Welcome to the latest Newsletter from the Royal Commission into Aged Care Quality and Safety. There’s news from hearings, community forums, and from behind the scenes at the Royal Commission information line. Turn to the back page for information on how to get in touch.

REMOTE AND REGIONAL AGED CARE

The Royal Commission has held hearings in Broome, Darwin and Cairns that focused on aged care for people in remote, rural and regional locations in recent weeks. The Commission heard about aged care in the Kimberley, the desert regions in central Australia, the Torres Strait Islands, far north Queensland and the Northern Territory.

Aged care providers, health services and people with direct experience in providing or receiving aged care outside of Australia’s major cities gave evidence about the challenges in these locations. These include high costs, difficulties attracting and retaining staff and the lack of supporting services to maintain buildings and facilities.

Witnesses explained how a person’s ability to remain living healthily at home is closely linked to the efficacy and accessibility of health services provided by nurses, doctors and dentists. People living outside of urban centres can struggle to access these types of services. If their health deteriorates, they may have to move away from their home and community to a regional or urban centre in order to get the aged care and health care they require.

The Broome and Darwin hearings also explored aged care for Aboriginal and Torres Strait Islander people. Many of the witnesses were Aboriginal and Torres Strait Islander people who deliver aged care and health services across Australia. Several witnesses came from remote Aboriginal communities to talk about their aged care experiences.

Following the Broome hearing, Commissioner Briggs, together with some of the Commission’s staff travelled to the remote Aboriginal community of Bidyadanga, almost 200kms south of Broome.

The Commission met with aged care workers, health service workers and members of the community in Bidyadanga, one of whom generously shared a location of cultural significance at the nearby beach with the Commissioner’s staff.

The Darwin hearing took place during NAIDOC Week celebrations. At that hearing, Ms Numamurdiri, an Aboriginal Elder from the remote community of Numbulwar, spoke about her distress and sadness at having to leave her community and move 800kms away from her family to get the care she needs. Many witnesses explained the importance of home and residential aged care providers understanding and meeting the cultural needs of their Aboriginal and Torres Strait clients.

The Royal Commission heard about the unique circumstances in the Northern Territory, and how services could be improved if health and aged care providers shared more information.

While in Darwin, Commissioners and Royal Commission staff visited the Juninga Centre for Aboriginal and Torres Strait Islander people. The centre is run by Australian Regional and Remote Community Services.

Above - Royal Commission staff with Commissioner Briggs (centre) and Bidyadanga resident Madeleine Jadai at Bidyadanga Beach in the Kimberley Region.

PEOPLE LIVING OUTSIDE OF URBAN CENTRES CAN STRUGGLE TO ACCESS THESE TYPES OF SERVICES. IF THEIR HEALTH DETERIORATES, THEY MAY HAVE TO MOVE FROM THEIR HOME AND COMMUNITY TO A REGIONAL CENTRE TO GET THE CARE THEY REQUIRE

FOR INFORMATION ON SUPPORT SERVICES, SEE THE END OF THIS NEWSLETTER
The Royal Commission turned its inquiry to the quality and safety of residential aged care, particularly in relation to dementia, in hearings conducted in Sydney over eight days from 6 May 2019.

The need for dignity and respect for aged care residents emerged as constant themes.

There were a number of firsts in these hearings, with four case studies, comprised of investigations into the experiences of individuals with dementia in residential aged care, and of their families, presented to the Royal Commission.

The Royal Commission heard for the first time from residents living in aged care facilities. It also heard from aged care staff, including a registered nurse and several assistants in nursing.

The hearing began with evidence from two residents living in aged care facilities about their experiences and impressions of living in aged care—Ms Merle Mitchell AM and Ms Darryl Melchhart.

Ms Mitchell referred to the sense of loss of her way of life, finding herself suddenly in an institution without choices of activities, including when to get up or when to eat. She did not regard residential aged care as her home and said:

‘That there’s just that feeling that this isn’t a proper life. And so there is that feeling that the quicker it’s all over, the better it is for everybody.’

Ms Mitchell added that even though the aged care facility was where she lived, it was not home.

Ms Melchhart described her experiences in residential care as a never-ending battle to be seen as a fully competent adult and stated that her wishes for autonomy and privacy were often disregarded by staff.

Personal Care Attendant, Kathryn Nobes, gave a detailed account of the daily challenges she faces caring for older residents with dementia.

The Royal Commission also heard evidence from family members about the deterioration of loved ones as a result of physical or chemical restraint.

In the second week of the hearings, the Royal Commission heard evidence about models of best practice care for residents with dementia from the leadership of three aged care providers: Group Homes Australia, Glenview Community Services; and Brightwater Care Group. There was also expert evidence from academics including Professor Henry Brodaty and Professor Joseph Ibrahim in relation to dementia care.

The hearing concluded with the evidence of Mr Trevor Crosby and Ms Kate Swaffer both of whom are living with early onset dementia. They told the Commission about how it had changed their lives and that of their families.

In his closing remarks to the Sydney hearing Senior Counsel Assisting, Peter Gray QC, said: ‘Older Australians who move into residential care do not leave their rights at the door.... A resident living with dementia is entitled to respect and dignity and the freedom to live their life as they choose....’
The Royal Commission headed to Western Australia in June for a two and a half day hearing in Broome – the first hearing outside a capital city. This was followed by a five day hearing in Perth. The Broome hearing focused on care in remote areas, unique care needs of Indigenous Australians and issues of access and inclusion.

There were stories about the challenges in regional and remote care facilities. Nurse Yvonne Grosser told the Royal Commission that there was a need for greater cultural awareness training in aged care.

Community care supervisor Faye Dean from the Bidyadanga Aboriginal community described how they provided culturally appropriate care at their facility. When asked about the most important thing in delivering care, she said:

*Respect again, and dignity.*
*You go, you know, very slowly. You go at their pace.*

Professor of geriatric medicine Leon Flicker spoke about how Aboriginal and Torres Strait Islander People do not immediately accept that a person in authority is there to do them good. He said:

*The legacy of the Stolen Generations presents a stark reminder of why Aboriginal and Torres Strait Islander People won’t necessarily trust non-Aboriginal and Torres Strait Islander People.*

Professor Flicker said that Indigenous People were under-represented in residential care because of ‘a lack of cultural safety’.

The Perth hearing investigated the nature of person-centred care, advanced care planning and palliative care services. UK expert in aged care, Dr Lisa Trigg, gave evidence on the final day of the hearing where she spoke of brilliant but also disappointing examples of aged care in Australia’s system and some instances of poor dementia and end of life care.

She said she was surprised that 98% of aged care providers passed accreditation ratings.

Ms Shannon Ruddock described the guilt she felt in her hoping that her father’s health would deteriorate so that he wouldn’t have to return from hospital to his aged care home.

The hearings moved to Darwin in July. The focus was on clinical care, with a close look at remote settings. The Commission heard evidence about poorer access of older Indigenous People to aged care services and treatment in Australia compared to other older Australians.

Evidence given by Northern Territory-based Olga Havnen, chief executive for Danila Dilba Health Service, said that, ‘Aboriginal people have by far the most complex health conditions and most complex level of needs but receive the least level of service’.

Three days of hearings in Cairns investigated nutrition, food quality, cultural safety and clinical care. There was evidence of sub-standard care accelerating residents deaths, of poor food hygiene and cost restrictions on food leading to poor nutrition.

Maggie Beer AM, founder of the Maggie Beer Foundation advocated for better food practices in aged care. She gave evidence, saying: ‘We owe it to our elderly residents and also those in the community who are alone and no longer cooking for themselves. We need to look after them.’

Below - Mikaela from The Royal Commission logistics team gets ready for the road.
BACKGROUND PAPERS HONE-IN ON ISSUES

Family and friends who provide informal and unpaid care to older Australians are critical to the sustainability of the aged care system, and as the population in Australia continues to age, the reliance on informal carers is set to increase.

That is a key conclusion of Background Paper 6: Carers of Older Australians, which is the Commission’s most recent background paper. Background papers are being prepared to support the work of Commissioners Richard Tracey and Lynelle Briggs in inquiring into the operations, challenges, successes and failures of aged care Australia.

Each paper tackles a specific theme and is published on the Royal Commission’s website www.agedcare.royalcommission.gov.au. This work complements the Royal Commission’s own research projects, examinations of thousands of submissions from across Australia and the evidence of witnesses, led by Counsel Assisting the Royal Commission.

It was clear at the outset of the Royal Commission that navigating the maze of Australia’s aged care system is complex. This is the topic of Background Paper 1.

The second background paper puts the changing demographics of Australia under the microscope to explore the medium and long-term pressures on the system.

Further background papers have been published by the Royal Commission. They include Background Paper 3, which investigates dementia in Australia — it’s nature, prevalence and care — and Background Paper 4 which outlines restrictive practices in aged care. It considers the use and impact of both physical and chemical restraints imposed on people in residential aged care with dementia.

Meanwhile, issues surrounding advance care planning are examined in Background Paper 5, entitled Advanced Care Planning in Australia. It states that most older Australians are not set up to direct the way they are cared for in the event that they become incapable of communicating as a result of accident, dementia, or illness. Even those aged 65-plus years are often ill-prepared, with only 3% having a legal advance care directive in place.

Additional papers are planned and will be made available on the Royal Commission’s website.
UPDATE ON COMMUNITY FORUMS

The Royal Commission has held a number of community forums across the country. More than 700 people attended forums in Bankstown, Bendigo and Wollongong in March. In May, June and July, community forums were held in Melbourne, Broome and Townsville.

Members of the public are invited to attend a community forum near them so they can hear about the work of the Royal Commission. They are also welcome to register to speak at a forum and offer their ideas on the challenges and strengths of aged care.

Maidstone, Melbourne VIC

The fourth community forum was held in Maidstone, Western Melbourne, on 3 May. The Commissioners heard moving stories of issues in aged care, including the lack of alternative care for young people with disabilities.

Speakers discussed a variety of challenges that involved many aspects of aged care such as: residential care, home care, dementia, rehabilitation and guardianship. They also spoke about concerns they had about aged care accreditation and complaints, and how the system interacts with the National Disability Insurance Scheme.

Broome, WA

The fifth community forum was held at the Broome Civic Centre on 19 June. Some speakers travelled long distances from across the Kimberley region to share their experiences about aged care in remote areas of Western Australia.

The Royal Commission heard upsetting accounts of aged care. Speakers also talked about the importance of culturally appropriate care for Aboriginal and Torres Strait Islander people, the opportunity to return to country and barriers to accessing aged care. There was some important guidance about aged care practices which were working and which could be expanded.

Townsville, QLD

On Thursday 18 July, more than 180 people attended a community forum in Townsville. There were 20 speakers at the venue in Southbank. Many provided emotional and heartfelt statements to Commissioner Briggs. People shared stories about neglectful care, poor food quality, medication administered without consent and the need for adequate care plans. There were stories about the needs of those who had experienced abuse in institutional settings. Aboriginal and Torres Strait Islander people spoke about the importance of recognising kinship and the challenges of communicating across languages. Community members heard about challenges common to culturally and linguistically diverse groups in aged care.

For information on support services, see the end of this newsletter
THE HUB OF THE
ROYAL COMMISSION

The Royal Commission has an in-house information line that members of the public can call with any queries. Staff take calls, assist the community with making a submission and answer email and letter enquiries. It’s referred to internally as ‘The Hub – voice of the people’.

Within the ‘Hub’ there is also a counselling and support team. Members of the public can talk to one of them should they need to. Anyone can make a submission over the phone or get advice on how to make a submission. They can access specific information on upcoming community forums or hearings and they are referred to other pathways to receive advice and assistance.

“Sometimes, it’s the first time they have spoken to anyone about their story and they want to know that their story has been heard, that we acknowledge the persons’ experience. Potentially some of the people (who call in) will become involved in the Royal Commission in other ways, either as speakers at community forums or potential witnesses at hearings. It’s crucially important that the information recorded reflects the individual’s voice and that they know their story will inform future reports and recommendations of the Royal Commission.”

It was important to have a team of people who were ‘in house’ so that staff taking the calls can immediately share their knowledge and information with other teams in the commission, legal, policy or community engagement teams to best inform the work of the Commission.

“Director of Counselling, Enquiry and Correspondence, Danielle Grant-Cross says that the ‘Hub’ staff are often the first contact members of the community have with the Royal Commission:

“The Hub staff are a very important link with the community the Royal Commission serves. It’s important that people can call and speak to listeners who can empathise. It can be very distressing for the caller to speak about their own or their family member or friend’s personal story,” said Ms Grant-Cross.

“It’s so vital that we can share emerging themes and information on calls and submissions we are receiving in real time. The ‘Hub’ really does capture the voice of the people and in essence reflects what the community are saying,” explained Ms Grant-Cross.

The Hub has received 5,258 submissions and 3,013 phone calls to date. It’s open from 8am to 6.30pm ACST. You can call the information line on 1800 960 711.

Above - Members of the hub team.
SUBMISSIONS BY STATE

To date the Royal Commission has received 5258 submissions from across the country. If you would like to make a submission, go to: https://agedcare.royalcommission.gov.au/submissions

Have you got any questions about the Royal Commission? Read our FAQs on the website: https://agedcare.royalcommission.gov.au

(Q) “CAN I MAKE A SUBMISSION WITHOUT GIVING MY NAME?”

(A) “YOU CAN MAKE YOUR SUBMISSION ANONYMOUSLY AND YOU MAY CHOOSE NOT TO PROVIDE CONTACT DETAILS.”

(Q) “HOW DO I ATTEND A COMMUNITY FORUM?”

(A) “SIGN UP TO OUR MAILING LIST AND KEEP AN EYE ON OUR WEBSITE AND FACEBOOK PAGE FOR ANNOUNCEMENTS AND LINKS TO REGISTER TO ATTEND.”
TO DATE, THE ROYAL COMMISSION HAS RECEIVED 5258 SUBMISSIONS.

WE HAVE RECEIVED 3013 PHONE CALLS TO OUR INFORMATION LINE TO THE COMMISSION ON OUR 1800 960 711 INFORMATION LINE.

ACCESIBILITY AND SUPPORT

Accessibility services

Individuals who are visually impaired can call our inquiry line on 1800 960 711 for assistance with a question or to make a submission.

For people who are hearing-impaired or have complex communication needs, we are using a phone service provided by the National Relay Service. The Royal Commission can provide an Auslan interpreter at hearings and community forums upon request.

We can also accept submissions in other languages over the phone or via hard copy. We are using the Translating and Interpreting Service to help support this.

Counselling and support

Trained operators are available through the Royal Commission information line to offer information and support for callers who are distressed. Phone 1800 960 711 8am–6.30pm ACST, Monday–Friday except on public holidays. An interpreter service is also available. Please go to our website to see a full list of support services that are available to you.

Contact us:

There are a number of ways you can in touch with the Royal Commission:

By email: ACRCenquiries@royalcommission.gov.au

By telephone: 1800 960 711 (8am – 6.30pm ACST, Mon-Fri except public holidays)

By post: GPO Box 1151, Adelaide, SA 5001

Go to our website: https://agedcare.royalcommission.gov.au

We are also on Facebook: www.facebook.com/agedcareroyalcommission/

'Like' our Facebook page:
@Agedcareroyalcommission

Sign up to our mailing list via our website:

Below - Commissioner Briggs at the Royal Flying Doctor base in Broome.

https://www.facebook.com/agedcareroyalcommission/

2019 ACRC