical and financial circumstances?*

## **ROLES**

*Carers have multiple roles, which if individually remunerated would amount to quite a good income. I have been wife, cook, cleaner, nurse, masseuse, farm and home manager, farmhand, fencer, chauffeur, nutritionist, trainer, physiotherapist, speech and occupational therapist, gardener, accountant, correspondent, personal valet to name a few.*

## **SEXUAL RELATIONS**

*For many these are virtually non-existent. The personal dynamics between two healthy individuals is very different from the unavoidable dependency experienced by the disable and the parental role of carers.*

*Caring partners can do so much, but as the caring role is already all consuming of time and energy, there isn't much energy left for the carer to launch into yet another sensitive and supportive role in bed.*

*Without being too specific, the disabled partner often has low self-esteem and may become very self-absorbed and self-centred understandably so in most instances. Former intimacy and reciprocal relations are not easy to achieve although cuddles and kisses are important.*

## **SIMPLE PLEASURES**

*I want to cry or scream when I see all those television advertisements of retired couples walking hand in hand along the beach and in other happy poses. To walk hand in hand along the sand, although a simple pleasure, would be so wonderful.*

## **SOLACE**

*Consolation can be found in memories and in Wordsworth's poetry "strength in what remains behind"; "splendour in the grass and glory in the flower". Our present situation does have the advantage of providing, increasingly time to ponder and appreciate what we do have and other realities beyond our own immediate circumstances.*

## **SOUL**

## **STRENGTH**

*Carers have to be strong in body, mind and Spirit.*

## **SUICIDE**

*There have been fleeting moments, especially in the first few years when I was living in isolation on our farm and on duty 24 hours a day, seven days a week, when I contemplated ending it all. Fortunately, with ongoing support my husband is now not as dependent as he was then and I now feel more positive being back in Sydney and closer to friends and medical support.*

## **SUPPORT GROUPS**

*Support groups are very important to provide understanding and the insights of others in similar circumstances. I am truly appreciative of groups with which we have been involved. When I was living in the Central West of NSW, after my husband's stroke, I set up a Stroke Recovery group in Bathurst and Orange and have been actively involved in Sydney groups and with individuals who have been referred to me for advice and support.*

## **SUPERANNUATION**

*Carers don't get superannuation and their caring counts for little with the demise of the person they are caring for. Managing on a pension for a couple is challenging enough, but for a carer then to be "rewarded" by being reduced to a single pension is a betrayal of the sacrifice they have made for their loved one. Carers who are not related but employed to care for someone, who is initially a stranger, get an hourly rate for caring, and I presume superannuation far in excess of what a married carer or parent receives. Message is not to let your heart rule your head.*

## **TRANSPORT**

*It is essential to have access to affordable transport. For most carers the use of public transport is in the too hard basket. Have you any idea how difficult it is for one person to manoeuvre another, usually heavier adult across uneven ground, up inclines etc? Elderly carers often find the sheer physical effort beyond them.*

## **TRAUMA**

*Carers may be significantly traumatised but still are expected to function as if nothing has changed.*

## **TRAVEL**

*Requires sound finances, much planning and generally the carer needs a holiday after a holiday because the effort of negotiating new places and situations robs them of much of the enjoyment.*

## **UNCERTAINTY**

*We all live with uncertainty, but caring for someone is fraught with daily uncertainty*

## **UNDERSTANDING**

*So much appreciated when in evidence, so frustrating when absent.*

## **VOLUNTEERS**

*Without volunteers, communities and the country would be so much poorer.*

## **YOUTH**

*I have deep respect for young people and very much miss my professional life, as an educator, with them.*

*There is, however, an over-emphasis on youth over experience, which is reflected in recruitment strategies and the employment sector generally.*

*There is also a great deal of nonsense about skills shortages when some of the brightest and best young people are wasting intelligence, time and energy in call centres and the like.*

*There are also many people over middle age who are underemployed and many in retirement whose skills are untapped.*

*Most employers are still thinking in terms of the Industrial Revolution. Today we are in peril as we face global problems which can no longer be ignored.*

*In more traditional societies the Wisdom of the Elders is highly respected and valued. We could learn a great deal from this worldview.*

## **ZEAL**

*It is going to require more than a talkfest to bring about real change to those whose circumstances I have tried to highlight in this A-Z summary. It will require bi-partisan commitment to real stewardship and expenditure of public monies in the budgets of Federal and State governments. It will also require passion to maintain parity with regard to a wide range of needs across all Government Departments. The choices made as to priority areas of expenditure will speak volumes to contemporary commentators and to posterity. It is obvious that there have been many glaring examples of financial mismanagement by governments, too easily glossed over. There will always be infinite wants and finite resources, but failure to spend on key areas has a way of emerging somewhere else, often as a much greater expense.*

## **POSTSCRIPT.**

*We live in uncertain times, in a world that is characterised by inequality and injustice. Living as we do in this still "lucky country" of Australia we are among the most fortunate in the world and for this we are most grateful.*

*It is, however, becoming more common in the rhetoric of unfettered laissez-faire capitalism and rugged individualism to endorse those who appear to be winners. It is often forgotten that the foundations for winning and wealth may have been the direct result of the past efforts of some who may no longer be actively involved in the economy as "working families,"*

*For Federal politicians, it might be worth mentioning that the telecommunications systems and networks they now enjoy were project managed very ably by my husband, as were those of Government House, ASIO, and the national networks of a number of notable retail companies such as David Jones and Woolworths.*

*For his commitment and diligence over 36 years my husband was not even given the dignity of a farewell lunch in the unholy rush to privatise, and being over 50, he was considered past his "use by" date.*

*In my own case, as a secondary teacher, university lecturer and employee within state and federal government bodies, I have spent more than 30 years educating and mentoring others while juggling the responsibilities of raising three children and community involvement.*

*Until 1999, we managed our lives and financial affairs without any government financial or other assistance. We paid our taxes diligently, contributed to our families, workplaces and the communities in which we lived and worked. We are law-abiding and responsible citizens. We did not live extravagantly, but generously.*

*My husband's stroke was not the only challenge which has confronted us. It has proven, however, to have had the most serious impact on our ability to live independently, which is, at any rate, a mythical state.*

*No one is truly independent, but interdependent, reliant upon the generosity and good will of others and ultimately on the grace of God.*

*Yours sincerely,*

*Lyn*