Dr Joan Tierney *MBBS FRACGP*

---

91 Princess St
Kew 3101

Correspondence:
PO Box 269
Kew 3101

Provider No: 0482549J

Ph: 9852 9363
Fax: 9852 9343
Mob: 0407 512 669

Report to: Senate Enquiry into Aged Care
From: Dr Joan Tierney MBBS. FRACGP
Date: 30th January 2005
Re: (c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements.

Background: I am a GP with more than 25 years experience in the medical management of residents of aged care facilities, and in particular young people with acquired brain injuries. Some of my medical experience includes:

- 16 years as a principal of a group practice primarily caring for socially disadvantaged patients in inner Melbourne. This included a large number of patients in aged care facilities, many of whom were under 65 years. Those experiencing conditions such as homelessness, chronic mental illness, drug and alcohol problems tend to develop aged related medical problems and need for supported care at a much younger age to the general population. They are also in very high risk categories for acquiring a brain injury from falls, assaults, overdoses, alcohol abuse etc.
- The last 6 years as a "special interest" solo general practitioner in the community management of young people with severe acquired brain injury.
- 1996 – I conducted a research project on outcomes and satisfaction with outcome for a group of 18 young people with extremely severe acquired brain injuries requiring nursing home levels of care who had access to a slow stream rehabilitation program[1]
- 2002 – I conducted a further follow up research project on this group 10-15 years post injury to ascertain if outcomes in terms of accommodation, relationship status and satisfaction with outcome had been durable[2]
- Since 1992, I have been a sessional medical consultant to the Brain Disorders Program, Austin Health. This is a statewide service for those 18-65 years with acquired brain injury or neurodegenerative disorders associated with serious mental illness including severe behavioural disorders. In 1997, as part of the mainstreaming of psychiatric services in Victoria, 20 of the inpatient beds were designated as transitional nursing home beds under a dual funding arrangement. Majority of admissions to these transitional NH beds follow breakdown in accommodation and the bulk of these are young people who were admitted to aged care facilities in the early stages of recovery post acquired brain injury.

I consider this extensive clinical experience in the management of young people with acquired brain injury requiring nursing home levels of care, places me in a unique position to comment on the appropriateness of accommodating young people with disabilities in aged care facilities.

---

[1] Tierney, J: Rehabilitation following very severe brain injury – patient/family satisfaction with outcome (1996) International Perspectives in Traumatic Brain Injury, Proceedings of the 5th Conference of the International Association for Study of Traumatic Brain Injury. 373-377 Australian Academic Press

[2] Tierney, J: No hope…who says? A follow up study of life after the vegetative/minimally conscious state. Brain Injury(2003) 17(Supp 1):103

What do we know about the recovery process following severe ABI?

- Neural repair and reorganisation of neural networks are possible following ABI[3]
- Both enriched environment and access to rehabilitation are essential to optimal outcome
- Recovery may continue over a very prolonged period of time[4] [5]
- The recovery process needs to be carefully shaped to optimise outcome and to prevent the development of negative sequelae such as intractable challenging behaviours, permanent contractures etc
- Development of challenging behaviours frequently accompanies the recovery process, especially in the early years post injury but with skilled management can be shaped towards a positive outcome[6]
- The main means of learning after severe brain injury is by procedural learning ie learning by doing - having frequent opportunities for repeated practice of the same activity in exactly the same way
- Long-term accommodation and support needs are frequently not known for at least 3-5 years post injury
- Acquired brain injury affects not just the individual but the whole family. Family and close others must also undergo a recovery process in order to adapt to their altered family system, to reform relationship with the injured family member and to reform a stable family system albeit with altered roles and family dynamics.[7]
- Survivors of catastrophic brain injuries can go on to lead productive lives within their families and communities[8]

What do we know about neural recovery following severe ABI?

- Neural repair and reorganisation of neural networks are possible following ABI. There is now a large body of literature to support these theories of neural plasticity.
- Environment is a potent determinant of neural recovery and outcome.
- It is well recognised in the scientific literature that animals housed in enriched environments have better outcomes post injury than those housed in standard laboratory conditions.

---

[3] Elbert T, Rockstroh B. (2004) Reorganisation of human cerebral cortex: the range of changes following use and injury. Neuroscientist 10(2):129-141

[4] Tate R.L: Long-term outcomes and support needs after traumatic brain injury: a 20-26 year perspective. Proceedings VBIRA Workshop(2003) Hospital to where? Exploring strategies for developing and maintaining new life for those with acquired brain injury

[5] Ponsford, J: Outcomes ten years following traumatic brain injury. Paper presented 26th Annual brain Impairment Conference, Sydney, April 2003

[6] Tierney, J: Behaviour disorders after prolonged coma: the beginning of the search for meaning. Paper presented 3rd Conference of the International Association for Study of Traumatic Brain Injury Tokyo 1993

[7] Butera-Prinzi F, Charles N: Telling it how it is: Family experiences of living with acquired brain injury. VBIRA Workshop 2002: Possibilities…Probabilities…Outcomes for life – Exploring long-term outcomes following traumatic brain injury. P26-29

[8] Tierney, J: No hope…who says? A follow up study of life after the vegetative/minimally conscious state. Brain Injury(2003) 17(Supp 1):103

- Enriched environments have been shown in scientific models to both switch on and maintain the process of neurogenesis and neural network repair.[9]

- Enriched environment combined with specific rehabilitative therapies result in better outcomes than either enriched environment or rehabilitation alone

- Cortical reorganisation – the injured brain is capable of significant reorganisation of its cortical circuitry[3] but it is reliant on specific environmental and experiential conditions for this to occur in an adaptive manner.

- Stress and pain are potent inhibitors of neurogenesis and adaptive neural repair

- Components of an "unenriched/standard environment" for a laboratory animal include
    - living in a standard laboratory cage with limited space to roam,
    - well fed, watered and clean
    - no meaningful activities
    - little opportunity for voluntary or skill related exercise.
    - socially isolated

Characteristics of an enriched environment to facilitate neural recovery in humans:[9]

- Stress free
- Pain free
- Behaviourally relevant and meaningful
- Abundant informal learning opportunities that are meaningful and rewarding
- Maximisation of learning opportunities by identifying the individual's specific learning modalities, implementing "Errorless Learning" techniques, and opportunities for repetitive and daily practice of behaviourally relevant and meaningful tasks[i]
- Skill acquisition shaped within limits of frustration tolerance
- Sensory stimulation associated with learning and reward
- Opportunities for voluntary exercise and freedom of movement
- Opportunities to learn new skilled motor movement and repetitive daily practice of these skills
- Socially stimulating to reduce psychosocial stress and to provide opportunities for behavioural shaping
- Retained skills identified and kept in use
- Avoidance of sensorimotor experiences likely to lead to dysfunctional reorganisation

---

[9] Tierney J. Environmental enrichment: putting evidence into practice. VBIRA Workshop 2004 Making New Connections – exploring the interface of neuroscience and clinical practice. P57-63

[10] Tierney J. Environmental enrichment: putting evidence into practice. VBIRA Workshop 2004 Making New Connections – exploring the interface of neuroscience and clinical practice. P35-43

Clinical characteristics of young people with severe ABI requiring nursing home level of care:

Most young people with severe ABI are admitted to aged care facilities while they are still in a vegetative or minimally conscious state. Discharge to an aged care facility usually occurs as soon as the person is medically stable so they do not require high level acute hospital care and they have not been accepted into an acute rehabilitation program. Discharge is often as early as 4- 6 weeks post injury, though I have had one patient discharged from acute care to an aged care facility within 2 weeks of sustaining an extremely severe acquired brain injury.

The person at this stage of recovery is usually:

- Non verbal with no reliable means of communication. – no means of communication does not mean the person has no awareness
- Inability to safely swallow, sometimes unable to even safely swallow own saliva.
- All nutrition, hydration and medication administered by Percutaneous Enteral Gastrostomy/Jejunostomy (PEG/PEGJ) tube.
- Bite reflex may be intense making oral care extremely difficult Bite reflex may result in severe lip biting.
- High risk of aspiration from own saliva or regurgitation of PEG feeds
- Spasticity - There is likely to be high levels of spasticity in limbs. Spasticity may increase in the months post injury to such high levels that nursing interventions can only be done with great difficulty. The patient is likely to experience pain with most attempts of movement for either positioning or personal care.
- Tonal patterns may make bed and chair positioning difficult, for example extensor tone may make it difficult to maintain airway or safely swallow saliva. Managing tone is complex.
- A grossly exaggerated startle reflex may be present triggered by even minor sensory stimulation such as sound, touch or movement. Following the startle reflex patients may remain locked in spastic patterns of movement and position.
- Voluntary movement even to blink eyes voluntarily may be impossible due to severe dyspraxia (inability to independently organise and execute the components of a movement)
- May have visual impairments eg cortical blindness common after hypoxic injury
- May need high level pressure care and specialised pressure mattress
- Specialised equipment needs in excess of any available in and aged care facility such as customised bed, high level pressure care mattress, customised wheelchair, customised shower chair etc.

Now consider the complexity of providing an environment to facilitate neural recovery for a person who is so severely and multiply disabled with the above characteristics, placed in an aged care facility.

The medical and nursing care needs for such a patient are extremely complex, labour intensive and beyond the training and experience of most medical and nursing staff working in the aged care sector. Therapy needs at this stage of recovery are enormous. Interventions usually need to be of a very specialised nature and need to be carried out in a consistent manner by all carers/staff interfacing with the patient to be effective.[11] There is only a small number of specialist ABI providers with experience and expertise in working with this very complex patient group.

As each aspect of the person’s recovery changes so do the environmental supports to enable recovery to continue in an adaptive manner. It is a process of continued clinical evaluation, skill building and monitoring to ensure the therapy and environmental supports in place are supporting the process of recovery.[12] Complex behaviour management requiring a high levels of 1:1 intervention and supervision may be required as progress continues.

If management is not optimum a maladaptive recovery trajectory may ensue. This includes the development of challenging behaviours or physical problems such as permanent contractures.

A mismatch of patient needs and available environmental supports and resources in an aged care facility commonly results in accommodation breakdown after prolonged periods of distress for all parties.

Why aged care facilities are not appropriate for young people with disabilities associated with acquired brain injury:

It is quite appropriate for the young person with an acquired brain injury to be discharged from acute hospital care as soon as clinically indicated. It is not appropriate to discharge such a patient to an environment that is unable at many levels to provide an environment to facilitate recovery.

Aged care facilities do not have the resources, expertise or culture to provide an optimal environment to support neural recovery. The care requirements of a young person recovering from severe ABI are well in excess of the highest level of nursing care provided in any aged care facility no matter how skilled the facility in providing optimal levels of care for the aged.

Staff resources are stretched to the limit and the numbers of trained nursing staff are at a minimum in most facilities. With all the best will in the world there is no possibility for one individual resident to have the luxury of each personal care intervention done over a prolonged period of time in a slow and controlled manner that enables the person to learn ways to participate in the movement and relax out of their spastic pattern.

Even when staff are trained by specialist therapists, in ways to enable the resident to assist with movement or participate in communication and choice making, staff rarely have the time, energy or motivation to stop, slow down and provide interventions in a way likely to assist the resident learn new skills.

---

[11] Darcy M, French M, Mackey J: Integrated Therapy. VBIRA Workshop 2001: Coma to Community - towards best practice with severely and multiply disabled people with acquired brain injury P17-22

[12] Tierney J: Returning to Life – Recovery from catastrophic brain injury. VBIRA Workshop 2001: Coma to Community - towards best practice with severely and multiply disabled people with acquired brain injury. P3-6

An aged care facility does not have the staff resources at a nursing, medical or therapist level to provide even the most basic interventions to support recovery in this patient group.

Aged care facilities are designed to provide end of life care – they are not designed physically or culturally to provide for the needs of a young person trying to reclaim their life following catastrophic brain injury.

I have had families report feeling pressured by staff and branded “bad parents” when they have requested treatment for their young relative with a sudden medical condition. Staff expectation is often for palliative care only to be given for a potentially life threatening but treatable condition seemingly unaware of the amount of joy the person still experienced in living albeit with disabilities.

Some young residents of aged care facilities in Victoria are fortunate to obtain Slow to Recover funding packages for additional specialist therapy and specialised equipment needs.

Most younger residents of aged care facilities, however, do not have access to funding for specialised equipment to provide for their basic needs and comforts. It is not unusual for me to see patients who have not been out of bed for years because they do not have a customised wheelchair, some have been having bed baths for years because they do not have access to customised shower chairs or suitable shower trolley or bath. Available Hoist Slings often don’t fit to enable safe and comfortable transfers from bed to chair etc

Family often wish to be actively involved in their relative’s care and rehab program. This often causes considerable conflict between staff and family. Many facilities do not appreciate family members or specialist external service providers actively participating in care decisions and care planning. Conflict often arises around who is the main stake holder in “duty of care” issues. I have experienced families denied access to facilities except for designated periods of the day, and family members who are not allowed to speak to any members of staff except for the Director of Nursing – not particularly helpful if you find your husband with limited communication skills in extreme discomfort and the DON is not available.

Children have a particular aversion to visiting a parent in an aged care facility. Aged care facilities are not designed for the needs of young children, let alone children who are trying to cope with a parent in such a dramatically altered form.

Most aged care facilities cannot cater for the intimacy needs of a spouse or partner.

It is difficult enough to get a young person’s basic physical needs met in an aged care facility, it is well nigh impossible to get any of their psychosocial needs met.

Many young people in aged care facilities are unable to access any appropriate means of sexual expression.

A young person’s friends usually don’t not like visiting an aged care facility and even if they did, there is usually no space for “hanging out’ with friends without disturbing other older residents’ sensibilities.

It is common for young people in aged care facilities to lose all contact with friends and often with all but the most committed family members because relationships become impossible to maintain within the confines of an aged care environment.

Those young people without STR funding are usually denied access to case management services and access to other DHS Funding packages for things such as recreation support. Disposable income is so limited after fees are met that very few have any money to pay for maxi taxi fees let alone the attendant care support needed to safely access community.

This is just a brief snapshot of why aged care facilities are not appropriate for young people.

Survivors of catastrophic brain injuries can go on to lead productive lives within their families and communities. In my long term follow up group of patients surviving vegetative and minimally conscious states, only 2 out of 18 eventually moved to an aged care residential facility after undergoing a lengthy period of slow stream rehabilitation. The 2 who moved to aged care facilities were dead at follow up 10-15 years post injury, both from aspiration pneumonia. Those who returned home or moved to specialised small community residential units, are still continuing to make functional gains. Several of these young men have since married and become the very proud parents of young children – a long way from a life in an aged care facility.

Some insightful responses from survivors interviewed in the study exploring patient and family satisfaction with outcome –

“I’m so happy my parents didn’t listen to the doctors and put me in an old people’s home. I would never have got better there because I would have got SO SO ANGRY. I know I’ll need help for the rest of my life but it’s much better to be home.”

“I was so frightened when I started to wake up and realise something real bad had happened to me – I needed my parents and my brother and sister there all the time to make me feel safe. I used to get really upset when the nurse made my family go”

“Tell people to never give up, which is so easy to do when no one knows you understand everything that’s happening”

“Why would I want to live in a nursing home – I’m not ready to die yet!”

Dr Joan Tierney 30/1/05

Summary -

Young people are frequently admitted to aged care facilities within weeks to months of sustaining a severe acquired brain injury. This group of patients have very specialised care and therapy needs far in excess of the resources available in any aged care facility.

Neural repair and reorganisation of neural networks are possible following acquired brain injury. Environment is a crucial factor in neural recovery. An enriched environment has the ability to switch on the processes of neural repair at multiple levels.

Both an enriched environment and access to appropriate therapy are essential to optimal outcome.

Aged care facilities are not able to provide the environmental conditions necessary to support the process of neural recovery. Even where substantial amounts of additional funding are provided for therapy services within aged care facilities, outcomes are frequently suboptimal. Accommodation breakdown is a frequent occurrence during the early years of recovery following acquired brain injury for young people who reside in aged care facilities, even when large sums of additional funding have been provided though Slow to Recover type funding packages.

A young person with severe acquired brain injury, well medically managed is likely to have a near normal lifespan – Does it make moral or financial sense to manage them from the outset in environmental conditions that are likely to maximise disability, when relatively simple environmental manipulations could maximise potential for recovery and minimise disability and long-term care needs?

There is an urgent need for

1. Transitional care units to provide both the specialised environment and therapy needed to maximise recovery and long-term outcomes following severe acquired brain injury while the person still requires high levels of nursing care but not requiring acute hospital care
2. Development and expansion of a range of long term community based accommodation options and support services. There are already models successfully operating but they are too few in number and none as yet suitable for the person with high medical and nursing support needs.
3. Increased numbers of community based support packages such as Home First and Support and Choice, to support those with moderately high needs in community settings

---