

AOC 4/8/06

Submission No. 1198

(Inq into better support for carers) ■

Hi, my name is _____, I am 54 the sole parent carer of my adult daughter Renee. I didn't have a working life so I care from the basis of a carer payment, a bit like receiving a premature old age pension for my work., no life savings, no superannuation, no sick leave, no annual leave, consequential the financial impact and limitations become inter-generational.

I think family carers are one of Australias' greatest natural resources, and we deserve the same kind of attention as is currently being given to the River Murray, as like the river, there is more being taken out of us than is being put into us. I wish we had clubhouses like the RSL or CWA, but we are too busy caring to organize ourselves- simply put a family carer is the person within a family who has most capacity to care when the need arise, it is conceivable that in future I will have less capacity than my daughter with disability, indeed I am certain folk with an intellectual disability are family carers for their aging parents. I would love to have ongoing involvement in the inquiry and contribute to resolution of some of the most urgent issues in anyway possible, I will forward some other notes I have written about the issues and also a photograph of my daughter and me from the inventors newsletter as family carers are also great achievers, my very best wishes for successful deliberations, kindest regards Annette



SA Inventors
Award Page 2.JPG ..

Re Inquiry, family carers, The attached is a photo article re family carer receiving inventors award in sa- necessity is the mother of inventions, affordable personal warmth due to low income. Every issue that impacts on all people hits us hard, high cost of mortgage-interest rates, petrol, power and water. Many of us are at home caring 24 hours, 7 days a week, thus we need comfortable functional affordable homes. We are most vulnerable to escalating costs due to fixed low income and high costs of caring. We need affordable technology, kindest regards,

Hello Inquiry, I think it is really vital that family carers are resourced and supported to speak for ourselves re these issues as we have authentic experience of the issues, it strikes me that paid workers are not as passionate nor motivated to achieve change and a fair go as we are- it is hard to get family carers on committees as we are so bound up in our caring responsibilities, but I am certain it is possible with determination, kindest regards.

-----Original Message-----

From: |
Sent: Tuesday, 1 July 2008 9:54 PM
To:
Subject: Govt Inquiry, better support for family carers

Hi Phil, Peter and Bette, I have struggled with what to say about this inquiry as any individual comment would have seemed under the circumstances a bit "twee".

Then this evening as I was turning it ova and ova, it came to me, so I am hoping my comments will be of use to you and that you will free to use my analogy for the benefit of all family carers.

In Australia today family carers are an enormous mass, the biggest single group of providers of care to people with disability, people with chronic illness and to people who are elderly. You might like to think of us as being the backbone of care in Australia today, and historically we always have been. Typically we provide care in really difficult and enduring circumstances.

Perhaps the most poignant way I can describe the extent of difficulties is to ask you to think about the enormous mass of we family carers is think us as being the mass of River Murray and the enduring impact of the drought over many years. Whereas the River Murray trickles on without incoming and sustaining rains, family carers struggle on without adequate income, becoming poorer ova time, without holidays, sick leave or superannuation, without the tools or equipment for the job. The depleted water of the River Murray is turning to salt, the depleted spirit of family carers is flagging and sad-sour.

Protesting on the banks of the River Murray are farmers, industry and citizens, lobby from local government, state and federal governments, the impact is recognized far and wide. People with disability, chronic or acute illness and aged Australians are the most vulnerable collective in our society. They make neither protest nor lobby and suffer on in silence.

The River Murray sized mass of we family carers soldier on in our isolated world of silence. The majority knowing full well as I write, that in every accommodation service for people with disability, people with chronic illness and aged care facility tonight, right around Australia, the manager of that facility would have struggled to fill or will have left partial vacancies in the roster. There is, as I write an acute crisis in filling the rosters of every direct care facility around the country due to a labor shortage of paid direct care providers. The impact of this labor shortage trickles through to family carer support services so that the very same crisis exists in respite facilities and in the delivery of in home respite and family carer support services.

Consequently the primary need of family carers in Australia today, the River Murray sized mass of us is for Governments, Federal, state and local to do the math, crunch the numbers, review the population figures. Family carers know only too well that equal opportunity is in short supply, there is never enough to go around, but our current needs must take precedence over that. Our current need is to review the math, the crunch numbers, a reality check, which will predict the inevitable reliance on the expansion of the availability and probability of family based care for an increasing number of citizens who have disability, chronic illness and the aging. When the

numbers are known there will be an indicator of the volume of the work force needed to provide direct care services in support of family carers. When this information is available family carers can then deliberate whether or not part or full time work force participation is a viable option in addition to their 24/7 responsibility of family caring.

As the River Murray is the life blood of the water supply to Australians citizens it is family carers who are ensuring citizens with disability, chronic illness or who are aging have air and the comfort to breathe and it is for the Australian government to ensure a working wage instead of an income for carers whole of life equal to the old age pension. It is for the Australian government to ensure that family carers have the tools and resources to continue this very vital life sustaining and quality of life ensuring work. After all, at the end of the day, all most of us seek is the opportunity to care, work in comfort, with pride and peace, to be happy.

Dear Inquiry, this is the last of my notes re the needs of family carers, I wish you all a successful Inquiry, kindest regards Annette

-----Original Message-----

From: [|
Sent: Wednesday, 2 July 2008 8:03 AM
To:
Subject: senate inquiry

Hi Agen, Bette , Phil and Peter, The point of my River Murray analogy and family carers is to try to get government to conceptualize the magnitude and complexity of the problem, that the challenges are inter-generational, enduring and complex- no quick fix here! The vital issue for the analogy is like the River Murray- there is much more being taken out of the mass family carers than there is being put into them. Australia has a position about natural resources and the environment, we do not have a position about family caring, sustaining natural relationships, nor the prevention of abandonment of children with disability or folk who are aging or whom have chronic illness- in fact we still have beliefs that these folk belong somewhere else in some one else's care and for some a mistaken belief that that somewhere else is available. The point of my analogy, the aim is to achieve a government body with the profile, resources and determination as has over sight to the resolution of the River Murray- we need to use the senate inquiry as an opportunity to lobby for that and a beginning framework for terms of reference and time frame. You will know well some of the issues which construct the scope of need. Or example, the intergenerational impact of family caring, poverty of long term family caring, work force participation, access to technology, access to support services, the crisis in funded direct care provision due to labour force shortages, family carer access to carer support packages and self managed funds, special needs groups within the family caring population, for example, child carers, indigenous carers, multicultural carers, carers who have disability, who have chronic illness, family carers who are themselves aging. This done then there has to be a sense of the urgent which is to be resolved and some timelines, but above all else it has to sit in a policy and values framework which has an acceptance and appeal to all Australians, kindest regards

The tidy gene, it escaped me; usually you can see chaos where ever I have been and am. Likewise, I am domestically inept. I can see the nonsense of it. Why would anyone collect ornaments, Royal Dolton or Wedgewood to sit on a table or shelf to gather dust? It is much more practical to gather trappings of beauty and place them in one's garden, and then at least winter showers will make certain that they are rinsed clean regularly and the wind is ever willing to dust.

Every institution has at its gate, a monument, as does ours. Our statue is a living thing, a topiary form on a metal frame, a couple of metres long and more than a metre high. She is a very friendly dragon - almost smiling. Growing about her intricacy is a thriving jasmine vine, shooting vigorously with all the recent rain and adorned with a million tiny buds, soon to burst forth with delicate deep fragrance. A symbol of transcendence, antiseptic, immunity aphrodisiac, vitality.

When ever one decides to shares chapters from the journey of life the question becomes "Where to begin?"

One devastating day about 10 years ago, Renee returned from her work, where she was supported to assist a friend with administrative tasks in a private consultancy business announcing that she had quit. A quick summary glance at her body language, emphatic posture, determined facial expression caused me to conclude an immovable position; nothing here is up for negotiation.

I muttered all the expletives and took the lord's name in vain internally more than once, and muttered the unspoken four lettered word, and said "What are we to do now!"

Renee should have known she had just slammed the door on the opportunity of a lifetime, that many folk with disability would have given their eye teeth to have.

Just like many other mothers in similar circumstances I knew that one door closing simply meant another one would have to be opened. No way in the world was Renee staying home with me all day doing nothing; the prospects of just her non stop talking would certainly drive me mad. I audited our lifestyle and our possessions, what did we have to make work out of, what connections, what capital, what opportunities! Not many, not much!

We agreed I would bunch flowers from our garden and Renee could sell them. We would start in familiar settings among known potential customers. Really the only people we knew were providers of disability services. Likely that would be a safe place to start. One thing led to another and before very long Renee had a contract to deliver fresh flowers on a weekly basis to a café next to a disability service provider. Not much time later a soap maker on hearing about our organic garden came in search of calendula and rose petals for her natural beauty products. This kind lady taught us to make bath infusions too, supplying essential information about stockists and ingredients. A neighbour, a long time customer of the free range eggs Renee had delivered suggested it should be possible for Renee to fill heat packs with wheat if I stitched the outer lining, the stitched them closed

Time passed and life became a hard slog. Over weeks and months, perhaps two or three years, in spite of our chapters out of what might look like a good life, Renee seemed to be becoming less and less well. Ironically her primary excuse for quitting her job was that she simply wasn't well enough to do it.

Like many folk with cerebral palsy Renee had endured many investigations for epilepsy. Always the test results came back negative. Other explanations were that she had fainted or had a temporary lapse in the face of something unmanageable or too stressful. Renee's epilepsy meanwhile gathered a momentum which ensured the existence of the disease could no longer be denied. Ambulance trips to hospital became common place. One lucky day we arrived by cab minutes before a major seizure erupted. A few weeks later, history repeated itself. This time Renee needed to be resuscitated at home and the ambulance journey was dramatically accompanied by bells and whistles then a fast track through accident and emergency to the intensive care ward where Renée was wired up to life support.

When Renée returned home a few days later it was to revisit her every life stage, to share old memories of long ago, her speech more slurred now and her mobility more impaired. Terrified of losing her I scarcely took my eyes off her. All kinds of life events cause us to lose our sense of trust. There is no betrayal of trust like the possibility of losing a cherished adult child right before your eyes. Determined that Renée would survive, I abandoned all of my life delights like gardening, reading, and writing and scarcely left her side. I set up my sewing machine right next to her, determined even though the fresh flowers and the gardening were gone that I could still make wheat packs, and bath infusions. Not very exciting nor creative, but something is better than nothing.

Not many days passed before I became curious about the possibility of a wheat pack that would stay in place. I rarely drove the car, I didn't need a seat belt, my life was wobbly, what I needed more than anything else was a wheat belt to feel safe in my life on land. I didn't ever swim much either, so I had no use for a life jacket in water, my requirement was a warm life jacket for my dry land life.

So began the Uneke wheat dream. One of my weaknesses has always been to see life in pictures, ambitious full living colour. Renee's podiatrist encouraged that we should register the designs of our wheat heat packs, and so I did, seduced by the idea of not being poor for ever more.

(A family income of a disability support pension, carer payment, hourly paid work and a consumer self managed package are an excellent framework within which to explore the establishment of a small business. Notably many mainstream families in times of low employment or redundancy have established family business to ensure daughters and sons have work.)

In the midst of our preoccupation for survival I consented for Renée to be taken to a support workers home on a regular basis. Weeks later on a tram to the city with friends, Renée alleged that she was being sexually assaulted, threatened with choking, photographed, videoed and told that, dare she tell a soul about these atrocities, her mother would be killed?

Our lives became mud and sludge, overwhelming, painfully impossible, but over time we recovered. I stood firm but heart broken when Renee became hysterical if we ventured any where near or even the direction of where the alleged assaults occurred. We took work to Renée's room, where she could have something purposeful to do in bed; we made her environment as comfortable as possible.

The Children in State Care inquiry presented hope, an opportunity to speak of our endurance of sexual assault, to comprehend that it was little about us personally and more about the cohorts to which we belonged, illegitimate children, people with

disability, daughters or sons of adult parents who had also been assaulted. The incidence of sexual assault onto people with disability for example is approximately 80%. We may wonder then about why the perpetrators are not all imprisoned. Factually, these matters only get to court when the police and Public Prosecutor are confident of achieving a conviction. Consequently it is rare for allegations of sexual assault onto people with disability, who are poorly placed to stand up as robust witnesses, to actually get to court. Our imperative thus is to be profoundly determined that the lives of people with disability present no opportunity for the perpetration of violence, neglect or sexual assault. Simultaneously it is our responsibility to inform ourselves of the finesse and seductive behaviours of perpetrators.

One outcome of the Children in State Care Inquiry has been the offer of counseling support. Both Renée and I enrolled. When I inquired months later about what was available to us, I discovered our names had been overlooked. We were then offered counseling with a provider of our choice. Embracing this opportunity with both hands we made arrangements with a counselor with a track record about clarifying responsibility. During our visit I heard Renée confidently tell him she could not possibly fetch her own firewood, least she get dirt under her fingernails. "That is Annette's job". Tears streamed down my face as I reconciled my intrinsic fatigue with the redirection and that today's adults with disability are much like today's mainstream adults, highly articulate about their rights, steadfastly slow learning about their responsibilities.

In my life journey it has been my good fortune to meet some most amazing men; I have envied their status, their income, their capacity to cope, to juggle, to respond. I came to learn almost without exception that at work these quite special talented men are supported by equally extra-ordinary women (their personal assistants), whom should you choose to take the men out of the picture, their personal assistants have the capacity to keep that show(work) on the road. At the that moment I decided we would have no more support workers, but that we would have instead personal assistants. In my admiration for the women whom I have come to know, not once have I heard them disclose the health issues of those whom they assist, nor their bad habits, nor their idiosyncrasies. The women conduct their responsibilities which such great finesse they always enable the person they assist to be their best, to look their best and to know what is best, Yes, we will have some of what the men are having.

I note that the role of the support worker, without much education and training has become the resolver of all challenges and that for many people with disability it is rare for them to have access to a beautician, manicurist podiatrist, life coach, psychologist - I could go on. What I mean is that most of the mainstream needs of people with disability have been subjugated to support workers, when really the role of the personal assistant is to make the appointments and accompany the individual to the specific service or support in question, ensuring too, that people with disability access some of what people in the mainstream are having.

As the mother manager of a package of support to enable Renee to have a life in the community, unsurprisingly tough decisions had to be made. Always scouting around for something philosophically coherent to make sense of our lives, blessed to have the opportunity to listen to the small business mentor we have adopted.....

Valuing people,
raising self esteem and
achieving our potential,
this is what binds us together, an inherent set of beliefs which embrace us all.

Frequently Renee's health care needs threatened to overwhelm us, just the trauma from my perspective of witnessing the almost tragic consequences of her status epilepsy presented a debilitating obstacle, but for me the comfort was in hearing over and over, the RDNS nurse teach us how to respond should the circumstance arise again. I drew strength from her carefully constructed health care plan and remain able to honor it and my intuition. These may seem like trite concerns, but to have this back up, and a partnership with the manager of Renee's accommodation service who has accompanied her for blood tests and to the theatre for general anesthetics when the need arise to transfers anxiety from Renèe and me. There is joy in witnessing simple achievements like the capacity to tie ones own shoe laces, to lock up and unlock ones own bike.

Changing the narrative, from disability politics and provision to orchestrating a small business there is no motivator to be come productive like sizeable debt. As I have invested many thousands of dollars in registering the designs of our Uneke wheat products, the borrowings against patent attorney's bill remain constant inspiration to achieve business success. I did this at a time when there seemed to be little or no design features in wheat heat packs. A quick search on eBay will illustrate that there a masses of simple wheat packs available. Offerings which feature design are rare.

Four years ago, I pounded the pavement and asked retailers to stock our product in a consignment arrangement. I stalked men on building sites, looking for individuals in pain who might trial our products then write positive testimonials, or at least dictate them. Often the last thing I do before I go to bed is complete a wheat pack and regularly the first thing on my list each day is to make one. A trip to the fabric store promises an adrenalin rush, likewise the essential oil shop. I am addicted.

In the beginning, the complexities of small business were overwhelming. I looked at other small business owners with envy, their confidence and knowledge leaving me feeling pail and weak, like a fish out of water. This is not what I was trained to do. As in our other life domains I quickly committed to using everything which is available to shore up our position. I scan the business pages in the newspaper, watch the business television programs and hear carefully the language of product promotion and marketing. Unfortunately, not even the language of marketing could save my role in this aspect of our business with Renee, who with the help of her personal assistant, always produces sales figures which outstrip mine. The opportunity to do this important work was no longer my own.

During working hours we walk the walk and talk the talk of small business owners. Are there any cheques to be banked, do we have labels for this, what fabric should we use for that, what product does that customer require, how much will we charge? It would be naïve to suggest that all is well in our lives, that our struggle has been or is a walk in the park. Far from it, we have stockpiled our support resources to construct a working life and the foundations of good home lives. It is rare for us to participate in a recreation or social life, but we are getting in place the foundations for these past times to occur. We are blessed to have something to offer other folk who are cold or in pain; we honour our vulnerabilities and know much about the suffering of fellow disadvantaged citizens as well as our personal limitations. Consequently, in closing, some words of courage, humility and hope.

It is not what we heard
it is not what we saw
it is not what was done to us

It is not about what we have lost
or how frightened
terrorized
how violated we were

It is about how we choose
to live our lives now,
that we are all standing here for.

Dear Inquiry, I am writing about family carers and dependent adult daughters and sons with disability. Historically many off spring with disability have been placed in residential care in preparation for the death of aging parent carers. Now some of we family carers of adults with disability are saying our relationship with our daughter or son with disability is our most important life relationship, we recognize we will be too old and frail to care for them, but we still want to be near each other. Consequently we are planning a concept called the "Village Green"- which is a purpose built community where aged family carers will have semi independent units co-located with individual units for adult sons and daughters with disability. In addition there will be shared facilities like dining rooms and recreation spaces, perhaps a community garden. In this model family carers will be able to take holidays, but also provide critical information, guidance and over sight for the term of our natural lives. Typically, currently we are all providers of passive night care. In the Village, the night care can be provided by a service and shared without the people with disability having to go into residential care to ensure no risk nor vulnerability. When it is time to "pass on" we will be able to do so in peace knowing we have upheld and contributed to quality and appropriate care and support for our daughters and sons. Should our daughter or son predecease us, we will have a secure life in the village alongside other like minded caring families. A residential facility in South Australia, Minda Incorporated will build the first model of this kind soon, as families want to live co-located with their adult children. Kindest regards,