



Submission to The Royal Commission into Aged Care Quality & Safety

This is a good news story.

A story, that in light of the many that will be recounted to the Royal Commission, we want to be held up and shared as an example of what can be achieved when the right model of care is delivered and embraced.

A story, told by those who have experienced it, which will create hope for other communities across the country.

A good news story that needs to be heard to inspire other organisations and communities to take a leaf out of its book.

A story that will change the way others view the ageing and dying process.

A positive story that we would ask the Royal Commission to consider.

We're very proud of this special Fernlea story. But don't just take our word for it - let those who have the "lived experience" speak for themselves.



Who is Fernlea Community Care?

Fernlea Community Care Inc provides centre-based day respite and in-home care to people with a life-limiting illness, chronic conditions or dementia. Located in the Dandenong Ranges, our services cover the outer eastern and southern suburbs of Melbourne, across Knox, Yarra Ranges, Cardinia and Casey local government areas, which research shows is one of the leading growth areas in Australia for over-65's.

Fernlea opened its doors in 2005, as a direct response to the local community identifying a lack of support within their community for people with a palliative illness. Way before in-home care became a government strategy, Fernlea's founders and early supporters identified the importance of providing this support within a home-like environment, and of making communities part of the solution. The value of this was recognised by the Commonwealth government, who supported us with an \$800,000 grant through the Department of Health. This innovative service model was also recognised by Jason Wood MP, who spoke about Fernlea in his maiden speech to federal parliament.

This community-driven, grassroots beginning set the tone and approach, which still today informs and underpins our model of care – a model where the person is placed and remains at the centre of everything we do, where they are listened to, their abilities, likes and dislikes are heard and taken into account as an integral part of our service delivery; where they maintain or regain control over their lives; where their age or illness is not the focus – they are. It is not a clinical model or merely transactional, but instead the emphasis is on our clients – who we call guests – having a nice day, in an inclusive, positive and social environment shared with others.

Our staff and volunteers form deep, lasting relationships, not only with the people they care for, but also with their carers, who we see as partners. We see first-hand and in a very personal way, the challenges that ageing and dying present, but we also see what those people who are aging and dying need to live fulfilling, valued lives. Our work cuts across aged care, palliative care, carer welfare, disability, volunteering and community – we are living proof that 'it takes a village'. But we are also proof of a model that works – a model that we believe could be adopted across a troubled aged care sector.

Fernlea has a story to tell. It's a story from a grass-roots service that has not lost sight of what and who is important, and why we started on this journey all those years ago to make a positive difference in people's lives when they need it most.

“Fernlea was oh, like a shining star to begin with and it still is. I thought ‘oh wow, this is wonderful’. It’s given John somewhere to go and he loves it. I think it’s because it’s such a nice warm environment created by everyone who works and volunteers there”

Libby, carer

About This Submission

This submission focuses on the terms of reference criteria (d) and associated criteria (c) & (e):

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

Fernlea's Submission

SETTING THE SCENE – WHAT DRIVES US

According to the Grattan Institute's *'Dying Well'* report, 70% of people want to die at home, but only 14% do¹.

Statistics also show that Australia has an ageing population. In 2017 more than 1 in 7 people (or 15%) were over 65 years old, increasing from 9% in 1977. By 2057 that is expected to grow to 22% and by 2097 to 25%². Scientists have recently suggested that the first person who will live to 150 has already been born, and even people with a serious or palliative illness, will live longer lives as further cures and life-prolonging interventions are discovered. All of this means that the need for innovative and humane aged and end-of-life care models will only increase. Despite this, it appears we still struggle with how to manage older people kindly, with dignity and in a way that creates a life they can enjoy, especially as they become unwell and die.

In March 2019 it was reported that 128,000 people who had been assessed for a Home Care Package were still waiting for their funding to come through³. We know anecdotally, and from our own experience, that people die while waiting for their Home Care Package funding to come through – in fact, the Commission noted in its interim report *'Neglect'* that 16,000 people died in 2018 waiting for their Home Care Package. Not fully funding in-home care forces people who would choose to die at home, into residential aged care. This is not only far more costly, both economically and in human terms, it is also the exact opposite of what the Government had hoped to achieve by creating its home care strategy.

The type and quality of care that most Australians experience towards the end of life often does not reflect their values, goals, or choices. Creating that place is what drives us.

¹ Grattan Institute, *Dying Well*, September 2014

² Australian Institute of Health and Welfare, *Older Australia at a Glance*, Sept 2018

³ www.australianageingagenda.com.au, *Figures show home care queue jumps to 128,000*, March 2019

FERNLEA'S MODEL OF CARE

The word 'care' is defined as 'the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something' or 'serious attention or consideration applied to doing something correctly or to avoid damage or risk'. Some of the stories we are hearing come out at the Royal Commission reflect neither of these definitions in terms of welfare, protection, and avoiding damage or risk.

It is difficult to know for sure what has gone wrong in aged care that has brought us to the point of needing a Royal Commission. Themes are emerging, including staff ratios, training and qualifications, rising costs, the push to make a profit and therefore becoming more 'efficient' to cut costs without any subsequent increase in the quality of care.

But how do you create and sustain high quality care against this backdrop? Our experience shows it can be done, with relatively small amounts of funding, but that there are clear elements that help create it.

Person-Centred

The key to Fernlea's model of care is that it focuses on the whole person, and doesn't allow their medical condition to define them. This sounds clichéd, but when our guests come to us with a life-limiting illness, they have already experienced so much medical intervention that it seems like the sole focus. Our aim is to place that focus back on them as whole person, to give them back some independence and control over their lives.

Firstly, and most importantly, we consider our care to be an important part of their overall treatment. It isn't just a series of isolated transactional tasks - quality care is a continuum and a critical element for improving our guests' well-being and quality of life. Much of what we do is not measurable but it is in small things, practices like actively listening and allowing the person to do things in their own time without rushing them, using their name, maintaining eye contact and understanding the importance of touch and human contact, including our staff and volunteers providing hand and foot massages. It is about building relationships - alongside qualified staff, we have trained volunteers, which allows us to often provide one-on-one care for our guests, creating an environment where our staff and volunteers truly get to form relationships with the people they care for. For example, when our guests transition from centre-based respite to in-home care, we try wherever possible to have the same staff member look after them so there is familiarity and minimal disruption for them.

Secondly, we regard 'slowness' as a principle that underpins our model. To the onlooker, what happens at Fernlea may appear casual and unhurried - it is intended to, although a lot of planning happens behind the scenes. We train and encourage our staff to not only use their clinical knowledge but also to trust their intuition. Our environment is not clinical or slick and modern - it is deliberately homely. We provide a range of group and individual activities suited to what clients (guests) tell us they like. We involve them in activities like gardening so they can continue to experience the things they did before they became frail or unwell.

Another important part of being person-centred is that we not only focus on the guests, but also on their carers, because we know when carers struggle, so do their loved ones. We do this by creating a care plan for carers as well as guests, so that we can monitor their journey. While our services are intended to provide carers with a break, we recognise the need to continue working in partnership with carers, and to build trust and transparency, so carers are communicated with regularly and encouraged to visit whenever they want.

Wellness

Ageing and death have become very medicalised, with the focus often being on prolonging life, at the expense of quality of life. A focus on the medical however, does not always equate to being well – there is a difference between living and just existing. While palliative illness and wellness may seem at odds with each other, wellness and reablement are goals we work with our guests and their carers to achieve. Through care planning, we work with our guests and their carers to set purposeful goals for how they wish to live to help regain their independence and autonomy, and to giving meaning back to their lives.

“An excellent model of care, unique to Fernlea only. A place where the focus is on ability, not disability”

Pamela, Nurse Manager

Food and Nutrition

Food has been a big focus for the Commission, with some upsetting stories emerging. For Fernlea, food has become a key component in delivering quality care to our guests.

- We use fresh and seasonal produce that we grow organically ourselves, or source locally
- We employ a qualified chef who prepares fresh food daily and is passionate about his work
- Food quality, visual appeal and nutritional value underpin every meal produced
- We tailor and produce meals for our guests that help maximise nutrition, reignite their interest in food and support challenging health conditions such as dementia and cognitive decline
- Our meals nourish the soul and trigger fond memories through taste & recreating traditional recipes



We do all of this within a restricted budget but without the focus being on cost-cutting. Yes, it is possible!

“Food should be a pleasant experience. We shouldn’t just eat for wellness, we should enjoy what we eat. The food at Fernlea is fresh, it’s lovely to look at and it tastes amazing. The chef does a beautiful job”.

Paula, guest/client

Quality food, lovingly prepared and eaten in the company of others has far greater benefits than just nutrition – it has helped our guests to stop being lonely and to create social connections. It has also evoked cherished memories for people with dementia.

Peter's Story:

We know the importance of good food and nutrition. It is an added bonus when the meals our chef makes resonate with our guests on an emotional and sensory level. Last week, David recreated a traditional favourite, corned beef with mustard sauce. Peter, one of our guests, said it was the best meal he ever had, and it reminded him of his mother's mustard sauce and corned beef he enjoyed so much growing up.

Even gestures that seem so small can make a big difference.

Heather's Story:

When staff asked our guest Heather what cake she'd like to celebrate her birthday she jokingly said she wanted to have a croquembouche, a French dessert made by combining custard-filled choux pastry puffs piled into a cone and decorated with threads of caramel. Heather's wish came true when our chef David set about creating Heather's cake. We hope this birthday holds very special memories for Heather to cherish.

Fernlea is encouraged by and supports the work that Maggie Beer is doing and hopes that she and others are able to positively influence outcomes for people in aged care.



"Your video made our day, thank you, David, Paula and all those on the video for their contribution, it means a lot to us..."

Maggie Beer Foundation

IT TAKES A COMMUNITY

Fernlea advocates a 'community-participation' approach to supporting people to age and die at home. Community members and organisations, not just health professionals, must be a fundamental part of the care landscape. This is especially true if the benefits of the Australian Government's Home Care Package model are to be maximised. Research shows that supporting people to die within their own community not only has a wide range of benefits for the person, but also for the wider community⁴.

⁴ Grande & Ewing, *Palliative Medicine* (22) pp 971-972, 2008

The Role of Community-Based Organisations

A large body of research links social isolation with adverse outcomes such as increased depression rates, cognitive decline and premature death. While the Grattan Institute's *'Dying Well'* report identified that a majority of people want to age and die at home, facilitating that alone will not necessarily prevent social isolation.

The ability to be cared for within the home meets many of people's needs as they age and grow frail, however, even with in-home care, people can become socially isolated. Services like Fernlea that are delivered out in the community are a good adjunct to, and complement home care, serving several purposes. Firstly, they offer a place to come to not only develop and maintain social connectedness, but also a place to take part in activities that can improve clients' (guests') quality of life and provide a focus other than their illness.

A young man came to us with a brain tumour and a prognosis of less than six months to live. He had become socially isolated at home because he felt so unwell and the financial impact of having to stop work. He was with us for seven years, and while only anecdotal, he often talked about how important the friends he made through Fernlea were to him, and the part he believed that played in him living so much longer.

It is also well-documented that the role of carer, while often rewarding, can at times be relentless and stressful, as they deal with not the impending loss of a partner or loved one but also take on additional tasks like symptom management, personal care and increased medical appointments. Unsurprisingly, carer burden has been shown to be associated with depression, anxiety, anticipatory grief and bereavement beyond their caring role⁵. Services like Fernlea not only help to reduce social isolation and improve quality of life outcomes, they also provide an important opportunity for carers to have a break.

Fernlea supports the consumer-directed model for aged care, as it gives control and independence back to consumers. However, for people over 65 who don't yet have a package, those with a package but a need for social connections, and for carers who need a break, the continued funding of community services is critical.

The Role of Volunteers

Volunteers are an integral part of the success of Fernlea's model, not only because it brings together and engages our community, it also provides a resource our organisation couldn't otherwise afford, which in turn improves the depth and quality of our service. This is a particularly important model for regional, rural and remote communities, where access to formal services can be problematic. In these circumstances, a community-participation model can support people who live in these areas to age and die within their own communities.

"I volunteer because I want to give back to the community, to give back to people so they can have some quality time, some 'me' time, that's why I'm here"

Petra, volunteer

⁵ Australian Institute of Health and Welfare, *Dementia in Australia: national data analysis and development*, 2007
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Conclusion & Recommendations

Our aim in doing this submission was not only to tell the Commission about our model of care through the people we care for, but to do so because we truly believe it is a model that could be adopted across aged care, to bring about better outcomes.

We thank the Commission for the opportunity to brief them about these important issues, and recommend:

- A paradigm cultural shift across aged care services, to embed a person-centred model of care, which focuses on the client as an individual, and discourages care being seen merely as a series of transactional tasks. For example, in any major hotel chain, they use key benchmarks that denote the level of service guests can expect. Similar benchmarks should be set for the aged care industry, which focus on the person as a guest to build a relationship with, rather than a problem to be dealt with through transactional tasks
- Develop a 'community-participation' approach to supporting ageing and end-of-life, which engages the community as part of the solution to support people to live independently at home for as long as possible, or preferably to die at home
- The Government continue to fund community-based services that support and work in parallel with Home Care Packages to reduce social isolation and improve quality of life

