
“Permanent discharge”: Deaths of people under 50 years of age in residential aged care in Victoria

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In June 2007 there were 210 people under 50 years of age living in residential aged care in Victoria, Australia, most of whom had acquired brain injuries. There are an average of 21 deaths per year in this group yet very little is known about the causes of such deaths. While the Coroners Act 2008 (Vic) requires mandatory reporting of “unexpected” and “accidental” deaths, anecdotal evidence and data from the Coroner’s Office suggest that most deaths of people under 50 years of age in residential aged care are not reported. This research presents the cases of three “preventable” deaths, none of which was reported to the coroner and all of which have implications for systemic reform. It concludes that cross-sectoral solutions to meet the complex needs of people under 50 years of age with disabilities in residential aged care are urgently needed as well as monitoring to help us to understand better the needs of young people in residential aged care.

INTRODUCTION

Residential aged care is the only accommodation option for many people with complex needs and severe disabilities who would previously either not have survived or lived for so long.¹ In June 2007, there were 210 people under 50 years of age living in residential aged care in Victoria, Australia.²

Between 1999 and 2005, increasing numbers of people under 50 years of age needing residential aged care were reported to be requiring a high-needs response.³ Most younger people in residential aged care require high care, with 43% requiring the highest level of care. The most common disability for people under 50 years of age in Victorian residential aged care is acquired brain injury (58%) followed by neurodegenerative conditions such as multiple sclerosis (13%) and Huntington’s disease (9%).⁴

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In the title of this article, “permanent discharge” refers to the way the departures from residential aged care are coded by the Victorian Department of Health and Ageing. Death is the single most common reason for permanent discharge for people aged less than 50 years.

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¹ Winkler D, Farnworth L, Sloan S, Brown T and Callaway L, “Comparison of People with ABI Living in Two Accommodation Settings: Shared Supported Accommodation and Residential Aged Care” (2010) 11(3) *Brain Impairment* 313.

² Victoria, Department of Human Services, *Better Living Options for Younger People in, or at Risk of Entry to Residential Aged Care: My Future My Choice Program Progress Report* (March 2008). Subsequent to the completion of this research, the figure for people under 50 years of age in residential aged care has been revised down to 140 people by the Department of Human Services. This figure is yet to be published.

³ Victoria, Department of Human Services, *Creating New Opportunities: Responding to the Needs of Younger People in Victoria’s Residential Aged Care Services* (Victorian Government, 2005).

⁴ Winkler D, Sloan S and Callaway L, *Younger People in Residential Aged Care: Support Needs, Preferences and Future Directions* (Summer Foundation, 2007).

Residential aged care has been consistently acknowledged as providing an inappropriate option for young people.⁵ While people are usually discharged into residential aged care because there are a limited number of established community-based service models to meet high levels of health and clinical care needs, residential aged care services generally do not have the resources or staff to meet the specialised needs of this group.⁶ Residential aged care facilities have a primary focus on supporting frail, elderly people and, as such, have limited capacity to meet the complex physical, social and rehabilitation needs of young people.⁷ While many residential aged care facilities attempt to meet their clients' needs, they are "simultaneously faced with limited resources, poor funding and inadequate training for this specialist area of care".⁸

The shortcomings of the residential aged care model include:

- specialist/technical health/clinical support;
- personalised equipment/ disability aids;
- staff training and development in relation to specialist care requirements;
- community inclusion;
- age-appropriate recreational and social needs; and
- case management.⁹

These facilities do not have the rehabilitation focus critical to the ongoing care of people with an acquired brain injury and research suggests that placement of young adults in this setting can compromise the gains made in post-acute settings.¹⁰

There are an average of 45 "permanent discharges" of people under 50 years of age from residential aged care per year, of which death is the single most common cause.¹¹ The rate of death between July 1999 and June 2005 averaged 21.4 per year.¹² The actual number is likely to be higher as 15-46% of all permanent discharges are to hospital, of which a number will also result in death.¹³ The most recent data publicly available from the Australian Institute of Health and Welfare show that there were 32 deaths in Victoria for people under 50 years of age in Commonwealth-funded residential aged care in the 2008-2009 period.¹⁴

The majority of deaths for people under 50 years of age occur within two years of admission to residential aged care.¹⁵ There is a possibility that people in residential aged care who die within the

⁵ Senate Community Affairs References Committee, *Quality and Equity in Aged Care* (Canberra, 2005); Australian Healthcare Associates, *Investigation of Support Needs and Service Models for Younger People with High Clinical Needs* (Australia, 2007); Morkham B, "Moving Young People out of Nursing Homes" (2004-2005) 3 *Australian Health Consumer* 9; Winkler et al, n 4; Victoria, Department of Human Services, n 3.

⁶ Victoria, Department of Human Services, n 3.

⁷ Stringer K, *Study into the Accommodation Needs for Young People Requiring Nursing Home Level of Care* (Melbourne City Mission, 1999) p 4.

⁸ Cameron C, Pirozzo S and Tooth L, "Long-term Care of People Below Age 65 with Severe Acquired Brain Injury: Appropriateness of Aged Care Facilities" (2001) 25(3) *ANZJPH* 261.

⁹ Strettle B, Bush M, Simpson G and Gillet L, *Accommodation in NSW for Adults with High Care Needs After Traumatic Brain Injury* (Brain Injury Rehabilitation Unit, Liverpool Health Service, Sydney, 2005); Cameron et al, n 8; Winkler et al, n 4.

¹⁰ O'Reilly K and Pryor J, "Young People with Brain Injury in Nursing Homes: Not the Best Option!" (2002) 25(3) *AHR* 46; Stringer, n 7; Colantonio A, Howse D and Patel J, "Young Adults with Traumatic Brain Injury in Long-term Care Homes: A Population-based Study" (May 2010) 11(1) *Brain Impairment* 31.

¹¹ Victoria, Department of Human Services, n 3.

¹² Victoria, Department of Human Services, n 3.

¹³ Victoria, Department of Human Services, n 3; Winkler et al, n 4.

¹⁴ Australian Institute of Health and Welfare, *Residential Aged Care Data Cubes (Client Separations) 2008-2009 Data*, <http://www.aihw.gov.au/publication-detail?id=6442472446&tab=3> viewed January 2011.

¹⁵ Victoria, Department of Human Services, n 3.

first two years are people who were admitted to care with a poor prognosis.¹⁶ However, while degenerative conditions and cancer are likely to account for some early deaths, these conditions do not account for all deaths.¹⁷

Young people with very high care needs living in residential aged care are highly susceptible to secondary conditions that will make them critically ill or result in premature death.¹⁸ A landmark study by the Summer Foundation reported in 2007 that 67% of people under 50 years of age in residential aged care had had an illness or infection in the 12 months prior, with 22% of those contracting chest infections or pneumonia. Thirty-six people had an accidental injury in the 12 months prior to the research.¹⁹

Many of the high risks associated with ill health, secondary conditions or functional losses for people with chronic or disabling conditions are predictable.²⁰ Poor oral hygiene and dental care can increase the risk of chest infections, as can too much time spent lying down because of contractures or lack of appropriate equipment for supported seating.²¹ While there is a high risk of choking due to aspiration of food or oral secretions for residents in residential aged care, there is strong evidence that choking is a preventable hazard.²²

Researchers for the Summer Foundation suggested that many episodes of illness and resultant hospital admissions identified in their study of people under 50 years of age in residential aged care “appear to be predictable and preventable and further research is required to determine if health promotion and preventative measures can improve the health outcomes for this population”.²³

MONITORING AND REPORTING OF DEATHS OF YOUNG PEOPLE IN RESIDENTIAL AGED CARE

Despite the relatively high death rate of people under 50 years of age in residential aged care, very little is known about the causes of such deaths. Population-based epidemiological data on causes of mortality and morbidity in residential aged care are not readily available.²⁴ While the Australian Institute of Health and Welfare holds Commonwealth Department of Health and Ageing data, medical details to indicate the causes of death are not a part of the data set. A cross-referencing with the National Death Index would be required to correlate cause of death with place of death.²⁵

There is no systematic monitoring or reporting of deaths of people in residential aged care, other than what is reported to the coroner as an “unexpected” death. Data sourced from the National Coronial Information Database for this project show that only around one case of a death of a person

¹⁶ Victoria, Department of Human Services, n 3.

¹⁷ Winkler et al, n 4.

¹⁸ Winkler et al, n 4.

¹⁹ Winkler et al, n 4.

²⁰ Sutton J and DeJong G, “Managed Care and People with Disabilities: Framing the Issues” (October 1998) 79 *Archives of Physical Medicine and Rehabilitation* 1312.

²¹ Winkler et al, n 4.

²² Victorian Institute of Forensic Medicine, *Residential Aged Care Coronial Communique* (3 June 2007).

²³ Winkler et al, n 4, p 29.

²⁴ Calver J, Horner B, Boldy D and Bulsara M, “The Burden of Infectious Diseases in Western Australian Residential Aged Care Facilities: A Population-based Record Linkage Study” (September 2006) 11(3) *Australian Infection Control* 79.

²⁵ The Australian Institute for Health and Welfare (AIHW) has access to data that would enable a cohort study to be undertaken to examine the link between deaths in residential aged care and the National Death index. This analysis would require AIHW Ethics Committee approval.

under 50 years of age was reported every year in Victoria for the five years up to 2010.²⁶ This contrasts with the relative frequency of deaths for this group, suggesting that unexpected deaths may be under-reported.²⁷

The monitoring of deaths in residential aged care contrasts poorly with the monitoring of deaths of people in other disability settings in Victoria. The *Coroners Act 2008* (Vic) requires the reporting of the death of a person who, immediately before death, was a person placed “in custody” or “in care” or who “was a patient within the meaning of the *Mental Health Act 1986*”.²⁸ Deaths in mental health units, prisons and in Department of Human Services (DHS) residential care are all reportable. Other reportable deaths are those which appear to have been unexpected, unnatural or violent or to have resulted, directly or indirectly, from an accident or injury.²⁹

The Victorian DHS’s *Adverse Events Management Policy* requires deaths of people with disabilities living in DHS-funded residential care run by community service organisations to be reported.³⁰ The DHS also requires category-one incidents in disability residential services to be reported, as outlined in the *Residential Services Practice Manual*.³¹ This reporting enables DHS to initiate a feedback cycle with analysis and feedback on adverse events at program, regional and service provider levels, enabling the consideration of cross-program and systemic issues.³²

Mechanisms for reporting the deaths of young people with disabilities living in residential aged care are not on a par with these reporting requirements. While the mandatory reporting of deaths in care under the *Coroners Act* and the mandatory reporting of deaths by community service organisations and disability residential services allow for a systematic monitoring and analysis of cause of death, there is no mechanism in place to enable the analysis of deaths of people in residential aged care. Better monitoring and reporting would help us understand whether younger people in residential aged care are dying from “natural causes” or systemic failure, providing information that could be used to inform policy and practice.

POLICY CONTEXT

The 2006-2011 \$244 million Council of Australian Governments (COAG) Young People in Residential Aged Care program was a breakthrough in shared responsibility for young people in residential aged care. It was welcomed by disability advocates who had argued that the needs of this group could not be met without collapsing the traditional boundaries between Commonwealth and State funding and between disability, health and residential aged care.³³ The \$60.4 million *My Future My Choice* program in Victoria provided a comprehensive assessment of all people under 50 in residential aged care, on which basis funding was allocated to either supplement the residential aged care environment or to assist people to relocate into more appropriate accommodation. This was a clear acknowledgment that residential aged care needs additional resourcing and support if it is to provide for the needs of this complex group.

THE RESEARCH

This research examines factors contributing to the “preventable deaths” of people under 50 years of age in residential aged care. Interviews with case managers of people who died form the basis of the

²⁶ National Coronial Information System (NCIS), *Deaths of Nursing Home Residents Aged under 65 Years Reported to a Victorian Coroner 2005-2010* (Report generated for the Office of the Public Advocate, 2010) Table 2.

²⁷ NCIS data obtained for this project in 2010 only includes cases closed following a coronial investigation. There may be cases of relevance that were not included because they remain open.

²⁸ *Coroners Act 2008* (Vic), s 4(2)(b).

²⁹ *Coroners Act 2008* (Vic), s 4(2)(a).

³⁰ Victoria, Department of Human Services, *Promoting Better Outcomes: Adverse Events Management Policy* (Disability Services Division, Victorian Government, 2008).

³¹ Victoria, Department of Human Services, *Residential Services Practice Manual* (2nd ed) (Disability Services Division, Victorian Government, 2009).

³² Victoria, Department of Human Services, n 30, p 9.

³³ See eg Morkham, n 5.

research. “Preventable deaths” are defined for the purpose of the research as those that did not stem from an organic cause relating to the person’s primary condition for which there was a specific prognosis but from a secondary condition or an accident or where the death was due to system failure.

The research provides evidence to support the call from the disability advocacy sector for the ongoing commitment to funding of *My Future My Choice* beyond 2011³⁴ as a way of maintaining oversight of what is happening to young people in residential aged care.

The purpose of the research was

- to contribute qualitative evidence that will help make the case for better systematic monitoring of young people in residential aged care; and
- to explore themes relating to mortality and the level of care able to be provided in the residential aged care environment.

METHOD

Design

A case study approach using unstructured interviews was used in the research. The case study method is based on an in-depth investigation of a single individual, group or event. Explanatory case studies are used to explore causation or to understand underlying principles.³⁵ In this research, themes emerging from the case studies are presented as a preliminary exploration of the issue.

Limitations of the research

The case studies were based on interviews with case managers from community service organisations.³⁶ Where possible, the researcher gained access to case notes and assessment, not seeking to corroborate the findings from case managers with nursing or medical staff of nursing homes as it was highly unlikely, given the focus of the research on “preventable” deaths and the possible legal implications, that facilities would agree to participate. The Office of the Public Advocate does not have the authority to view medical or nursing notes. For the death to be included, families needed to view the death as “preventable” or due to system failure. Initially, the researcher hoped for 10 case studies but after a protracted recruitment period, it became clear that it would only be possible to gain access to three or four cases.

The two main barriers to accessing cases included potential interviewees having left the sector and the difficulty in gaining family consent. Many case managers employed by the *My Future My Choice* program, who would be the most likely people to have close contact with potential subjects, were no longer contactable as most were employed between 2006 and 2008 and by 2010 they were no longer working in these roles. Family consent was difficult to obtain because either the location of families was unknown, case managers indicated that it was not appropriate to ask due to the sensitivity of the issues, or because families refused consent.

Working group

A working group external to the Office of the Public Advocate was established for the purpose of the research. The group comprised a specialist clinician, case manager and operational manager of a community-based disability organisation, a researcher from a specialist research organisation and a carer representative. The group was convened three times during 2010. The group provided expert feedback and scrutiny around ethical issues, as well as providing support with recruitment.

³⁴ See Young People in Nursing Homes Consortium, *Call to Action* (2010), <http://www.vcasp.org.au/site/items/2010/09/88761-upload-00001.pdf> viewed 28 February 2011.

³⁵ Yin RK, *Case Study Research: Design and Methods* (4th ed, Sage Publications, California, 2009).

³⁶ While the researcher sought to recruit health professionals and clinicians broadly, the interviewees were all former case managers with the *My Future My Choice* program. It is likely that they had the closest working relationship with young people who were admitted to residential aged care.

Ethics approval

The Office of the Public Advocate submitted the research proposal for ethics approval to the Department of Justice Ethics Approval Committee in March 2010. Approval was sought to interview clinicians, case managers and health professionals. Approval was given contingent on cases being de-identified and subject to legal considerations being met. Participants were required to sign participant information and consent forms which stipulated that all information gathered in the course of the research would be de-identified.

Participant recruitment

Recruitment of potential interviewees commenced in June 2010 using formal and informal methods. Formal recruitment methods included the distribution of a flier through email networks (eg organisations that had undertaken *My Future My Choice* assessments, community-based organisations that are engaged with disability case management and allied health networks), and the placement of an advertisement on websites (eg Victorian Brain Injury Recovery Association, the Victorian Coalition of ABI Service Providers, the MS Society and Infoxchange). Informal recruitment methods involved the researcher contacting clinicians, case managers and health care professionals working with young people in residential aged care where, through word of mouth, the researcher had been informed of a potential case study.

Selection criteria

Cases for potential interview had to meet the inclusion criteria. The criteria were as follows:

- death occurred within the last five years;
- the deceased person was 50 years of age or less;
- death occurred within residential aged care, or in an acute or respite setting after discharge from residential aged care;
- the interviewee had good knowledge of the person's case, ie they had worked as their clinician or case manager or occupational therapist or in some significant health role;
- the interviewee had reasonable cause to believe that the death may have been preventable;
- the family/significant other had conceptualised the death as preventable; and
- the family/significant other had consented to disclosure of information.

Cases reported to the Office of the Public Advocate during the recruitment period

A total of 22 deaths were reported to the researcher. While all contained elements of systemic failure and many were identified as "preventable" by potential interviewees, only three fully met the selection criteria: see Table 1.

TABLE 1 Total number of deaths reported to the Office of the Public Advocate

Category	Number
Full cases that meet selection criteria	3
Cases that meet selection criteria but where the researcher did not gain family permission	5
Cases that highlight quality-of-life issues in residential aged care	12
Example of death that doesn't meet selection criteria – wrong age	1
Example of death that doesn't meet selection criteria – wrong institution	1
Total	22

In five cases, although they met the key selection criteria, family permission was refused or was not sought due to concerns about family sensitivities or family members were not able to be found. These cases are outlined in Appendix 1.

There were 12 cases of death where quality-of-life issues were raised for people living in residential aged care, which may or may not have contributed in some way to their deterioration and death. A brief description of five of these cases is in Appendix 2. There were two deaths that did not meet the criteria pertaining to age and location.

Cases selected for interview

Four cases studies were selected for interview and three were ultimately included in the research.³⁷ All three interviews included were with case managers working with non-government organisations. All had been working as case managers in the disability field for many years and all had undertaken comprehensive assessments of the deceased for the *My Future My Choice* program between 2006 and 2008. They or their organisations had also been involved in planning and implementing the associated funding packages. Two of the three interviewees were still working for the same community service organisation and one was working outside the sector.

The deaths of all the deceased persons were believed to be “preventable” (eg not directly related to the person’s prognosis). The three deceased persons were aged between 24 and 45 years of age and had lived in residential aged care for between two and six years. All three had *My Future My Choice* funding and one was also had *Slow to Recover* funding. See Table 2.

TABLE 2 Characteristics of deceased

Name	Age at death	Injury or illness	Cause of death	Year of injury	Time in residential aged care	Time in residence where death occurred	Year of death
Mary	44	Intellectual disability and acquired brain injury	Aspiration pneumonia	2004	4 years	6 months	2008
Sheree	24	Congenital condition and degenerative condition	Aspirated vomit and choked	Congenital	6 years	1 year	2008
Chris	24	Acquired brain injury	Aspiration pneumonia	2006	2 years	2 years	2009

Two of the deaths were caused by aspiration pneumonia and one was caused by choking. Each of the deceased persons was at a high risk for choking and aspiration pneumonia due to the aphagia associated with their disability. One had developed significant oral hygiene problems and was PEG-fed, putting her at greater risk of choking.³⁸ A second was also PEG-fed. All participants had communication impairments which made it difficult for them to express their needs in relation to feeding, pain or other basic needs.

In the two deaths caused by aspiration pneumonia, one was reported to have resulted from incorrect feeding. The second was likely to have been related to postural issues and restrictions in movement caused by contractures, although the interviewee was not able to provide this level of detail. In the death caused by choking, incorrect PEG-feeding/overfeeding was identified as the key contributing factor. It is unclear whether the actual cause of death was “failure to respond to resuscitation”, “airway obstruction” or “cardiac arrest”. In all cases, the family and case manager reported that they considered the deaths preventable and due to system failure.

³⁷ One of the four cases selected for interview was dropped after the interview. Initially it had been thought that this death by choking was preventable but the interview revealed that the timing of death was in accordance with the patient’s prognosis and there was insufficient information about how the death occurred. Even though there were some unanswered questions about whether choking could be considered a “natural” cause of death and whether residential aged care was able to provide the palliative support that the patient required, the case was not suitable for inclusion. See Appendix 2 below.

³⁸ Oral Cancer Foundation, *PEG Complication Chart* (March 2009), http://www.oralcancerfoundation.org/dental/peg_complication_chart.htm viewed January 2011.

None of the cases was reported to the coroner. In the death caused by choking, significant others had sought an acknowledgment of fault by the facility. The case manager reported that the facility had acknowledged fault and apologised and that the family had sought no further remediation.

Findings and discussion

Death in all three cases was from choking and/or aspiration pneumonia. This is consistent with the risks in residential aged care for people with high needs.

Pneumonia is a major cause of death in nursing home populations³⁹ and choking is a high risk for many people living in residential aged care.⁴⁰ Swallowing difficulties, a poor cough reflex and difficulties coordinating eating are common in people with cognitive disorders like acquired brain injury.⁴¹ This can lead to aspiration of food into the lungs which can cause airway obstruction and aspiration pneumonia. Factors contributing to aspiration pneumonia include incorrect feeding, PEG-feeding, poor oral hygiene, poor posture and low levels of physical activity.⁴²

Most people under 50 years of age in residential aged care assessed for the *My Future My Choice* program (79%) required high-level care, with 43% requiring the highest level of care.⁴³ The very high needs group are “highly dependent on others for positioning, mobility, communication and meal assistance”.⁴⁴ Risks associated with not attending to these needs are pain, pressure sores, choking and respiratory tract infections.⁴⁵

Themes

The analysis resulted in three main categories and 11 subcategories. These represent the key components pertinent to the death and quality of life leading up to the death of the individuals: see Figure 1.

A summary of the main findings pertinent to death in each of the three main categories follows.

Environment

The care requirements of a young person recovering from severe acquired brain injury are “well in excess of the highest level of nursing care provided in any aged care facility”.⁴⁶ Aged care facilities “do not have the resources, expertise or culture to provide an optimal environment to support neural recovery”.⁴⁷

³⁹ Beck-Sague C, Shailen Banerjee S and Jarvis W, “Infectious Diseases and Mortality Among US Nursing Home Residents” (1993) 83(12) *AJPH* 1739; Bassim C, Gibson G, Ward T, Paphides B and DeNucci D, “Modification of the Risk of Mortality from Pneumonia with Oral Hygiene Care” (2008) 56 *Journal of the American Geriatrics Society* 1601; Brandt H, Ooms M, Deliens L, van der Wal G and Ribbe M, “The Last Two Days of Life of Nursing Home Patients – A Nationwide Study on Causes of Death and Burdensome Symptoms in The Netherlands” (2006) 20 *Palliative Medicine* 533.

⁴⁰ Victorian Institute of Forensic Medicine, n 22.

⁴¹ Welch-West P, Aubut J, Foley N and Teasell R, *Dysphagia and Nutritional Interventions for Patients with Acquired Brain Injuries* (2005), http://www.abiebr.com/modules/modules/5_8_assets/module5.pdf viewed 28 February 2011.

⁴² Welch-West et al, n 41; Weed H, “Enhanced Oral Hygiene Prevents Respiratory Infection in Older Persons in Hospitals and Nursing Homes” (2008) 150(3) *American College of Physicians Journal Club* 5; Langmore S, Skarupski K, Park P and Fries B, “Predictors of Aspiration Pneumonia in Nursing Home Residents” (2002) 17(4) *Dysphagia* 298; Victorian Institute of Forensic Medicine, *Residential Aged Care Coronial Communique* (March 2009); Winkler et al, n 4; Beck-Sague et al, n 39.

⁴³ Winkler et al, n 4; see Australian Institute for Health and Welfare data cubes (ACFI characteristics) which show that in 2008-2009 88% of people under 55 years of age in residential aged care were defined as having high-dependency needs: <http://www.aihw.gov.au/publication-detail/?id=6442472446&tab=3> viewed 2011.

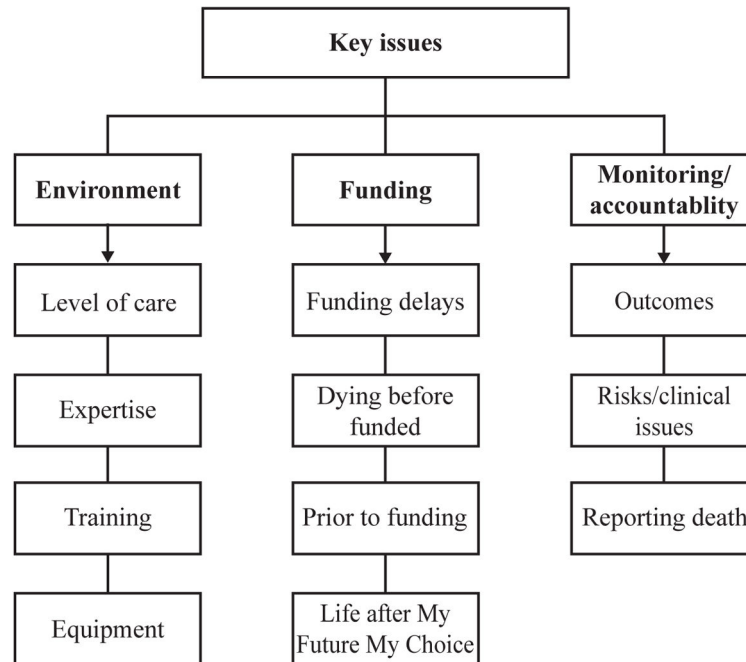
⁴⁴ Winkler et al, n 4, p 48.

⁴⁵ Winkler et al, n 4.

⁴⁶ Tierney J, *Submission to Senate Inquiry into Aged Care* (Victoria, 2005) p 5.

⁴⁷ Tierney, n 46, p 5.

FIGURE 1 Key issues identified



Level of care, expertise and training of staff, the lack of equipment and the time available to support residents were raised in all the interviews. All of the deceased persons had multiple and complex needs that required a specialist expertise not available in the residential aged care environment. Chris, who was 24 when he died, had sustained a catastrophic brain injury resulting in significant physical and cognitive changes and was admitted to residential aged care less than six months after his brain injury:

The staff very early on in [nursing home] really identified this man as just too hard for them. And this was a very common occurrence with many of the young people.

[Case Manager No 1]

Having made significant gains in his rehabilitation prior to entering residential aged care, Chris needed ongoing intensive physiotherapy, occupational therapy and speech pathology in order to continue his recovery:

There's an assumption that when you go into aged care that's it. There was an assumption that it's not about rehabilitation or maintenance of skills. There was this bizarre attitude that we need something extra if we're going to do that kind of work with people.

[Case Manager No 1]

Sheree, who was 24, had a congenital condition and complex needs and died from choking-related causes six months after admission to a residential aged care home. She had oral problems, including ulcers and tooth abscesses, and continual problems with PEG-feeding that do not appear to have been managed well:

At the end of the day she shouldn't have been in a nursing home. She should have been in somewhere where there are young people with swallowing issues who need PEG-feeding with social support there, specialist care to provide it.

[Case Manager No 2]

It appeared that staff may have restrained Sheree in order to administer her PEG feeds:

I don't know whether it was restraint or whether it was to keep her still in order to feed her properly. I don't know whether it was a lack of skill but [mother of deceased's] major message she kept reiterating

over and over again was *they didn't have the skilled staff. They didn't know how to manage [deceased] and her needs.*

[Case Manager No 2]

A 2007 Victorian Coronial Communiqué which reported on deaths from choking in aged care said that choking, although a high risk in aged care, is a “preventable hazard” that is exacerbated by the practice of the person with eating difficulties “being assisted by the least qualified staff, volunteers and/or family”.⁴⁸

Mary, who was 45 when she died, had an intellectual disability and had lived in institutional care all her life. She moved from a community residential unit into residential aged care after an unexplained deterioration, which was later concluded to most likely have been an acquired brain injury. She died in the third residential aged care facility she lived in, six months after a speech pathology report indicated a high risk of contracting aspiration pneumonia. The report stated:

Mary needs to remain on a diet of vitamised feeds and needs to sit fully upright and even tilted slightly forward. She needs to be fed slowly and will indicate when she is orally ready for a mouthful by opening her mouth.

[Case Manager No 3]

The nursing home staff did not appear to have the resources or capacity to manage Mary's need to be fed slowly and to be postured correctly:

And I came in and found her coughing and spluttering and the nurse that was feeding her at the time was actually feeding her inappropriately and we'd already had the speech pathologist to explain to them why she needed to be sat up properly.

[Case Manager No 3]

A lack of time to attend to individual needs was reported in two of the interviews. Chris was developing the skills to eat pureed meals in rehabilitation but in the nursing home, his food was given to him by a PEG because the staff did not have time to help him feed himself. The PEG-feeding subjected him to additional risks, one of which is aspiration.⁴⁹

The lack of time to attend to his needs and a lack of physiotherapy also meant that Chris lost the capacity for independent mobility that he was developing, placing him at risk for complications like aspiration pneumonia and contractures. Six months prior to his admission to residential aged care, Chris was able to use a slide board to transfer himself from the bed to a chair in rehabilitation but quickly lost this skill in residential aged care:

His great achievement was being able to use the slide board with assistance for transfers. Now he flinches in pain when being transferred by hoist having lost all of his previous mobility.

[Case Manager No 1]

Mary's speech pathology report acknowledged that the time needed to feed her in order to reduce the risk of choking may not be available in the nursing home:

I understand that the nursing staff have limited time to feed residents however Mary requires a greater amount of time in order to safely manage her diet. I therefore highly recommend further trained carer time to assist with as many meals as possible.

[Speech therapy report provided by Case Manager No 3]

Shortages of equipment are a constant theme raised by disability advocates as people in residential aged care are not eligible for Victorian Aids and Equipment funding.⁵⁰ People generally have to rely on the facility to purchase equipment or fund specialised equipment themselves. Equipment such as wheelchairs is essential for independence and other equipment, like specialised chairs for sitting out of bed, is critical for correct posturing. Some people under 50 years of age living

⁴⁸ Victorian Institute of Forensic Medicine, n 22, p 3.

⁴⁹ Oral Cancer Foundation, n 38.

⁵⁰ Young People in Nursing Homes National Alliance, MS Society, Brain Injury Australia, *Joint Submission to the Department of Health and Ageing's Review of the Aged Care Funding Instrument* (Australia, 2010).



in residential aged care have received funding for equipment through the current five-year *My Future My Choice* program. However, this program ended in June 2011.

In the case of Mary, who was seated in a reclinable chair and did not have a wheelchair of her own, a supportive wheelchair with head support would have enabled her both to be positioned properly for eating as well as to go outside and on outings. An occupational therapy report, four months before she died, noted that she was at “severe risk of aspirating given her poor positioning”. The case manager reported:

We didn't have the equipment in yet because again it was something that needed to be purpose built so it was going to take a little while for us to be able to get that ... and so they were still very much putting her in one of those princess chairs. She wasn't sitting properly. She got the chest infection. She ended up ... dying from aspiration pneumonia.

[Case Manager No 3]

Funding

There is widespread support for the view that residential aged care does not provide an appropriate model of care for young people and that there are significant service gaps in the level of support and care that is provided.⁵¹ Residential aged care is funded to provide care in the final stages of life, yet many younger people admitted to residential aged care require ongoing clinical care and rehabilitation that is not funded within the setting.⁵²

Prior to the *My Future My Choice* program, funding was not available for people in residential aged care unless they had an acquired brain injury and were eligible for *Slow to Recover*, a program that has been in operation since 1996. Prior to receiving funding, Mary spent three years in residential aged care without any specialised funding support. She had not had any assessments or allied health support and there was no plan to enable her to maximise her independence:

There were no services. She had no equipment, had no one external like attendant carers taking her out, she had no opportunity to re-engage with her friends or day program or anything like that. She had quite literally been cut off from her previous life.

[Case Manager No 3]

Interviewees spoke about the impact of funding delays on participants. This was particularly pertinent in Chris's case. The *My Future My Choice* planning team were notified about Chris while he was still in hospital. He was making significant gains in rehabilitation and there was hope he would receive a quick assessment so that his rehabilitation could continue and he would continue to make improvements:

But we had a real sense that if things can be put in place, it sounds like this man's going to make quite a bit of progress. So, we approached DHS as soon as we heard – in fact we heard through the grapevine – we were planning with someone else out at [name of nursing home] and they said “we've just heard there's a young man coming over to us within the next month or so”. So we approached DHS and DHS said, “yes, we know that this man is going to be a My Future My Choice person but our processes are such that we will need to wait for a referral to come through before you will be able to engage with him and start planning”.

[Case Manager No 1]

Chris's injury occurred right at the start of the new program and delays meant that Chris spent five months in residential aged care without any rehabilitation support before the planners were able to start planning with him:

And in fact it took around three to four months before we actually received approval to plan with this young man. Now, this was the most tragic part because what we saw happening while this delay was occurring was this young man came in certainly with a significant disability but you could actually see

⁵¹ Victoria, Department of Human Services, n 3; Fyffe C, McCubbery J and Honey K, *Young People with ABI Less Than 65 Years Requiring Nursing Home Level Care: Final Report* (Melbourne, 2003); Winkler D, Farnworth L and Sloane S, “People Under 60 Living in Aged Care Facilities in Victoria” (2006) 30(1) *Australian Health Review* 100.

⁵² Fyffe et al, n 51.

contractures happening. Every time I'd come in and visit I'd see this young man shrinking basically, his arms tightening and the staff would talk about the fact that he was becoming stiff and harder to move because he had come from intensive rehabilitation and therapy to nothing. Nothing. There was no physio. There was no follow through. There was nothing. So suddenly this young man was parked, waiting.

[Case Manager No 1]

Chris experienced time delays between approval for funding, assessment and planning and final implementation of his funding package:

Well it was just about a year I'd say because he came into the aged care facility in the July and it wouldn't have been until early the following year that he received the funding. So it was about a year. And you know, six months was too long. Three months was too long for this man. So to have to go through that was enormous.

[Case Manager No 1]

While there were some delays in one of Chris's *My Future My Choice* funding, his *Slow to Recover* was approved just before he died:

Just prior to Chris passing away he also managed to get *Slow to Recover* funding. He had been on a wait list for *Slow to Recover* from prior to, from when he left rehab basically, until a couple of months before he passed away ...

... I don't know how much he got through *Slow to Recover* but I know that it was a very significant amount and we were all floored and we suddenly said, "yes, we can do this now" [but it was] too late.

[Case Manager No 1]

Mary's lack of an appropriate wheelchair meant that she was not able to be positioned correctly and that she was unable to go outside. She died before the wheelchair could be made:

Well I had to cancel the wheelchair when she passed away because it was being made.

[Case Manager No 3]

Once *My Future My Choice* funding was in place, case managers spoke in positive terms about the level of funding provided to recipients and the difference it made to their lives. Mary's funding package was enough to make a difference and was in stark contrast to what was available to her in her first few years in residential aged care:

I got \$20,000 which was largely equipment and a whole range of other things. And a recurrent package of \$14,000 and that included attendant care, massage, physio, speech, and OT interventions, the equipment that was required for that, cab charges.

[Case Manager No 3]

Monitoring/accountability

Residential aged care is governed by the *Aged Care Act 1987* (Cth). The aged care environment has a "focus on providing support for people with problems with orientation, mobility or continence during the last phases of their lives".⁵³ Neither the Act nor the Aged Care Accreditation Standards mention younger people with disabilities. While the standards mention rehabilitation (Standard 2.14), services are not funded to provide a rehabilitation environment for a young person with an acquired brain injury.⁵⁴

One of the main barriers to optimal support for people with severe acquired brain injury in residential aged care is the lack of interface between health, disability and aged care services. Once someone has been deemed "unsuitable for rehabilitation" and has been discharged into aged care, there is no formal process to facilitate their ongoing engagement with rehabilitation.⁵⁵ A recent

⁵³ Victoria, Department of Human Services, n 3, p 22.

⁵⁴ Wales L and Bernhardt J, "A Case for Slow to Recover Rehabilitation Services Following Severe Acquired Brain Injury" (2000) 46 *Australian Journal of Physiotherapy* 143.

⁵⁵ Foster M, Fleming J and Tilse C, "Council of Australian Governments' (COAG) Initiative for Young People in Residential Aged Care: What Are the Issues for Acquired Brain Injury?" (2007) 8(3) *Brain Impairment* 312.



Queensland survey showed that there were barriers to accessing funding for specialist services for people with an acquired brain injury because they were living in residential aged care. The study concluded that “many clients are prevented from reaching their full potential for recovery and increased independence”.⁵⁶

Chris’s case manager reported that Chris’s rehabilitation outcomes were compromised because of a lack of continuity of funding. It was as if, once he was discharged from the rehabilitation setting into aged care, no-one was accountable for further rehabilitation outcomes:

Now I know that this is about different systems and different buckets of money and neither the two shall meet but at the end of the day that intensive physio had to go with him. Whether he slept in that bed or slept in that bed made no difference. But the physio did. He needed that intensive rehabilitation and that’s what stopped. I believe that that certainly would have made the difference until we were able to implement this package and then start maybe the physio in a different way.

[Case Manager No 1]

The gains Chris had previously made in rehabilitation were lost in residential aged care. His case manager reported that she could see contractures occurring – his arms were tightening and he was becoming stiff and harder to move:

If he was able to use a slide board [chair to a bed] to transfer with assistance six months prior yet was agonised to move six months later, we don’t know where he would have gone to ... so they got him to a point where this young man could slide, with assistance of staff, from his chair over to bed or another chair. Not using the hoist basically. Yet he went over the aged care facility and was in a hoist. Because that’s what you do in an aged care facility, you use a hoist and you use two people.

[Case Manager No 1]

This sense of frustration about what was available was expressed in Chris’s *My Future My Choice* plan:

Delays in appropriate support have resulted in a huge human cost for Chris who moved from the [name of rehab] to [nursing home] in 2007. At 24 years of age, Chris spends most of his hours watching TV. He has severe contractures and his level of depression is high. Six months previously his rehabilitation program was going extremely well ... All of those people in Chris’s life including family and professionals ask why there is not more of a continued plan of support beyond rehabilitation for such a young person with high needs.

[Case Manager No 1]

Younger people with very high needs in residential aged care are susceptible to secondary conditions that can make them critically ill or result in premature death.⁵⁷ Assessments undertaken on people under 50 years of age in Victorian residential aged care showed that the majority of people studied had developed an illness or infection in the past 12 months, the most common being a chest infection or a urinary tract infection. Thirty percent had had non-elective hospital admissions within the year prior to the study.⁵⁸

The three deaths in this research were all in areas of high risk for people in residential aged care facilities. In the case of Mary, there was an occupational therapy and a speech pathology report that clearly stated she was at high risk for aspiration pneumonia. Given that she died from a choking-related complication, it appears that adequate monitoring may not have taken place, despite the known risks:

Mary will require ongoing swallowing reviews as she’s recently an inpatient at St Vincent’s. She may have had a swallowing videofluoroscopy, modified barium swallowing followed by a speech pathologist there. Contacting the speech pathology department in order to obtain a swallowing report would

⁵⁶ Cameron et al, n 8 at 263.

⁵⁷ Winkler et al, n 4.

⁵⁸ Winkler et al, n 4.

therefore be highly recommended. This [speech therapy report] was discussed with the care coordinator at [nursing home] on the day of the assessment.

[Speech therapy report provided by Case Manager No 3]

Sheree was at risk of choking due to dysphagia and PEG-feeding. Complications from PEG-feeding can include aspiration by vomiting, abdominal bloating, tube displacement, diarrhoea and constipation. PEG-feeding needs to be clinically monitored by someone with the appropriate level of expertise. Attention to oral hygiene is also important. Rate of feed, formula and amount of feed also need specialist attention.⁵⁹

There is some suggestion that, unable to manage Sheree's physical resistance to PEG feeds, staff physically restrained Sheree and that her feeds were not adequately reviewed or monitored. While there were many physical and verbal indicators of pain, including Sheree hitting and biting herself, the cause of pain does not appear to have been addressed. The case manager reported the mother's concerns that Sheree continued to receive PEG feeds despite her obvious signs of pain and discomfort:

She was thrashing about. [Mother of deceased] had stated on a number of occasions that they were overfeeding her. She was stating on a number of occasions that she was unhappy. Very unhappy with this.

Bolus feeding her, that was it. Basically too fast and too much. Because she was non-verbal she was doing things like she was hitting herself and she was biting and she was thrashing about ...

[Case Manager No 2]

Sheree had also developed oral hygiene problems in the second nursing home that were acute compared to what she had experienced in her first nursing home. These included mouth ulcers and tooth abscesses which exacerbated her swallowing difficulties. These caused significant distress for a period of time and there is some evidence that she did not receive the oral hygiene and dental monitoring that she required.

There is no mandatory reporting of deaths in residential aged care as there is for deaths in other people with disabilities in care in Victoria and so the coroner is reliant on cases being voluntarily reported. We can only speculate as to why none of these deaths was reported to the coroner. The fact that they were not reported, despite questions about the level of care that all of the deceased received, does raise issues about whether current monitoring mechanisms are adequate.

One explanation for deaths not being reported to the coroner is that families did not have the capacity. Families traumatised by their loved ones' deaths and who had experienced a level of system failure may not have had the energy to fight any further. Sheree's mother did not want to tackle the issue any further:

Well [mother of deceased] actually said "I don't want it to go any further". They were offered a chance to sue for malpractice or neglect or whatever. They had a round table conference with the nursing home and the nursing home said "yes it was neglect and we are sorry" and [mother of deceased] was happy with that.

[Case Manager No 2]

Chris's mother had already experienced a disempowering level of system failure, such that it was difficult for her to raise issues about her son's care and so it was perhaps unlikely that she would report his death, although she was very willing to have Chris's case included in this research:

She was certainly raising the issues. She could very clearly see the fact that her son's support was not there. That it had all come too late. She could see very clearly that he was not given the opportunity to communicate. And she knew that he was extremely depressed and she knew that this was sure to be contributing to his physical health state. But she was not the sort of person to go in there and say "hey what's happening here?"

[Case Manager No 1]

⁵⁹ Oral Cancer Foundation, n 38.



Mary’s case manager strongly believed that Mary’s death should have been investigated:

But I absolutely think [deceased] had a right to have had her death investigated by the Coroner.

[Case Manager No 3]

This finding supports the case for better systematic monitoring of young people in residential aged care.

CONCLUSION AND RECOMMENDATIONS

The findings provide some insight into issues relating to the deaths of three people under 50 years of age in residential aged care. The cases illustrate that, without adequate assessment, rehabilitation support, specialist clinical support and specialist equipment, people can die. Given the high proportion of people in residential aged care with conditions predisposed to swallowing difficulties, choking and aspiration pneumonia, it is possible that many of the deaths of young people in residential aged care are due to aspiration pneumonia and choking. However, this information is currently unavailable.

The placement of younger people in residential aged care where death is an accepted and expected occurrence may contribute to the false perception that residents are in the end stages of life “awaiting death”.⁶⁰ However, people under 50 with disabilities in residential aged care may have many years of life ahead of them as well as the potential for a level of recovery and a better quality of life.

A report into the deaths of six people with intellectual disabilities due to the failure of health care in the United Kingdom, *Death by Indifference*, shows how judgments on the value of life can affect the treatment of people with disabilities.⁶¹ The Public Advocate’s position is that all people with disabilities should have an equal chance of receiving treatment and care that will enable them to live optimal lives and that the premature death of people with disabilities due to service system failure is a breach of the fundamental human right to life.

Given what is already known about the struggles that residential aged care facilities have in meeting the high needs of young people with complex conditions and disabilities, more support is required to ensure that facilities have the resources to care for this group. The following recommendations are made with a view to both improving the monitoring of deaths of young people in residential aged care and enhancing access to much-needed services and support:

- the establishment of a category for “people under 50 years of age in residential aged care” as a class of “reviewable deaths” to the coroner;
- the establishment of a mechanism for the systematic monitoring of young people in residential aged care by the Disability Services Branch of the Department of Human Services; and
- the development of procedures to facilitate a stronger interface between health, disability and ageing to enable ongoing engagement with rehabilitation and to enhance access to allied health and specialist aids and equipment.

APPENDIX 1 CASES THAT MET SELECTION CRITERIA WITHOUT FAMILY PERMISSION

Brief description of case	Reason not included
A young woman with children in her late 20s with a catastrophic brain injury who died unexpectedly. She had waited over a year for funding.	Family unable to be found.
A man in his 40s with a congenital condition who was active prior to admission to residential aged care and died of pneumonia. He was unable to get funding for therapy and support that he needed. According to his case manager, there was a lack of attention to his medical needs.	Family permission not sought due to sensitivity of issue.

⁶⁰ Brain Injury Association (NSW), MS Society, Multicultural Disability Advocacy Association (NSW), NSW Council for Intellectual Disability, NCOSS, People With Disabilities, and Physical Disability Council of NSW, *Younger People with Disability out of Nursing Homes: A Discussion Paper* (2002).

⁶¹ Mencap, *Death by Indifference: Following up the Treat Me Right! Report* (London, 2010), <http://www.mencap.org.uk/sites/default/files/documents/2008-03/DBIreport.pdf> viewed 28 February 2011.



Brief description of case	Reason not included
A person with a neurodegenerative condition who had died due to a head injury reportedly sustained in residential aged care due to lack of correct equipment.	Family refused consent.
A 50-year-old woman who spent several years in residential aged care after suffering a stroke. She had waited three years for funding and died after aspirating food reportedly due to incorrect PEG-feeding.	Family permission not sought due to sensitivity of issue.
A man in his 30s with a hypoxic brain injury who died from pneumonia after many years of reportedly poor care in residential aged care. In the first few years of his injury, he did not receive adequate rehabilitation or ongoing support which resulted in later complications.	Family permission not sought due to sensitivity of issue.

APPENDIX 2 DEATHS THAT HIGHLIGHT QUALITY-OF-LIFE ISSUE IN RESIDENTIAL AGED CARE BUT DID NOT MEET SELECTION CRITERIA

Brief description of case	Issue
A man in his mid-30s with a degenerative condition who needed an appropriate wheelchair as he was unable to go outside the facility. He received funding just before he died.	While his death was due to the disease, the case highlights quality-of-life issues.
A woman with a neurodegenerative condition who slept on the floor between two mattresses because of a lack of funding for specialist equipment and support.	While her death was due to the disease process, she experienced more suffering than necessary.
A young man with an acquired brain injury in his early 20s who made gains in one specialist nursing home deteriorated rapidly in the second nursing home where he ended up emaciated and with pressure sores.	Although he finally died in palliative care after a series of “medical mishaps”, the quality of care in the second nursing home had an impact on his quality and length of life.
A 43-year-old woman who was in residential aged care after sustaining a profound brain injury waited two and a half years before she received funding for physio, OT, attendant care, transport and a wheelchair. She had advanced contractures due to a lack of exercise, proper splinting and physiotherapy. When funding came through after two and a half years, it significantly improved her quality of life, particularly her relationship with her children.	Funding, once received, was described as “too little too late” by the case manager. A refusal to provide palliative care by the hospital she was admitted to following a choking episode, meant that she went back to the nursing home where her death was protracted.
A 45-year-old woman with terminal illness was in low-level residential aged care but needed higher level care. She experienced much pain and suffering as a result of PEG-feeding and what was reported as inappropriate pain management. She did not receive appropriate specialist clinical support and was admitted to hospital several times due to constipation resulting from PEG feeds. She died after a choking episode. While DHS were responsive to her needs and she received interim funding, she experienced many periods without funding due to funds being exhausted.	Residential aged care was not able to provide the appropriate level of specialist care and this person’s quality of life was very poor. It is unclear why she was not in palliative care, particularly in the end stages of her disease. While her death was not unexpected, it is unclear whether her death from “choking” would be considered a “natural” cause.

