Dementia Training Australia

Nungoo ngich, dunga ngich
See me, hear me

The story behind the story

In order to respect privacy, confidentiality and cultural sensitivities regarding the exposure of people after death, the faces of Aboriginal residents in this film have been pixelated.

DVD to be put in pouch here

Acknowledgements

We acknowledge the Noongar People and their Elders, the traditional owners of the land on which this documentary was filmed.

Dementia Training Australia (DTA) also acknowledges all of those who have had an input into the development of this resource.

Project team

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HALL & PRIOR
Health & Aged Care Group

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Table of Contents

Section I: About this resource

This booklet and DVD were originally produced by the Western Australian Dementia Training Study Centre (WA DTSC), and are intended to be viewed prior to attending the workshop, 'Completing a culturally safe assessment of Aboriginal and Torres Strait Islander people with dementia'. The DVD and booklet resources highlight some cultural considerations which will be further explored in the workshop.

> *When an Aboriginal or Torres Strait Islander person moves into a residential aged care facility (RACF), the experience may become one of re-institutionalisation at a time of greatest vulnerability for themselves and their family. Understanding how the individual's personal and social history, their culture and beliefs impact on their experience and interpretation of their environment, may lead to improved care approaches and enable the Aboriginal or Torres Strait Islander person to retain their social and cultural identity.*
>
> *Heather Freegard*

In 2012, the WA DTSC collaborated with the Hall & Prior Health & Aged Care Group, to carry out this project at a Hall & Prior aged care facility named Windsor Park in Perth, Western Australia. An Aboriginal artist, Ron Gidgup worked with the Aboriginal residents of Windsor Park to produce three meaningful artworks that told the residents' stories, explored their cultural beliefs and illustrated some of the recent history of Aboriginal people in Australia.

In this booklet the lived experience of some of the Aboriginal residents at Windsor Park are documented, followed by a brief overview of the project and its outcomes. All stories have been anonymised to protect the identity of the residents. Within this booklet the word 'Aboriginal' is used to refer collectively to all Australian Aboriginal and Torres Strait Islander peoples. Wherever possible, reference to more specific communities or groups is made; however, we are sharing the stories of old people with cognitive impairment, many displaced and dislocated from country and family and with incomplete knowledge of their own beginnings. It is a sad truth that for some of the residents we have not been able to locate their histories. The film is named *Nungoo ngich, Dunga ngich* or *See me, Hear me* - this booklet is 'The story behind the story'.

Dementia in the Australian Aboriginal context

Dementia is the ninth National Health Priority of the Australian Federal Government.

Presently there are an estimated 400,833 Australians living with dementia[1]

The prevalence of dementia in Aboriginal Australians is between 3 and 5 times higher than that in the general Australian population[2]

Aboriginal people tend to have a younger onset of dementia than the general Australian population- between 45 and 64 years of age, compared with 65 to 84 years[3]

Dementia is viewed differently in Aboriginal culture and there is no Aboriginal word for it. It therefore often goes unrecognised as a medical condition[4]

Section II: Traditional Aboriginal culture, health and well-being

Australian Aboriginal people have been in Australia for at least 50,000, some say up to 75,000 years[5]. Traditional Aboriginal spirituality or culture is based around the belief that there is an *'interconnectedness of the land and universe, animate and inanimate, whereby people, the plants and animals, landforms and celestial bodies are interrelated'* [6]. How the world is viewed, including how it came to be, how it should be cared for and how people should interact with one another, is explained in the Dreaming. The Dreaming is a Western construct to explain the Aboriginal view of geographical and human history, moral stories, law and present reality[6].

The Dreaming

"The Dreaming is many things in one. Among them, a kind of narrative of things that once happened; a kind of character of things that still happen; and a kind of logos or principle of order transcending everything significant for Aboriginal man… It is a cosmogony, an account of the begetting of the universe, a study about creation. It is also a cosmology, an account or theory of how what was created became an ordered system. To be more precise, how the universe became a moral system" [7]

William Edward Hanley Stanner

Aboriginal people are connected to the land, sea, plants, animals and one another. The connection is explained through the Dreaming and is maintained through Aboriginal Law.

The Law

"The Law ensures that each person knows his or her connectedness and responsibilities for other people (their kin), for country (including watercourses, landforms, the species and the universe), and for their ongoing relationship with the ancestor spirits themselves" [6]

Vicki Grieves

Health and wellbeing are related concepts in Aboriginal culture, and are more holistic and grounded in spirituality than the Western model of health[8,9]. Being healthy is more likely to mean being able to connect with country, close family and kin and be able to express spirituality. In Aboriginal culture, having dementia may be inconsequential, as long as connection to country, spiritual and family needs are being met.

Spirituality

"Aboriginal spirituality is defined as at the core of Aboriginal being, their very identity. It gives meaning to all aspects of life including relationships with one another and the environment. All objects are living and share the same soul and spirit as Aboriginals. There is a kinship with the environment. Aboriginal spirituality can be expressed visually, musically and ceremonially"[6]

Elizabeth Grant

Section II: Traditional Aboriginal culture, health and well-being

Aboriginal expression of spirituality and culture can be through art, music and ceremony[6], and this understanding is upon what the 'Creative arts' project is based.

Health

Aboriginal health means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their community.

It is a whole of life view and includes the cyclical concept of life-death-life[10]

Section III: The lived experience

Eighteen of the residents of Windsor Park at the time this documentary was produced recalled suffering from racism and discrimination as a result of laws and practices that were commonplace throughout the 20th century. They had experienced removal from traditional lands; being employed for rations, clothing and blankets; being denied access to education; being taken into custody without trial or appeal; requiring a permit to enter prescribed towns; and the forced removal of children from parents. Details are scant about many of these residents; however, we do know that all were resilient to these hardships. Despite actions designed to extinguish their culture, they maintained their traditional practices and beliefs through language, art, dance and music, food gathering and bush medicines.

The following stories were gathered from these residents during the production of this film (names have been changed to maintain anonymity).

DM was probably born in the Western Desert, around 1939, and with her brother and parents lived the traditional life of the Martu*. Known to be some of the last Aboriginal people 'to come in from the desert' it is not clear at what age DM first made contact with white people- in the 1960s (when DM was a young adult), some Martu had never encountered white people. Around this time the Martu were removed from their lands to live on missions or native settlements to make way for the Blue Streak missile tests at the Woomera Test Range, South Australia.

As a young adult she and her partner were banished from her community for an improper relationship. We do know that English was her second, possibly third or fourth language, that she had no children of her own, that she cared for the children of a station manager, was a good cook, and helped with mustering.

In 2008, (age around 69 Years) DM came to Windsor Park as a resident with cognitive impairment and other complex health needs. Her partner was her only visitor, whose visits stopped when the partner's frailty and mobility problems made travel too difficult.

WB, a Noongar man born in 1935, could not (or chose not to) remember where he was born and nothing is known of his early life. As a young adult he and his brother joined a travelling tent boxing troupe. Following the fairs and agricultural shows they would put up their tent and take on all-comers in the ring for cash. For poorly educated, fit Aboriginal men versed in the rudiments of boxing, it was a relatively steady means of employment until the practice ceased in the 1960's. He lived with his defacto wife of 30 years in the northern suburbs of Perth before coming to Windsor Park. She did not visit him due to a history of abuse toward her and other disruptive behaviours.

*The Martu people were some of the last of Australia's Indigenous people to make contact with European Australians, and are traditional owners of areas in central Western Australia. See http://www.kj.org.au/about-martu/ for more information about the Martu.

Section III: The lived experience

AK, born 1940, was removed from his family and taken to Carrolup farm training school (later known as Marribank, near Katanning, Western Australia) as a young boy, and was one of the few remaining Carrolup artists. Originally known as Carrolup Native Settlement, it was one of the first settlements to hold families forcibly removed from surrounding towns in South West WA. He was one of many five to fourteen year old boys, who, poorly fed and badly housed, were encouraged to paint the landscape by the school principal Noel White. A distinctive style of tree and animal silhouettes against a sunset sky emerged. As an adult AK married and worked with WA Government Railways. He continued to mentor younger artists and became a popular and accomplished harmonica player. Resident at Windsor Park for a number of years, he returned to a large South West town to be closer to his family.

Like AK, **AU** (1945), **DJ** (1946), **BD** (1947), **CJ** (1948) and **DH** (1962) were members of the 'Stolen Generations.' They were from different areas and different communities- Wongai, Noongar, Tjuntjujarra and Wadjarri. Whilst all had different stories, they had all experienced life in missions and native settlements following their forceful separation from parents and siblings. Away from country, they were forbidden to speak their own language or practice their native culture. While not a universal experience, most were poorly fed and housed, and minimally educated. All entered adulthood with minimal literacy and numeracy to return to live in reserves on the outskirts of towns where they found work as and when they could; shearing, harvesting, sewing, cleaning, shunting cleaning wells or working stock. They had all resorted to alcohol to cope with memories of the past and fractured family situations.

Section IV: The resident's reactions throughout the project

At the start of the project, Ron Gidgup met the residents and yarned with them about their lives and life in general. He talked with Heather Freegard about dementia and its effects. Gradually, he formed a plan for three artworks that he completed on-site and in his studio. These are some of the reactions to Ron's presence at Windsor Park and his work.

AB was a new resident. He was young- around fifty years of age- and had lived a traditional life. Upon discharge from acute care, he needed a place to stay while long term treatment resolved some of his complicated health and cognitive problems. He was finding it hard to adjust to the routines, confined spaces and the busyness of life at Windsor Park.

Ron set up his equipment near the garden wall and prepared to start the day's painting. AB came out with a canvas of his own and settled cross-legged nearby. Through subtle signs the two artists communicated and, using Ron's brushes and paints, AB relaxed as he became absorbed in his own work.

Later when discussing the day and the nature of the interaction, Ron said, "Yes, he was able to go back to his own country through painting".

JT was a Wadjarri man who had lived at Windsor Park for several years. He had worked all his life as a truck driver. He was a talented guitar player and country and western singer, and had supplemented his income by busking around Fremantle. Mostly his conversation at Windsor Park was limited to polite questions: "Excuse me, what day is it today?", "When is lunch?", "May I have some tea?" or "When is Christmas?". One morning Ron's father, Ron senior, also visited the group. A lively yarn ensued as each person identified themselves by cultural location and connections with Ron senior and his family were established in the proper way. JT was interested in the conversations but did not make any personal connections. Then Ron senior asked JT directly, "Where are you from?". JT replied, "Carnarvon", to which Ron senior mentioned some of the people he knew from that area and JT recognised some of the names. At this point JT became very animated and said with great excitement, "He knows my mob, he knows my mob!", and remained attentive and engaged for the remainder of the session. As the session wrapped up for lunch, a carer approached JT and said, "Hello JT, it's time for lunch, may I walk with you to the dining room?" JT sat up straight and said proudly, "That's Mr T to you!". He remained in the meeting room to prolong the connections and ate his lunch amid the chaos of packing up, staff banter and conversation.

Section V: Overview of the Creative Arts project

Creative Arts project team

Ron Gidgup is a Noongar man and artist skilled in community development.

Ron has initiated and participated in many Aboriginal youth and community projects, presenting art-based workshops that promote self-esteem, strengthen identity, and reinforce an understanding of cultural heritage. He uses a variety of media including paint, fabric and craft.

Arun Raj is a film producer with Tuco Films.

Arun worked closely with Ron and Heather to deliver a documentary style film that transports the viewer into the world of Aboriginal residents at Windsor Park.

Sharyn McDavitt is the Executive Manager at Windsor Park Aged Care

Sharyn's dynamic and caring personality was essential to the success of this project. Her dedication to the residents and the Windsor Park staff helped the team to complete the project in a sensitive manner.

Heather Freegard was the Creative Arts Project Coordinator at WA DTSC.

This booklet is based on Heather's recollections of the project.

Associate Professor Barbara J Horner was Director, Centre for Research on Ageing, and Director of WA DTSC, Curtin University.

Barbara oversaw the successful completion of this project and her considerable strategic influence made it all possible.

Section V: Overview of the Creative Arts project

Aim

The aim of the project was to improve staff capability through cultural awareness education presented through the medium of art. A respected Aboriginal artist with community development experience was engaged to create murals with staff and 18 Aboriginal residents and families.

Objectives

- Involve Aboriginal residents and their families in the preparation and production of culturally appropriate pieces of communal art
- Engage staff in cultural awareness education through observation and participation

Context

Many residents living in RACFs have complex health, psychological and social needs. Medical and funding frameworks place emphasis on physical care and behaviour management with less attention to social and cultural needs.

The facility

Established in 1993, Hall & Prior Aged Care organisation is an Australian private family owned organisation providing residential aged care services. At this time of writing, Hall & Prior now serves the needs of well over 1,000 residents in fourteen homes in WA and six in New South Wales. Windsor Park Aged Care Home (Windsor Park) is located in Carlisle, a well-established suburb close to Perth central business district. The staff population, representative of multicultural Australia, is as large as it is diverse, with more than 100 people from around 20 different countries. The home, led by Executive Manager Sharyn McDavitt, won a 2013 Better Practice Award in the Staff Development and Retention category for their Workplace Harmonisation Program, which empowers and supports its culturally diverse staff.

Beginning the project

Meeting the families

Before the project could begin, a meeting for families to introduce the creative team was arranged. No family came. The sole person to attend was a Public Guardian responsible for several of the residents. While the outcomes were somewhat disappointing, the conversation with the Guardian was very enlightening about some of the issues faced when undertaking work in this area.

Section V: Overview of the Creative Arts project

The Public Guardian

The Public Guardian had been appointed to take responsibility of the affairs of a number of the Aboriginal residents who could no longer do so themselves. In some cases this had resulted from misunderstandings between some of the Aboriginal residents' family members and the RACF management involving control of the residents' financial affairs. Used to the public health system where admission to hospital and treatment was free of charge, families could not understand why the RACF expected residents to contribute most of their pension to pay for board and lodging.

The Public Guardian was enthusiastic about the project and fully supportive of the residents' involvement in the mural making and activities within the facility; however, their powers were limited by the *Guardianship and Administration Act*. They could not give consent for the residents to be identified in the documentary as this was not directly related to the care of the resident. The residents themselves were unable to give informed consent due to their cognitive impairment, and gaining family consent within the complexities of Aboriginal family structure was logistically challenging. Consequently, all residents' faces were pixelated in the film to protect their identity.

Staff engagement

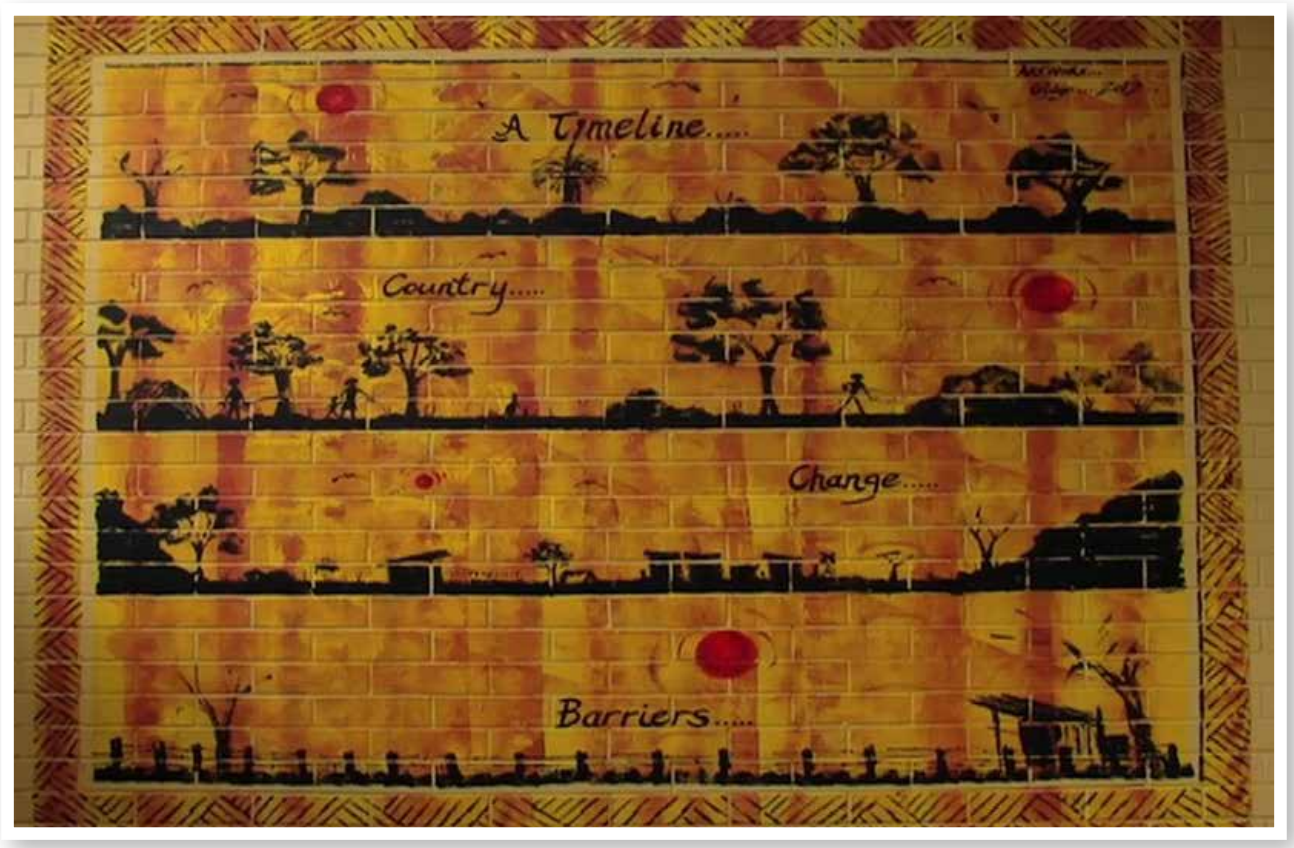
A meeting for staff was also arranged to explain the project, what was expected of staff and how they could participate or otherwise. Fifteen staff members attended; three were enthusiastic and excited about the opportunity. In contrast, two were resistant and did not want to participate in any way. The remainder were interested but apprehensive. Once their questions and comments were responded to and the voluntary nature of their participation explained, most provided their consent to be filmed.

It was agreed at this time that a sign would be placed outside the location when filming was in progress so that those that did not want to be filmed could avoid the area.

The artwork

Facilitated by the occupational therapist, Ron initially yarned with the residents in small groups, men and women separately. Later as everyone began to relax and feel comfortable, he yarned with individuals and in mixed groups. The yarns were magical. Despite severe cognitive impairment each resident blossomed and became proud. They remembered their childhood and early adulthood. They recalled bush medicines and foods. They told stories and jokes. They made connections with each other. The staff were amazed at the transformation of the quiet, reserved and shy men and women into a laughing, alert and engaged group. Some of the women were severely cognitively impaired, but they also responded to Ron's voice and use of traditional language. He told them of their connections through country and family and they too became more alert and relaxed.

Section V: Overview of the Creative Arts project



The timeline mural

The timeline was the first of the two murals created. It is located on the veranda of Coolibah House, one of the two houses at Windsor Park. This site was chosen because it is easily accessed and used frequently by residents, staff and family. It was considered to be an ideal location because it enabled residents and staff to engage with Ron in discussion about the meaning and content of the mural.

The top row depicts country and the Dreaming which describes how the elements of country and all living things in and on it came into being. The next row depicts how Aboriginal people lived with and on the land for at least 60,000 years. By respecting the land, the environment provided all that Aboriginal people required and they in turn cared for the land and the spirits within. The third row depicts the changes that occurred with European settlement 200 years ago. The changes resulted in Aboriginal people separated from the land, their spiritual and economic 'home', forced to live in restricted areas and watch the destruction of the land, water and animals. The bottom row shows a fence to depict the barriers that Aboriginal people have faced and continue to experience in their day to day lives.

The mural is a powerful device for teaching new staff and visitors about the history of Aboriginal ownership and European settlement. For Aboriginal residents it affirms their heritage and history. For families it communicates that the people within the facility respect the history and heritage of Aboriginal people.

Section V: Overview of the Creative Arts project

The wall hanging

The second piece celebrates the role of women in Aboriginal culture. It hangs in the dining room of The Lodge, a separate wing reserved for women. Linoleum-cut prints embroidered onto block printed fabric depict the significance of women's business, relationships, family and kinship, foods and medicines, and spirituality.

The materials chosen for this wall hanging represent the tools and skills, such as weaving and stitching that are the domain for women in traditional Aboriginal culture.

Section V: Overview of the Creative Arts project

The tree mural

The third piece depicting community, with reference to the community within Windsor Park, was the most challenging for Ron to paint. The concept of 'community' is many-faceted and multidimensional. Finding a way to depict the relevance of the past, present and future, the many 'communities' that are simultaneously occupied by any one person, the nature of Aboriginal and non-Aboriginal culture and the coming together within Windsor Park are all important.

The weather became an issue. Located on the garden wall there was no protection from sun or rain. Not only did the creative arts team have to work around the routines of the nursing home and the availabilities of Ron and the rest of the team, they had to be alert to the weather forecast. After rain, a period of fine weather was needed to ensure the wall was dry. As it was now spring there was a combination of very hot days, very wet days and very cold mornings with which to contend. Many of the residents were now well tuned into the project and its activities, and including them in the proceedings was vital. Dry chairs, shelter for shade and or showers, moving residents as the shade moved or a shower passed over was all part of the process.

Section V: Overview of the Creative Arts project

Learning outcomes from the project

Objective one

Involve Aboriginal residents and their families in the preparation and production of culturally appropriate pieces of communal art.

Aboriginal residents engaged very positively with the Aboriginal artist, and art facilitated making connections between the residents and reminiscence about family, land and history.

a. Facilitated by the artist, Aboriginal residents, whether Noongar or otherwise, responded to culturally appropriate ways of making connections with each other.

b. The residents were strongly connected to their cultural roots, as evidenced by their enthusiastic reminiscence and use of traditional language.

c. Communication channels to reach Aboriginal people are informal and verbal, which can challenge Western approaches to confidentiality and written records. For example, it has become usual practice at Windsor Park for all Aboriginal deaths to be reported to Derbarl Yerrigan (a Western Australian Aboriginal health service centre), as the centre has become the place for contact and information exchange regarding the whereabouts of Aboriginal people. The standard practice is that family are responsible for such notifications; however, as many families are disconnected with the person in residential care, involving Derbarl Yerrigan aids communication.

d. Formal procedures and protocols dictated by State and Commonwealth law and interpreted and implemented by Hall & Prior are designed to protect residents and staff from harm. Whilst these rules and regulations have been developed under the precedents and philosophies of Western law, some were found to impede effective communication and involvement with Aboriginal families. For example, the status of next-of-kin may be defined differently under Western versus Aboriginal culture, such that Hall & Prior may not be liaising with the most appropriate person to make decisions about a person's care.

e. Ongoing participation with the Aboriginal community and elders to design culturally appropriate spaces and practices, including healing and yarning, are essential for overall acceptance and use.

Family involvement was less successful, although during the final weeks of the project some family members did engage briefly while visiting. Engaging with families is a long term investment as the engagement process requires negotiation of cultural protocols before relationships can be built.

Section V: Overview of the Creative Arts project

Objective two

Engage staff in cultural awareness education through observation and participation

Two stages of staff education were utilised:

Stage one: all staff participated in two half-day workshops. Workshop One provided an overview of common types of cognitive impairments and mental illnesses, and the philosophy of care and management at Windsor Park. Workshop Two explored the various cultural heritages among staff, provided an outline of Aboriginal history and engagement with Western culture experienced by current residents, and an overview of Aboriginal culture with emphasis on the diversity of Australian Aboriginal cultures.

Stage two: throughout the project, all staff working at Windsor Park were encouraged to be involved in the creation of the artwork. Whilst it seemed that there were fewer opportunities for engagement by staff than anticipated, several staff members became greatly involved. In particular, the occupational therapy and leisure team assisted with recruiting and bringing residents to sessions, and these staff engaged directly with the artist in discussions of culture and cultural heritage. Other staff tended to engage only briefly, for example, to deliver morning tea.

Section VI: Conclusion

This was a very ambitious project that sought to improve care of Aboriginal people living in residential aged care through a creative arts framework. The most obvious legacy of the project are three beautiful and meaningful artworks that highlight to all at Windsor Park some of the rich cultural heritage of the Aboriginal residents at the facility. It is anticipated that these artworks may also serve as an intimation for new staff, residents and their families of the history and culture of these residents.

A number of important understandings were gained that informed future work in this area. Many of the learnings from this project informed a subsequent project that developed a unique cultural assessment tool that can be used by care staff when admitting a new Aboriginal resident. This tool allows for the exploration of a resident's cultural history, and identifies their unique needs to provide more holistic care for the resident.

Beneath the differences there are many common values and goals; food, water and shelter, safety, connections with others especially family, satisfaction and pleasure, and an appreciation of the meaning of life. Appreciating and understanding Aboriginal systems, skills and solutions have the potential in the global world, if we could only see and hear.

Heather Freegard

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