TO: The Secretary
The Senate Community Affairs
Reference Committee

Suite S1 59
Parliament House
CANBERRA ACT 2600
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INQUIRY INTO AGED CARE
(2004)

• The Fuller-Way Submission •

(3 part submission cover letter)

As a family we have provided a three part submission

- **Part 1 from Gordon Fuller – Solutions.**
- **Part 2 from Margaret Fuller – The problem: A Case Study.**
- **Part 3 from Cameron Way – Failures of the current system.**

With:

- **Supporting documents from Gordon and Margaret.**
- **Supporting documents from Cameron. (Confidential)**

Request to be called as witnesses:

All three; Gordon, Margaret, Cameron wish to be called as witnesses to the Senate Inquiry.

Cameron would like to add some brief information "In Camera" at the Hearing.

All three can attend a Hearing in Sydney.

<u>The 3 submissions in summary:</u>

Part 1 – Gordon Fuller – Solutions.

Provides solutions to the issue of young people in nursing homes with focus on the need for alternative appropriate accommodation for young people. Includes proposed design for such facilities.

Part 2 – Margaret Fuller– The problem: A Case Study.

Provides a case study of a young person in a nursing home (ypinh), the impact on her, and her family. A full well documented account of what the Commonwealth currently presides over.

Part 3 – Cameron Way – Failures of the current system.

Provides an account of the current failures of existing processes utilising the same case study. These failures, while documented for a young person in a nursing home, apply to all residents of an aged care facility.

Regards,

Cameron Way.

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PART 3 of 3: SUBMISSION BY:

Cameron Way

30th July 2004

INQUIRY INTO AGED CARE

Submission covering all the terms of reference, though mostly Parts B and C.

- I present the story of my sister, at least the parts relevant to this Inquiry.

- I return to the terms of reference in brief at the end.

Summary:

The previous submissions have focused on Part C the issue of young people in nursing homes. While this is a relevant part of our story, it is only one aspect.

I am covering the aspect of the failure of current complaint processes and overall failure of effective duty of care by both Commonwealth and State governments, as has been, in my view, present in the case of my sister and my family.

While the context of our situation is of a young person in a nursing home, as the current system makes no discrimination between and aged person and a young person, what has happened in our case is representative of anyone in an aged care facility.

What is significant about this case is that my sister has an active skilled family of three as her advocates, and thus we have had the capacity to engage available complaint processes and see them through to completion. Most next of kin of a family would not have this capacity.

Hence we are a test case of whether the current system works.

It failed. Totally.

We are also in an excellent position to explain where and why it failed.

The failure has been systemic, including the Commonwealth Complaints Resolution Scheme, the Aged Care Standards and Accreditation Agency (in particular), as well as NSW state agencies.

There has also been a failure with "failure capture" mechanisms such as the Commonwealth and State Ombudsman's Offices acting as a last non legal recourse for citizens.

The failures have been part failure of process, and part due to lack of capacity as granted under respective legislation.

In this case, the failure is serious in magnitude and consequence:

1. **For my sister, a resident of an aged care facility,**
2. **Her immediate family, and our families,**
3. **Nursing staff at the aged care facility,**
4. **The facility,**
5. **The Australian and NSW public with respect to exaggerated and avoidable cost to this society.**

My sister had the probable capacity for sufficient recovery to be walking and exiting the aged care facility by this time.

If it were not for the events, unaddressed by complaint processes, there would be one aged care placement freed up by now.

The purely economic public cost with complaint processes alone I would estimate to be greater than $100,000 over the last 3 years. Outcomes being entirely counter to the purpose of the existence of these processes.

As for personal cost to my sister and her immediate family, I have not covered this, except possibly in one aspect only. The cost is high, and expanding even now.

This represents a further significant hidden economic cost to the community.

Contents:

The case of my sister:

What makes the story of my sister so significant to this inquiry, is that as a Commonwealth funded category 1 placement, in an accredited approved aged care facility, she has had three advocates

Yet despite their full efforts to engage with "the system" she has remained victimised, mistreated and abused over 3 years in an aged care facility..

The car accident:

It is a tragic situation. A young person injured in NSW in a motor vehicle accident through no significant fault of her own. Not drunk, not driving recklessly, just an unfortunate low speed suburban accident where car meets tree. Both friends in the same car sustained no significant injuries. Despite compulsory "Greenslip" insurance in NSW to cover all seriously injured in a motor vehicle accident, a non-compensable case. No safety net.

Next of kin not wealthy either!

The public health system:

The public health system saved her life, then failed to follow through to rehabilitate her, leaving the job half done.

In so doing the invested public dollar cost into this event was beautifully balanced to maximise the invested public dollar on one hand at the beginning, then act to maximise the long term cost to her and society by not finishing the job.

I am sure it looks like the most sharp economic efficiency on paper somewhere!

When the public system failed to have the resources, family stepped in to do the job.

Our actions in this regard were to the benefit of my sister and the "common-wealth" of this society through seeking to maximise her recovery.

I would have thought that for a family to seek to care for an injured next of kin was reasonable action in this society; one to be recognised and supported.

It is clear from our experience that this is no longer so. I do not say this simply because family have been obstructed, but because there is no concern in the full knowledge of the fact we have been obstructed, as demonstrated by a lack of any real action.

The experience of "obstruction" within the public health system was to some extent accountable by the degree to which the public system is stressed. The "obstruction" in the aged care facility however, has been an act of unaddressed human malevolence.

The family team:

It is the level of our efforts as a family that makes our story significant - when contrasted with the response and outcomes it has brought after 3 years.

Most residents of an aged care facility have, at most, one dedicated family member looking out for their interests.

My sister has had a team of three dedicated family members acting as advocates seeking to raise serious and disturbing circumstances. Even so, with three skilled members, the eventual demands of available processes has overwhelmed and silenced our intended endeavours for my sister to date. Given the strength and determination of our endeavours to rehabilitate my sister, this is stunning fact in its own right.

There would be very few residents in an aged care facility with a more diversely skilled and active team acting as advocates and carers.

Margaret, a dedicated mother to my sister.

- A practicing psychologist, and in her past an RN, teacher, and school counsellor.
- A women who originated and pioneered (never duly recognised) the original peer support program in schools, the original program hosting immense success with drug prevention and reduction of other social negative issues for youth.
- A person who has also fostered testing and recognition of children (and adults) with Attention Deficit Disorder well before drug companies realised the benefits of widespread recognition.
- Margaret has also had Chronic Fatigue Syndrome and has direct experience of the effects of disability.
- An innovative, capable, and experienced individual.

Gordon, Margaret's husband, and my sisters warmly adopted step father.

- An experienced architect.
- Experience of being on the board of an aged care facility.
- Successful business man, father of three.
- JP, respected member of Rotary.
- Gordon has also the distressful experience of his first wife with an acquire brain injury, and the task of seeking her care over a period of years.
- Gordon is a resource of connections. He has brought much dedication and insight to my sisters situation.

Myself, Cameron, brother.

- Past employment includes working in the public hospital system as a wardsman often doing EN and AIN (ie hands on care in nursing homes) type work. This was in a rehabilitation hospital.
- Several years working with clients with intellectual disabilities within residential care service pursing the goals of normalisation (Challenge Foundation of NSW - Ryde, Hornsby, Armidale.) This work included specifically the design and implementation of behaviour management programs.
- A person with a significant science background (science degree unfinished), capable of statistical analysis and understanding technical as well as medical issues. While degree unfinished, was recognised as having significant, "world class" science skills by senior research scientist of one CSIRO division, but tertiary studies and career subsequently cut short by a chronic illness, Chronic Fatigue Syndrome.
- In view of 25+ years of Chronic Fatigue Syndrome, a person experienced with disability, including cognitive disability, and discrimination from disability.
- An advocate of some experience re this condition, and hence a person familiar with the difficult task of advocacy and navigating through the maize of government, professional and community services.

What a team of three Australians to look after one resident in an aged care facility.

Magnitude of the team's endeavours:

Over 2000 family's focus was on my sisters initial injury and rehabilitation in the public health system.

From 2001to 2004 my sister has been placed at the aged care facility. From her accident Dec 1999 up until late 2003, the level of involvement with my sisters situation from each of us was equivalent approximately to a part time job, providing in combination the equivalent of about 1.5 full time advocacy per week. This is considerably more time than clients of most advocacy services, and persons under public guardianship.

While a skilled team, we have not relied on our resources alone.

We have engaged available support from all locatable and available support agencies with a role to play to my sister, or to ourselves in our advocacy role.

A list of some of the agencies we have engaged:

- AAT Administrative Appeals Tribunal
- Attorney Generals Department (NSW)
- Attorney Generals Department (C'th)
- BIRDS Brain Injury Rehab Activity Centre
- BIA Brain Injury Association
- BIU Brain Injury Unit (Ryde)
- Centrelink
- Community Health (NSW)
- Community Visitors Scheme
- CRS Complaints Resolution Scheme (C'th)
- DADHC Aging Disability and Home Care (NSW)
- Equalis
- GT Guardianship Tribunal (NSW)
- HAC Health and Aging (C'th)
- HCCC Health Care Complaints Commission (NSW)
- Health Minister (NSW)
- Home and Community Care HACC (NSW)
- Home Care - Epping
- Hornsby Hospital
- Hornsby Kuringai Lifeline & Community Aid.
- Hornsby Police (NSW)
- House with no Steps
- HREOC Human Rights & Equal Opportunity Commission.
- IRDS Intellectual Disability Rights Service (NSW)
- Ku - ring-gai Neighbour Aid
- Law Access NSW
- LISA Legal Info Access Centre
- Mental Health Advocacy Service

- Mercy Family Volunteers Service
- Minefields
- NSW Nurses Association
- Nth Syd Carers Respite Centre
- OCCC Office of the C'th Commissioner of Complaints. (C'th)
- OLSC Office of the Legal Services Commissioner (NSW)
- Ombudsman C'th
- Ombudsman NSW
- Paraquad
- PGSU Private Guardianship Support Unit (NSW)
- PHCB Private Health Care Branch (NSW)
- Privacy Commission (C'th)
- Privacy Commission (NSW)
- PWD People With Disabilities (NSW)
- Royal North Shore Hospital RNSH
- San Hospital
- Salvation Army
- Spastic Centre of NSW
- St Vincent DePaul Society
- TARS Aged Care Rights Service (NSW)
- Technical Aid for the Disabled (Ryde) TAD
- Victims of Crime
- Westmead Hospital
- Workcover (NSW)
- Young People In Nursing Homes (YPINH) National

As a team our use of available services, agencies, resources has been most comprehensive.

As a team we informed ourselves and pursued all available complaint process that had a capacity for effective engagement to my sisters situation.

With the complaint processes we engaged, we did so with care and diligence to the best of our abilities.

Despite all of these efforts, a sustained victimisation of my sister in an aged care facility over 2001, 2002, 2003 and into 2004 has remained mostly unrecognised, unchallenged and unaddressed.

Uncovering victimisation:

The reality of wilful orchestrated victimisation came to light gradually.

- Initially a range of observations hinted at what was to come, though their significance only apparent in hindsight.

- Then puzzling consistent obstruction of efforts by family and other service providers to engage with my sister and issues of complaint raised by the facility.

- Then some clear hints and direct comments by some staff.

- At the end of the first year, the first trails of evidence from our analysis of facility records.

- Then came submissions by the facility to complaint processes dominated by careful "selective memory", misinformation and plain deception. This made the reality that something behind the scenes was seriously awry clear, though details of whom, how and why remained lacking in detail.

- Finally over 2002, and to which we owe gratitude, detailed witness arrived from a few separate staff members of the aged care facility.

  - These individuals admiring of our persistent efforts and appalled at what was happening behind the scenes outside our knowledge. They took the risk of locating us personally and advising us of what was going on. Their witness was clear, consistent across individuals, and in considerable detail, confirming many speculations and observations. There was no remaining doubt of the reality of intentional and sustained victimisation.

  - These individuals all expressed fear that if their actions of informing us were to become known, it would place themselves in a position of victimisation, to which their careers and personal lives would be severely compromised. They felt this fear of compromise whether or not they remained employed at this facility. They had no question as they had seen this happen to other whistleblower colleagues who had raised legitimate and equally serious issues.

  - We have been thankful for their witness, and thankfully have been able to honour their trust to date.

The victimisation:

A significant number of staff were participant in this victimisation.

The majority were mostly unaware of what they were participating in. Most staff were left uninformed, hoodwinked and manipulated. Work place bullying practices were a key part of the equation, as well as individuals with personal agenda's.

More to the core was an inner circle of three or four individuals, with one primary very skilled, competent, and dominant "ring leader".

Without the activities and actions of the ring leader, a person in a position of key responsibility, there would be no sustained victimisation.
In parallel there were a range of events with another individual on the Board with a different agenda operating with apparent commercial self interest, which inturn appeared to affect the ability for these staff bully issues to be realised or acted upon if raised internally.

This individual is also in a position of key responsibility, and the presence of this second situation, has made the overall situation more difficult to address.

This is the story as we have established through the witness given to us, and other information.

A key member of the nursing staff, with considerable influence over all paperwork and nursing staff, decided that she and a few of her immediate colleagues did not want a young person in "their" nursing home.

Within weeks of arrival a campaign to foster my sisters challenging behaviour, rather than seek to manage it constructively, began.

A few months later in early 2001 the DON went on leave for 4 weeks. It was in this period that the foundation of the deceptions required to legitimise sustain ongoing victimisation were established.

During this time these individuals worked to foster as negative an attitude environment amongst staff around my sister (and us her family) as possible.

Junior staff were "educated" informally that she should not be here, there were other more appropriate places, they should not have to put up with her "extreme" challenging behaviour, that her behaviour was wilful and deliberate, that she was a nasty minded girl, that she was psychiatric, that the family were unreasonable and did not care about staff and were doing the wrong thing by the resident (sister). As hands on caring staff they were being mistreated, indeed victimised, in expecting to provide care to this resident.

Most AIN's and EN's as hands on staff had no training, knowledge or perspective of what was normal re challenging behaviour. They were kept unaware that there were in fact no other residential care options for my sister, were kept isolated from understandings of "dis-inhibition" and triggers relevant to providing care without triggering challenging behaviour, and through these edits of knowledge, set up to fail in their interactions with my sister constantly. A number of the staff could not read or write, and hence were fully dependent on what they were told.

Thus a self feeding cycle of negative interaction between staff and my sister was established.

Four weeks later the DON returned from leave to a staff mutiny and threatened walk out of approximately half her staff. "Resident goes or we go!"

Naturally this put the facility in a panic!

In months following the DON's return:

- Family organised a case conference in June, with my sister's challenging behaviour the first priority on the agenda. Despite every effort and good will by family to consult with staff of the facility prior to this meeting, information was withheld, the meeting was sabotaged.

- A few weeks after this, the Board advised family my sister had to be relocated.

- Family met with the Board in Oct 2001, to be told the Board was aware there were no other options for young people "but that was not their problem".

- The Board rejected without consideration that the real issue may be an internal staff problem within their facility, and not really the alleged unmanageable challenging behaviour of "the resident". When family sought to take notes of the meeting, simple notes not even formal minutes, Board members stood up and threatened to leave closing any opportunity for the meeting to proceed and there bye any chance for a constructive solution.

- Family, with all efforts extinguished, finally lodged a complaint with the Aged Care Complaints Resolution Scheme, feeling they had no other option.

- My sisters care continued to deteriorate, with at times total withdrawal of all care.

From then on, it was a matter of the victimisers maintaining the situation through:

- continuing to foster staff perceptions of injustice,
- foster rather than manage her challenging behaviour,
- distort and exaggerate records,
- write reports misrepresenting and exaggerating the situation.

Over the next few years the aged care facility, relying upon the "professional reporting" of its senior internal staff, have:

- sought to terminate my sisters residency,
- accepted substandard daily care of her,
- accepted several periods of "total withdrawals of care",
- sought to remove the family as guardians, and
- sought to have her permanently sedated under false pretences.

The Core Deception:

The basis of the facility in all its actions and complaint processes since 2001 has been that my sister has **"extreme**" and **"severe"** challenging behaviour.

Further, this behaviour, despite their best efforts, is beyond their capacity to manage, and threatens the viability of their facility.

The fact is, my sister does not have "extreme" or "severe" challenging behaviour.

The evidence of this fact exits.

The Incident Report record of the facility, even if it were accepted in whole as accurate and true (which it is not) does not warrant descriptive category of "severe" or "extreme" challenging behaviour. Nothing near it!

A review of all Incident Reports over approximately one year by an independent and well regards behaviour consultant firm Equalis assessed the level of challenging behaviour as within the normal range routinely met by aged care facilities.

The fact all other parties that engage with my sister regularly, such as physio's, speech therapists, GP's, some of whom need to do some quite intrusive and demanding things with my sister, have no problems interacting with her.

On the occasions they have seen challenging behaviour at all, they can identify evident reasons for her agitation. Given the trauma of her circumstances, and the existence of dis-inhibition, it would be disturbingly abnormal for her to not have some challenging behaviour.

There is also evidence for the (a) fostering and (b) exaggerated reporting of her challenging behaviour.

As for my sister being responsible for the loss of viability of this facility; I think it would help if she could walk, push her own wheel chair, or at least be able to get out of bed.

In short, the constant presentation that my sister has severe challenging behaviour is a falsehood.

To the extent it can be said that challenging behaviour exists, it is in large part due to the active avoidance of options for constructive behaviour management, combined with actions to frustrate, antagonise and incite challenging behaviour.

The techniques of victimisation:

Until one has worked with individuals with dis-inhibition, with even very light degrees of challenging behaviour, it is hard to appreciate just how easy it is to set such people up to fail - if one has the will to do so.

It is as simple as an adult, with all the understandings and power advantage of an adult mind, chastising a 3 year old until the child is driven to powerlessness, distress and tantrum.

One then records only the tantrum.

It should be noted that all efforts by family and the Brain Injury Unit, Ryde over 2001, and subsequent years, to provide appropriate understanding and training to staff on the management of her challenging behaviour, avoidance of triggers, etc, were obstructed.

We now realise in hindsight, this was an intentional strategy to keep hands on junior staff 'a captive audience to the cause'. This establishment of a closed bubble of information and awareness used in this instance to maintain an environment for victimisation is a technique I come to tag: "the china syndrome".

There were many strategies to victimise my sister and her family, and confound all constructive efforts initiated by them.

A list of some of the many strategies engaged. Note: These are repeated behaviours, not one off's.

- Staff pursued and harassed to fill out incident reports for any slight incident with my sister, but not for other residents.

- When staff members engaged with my sister well and positively without difficulty, gaining her confidence and cooperation, they were promptly re rostered to different areas. Staff that attract a negative response are rostered in preference.

- When family make a positive compliment about a staff member, the staff member is told instead that family has made a complaint against them.

- When my sister clearly expresses she did not want to be showered by males, males were rostered constantly to shower her. Her reaction is then documented with incident reports of her "agitated behaviour". Once these practices were sustained for several months, with her subject to shame, she adopts the only counter behaviour she can offer, shame back. Facility then raise complaint she shows inappropriate sexual responses to staff. There is something quite elegant in the skill, even if in a sadistical fashion, of the way things are twisted so neatly back on the resident.

- Given knowledge of extreme fatigue from relapsed Chronic Fatigue Syndrome concurrent with her brain injury, (a)contrary to instructions she is regularly shower as early as possible, eg 6:30 am, (b) left sitting upright in a wheelchair for many hours. With (b), sometimes her fatigue become so distressful she would manage to undo herself and throw herself onto the floor just so she had the relief of being horizontal. My sister, while with brain injury, was capable of being aware and comprehending the intent of these actions by some staff and the silent torture involved.

- Leave her unattended for hours at time sitting in her wheelchair, or in bed, no stimulation, no access to call for help with buzzer, no query as to her needs. Write incident reports when she makes noise disrupting the environment.

- Regularly leave her unchanged, demoralising her, and causing her intense embarrassment and discomfort when visitors arrive. When family provide better reusable continence pads that need changing less often reducing staff interaction (at their own expense) promptly ensure all are lost. Leave her naked with only a thin blue liner underneath her, including when visitors arrive.

- Do the same above regularly before any therapy such that many therapy sessions, privately paid for by family, involve changing and cleaning her up first. This delay

proves significant as family only have sufficient resources to pay for two physio sessions per week, a level of rehabilitation barely above 'sustain current level only'. Facility, after such relentless obstruction for years, later claim that she shows little evidence of having a capacity for rehabilitation. This is why.

- Leave her glasses off so she can not see who is coming into her room, maximising her disorientation and fear of what may happen next.

- Place her in main thorough fares, leave for hours unattended, relying on her eventual frustration and dis-inhibition to eventually create incidents – then duly filled out incident reports.

- When family request she be kept in her room so that she can not set up to fail in this above way, use this request to demonstrate the cruelty of the family in subjecting the resident to such isolation, and subsequently present their unfitness as guardians.

- When friends arrive to visit and take her out, have staff ignore all requests for help. For example ignore request for assistance with the simple task of transferring her from bed to wheelchair so she can be taken for a wheelchair walk out side. This ignore visitor request for assistance was often sustained for 3 hours, visitors eventually leaving so emotionally distressed they are greatly discouraged from ever returning. Once again, having driven away her friends, promote concern of her social isolation and the negligence of the current guardians.

- Verbal engagement with her while alone of how family are not doing the right thing by her, and that she would be better somewhere else. This was followed with efforts to have the family as guardians removed with two challenges to the NSW Guardianship Tribunal.

  - The first challenge to the Guardianship Tribunal, early 2002, a cooperative venture with an ex family member whom my sister greatly fears, and has suspected may have affected abuse of some form when she was a child. Even though my sister witnessed a letter clarifying her wishes that this individual have no access to her or any information about her, the facility provided all requested information to this individual, and obstructed the established guardians from having access to information. The nursing home subsequently supported this other individuals application to become guardian of her.

  - The second, early 2003, involved the presentation that the only solution for my sister to receive nursing care was for her to be permanently chemically restrained on the basis she has "extreme" challenging behaviour that is fully unmanageable by any other means. This is a false presentation by the facility, internally reliant on the presentations of the individuals concerned with this victimisation. It is presented to the Tribunal that full sedation should take place, even though this would mean the forfeit of any further meaningful engagement with rehabilitation, or exit from this facility – for life. The argument being that the current guardians (family) should be

removed as they will not comply with this full sedation (even though guardians had in fact consented to a trial). Given the presentations of her level of behaviour are clearly false, I believe such attempted removal of liberty of a citizen under such false pretences involves a criminal level of intent.

- Claim the facility and its staff have no capacity to collect data to identify triggers for her challenging behaviour, even when stated as necessary by support and advising agencies such as the Brain Injury Unit Outreach Team, Ryde. When family seek to take the long route of requesting copies of Incident Reports and RN Progress Notes such that they can trawl through the long way to extract potential triggers, refuse to provide access to these documents as long as possible.

- Respond to goodwill by family with hints that the guardians may be "engaged" to recover costs of future harm caused by my sister to staff, visitors, other residents, or the facility.

It should be noted that in view of a new Director of Care (DOC) at this aged care facility, the opportunity for these practices to continue have been significantly reduced over the last 12 months.

All the same, at this time July 2004, I believe it is quite possible that the level of trauma, psychological harm and distress my sister carries from her treatment in an aged care facility is greater than the same from her car accident.

Recognition of victimisation by complaint processes.

It is true that this victimisation was moderately disguised behind a veil of "legitimacy and justification".

This does make it more difficult for complaint agencies that look only at paperwork from a distance to recognise the situation they have on hand.

However, complaint processes need to be equipped to make such discriminations and uncover such practices. Few who do harm on the scale involved here do so openly.

Further, in this particular case, we did the work, uncovered the situation, and made the situation as it came to light known to complaint processes.

Translation of this case to the aged care sector nationally:

With respect to the issue of work place bullying within aged care facilities, when allegations of this behaviour were raised with a professional body representing workers in this sector, the comment made was that the aged care sector was "peppered with people like this".

Part of the problem (as they stated, and clearly this view has foundation) is that levels of funding in recent years and subsequent wages are such that aged care facilities struggle for staff, with most facilities simply unable to afford to pick and choose who they employ and retain. Hence workplace bullies, as is the case here, remain unchallenged even when identified. A view repeatedly confirmed to us by many individuals working in the aged care industry.

The harm these individuals bring to residents and fellow staff alike is very high.

Over these four years family members have spoken to many individuals, staff working in the aged care sector, families with a member in an aged care facility, organisations handling complaints or information or advocacy roles, individuals within government departments.

It would appear that my sister with her treatment and victimisation is the exception only in one regard: - The victimisation and mistreatment has been identified and uncovered through the active work of three dedicated people over years.

Most aged care residents have at best one regular visitor, and even then usually a visitor with no active reviewing and inquiring care, advocacy, or case management role to the resident.

Exercising of Complaint Processes:

My experience of the diligent exercising of complaint processes can be summaries by a simple statement:

> Engaging complaint processes took a situation of a family and resident subject to serious victimisation, and turned that situation through non action into one of persecution.

A strong statement!

Simply because the persecution has not been affected through intention of any one individual, does not remove the reality of the outcome of persecution.

Three main complaint processes:

There are three complaint agencies relevant to my sisters situation. One Commonwealth, and two NSW based agencies.

They are:

- Complaints Resolution Scheme (CRS) – C'th Dept of Health and Aging.
- Private Health Care Branch (PHCB) - NSW
- Health Care Complaints Commission (HCCC) – NSW

The Complaints Resolution Scheme (CRS) – C'th Dept of Health and Aging is the primary complaint process relevant to my sister as a resident in an aged care facility, and also in view of her having a Commonwealth funded Category 1 placement.

The NSW Private Health Care Branch (PHCB) also has the specific concern and role for the conduct of aged care facilities in NSW.

The NSW Health Care Complaints Commission (HCCC) has a specific role in regard to individual professional conduct within the public health system.

We also explored other possible options.

In regard to the Board member, and information that came to light during the second Guardianship Tribunal, complaint was an option with OLSC Office of the Legal Services Commissioner (NSW).

In terms of the professional conduct of certain individuals we have looked at the NSW Nurses Registration Board, and the NSW Medical Tribunal. Also inquiries were made to NSW and Federal Police (eg deception, misrepresentation to Commonwealth complaint processes.)

There has also been need to reference or consider such bodies as Privacy Commissioners, Union organisations, Disability and Legal advocacy organisations, NSW Work cover, and more.

The failure of the three main complaint processes:

The process of victimisation was relevant to all three of these complaint agencies.

As the situation at the facility worsened and the picture of victimisation emerged, we extensively explored the options of the two State based agencies in addition to the CRS process we were already engaged with.

It became apparent with careful investigation, that none of these agencies had the capacity to act in an effective investigative manner to the situation.

This lack of capacity is a legislative failure at both Commonwealth and NSW State level.

Because of this lack of capacity, we did not proceed with lodging complaint (except in one instance to the PHCB in view of total withdrawal of care to her) as doing so was clearly not going to achieve anything except further drain our, and everyone else's, time.

The crux of the problem was this.

All three complaint processes within their current legislative powers can only review paperwork. They have no other investigative capacity.

In the specific situation of my sister, those driving the victimisation had considerable control over the documentation within the aged care facility. They could and did document a case that fitted what they wanted.

We had clear witness from several staff that this was occurring, such as the harassing of staff to fill out Incident Reports only in instances concerning my sister, so as to build and exaggerated record of her challenging behaviour.

All three complaint agencies had no investigative capacity to interview staff of the facility.

(The CRS has the capacity, but only as far as to determine if there is a complaint, not to gain information or evidence of the substance of a complaint.)

Hence complaints process by any one of these agencies comes down to our word and paper work against the facilities. A paper war!

Add to this two further factors:

- The general fear of error by complaint agencies such that they assume, and process any complaint on the basis that, the problem is with both parties. This view these days seems to be a permanent insisted assumption.

- Government agencies are reluctant to act unless they have sufficient evidence to uphold their actions in court. Bureaucrats fear this as much as private citizens. Hence their willingness to act comes down to having hard evidence, and no matter how severe and disturbing the allegations.

The issue of hard evidence:

Hard evidence was the one thing we did not have. All the evidence was with witnesses – the staff. No agency could engage with this body of potential evidence.

So agencies required hard evidence, but did not have the faculty to acquire or capture the hard evidence – in this instance.

We knew we were speaking the truth of all we presented, but that is not the same. Clearly we were not being believed, as evidenced by some comments with two of the three complaint processes.

By 2002, we did have several clear witnesses to the reality of orchestrated victimisation. However, none of these individuals were willing to put their witness on paper for fear of victimisation against themselves.

This was when I began to explore NSW and Commonwealth police services to see if they could play an investigative role. Given the level of harm to a vulnerable member of the community, I did not think this was unreasonable thinking.

Another difficulty was our own limited financial resources. If my sisters case was compensable, we would have more financial resources to engage with independent assessments and reports, or hire private investigators, to establish the evidence via several independent reports.

All this running around was very frustrating. All professionals with regular involvement with my sister (therapists, GP, specialists, etc) were all clear my sister did not have a significant challenging behaviour problem, and that with some effort, attention and good will the facility could well manage her care.

However, while this was self evident to every one, in the current litigious environment no one wants to put their hand up and put it in writing – to actually explicitly say it!

Some now have included comments on my sisters behaviour and general compliance as they experience it professionally in their reports, so evidence is mounting.

We also have some documented witness of other support people, friends, etc covering some aspects of the situation, giving witness to some of what we have reported.

I also have some statistical evidence derived from some of the facilities own records, which interestingly, some agencies have not shown much interest in. I think they do not understand what it is I am showing them. While this evidence is not conclusive, it does strongly suggest that our concerns and allegations can not be simply dismissed as "hysterical rels hell bent on complaint!"

Overall, I think we have done extremely well on the resources we have.

The Complaints Resolution Scheme:

Our initial and overall main complaint process was with the Complaints Resolution Scheme.

This scheme has a three stage process.

1. Negotiation.
2. Mediation.
3. Determination.

I support the basic philosophy of this three stage approach. I think it has merit, though it is a lot more involved than it seems with a complaint like ours.

In our case, the CRS process really had 7 stages:

1. Negotiation.
2. Mediation.
3. Determination.

4. Review of Determination.
5. Resident/family engagement with facility re compliance with final Determination.
6. Assessment of Compliance.
7. Transfer to Aged Care Standards and Accreditation Agency re non-compliance for action.

   Also….
8. Sanctions by Minister (not relevant as stage 7 failed.)

In over view:

- We initiated our complaint in Nov/Dec 2001.

- The process to a final Determination decision took about 9 months.

- The final decision was a Review of Determination Decision. One of a half dozen only of a few hundred complaints lodged in NSW each year that go this far. The final decision was strongly in our favour as the complainants.

- The Determination Decision involved requirements upon the facility to meet and correct with us stated matters within several weeks. We took hope with this decision. We felt with compliance with this decision, we would be able to return to where we tried to start with my sister back in early 2001- to establish an environment were we could engage with effective rehabilitation for my sister.

Family's other demands during the Complaints Resolution Scheme process:

During this process we had assistance from the NSW Private Guardians Support Unit (PGSU).

This is a unit within the NSW Office of the Public Guardian. Some staffed have acted as public guardians, and hence are in an excellent position to provide support.

We sought PGSU comment and review of much of what we did, including submissions to complaint processes.

Their general comment was that our submissions to all processes were quite professional, well constructed, evidence based as far as evidence was available, and well beyond the standard of that most families manage to submit.

By the time we finished this process, we were, or had:

- Attended one Hearing at the Guardianship Tribunal,
- Met CRS Mediation, Determination, and Review of Determination.
- Learnt about all the process we had to engage with, to the point that by the end of 2002 we were often responsible for advising senior public servants at State and Federal level of how the other agencies worked, their jurisdiction, etc, often to demonstrate why their referral to the other agency or agencies truly were not appropriate or a solution!!!
- Continued to meet a very challenging ongoing daily crises situation at the aged care facility,
- Try to get to the bottom of what was happening at the facility,
- Maintain information and support to friends of my sister in an effort to maintain her peer social support,
- Engaged with several state based agencies re services and alternate accommodation options (with no positive outcomes),
- Engaged with two other NSW based complaint agencies as appropriate to each of their role and as sometimes suggested by CRS or others,
- Sought to assemble a case management plan for my sister, which proved immensely difficult as other parties, professional etc often acted with out regard to the developing issues, politics and understandings outside their immediate focus as understood and represented by family,
- Pursued a range of novel left of centre solutions to a set of complex issues by necessity, particularly given the additional restraint of a non-compensable case.

Within about 12 months we went from inexperienced individuals not really understanding the roles of guardians, to weary but more educated and grimly determined informed guardians.

At the end of our first 12 months as enduring guardians (mid 2002) members within the Private Guardians Support Unit supporting many private guardians around the state were increasingly unsure of what support or further suggestions they could provide to us.

From their point of view, we had gone well beyond their resources on several fronts and they reported they were, in effect, now learning from us.

We were no longer just one of the most active families in their state wide support service to private guardians, our efforts and grim determination extended now beyond the normal limits such that they saw us in a league entirely of our own. Words like "outstanding" and "exceptional" were being used.

Encouraging words telling us how we were going, yet distressing. My sister's situation, from her point of view, was no better. Trauma and increasing abandonment the only reality for her.

Failures of the Complaints Resolution Scheme:

In terms of the outcome of an appropriate decision on the matters of our original complaint, this scheme did not fail.

The key failure of the overall process was the lack of action by the Aged Care Standards and Accreditation Agency when the facility showed no compliance with the Review of Determination decision.

This scheme did fail however in three significant ways:

1. Total time to recognise and achieve action on a serious situation of victimisation in an aged care facility. (about 12 months).

2. Disregard of the capacity of the complainants to meet the process leading to substantial additional loss and hardship.

3. Transparency of final outcomes to the complainants.

1.- CRS - Total Time:

The time failure can not be addressed simply by seeking to speed up the rate at which complaints are processed.

It needs to be recognised that (I speculate) the Complaints Resolution Scheme does handle a wide range of complaints, some resolvable with the first stage and hence resolved relatively quickly. (Annual reports available on their website.)

The solution from my experience in a case like ours requires someone on the ground with face to face investigative capacity by a representative of the agency.

In our case, this would have enabled the credibility of our presentations to be identified early, and also the seriousness of the situation to be identified, early..

For example:

- We would have suggested such a representative talk with non facility employed professionals working with my sister. The representative would have heard consistently from these professionals comments like .. "No she is fine, not a problem really.. ".

- Further inquiry of hands on staff of the facility, if by "random walk in" method, would have found several staff who also would have said the same – "no she is fine, not a problem". It would be apparent then that something was not adding up.

- This could have then lead to some closer inspection perhaps of facility records such as the Incident Reports. A significant number of which are simply a nonsense – "resident pulled GP's tie", and "resident gave me the finger".

- Further inquiries of us, the family and guardians, would have found clear evidence of our uncommon efforts to provide interventions in response to the facilities complaints, with all these initiatives clearly obstructed.

By this time it becomes quite apparent where the problem lies. It was not a two sided one this time!

With this assessment, some interim orders could be placed upon the facility while the complaint process proceeds. The work of monitoring the situation could be transferred to State based agencies.

2.- CRS - Disregard of the capacity of the complainants:

This second failure has been very significant in its own right: A key component of turning victimisation into persecution.

As an Australian citizen, I have struggled with more than 25 years of Chronic Fatigue Syndrome (CFS). I am currently on Disability Support Pension (DSP), with some casual earnings with a steady job in this small rural village.

With CFS I have been managing an ever so gradual recovery, progress measured by changes only observable from one year to the next, but with progress to the point I now have a semi functional life.

I was able to form a relationship several years ago, and we now have a son, age 6. We initially were not planning a long term relationship, nor children.

In view of significant disability I did not feel I was in a position to be provide the support of a full time partner. We are however both thoughtful, genuine, responsible minded individuals, and over the years have progressively moved towards a more defacto style relationship. This I have valued.

We live in separate houses for a set of reasons that, if I were to take the time to explain would make sense. Included in the reasons are, my need for rest in isolation for lengthy periods, and my need to have flexible control over daily activities as an essential part of CFS management. Another reason was practical, my abode has no running water or mains electricity, so not very functional for the practicalities of raising children.

A key to my recovery from CFS has been the stability of DSP and this environment, including the small rural village I live in. The combination has enabled me to gradually rebuild my functional capacities.

My partner, also of very low income, moved to this small village of 20 people or so to be closer to me. By doing so she was also able to buy an acre of land and build a very small (most minimal within regulations) 2 bedroom cottage kit home with repayments less than the rent she was paying in town. This small difference in weekly expenses sufficient to begin the path out of the poverty trap.

My partner has an older boy with a autistic spectrum disorder, and a second quite serious personality disorder. There has been very deep concerns over his development by a number of parties, with concern for the youngest.

My partner has come to realise that she too has a degree of an autism spectrum disorder. Our growing mergence towards partnership has been necessarily slow. This has also been her first long term intimate relationship, undertaken in her late 30's, with me in my early 40's.

With all this, and our limitations, it has been very challenging. We have been getting there, gradually improving our lives towards more productive and capable ones.

I have been able to play a very valuable and critical role with her older son, in moderating some aspects of his potential for certain future behaviour. This is a very serious matter that concerns his life, and the life of others.

My sister's accident occurred around the same time as my partner moved to this small rural village.

We continued to meet our respective loads and challenges within our functional limitations and very low income.

Everyone and every relationship has its limits. By the end of 2001, there had been no break with my sisters situation. There should have been with her move to the nursing home. Instead it became a new marathon crises.

My partner has been very patient with this situation. My partner had had to build and move house virtually with no support or assistance from me in view of the back to back crises we faced, and then my need for my own rest time re CFS.

Such has our circumstances been, so compelled by the immediate urgencies since my sisters accident in Dec 1999, that I imagine we are one of the few families where Sept 11, and Oct 12 have hardly registered with us.

By the beginning of 2002, midway through the Complaints Resolution Scheme process, also contending with the first Guardianship Hearing, the unrelenting pace was crushing us and our growing relationship. We both were aware that these kind of chronic stresses can overwhelm relationships. Hence we were both alert to the need for pro-active attention on its survival. We are fairly independent people used to managing our own affairs, so that has stood us well.

Unusually, my partner expressed at the beginning of 2002, that there had been no break since my sister's accident over 2 years ago, and it was getting to her. She expressed that she needed some time out, or she could find that she will not make it. Her ability to keep going extinguished.

Any statement like this from someone with this autism spectrum disorder is very significant. I understood what was being said.

I immediately negotiated with Margaret and Gordon for a break from my involvement with my sister for a month. I let my partner know that I would be available uninterrupted for a month. She felt the need to have me with her for the daily grid for awhile, so that we do not loose all connection. It is in this stuff that partnerships really mesh and can discover reaffirmation.

It was at this time that we had recently completed CRS Mediation, and were seeking to complete the follow up on our obligations in view of the agreement reached at Mediation. The outcome of this would determine if we needed to proceed to next stage of Determination. The CRS wanted to know if the matter was resolved by Mediation, or

whether the matter needed to go to Determination. We did not know in view of the process we were and, and further our advisers were in contradiction in their assessment of the situation..

I explained the personal situation I was in.

The two complaint process of CRS and the Guardianship Tribunal were a heavy load for any individual to meet, let alone someone with CFS. I explained my fact of disability, the difficulty with writing submissions, the complexity of our case that required a great deal of this if we were to be effectively represented. I explained the length of time since my sisters accident. I explained the circumstances of my growing partnership, and of the immediate additional challenges of the older boy, and the immense stress, equal to my sisters situation, on my partner in view of this. I explained her statement of need to have a break in order to be able to look after and sustain our relationship under this dual load of challenge.

In view of this I requested an extension of the time line for our Determination Hearing, should, as I suspected, we would need to proceed to that step. I was told no, this was not going to be possible.

I explained that my capacity to engage at this time with yet another deadline imposed from outside, was likely to be beyond my functional capacity. I had to have a break re CFS, and my personal relationship circumstances.

Mid this month break with my partner, I received a call from CRS where I was severely heavied on our need to decide if we were going to go to Determination. I reiterated my situation clearly. There was no way of any further delay I was told. I was given the ultimatum that if I did not make a decision concerning my sister within weeks, it would be made for us.

I found my self placed in a situation of my sisters life and welfare on one hand, and putting my relationship at risk through consenting to another deadline on the other hand.

I argued strongly and firmly. I begged!

Given no choice I returned to my partner and asked if she could manage one more month. I had been assured by CRS that there was this one more step and that would be it. My partner felt she could manage this, as long as this really was all there was to go.

So I engaged with our submission to the Determination Hearing.

I, with family, attended the Hearing.

In contradiction to the assurance of the CRS, this was not the only and final stage as I had been assured.

Next there was a Review of Determination in view of the facility challenging the Determination. Then the process of engaging with the facility over the Determination. This pushed the "just one month more" in April, through to September.

Around September, having obtain a final decision from CRS, I went away on my first holiday with my partner and kids for 3 years. During this "time out" the momentum of the ordeal of my sisters situation upon us her came home to her. With the previous assurance of one more month broken, her perception was that it was never going to end. This overcame my partner emotionally and, while declaring that she would absolutely trust me with her life in a way that no one even came close to in her life, she came to the conclusion she just could not go any further.

She ended the relationship.

I was shattered. Given we now had a final "Review of Determination" decision, I felt I was just seeing my way clear, to begin to return to my life and be more available to her and us.

Over the next few months, I worked hard on reconciliation of this relationship. In Jan 2003, my partner heard my presentations, and there was a return of the relationship.

During this time, I confirmed that in terms of her and I, the connection between us was still there. It was not the relationship between us, but what was happening to us. The need to prepare again for a second Guardianship Tribunal Hearing that February to protect my sister from inappropriate chemical restraint did not help rebuild trust. Yet the strength of our underlying relationship was able to meet this.

After this Hearing, I stepped right back from my sister's situation as much as possible in my effort to look after my personal life and the recovery of this relationship.

The damage was deep though, and the trust that my sister's situation would not progressively end, making my presence as a partner possible in the longer term, was fragile.

When the CRS process failed to address the situation, more harm to my sister continued over the next several months. For example, over the next few months family had to admit my sister to hospital in view of starvation. As a result I did have to make some trips to Sydney. Margaret and Gordon were placed under additional strain with my absence from the team, and my mother Margaret was subsequently at increased health risk.

With these ongoing developments, it did seem that my sister's situation was never going to end.

In Aug 2003 I received a letter from my partner saying, No it is over.

I still question how deep that goes for her, but also, I see the mountain of trauma, frustration, loss in her. She feels betrayed, overwhelmed. To much! My credibility gone.

And so it remains a year later.

I believe my request for an extension to the CRS process, when my partner and I both knew we needed it early 2002, was a reasonable request. The magnitude of the personal circumstances fully explained to the CRS. As also my disability with written submissions in view of CFS. They take me much more time than for a normal person.

I believe the only real reason why an extension was not granted, and instead I was harassed and bullied into meeting the next deadline, was because the CRS wanted to maintain tidy statistics for its annual report. To keep itself looking good.

I can recall that phone call from even now back in March 2002. I was left physically shaking uncontrollably over an hour of this call finished.

There is a clear fact to my mind in this situation. When the CRS overrode our request for an extension of time in this process, it decided that its role and existence was primarily to itself and government, not me as a member of the public lodging complaint to which they exist for. Particularly significant in this instance was that I was also acting within my legal role as a guardian.

They may argue that they also have an obligation to the facility. When the truth finally comes out how all the cost in time has really been due to a wilful game by the facility, how then will this personal loss be corrected. A situation that would appear now not redeemable.

I understand such a department can not be responsible for an individuals personal affairs, however, in this instance they could have when advised. I did advise them fully of this situation.

I believe there was no excuse for the rejection of my request in these circumstances. Under immense pressured we had met all other deadlines imposed upon us. It was a single and only request to protect my relationship, my personal circumstances.

It needs to be understood the cost and loss is more than just my emotional loss of a significant relationship.

Firstly, I face the loss of my possibly singular opportunity for partnership in my quite limited circumstances.

Some time in the future without warning, I may well have to watch this person begin a new relationship in this small village, right in front of me.

It is hard to understand how confronting such an intimate loss is in a small rural close knit village of 20 people. It is like facing the prospect of your ex-partner starting a new happy relationship, night after night, watching their peels of joy and new discovery - in your lounge room. It is not much less that this.

The reality for me is that I am not in a position to move away for a significant set of circumstances. Not at least with out liabilities and risks as great or more certain than remaining here. This place is my sanctuary that I have needed in order to maintain my progress with recovery from CFS.

Also, this change of relationship within a small rural community of "hard workers" has the potential to further marginalise my position here. It is complicated.

Secondly and more seriously there is concerns re the older boy. My partner and others have had concern of the potential between the older boy with the younger lad. Several people have serious concern. Normally I could seek to have primary parent hood, where we essentially split the kids, with me taking the youngest.

However, the constraints are immediate and practical. I have no running water, mains electricity, or an inside loo in my dwelling. Functionally, along with CFS disability, this is hardly viable. I would also need a reliable vehicle as a primary carer in a remote area with the youngest having asthma. This I currently do not have.

The current estimates of establishing a reliable vehicle, and alter this dwelling for basic services, doing most myself slowly with the help of friends, is between $30,000 and $60,000.

Given the quality of return of the relationship over early 2003, I have no question that the loss of this relationship has been avoidable and needless. A direct consequence of the failure to accommodate an extension. .

In summary:

I now face, in addition to the harm and suffering of my sister, lifetime loss of meaningful partnership. Not simply the loss of this partnership, but in these circumstances, the possible loss of any further partnership.

I entered these complaint processes with one of my closest kin at significant life risk. As a direct consequence of seeking to gain the intended purpose and outcome of that processes, I now have the two people closest to me at significant life risk.

And let me add, over this last 2 years, my mother has been driven close, at one point, to life threatening health crises.

In this regard the victimisation of the facility has been turned to persecution of our entire family by non-action.

3. - CRS - Transparency of final outcomes to the complainants:

There was no engagement or follow up with us directly in regard to our satisfaction with the compliance of the facility with our complaint.

When there was no compliance, there was no letter to advise us of what was happening about this, or what the outcome was. There was just silence.

We know what we do now, only in view of our efforts, research, and information that came to our attention through other submissions and complaint processes.

Without our own actions, the facility would have simply ignored the Review of Determination, and we would have been left in silence with no outcome, and this apparently would have been fully satisfactory to this process, and everyone.

This strongly lends itself to aged care facilities simply ignoring the entire complaints process.

Privacy of an aged care facility, public or private, should not take precedent over the information needs for the care and protection of a resident at risk.

Having lodged complaint and having had that complaint upheld, in my view there is no reasonable justification for a resident or their representative to not be allowed to know what action or actions have been taken with the facility.

After Review of Determination – transfer to Accreditation Agency:

The facility showed total disregard for this Determination Decision.

We notified the Complaints Resolution Scheme with a fax letter.

I also tracked down the Compliance Section within the Department Health and Aging, and advised them of our experiences.

We were also as a family by this time, exhausted. Writing any further letter was extremely difficult. Burn out!

We were never formally engaged to ask our view of the compliance by the aged care facility. That is, there was no direct inquiry to learn of our perception and satisfaction with the facility's response to the Determination.

I was advised by the Compliance Section that this was because, in view of our letter back to the Complaints Resolution Scheme, non compliance by the facility was sufficiently self evident that engagement with us was not necessary.

We were advised the facility, in view of non-compliance, would be passed onto the Aged Care Standards and Accreditation Agency, evidently for the "big stick" approach.

By this time, this was fully warranted. The situation was appalling. My sister and our suffering was immense.

By this time the Complaints Resolution Scheme complaint process, along with the first Guardianship Tribunal Hearing of Feb 2002, had consumed about 70% of our time and energy over the previous 9 months. Time and energy taken away from our direct support to my sister.

Having pursued the Complaints Resolution Scheme process to its full extent, and received a clear decision in support of our case, the process become invisible to us (and behind this veil the Aged Care Standards and Accreditation Agency took no action!)

We were not allowed to know what happened. To this end, we confirmed this when we exercised an FOI, with no information granted on the basis that all information was "private" to the aged care facility.

Silence. Information white out. Behind closed doors.

This left us with no means to know the outcome of our complaints process or be in a position to assess our position or best actions on behalf of my sister.

This was a particularly serious situation in the instance of my sister.

Firstly, by this time my sister was at significant life risk in this facility. Even when this was made known we were not allowed to know what action, if any, had been taken.

Secondly a short time later, the facility took us to the Guardianship Tribunal seeking our removal as my sisters guardians.

They were presenting that my sister had “severe challenging behaviour” and wanted consent for full chemical restraint. We had not given immediate permission, rather seeking second medical opinions.

Even though we were aware the presented position and justification for this intention was unfounded, given the difficulty of independent evidence, it was our word against the facility.

In this regard, the behaviour of the facility in response to the outcomes of the Complaints Resolution Scheme Determination Decision was important, possibly critical evidence of the general character and trustworthiness of the facility and its presentations to the Tribunal.

We felt is was important that the Guardianship Tribunal, a court of NSW, have access to the outcomes of this process, given they had the role of forming a judgement of who were the best people to make decisions on behalf of my sister.

This was particularly critical as my sister’s life was at considerable risk by the aged care facility on two fronts.

Firstly in consequence to her daily care, at the risk of choking. Secondly in respect to the facility’s determination to have her fully sedated at the exclusion of any further prospects of rehabilitation and exit from a life spent in a nursing home.

That is there was serious risk and threat to the life and welfare of my sister as a citizen.

I was willing to accept the presentation that the facility had a right to privacy. However also the Guardianship Tribunal, a court of NSW in order for it to make effective decisions must be supported with access to appropriate information so that it can fulfil its duties. Hence it should have access to this information. I outlined the seriousness of the situation of my sister being at significant life risk.

In view of these considerations I argued that it was reasonable for the Compliance section to provide the information of the lack of compliance with Determination by the facility and the actions the Commonwealth was taking against the facility, direct to the Guardianship Tribunal.

This way we would never see the information. This way the Tribunal would be respected, and the privacy of the facility respected.

“No” was the answer.

At the Guardianship Tribunal Hearing, I asked the facility representatives what action the Commonwealth had taken in view of their non-compliance with the Determination.

The facility reported that no action had been taken.

They presented that they had been reviewed recently by the Aged Care Standards and Accreditation Agency in view of complaint by the family, with no problems found by this agency. The facility added that another recent complaint also lodged by the family to the NSW Private Health Care Branch had also found no error with the facility in its practices.

They went on to present that the current guardians had raised several complaints and no fault had been found with the facility time and time again.

The implications were clear. We were overzealous complainants with no real substance to any of our concerns.

It was only through being active guardians that we had sufficient other evidence in our submission of our case before the Tribunal for the presentations of the facility to not have sway on the day. At least this is my assessment.

If we had not been active guardians, this lack of action by the Dept of Health and Aging may have resulted in the loss of our guardianship, and subsequently life time mistreatment of my sister.

I was able indirectly to later confirm that no action had been taken by the Aged Care Standards and Accreditation Agency against the aged care facility.

The facility, having completely disregarded a Review of Determination Decision, was given a clean bill of health. We were stunned! With all that my sister had been through, and us. It was almost surreal, unbelievable. Still is today!

The fact remains to this day that we engaged this entire process, at considerable expense of our support to my sister, for nothing. In large part, my sister and all of us would have been better of if we had not done so. This would be to accept that there is no meaningful mode of complaint, and the aged care facility is really free to act as it will.

In this regard along there is a breakdown of effective duty of care of the Commonwealth.

This outcome did not go unchallenged by me.

I engaged with the person representing the Compliance Section. I will call him A, myself C.

Our conversations when something close to the following:

C: How can you explain that no action has been taken?

A: I can give no information of what action, or no action, has taken place.

C: OK, at this stage my sister is not safe, problems continue, she is in a worse position than at the beginning of our complaint. What are our options?

A: We can make a fresh complaint to the Complaints Resolution Scheme. However, if your complaint covers the same issues as your original complaint it may be rejected.

C: Given the time this complaint process has taken and the compromise we have sustained in pursuing this process – why would we do this?

A: If we have a problem with the facility, this is your option.

C: I undertook a review to A of the significant personal cost of pursuing the process of this first complaint. I restated the fact, despite a clear outcome with the Determination Decision, strengthened with Review, that the aged care facility has simply ignored it. It would appear that there is no consequence, no action to been taken. So it defies logic that he could be sincerely presenting the response he is unless I am missing something significant. I ask what it is that I am missing or not understanding.

A: You appear to understand the situation Mr Way.

C: I asked again, is there any reason to expect a outcome different to this past complaint we have just completed, if we make a second complaint.

A: No.

C: Would the fact we have raised a second complaint following the first complaint make things different in any way.

A: No. It would be fully independent of the first complaint.

C: Then for what reason would we initiate another complaint and go through this whole process all over again, have our time and energy taken away from our engagement with my sister for another 12 months - for no effective outcome?

A: This is your choice! You have choice. It is up to you. We all have choice! It is your choice.

C: I did attempt to explain that from my position and understanding this was not a meaningful choice. I was puzzled as he seemed to think so. OK, so I am missing something. I explained my predicament and asked if he can identify what I might be missing here! I re-explored it. Same outcome.

I recall being in shocked puzzlement. Surely this situation could not be as it appears! This was like something straight out of BBC, Yes Minister, or Douglas Adams, Hitch Hikers Guide to the Galaxy. This was seriously a joke, surely?

I let this situation go for some time, weeks. Later I re-explored it again. Same outcome: I can lodge a new complaint. No, it will not be any different.

In this later phone call I asked:

C: When will we be advised of the final outcome of our first complaint?

A: The complaint has been resolved.

C: Pardon! How can that be? We are the complainants and we are not resolved. The situation of complaint is unchanged. Her situation is worse.

A: Your complaint has been resolved.

C: But we have had no letter, nothing. Nothing to clarify or advise us of the outcome of this whole process. I understand we have the Determination Decision and the Review of Determination Decision, but we have no indication of the outcome in view of non-compliance of the facility.

A: The matter is resolved I can assure you.

I struggled with this, and then it was explained to me….

A: The Complaints Resolution Scheme does not give guarantee that all parties will be resolved with the process.

C: But hold on. We are the complainants. My sister is a resident of a facility, she is vulnerable, unable to defend herself. She has been mistreated. The scheme is there to hear and receive complaints about poor treatment or harm to residents. To protect her in such instance. How can the complaint be resolved. We do not agree it is resolved. We are the complainants.

A: Your complaint has been resolved Mr Way.

C: But we have nothing, not even a letter of outcome. I know we have the Determination Decision, which we value, but no letter of the final outcome.

A: Mr Way, as I have said, the complaint has been resolved. If you have ongoing concerns you have the choice of lodging a complaint with the Complaints Resolution Scheme. You have choice.

I began lodging our complaint, way back in Nov, Dec, 2001 I am very clear that no one said this to me.

I explored at some length the process of this complaints scheme before engaging.

I recall clearly expressing my reluctance with entering a Commonwealth complaint processes, as desperate as our situation was. I had not had positive experiences with some previous complaint processes re Chronic Fatigue Syndrome. I felt, in sceptical moments that perhaps government complaint processes were really designed to drain, exhaust and extinguish potential complainants, and effectively silence any legitimate complaint.

I was assured this was not so. It would be fine. I had no question that the person providing me with this response was being completely sincere.

In making a decision to engage with the CRS complaint process, I expressed my concern of the possible time and energy involved. That given our limited time and energy already available to My sister, if the process was to involving, it would take us away from her even more.

I recall the assurances. It was a simple three stage process. All we need to do is provide a little information, and lodge a complaint. They will take it from there. The information does not need to be detailed or comprehensive.

I recall the encouragement. Hope you do soon. Sounds very concerning.

We can not act until you do!

Failures of the Aged Care Standards and Accreditation Agency:

The Aged Care Standards and Accreditation Agency (ACSAA) has been the primary point of failure. It has failed in two ways:

1. It failed to take action against the facility for non-compliance.

2. It failed to assess the facility competently.

These were serious and critical failures.

1. – ACSAA - Failure to Act on Non-Compliance:

The failure to act was more serious in consequence than simply a wasted complaint process with no correction of the situation of complaint. It was additionally damaging through greatly reducing our capacity to exercise further complaint processes at State or Commonwealth level.

The reason for this was as follows.

The failure of the Aged Care Standards and Accreditation Agency to act, and instead providing the facility with a big tick - clean bill of health, made us look like we were zealous complainants with no substance or credibility.

The facility does not submit or make known the outcomes of Review of Determination. Rather they present, as they did to the NSW Guardianship Tribunal, the Aged Care Standards and Accreditation Agency "big tick -clean bill of health".

This enables the facility to present the perception that the extensive process of complaint by the family/guardians was fully investigated and found completely unfounded.

This places us in a very difficult position.

If we continued to raise legitimate complaint, given the evident high risk of more incompetent outcomes like this, the failure of even one more complaint process going the same way would likely seal the perception that our complaints and concerns with all complaint agencies as having no credibility.

It would establish the perception that the facility was the one being victimised. We were "unreasonable next of kin" failing to consider the immense cost to this facility of our family member's "extreme" challenging behaviour. Grief and denial and all that! Remember, we had already been fighting this perception already with some of the complaint agencies we had engaged.

With the perception established, it would greatly strength the case for, and process of, ongoing victimisation.

The potential outcome was plain in terms of the likely consequence. The full permanent sedation of my sister under misrepresented circumstances, and the removal of her opportunity for exit from this facility – for life.

A second equally compelling effect is that we have been silenced from even considering making a fresh complaint to the CRS. It has destroyed all credibility of this complaint process.

2. - ACSAA - Failure of Competency:

I am fortunate to have obtained a copy of an Aged Care Standards and Accreditation Agency report of the facility in question dated 7 Jan 2003.

I assume this represents the response and actions of the agency to the failure of compliance to the Review of Determination decision.

The context is important in this instance. The reason for their review leading to this document is our complaint, and Review of Determination Decision.

Reading this report I have to draw the conclusion that the Aged Care Standards and Accreditation Agency must have had no access to the content of our complaint file with the CRS.

If this agency does have access to this file, then this document indicates a sufficient level of incompetency as to be simply and fully negligent.

If this agency has had access only to the Review, then the same applies to a slightly lesser extent. Still incompetent to be simply negligent.

Let me respond to a few points in this report.

P 2 &3: **"Part 1 Continuous Improvement. "**

With the exception of the last 12 months, there has been no improvement in this facility with my sister!

P4 (1st Para): **"reviewed ten clinical records".**

As far as I can determine from this report this refers to a random selection of 10 client files, this approach the basis of this agency signing off this facility as "in good order".

My sister, as evidenced in the complaints process, is a case of specific individual victimisation. Taking the statistical approach of a random sample of 10 from a 100 plus residents is clearly a completely inappropriate approach for review.

There is no indication in this report that any initiative or investigation has been undertaken to review my sister's care specifically.

P4 (2nd last Para): **"The team sighted several assessments including pressure sore assessments, continence charts, behaviour assessments and physiotherapy assessments. These were completed as regularly as required and progress notes gave no indication that required actions were not being carried out by care staff."**

So much I could say on this. Just one!

My sister has been able to feel most times when she needs to urinate, and has often requested when family is present, to have the opportunity to use the toilet. When family have assisted her, she has been able to use the toilet.

Family as case managers and guardians have raised the need for review my sisters continence management, with a view to supporting her recovery of continence. The issue of her care in this area was a specific issue identified in our original complaint.

For three years she has remained on heavy use of enemas and other medications, plus constant and often thin inadequate incontinence pads. The level of bowel medication may have caused her permanent damage in this aspect of her functioning.

This statement shows a lack of any effective investigation.

P4 (bottom line): **"The needs of residents with challenging behaviours are managed effectively."**

This single statement alone shows a level of inadequacy of investigation by this agency as to be incompetent.

Have they not read the Review of Determination Decision?

An example of the level of monitoring of challenging behaviour by this facility. I recall 2001 where family arranged for an increase in a medication moderating my sisters challenging behaviour. All inquiries to the facility in following months advised us there was no moderation of her behaviour in view of this medication.

At the end of the year when we accessed the records of the facility, we found retrospectively that following this medication increase there had not been a single incident report for over 5 weeks. Not a single one!

The facility was either entirely unaware, or wilfully denying the effectiveness of this intervention.

There had been no change in the facility's attitude since.

Very serious!

A further example. During the Determination Hearing (transcript available in Melbourne), the facility presented that none of its staff were trained or able to manage behaviour management programs. Their staff had no time for filling out monitoring charts in order to identify triggers for challenging behaviour, a prerequisite for effective behaviour management.

P6. Full page.

"Resident X" is clearly my sister. This page shows a lack of any comprehension of our complaint and the Review of Determination.

"**The deputy director of nursing also stated that ongoing discussion regarding the behavioural management and overall care planning of the resident is occurring with the resident's family members and that chemical restraint was being considered."**

Hmm…! No.

That is what the Acting DON told the Accreditation Agency. But did the Accreditation Agency check with us that this had happened. No!

The date listed on this report of the two Quality Assessors is 27 December 2002.

On Jan 4, 2003, I received call from a Doctor who had been invited to the facility without our guardians consent to see my sister.

He found her in a shocking state, and was clearly (suitably) shocked himself. She had not been attended by staff for some time, a day or two, and was covered in her own faeces. It was explained to him that this was because staff could not attend her because of her severe unmanageable behaviour. He bought it!

He immediately prescribed Risperidone, a drug widely used in the aged care industry to chemically restrain residents.

Interestingly enough, as has happened before, this all took place precisely when my sisters mother and step father had left Sydney to spend two days travelling to me in Northern NSW. It was their first opportunity for a stress break in three years.

I received the call from the doctor 1 hour before their arrival, and instead of a holiday, we went straight into several days of crises – again!

This doctor was not even the appointed doctor managing my sisters medication.

This was the first we heard about "chemical restraint". There was no consultation.

My failure as a guardian to immediately consent to chemical restraint of my sister on the phone call of this doctor on the 4th of Jan, lead to the facility lodging an application two weeks later to have us removed as guardians. Interestingly, the facility submitted this application after it received advise we had consented to a trial of this medication.

Nice to know the Aged Care Standards and Accreditation Agency is thorough in its review of aged care facilities and their practices. How all those frail aged residence out there are safe! Getting good quality care.

NSW Police Involvement:

In Oct 2003, we were presented with a very distressed staff of the aged care facility reporting very disturbing events, physical assault and more. There was a second witness involved as well.

One witness contacted family very concerned that a male member of staff was going to kill my sister in view of the fact she had damaged his glasses or watch, that weekend. She was extremely concerned that we had to ensure he had no contact with her ever again.

She reported that for several months two males of three problem males, while always speaking ill of my sister, also insisted on rostering themselves on in her section on the weekend. They would shower her at 6:30 am or so, just before the changeover of RN shift. The witness reported that when having her morning tea downstairs below the concrete reinforced floor she could still hear my sister screaming for her life – most weekends. This had been happening for months. No one apparently can be found who actually checked to find out what was happening.

She also reported that another colleague had witness one of the "three males" who put his fist down my sisters throat threatening to kill her, drawing blood.

The call from this witness was received by Margaret, who by the end of the call was too distraught to act on this contact, so she rang me. During the call, this witness was very critical of family as she had the perception we did not give a damn, ….otherwise we would be doing more! And why would we leave her there! This is apparently a wide spread perception amongst staff at the facility. We do not do anything about her situation!

I followed up on this witness and the other witness to events she referred. She reported she has already spoken to police and a complaint agency. She was not sure of what agency she rang "accreditation board .. something??". Apparently this agency immediately recognised the name of my sister, first name only was sufficient, and listened. They knew exactly who the witness was talking about.

They said this was serious and would refer it to the right agency and someone would ring her. A women did ring the witness back fairly soon after. This second person was disgusted at what she was told.

From my research I understand this second person was from the Dept of Health and Aging, though once again the Department is not allowed to confirm or deny this to us, even though we are the legal guardians.

I also followed up with her report of having rung police. This was confirmed. Police however were not following the matter, as they were awaiting her promised return contact.

The witness herself was very traumatised by what she had witnessed over the many previous months working at the facility specifically in regards to the treatment of my sister. Late in our lengthy conversation she said:

> "I am a nurse for f**ks sake. I did not come into nursing to see people abused. X (my sister) is not being cared for mentally or physically. Not by AIN's or RN's."

She had a lot to say…..

I followed up on the other witness she had referred to. Both were determined to follow through with their witness. In my view their stories corroborated on many matters concerning the facility, though the two key events they had witnessed had each been witnessed separately.

I also followed up on aspects of both these witness's stories with some other ex staff members to check that their story corroborated. It did – unfortunately!

Police later confirmed that they had checked both stories with each other and also felt there was good corroboration.

I endeavoured to engage both to put their witness in writing to us. In the end this never eventuated. In part because I was successful in engaging police on this matter, and being an assault, I needed to not contact witnesses. In the following period they both withdrew.

It took me weeks of persistence before I persuaded police that they had an investigative role to play and actually followed up with the witnesses.

From a police point of view (State and Federal) this was a PHCB, HCCC, Health Department issue, and not their jurisdiction.

I had hoped it would help when I drew the analogy of how domestic violence was once not considered 'real assault' and likewise they should not make the same error because this alleged assault had taken place in an aged care facility. "This is her place of residence you know!" I said.

No go!

Thankfully, assistance from one officer advising me that I could insist on making a police report, such that a formal 'event' was logged on the system, did in the end force their hand.

So my argument re domestic violence really had nothing to do with it.

Once involved they were good.

After inquiries, and some weeks, the investigating detective affirmed they were very concerned, even though the two investigating witnesses had withdrawn.

It was in view of their concern, and a better grasp of the complexity of the situation, that they suggested we seek the authority to put surveillance in her room to obtain evidence. It appeared that had not the witnesses withdrawn leaving them with no case, they were considering doing so. However they now had to drop the matter.

I did follow up on this. Family seeking this authority would again involve money, application to the NSW Supreme Court being about $500. On further investigation I felt it was unlikely we, as legal guardians, would be considered within the Listening Devices Act (NSW) as an "investigative authority". (Another path to evidence extinguished.)

Such information, through providing a record of what happened when, would have provided us with an opportunity to determine just what level of care or neglect she was being subject to on a typical day. The information in this regard, would greatly aid our decision making and, with such evidence, enable speedy, effective and definitive complaint process to occur if appropriate.

Concerning these alleged assaults, there was an internal investigation held by the facility (I think prompted, and required, by the Dept of Health and Aging).

The internal investigation dismissed the credibility of the alleged assaults.

From what we can gather, this is on the basis that one of the witnesses was never rostered on with the alleged assault person. It would appear that the reason for this discrepancy is that they checked the wrong individual of the two witnesses with the roster.

Always these little errors!

The report notes that the alleged assault person when asked to come to an interview failed to appear and promptly left his employment never to return. Guess that was just coincidence.

I am struck by almost every party's determination to give credit to family, guardian or witness views last, and only when cornered to the point they have no choice.

Within the attitude culture of complaint agencies, there is no common sense balance of: "… until proven yes we must be cautious, yes, but also - we can not dismiss these allegations either."

My sister has suffered as a consequence of this systemic attitude within complaint agency culture, as have all of us.

Overwhelming paper work upon the facility.

In the several months that followed, the new Director of Care was clear that she was snowed under with one requirement after another from agencies, with a resentful look our direction.

No action of ours created this. Our complaint process of 9 months had long ended with a total zero response.

I can only gather that the Aged Care Standards and Accreditation Agency, and the Commonwealth Dept of Health and Aging, having been so disregarding of our presentations and complaint siding with the "poor facility", found themselves with fresh realisation and feeling very exposed.

And hence the sudden rush of review, requests, requirements ,etc upon this aged care facility.

The aged care facility in our previous complaint processes was represented by peak industry representatives (such as Jill Pritty).

I hence speculate that the presence in the terms of reference for this inquiry for:

> Part B, … (iii) implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff;

has probably been generated in part by my sisters case at this facility. Perhaps not?

If so let it be noted:

It was the actions, or more to the point, lack of actions, of the aged care facility over three years, in response to my sister and all our efforts of good will, that has generated themselves so much paper work for 6 months.

Let it also be noted:

I have 3 full boxes of documents, and a folder with my sisters name on it on my computer that has currently 260 MB of mostly documents, of which a significant portion are word documents, all of which I have personally written and generated over 4 years.

I am one of three in our family. This family is the only party that is not being paid! And we do not go home for the weekend!

The victimisation of my sister has extended to us, her immediate family of three, and in view of events last year, now extends even further to my family and son.

I wonder where this violation and violence is going to stop?

In conclusion:

Reflecting on our experiences, and given:

- the magnitude and dedication of our efforts over years uncovering victimisation,
- the effectiveness of current complaint and compliance processes even when diligently pursued to their maximum extent by us,

the only conclusion I can draw is that:

There is not one individual in an aged care facility within this country that can be assumed to be safe.

Further: The extent of failure from my experience is to the point that there needs to be serious question of whether the Commonwealth (and in our case, also State of NSW) is affecting a reasonable and adequate "Duty of Care".

I am aware this is a view directly contradictory to the glossy and assuring pdf annual statements available to the general public by each of the various agencies and departments.

It should not, and need not be this way.

With respect to the Terms of Reference:

PART (A)

The adequacy of current proposals, including those in the 2004 Budget, in overcoming aged care workforce shortages and training;

While I do not know the current budget, I do know that past lack of adequate funding providing substandard wages of hands on staff in aged care facilities (AIN's, EN's) has had a significant impact on our situation of the last 4 years.

This non-spreadsheet hidden cost in the quality of care and indirect cost to the community through "working poor wages" I would guess is not overall economic in view of the fear of facilities being unable to locate replacement staff for staff who are clearly undesirable.

PART (B)

The performance and effectiveness of the Aged Care Standards and Accreditation Agency in:

(i) assessing and monitoring care, health and safety,

Effectively zero.
Currently a liability to the Commonwealth in terms of legal exposure.

(ii) identifying best practice and providing information, education and training to aged care facilities, and

Effectively zero.
Currently a liability to the Commonwealth in terms of legal exposure.

(iii) implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff;

Generally no. The exception when the facility has created its own mess, (and current agencies fear exposure).

PART (C)

The appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

The first half of this matter is self evident. One does not need a senate inquiry to know that young people do not belong in an aged care facility.

The commonwealth is fully aware of the situation. It keeps the statistics. Both Commonwealth and States are aware of the CSDA. There remain no appropriate accommodation options for young people.

As for service needs, current policy excludes services funded by HACC, etc to provide a service to people in an aged care facility. There are currently no services to young people in nursing homes.

PART (D)

The adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly; and

Elderly in nursing homes, from my observations of being a visitor, need input from outside their institution. Otherwise the internal environment grows back in on itself, and stagnates.

PART (E)

The effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.

One observation:

Stressed public health system! One key factor is a significant percentage of available hospital beds are taken with aged persons who need placement in an aged care facility.

If you build appropriate facilities for the 6,000 plus non-aged people in current aged care facilities, one will also provide significant freeing up of public hospital bed spaces. Considerable dual funding effect.

To confirm, go ask an emergency casualty RN in a metropolitan hospital, any State in Australia.

On behalf of:

Fiona Way,
Citizen of the Commonwealth of Australia.

And, Citizens in aged care facilities.

Cameron Way.