



1. About the Alliance for Forgotten Australians

The Alliance for Forgotten Australians (AFA) is the national peak body which promotes the interests of the estimated 500,000 people who experienced institutional or other out-of-home care as children and young people last century. We have a membership from across Australia, a majority being Forgotten Australians, and operate as an incorporated body.

The Alliance for Forgotten Australian's objectives are to see a national redress scheme implemented across Australia, open to *all* who experienced institutional 'care', the creation of an accessible and freely available health and aged care system and the continued operation of the current state- and territory- based support services.

It is no accident that our members have adopted the title *Forgotten*. Our members are ageing and time is running out to give them justice. We are acutely aware of the fear, anger and despair felt by Forgotten Australians at the prospect of being re-institutionalised into the aged care system – no matter how good it might sometimes be, or how much better it might become as a result of the outcomes of government responses to this Royal Commission.

2. The terror of being re-institutionalised

A senior policy maker recently glibly said to us: 'Oh, no-one wants to go into aged care.' Unspoken was the question of why we should be any different. This simple statement demonstrates the deep ignorance of the historical footprint of institutional 'care' in Australia last century, and the profound, traumatic, and lasting impact on the adult survivors who are facing the end of their lives.

The Alliance for Forgotten Australians made a submission about the terms of reference for the Royal Commission, suggesting that Forgotten Australians should be specifically identified as a vulnerable group for the Royal Commission in the way the 'care leavers' are designated as a special needs group in the Aged Care legislation. (Term of reference b.) Unfortunately, this was not acted upon.

Despite 17 inquiries since 1995 about the historical abuse of children in out-of-home care, including the threshold Senate Inquiry report *Forgotten Australians* in 2014, very few know who we are. That there are 500,000 of us doesn't seem to have registered with many policy

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makers or aged care professionals. Most commonly, we are mistaken for the Stolen Generations (although some Forgotten Australians identify as Indigenous). We have also been mistaken for the 'boat people', Chinese immigrants to the goldfields, and the Afghan cameleers in central Australia in the 19th century.

How can services be improved when we are not just forgotten, but unknown? And that policy makers shunt us all into the same homogenous 'blob' as every other ageing person?

3. Voluntary euthanasia

- c. *the future challenges and opportunities for delivering accessible, affordable and high-quality aged care services in Australia, including:*
 - i. *in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and*
 - ii. *in remote, rural and regional Australia;*

For Forgotten Australians, and other survivors of institutional 'care', the prospect of being re-institutionalised is life threatening and distressing at a deep, fundamental and existential level. We know that many have taken their lives rather than being placed into an institution, no matter how good that institution may be. No legislation in Australia, including Victoria's recent assisted dying legislation, comes anywhere near proving an avenue for those who wish to choose the time of their death.

Some Forgotten Australians would prefer to die rather than be re-institutionalised. We've been there. We know what it's like.

All our lives governments and bureaucracies denied us choice. Institutional 'care' was not a choice. Separation from families was not a choice. Slave labour was not a choice. And now, the loneliness, ill health, homelessness and poverty many of us experience is not a choice. Our disadvantage has been cumulative. The only end in sight is our demise.

We didn't have a choice when we started out in life. We want a choice as we finish in life.

Many will *not* exercise that choice. Some *will* want to. We acknowledge that these are deeply personal and confronting issues to raise. But they won't go away.

We don't want the mean, painful, squalid, lonely pathway of hoarding pills, jumping in front of trains or starving ourselves to death. **We want euthanasia to be recognised as a legitimate, supported option for those who wish, at the end, to take control, when all their lives control was taken away from them.**

I may not be ok

‘I look good. People see me and think I’m alright. I don’t *look* different. They have no idea what’s going on inside’. (*words of a Forgotten Australian*).

The impact of institutional ‘care’ and the responses or behaviours many Forgotten Australians exhibit is well documented in the Senate Inquiry Report *Forgotten Australians* (2004), as well as the reports of the Royal Commission into Institutional Responses to Child Sexual Abuse. While the following list is not exhaustive, it provides some background about **why some people behave in ways which many aged care staff may struggle to understand**. These responses or behaviours may be triggered whether the person is receiving in-home support, or is in an aged care facility.

‘The nuns never believed me when I said I was sick. I find it hard now to seek medical treatment. I just keep on going until I fall over.’ (*words of a Forgotten Australian*).

- Fear of authority figures and people in uniform.
- Trauma triggers, such as religious figures and symbolism.
- A fear of being in a confined space, a communal space, closed doors, bars on windows.
- Institutional food – mushy food, food with white sauce, porridge, fish fingers, etc.
- Strong reactions to people touching their possessions or invading personal space.
- An overwhelming need for privacy.
- An aversion to strict regimes and rules.
- Night terrors.
- Disproportionately strong responses to medical staff and a reluctance to seek medical help.
- Aversion to physical examinations, dental treatment, oxygen masks or any medical devices which compromise personal space or involve intimate contact.
- Distress at what are often commonly celebrated occasions such as birthdays, mothers’ day and fathers’ day and Christmas.

‘I can’t fill in a form. I can help other fill in forms; I do it all the time. I freeze; I just go blank. I can’t keep thinking about my past.’ (*words of a Forgotten Australian*).

The final report of the Royal Commission into Institutional Responses to Child Sexual Abuse (Volume 3, *Impacts*, pp 28-29) explains the experience of ageing on survivors of abuse:

In the *Nature, cause and impact of child sexual abuse* case study, Dr Philomena Horsley, Research Fellow at La Trobe University, described the particular vulnerabilities of survivors of child sexual abuse as they become frail:

As people age and become older, particularly those in their 70s and 80s and 90s, there's a physical frailty, there's often a cognitive impairment of some kind, or moving into that space, as well as, in a social sense, greater isolation from networks, particularly if one is in care or going into care, and so lack of support. I think what can happen is as those feelings of vulnerability and lack of safety occur in someone's life, it can re-trigger memories, either specific memories or just a more generalised sense of feeling vulnerable, not feeling safe, feeling a lack of control about their physical surroundings, whether they're in a family home or whether they're in an aged-care facility or whether they're in a prison, for instance, which I think is a really under-recognised area. People become less physically mobile, so [have] less [of] a sense of empowerment in themselves.

Older survivors entering aged care facilities face particular challenges relating to the loss of privacy and loss of control. As Dr Horsley described:

What happens particularly in aged care settings and in many cases hospital settings where a lot [of] older people spend significant periods of time, is they lose their privacy. They often have intrusive physical examinations, they may be catheterised, they may have a range of UTIs [urinary tract infections], which is really common in older people, all of which involve other people touching their genitals or their body generally, who they don't know or have a relationship with.

For example, Dr Horsley described how in one aged care facility, in order to manage the incontinence of residents, staff would go around at night while people were asleep and put their hands down into their nappies to check whether or not they were wet. She said, 'You can imagine the experience that that would be for somebody who wakes or is subconsciously experiencing that'.

4. Support for accessing aged care

- e. *how to ensure that aged care services are person centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care related matters;*

The background paper *Navigating the Maze* published by the Royal Commission in February 2019 references the intended single gateway developed by the Australian Government in the My Aged Care portal to help people navigate the aged care system. However, this entry point is premised on people's ability to access and use the Internet.

The proliferation of fee for service brokers to assist people access aged care services is indicative of the complexity and risk within the system. If it's so complex for many professionals to navigate the aged care system, how could it be possible for a Forgotten Australian? Many had no education. Some managed to catch up and even go on to tertiary education. But many are not literate or numerate. In the study *No Child Should Grow Up Like This* undertaken by the University of New South Wales in 2016, the average age for Forgotten Australians for leaving school was 15. In addition, 56.9 per cent did not obtain any school certificate.

The traditional (and largely middle class) tools of contemporary service provision where cost-savings measures require people to do things online or by phone simply don't work for many Forgotten Australians. In the same study referred to in the above paragraph, 46 per cent of Forgotten Australians had experienced homelessness. Forty-eight per cent lived in public housing. Sixty-nine per cent reported that they could not access services due to the cost involved.

Many Forgotten Australians do not have access to a computer or use the Internet. Many who use mobile phones are on restricted plans which are quickly used up. For them, an iPhone is unimaginable. People can't afford the Internet or generous phone plans, and often they live in isolated rural places where they can hide away as far as possible from the governments and institutions in which they were abused. If they use the Internet, it may be when they have enough money for petrol to drive to the nearest town to shop and use the facility in the local library or neighborhood house.

We are proposing an 'aged care navigator' role to support Forgotten Australians who wish to access any form of aged care. This must be face-to-face. Many Forgotten Australians find it difficult to trust anyone. They take time to build relationships. It doesn't happen in cyber space.

An aged care navigator might be a Forgotten Australian, or work side-by-side with a Forgotten Australian, who performs the following role:

- Understands the historical footprint of institutional 'care' and can therefore provide advice and support with understanding, sensitivity and empathy.
- Links the individual with the service system and other options for support such as peer support.
- Assists an individual find the right help to do practical things around their health – adjusting a hearing aid, caring for their teeth, getting used to and getting the most from a C-pap, getting the right mobility device for their needs, options for continence aids etc.

Evidence to the Royal Commission thus far from residents and their advocates shows us that for many the aged care system is a brutal place. It is underfunded. Caring roles are

undervalued and underpaid. Many see working in the aged care system as a stepping stone to a better career. Continuity is a major issue. Evidence from *The Aged Care Workforce 2016* undertaken by the National Institute of Labour Studies at Flinders University for the Australian Government shows that one tenth of the residential workforce was currently seeking alternative work; one tenth held another job; and aged care was a first occupation for only a small minority of workers. 'Apart from nursing, there were no clear pathways into aged care. The aged care sector draws its workers from the broader labour market'. (key findings, section 3).

As previously mentioned, Forgotten Australians take time to build trust. While it is a sad reality, staff turnover means people have to get to know someone new, and often tell the story of their history in institutions again and again – whether overtly, or covertly. An aged care navigator may be one practical way of minimising the impact of a fluid workforce.

5. Training and education for aged care professionals

- d. *what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;*

There must be properly resourced nation strategies for educating providers about the historical foot print of institutional care and its impact on survivors entering the system.

The Aged Care Workforce 2016 report shows that 29 per cent of all workers in the residential aged care sector are migrants, and 31 per cent had been in Australia for 5 years or less (3.8). The fact sheet *Markets, Migration and the Work of Care* produced by RMIT, UNSW, The University of Sydney and University of Toronto shows that many workers are from Southern Asia (mainly India, Sri Lanka, Nepal and Bangladesh), Africa and the Philippines. Countries in Southern Asia strongly rely on systems of familial care for the aged; institutional care is less common. The hard working and underpaid staff in Australia's aged care services face multiple barriers in performing their roles, just one of which is a lack of familiarity with Western-style welfare systems and policies and their impact on individuals who have been institutionalised.

In 2016, the Department of Health published the *Caring for Forgotten Australians, Former Child Migrants and Stolen Generations* information package (the Aged Care Package). (<https://www.myagedcare.gov.au/eligibility-diverse-needs/care-leavers>). This was produced with the input of Forgotten Australians and other survivor groups. The package was intended to assist professionals working in aged care understand the concerns, fears and anxieties of Forgotten Australians, Former Child Migrants and Stolen Generations in being re-institutionalised when they access aged care.



The Alliance for Forgotten Australians received \$10,000 to promote the package nationally. While this funding was welcome, it's a drop in the ocean for what is needed to promote the package systematically and comprehensively. Many Forgotten Australian advocates (including our members) use their own resources – time, travel expenses, postage – to engage with professionals to educate them about who are the Forgotten Australians, and their concerns about aged care. They are the volunteer aged care navigators. They do this because no-one else will. Successive Commonwealth Governments have not taken such promotion seriously and provided support beyond the development of the package and a modest amount for its initial promotion.

In 2017, the *Australian Ageing Agenda* published an article by the Alliance for Forgotten Australians about Forgotten Australians' fear of being re-institutionalised:
<https://www.australianageingagenda.com.au/2017/11/08/support-available-care-leavers-residential-care/>

Educational activities around Australia about Forgotten Australians and ageing have varied.

In Victoria, an extensive education program through Open Place, a support service funded by the Victorian and Australian Governments, has reached an estimated 3,000 aged care professionals in the last year.

In South Australia, Helping Hand Aged Care, a not-for-profit organisation offering aged care services, produced the resource *Real Care the Second Time Around*, with input from a group of Forgotten Australians, and with the support of the Relationships Australia service Elm Place <http://www.helpinghand.org.au/forgotten-australians-guide-launch/>.

In the 2019 Federal Budget, Helping Hand received \$500,000 through the Health Department to further develop this project.
<http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediareel-yr2019-wyatt079.htm>

Wattle Place (Relationships Australia New South Wales) recently held a forum to educate professionals about Forgotten Australians and aged care.

In themselves, these initiatives are valuable, but they do not constitute comprehensive, strategic, national educational strategies.

6. Premature ageing

- g. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

Government policies acknowledge that Indigenous people age prematurely and identify 50 years of age as a policy threshold. No government policies acknowledge that Forgotten Australians also age prematurely. While Indigenous Peoples face many distinctly different issues than those of Forgotten Australians, many have in common the experience of institutional care; removal from family; comorbidity; homelessness; mental illness; substance abuse; and poverty.

Australia has a habit of treating its disadvantaged differently, unintentionally – or intentionally - pitting one group against another in competition for recognition, funding or service provision. **Policies around premature ageing should apply to *all* survivors of institutional ‘care’, whether they be Indigenous People, Forgotten Australians and Former Child Migrants.**

7. Identity card

Forgotten Australians have long been asking for an identity card, which briefly explains *what* is a Forgotten Australian, and how the trauma of their childhoods may affect how they interact with people. Such a card means they may not have to continuously tell their story, particularly to health professionals they deal with. Based on examples previously developed by the Historical Abuse Network in Queensland, the Alliance for Forgotten Australians developed a pilot card in 2018 and more than 4,000 were distributed across Australia. Feedback from users of the card has been very extremely positive. A number of Forgotten Australians have told us that showing the card to medical staff, police and other professionals has short circuited difficult situations where they found it difficult to explain their responses or deal with a crisis.

I had to deal with a social worker at the hospital regarding an old friend who I'd been caring for over the last three years getting a prognosis of having to enter an old people home. I had been trying to find out what has been happening with G. for three weeks and having no success. The social worker had just given me some more mirror treatment (I'll look in to it.) after I'd just expressed my concerns yet again.

I felt the fingers tighten on the hair touch action of my emotional triggers. Having lost competency over my internal locus of control recently trying to be heard it reminded me that I had the card. Even that act of disengaging from the dynamic to get the card out created space for me to breathe. I handed Tim the card and read his biofeedback as he read the card. I saw the light of comprehension dawn and the total dynamic shifted to give me the space and time to be heard.

At the end of our now very productive discussion Tim thanked me for giving him the card and affirmed my courage to bring it out. As the discussion was about me getting to have a discussion with G's treating doctor Tim suggested I have a card handy for

the doctor. (*Experience of a Forgotten Australian*).

Many Forgotten Australians would like the identity card to become a formal document issued by the Australian Government, and include their name and possibly other identifying information. While this feedback has been provided to the Department of Social Services, it has not been actioned.

8. End-of-life support – your story, your life

The estimated 500,000 Forgotten Australians, care leavers and Former Child Migrants are 50 years of age and upwards. Many are experiencing old age and preparation for, or fear of aged care and death. A part of this preparation is attempting to come to terms with their experience, explaining it and leaving a record of it for their families or significant others. For many, coming to terms with the past will be triggered or escalated by crises in their life such as health, or admission into some form of aged care.

Many Forgotten Australians have been seeking, or have found the records of their time in 'care'. Others have no written records and only memories remain. Such records as exist are often wrong, or offensive, or expressed in institutional language. Records often don't match memories. Many people have never told the story of their period in 'care'. Some do not wish to do so; others have not found the language or opportunity.

With the establishment of state and territory records tracing services, Commonwealth Find & Connect support services, and increased attention to the importance of identity, Forgotten Australians would like to make sense of what has happened to them, describe it in their own words, claim an identity, and hand over *their* version of their life to their families – if they have them.

While some Forgotten Australians are skilled and literate, others will need support to write the story of their life.

The Alliance for Forgotten Australians believes that as an essential element of healing and justice, **funding should be made available as a part of end-of-life care for Forgotten Australians to work with a professional writer to write their version of their story** which is:

- Based on their records where possible;
- Corrects errors in the records;
- Reconciles records and memories;
- Provides an opportunity for reflection and resolution;
- Provides something tangible to hand down to families.

10. Coming full circle

The greatest irony observed by Forgotten Australians is that many of the institutions which housed them as children have now diversified into aged care. A survivor of institutional 'care' may be faced with the prospect of entering the same physical institution in old age in which they spent their childhood, run by the same operator, with the same religious (or secular) imagery and ethos carefully rebranded for contemporary consumption. These same institutions and their operators may receive government funding for aged care. They may be part of larger agencies which have thus far failed to join the National Redress Scheme. They may be institutions and operators which have not apologised for the abuse which occurred on their watch, which have repeatedly refused to make compensation payments, and which have aggressively litigated against claimants.

Survivors want to be protected from abuse in aged care; it must not happen again. The operators of institutions offering aged care must be held to account for the abuse of children which occurred under their watch. The Australian Government must use the levers of its funding streams, tax concessions and charity status.

The Tasmanian Government has reportedly decided to transition out of funding agreements with taxpayer-funded organisations that have not taken steps to join the National Redress Scheme and which have a significant liability for child abuse under the scheme. <https://www.abc.net.au/news/2019-03-29/tasmanian-foster-care-provider-faces-funding-cut/10950722>

An important aspect of healing work for both the children in 'care' today and survivors in 'care' from yesterday, who are on the verge of entering care again today, is about processing and remembering the past. Neither the child nor the survivor enters the 'care system' as a blank slate. Both a child and an ageing survivor have a past and a future. The essential quality of care they receive today, the *agape* of care and the imagination that is provided in giving this care, whether to a child or to an ageing survivor, can either diminish or reinforce a sense of safety and security.

When Forgotten Australians see the institutions and operators which housed them as children now offering aged care services, is it any wonder that they believe that justice has not been done, and is unlikely to be done?

11. Summary of recommendations

- I. We want euthanasia to be recognised as a legitimate, supported option for those who wish, at the end, to take control, when all their lives control was taken away from them.



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- II. All aged care professionals must be educated, on a practical level, and with the involvement of Forgotten Australian advocates, to understand the triggers for trauma for those Forgotten Australians and other survivors receiving any form of aged care.
- III. The establishment of a national network of ‘aged care navigator’ roles to support Forgotten Australians who wish to access any form of aged care.
- IV. The development of properly resourced nation strategies for educating providers, aged care and health care professionals about the historical foot print of institutional care and its impact on survivors entering the system.
- V. Policies around premature ageing should apply to *all* survivors of institutional ‘care’, whether they be Indigenous People, Forgotten Australians and Former Child Migrants.
- VI. Access to a national identity card, which briefly explains *what* is a Forgotten Australian, and how the trauma of their childhoods may affect how they interact with people.
- VII. Funding should be made available as a part of end-of-life care for Forgotten Australians to work with a professional writer to write their version of their story as an essential part of healing and justice.
- VIII. Survivors want to be protected from abuse in aged care; it must not happen again. The operators of institutions offering aged care must be held to account for the abuse of children which occurred under their watch. The Australian Government must use the levers of its funding streams, tax concessions and charity status.

Note: AFA is happy for this submission to be made public. We would be pleased to give evidence at a public hearing or provide additional information. Contact details are on page 1.

(8 July 2019)



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