

## Update to Submission 149, Part 3 (149b):

**From:** Cameron Way.

**Date:** 4 Mar 2005.

### 1. Chunky bits for Senators

At this stage Senators probably need some succinct chunky points, and some solutions!

As citizens “on the ground”, there are several observations of the problem within aged care, and solutions, that are self evident.

Here they are:

#### **HACC Policy change – an immediate intervention?:**

Most volunteer community based organisations with a relevant service to Fiona are funded by HACC.

HACC’s purpose is to support people to remain out of nursing homes as long as possible. Good policy thinking.

However, the current policy does not accommodate the existence of young people (under 65) with a disability who do have a relevant need for HACC services.

If such services were available, they would assist in some instances a young disabled person to improve and exit aged care accommodation.

This would free up a bed space, and in so doing support the funding aim of HACC.

As far as I can determine (from letter NSW Minister John Della Bosca MLC to Federal Minister Brendan Nelson) the current HACC policy is maintained by State and Federal Government agreements.

A change to this policy would provide an immediate “relief” solution to the current crises of inadequate support to ypinh.

#### **Labour market in the Aged Care Sector:**

##### *Staff Shortage:*

There is a chronically short level of staff in the aged care sector. Not only is this obvious from our direct observation, but also affirmed from all I have had contact with in the industry over the last 5 years. With existing staff levels it is not possible for adequate basic daily care to be provided to the aged. Many of the aged are suffering daily as a consequence.

I estimate the shortfall is at minimum a full third of the current levels of direct hands on staff.

I understand there is wide recognition of a national nursing (RN) shortage. However the primary shortfall for the quality of care of individuals in aged care facilities is direct hands on carer's (EN's, AIN's, PCA's etc).

*Ministers Pamphlet before the last election:*

The Federal Minister's release of the pamphlet reporting research outcomes just prior to the last election that there is no staffing crises in the aged care sector is a nonsense.

I believe any systematic inquiry of DON's of nursing homes with the simple question: "Do you experience a shortage of suitable workers in the aged care sector in recent years?" will tell you otherwise.

I think the Senate Committee should take a close look at this.

*Link between staff shortage and poor quality of care:*

It has been reported to us repeatedly that a primary part of the problem with the quality of care is the labour market shortage. For years nursing homes have been afraid to dismiss clearly undesirable staff, as they fear not being able to find their replacement, and through lacking adequate staff, fear threat to their accreditation etc.

I have spoken with aged care workers working in regional areas of NSW as well as Sydney. I find the same situation reported consistently. Most workers speak also of systemic problems with workplace bullies and sociopathic individuals in the industry. These individuals being often highly competent individuals, they seem to thrive in a stressed system preying on the vulnerable, residents and facilities. The presence of such individuals "peppering the industry" was also commented on, and clearly recognised by one union representing workers in NSW.

This industry wide problem of bullies is not addressable in large part because of the lack of the labour market shortage.

*Loss of caring staff:*

There is currently a negative spiral similar to "the brain drain" of national intellectual achievers. The caring workers are leaving the aged care sector.

The presence of hands on co-workers who lack a caring attitude adds considerable stress to the workers that perform their job ( or desire to perform their job) with care. This has lead many good workers to become themselves traumatised by what they witness, resulting in burn out. They leave this sector.

*More staff training is not always the solution:*

More training is, unfortunately, not the cure all!

Emotional caring can not be trained at TAFE. Training that provides more knowledge of residents, dementia, brain injury, can bring some shifts in personal understanding and attitudes. However, this only goes so far. Those who do not have a care – it is just a job – are little affected by such training.

*Language and Culture of Workers:*

Adequate care for the aged in an aged care facility requires hands on staff that speak the language of the residents (and the facility), and have the cultural understanding of the residents.

**Financial resources committed to physical infrastructure change in aged care:**

My understanding is there are strong requirements upon nursing homes to ensure by set years (eg 2007) that all rooms have no more than 2 residents, each room with an on-suite bathroom, etc. These new requirements require often the complete rebuilding of facilities.

These costly physical infrastructure changes are needed and desirable. However, to see millions spent (even if by the facilities) at the expense of funding adequate levels of staff – is to void and nullify the improved quality of care these physical changes are designed to achieve for the aged.

Better balance is required here I think! I think the Senate Committee should look at this.

**Broad shift in current national model of aged and high care:**

Given the current system can not meet current needs, and the impending baby boomers, there is need for a broad shift in the model for care for both the aged and disabled. A move to a social model incorporating medical care, rather than an institutional medical model.

For example, it may be constructive for national policy to look at funding to provide house renovations for aged to be cared for at home, with a daily nursing care service, up to time of death. Some legislative changes may be required re individuals remaining at home till death.

These initiatives would be in compliment to the current aged care facilities.

If facilities are to be built for young people, I recommend facilities and services that are:

- nearer places friends and family find easy or attractive to visit. For example near suburban shopping centres, or at an attractive country location with low cost visitors accommodation as part of the facility.
- designed in some instances to reside a social mix of low income non disabled people as well as young disabled. (Selection of non-disabled necessary eg students training to be in the disability field or nursing profession).
- Provision of single rooms for most disabled residents.

One must break from the current social “monoculture” model in institutions. The aged in aged care facilities would benefit immensely from this shift also.

### **Location of accommodation services for young people:**

Young people (under 65) with disability need to remain located near their social support of immediate family and friends. Hence building a few large centralised facilities in each State is not a viable solution. Cross that off the list.

Being near social support, those already familiar with the disabled person is a highly critical factor for young people in nursing homes – a factor not self evident on first inspection of the ypinh issue.

The radio story (available from the web) “Locked in with friends” – by Cath Dwyer on ypinh. ABC JJJ Radio National, illustrates well the valuable role of friends and social support to ypinh.

<http://www.abc.net.au/rn/history/streets/stories/s1291965.htm>

### **No fault compensation:**

Some people who incur disability from a degree of reckless or risky behaviour receive large compensations, Others who are injured through no fault of their own receive none.

This has to change.

### **Public Health System:**

The increasingly stressed public health system is weakening in its capacity to follow through in injuries such as traumatic brain injury to ensure best outcomes and public cost minimisation in the longer term.

#### *One key observation:*

In the time stressed public health system, medical professionals have the expertise for effective intervention, but not the time with each patient to apply that expertise competently.

Under the stressed public health system, a medical professional may have 20 minutes to address a complex set of issues affecting the disabled persons health and rehabilitation, as well as assess the significance of surrounding issues. They hear and have time to understand maybe 20% of the factors in that time and make their best guess decision. Often wrong! For people with brain injury, unable to remember or speak, many careful observations, responses, etc need to be worked through to understand what the real issues may be, and hence make relevant and effective decisions. This may involve 2or 3 hours of time.

### **Litigious Environment and Medical Professional Care:**

In cases of ongoing disability, given the stressed health system and the shortage of time of professionals involved family can be a great asset.

Usually only family have the extensive time needed to work out what is happening for the injured person. Such careful observation is important information for the medical professional to direct their expertise appropriately and correctly.

Medical professionals however in the current litigious environment are often reluctant or simply will not

incorporate observation by family in their clinical decisions – legally their observations and views are not those of a fellow “professional”.

Legal concerns consequently hinder effective teamwork to get the person well.

### **Telecommunications:**

Simultaneous use of voice and internet/email/fax is increasingly essential. Access to a broader band service than a single phone line is increasingly necessary.

For example, as a guardian I have had several situations where urgent decisions need to be made within a few days. Effective decision making involved contact with a range of medical professionals, several with key expertise to the decision. One also needs to check internet information re legislation, or medication, or access to services. Communication with medical professionals depends on each one, fax, office, mobile, email. Miss a return call from one of the key medical professionals because you are one the phone checking emails, and one may not successfully get back to that professional for another week or two.

Email and internet access is already an essential for families playing an active case management role.

### **Recognition of non-home based carers:**

Roles of care, support, case management of a traumatically injured and permanently disabled person is a time consuming and financially costly task. Such activity when undertaken by a family is a significant contribution to lowering the long term societal cost of the injuries.

Family members acting in this capacity are acting as carers, even though they are not caring for the person at home.

In non-compensable cases lack of current recognition and support for their role affects the quality of the outcomes they can achieve. Hence, better recognition of these people would likely result in better outcomes, ie lower long term public cost.

Home based careers typically have an even tougher job and need to be better recognised in my view for their role of caring for loved ones at home in terms of financial assistance and access to respite care.

*Possible options???*

*Financial:*

- Extending the carers allowance to active individuals if their role remains ongoing for more than 6 months.
- Tax recognition for expenses incurred, or income lost.
- Commonwealth or State grant packages of a few years for case management by families.

*Time and service:*

- Improved recognition in policy and law of individuals performing case management and guardianship roles to a disabled person.
- Recognition within social security “mutual obligation” requirements of providing voluntary service and assistance to a disabled person.

## **CSTDA**

It would appear that State Governments, mostly Labour governments, are not fulfilling their responsibilities under the CSTDA re appropriate accommodation for young people in nursing homes.

It seems part of the problem is the loggerhead between State and Federal Government re the CSTDA.

On reading the CSTDA, I am lead to wonder if this lack of capacity for cooperation is a convenient way for both parties to avoid addressing the problem – to mutual convenience.

I can only hope this view is on this occasion, an erroneous perception.

Mutual obligation to whom? Given no facilities for young people for over a decade, yet the details of the problem clearly known, clearly there is not a mutual obligation to those with disability.

## **Update to matters covered in submission 149b.**

A further six months has passed since I wrote this submission. Let me add briefly:

### *Failure of the Commonwealth and NSW State complaint processes:*

I have engaged with both the Commonwealth and NSW State Ombudsman’s offices. It would appear that no avenue for effective address to the failed complaint process outcomes is within their powers.

I have contact the Office of the Commissioner of Complaints in the hope they would make a submission in regard to their concerns of failure of follow up to Determination Decisions. It would appear they have not, and my call of a few weeks back has not been returned (unusual).

I have also had personal discussions with the Human Rights and Equal Opportunity Commission, Sydney Office, with the same outcome.

I have also followed the recommendation of engaging with the NSW Disability Discrimination Legal Centre (DDLCL) with regard to lodging a case with the Human Rights and Equal Opportunity Commission (one of several legal options on one or more aspects of this situation).

At the time of engagement, the two solicitors of this organisation left, and hence there has been delay with the location and settling in of two new solicitors at this legal service. A letter was subsequently received December 2004 expressing that they were unclear on what grounds we felt there was a case with the Human Rights and Equal Opportunity Commission. Unfortunately, with other demands over summer months, I have not had the personal time to follow up on this matter to date, though I hope to shortly.

I have also made phone comment to NSW DADHC consultation process. One comment made re HACC is that this was unlikely to change in view of the politics between State and Federal Government.

The general experience has remained to be one of closed doors, no meaningful or effective options, zero effective accountability.

It would have been better if family had not lodged any complaint process.

*Section covering personal cost in previous submission 149b:*

With respect to the personal cost to me outlined in one part of the August submission, I would have liked to re-write this section to articulate better, by way of an example, the particularly high personal cost of the failures outlined for myself, and other family members. I believe this is relevant to the Committee. Time however, has not permitted this.

*Generally:*

As far as I can determine at this time, the original submission and support documents covers most of the situation leading to exercising of complaint processes, and the outcomes of pursuing complaint processes.

At least as far as this Committee's TOR.

Fiona's case represents both the situation of many young people in nursing homes (ypinh), and the situation of residents of any age generally in an aged care facility.

Having provided to the best of my ability the background details, I value the opportunity to make some final summary comments on the day of the Hearing.

### **Why such a detailed submission:**

Unfortunately the extent and nature of Fiona's case is only made known through including the details.

Without providing the details, frequently the experience from engaging agencies has been: If her care is so bad, why doesn't family just.....

- (a) move her,
- (b) care for her at home,
- (c) get her to a public hospital,

- (d) lodge complaint with the government,
- (e) tell your local MP about so they can fix the problem,
- (f).take legal action.

Our presentations of difficulty have typically been dismissed by engaged persons/departments. They assume one of the above options must be an available solution. They assess we should be left to exercise one of these options. There is often a value judgment that if we really had a will to find a solution, we would exercise one of these. Given their tight resources, it is justified that the situation we present is not really worthy of their attention and resources. Such quick evaluations and judgements are usually silent, not discussed. We just get advised that their services are not relevant to us.

It may be 12 months later, and after several approaches, and after providing details, explaining why assumed options (above) really are not viable or possible, does the assessment finally come forth to conclude “Oh I see. I misunderstood X. Now I understand more fully, I see your need.” Then comes the request ... “ ..can you put all that in writing.”

The door, previous closed 12 months ago, opens.

We have learnt the details, while no one wants them, are almost always essential!

### **Fiona’s case –Update:**

Fiona has been subject to strong degradation through sustained emotional psychological and some physical harm since her placement in the nursing home.

There have been no other viable placements for her.

While Fiona is showing signs of physical recovery, Fiona is also showing signs of a decline in her emotional state in the last year.

This situation of decline is not a consequence of her original injuries. The only association is that her original injuries have placed her in a position of vulnerability for this to happen.

In the last year Fiona has regained short term event memory. The consequence is that she is now remembering her ongoing ordeal, comprehending as you or I would the intent and manner of attitudes and actions towards her by selected staff, while also comprehending she has no means to protect herself, and faces a lifetime of being subject to this suffering.

Fiona comprehends that over this last year there has been little change to her circumstances, and hence her hope has faded, her desperation increasing. With ongoing mistreatment (by selected staff) and poor care, Fiona is developing more severe challenging behaviour responses with increasing loss of discrimination to whom.

These outcomes are a direct consequence of her treatment over 4 years in this aged care facility, and a consequence of unaddressed victimisation.

Over these years family have acted in good faith with the nursing home, and all available relevant agencies.

Family, friends, professionals and supporters to Fiona are increasingly affected and traumatised. So are staff within the facility, most largely unaware of the bigger picture surrounding their experiences in their daily work shift.



In 2000 Fiona had hemiplegia, no speech, no capacity for eating by mouth, and profound loss of short term memory and consequent disorientation.

Despite very limited resources for rehabilitation and obstruction to rehab at the aged care facility, this year in 2005 Fiona has achieved partial recovery from all four of these major disabilities. Professional opinion has been expressed that without obstruction Fiona would by now have close to full recovery of these functions by now, 2005.

Recent assessment indicates this recovery is not yet sufficient for semi independent living in a community accommodation service because of some ongoing dependencies with care.

The harm to Fiona of the last four years is now clear and evident to those close to her. I, and others involved find this very painful and distressing. Many friends express their difficulty visiting simply as the degradation of Fiona is so evident to them, and so emotionally difficult to face. Mandy has captured this well in one of her emails, copy added as attachment.

The overall situation of her care at the nursing home is little changed. While family seek to create appropriate facilities (re Part 1, Gordon's initiatives) as part of addressing the problem in the long term, in the short term there remain no available options.

I feel it is important to note that there has been some significant efforts by the new Director of Care (DOC) of the nursing home over the past 18 + months, resulting in moderation of some of the destructive elements of the environment at the nursing home that has lead to Fiona, and to a lesser extent all involved parties. These efforts are to be commended, a major achievement in the circumstances. However, the overall change in Fiona's situation is, on net balance, minimal, and remains very poor.

Fiona's teeth are an example of current care.

Daily care is typically not provided on the basis that Fiona has unacceptable levels of challenging behavior. Hence for periods she is not fed, changed, showered, teeth cleaned or even checked on.

Recently a dental review indicated Fiona's dental hygiene has been so poor for so long the enamel of her teeth is showing signs of de-mineralisation. The dentist concludes his report:

"Fiona is in desperate need of effective plaque control twice daily. I am fearful of the deterioration that will occur if this is not achieved."

Dr Peter Adair, Dental Surgeon. 15<sup>th</sup> Nov 2004.

We are advised that if there is no change in the direction of the nursing homes practices, she is at risk of loosing some of her teeth.

The fact is this: Fiona most times can clean her teeth if provided with the opportunity, and supported by someone (hand toothbrush and toothpaste to her). Fiona has been provided with special toothpaste and an electric toothbrush as recommended by the dentist. Family have made known repeatedly these recommendations and practices. They continue to not be carried out on most days.

Like other aspects of her care, the situation of her decline in dental care is, in the minds of staff justified by the view she has "extreme challenging behaviour" and hence it is the residents fault. Dismissal of responsibility goes something like: "... this can not be helped, .. she does not want to, .. she wont be helped, ... if she learnt to behave we would do more! "

A significant factor in this long standing situation has been systematic attitudes within the staff (with some staff a clear positive exception).

Another example of neglected care in recent weeks:

Fiona was taken out by family, returning late in the evening with soiled slacks and top. Family made known the situation to night staff, asking that her cloths be changed. Four days later, even though family were assured that she had been showered that very morning, Fiona was still in the same soiled smelly cloths.

Equally relevant to Fiona's quality of care is the situation of inadequate staffing levels.

Staff are often so stretched to meet all tasks in their shift that such basic daily care tasks (which require calm quiet engagement) feel beyond the capacity of the AIN/EN/PCA simply because of the time involved. Often there is not enough time rostered to meet basic care needs. If staff person takes the time to do such tasks, they fear repercussions.

Of family can see staff levels are inadequate and funding insufficient for more staff – what can they do? Demand another resident be neglected so that their relative is minimally appropriately cared for?

## **Friends and the Community – A positive development:**

*Walker:*

Friends and the local community have raised funds to purchase a Walker machine (Golvo Liko) for Fiona and given voluntary time to assist her in using this equipment. This enables Fiona to practice walking. If she can relearn to walk, this means greater independence for her, and increases the possibility of alternative accommodation options for Fiona in the future.

The Walker (value \$8000) has been a wonderful effort and contribution by many in the surrounding community. There are to many individuals to mention. This development has been one of the few strong positives for Fiona. Fiona is using the walker now. Last weekend she walked 40 steps or so with a normal aluminium walker (no wheels or support) and was placing both feet fully flat on the ground as she walked.

The Walker has been an excellent and much needed initiative.

*Information support to volunteers:*

The Walker alone is not sufficient to rescue Fiona from her full circumstances.

We have a growing group of friends and community members (volunteers) concerned for Fiona and offering active help.

For a long time family have wanted to hold some information sessions on Fiona, her situation, options, current needs. We believe this will clarify a lot of issues for people volunteering support to Fiona, and help them remain

involved longer.

We hope through this growing volunteer support Fiona may gain a more positive social and emotional environment around her. This is a critical need for Fiona given her degraded emotional state.

### **The option of legal action:**

Does there exist an effective option in this direction?

Driven by the necessity to find some way forward, we have sought advise and researched our options as far as time and our capacities permitted.

There is no straight forward solution here. The constraints are:

- (a) Adequate and effective redress would appear to involve several actions against half a dozen parties.
- (b) With even one legal action, the task would involve all our time for several months, at the expense of our attention and care to Fiona over this time. Given treatment in the nursing home, we may win the case, and she may die from poor care in our absence. That is not a “win”.
- (c) The legal process would subject family members to further high levels of stress, to which by this time I held concern given our already diminished health and traumatised emotional state. We needed a significant break first to regain our personal capacities.
- (d) Assessing evidence was a necessary first task, and though some effort was made, we did not have the time to fully pursue this. Given we wanted to honor the whistleblowers to date (several) by not calling them as witnesses, it was uncertain if we would have sufficient evidence. Given the confirmed lack of any investigative authority at State or Federal level, family alone must be able to find and access the evidence. We had established we could not access relevant documents under FOI, or access transcripts, and it would be expensive to locate past staff given significant a number of the significant events occurred early 2001. Our capacity and opportunity to access the sources of evidence was limited.
- (e) Until one gains the evidence, one can not have a solicitor assess the merits of the case.
- (f) Even if we did, estimates of the cost to get that far were around \$30,00 to \$40,000. Solicitor fees, costs of expert assessments, etc. We simply did not have the money.
- (g) Cases with merit in terms of actual events and injustice done, can be lost on technical legal grounds. Seems to happen a lot. Indeed, having seen fully confident assured complaints processes dissolve to nothing having given them our complete and best effort, and even though they upheld and acknowledged our complaint – there was no positive outcome. With such experiences, confidence in pursuing an outcome in a court process is greatly diminished.
- (h) The financial risk. If we lost the case, and lost house, assets, we would then have no resources with which to seek Fiona’s ongoing rehabilitation. That would be terminating for Fiona re any recovery or release from her terrible circumstances. Such release being the reason for considering legal action in the first place!!!
- (i) Relevant options included “Failure of duty of care” by Commonwealth and State governments. This option as the next step was reluctantly pointed out by one Ombudsman’s Office assessor after he discovered we had already done all he could suggest. Everyone’s view on this option was, no matter how legitimate a case you may have, don’t do it. You will loose everything and the next 20 years of your lives. From these responses it

would appear to me that government (State and Federal) are now effectively above the law.

- (j) Access to legal aid and other legal services is very slow, they seek very limited actions, prefer personal matters, and state simply they do not have the resources to take on big cases like Fiona's. They refer you, in which case you have one hour to outline your case. In terms of the significant detail of this case, this can not be conveyed in under several hours. Essentially then one can not gain a legal opinion in which one can have confidence. (Though through one referral I did receive some very helpful outline of legal options broadly, to which I am most thankful.)
- (k) By the time I recovered from my depleted and exhausted state, and the urgencies on my neglected personal live affairs after 3 years of nonstop crises, to then inquire and realise there were no further avenues to pursue by non legal processes, it was May 2003. A number of statutory limits, some of which are as short as 12 months, were by that time thought to have expired. A stunning fact given there was no way we could have acted quicker.

### **Family's current position:**

Since Fiona's accident in Dec 1999, there has not been 5 minutes for grief. Sept 11, Oct 12 and an Iraq war have apparently taken place somewhere?

Right from the beginning, there were repeated and reasonable expectations that the crises of Fiona's accident and subsequent care would be over when x was completed or resolved – another 3 months or 6 months. Yet here it is 5 years later.

Once again it is important to realise it is not her initial injuries but the harm of one principal individual aided by others in a nursing home, and failure or incapacity of government agencies and complaint processes that has lead to this outcome.

I question if it is possible for any family to sustain the level of effort and advocacy continuously, that we were sustaining - indefinitely. Over the last 2 years, we have been forced to step back in our efforts for Fiona on a few fronts as we had to address long neglected personal affairs and significant health issues. This has been a considerable source of frustration.

### **My current position:**

I have written on these matters as I think it is important to realise the limitations many carers work with.

#### *Difficulty with volume of writing:*

A key constraint for me has been the loss of capacity for several months to write anything of length without significant compromise. This is in part a consequence of CFS disability and fatigue processes, and also a product of the sheer excessive amount of writing needed to seek change for Fiona. Every significant advocacy action requires careful considered writing.

To not be able to write, is to be effectively silenced. Nothing proceeds without "can you put that in writing". Writing has also included journal notes with most phone calls, etc.

#### *Speech to Text:*

As part of seeking a solution, I have invested in speech to text software at considerable expense. I have invested in Mac usable software called iListen by Macspeech, a US software company. ( Dragonspeak is not available for Mac.) Unfortunately I have met significant problems with this software, and problems with Apple laptops (also not acknowledged) re USB and power supply hum contamination of audio input.

This software is still not at a usable level after \$1,000's in computer upgrades and around 200 + hours of work over the last 6 months. I suspect the company is giving me the run around after confirming problems with sending requested information to the company occurred for Apple representatives in Australia as well as for me.

There has been some improvement in performance with time however and hence there is some hope that with more time a useful level of performance may be achieved. I have persisted with this considerable investment of time as it is not possible to meet the full writing and documentation demands necessary to progress Fiona's situation in a reasonable time without this.

*Emotional:*

Emotionally in recent years it has become very difficult at times to engage with any advocacy without returning to strong involuntary and negative emotions of the loss, injustice and harm occurring for Fiona, family and myself. This has been of such intensity that for several periods I simply have had to not engage.

*Additional Challenge:*

In recent 2 years I have faced an additional difficult emotional event of changes to a personal relationship. A difficult emotional challenge at a time when I was already emotionally depleted with no resilience.

This change, I am clear, is a direct consequence of failure of complaint processes.

One consequence is that I now have two, not one next of kin to which I have good reason to hold serious concern for their physical and emotional wellbeing and safety. Again I am not alone in the holding of this concern. My options at this point are very limited. It appears I can only wait and see.

This is a second reason why over the last 2 years it has been difficult to follow through with additional initiatives for Fiona. I have had to redirect my attention first to my emotional state, and then to assessing my options with this second situation of concern. It has been important also to be as available as possible at home.

Both these challenges have been made additionally difficult in view of my limited circumstances.

Firstly 25 + years of CFS. My present level of recovery enabling a more active life, is a product of careful daily management over many years, this management in turn is dependant on living where I do. Related to this is my limited financial resources with an average income of about \$250 per week. My residence, while functional, has no mains electricity or running water. I have a small amount of solar enabling laptop use and internet access.

I have been fortunate to have been able to live where I am, within a small community I value, with paid work I can sustain. Through these things I have had the opportunity to progress my recovery year by year, and in doing so have an opportunity to gain a more productive life. Already in my 40's, every year counts.

The tragic situation of my sisters car accident would normally involve the loss of about one year of one's personal life, before things become settled in ones life routine again. Instead, it has been 5 years.

While these circumstances are challenging, and I have felt pushed on several occasions to the limits of my personal capacities, I am sustained by a knowledge of having made every possible effort within my capacities, to circumstances that compel and warrant every effort, with the knowledge that I have been making the best decisions I am able at every point, with all actions made to my best ability in good conscience.

Where others do not see this in my actions, this is often because they do not have understanding (often by choice) of all that I need consider, accommodate and respond to in my immediate and long term decisions.

*Personal concern re trends in government:*

The experiences of the last 5 years has lead me to observe a loss of effective duty of care of government and its agencies at both State and Federal level, and more seriously the loss of capacity for citizens to hold government to

effective account.

In this regard I observe a serious and concerning trend.

**Cameron Way.**

### **Attachments from others adding to our submission:**

A. Attached is a letter giving comment on Fiona's situation and the situation of young people in nursing homes from Olive. Olive is Fiona's birth grandmother. Thank you Olive.

B. Attached a copy of an email from Mandy. Mandy is a long term friend of Fiona's currently living in Singapore. This email from Mandy (submitted with permission) give a frank account of Mandy and her children's experience upon their last visit to Fiona, January 2005. Thank you Mandy.

Thank you also to others who have made similar contributions in the past.

C. Attached a letter from the PGSU as a support document to this update to our submission. This letter comments on the level and quality of advocacy by family, and lack of outcomes to date. Thank you PGSU.

D 3 Photos. (Provided as separate document.)

**[Attachment A] Letter from Olivia.**

RE SENATE INQUIRY INTO AGED CARE

REF; CASE FOR FIONA WAY CASE 149

The Australian government should be ashamed for their lack of care and attention for the welfare of young people with brain injuries.

To place them in Nursing Homes, originally intended for the elderly, without the specialised care they need is a disgrace.

In spite of Family and Friends continued efforts on their behalf for a very long time, no action is taken, no outcome or results. This subject has been ignored for far too long.

On my visits to Fiona, she sits or lies in her room, obviously bored and lonely, she seems to be left alone for far too long, she, and others, need specialised care and more appropriate environment. No effort seems to be made to develop abilities, no special activities, this of course leads to loss in her previous skills. If she had more attention, and rehabilitation it would enable her to tend to her own personal care, instead we often find her with her last meal all over her face clothing and bedding, this will clearly result in even lower self esteem.

Obviously, this is due to underfunding and it is time that the Department takes responsibility for adequate funding and care.

One hopes that the forthcoming inquiry attends to this urgent matter without delay.

Olive Rich

24.02.05



**[Attachment B] Email letter from Mandy.**

Subject: Hi Cam saw Fe in Feb from Mandy

Date: Sat, 12 Feb 2005

Hi Cam,

Took the kids to see Fe when I was home. Thought she looked dreadful. Mees whom is usually a real extrovert and will talk to everyone was really quite scared of her. Lily was great but she remembers Fe and has seen her over the years through her many various stages of "recovery" as for myself I got a real shock and actually went into a bit of shock at seeing her I think as I was shaking and felt really upset. The sore on the mouth seems to be eating away at her cheek area and was obviously infected as it was red as if through infection above the site of the wound. She was sitting in a filthy bed faeces and urine soaked sheets through to the blanket which obviously smelt unpleasant and made the whole experience of visiting that much worse, is it really any wonder people stay away. I approached a member of staff to let them know she needed changing and she replied something along the lines of "Well we can try but it really depends on her" I was pretty pissed off and upset about seeing Fe like she was and really just didn't have any tolerance for her attitude and replied curtly, "Why don't you just do it and stop bitching about it", sorry Cam I know I probably didn't help matters but the attitude was just the pits. Honestly I know they go on about Fe being brain damaged and that that is different to the type of nursing they are used to but that is pure rubbish. I worked with ALOT of elderly in my time in the Nursing Homes who suffered from terrible brain damage due to senility and I can assure you at the end of the day it is all the bloody same, they scratch, they get angry, and aggressive and they DO get a real sense of who they like and dislike because of the way they are treated by the respective caregiver. Some are aggressive with even the sweetest of staff, my point being there using Fe's brain injury as an excuse to discriminate against her just doesn't cut it.

Finally they did come in to help change her and they dealt with it just as you would expect a couple of uneducated, unworldly, young, slightly socially challenged individuals would. I could hear the struggle from outside the door and let myself in to coax Fe into helping them help her, what can she do, it's just better not to struggle and that way it is over and done with, it is never going to be pleasant. They didn't explain anything and they left her genitals uncovered when it was easy to just fold the draw sheet back over her until they were finished. I tried to explain to them a little about how hard it is for Fe, especially as she used to work in nursing homes herself but they really don't seem interested. I told Fe to co operate and behave and she would turn around and apologize to me and then turn back and sneer at the staff and stick her finger up at them, it's just hard for everyone involved.

I stayed to feed her her lunch which she ate with the amount of enthusiasm you would expect to find in an Ethiopian famine victim, given the sort of unappetizing food we are talking about here I found that shocking to say the least so I expect she isn't being fed as frequently as she would like.

Anyway, just wanted to fill you in on what I saw oh and by the way when they changed her draw sheet I had to point out that her top sheet and blanket were stained with old and relatively new urine stains which were damp not newly wet and stained, they stank. I also suggested that they change her soiled and smelling t-shirt whilst I was there to freshen her up. It really is very sub standard care she is receiving, the same nurse whom I spoke of initially was making a point of it when Fe was digging her nails into the assistant nurses arm, as if trying to impress upon me how difficult she is as a patient, sorry but that just

comes with the territory. I dealt with that behaviour and worse at least daily, usually many times per shift when working in nursing homes, IT IS NORMAL!! If you don't like it don't bloody well work there and I might add the nurses attitude DOES make a HUGE difference in the incidence of this sort of behaviour, Fe was VERY responsive to me when I told her to co operate, it did calm her down to all be it for small periods. Constant reassurance would work wonders with a little TLC in that place, talking from experience ,I have no doubts about that.

Anyway, I was talking to Fe about the money I have for her and asked if she had heard of Kath and Kim. She said no but said she would like to see it, I know she will love it so I hope you don't mind but I took the liberty of spending some of the money on a couple dvd's, mum and dad have them, Kath and Kim and The Goodies, I know she will really enjoy the memories The Goodies will conjure up and she did mention that she would like The Fawlty Towers series so could you get that for her from the money too? Mum got the others for me and was astonished at the prices but I think comedy is one of the most important medicines and let's face it Fe can use all the laughs she can get at the moment. Let me know if she has the dvd's already. I will arrange for mum and dad to drop the dvd's and the remainder of the money into Gordon's office, is he still in Wahroonga, can you send me the number?

I have to say I still left feeling in some way uplifted from my visit but it's almost like Fe has finally let some of her guard down, I don't know how to explain it but she has always been so guarded and one way or another that is less than it was, and she still has her wicked sense of humor, I really miss her Cam.

**[Attachment C] Letter from PGSU, Office of the Public Guardian. NSW Attorney Generals Department.**

**( Original letter on letterhead held. )**

**February 24<sup>th</sup> 2005**

To Whom It May Concern,

The Private Guardian Support Unit (PGSU) provides support and information to legal guardians in NSW. Mr. Cameron Way and Ms Margaret Fuller have had contact with the PGSU since 2001 as guardians for Ms Fiona Way. The PGSU is aware of the guardian's efforts to actively involve other family members and support networks for Ms Fiona Way's benefit.

Mr. Way and Ms Fuller have shown a collaborative approach to decision making and work very effectively as a team. Mr. Way and Ms Fuller have demonstrated a thorough understanding of the health and disability service system and have an excellent understanding of the Principles of the Guardianship Act (1987).

Mr. Way and Ms Fuller have superior research, advocacy and guardianship skills and staff of the PGSU have been impressed by the high standard of submissions and reports they have provided to agencies to advocate on Ms Fiona Way's behalf. The PGSU has observed

- High level analysis and collection of data for behaviour management purposes
- Case management skills
- Appropriate referral to other government agencies and health/disability services to assist Ms Fiona Way's rehabilitation

It is clear to staff of the PGSU that sadly there seems to have been little effective improvement in Ms Way's situation in spite of their dedicated efforts.