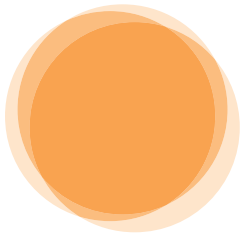


SUMMER  
FOUNDATION



**Thoughts & Perspectives**  
on Young People in  
Nursing Homes

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# Thoughts & Perspectives on Young People in Nursing Homes

On 10 December 2008 the Summer Foundation hosted a lunch, supported by the Macquarie Group, which presented an opportunity for interested young people, their parents, friends and carers to discuss a range of issues relevant to young people living in nursing homes.

The young people who attended were either currently living in aged care, had previously lived in an aged care facility, or faced the prospect of entering an aged care facility as a young person in the future.

This report is a compilation of the thoughts, perspectives and issues raised by the participants in this discussion.



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## Introduction

Young people make choices about their lives on a daily basis. It is reasonable and usual for young people to have control and influence over such things such as where they live, who they chose to live with and the types of possessions with which they surround themselves. Young people expect the opportunity to pursue their hobbies and engage in activities that give them pleasure and satisfaction. Making social arrangements and planning outings are an everyday part of a young person's life.

For young people living in nursing homes, or who may be facing the prospect of entering one, choices relating to many basic aspects of life are dramatically reduced. In addition, basic rights such as privacy and respect are frequently compromised.

On no level is this report a condemnation of aged care facilities. It is acknowledged that young people living in nursing homes have high level and complex needs. This report focuses on the age inappropriateness of nursing homes for young people - in the context of considering next generation accommodation options for young people. It is acknowledged that there are many beneficial aspects of aged care settings (such as security, support, companionship etc), which are a significant element of any alternate accommodation model. Indeed throughout the discussion, some positive elements of life in a nursing home for a young person were identified, along with some of the negative elements.



## Background

There are too many young Australians stuck in nursing homes. This is a serious social issue, which can and *must* be fixed. An estimated 3500 people under the age of 60 live in nursing homes, which are not suited to their needs. Many of these people are socially isolated and have been forgotten. 53% young people in nursing homes receive a visit from a friend less often than once a year. Every year 70 additional young people enter aged care facilities in Victoria alone, where the average age of residents is 83.

The *my future my choice* Commonwealth-State Government initiative is providing real support to a percentage of young Victorians in nursing homes. However the initiative does not reach far enough, and is finite. The mission of the Summer Foundation is to foster the development of the next generation of solutions that enable and empower people with acquired and late-onset disabilities to participate in the community and pursue a lifestyle of choice.

The lunch hosted by the Macquarie Group provided an opportunity for young people with a vested interest in this issue to meet and discuss the real concerns they have faced, and continue to face in the areas of accommodation and lifestyle. There were several clear and strong themes which emerged from the discussion, supported by many poignant and moving perspectives.

The relevance and significance of this report is greatly enhanced by the fact that the perspectives offered come directly from the people and those close to them who have first hand experience of life in a nursing home as a young person. The Summer Foundation is proud to provide a public voice to the key messages expressed by the participants in this discussion.

# Themes and Issues Arising from the Discussion

## 1. Privacy and Respect

Many of the contributions to the discussion centred around the key issues of privacy and respect. For many young people living in nursing homes lack of privacy and respect were significant and constant areas of concern. It seemed that the institutional feel of nursing homes by their very nature largely contributed to this issue. Even those participants who felt they were personally treated with respect and dignity craved a higher level of privacy.

- 1.1 A number of participants commented on the fact that they are constantly reminded that their home is an institution. This often manifested in the way some staff regarded the facilities. The overwhelming notion was that these facilities are not primarily viewed as 'the home' of the residents. Nursing homes tend to be viewed and treated as a workplace, a place of service provision, and an accommodation facility.

*"I don't want to be treated as though I'm in a nursing home...  
it is my home...."*

*"the staff at times treat the home as theirs, rather than ours.  
I would like more privacy and respect...."*

- 1.2 An additional issue relating to privacy and respect emerged regarding carers and support staff. For those who were treated with dignity and respect this aspect was a highlight.

*"I enjoy the friendships I have with the staff – they are  
more to me than staff..."*

However for others their experiences had not all been as positive, and the need for support staff to respect the dignity and privacy of young people was raised.

*"in my ideal home the support workers would understand the needs  
of young people. They would have the compassion and  
empathy to care for people with dignity..."*

- 1.3 For those who had the experience of sharing bathroom facilities, lack of privacy was a very significant issue. Although this issue seems simple, it was raised by all participants – a strong positive for those who had an ensuite and an even stronger negative for those who did not.

*“....there were unpleasant issues with her having to share an ensuite...”*

*“...I have my own room and my own ensuite – I enjoy being able to escape to my own space...”*



## 2. Choices

The question of choice was a strong theme throughout the discussion. Choice as it relates to where a person lives, who they live with, who provides their care and support, and what their living environment is like (layout, ambience, furnishings etc). Young people are typically placed in nursing homes as a result of disability from acquired brain injury or late onset disability from neurological disorders. Consequently prior to entering nursing homes, the young people participating in this discussion had all experienced or anticipated the same freedom of choice that their young (non disabled) peers take for granted. To have these choices dramatically and completely removed is devastating.

2.1 Choice of housemate(s) was a critical issue. Several people contributing to the discussion had experienced difficulties with the people they found themselves living with, while others had positive experiences to recount. Either way the significance of having choice around whom you live with was a dominating theme.

*“How you feel about where you live has more to do with the people who surround you...”*

*“If I were to share accommodation, it would be important to me to share with someone of my choice – not someone independently paired with me.”*

*“I would change not being the youngest by a third of all the people I live with”*

2.2 Several key elements relating to location were raised. Many of the participants felt a strong level of comfort that they were living in close proximity to family, friends and the area they had grown up in. For others, critical aspects of location included ready access to appropriate public transport and other services. Being in a vibrant, central location was also raised by several participants.

*“...ideal home would be near public transport and shops, inner city, near young people and support...”*

- 2.3 Without exception all participants felt restricted by lack of space. In most cases the only space they could call their own was a small bedroom. Even those who had experienced generous sized bedrooms commented that these were still not sufficient to adequately accommodate their hobbies/interests.

*“I would love to be able to have a cat....”*

*“....need more than just a bedroom. I don't have the space to pursue my interests. An office would be ideal so I could spread out and set up my computers properly...”*

*“....more space to pursue my craft interests – if I had a designated space for this I wouldn't have to pack up whenever I left the activities for a period of time...”*

- 2.4 Food was another aspect where the desire for a greater range of choice was expressed. Some people commented on the lack of control/choice about food, others mentioned the desire to prepare their own meals, while others raised the lack of opportunity to have friends over for a meal.

*“in my ideal home the food would be age appropriate and taste good, and suit individual needs...”*

*“I would love to have my own kitchen facility...I would love to have access to a BBQ...”*

*“I would love to invite people home for a meal...”*

- 2.5 The facilities and resources available on a daily basis to young people without disabilities are typically not available to young people living in nursing homes. Young people in aged care facilities often do not have individual access to a TV, a computer, internet etc. Agreement was reached by all that having access to the resources and facilities that most other young people take for granted would make an enormous difference to their lives.

*“The ideal living environment should involve choices, access to all things in a regular home...it needs to be homely...”*

- 2.6 Although a couple of the young people involved in this discussion have been able to access external activities, pursuits, rehabilitation and other services – largely through the *my future my choice* initiative, the general consensus was there should be a much larger rate of participation in community based activities and groups. Living in a nursing home however, hinders the ability to participate in these external activities.



*“I haven’t been socially active, but would like to get back into living a normal life, and live as closely as possible to how I would have...”*

*“...shouldn’t be forced to live with other people with disabilities; this reduces opportunities for socialising....needs to have as many opportunities as possible to mix with people”*

### **3. Friendships**

Another key theme raised by participants was the impact of their disability upon their friendships and relationships. Many aspects of this related directly to the nursing home environment.

- 3.1 One of the most significant issues for the young people participating in this discussion was the lack of opportunity for social interaction. Most nursing homes have at best communal areas for visitors. In addition, the lack of a private space or recreation area to spend time with visitors often makes it uncomfortable and discourages young visitors such as friends and family members.

*“There is nothing relevant to young visitors in a nursing home – nothing inviting. Simple things like a pool table/dart board etc would help young visitors feel more at ease and give them a focus....”*

*“The nursing home environment contributed to the deterioration of my friendships...”*

3.2 The lack of opportunity for private entertaining was an issue raised by a number of participants.

*“I would like more space, more private space – the socialising space where I live is communal...”*

*“The (lack of) potential for intimacy is a huge issue – I can’t bring anyone home, it’s like living with my parents again...”*

*“I would like room to entertain – with some privacy.”*

3.3 Another common theme was that friends had undergone a ‘grieving’ process, and the nursing home environment did not support or make allowances for this.

*“friends go through a grieving process – they grieve the friend and relationship they had. They need support and help to work through this and reconnect with their friend.”*

*“ My friends were very supportive when I was in hospital, visiting regularly. The problem is they were not given information about what to expect and what the implications of my accident were for me. They rarely now make contact. I don’t believe the problem was with them, their support faded because there were insufficient measures in place to support them...”*



## 4. Security and Support

Security and support emerged as a significant area of consideration. While all participants want to see accommodation options which move significantly away from the institutionalisation of nursing homes, combining this with the necessary and appropriate level of security and support is critical.

- 4.1 An appropriate physical environment is one which accommodates wheelchairs, walking frames and other requirements. While the physical environment of nursing homes caters for these needs, it is also important for these issues to be addressed in a non-institutional manner in any alternate accommodation.

*“Where I live now facilitates my mobility with flat surfaces, supporting rails and room to manipulate my walker...”*

- 4.2 Access to appropriately trained support staff is critical in any accommodation model put forward. The key appears to be blending a sufficient level of appropriate support, into a *homely* and typical living environment.

*“Ideally they should be supported by people who are motivated by care and love...”*

*“To facilitate young people exploring their needs/interests there needs to be an appropriate ratio of support staff to young people – many activities require one-on-one care...”*

*“Young people need a balance between support and privacy. The staff can make an enormous difference”*

*“...needs to be treated like other young people. Treating her differently makes her feel humiliated...”*

- 4.3 Security is a significant area of concern which needs to be addressed when considering alternatives to nursing homes.

*“These young people are vulnerable – any accommodation model needs to address this and measures need to be put in place to reduce their vulnerability...”*

*“I appreciate the security of where I live now...”*

## Conclusion

The discussion was concluded by asking participants what their key message would be regarding the issue of young people in nursing homes.

*“...Give us a go, just because we can't walk/talk/see or whatever else our disability might be, doesn't make us any less of a person with hopes, dreams, goals and aspirations. The fact we mightn't be able to tell or show you something doesn't just make it go away. It just means we need your love, support and friendship even more. We still have a heart....it's now even more easily broken....just because something doesn't work quite the way it used to, doesn't make us any less an important human being.”*

Anj, age 23

*“...Young people just don't belong here. Some of us had no choice. I would love to see an age appropriate care facility for young people in the future . . . somewhere that supports an appreciation of individuality, individual interests and personal tastes...”*

Michelle, age 25

*“....Should anyone be in nursing homes? Society doesn't make this issue a high enough priority....”*

John, age 48

*“....The ideal living environment should involve choices, access to all things in a regular home and it needs to be homely. It should have a feel of community and needs to offer privacy...”*

Helen, parent

## About the Summer Foundation

The Summer Foundation is a not-for-profit organisation that collaborates with people with disabilities, their families, government, disability organisations and housing associations to develop alternatives for young people living in nursing homes. The key aim of the Summer Foundation is to change human service policy and practice related to young people in nursing homes (YPINH). We utilise a range of strategies to influence health, housing and disability services policy and practice related to this target group.

We want a range of creative and innovative solutions to enable young people in nursing homes to actively participate in the community and have a real choice about where they live. In Victoria, approximately 70 people under 50 are admitted to aged care each year. There needs to be systemic change and a dramatic increase in the number of supported housing options in this state to stem the flow of young people into aged care.

The Summer Foundation aims to foster the next generation of supported housing for people with disabilities that is integrated into larger residential developments. This will fulfil the Victorian State Disability Plan and, which states that ‘people with a disability should be able to choose where they live, with whom and in what type of housing.’

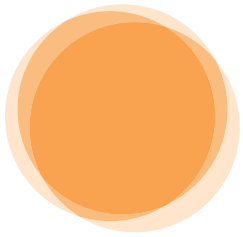
In March 2009 the Summer Foundation launched the Building Better Lives™ campaign, which aims to engage the business community and the general public in raising \$10 million to build alternatives for young people living in nursing homes. These funds will be used to ensure that these shared supported accommodation services are places of excellence in terms of physical design, fit-out and the use of technology to enable the residents to be as independent as possible. These funds will also be used as leverage to increase the number of places developed for this target group.

For further information about the campaign and how you can help, please go to [www.buildingbetterlives.org.au](http://www.buildingbetterlives.org.au)

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