



CARE LEAVERS AUSTRALASIA NETWORK

CLAN is a National, Independent, Peak Membership Body which supports, represents and advocates for people who were raised in Australian Orphanages, Children's Homes, Foster Care & Other Institutions.

**Submission to the Australian Government
Department of Health in response to the
discussion paper:**

**'Future Reform – An Integrated Care at Home
Program to Support Older Australians'**

CLAN - Care Leavers Australasia Network is a national, independent, peak membership body which represents and advocates for those who were raised in Australia and New Zealand's Orphanages, Children's Homes, other Institutions and Foster Care. There were more than 500 000 children in Australia who grew up in 900 plus institutions. CLAN's main objective is to assist and support Care Leavers and their families through the wide variety of work we do including but not limited to advocacy, counselling, casework, records searching and publishing Care Leaver's stories.

CLAN would like to applaud the Australian Government for giving us the opportunity to comment on your current discussion paper. We applaud the Australian Government for recognising that there is further need for reform to better support older Australians to remain living in their homes and in their communities. Whilst this is the ideal scenario for the average Australian it is a **need for Care Leavers**.

Care Leavers (or as others refer to them as Forgotten Australians) have been identified by the Australian Government as a special needs group and more recently the Department of Health released an Aged Care Package titled "Caring for Forgotten Australians, Former Child Migrants and Stolen Generations". It is wonderful that the Department of Health is attempting to broaden Aged Care Services understanding and awareness of these special needs groups, however Aged Care reform needs to take this one step further.

CLAN contributed to the creation of this package and also helped to disseminate the information. CLAN was listed as one of two organisations in this information package as a resource to gain further information and training on Care Leavers. CLAN sent information and a specialised newsletter to **every single residential care facility in Australia**. We had less than 10 responses in regards to this information package. This demonstrates to us that Aged Care Service Providers are not taking this information seriously and that they are not engaging in best practice to ensure their residents are receiving the best care possible. If the Department of health is serious about Care Leavers and other special needs groups being recognised and having their needs met, then reform also needs to occur to legislate that these groups are treated differently. Information Packages are just not enough are not taken seriously.

Whilst we are aware that the Department of Health is obviously cognisant of who Care Leavers are CLAN would like to take a moment to remind you of why they are a special needs group.

Who are Care Leavers and why are they a special needs group?

For most Care Leavers, the time that was spent in 'care' was characterised by emotional and psychological abuse, physical abuse, sexual abuse, neglect, malnourishment, unpaid forced labour, lack of education and separation from family and identity. Children in care were often told they were 'no hopers', 'worthless', that nobody loved them and that their parents didn't want them, at times they were also told their parents were dead and were stripped of their identities often being renamed or given a number instead of a name. It is clear that children in 'care' were denied their fundamental and basic human rights. Due to this horrific abuse and neglectful treatment, many Care Leavers are now experiencing an adulthood characterised by social exclusion and multiple entrenched disadvantage.

As a result many Care Leavers suffer from the following Mental Health issues:

- Post-Traumatic Stress Disorder
- Chronic Depression

- Generalised Anxiety
- Drug and Alcohol Addictions
- Phobias
- Suicidal Ideation
- Hypervigilance

Many Care leavers also experience a plethora of physical health issues including but not limited to:

- common back and knee problems (created by forced labour whilst in care),
- issues with dental care,
- heart issues
- issues such as cervical, testicular and prostate cancer which were diagnosed later (commonly because many Care Leavers are too fearful to undergo the simple preventative/early diagnostic tests due to prior abuse).

Furthermore many Care Leavers are also isolated from their families due to various difficulties and issues over their lifespan. Firstly many Care Leavers lack their own biological parents, siblings and extended family due to being separated at a young age. Many never make contact with their biological families after they leave care and those that do often have an unsuccessful or strained relationship with their family members. CLAN often hear of difficulties between Care Leavers and their own children. Often a Care Leaver's mental health issues and lack of guidance and support in raising a family can often create complex relationships between a Care Leaver and their child/children. CLAN have also heard a lot of anecdotal evidence regarding the intergenerational effects of care resulting in many Care Leavers children also spending some time in the child welfare system. These sorts of outcomes often have a detrimental effect on the relationship in families and often lead to difficulties with Care Leavers having a relationship or access to the next generation – their grandchildren.

Care Leavers may also have other difficulties like literacy issues which make it difficult for them to read and comprehend paperwork as well as fill out paperwork. Many also still carry the stigma of a childhood in care with them meaning it is hard for many Care Leavers to open up and disclose that they were in care. The Senate Inquiry (2004) acknowledged the unique needs and fears of Care Leavers regarding their old age stating "Care Leavers will have particular issues as they age and service providers are currently unaware of these issues...additionally the broader population needs to be aware of these issues so that services now and into the future can be better able to respond to this group in our community.". Whilst this has come a long way since the Senate Inquiry in 2004 the majority of aged care workers are not educated and trained in understanding and assisting this vulnerable group of people. Whilst the Department of Health's Aged Care Package has attempted to remedy this, the lack of response from the services it was aimed at has only demonstrated that they either still have no understanding and awareness or do not care. Either way. Just because the information is out there does not mean these services are yet capable of dealing with Care Leavers effectively.

The Adverse Childhood Experiences Study

The Adverse Childhood Experiences (ACE) study is an American Study which examined over 17000 individuals between 1995 and 1997. This study was able to draw correlation between the higher the number of adverse childhood experiences the higher the chance of illness, disability and early death. This study is concerning for Care Leavers as due to the repeated traumatising of Care Leavers in their childhood, many would have quite high ACE scores. To put the studies findings into perspective

an ACE score of 4 means that an individual is 12 times more likely to attempt suicide and 7 times more likely to engage in drug taking than an individual that has a zero ACE score. Many Care Leavers would have an ACE score of five or higher thus placing them at great risk as they age. Obviously, in relating this study to aged care and elder abuse, there is a clear link between childhood trauma and chronic health issues and early death. Chronic illnesses will increase the likelihood of Care Leavers needing assistance and aged care as they get older. This link has been well established in other research and literature where past traumatic life events have some sort of correlation with elder abuse (Acierno et al., 2010; Mann et al., 2014; UNDESA, 2013).

How do Care Leavers Feel About Aged Care?

In 2011 CLAN conducted a survey of our members to which we had 577 respondents. In this survey we asked questions focusing on their life after 'care' including how 'care' effects them in their lives today. An important issue which arose from responses to this survey was a common unwillingness to be placed in an aged care facility. We received responses such as:

- "I will never live in care again. I am scared of being abused again"
- "I would rather die"
- "I don't want to die in an institution"
- "I would rather live on the streets than in a nursing home"

These responses were fairly typical of how most people responded to this question. Not surprisingly, it was determined that for the vast majority, living in their own home would be their first preference and living in an aged-care facility would be their last preference. Many Care Leavers feel they cannot trust the government or other organisations run by churches or charities due to past experiences. Many have extreme anxiety about being placed in an institution again especially if it is run by the same provider who ran the Orphanage or Children's Home that they grew up in. For many spending their older years in a Nursing Home is their greatest fear and for many this fear is not unfounded. Please see the attached Appendix which is the newsletter CLAN sent to all residential care services in Australia. It has the stories of two elderly Care Leavers and their fears and concerns regarding residential aged care.

It is also well documented that some residents in aged care facilities are the victims of elder abuse, and are preyed upon as vulnerable persons. Care Leavers who are already vulnerable feel particularly susceptible to this abuse because of their trauma histories, as we have already discussed those who have had previous trauma are more likely to experience elder abuse. Whilst your discussion paper does not focus on elder abuse, it is a very real concern for Care Leavers and deserves to be heard and understood.

How Can Aged Care Reforms can be Better Targeted to assist Care Leavers as a Special Needs Group?

First and foremost and reform needs to mandate that those working in both residential and non-residential aged care services are properly trained to deal with Care Leavers. This includes at an organisational level being aware of Care Leavers as a special needs group and understanding their trauma histories, but also at the individual worker level understanding how a Care Leavers immediate environment and everyday interactions can be affected by their trauma and the triggers that aged care workers need to avoid. Furthermore this training should extend beyond those as paid

workers in relevant services and it should also include any friends, relatives or support people who are paid a carers allowance or payment through Centrelink for a Care Leaver. Whilst we understand reform in this area may be hard to mandate we believe it is a vital first step to Care Leavers receiving the care and support they require. ANYONE caring for an aged Care Leaver needs to undergo specialised education and training about the unique histories, circumstances, and specialised needs of Care Leavers. This training should be conducted by groups such as CLAN who have a lived experience of a childhood in 'care' and who have worked with Care Leavers for seventeen years. It is essential that those with a comprehensive understanding of the issues Care Leavers experience and an understanding of their needs in their older years deliver this sort of education and training. Those who work with Care Leavers need to understand how their childhood experiences will affect them in their older years, this includes fear of authority figures, PTSD and the types of flashbacks that may occur and various other triggers. Issues that may present themselves in aged care that workers need to be aware of include:

- Care Leavers who were punished for bedwetting as a child. Punishments ranged from emotional and psychological abuse, to severe physical beatings, to being made to stand with their urine soaked sheets over their head. Bedwetting may occur in a Care Leavers older years.
- Care Leavers were often malnourished, under fed, forced to eat rotten food, forced fed and if they vomited were force fed their vomit. Many Care Leavers can be fussy eaters due to this past, and institutionally cooked bulk made foods can often be reminiscent of food whilst in care.
- Care Leavers were often subjected to humiliating, distressing, and painful medical examinations including internal exams which were a huge violation. This can often make it hard for older Care Leavers to be examined by doctors, nurses, have treatment and be tested preventatively.
- Medical experimentation. Many Care Leavers were subjected to medical experimentation which can make them quite wary of medications and injections.
- Psychological, physical and sexual abuse. The general abuse that Care Leavers were subjected to will make them wary of anyone who is in charge of caring for them when they are in a vulnerable helpless state. Losing their independence as an elderly person will make them dependant on those caring for them which can trigger feelings of worthlessness from childhood.
- Sometimes the names of the Aged Care facility carry the same name as Orphanages or Children's Homes that Care Leavers grew up in. For example in Wangaratta there is a hostel called St Catherine's Hostel, and in Geelong there was an orphanage called St Catherine's Orphanage. Similarly you will read in the attached newsletter the story of Frances who was in St Josephs Orphanage at Lane Cove and who had to place her husband in a Nursing Home and was faced with only one option – St Josephs Aged Care Home. Unfortunately for Frances her husband died three days later. Whilst we would like to encourage the Australian Government and Aged Care Providers to be mindful of this and to change this, in the meantime it is necessary that those working with Care Leavers understand the anxiety that this can cause and that it can be a trigger to a Care Leavers PTSD.

All of the abovementioned issues make it essential that those working with elderly Care Leavers understand these sorts of triggers, thus it is important that they are well versed in trauma informed care and are of course Care Leaver informed. Being trauma informed and Care Leaver informed involves a detailed understanding by aged care professionals and others caring for Care Leavers, of

the psychological, neurological, biological and social effects of trauma and violence on children separated from their families and raised in orphanages, Children's Homes, and foster care. Understanding the high prevalence of traumatic experiences for adults who now receive mental health services and those who are in aged care is essential. Having the correct training and supervision to work with, treat and assess individuals with trauma histories including an abusive childhood is imperative.

Additionally CLAN believe it is important that all Care Leavers (as well as other individuals who are formally cared for whether institutionally or at home) should be educated on their rights and be given information about various support systems and organisations in place to assist them. This would take place with a social worker or an 'aged care advocate'. These individuals would be tasked with educating those being cared for (including Care Leavers) with what their rights and entitlements are, numbers to call and even websites to go to for more information. They could set up Care Leavers with support and advocacy organisations such as CLAN (and other appropriate organisations for other individuals). For those who don't enter institutional care it is important that social workers or 'aged care advocates' are still involved. This may take place when an individual applies for carers allowance or payment in relation to an elderly person, or formalised in home care is funded through various government assistance programs. As you have spoken about in your discussion paper, ensuring older Australians have the capacity to be better informed and to exercise choice and control is fundamental and this is even more so in the case of Care Leavers and other vulnerable elderly Australians. It is also essential that 'aged care advocates' routinely visit elderly Care Leavers (and other elderly individuals) to assess their condition and advocate for their needs. This is particularly necessary for those Care Leavers and other elderly individuals with particular disabilities, especially sensory or cognitive impairments.

Lastly it is important that Care Leavers as a special needs group are given extra provisions to enable them to live in their own homes for longer. Any reform that takes place needs to dedicate specialised funds to Care Leavers and other special needs groups. These funds will obviously be used to ensure that Care Leavers have access to in home care for as long as possible. These funds can also be used to help support family members who may be providing in home care or high levels of care to a family member who is a Care Leaver. The Department of Health has demonstrated in this paper that keeping older Australians in their home for longer is a priority, and as already mentioned in our paper due to Care Leaver histories residential care for Care Leavers is the last option with many preferring to be homeless rather than spend their final days in an aged care facility. Whilst directing funds to a national information aged care package was a great first step, it is not enough. Care Leavers and other special needs groups need funds directed to actually providing assistance for keeping them in their own homes. This physical and tangible assistance will do a lot more than an education package on its own. Perhaps as part of restructuring home care packages, Care Leavers can automatically be assessed as needing the highest level of care despite their physical status but as recognition of their psychological state and their trauma history.

Summary of Recommendations for Reform concerning Care Leavers:

- 1. Mandated training for all those who receive funding i.e. Aged Care Services as well as those who are provided with a government payment i.e. Carers pension or allowance to look after Care Leavers. Failure to take part in this training or failure of services to ensure all employees are trained and aware of Care Leaver needs will result in funding or payments being ceased.**

- 2. Aged Care advocates provided to all those involved in accessing aged care services, but in particular Care Leavers and other special needs groups.**
- 3. Specialised funding directed to Care Leavers and other special needs groups to keep them in their homes for longer.**

CLAN once again thanks you for the opportunity to respond to your discussion paper regarding Aged Care Reforms. We are pleased and encouraged that the Australian Government is aiming to keep older Australians in their homes for longer. We just ask that you recognise the additional needs to Care Leavers as a special needs group and that funds associated with aged care are properly directed to reflect this understanding of their trauma history and the affect residential aged care can have on a Care Leaver.

Caring for Care Leavers in Australia's Aged Care sector



Care Leavers Australasia Network (CLAN) is a national, independent, peak membership body that represents and advocates for people who were raised in Australian orphanages, Children's Homes and foster care.

CLAN has been operating since 2000 and has offices in Sydney and Melbourne.

CLAN offers the following services

- Free telephone or face to face counselling
- Socials in all States
- Reunion support
- Bi-monthly newsletter
- Help to obtain your Ward or Home File
- Help to write your personal story
- Free advertising in the CLAN newsletter to locate lost family members or Home friends
- Assistance in family research

The Care Leavers Australasia Network represents people who lived in Australia's orphanages, Children's Homes, foster care and mental institutions.

We are the survivors of a child welfare care system that existed in Australia for most of the 20th century.

Around half a million people in Australia share our experience. That's equivalent to the population of Tasmania.

Care Leavers live in every state and territory in Australia and our oldest member is aged 99.

For many Care Leavers, life has been greatly diminished by the abuse, neglect and cruelty we suffered in institutional care.

Injuries and untreated illnesses from that time have had lasting impact on our physical and mental health.

Depression is common among Care Leavers, particularly those who experienced childhood sexual abuse. Anxiety disorders are also common.

As Care Leavers approach old age, many fear the prospect of returning to an institution for supportive care.

The prospect of living in a nursing home is frightening for people whose only memory of residential institutions is harrowing and hurtful.

How can you help?

CLAN is writing to aged care providers across Australia to raise awareness of the special needs of Care Leavers.

We hope to improve understanding of the painful burden of childhood trauma and ensure Care Leavers receive the most appropriate support and understanding while living in your facility. Please contact CLAN for further information in regards to our Care Leaver Training

PO Box 164, Georges Hall NSW 2198

support@clan.org.au – 1800 008 774

Survey of Care Leavers hopes for residential care

We recently surveyed Care Leavers and asked them about their accommodation preferences for the future.

Seventy per cent of respondents said they want to remain living in their own home. Their next preference was to live with family, then in a retirement village and, finally, in aged care.

The strength of feeling about remaining at home is evident in that none of the respondents marked this as their last preference. Most Care Leavers have a strong desire to live at home and remain in close contact with family.

These are some of the comments by respondents about their desire to remain at home:

- "My one and only choice"
- "I think I will be happiest here"
- "I want to live my life seeing my grandchildren"
- "I can live happily in my own home"

Many comments demonstrate Care Leavers' fear of being institutionalised again:

- "I will never live in 'care' again, I am scared of being abused again"
- "Institutionalisation"
- "I have a fear of ending up like we started"
- "I would rather die"
- "I don't want to die in an institution"
- "I would rather live on the streets than in a nursing home"
- "I need a place where my dogs can run around"
- "I would love to live anywhere that I can come and go as I please"
- "I can be free"

Some important information about Care Leavers

For many Care Leavers, certain situations trigger traumatic memories of past experiences. It is important that people working in residential facilities understand these episodes can be extremely distressing for Care Leavers and need careful management.

An example of common triggers:

- Certain foods
- Christmas
- Birthdays
- Episodes of incontinence
- News stories about the Royal Commission into Child Sexual Abuse



***Frances Muller, 93, Maitland,
NSW***

***Photographs of Frances as a
young girl and as she is today***

At age 93, France Muller still lives in her family home in Maitland. With family support, she manages her own care despite some health issues and reduced mobility after breaking her hip. This independence is important to Frances. Her Care Leaver experience helps explains why.

Frances was six when her mother left home and she and her four siblings were forced to fend for themselves when their father returned to work at sea. After three weeks, an aunt took in Frances's two brothers, aged 12 and three. Frances and her sisters, aged eight and 10, were placed in St Joseph's Girls Home at Gore Hill (Lane Cove) in Sydney.

Frances describes her six years in the orphanage as a living hell, where the nuns ruled the strict daily routine without mercy, using sticks and canes to discipline girls for even daring to speak at mealtimes. She says she's never seen cruelty like it. Those years in the orphanage left a permanent mark: "You lose your childhood and that's it," she says matter-of-factly.

Although eventually reunited with her mother, Frances says the family was permanently fractured.

Now surrounded by her own large, loving family of five children, 18 grandchildren and 30 great grandchildren, she is determined to stay in her own home and lives in dread of waking up in a nursing home.

"It's absolutely terrifying," says Frances. "I'd rather die than let that happen to me. All those rules and regulations; the thought of living in an institution under someone else's control really frightens me."

Frances says she was forced to make the reluctant choice to put her husband in aged care when, already suffering dementia, he broke his hip. The difficult decision was made worse because the home had the same name as her childhood orphanage. Her husband died four days after being placed in care and Frances still finds those memories painful: "I felt incredibly guilty."

Frances believes many Care Leavers share her fears of aged care and operators need to understand that these childhood experiences have life-long impact.



Alf Stirling, 75, with his wife Bev from Lalor, Victoria

Alf has been married to his wife Bev for 54 years. They have two children. Alf has lived on a disability pension since 1976. His body is covered in 70 scars from the beatings he endured as a teenager living in the Salvation Army's Bayswater Boys' Home in Melbourne.

Nearly sixty years later, Alf still sleeps with an axe and knife under his bed as a result of his Care Leaver experience.

Alf was 14 when he was falsely accused of stealing a friend's bike. Despite having a job, the court made him a ward of the state and he was sent to Bayswater Boys' Home "to make him a good person."

Alf says Bayswater was not a home, it was a slave labour camp or prison. He was forced to work on a mobile sawmill, 11 hours a day and sleep in a small cell-like bedroom. He sustained life-long damage to his back and loss of hearing as a result of severe beatings but it was the repeated sexual assaults that continue to haunt him. Those assaults were a secret he kept from everyone including Bev until 11 years ago.

Alf can only sleep three or four hours a night, he won't relax if there's a light on in the house and is easily woken.

The brutality of those teenage years has left him short-tempered, quick to anger and violent. He doesn't like anyone sitting or standing behind him.

Alf says the thought of living in an aged care facility fills him with dread. He knows he would find the experience stressful and considers a grim alternative: "They should leave us with a needle, if we choose, rather than live in a nursing home."

For Bev, the future is filled with uncertainty. As Alf's health deteriorates, she acknowledges she will eventually find it too difficult to manage him and worries about the options available. She understands Alf will require specialist care but worries about how that would be provided. It is, she says, a terrible burden for them both.

For further information about CLAN and the work we do or to access further advice and guidance about support for Care Leavers living in your residential facility, please contact us on 1800 008 774 or support@clan.org.au