

SENATE ENQUIRY INTO AGED CARE

TERM OF REFERENCE C

**THE APPROPRIATENESS OF YOUNG PEOPLE WITH DISABILITIES IN
RESIDENTIAL AGED CARE FACILITIES AND THE EXTENT TO WHICH
RESIDENTS WITH SEPCIAL NEEDS SUCH AS DEMENTIA, MENTAL
ILLNESS OR SPECIFIC CONDITIONS ARE MET BY CURRENT
FUNDING ARRANGEMENTS**

SUBMISSION FROM

MARY NOLAN

**I THANK THE SENATE FOR INCLUDING THIS TERM OF REFERENCE
AND FOR THE OPPORTUNITY TO MAKE THIS SUBMISSION**

I REQUEST TO APPEAR AT A PUBLIC HEARING

1 AUGUST 2004

SUMMARY

The paper is arranged in the following format and, as well as addressing the Term of Reference © attempts to offer an overview of ABI and the special needs of a YPINH. It is impossible to understand and be with YPINH with ABI without context.

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INTRODUCTION

***‘What is ABI (Acquired Brain Injury) and why is Chris as a young person here in an aged nursing home?
What’s going to happen to him when it closes and moves to an outer suburb?
What do you want?’***

These questions came from the concerned son of an elderly resident in August 2003, after the organisation announced the closure and re-location of the Nursing Home to an outer suburb by 2006. Our son, Chris, suffered a severe ABI in 1996, and has lived at the NH for the past 8 years.

The questions prompted a reply which has changed as I continue to learn, and for different audiences, and has now developed in to this Submission.

I thank the Senate for this Enquiry and especially for including the Term of reference (c) – the appropriateness of young people with disabilities and the extent to which people with special needs .. are met with current funding arrangements

In this Submission to the Senate Enquiry, I will focus on my son, Chris, and a sub group of YPINH – those with very severe ABI who are mostly unable to speak, and who have special care needs. I will attempt to give some overview of :

- the impact of severe ABI on the young person but also the family and whole networks - without too much subjectivity (!)
- The complexity of a system which is not working for Young People in Nursing Homes (YPINH) with severe ABI
- The inappropriateness of Aged Care facilities and the inability to meet the special needs of this group of YP with severe ABI
- Some insight in to the special needs of the YPINH with ABI that are not being met. And the scant knowledge of those people and their needs. Critical is whether or not decision makers at all levels acknowledge that many of these YPINH are aware and understanding and treat them accordingly.
- ABI as a comparatively new disability group and the service system, and the context in which our son, Chris, is presently living life among friends and family and community.
- My own involvement at many levels, and knowledge of Chris and YPINH with ABI and non speaking. A credible witness and seeker and implementer of solutions
- Finally I hope I give a sense of what we have learned and glimpsed of:
 - the philosophical underpinning and practice of partnership we believe vital for a non speaking person with ABI
 - what is possible and how Chris and we have ‘broken ground’ and is trying to live life as he is with all the constraints
 - what is still to be discovered,
 - what we as friends and family with Chris, are presently doing in the vacuum of appropriate ‘models’ to articulate a solution
- Ideas for Solutions and How we are and can be involved in a solution outside the present known solutions – creating the future

SECTION ONE: CHRIS AND THE NOLAN STORY

Family

Mary and John Nolan lived on and worked the family farm (which has been in the Nolan family since before 1865) at Meredith, 2 hours west of Melbourne. Mary worked part time as a radiographer at Ballarat, and was on World Executive Council of World Christian Life Community (CLC) from 1990 – 2003, and National President of CLC for over 10 years until 2000.

Mary and John have a life time of community involvement on local and wider levels. Two children – Mary Louise born in 1966, and Christopher born 1968.

In 1988 Mary Louise, aged 21, died in a car accident – an event which was catastrophic and life changing for the family.

Chris: a high achiever – capacity for friendship

- School Captain of St Patrick's College, Ballarat, 1985. Prizes for academic subjects, leadership, public speaking and debating.
- 1989 -spent a year overseas during which he lived and worked for 6 months at Boys Hope, Cincinnati, Ohio, a home for boys who were socially/economically disadvantaged but intellectually able and being educated. Also 3 months in Central America
- Co- founder of the Meredith Music Festival. Began in 1991 with 250 people and 13th MMF in December 2003 attracted over 8000 -- still held on our farm,
- Graduated in 1991 in Economics/Law (Honours) Monash, Captain Meredith Cricket Team – 3 Premierships in 4 years. A, B and C Grade Champion of Meredith Golf Club
- 1992 – 1995 Worked as a lawyer with Melbourne Firm.
- June 1995 went to Hanoi to work with law firm with Austrade Fellowship learning Vietnamese.

Chris has a great capacity for a diversity of people and friendship – one friend describes him as a 'social' person in the full sense of the word. Among his many interests, music, sport and current affairs rate high. Chris had/has the greatest capacity of anyone I know for people and friendship, and a great sense of humour, and still does. Humour has been a great stress breaker.

Chris - ABI in 1996

In May 1996, while working as a lawyer in Hanoi, Chris suffered a multi organ collapse and a very severe hypoxic brain injury. Critically ill, he was airlifted to Singapore where he was in Intensive Care on life support for 3 weeks. Then back to St Vincent's Public Hospital, Melbourne, where he remained until December 1996. The first months were a medical and emotional rollercoaster with several times where he hovered between life and death. Medical opinion was that he would be vegetative, that is without any awareness or understanding if he survived.

After 6 months in coma, on 19 November 1996, Chris 'woke up' laughing at a joke his cousin had made in his room. He was hearing and understanding!

At St. V's, John and Mary set up a group of 4 to make decisions with doctors for Chris. That group was Mary and John and two close friends of Chris – a doctor and a lawyer. The decisions included with holding treatment. Despite, or perhaps in spite of, Chris was and is a 'stayer', Chris defied enormous odds to survive then and later. **This way of decision making was the foundation for all that came after.**

No options except a Choice of Nursing Home

When we realised that Chris was without compensation and his only option was an Aged Care NH, many people told us to put him in Ballarat or Geelong, 'keep him comfortable' and get on with our lives.

We decided, however, that we would keep Chris in Melbourne and on 23 December 1996, Chris moved to an aged care facility in North Fitzroy. Our reasons included:

- Chris was hearing and understanding and responding appropriately – that is cognitive
- Social and geographic location - close and accessible to his main friendship group who were still visiting, and to medical and allied health who seemed to have some expertise in this degree of brain injury
- Philosophy and Practice of Partnership in Care of the Nursing Home, which has been integral to all that has developed.
- Agreement with the Director of Nursing Home, Rosalie Hudson, now Dr Rosalie Hudson, who is contributing to this Enquiry, that we would work together with staff, therapists and friends and residents, etc.

Chris was one of the first funded under the Victorian State Acquired Brain Injury; Slow to Recover (ABI:STR) Program (1996 – 2004). There was no model, no experience of a YP with ABI and integrating slow to recover rehabilitation in the NH setting. I have been acknowledged as a 'driver' as we developed ways of working together with friends and family involved and an 'Approach'.

The 'Approach' developed and used with Chris has since been adapted for 3 other young people with ABI who have lived at the NH.

Mary's involvement with Chris and other YPINH with ABI

In 1999, Mary was invited on to a reference group for the Melbourne City Mission, *'Study in to the Accommodation Needs of Young people with Acquired Brain Injury Requiring Nursing Home Levels of Care'* - Kerry Stringer.¹ Mary wrote the Case Study for the Report and for the first time realised the uniqueness and value of the team/collaborative 'Approach' that had been developed for Chris and other YPINH with ABI and non speaking at HMcCH. This was a significant realisation that has motivated and led her ongoing commitment and work for Chris and other YPINH with ABI since then.

This includes Mary being a founding member of Inability Possability Inc and the 'Association for YPINH with ABI, families and friends', and the YPINH Consortium and receiving a Human Rights Award in 2002. (See SECTION FIVE)

Mary left the farm and home and work in May 1996 to go to Singapore and has not been home for longer than 10 days at a time since. She lives in Melbourne, and John visits from the farm at weekends. They take Chris to the farm every 8 weeks or so for a weekend. She says it's like living in a Different World where there is No Road Map².

¹ Stringer K. *'Study in to the Accommodation Needs of Young people with Acquired Brain Injury Requiring Nursing Home Levels of Care'* 1999 Melbourne Citymission

² Joint presentation entitled, *It's a Different World to National Aged and Community Services Conference 2000 Melbourne*. By Rosalie Hudson Director of Nursing *'The Nursing Home World'*; David Carlos *'Making It Different Manager ABI Services, Melbourne Citymission, Mary Nolan family member, 'No Road Map'*

SECTION TWO : A PERSONAL STORY AND EXPERIENCE – CHRIS NOLAN – A 'YPINH WITH AN ABI'—UNDERPINNING PHILOSOPHY AND PRACTICE PARTNERSHIP IN CARE INTEGRAL.

Chris is now 36 years old and has lived at an High Care Aged Care Nursing home in North Fitzroy for nearly 8 years – he has become a 'YPINH' with ABI³. Little by little he continues to make improvements, small by 'well' standards, but very significant for his quality of life. This includes some coming to terms with life as he is now with his possibilities and inabilities.

Chris hears and understands and communicates expressively and receptively with facial expressions and a long blink for Yes. He is 'trapped' in a profoundly disabled body and communication system – unable to move, speak or see much.

Despite these limitations, Chris continues to have a great capacity for people and friendship and has a strong and vibrant network of old and new friends who visit when they can, and he gets out and about with them. 'Nolsey, you are still doing what you always did well – bringing people together'.

Friends have been very significant also in developing an objective picture of Chris as cognitive and responsive, and of giving carers aspects of who he was and is. This is an exception – most YPINH with ABI are profoundly isolated and families regarded as subjective.

Chris lives in a *social and geographic location accessible* to friends and family, close to younger people friendly venues, and within walking distance to entertainment and services. This is vital for him and also means that taxi and transport costs are manageable. Because he gets out in this way, Chris has also become known to many in the neighbourhood as family/carers walk him to surrounding areas including Edinburgh Park, local pubs and streets. Parents take him to the farm for weekends every 8-10 weeks. During the past 2 years, however, Chris has had fewer regular visitors as people move and children arrive.

Always with a socio-political 'bent', in the past year or two Chris has gained purpose and some sense of his place in the world now as he has become increasingly involved in working to make a difference for himself and others like him in NH. He attends INABILITY POSSABILITY meetings and was involved in the Federation Parade and both National events for YPINH. He is not shy of media, in fact 'rises to the occasion and enjoys it' as a friend recently remarked. He wants to live life.

In August 2003, Chris attended the Inaugural Captain's Dinner at St Patrick's College Ballarat, where he was School Captain in 1985. Chris is a founder of the Meredith Music Festival, an annual event since 1991 and he attended the 13th Annual MMF in December 2003. See www.mmf.com.au. He attended the launch of '*still the doors are open-writings of life*' on 29 April as a member of Inability Possability Inc. He was keen to be involved in the TV news filming on 21 May, 2004.⁴

Such participation enables him to live as an interdependent member of society – giving and receiving. Surely, a right and responsibility of any person in our society? We can easily render people dependent and powerless. 'Chris wants to live life'.⁵

³ See 'YPINH' a friend's writing in '*Still the doors are open – writings of life*' Book available from Inability Possability Inc PO Box Carlton 3054 Vic Send cheque or money order for \$19.95. Final pages of book outline Chronology of Achievements and Statement of Purposes.

⁴ Channel 9 and 10 News Melbourne Friday 21 May 2004.

⁵ Ibid. Channel 9 news Chris's friend Jeremy Smith

Since 1996, based on the Philosophy and Practice of Partnership of Care of the NH where Chris lives, a pool of expertise in allied health therapists, attendant carers, nursing home Staff, medical practitioners has been built up. All try to work in partnership with family and friends to enable a quality of care and life for Chris and others like him. This is unique and is regarded as an example for people like him, but it struggles. Mary acknowledged as 'driver'

Chris is funded under the ABI: STRP mentioned previously. Chris is one of the earliest people funded and is acknowledged to have 'broken ground' for someone with such severity of injury. Funding periods have varied from 3 months to now one year, and we have appealed cuts several times.

Recent cuts were taken to Appeal, and the Appeal has resulted in further cuts. We have evidence that this is not enough for Chris's needs to survive and be 'maintained'. 8 hours per therapist per year is inadequate to keep him well and free of chest infections, contractures, spasticity and associated pain, much less comfortable enough to continue responsiveness and maximise improvements. As no one has gone beyond this level of Appeal, we now have to determine what to do next.

As with other families, the financial cost to us as parents in addition to the other issues e.g. of personal and emotional levels, is considerable. Mary has not worked since 1996. This is not sustainable.

With an aged care system in 'crisis', NH closing and funding cuts, and lack of understanding of this group like Chris, the struggle does not end, but seems to intensify. Chris needs life time support.

UNDERPINNING PHILOSOPHY AND PRACTICE OF PARTNERSHIP IN CARE AND VALUE FOR A NON SPEAKING YP WITH ABI.

When Chris went to the NH in 1996 as the first YP with ABI, the then Director of Nursing, Rosalie Hudson, and I agreed that we could be certain there would be problems. All we have done has been based and underpinned by the Philosophy and Practice of Partnership in Care for Chris as person in community⁶, and protocols, where inadequate, were amended. In any shared accommodation, a person has rights and also responsibilities.

'Partnership in Care' has been the basis of all we have built up and is profoundly relevant and essential for a YP with ABI especially one who is non speaking like Chris. With dedicated staff working with family/friends and therapists, it enables his 'voice' to be heard and his needs addressed with *better chance of correct interpretation and response*. We learn together to notice and interpret Chris's communication. Perhaps the only thing worse than being able to speak would be to be constantly misinterpreted. Airlie Kirkham speaks About her experience.⁷

⁶ Hudson Dr Rosalie , "Personhood, Community and Death: The Transforming Power of Relationships in the Nursing Home" Doctoral Thesis 2000

⁷ *How it feels .. to be in a coma* The Age 6 January 2004. Airlie Kirkham, 38, speaks of her experience of 6 years in a 'locked in' state where she was unable to communicate or move following a serious car accident.

SECTION THREE : OVERVIEW YPINH (INCLUDING THOSE WITH ABI) MOST WITH ACQUIRED DISABILITY.

The situation of YPINH has generally been hidden and silent, with most Australians unaware of the issue.

In 1990 there were 3,531 people under 65 in NH in Australia. At March 2004, there are more than 6000 people under 65 in NH. This includes about 1200 under 50, with 195 of these under 40.⁸

In Victoria at March 2004, there were 1536 people under 65, an increase of 97 since March 2003. **Of these about 170 people are under 50, and 50 people under 40.**

This group is a comparatively small one. Most are very isolated and unable to speak for themselves. These young people appear in statistics and records according to:

- their assessed level of care, that is the Aged Care Resident Classification assessment tool rating from 1 to 8, with RCS Category 1 being the highest level of care
- their age, but not the type of disability they have.

Most young people in nursing homes have an acquired disability. They have lived normal lives until an illness, such as multiple sclerosis (MS), or a sudden event, such as brain injury, means that the person now requires high levels of care.

About 30-40% of YPINH have an acquired brain injury and 30% neurological disability such as MS.

For those who do not have compensation, there is no alternative but an aged care nursing home.

Any one of us can acquire a disability at any time.

Who is responsible?

State Governments are responsible for people with disabilities and the Commonwealth Government is responsible for residential aged care. For years, these two levels of Government have continued to pass the buck with neither prepared to take responsibility for these young people with high care needs. Because they are in Commonwealth funded Aged Care, YPINH are mostly excluded from any State based disability funding for community access, equipment, therapy or rehabilitation, and the Commonwealth Government says it is the state responsibility. YPINH generally 'fall between the cracks'.

A woman told me this week that the **story of a friend of hers, a young man, 'Dominic', appeared in newspapers 30 years ago when he had no option but an aged care NH. This is too long!**

⁸ People under 65 in residential aged care at March 2004

SECTION FOUR: YPINH WITH ABI – A SUB GROUP OF YPINH

ABI IS A COMPARATIVELY NEWLY RECOGNISED DISABILITY/GROUP WITHIN THE DISABILITY SYSTEM. LITTLE KNOWLEDGE – PESSIMISM PERVADES. YPINH WITH ABI - WHO HAVE BEEN DESCRIBED AS THE MOST MARGINALISED WITHIN YPINH - WITH PARTICULAR REFERENCE TO VICTORIA.

To understand the situation one needs some understanding of the history and context for people with ABI. I offer this perspective from the Victorian context, as I understand it. I understand that Victoria is leading the way in some respects and that the situation is similar or worse in other states

ABI has only been recognised as a particular disability since the late 1980's, and the service system only began in the early 1990's. Impairment from ABI varies greatly from minimal to very severe (like Chris). While people have always suffered brain injury, prior to this time, the understanding led people with ABI to be categorised under intellectual disability or mental health. **A growing awareness that people with ABI were different led to change.**

This is acknowledged in the Background to the Acquired Brain Injury Strategic Plan⁹. This Plan was launched in March 2001 by the then Minister for Community Services, Christine Campbell, and signed off also by Minister for Health, John Thwaites, and Minister for Housing and Aged Care, Bronwyn Pike. **YPINH with ABI 'cross' three Ministries on state level and two on Commonwealth level, Family and Community Services and Aged Care.**

Acquired Brain Injury is a three word phrase which I am still 'unwrapping'. Disability Services began around people with a disability from birth, and originally people with Intellectual Disability (ID). People with ABI are still equated with people with ID, and some who make decisions believe that there is little difference.

While there may be some similarities in care needs, **a person with *acquired disability* and ABI, however, has particular and significant needs and issues which are quite different from those with those with birth disabilities.**

For example, pre injury, as an able person, Chris had a very full life, forming a unique personality in relationship with others, achieving a high level of functioning and maturity e.g. physically, emotionally, relationally, spiritually, and with processes laid down in his brain e.g. movement patterns which can be re-activated with the approach used by therapists

ABI is sudden with no warning – fit and well one day and in coma the next. Imagine 'waking up' after several months in coma to find yourself trapped in a profoundly disabled body and communication system and unable to speak.

Add to this the terror, confusion and grief of the loss of so much, and the 'coming to terms with' and finding purpose and meaning as he/she is now¹⁰. Over these past years Chris has 're-defined' himself as person, again in relationship, and has gained some purpose and sense

⁹ *Acquired Brain Injury Strategic Plan* Victorian Government Department of Human Services March 2001. Page 1 Background

"The service system for people with ABI has predominately only developed over the past decade. In the early 1990's the foundations of the service system were laid with:

- *The Head Injury Impact Project ..*
- *The Head Injury Services Plan..*
- *The Ministerial Implementation Committee on Head Injuries (MACHI)...*

"In 1994 leadership moved to Disability Services.. During this time the ABI:Slow to Recover Program was established providing slow steam rehabilitation". "In 1997 leadership moved to Aged Community mental Health (ACMH)"

¹⁰ *How it feels .. to be in a coma* The Age 6 January 2004. Airlie Kirkham, 38, speaks of her experience of 6 years in a 'locked in' state where she was unable to communicate or move following a serious car accident.

of his place in the world as he is now. **One aspect which has been important to what is a life long journey is his involvement in making a difference for himself and others – a reactivation of his old 'socio-political bent' – he can do something!** He wants to live life!

Dr Amaryll Perlesz, herself the daughter of a Holocaust survivor, describes the 'crisis of witnessing' of people with ABI and their families/friends and likens it to a similar experience of survivors of the Holocaust.¹¹ Perlesz writes of the co-existence of hope and despair.

Such is the impact and confrontational nature of severe ABI¹².

The level of knowledge about very severe ABI is scant and pessimism pervades all levels.¹³

Another writer, Neil Adams, says, "Positive change is often overlooked' and "However in the area of ABI, positive outcomes have been underreported in the literature which has focused for various reasons on maladaptation' Adams goes on to speak of the " need for a more positive though balanced view" and 'the widely-used terminology of 'plateauing' (or leveling out of functioning) is one that needs challenging...' and of the "Clinical research focus on the negative impact of ABI".

This pessimism affects assumptions and attitudes and decision making for people with severe ABI at all levels. There are many examples of people who are non speaking being viewed as non cognitive, including among medical/nursing/therapy sector, and decisions made accordingly.

Families are constantly coming up against the consequences of this pessimism and lack of understanding of the person with severe ABI especially those who are non speaking.

Causes of severe ABI include:

- **A focal head injury** e.g. accident.
- Anything which causes lack of oxygen even for a few minutes, and a **generalised or hypoxic injury** to the brain. Examples include breathing stopping or prolonged low blood pressure e.g. during epileptic fit, diabetes, asthma attack, stroke, drug overdose, near drowning, medical/surgery complications.

¹¹ Perlesz, Dr Amaryll, Senior Lecturer of Public Health, LaTrobe University. "Complex Responses to Trauma: Challenges in Bearing Witness" A.N.Z.J. Fam. Therapy., 1999, Vol.20, no 1 pp 11-19 Perlesz is the daughter of a Holocaust survivor.

¹² As a doctor at St Vincent's said to Mary Nolan in 1996, "You are everyone's worst nightmare. It could be one of us or our son or daughter"

¹³ 1996 Adams, Neil Clinical Psychologist, Bouverie Family Therapy Centre Melbourne "Positive Outcomes in Families Following Traumatic Brain Injury" A.N.Z.J Fam. Ther., Vol 17, no.2 pp 75-84. 'In an earlier paper, the relationship between spirituality, science and therapy was explored. In this paper spirituality is discussed in a more clinical context. Family response to trauma is outlined concentrating on the area of ABI and several models of adaptation are reviewed. There appear to be commonalities in response to different types of trauma. However in the area of ABI, positive outcomes have been underreported in the literature which has focused for various reasons on maladaptation. In viewing response to trauma as involving both the potential for positive transformation as well as suffering and burden, concepts of Frankl and Jung, spiritual belief and near death experiences are discussed. Examples of how families find meaning and positively appraise their experience of ABI are also given' In the paper Adams says: "The area of ABI provides therapists with a unique opportunity to explore and transcend the dualities with which life is filled, such as mind/body, hope/despair, optimism/pessimism, good/bad. However ABI workers have neglected a more holistic perspective in their focus on one side of the equation – the tragedy of the traumatic, consequent family burden and the pessimism in the rehabilitation system. Brain damage is viewed as disastrous both for the injured person associated with social stigma and isolation, disability, depression, poor health, cognitive deterioration, personality changes etc and for the family too. ... Adams goes on to speak of the " need for a more positive though balanced view" and 'the widely-used terminology of 'plateauing' (or leveling out of functioning) is one that needs challenging...' and of the "Clinical research focus on the negative impact of ABI"

There is usually no warning of brain injury and many are left with impaired communication. **Many YPINH with severe ABI are unable to speak and previously were regarded as vegetative with no hope of recovery. This view is still widely held. People with ABI who are non-speaking are often treated as if they are vegetative and not cognitive, that is they do not understand and are not able to participate in decision making, and decisions are made accordingly. They are regarded by many as the most marginalised group in society, depending on others to give them 'voice'.**

SERIOUS CONSEQUENCES FLOW FROM THE BELIEF OR NOT ABOUT WHETHER A PERSON IS AWARE AND COGNITIVE. THIS IS A CRITICAL POINT AND I ILLUSTRATE WITH SOME EXAMPLES.

Examples of other YPINH with ABI and the paucity of understanding of this group:

- A nurse, "N", told me this story. "N" did an agency night shift in an inner city NH. In 'handover', she was told that there was a young man, 'Sean', with ABI who was 'vegetative', that is, who did not know what was going on, had no awareness. "N", experienced with Chris and others with ABI, was disturbed when the regular nurse on duty with her treated 'Sean' as if he was 'not there'. That is, during the night she moved and turned him without telling him what she was about to do and talked over him. In contrast, "N" told 'Sean' she had experience with others who had a similar injury and that she would be trying to keep him comfortable looking after him during the night. Each time she attended to him, she told him what she was about to do and talked him through the process.
In the morning before she went off duty, 'N' went in to say goodbye to 'Sean' and told him she was going home. When she finished speaking he put out his hand to touch her arm and tears rolled down his face.
- Contractures and the 'tone'/spasticity associated with ABI causes considerable discomfort and pain. This is not well acknowledged and managed by decision makers.
A real life story: A young man, non speaking in a NH, is interpreted as having severe pain by family and therapists. His arms are bent and when he is in pain, his hands push up into his face, which shows distress. With an expert therapist and gentle movement, he is able to 'let go' and often gives a long sigh (a fairly common non verbal communication of relief). Nursing staff, however refuse to acknowledge the level of pain fall in to their category of and so he was not receiving regular pain relief.
- 'Philip' suffered a severe brain injury when he was 19. He came to the NH when he was 20, about 10 months after Chris. By that time staff had a fair idea of how to look after a person like him. 'Philip' had pressure sores and significant medical problems. Within a year or so, he was much better, getting out and about, and interacting with staff and family, and his parents (with others) made a decision to take him closer to where they lived to a new NH. Good handover.
His parents soon realised they had made a decision which they now say is the worst they have ever made. 10 months later, they took him out of the NH and admitted him to a private hospital with horrific pressure sores and malnourished, having lost a large amount of weight. He was never to fully recover from the alleged inappropriate care.
'Philip' lived in 2 acute and subacute facilities (not NH) in the next 4 years neither of which seemed to have the expertise or interest to give him the environment and care he needed. An example:
A doctor who treated him for over a year told his mother that he was not aware of where he was or what was happening and so decisions were made accordingly. On the other hand, friends and family testify that 'Philip' was well aware of what was happening and when someone interacted with him, was

most responsive, smiling and chuckling at jokes, attentive to news and someone reading to him.

In April 2004, 'Philip' had medical complications, was admitted to a hospital and a decision was made to treat him palliatively. He was very angry. On 8 May, weakened but aware, a friend and his mother took him home for the first time in 3 years. 'Philip' was obviously pleased to be home, listening to family conversation, the dogs he loved.

The next morning, 'Philip' deteriorated unexpectedly and died. He was 27.

At his funeral, held at the NH where he lived with Chris, many people from across the sector acknowledged the failure of the system to meet 'Philip' as person and his needs.

'Philip' remains an inspiration and motivation to many that his life and spirit must not be in vain.¹⁴

Examples with Chris:

- Some time ago, a general practitioner remarked to Mary, "Seeing Chris and what has happened, it haunts me now that I and my colleagues have placed young people with severe ABI in nursing homes to lie with their limbs becoming contracted and/or to die, believing there was no hope and no awareness or cognition (ability to understand their situation) Can you begin to imagine being in such a situation?"
- Friends have been invaluable in building an objective picture of Chris – most families/carers are on their own and regarded as subjective- 'wanting to believe'
- When a specialist approved a cut in Chris's funding for therapy a few years ago, I argued on the basis of his cognition. He said, 'You are his mother and subjective. I need objective evidence, but I will listen'. At that time the therapists provided the evidence, but I bought a camera and have since used visual images to tell the story. That same neurologist has since used pictures of Chris in presentations since.
- Some time ago, a man brought shower chairs to trial for Chris. Chris and I were waiting with the man as the therapists discussed the suitability etc. I said to him, Chris hears and understands but is unable to speak or see. He looked at me and then at Chris with pity and I knew he did not believe me. I said that some of his friends have told him he is sitting on a gold mine if he ever does get to talk, as they have told him so many of their secrets. At this Chris laughed, and the man looked aghast as if he had seen a ghost. Seeing is believing!
- Some years ago, I requested a review of Chris's anti epilepsy medication because he was very drowsy and unable to respond, and we thought the medication may be a contributing or main cause. A consulting neurologist was with us for about 10 minutes during which Chris was drowsy. A sympathetic man, obviously affected by Chris, I sensed he thought, Poor thing. She is his mother and needs to believe he is there. He said, 'If he is stable, why would you want to change?' However he agreed to alter the medication and the difference in Chris was remarkable – improved alertness and responsiveness

Examples from YP with ABI and non speaking who are now able to communicate.

- Julia Tavaloro, after a stroke at 32, spent 14 years in New York hospitals, deserted by family and everyone believing she was vegetative, until a therapist noticed she was looking up for Yes. In her book, Julia tells what it was like for her in this situation.¹⁵

¹⁴ See note 3 'still the doors are open – writings of life' Part of Philip's story appears in this book.

¹⁵ Tavaloro Julia and Tayson Richard, "Look Up for Yes" Penguin 1997. Julia had a stroke at 32 years of age. She spent the next 14 years in New York hospitals with everyone believing she was vegetative until a therapist noticed she was looking up for Yes! Her story is a powerful insight in to her experience, and that of others.

- Airlie Kirkham also tells of 'How it feels ... to be in Coma'¹⁶. **See Appendix One**

Decision makers at all levels, including bureaucracy and politicians, often do not know the reality and plight of people they are making decisions for or the context in which they live. At the National Conference for YPINH in 2003, the 450 participants included a great cross section of people from every state and territory, from aged care and disability services, service providers, bureaucrats, politicians, medicos, allied health, advocates, etc. and several YPINH and their families and carers. Papers were presented by a large cross section. See www.ypinh.org.au It was the first time that many had met a YPINH!
We need to work together to address YPINH with ABI

Brain injury can happen to any one of us at any time

HYPOXIC ABI: OUTCOMES AND WHAT IS POSSIBLE - LITTLE IS KNOWN

In the past, most people with severe brain injury died. Because of recent advances in medical science, some people with very severe brain injury (often hypoxic) now survive and these form a small emerging new disability group about whom little is known. Chris has a hypoxic ABI.

Examples:

- In The Age 1998, Professor Ross Harris was reported as saying, "Would you believe that nowhere in the world can you get any statement about what happens to people after they've had a severe acquired head injury?"¹⁷,
- Associate Professor Dr Barry Rawicki said in 2002 in Melbourne, that while outcomes can be generally predicted for a focal ABI, with present technology, it is impossible to predict outcomes for a person with hypoxic ABI.¹⁸
- At the National Conference of the Australian Rehabilitation Nurses Association (ARNA) in Brisbane in 2003, Mary Nolan was key note speaker on 'YPINH – an Australian Experience'. When asked what ARNA members wanted, I was told that nurses wanted to know what happens to YPINH with severe ABI (and hypoxia). They either see YP with severe ABI early in rehabilitation facilities or such people are not deemed rehabilitative and often moved to NH.
I used images of Chris to illustrate the journey 1996-2003. Images speak louder than words and nurses were very impressed and moved by Chris's obvious progress, ability to interact and respond, and the glimpse of what can be for a YP with severe ABI.
This is a professional group with considerable expertise and their opinion carries weight.

Disparities

Most disability groups have an organisation such as the MS Society and Scope (formerly the Spastic Society) working with them, who are able to drive advocacy, research and funding approaches etc. There is no comparable body or organisation which caters specifically for

¹⁶ See note 9 *How it feels ... to be in a coma* The Age 6 January 2004. Airlie Kirkham, 38, from Adelaide, speaks of her experience of 6 years in a 'locked in' state where she was unable to communicate or move following a serious car accident

¹⁷ The Age 19 December 1998 John Fairfax and Sons. When Professor Ross Harris, Professor of Pain Management and Rehabilitation at Sydney's Royal North Shore Hospital was funded to head the initial stages of a study to try and quantify the level and rate of recovery in the years after a severe head injury, he searched unsuccessfully through international literature. "Would you believe that nowhere in the world can you get any statement about what happens to people after they've had a severe acquired head injury?"

¹⁸ 2002 Rawicki Associate Professor Dr Barry said while outcomes can be generally predicted for a focal ABI, with present technology, it is impossible to predict outcomes for a person with hypoxic ABI. Victorian Brain Injury Recovery Association (VBIRA) Conference 2002

people with ABI. Headway Victoria is an information and advocacy and support organisation and a member of Brain Injury Council of Australia.

In March 2001, it was estimated that 72,800 people in Victoria had varying degrees of ABI¹⁹.

That number, I understand, is similar to the number of people with Intellectual Disability (ID) in Victoria. The number receiving disability supports services however is very different – People with ABI receive 4% of Disability Support Services while people with ID receive 66%. This is listed in Appendix Two of the Victorian State Disability Plan 2002-2012.²⁰ I use this not to take in any way from people with ID but to illustrate the reality for people with ABI.

I have been told by people from both cerebral palsy and intellectual disability sectors that we, with or supporting those with severe ABI, are where those two groups of people were 40-50 years ago. But, hopefully at a different starting point in attitudes to disability!

Another disparity is the difference between people who acquire a brain injury that is compensable, e.g. in a road accident and covered by Transport Accident Commission, (TAC) in Victoria, and those like Chris who are non compensable.

I know 2 men, one in late 20's and the other in his 50's with severe ABI and high needs living at home. They have 21 and 24 hours of paid active care per day in addition to the care provided by dedicated and loving family members. Both also receive medical, therapy, food, continence needs, equipment, etc for their ongoing care needs. In addition, their homes have had major alterations and each has a vehicle for transport.

MULTIPLE REPORTS AND STUDIES HAVE BEEN DONE IN VICTORIA OVER THE YEARS, including the previously mentioned ABI Strategic Plan 2001. Two of particular relevance to this group

- **A recent report is "Young People with ABI less than 65 requiring nursing home level of care" May 2003 Prepared by Fyffe, McCubbery and Honey** (A project funded by Disability Services Division, for Victorian Department of Human Services as part of the ABI Strategic Plan 2001)
Recommendations in the Fyffe report include YPINH having greater access to disability services from which they were previously excluded -- because they were in federally funded Aged Care! Preventing YP going in, better quality of life for those in NH and getting people out.
- **In 1996 the ABI: Slow to Recover Program (ABI: STRP)** was established by the Victorian State Government for young people with very severe acquired brain injury with NH levels of care who are non compensable. This is a unique program in Australia and from its original target of 100 people in 1996, has, in 2004 enabled 190 young people with ABI to receive services for therapy/rehabilitation and support with no real increase in budget - \$5 m/year. Most funding goes to clients – admin costs are low.
This program extended the 'window of recovery' for these people from 6 months to 2 years – an innovative move at that time in 1996. It is now acknowledged that improvement can

¹⁹ ABI Strategic Plan Page 3

²⁰ Appendix Two Victorian State Disability Plan 2002-2012 page 49. Disability Services Division, Victorian Department of Human Services September 2002 See www.dhs.vic.gov.au/disability

"Current Supports and Services for People with a Disability which include accommodation, day programs, personal care respite, aids and equipment.

Percentage of people accessing Disability Supports and Services by Disability Type 2001, Of a total of 14,382 people Intellectual disability 66%, Physical disability 13% Sensory disability 5 % neurological impairment 4%, other disability 8% and those with ABI made up only 4% of those receiving such supports.

continue 10 years and beyond given appropriate care, environment and resources^{21, 22}.
There is scant data and knowledge about this group, but ABI: STR is one group which has some data.

The ABI: STRP is presently being reviewed on both clinical and administrative levels.

The Clinical review first cut of data indicates high to extreme levels of stress in carers. The Draft of the Administrative Review (December 2003) created considerable concern in the sector and among families. A primary concern is the tension between the acute sector wanting to get new people in hospitals on to the program and those (like Chris) who will require ongoing support. **Without additional funding, it is difficult to see how this can be resolved. Another concern is the impact of inappropriate accommodation and environment on YP with ABI.**

While families have criticisms, there is unanimous agreement that this program has been of great benefit to YPINH with ABI, and without continuing support, they will deteriorate. Those who are without funding are a comparative example (but with only anecdotal evidence)

The final Report (with Recommendations) was presented to the Reference group on 10 June and will be taken forward by 3 divisions of DHS to the 3

State Ministers of Aged Care, Health and Community Services. It has to be signed off by the three!

WHILE ALL YPINH ARE DISADVANTAGED, I HAVE TRIED TO DEMONSTRATE THAT THOSE WITH ACQUIRED BRAIN INJURY (ABI) ARE PARTICULARLY VULNERABLE.

²¹ Undated about 1996/7 Graffam Dr Joe, Mr Peter Stebbins, "Report for TAC *The Future of Support for Acquired Brain Injury; Changes in our Understanding of Recovery, Changes in our Understanding of Support Needs, Changes in Service Models, Wider System Implications*". School of Disability Studies Deakin University Unpublished. "The presumed window of recovery for people with acquired brain injury is at least five years in duration (with evidence to extend the recognised length of time)"

²² 2001 Cameron Catherine, Pirozza Sandy, Tooth, Leigh. *Long-term care of Younger people with severe acquired Brain Injury: Appropriateness of Aged Care Facilities*. University of Queensland; Brain Injury Association of Queensland. Improvements can continue 10 years and beyond give appropriate care etc.

SECTION FIVE : 2001 – 2004 CREATING AWARENESS – WORKING TOGETHER FOR YPINH. THE 'BIG PICTURE'

Federation Parade and Inability Possability (IP). In early 2001, after Chris's Yes, a small group came together to plan and build a float for the Federation Parade to highlight the plight of *YPINH with ABI*. In May 2001, a crowd of 300,000 in Melbourne watched the Parade. The group defined their central message as INABILITY POSSABILITY. Moved by what they had experienced of the isolation of YPINH with ABI, they continued to meet and have since become an incorporated organisation, INABILITY POSSABILITY Inc working for YPINH with ABI.²³ In 2001, IP formed and continues to support an Association of YPINH with ABI, families and friends, and are in contact with 30 YPINH with ABI across Victoria. In April 2004, IP launched the second edition of their book, 'still the doors are open – writings of life' a compilation of writings about YPINH with ABI²⁴. Chris and Mary Nolan are founding and active members.

Formation of Consortium for YPINH. In September 2001, a group of concerned people from various organisations and family members (including Mary Nolan) met in Melbourne to discuss how to work together for YPINH. That group became known as the 'Consortium for YPINH'. The first Project was the 2001 Federal election and a successful email campaign resulted in the Democrats and Labour Parties including the YPINH in their Policy Platforms for the first time.

National Summit for YPINH. In May 2002, the Consortium for YPINH organised a National Summit about Young People in Nursing Homes (YPINH) in Melbourne. Mary Nolan was key note speaker, 'The Human Experience'. This one day event attracted 180 people across all sectors and from every State and Territory in Australia. Agreement was reached on a Call for Action and one of the structures proposed was a National Advocacy Alliance.

National Advocacy Alliance. Over the next months, the Consortium for YPINH led the formation of the National Advocacy Alliance and now has engine rooms established in every state and territory of the Commonwealth. These engine rooms work at state and local levels to raise awareness of the issue in the broader community, and aim to develop choices for YPINH and their families with regard to accommodation and care needs. A national email network links people and informs. Contact: ypinh@headwayvictoria.org.au²⁵

Human Rights Awards - Human Rights and Equal Opportunity Commission (HREOC). In December 2002, two people received high commendations in different sections of the Human Rights Awards (with different judges) for their work to raise awareness of the issue of YPINH. They were Cath Dwyer for her program with Chris's friends and others on Triple J radio in July 2002, and **Mary Nolan in the community section for her 'Ground breaking and pioneering work in bringing the issue of young people in nursing homes to public attention'**. This brought the issue of YPINH to this arena for the first time.

In 2003, Catherine Sullivan, Producer, and John Collis, Senior Reporter, for 7 Network's Sunday Sunrise, were nominated in the Television Category of the Human Rights Awards for their two programs in 2003 in which they highlighted the injustices experienced by people with disabilities, and their families, because of the crisis in the system of community care in Australia.

²³ Inability Possability Inc See www.inabilitypossability.org.au Ph. 0409 171 089
Email: secretary@inabilitypossability.org.au

²⁴ 'still the doors are open – writings of life' Book available from Inability Possability Inc PO Box Carlton 3054 Vic
Send cheque or money order for \$19.95. Final pages of book outline Chronology of Achievements and Statement of Purposes

²⁵ Headway Victoria – Acquired Brain Injury Association Inc. A001862E for information and advocacy
www.headwayvictoria.org.au

National Conference for YPINH 16/17 June, 2003, the National Advocacy Alliance met for the first time at the National Conference for YPINH, "Unlocking Potential", at the Grand Hyatt, Melbourne (organised by the Victorian Consortium). Nearly 450 people attended from across Australia and NZ, including representatives of peak bodies, media, family members, 30 YPINH from the age of 17, bureaucrats, service bodies, aged care, health, rehabilitation, disability services, politicians, etc. This was not an easy group with which to find consensus! **Many, including decision makers, had never met before been with people from other areas or any YPINH.**

But in recognising differences, agreement was reached:

- To continue to work together at all levels and with the wider disability movement to enable these young people their basic human rights and choice in where they live.
- And to take possible action with the Human Rights and Equal Opportunity Commission.

People spoke of the Conference as very moving and powerful²⁶.

Media. The issue itself and a range of personal stories have elicited a broad cross section of media coverage. See web site www.ypinh.org.au . Latest media:

21 May – Herald Sun front page, Radio stations, Chris and Mary on Melbourne TV news Ch 9 and 10,

22 May – Herald Sun + Editorial, Age,

Chris and Mary have been involved in print, radio and television media.

YPINH -- persons, diverse and scattered

'YPINH' are individuals and social persons like any of us, and just as unique and diverse as any similar group of 'able people'. Disability is 'normal'. YPINH have normative needs like any of us. They also have *particular care needs* and they are scattered across the country in NH, many close to whatever family they have left. Most are profoundly isolated with no friends.

The issue is complex and there is no one simple solution.

ACTION AT GOVERNMENT LEVEL –COMMONWEALTH AND STATE.

I understand there are presently two joint ongoing Commonwealth/State projects for YPINH – both set up some years ago and continuing to present. They are Cyril Jewell House at Keilor, Victoria, for people with MS, and the YPINH Project in WA.

In 2002, Commonwealth Aged Care opened the Innovations Pool to submissions to enable YPINH to move out of Aged Care. This relies on partnership between Commonwealth and State Governments and means the State has to take responsibility after the two year part funded period by Federal Government. It does not seem to enable YPINH with higher levels of needs that is ACAT RCS Category 1 or 2²⁷(such as Chris whose story follows) to be considered. In practice some State Governments have indicated they will not participate because of the limited funding. Two years is unrealistic for people like Chris who require life time support.

The first *'two pilot programs to assist young people with disabilities to live in more appropriate home environment than aged care homes'* were announced on 28 May 2004 by Minister Julie Bishop Minister for Aging²⁸. These are two projects for people with MS in

²⁶ See www.ypinh.org.au for further information and Conference papers. Ph. 03-9482 5655

²⁷ Aged Care Assessment Tool Resident Classification Scale (ACAT RCS)

²⁸ *'Pilot to help younger people out of aged care homes'* Media release The Hon Julie Bishop MP Minister for Aging 28 May 2004

Victoria initiated by the MS Society Victoria. They have been funded jointly by Commonwealth and Victorian Governments under the Innovations Pool. This is the first of its kind and involves about 20 people with MS – 3 moving out of NH and others being prevented from moving in to NH.

YPINH are one of 5 priorities of the State Disability Administrators.

I would argue that the sub group of YPINH with severe ABI and non speaking remains the most vulnerable, and 'hardest'. And they are unable to speak for themselves.

SECTION SIX: AGED CARE NURSING HOMES ARE INAPPROPRIATE²⁹ AND UNABLE TO MEET THE SPECIAL NEEDS OF YPINH WITH ABI AND NON SPEAKING – INADEQUACY OF FUNDING.

Many NH try to do their best. For Chris, a core group of staff at HMcCH have been quite heroic and have developed expertise second to none with Chris and others like him. Chris is the youngest resident and one of those who has lived there longest – 8 years.

However, Aged Nursing Homes remain inappropriate and unable to meet the special needs of YPINH and especially those with ABI who are non speaking.

As well as what I have attempted to demonstrate so far in this Submission, our experience over the past 8 years with Chris and others raises reasons including:

- **Attitude to the future and all that entails is a constant issue at all levels. Frail elderly come in to NH to appropriately 'let go of life' while YP with ABI are trying to engage again with life and people.** Those entering high care facilities are increasingly frail, often suffering with dementia, and recently it was cited that 40% now die within the first 6 months.³⁰ NH are places where most elderly, while living in the moment, are *appropriately letting go of life*. And, as one of Chris's visitors said, 'The sights and sounds and smells are of life winding down'. A young person with ABI who has 'woken up' from coma after weeks or months is trying over the following years *to re-engage with life and people. The two attitudes (and, 'cultures') are in opposition... This means a clash of culture and attitudes permeating all levels.*
- **It is *not* just a matter of different generations** – Chris has formed significant friendships with some residents and grieved when they have died. Constantly coping with dying and death is very distressing for YP and family/friends. 13 men died in Chris's 4 bed room in the first 4 years he was in the NH. He wept for the 3 or 4 who had become close friend and attended funerals.
- **An Appropriate environment (social, physical and emotional), care and support are vital for the YP with ABI.** Ylvisaker and Feeney write, '*Long term outcome is influenced by pre-injury factors, injury related factors, and post-injury factors, including the availability of acute rehabilitation, and long term supports, long term outcome, particularly in the area of social and behavioural adjustment. including supportive families, schools, work places, and social networks. Studies of children and adolescents have shown that the quality of family and social environment to which the child returns profoundly influences. Similarly, adults who return to highly supportive families, friends, enjoy a profound advantage in outcome over those who return to challenging and non- supportive life circumstances that would place them at risk without the added complication of disability caused by injury.*'³¹.

²⁹ See n 3 'still the doors are open-writings of life' – a compilations of writings about YPINH with ABI from YP, friends, family, professionals.

³⁰ ABC 774AM radio Mary Barry April/May 2004

³¹ Ylvisaker, M and Feeney, T. "Collaborative Brain Injury Intervention: Positive Everyday Routines, Singular Publishing group, 1998. pp41 and 51:

"It is well established that identical brain injury lesions in different people can have importantly different consequences, due to individual differences in neural architecture and to potentially major differences in the individuals themselves, including their age, pre-injury knowledge, skill, personality, and resilience, and their support systems after the injury. Similarly a given lesion in one individual can have importantly different consequences in the context of different life circumstances. Thus wisdom dictates caution in predicting outcome from knowledge of the lesion alone.

A simple example- normal conversation – life blood for Chris – few able to have normal conversation.

- **Friends and family find it very difficult to visit a YP and keep an optimistic attitude³², and most YPINH with ABI are left with no friends.** *'Hard to keep an attitude that Chris is now well, not dying, at the end of his life'* – a friend
- **'Blank Slate'** There are examples where the YP who is non speaking after a few years has no-one who knows him/her, and so becomes someone isolated with no past identity – no-one knows what he liked or disliked, and there is a helplessness to support and motivate. He/she becomes a 'blank slate' as it were, and frozen in time.³³
- **Boredom, loneliness and depression are rife.** Motivation is critical for a YP to move back in to life after such catastrophic injury and this is very difficult to sustain in the environment of aged care despite the best efforts of dedicated staff
- **It is acknowledged that a young person with ABI has significant needs over and above the average aged person at the same category level.**³⁴ I was told by one Manager that 'YP with ABI take from other residents'. How I wish it were not so. **There is no assessment tool for YPINH** – the Aged Care Assessment tool is the only one available
- **YP with ABI have special care and therapy needs which require funding for therapists and attendant care and training and consistency of staff.**
- **Non Speaking persons of any age are most vulnerable**
 - YPINH with ABI who are regarded as 'not there', as previously described in Section Four, are at particular risk of having decisions made for them by people
 - who do understand and/or believe they are functioning or aware and able to understand. Many of these decisions have profound and serious implications both day to day and long term.
 - **Few carers/staff have training and/or ability to observe, interpret and respond to the non verbal communication of the YP who is non speaking.**
 - **Staff are constantly under time pressure to respond to residents and the non speaking 'silent' person who cannot call for him/herself is often left when there are competing demands.**

Long term outcome is influenced by pre-injury factors, injury related factors, and post-injury factors, including the availability of acute rehabilitation, and long term supports, including supportive families, schools, work places, and social networks. Studies of children and adolescents have shown that the quality of family and social environment to which the child returns profoundly influences long term outcome, particularly in the area of social and behavioural adjustment.

Similarly, adults who return to highly supportive families, friends, enjoy a profound advantage in outcome over those who return to challenging and non- supportive life circumstances that would place them at risk without the added complication of disability caused by injury.

Finally the individual's psychological reactions and coping style influence outcome in obvious ways (Hinkeldey and Cirrigan, 1990; Moore and Stambrook, 1992) those who manage to retain an optimistic orientation towards their life and its possibilities are likely to achieve a level of personal success."

³² See note 3 writings in *'still the doors are open – writings of life'*

³³ See note 30 Ylvisaker

³⁴ Northern Metropolitan Region ABI Strategic Plan 2000

- ***A YPINH with ABI has a normal life expectancy but a narrow margin of health and so small problems need to be addressed before they compromise health and consequently cause further impairment and handicap.*** Examples: pressure care, chest care, spasticity patterns triggered and/or exacerbated by infection and pain, contractures. NH staff do not have this expertise and need access to expertise of therapists and experienced medicos.
One young man has been confined to bed for years due to contractures and consequences arising from lack of intervention early after ABI when he was 17.
- **The Aged Care System is in crisis and funding is simply not adequate for the aged. YPINH 'fall between the cracks' and are powerless and voiceless victims.**
- **Duty of care vs considered risk taking.**
Example: Some time ago on a warm afternoon, a friend took Chris for a walk in his wheel chair to the nearby park. After a great time together, they returned laughing and both a bit sweaty. The Charge Nurse immediately reprimanded the friend, who left feeling angry and powerless, and ordered that Chris not be taken out again if the temperature was over 25 degree C, and his immediate return to bed.
It took some discussion and negotiation to reverse that order and to acknowledge that Chris as a young man gets sweaty anyway. What might be inappropriate for an older person is a joy for Chris as a man in his 30's. Fortunately the friend could see the problem and continues to visit.
What is a risk and/or appropriate for an 80 year old is not necessarily the same for a 30 year old!
- **Pain management for this group is little understood.**
- **Participation in community, social and Quality of life issues³⁵.**
- **Funding is simply inadequate**

'CULTURES' OF ACUTE CARE, AGED CARE AND DISABILITY SERVICES

A friend's recent opinion/summary of the different 'cultures' is revealing, and gives some insight in to why YPINH with ABI and requiring life time support find themselves where they are:

Acute Care is about getting people well and out of hospital – discharge!

Aged Care is about end of life and no outcomes

Disability Services are generally built around people with a disability from birth. YPINH mostly have an acquired disability – little planning/place in the system for those with high needs who acquire a disability and little done to address their particular issues to enable them to live life as it is.

WHERE DO YPINH WITH ABI FIT?

³⁵ Storace Keith 'Quality of Life of people with an Acquired Brain Injury Living in Nursing Homes: Contributions of perceived Social Support and Psychological Well Being' 2003 Unpublished Research Project Australian Catholic University. Storace compared two groups – those living at home and those in NH, both with moderate to severe ABI. (It does not include those living in other situations such as group homes). Storace concludes P 29, 'The results of this study highlight a significant difference exists between people with a moderate to severe ABI living in NH and similar people living in a home environment with at least one primary carer in relation to quality of life, perceived social support, and psychological well being. Results also conclude that perceived social support and psychological well being account for a significant variation in quality of life'

SECTION SEVEN: CRISIS IN INNER CITY AGED CARE ACCOMMODATION IN MELBOURNE AND IMPACT ON CHRIS AND OTHERS - A THREAT OR OPPORTUNITY?

The present crisis in the inner city in the greatly diminishing availability of aged care places due to organisations closing and/or moving their aged beds to outer suburbs is very disturbing for the aging and for communities of the inner city generally. In November 2003, the State Minister for Aged Care, Gavin Jennings, met with the Mayors and CEOs of 6 inner city Councils to discuss this crisis.³⁶

As a young person with ABI who has lived almost 8 years in an inner city NH which will move in 2 years, **this situation is terrifying for Chris, family and friends.** All we have built up over this past 8 years is at risk - a body of expertise across allied health sectors, a partnership approach to eliciting Chris's choices and in care, accommodation and decision making, as well as social inclusion in the local community. In addition is the maintenance of a strong network of involved and committed friends many of whom, despite very busy work and personal lives are still committed to finding time for Chris. Despite everyone's best intentions, the reality is that few friends would be able to visit and involve Chris if he were living in an outer suburb.

Another aspect to consider is the loss of many hours of gratuitous care that Chris receives from family and friends and also dedicated therapists and staff.³⁷

Some YPINH with ABI who have moved to outer region, where there is little or no knowledge/expertise, have suffered serious consequences. As well as being socially isolated, alleged inappropriate or inexperienced care has resulted in the health and well being of YP being severely compromised with greater handicaps and often necessitating acute hospital placements of varying durations. This results in increased costs in the longer term. One young man, a friend of Chris, died recently.

In an outer suburb, not only would Chris be without the people, staff, therapists and medicos who know him, but he would be socially isolated, away from accessible venues, and unable to meet prohibitive costs to access others. (I have not costed a taxi fare to the city from Eltham or the availability of a taxi. Another factor is the extra time, probably 2 hours, he would have to spend in a wheel chair) As a non speaking person with a normal life span, this descent in to dependency and isolation is terrible to contemplate. Chris is a 'doer' and wants to live life and contribute. As Jeremy Smith said on

Channel Nine News "Nowhere to go" on 21 May, 2004, "Chris is not at the end of his life. He's made a decision to live. He could have died."

The promise of superior physical accommodation does nothing to compensate for the social loss and dissemination of the body of knowledge and experience of people who have become specialist in communicating with and caring for Chris and others like him.

Research indicates that lack of social support and social isolation is detrimental for health and well being for all of us.³⁸ For Chris social support is vital and this social support is generally much less available than it is for most of us, see references below.

³⁶ 'Leader' newspapers November 2003.

The Victorian Senior December 2003

³⁷ French, Michelle paper in which she included the cost of 'gratuitous care' in planning for life time support for people with ABI at Victorian Brain Injury Recovery Association (VBIRA) Conference Melbourne 2003

³⁸ The Melbourne Times 12 November 2003 P 8/9. " 'Social events...are good for mental, physical and social health. .. and 'lack of social support and social isolation is an important risk factor for heart disease...' VicHealth is promoting the benefits of stronger social ties.

Michael Kendrick says: *"It is generally recognized that a key predictor of human well being is social support. That is actually one of the best theories in human service"*³⁹

Professor Roger Rees; *".. recovery from brain injury has much to do with re-learning, effective social interaction and attainment of selfhood, than with physical healing. It's our experience that people with brain injury learn to communicate again with their close social network. This enhances confidence and eventually facilitates inclusion in the wider community. The key to developing communications skills is sustained social interaction which must be planned, supported, focused and never left to chance'.. 'Within a supported community, we observe that a narrative evolves. This narrative engages the communication skills of each person... these narratives must continue for the duration of a person's life so that no person succumbs unnecessarily to the definition of disabled selfhood imposed by others. The language of touch, of hope, the visual images ... and the words and music that surround them, are all used in self-reconstruction' ' We're inspired by the achievements of people with ABI who are helping us to improve our understanding of the factors influencing recovery.'*⁴⁰.

In a presentation at the National Conference fro YPINH in 2003, we presented our own experience and learning of the critical value of social support in 'Chris, Mary and Friends',⁴¹

Professor Roger Rees, also writes of the 'Value of Humour in Rehabilitation and Learning'. Most people like Chris are very isolated, and loneliness and depression are the norm.

In addition, the recent clinical review of the ABI: STR Program indicates high to extreme levels of stress in family members/carers of those young people with severe ABI.

We go to great lengths to ensure that people who are buried alive physically under buildings or earth slides are brought out if at all possible. Can you imagine suddenly finding yourself 'buried' in a profoundly disabled body and communication system? And, unable to speak or move?

**'Climbing back' slowly over years to engagement with life and people, and to some sense of security? And then faced with being re-located away from all who know and can understand you and with whom you interact?
This is what Chris and we face.**

Chris and others like him demonstrate the power of the human spirit and have a courage, perseverance and sense of humour which can be inspiring. They have much to teach us. But they need us to 'listen' and give them voice and a place.

³⁹ Kendrick Michael Proposed Overall Title: Influences and Catalysts for quality of service in a technocratic environment. Edited presentation to Victoria Dept. of Human Services Staff Melbourne 14 September 1999 *"It is generally recognized that a key predictor of human well being is social support. That is actually one of the best theories in human service."*

⁴⁰ Ockham's Razor Radio National 27 October 2002 "Recovering from Brain Injury". Professor Roger Rees Department of Disability Studies Flinders University Adelaide. *".. recovery from brain injury has much to do with re-learning, effective social interaction and attainment of selfhood, than with physical healing. It's our experience that people with brain injury learn to communicate again with their close social network. This enhances confidence and eventually facilitates inclusion in the wider community. The key to developing communications skills is sustained social interaction which must be planned, supported, focused and never left to chance'.. 'Within a supported community, we observe that a narrative evolves. This narrative engages the communication skills of each person... these narratives must continue for the duration of a person's life so that no person succumbs unnecessarily to the definition of disabled selfhood imposed by others. The language of touch, of hope, the visual images ... and the words and music that surround them, are all used in self-reconstruction' ' We're inspired by the achievements of people with ABI who are helping us to improve our understanding of the factors influencing recovery.'*

⁴¹ 'Chris, Mary and Friends' presentation by Mary Nolan with friends Chris McLeod and Eileen McCormack at National Conference YPINH 2003. Chris became emotional when I quoted him, 'Mims, my friends are very important to me' See www.ypinh.org.au

SECTION EIGHT: WHAT DO WE WANT AND WHAT WE ARE WE DOING AS FRIENDS AND FAMILY WITH CHRIS TO SEEK THE WAY AHEAD?

At times it can seem hopeless and just too big. We get so tired and dispirited! But, as I read Margaret Fulton quoted recently, 'If you think you are too small to make a difference, try spending a night in a room with a mosquito!'

Searching for 'the model'

Over these 8 years, I have visited facilities in 4 states and O/S and researched 'models' and met with many people who have expertise in particular areas. I was looking for the expert or 'model' who had the answer. While this has given me a great breadth of experience, refining my sense of what might be needed, and access to resources, I have found no 'model' which places someone like Chris as person in/of community at centre.

I articulated the difficulty some time ago as Chris needing something between the so called 'social' and 'medical' models, both of which are backed by people who believe each is right. I was delighted to find this tension referred to in the World Health Organisation International Classification of Functioning, Disability and Health 2001 and another way ahead being proposed. It is described as a 'bio psychosocial' model - whatever that means!⁴² The significant aspect for me is the acknowledgement that **another way is needed**. Integrating the two and finding another way seems, however, a huge challenge systematically.

In Melbourne March and May 2004, I attended forums with Michael Kendrick⁴³ who uses a personalised planning process and system of support which can be adapted for people with different needs. Michael also uses the notion of Right Relationships⁴⁴ of Buddhism as a basic philosophical underpinning of all levels. This is similar to the Christian, Love one another. Michael Leunig says this well, "Love one another. It is as simple and as difficult as that".

Using our experience and knowledge of Chris.

Over the past 8 years, we have knowledge of what Chris wants, what works in caring for Chris and interpreting his communication—although he might dispute that at times!

Communal/partnership decision making processes have been used from early days at St Vincent's with the group of 4 in 1996, and since then at HMcCH to develop the 'Approach' which includes the Primary Care team and Case management team, and more informally with friends. (The partnership way is also that of Inability Possability and the Consortium for YPINH). I place great value on the wisdom in a group of people who draw on experience of Chris, listen to his voice and themselves and others, exchange, discern and seek the way ahead. The 'wisdom' released in such a group is more than any individual. Making decisions, and review are part of that process of listening, reflection, action on personal and group levels.

While I am happy to be a 'mosquito', this is too big for us. To be authentic and true to the person of Chris as person of relationship in moving forward, then we need to do this together to enable truth for Chris at this time to emerge.

⁴² WHO ICF 2001 No 5.2 page 20. 'Medical and Social models' ... "The medical model views disability as a problem of the person directly cause by disease, trauma'... which requires medical care provided in the form of individual treatment by professionals....., The social model of disability, on the other hand, sees the issue mainly as a socially created problem and basically as a matter of the full social integration of individuals in to society." "ICF is based on the integration of these two opposing models. In order to capture the integration of the various perspectives of functioning, a 'biopsychosocial' approach is used. Thus ICF attempts to achieve a synthesis, in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective"

⁴³ Kendrick, Michael, USA See: <http://www.kendrickconsulting.org> See web site for papers including "When People matter more than Systems" December 2000 Keynote Presentation for Conference Albany NY

⁴⁴ *ibid.* "Right Relationships" Queensland Advocacy Incorporated Newsletter Part A and Part B March and July 2000

As Chris McLeod said in the triple J radio program in July 2002, "It's like Nolsey is 'locked in' twice. The first where he is unable to speak we can't do much about, but the second of being 'locked away' in a NH we should be able to rectify"

MEETINGS OF FRIENDS AND FAMILY TO DEFINE: WHAT DOES CHRIS/DO WE WANT?

The first two meetings of Friends and Family with Chris (18 people) took place on 16 June and 21 July, 2004, to define What does Chris/do we want? The group will meet monthly and aims to complete the process and formulation in November.

We meet as a group of people who each know Chris, hold a perspective of Chris as person and his 'voice' and with each having expertise on professional and personal/relationship levels to define, "What does Chris/do we want?" Each also has links with networks of friends/family.

The starting point is Chris and our experience and understanding of him, and our ability to communicate with him to ascertain what he wants.

Some characteristics needed for a home for Chris

- places the whole person of Chris⁴⁵ as social (and spiritual) being at centre⁴⁶, with family and friends involved
- enables Chris to participate interdependently in community/society with his care needs adequately addressed
- enables him to feel safe⁴⁷ ⁴⁸ and to feel valued (this is different from being told you are safe and valued!). To love and be loved.
- incorporates a philosophy and practice of partnership of care⁴⁹ at all stages from planning to old age, ⁵⁰
- in a social and geographic location close and accessible to family/friends and age appropriate venues
- based on the experience and learning to date for Chris and others especially at HMcCH^{51, 52}

⁴⁵ Questionnaire re Chris and accommodation Mary Nolan 2000 (22 replies)

⁴⁶ Nolan, Mary. "Community Participation for the Young Person with an ABI and non speaking: Fact or Fiction?" Australian Cerebral Palsy Conference 2000

Nolan Mary "Young People in Nursing Homes: an Australian Experience" Australian Rehabilitation Nurses Association (ARNA) National Conference 2003

⁴⁷ 2003 Boardman, Ian. Public Advocate Qld at Nat. Conference YPINH June 2003 "Safe guards – What keeps vulnerable people safe?" Formal service systems cannot by themselves ensure safety. People keep people safe. See: www.ypinh.org.au/index.cgi?tid=51

⁴⁸ September 2003 Melbourne Fratangelo Pat, Executive Officer of the Onondaga Community Living in Syracuse, New York. "Circles of people in people's lives – like spokes in a wheel – develop circle to be strong – circle keeps people safe – people keep people safe – not organisations"

⁴⁹ Hudson Dr Rosalie, "Personhood, Community and Death: The Transforming Power of Relationships in the Nursing Home" Doctoral Thesis 2000

⁵⁰ Ylvisaker M and Feeney T 1998 *Collaborative Brain Injury Intervention: Positive Everyday Routines*. San Diego: Singular Publishing Group, p41: "Some of the most effective rehabilitationists with whom we have worked over the years had little knowledge of brain function and dysfunction but were experienced teachers and great problem solvers, with an abundance of the attributes that define effective helping professionals: intuitive, optimistic, charismatic, respectful, and enthusiastic about collaborating with other professionals and everyday people". Having said this he goes on to urge "those in the rehabilitation of people with ABI to acquire a rich understanding of brain function and impairment... For this reason professionals with specialized insight into the consequences of specific types of injury can be invaluable contributors to collaborative teams of people seeking to provide effective and efficient interventions for people with ABI."

- incorporating an *ongoing* integrated, rehabilitative and collaborative approach⁵³ so that all work together to identify, unlock and maximise his potential for life and living.⁵⁴
- with evaluation and research as integral components

While this Project is focussed on Chris, we believe, like all we have done in this past 8 years, it is likely to have application for other YP with ABI. At least, to offer some framework and reference for others. With a unique group of competent people who have journeyed with Chris since 1996, we are hopeful of an 'outside the usual framework' solution which will focus on Chris as one of this group of people, YPINH with ABI is needed.

Perhaps a brief personal reflection will assist understanding

I invite you to look back to 1996 on your own personal life and reflect on the events/circumstances that have occurred or been thrown up, the decisions made and the changes in you as person now and your inner and outer worlds.

As we have changed in response to life during these past 8 years, that process will continue for us as we journey on in life knowing that each of us has undiscovered aspects of ourselves and others still to be revealed.

While Chris's life holds events we might rather have not happened, he has shown remarkable courage and determination in adapting and living life as he is now. Like us, some of his priorities have changed, qualities have been honed, etc. He still has dreams and aspirations, and hope in the future and what he is called to be and do – his vocation as person of community. Dan uses the notion of 'vocation' in "A Night with the Great Dirty Three"⁵⁵

⁵¹ Stringer, K. *Study into Accommodation Needs of young people with ABI requiring nursing home levels of care* (1999) Melbourne Citymission

⁵² Nolan, Mary "Accommodation Unit for Young People with an Acquired Brain Injury" (2000) Melbourne Citymission. In this study, the experience to that stage was outlined and a Unit attached to the NH was proposed.

⁵³ *Australian Rehabilitation Nursing Competency Standards for Registered Nurses 2003*. Describes 'rehabilitative approach' underlying all to maximize a person's potential. Australian Rehabilitation Nurses Association (ARNA)

⁵⁴ Ylvisaker, M and Feeney, T. "Collaborative Brain Injury Intervention: Positive Everyday Routines, Singular Publishing group, 1998. pp41 and 51:

"It is well established that identical brain injury lesions in different people can have importantly different consequences, due to individual differences in neural architecture and to potentially major differences in the individuals themselves, including their age, pre-injury knowledge, skill, personality, and resilience, and their support systems after the injury. Similarly a given lesion in one individual can have importantly different consequences in the context of different life circumstances. Thus wisdom dictates caution in predicting outcome from knowledge of the lesion alone.

Long term outcome is influenced by pre-injury factors, injury related factors, and post-injury factors, including the availability of acute rehabilitation, and long term supports, including supportive families, schools, work places, and social networks. Studies of children and adolescents have shown that the quality of family and social environment to which the child returns profoundly influences long term outcome, particularly in the area of social and behavioural adjustment.

Similarly, adults who return to highly supportive families, friends, enjoy a profound advantage in outcome over those who return to challenging and non-supportive life circumstances that would place them at risk without the added complication of disability caused by injury.

Finally the individual's psychological reactions and coping style influence outcome in obvious ways (Hinkeldey and Carrigan, 1990; Moore and Stambrook, 1992) those who manage to retain an optimistic orientation towards their life and its possibilities are likely to achieve a level of personal success."

⁵⁵ See note 3 "Since then (1994) much has changed. ... Both Nolesy and the Dirty Three remain defiant and graceful. Both share an understanding and acceptance that expressing, or at least trying to express, the sometimes unfathomable well of human emotion remains their difficult vocation" written by Dan Meagher (wrongly attributed to Darby)

The important thing now is to assist him to move on at this stage with living life as person! What does he want to do with his life? A home is basic – a right we take for granted. It may not be for ever – can we say we will live where we are for ever?

While most YPINH with ABI are profoundly isolated, and so Chris is not 'typical' in having friends still involved, he and we are acknowledged to have 'broken ground' in many ways. Chris does suffer

isolation and deep loneliness. Having glimpsed what is possible, we now want to assist him to live life as he is. As with all we have done, this is likely to have application for others or at least to offer some 'vision' and framework/reference against which others can plan for their loved ones.

And let me give the final word to Chris whose words now seem prophetic.

An extract from the Eulogy Chris (then 19 years old) gave at his sister Lou's Funeral Mass in May 1988 seems pertinent now:

"Lou was not a saint and with her typical frank honesty she would have been the first person to admit it too. She was an imperfect human being as we all are struggling with life and its challenges. Lou faced a great challenge in her life. One might question the justice of the illness which was part of her. However as a woman who lost her daughter from an illness said to me, it's easy to focus on the illness but Lou was gifted with a unique courage and determination which at times could be inspirational. Her guts, honesty and resourcefulness will remain with us forever'.

SECTION NINE: IDEAS TO GOVERNMENT FOR SOLUTIONS – PRINCIPLES AND IMMEDIATE – HOW WE CAN BE INVOLVED IN A SOLUTION OUTSIDE THE KNOWN

PRINCIPLES TO MOVE FORWARD

- 1. YPINH need political will, commitment and resources to change the situation on both short and long term.**
- 2. The starting point must be the person and so YPINH with ABI/carers, Government and NGOs need to work together**

3. YPINH need choice.

YPINH -- persons, diverse and scattered

'YPINH' are individuals and social persons like any of us, and just as unique and diverse as any similar group of 'able people'. Disability is 'normal'. YPINH have normative needs like any of us. They also have *particular care needs* and they are scattered across the country in NH, many close to whatever family they have left. Most are profoundly isolated with no friends. **The issue is complex and there is no one simple solution.**

There is little vision of what can be – most are rendered powerless, dependent, conditioned to pessimism and hopelessness. Some may choose to remain in the NH close to family with funding for equipment and recreation.

People need to have say in what they need and how they will live life. Decision makers and Service providers can change direction and focus and move people away from any social grouping. Some security of tenure, and voice in what happens.

- 3. It seems Cross Government cooperation is necessary to address YPINH.**
- 4. Disparities e.g. between compensable and non compensable, addressed. Example: a no fault Insurance scheme for all people with acquired disability.**
- 5. Philosophy and Practice of Partnership where all voices are listened to and structures to facilitate are put in place and reviewed regularly**

IMMEDIATE ACTION

- 1. We want to be involved in way forward for Chris and would like a Pilot based on the Project and solution we identify in the What does Chris /do we want? THIS SOLUTION WILL BE OUTSIDE ANY KNOWN SOLUTION. A small facility in inner city Melbourne to build on the learning and philosophy and practice of partnership in Care at HMcCH and also the body of expertise that has been built up in staff, therapists, carers, local community, friends and family.**

Two suggestions for funding of this:

- One way in which Commonwealth and State could cooperate is for the aged care funding for Chris to be transferred to a more flexible home solution such as a joint project with Victorian Government. This would not cost the Commonwealth any more but would offer a better quality of life for someone who will require life time support, and enable to State to top up to an appropriate level. (Precedents mentioned are WA YPINH and MS Keilor, Victoria)
- Another way is to expand the Aged Care Innovation Pool guidelines beyond the present 2 years to allow joint Projects with State to get YPINH who require life time support out in to more appropriate settings.

- 2. We believe that the sub group of YPINH with ABI and non speaking are at particular risk within the present system at all levels. It seems that this group and ABI needs something like the radical approach used with Mental Health some 10 or so years ago.**
- 4. Changing attitudes and assumptions used in making decisions for YP with ABI is an urgent need.**
- 5. Acknowledgement of what YPINH with ABI and their families/friends have to cope with and that they are breaking down under:**
 - the impact of a loved one with catastrophic ABI and all the uncertainty
 - little understanding of very severe and particularly hypoxic ABI
 - the pessimism inherent at all levels in the system
 - the ongoing trauma of seeing a loved one treated as if he/she is a 'vegetable' and suffer through being 'housed' inappropriately in a NH, with inadequate funding
 - trying to understand and find the way through the maze of complexity of a system which is fragmented and simply not working.
 - High to extreme stress and hardship at many levels – social, financial, emotional, psychological, health.

Mary Nolan on behalf of Chris, John and Mary Nolan

1 August 2004

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APPENDIX ONE HOW IT FEELS . . . To be in a coma

Author: As told to Michelle Hamer

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Airlie Kirkham, 38, spent six years in a ``locked-in" state, where she was unable to communicate or move, following a serious car accident.

I was a Japanese language teacher in Adelaide. I had a very satisfying and happy life. I loved teaching, enjoyed music and friendships. I had a wonderful boyfriend and friends from university where I had completed my Arts and Music degrees, and a graduate Diploma of Teaching.

When I was 25, I was driving along a country road to a kitchen-tea party. I somehow found myself on an unknown dirt road. Going round a bend, I skidded into the path of another car (I was not speeding but my wheel may have caught the gravel on the edge).

I was in a **coma** for several weeks with severe brain injury, several broken bones, and had my spleen removed. I was not expected to live. After the **coma**, I was very sleepy, but I remember my parents sitting by my bedside every day and night. I wasn't in pain.

Eventually I went to the Julia Farr Centre to begin rehabilitation. I was there for more than six years. I recall big wards, many people who rushed around looking too busy to be friendly. The rooms were full of people like me, accident victims who were unable to do more than pass the time.

My time seemed to drag. There was little to do except watch TV and I couldn't see that properly. They put us to bed so early. How could we complain? Few of us could talk.

At times people would come and talk over me, not to me. Many thought I was vegetative, because I could not communicate or respond, or even move a muscle. I could move my right leg a bit but that was all.

I felt locked in because I couldn't speak or even write. The ``locked-in state" is a diagnosis applied to people who demonstrate alertness and wakefulness but who cannot respond. I could see everything and everyone. I knew who they were. I could hear people talking about me and saying things I didn't like. I would have liked people to talk to me properly as I could hear and understand.

I felt very frustrated, at times angry, because often no one would come near me nor talk to me, only mum and dad, my visitors or therapists. I was frustrated because I couldn't make decisions, or tell people what I wanted. I wasn't in control of myself. I

learnt to wriggle my finger hoping someone would notice and talk to me. I wanted to tell everyone: "I'm still here. Inside me is Airlie. I have so much to say."

The seasons came and went. I made some progress but I was unable to assert myself or respond. I was bound by ritual, routine, habit, culture.

I set my sights on being able to communicate. Couldn't I do that? I had been an articulate person, once. I could be that again.

My right arm recovered some movement after about five years, then a miracle occurred. At mum's request, the occupational therapist was asked to see if she could help me learn to write again. She made me a special penholder and glove. The first word I wrote was, "Airlie". Then I answered a question from the therapist who asked if I wanted to learn to write again. I wrote, "Yes. I need your help."

At first I wrote like a kindergarten child. It took me more than six months to learn writing again and I have not stopped since. The pen and its holder are my lifeline to the world.

I proved I was not vegetative but locked in. Now I was free at last. I felt I had the whole world opening up in front of me. I wrote down all my questions. I had so much to catch up. I felt wonderful as I could talk to Mum and tell her all my problems and feelings. It was like a door opening, and all my thoughts came pouring out. I felt so excited now I could talk to everyone.

I felt so happy that I could tell everyone that my brain could still think, that I wasn't stupid or unable to understand. Even today, people still often say to mum, "Can she understand what I'm saying?" I felt so much love in my heart for God, who had answered the prayers to survive and to help me communicate again, and for my family who had looked after me so well. I turned to writing poetry. Poetry has always inspired me.

To other families with relatives in a similar situation, I would say, never give up hope: be strong and determined. They need to communicate to their loved one because even people in a **coma** can hear and think. They are sensitive to their environment and need to be aware of their family's strong hope and faith.

In 2002 I enrolled in a refresher subject of Bachelor of Music, and with the support of my carer and mother, achieved a distinction.

In 2003 I enrolled part-time for Bachelor of Music, Honours Musicology and achieved good results. I still need total support for daily activities, I still cannot walk and talk, but I can think and communicate using my pen and a delta talker machine which speaks for me. University is the best thing in my life at present. What the future holds, I don't know.

The path that I tread now is not the path I would have chosen. But I will walk it, with the strength of God whose steadfast love has never failed me.

How it feels to be in coma age 6.1.04/ABI/doc