

Changing the image of care

After 35 years as a Professor of Sociology at Rutgers University in the United States, Cathy Greenblat took an early retirement and decided to pursue her interest in photography. Over a decade later, Cathy is now a widely renowned and globally exhibited professional photographer and a pioneer for challenging misconceptions about dementia.

Cathy's photography focuses on capturing examples of high-quality care for people living with dementia. Her work has been pivotal in showing the world the possibilities of assisting people with dementia to live a rich and full life.

Cathy recently visited Australia to run a series of lectures and workshops sponsored by the NSW / ACT Dementia Training Study Centre, the *Australian Journal of Dementia Care*, the University of Wollongong's Global Challenges Program and UnitingCare Ageing. During her trip, Cathy spent a week photographing residents and staff at UnitingCare Ageing Starrett Lodge, an aged care facility on the NSW Central Coast.

Cathy used photography and film to document the exceptional high-quality care offered to residents with dementia at the lodge, adding to her growing set of illustrations of the possibilities for living a fulfilling life with dementia.

Cathy's story

When Cathy first took up photography following her retirement in the 1990s, she knew that she wanted to use her ethnography skills from her former career as a sociologist to photograph social issues. She set out to find a meaningful social issue to capture and promote using her developing abilities as a photographer.

Cathy had been personally touched by Alzheimer's disease

Fiona Calvert describes the mission of internationally renowned photographer Cathy Greenblat and her experience in the life-embracing environment of Australia's Starrett Lodge



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Family love ... mother, grandmother and great grand-daughter enjoy time together at Starrett Lodge. Photo: Cathy Greenblat, 2014

as both her maternal grandparents had been diagnosed with the illness. Unfortunately, her observations of the care they received were less than inspiring.

"I watched them wither away in nursing homes. They were fed well, medicated, kept safe and put in front of the TV and that was it. I really hated it," she explained.

Unsurprisingly, Cathy's initial feeling was that she would never photograph people with dementia. "At that point, I believed that once people had dementia, they were unreachable shadows of their former self. I had bought into that way of thinking".

Then in 2001, she visited an aged care home in Mexico as part of a master class led by American photographer Mary Ellen Mark. Cathy said she saw what was needed in long-term care by what was missing there. Despite well intentioned staff, people had nothing to do all day as there were so few resources.

A few months later she was invited to Silverado Senior Living's residential

community for people with Alzheimer's disease and related disorders in Escondido, California. "Within 15 minutes, I was captivated," Cathy said. "It was a completely different experience from anything I believed was possible. People were animated and engaged in conversations and the residents were receiving loving attention and care from the staff."

Cathy's experiences led her to photograph and interview residents with Alzheimer's at Silverado. These materials were published as a documentary photobook, *Alive with Alzheimer's*, in 2004. Cathy used her book and related exhibits to share the lessons she was learning about dementia care: people with dementia are still alive; and life-enriching dementia care is possible.

Following the publication of *Alive with Alzheimer's*, Cathy began building contacts with people who were writing about person-centred dementia care and their contributions to each other's work were invaluable for all. "They could talk about dementia care and I could



Cathy Greenblat and Colin McDonnell

show it. We fitted well together," Cathy said.

Her photographs were exhibited throughout the US, particularly at professional conferences. In exchange for her exhibitions, Cathy requested that the academics and professionals involved in the conferences find her the best dementia care locations in their area for her to photograph.

Through her photography Cathy aims to show the benefits and possibilities of person-centred care that emphasises communication, dignity, touch, love and laughter and to spread this message globally.

"People need to know that there are things we can do to let people live with dignity. I don't know how to tell them about this, but I can show them with my photos," she said.

Starrett Lodge

During her recent visit to Australia Cathy travelled to UnitingCare Ageing Starrett Lodge, an award-winning aged care home that is becoming renowned for its person-centred approach to dementia care.

Starrett Lodge Care Service Manager Colin McDonnell explained that the residents at the lodge are related to as "participants, not recipients of care".

He said the staff at Starrett Lodge are passionate about providing quality dementia care and the residents are

encouraged to lead active and independent lives, retaining their dignity and autonomy while living with dementia.

“People can still have a life with dementia, if given the chance. The residents plan a lot of activities and outings and they raise their own money. They cook and sell things and they run this whole process themselves. They have a committee and draw names for who takes on what responsibility.”

Starrett Lodge also strongly values supporting residents to try new activities and realise lifelong dreams. Colin explained that many residents at Starrett Lodge have a ‘bucket list’ – a list of activities and experiences the person would like to have in his or her lifetime. Staff at the lodge go to great lengths to assist the residents in making their dreams a reality [see story page 22].

“One resident wanted to take her close friend to Crowne Plaza Hotel for a nice dinner. The two of them got a stretch limo and off they went together. Another two went on a helicopter ride in the Hunter Valley. This was something they had always wanted to do, but had never got around to doing.”

Cathy's visit to Starrett Lodge

While at Starrett Lodge, Cathy was accompanied by Soo Borson, a geriatric psychiatrist from the US and Corinne Maunder, a producer at Fire



Left: “... We'll travel the road sharing our load, side by side” sings Mavis, holding hands with Ron, her husband of many years, during karaoke night at Starrett Lodge. Right: Sharing a private moment, at Starrett Lodge. Photos: Cathy Greenblat, 2014



Films, Melbourne. Following the success of the 2013 project *Love, loss and laughter: living with dementia*, a short film by Corinne featuring Cathy's photography, Cathy supported Corinne to do a day of filming at Starrett Lodge and another day at Arcare Helensvale, an aged care home on the Gold Coast, for a forthcoming multimedia project, *Side by side: love and joy in dementia care*. The project, likely to be completed early next year, will showcase Cathy's photographs, along with video footage, of inspirational dementia care from around the world.

“Cathy became part of the family at Starrett Lodge,” explained Colin. “She engaged in lots of different activities and got to know the residents very well. Cathy photographed our

karaoke night where relatives came along and everyone was singing. You had husbands and wives holding hands singing together and small children holding the microphones for residents with dementia while they sang”.

Since she began photographing people with dementia in 2001, Cathy has paid particular attention to music and its power.

“I very often find myself singing along when there are music or music therapy sessions. But this [karaoke night] was so much more than that. First, it was an event to which family were invited, and many came. Second, each of the 60 residents picked a song and did their piece. What a comfort and trust level they must have to be willing to do this at 100

per cent participation.”

For Cathy, the opportunity to witness and capture the karaoke night at Starrett Lodge was a personally moving experience.

“As they sang, often it was not just a special song they liked from childhood, but a song whose words had a special meaning. At least three times I found tears welling up in my eyes, as I heard the words they sang. ‘We don't know what's coming tomorrow, maybe it's trouble and sorrow, but we'll travel along, singing a song, side by side’ was one such song, selected and sung by the wife of a man with quite advanced dementia. The song words were so much more meaningful than usual, hearing them in this context.”

Cathy was also moved to see the strong connections between residents, staff and family members during the karaoke night. “Colin was also wonderful that evening. You could see why he is so beloved by the residents and staff. He arrived in a bear hat, laughed and joked and hugged all evening. I loved Starrett before that night, but it sealed my commitment, as the love around the room was palpable.”

Cathy also attended and photographed the babies' group, one of the more popular activities at Starrett Lodge according to Colin.

“Residents' grandchildren and great-grandchildren were coming to visit and the people with dementia were wanting to



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spend more time with them. So we started a group for this in 2010 and now it runs once a week," Colin said.

He explained this was an important group for Cathy to witness and photograph because of the connections formed between residents and staff that promote a high quality of care.

"It changes staff perceptions of our residents with dementia. They see that these people can still give love and care. The residents act instinctively in looking after the babies, as if they were just someone in their 20s or 30s looking after their own children."

Colin said that genuine human contact and warmth is an important part of dementia care at Starrett Lodge. Cathy photographed and filmed the caring interactions between residents and staff occurring constantly throughout the day at the lodge. "She was catching staff giving hugs and laughing with clients and capturing those moments in her photos."

The residents at Starrett Lodge welcomed Cathy's presence during her visit. "It was good for the residents to have people interested in hearing their stories, particularly people from the US," said Colin. "It gave them a lift."

Cathy was inspired by the quality of care provided by the staff: "The relationships between residents, relationships between residents and staff, and staff relationships with one another were all full of warmth and caring and respect. There was plenty of humour and laughter and just general good cheer – the ingredients that allow all of us to be relaxed and happy. I think I documented a lot of that, as I had hoped to."

Corinne was also deeply impressed by what she saw: "My Nan has been living with dementia for over 17 years, and I just wish she and my family could have experienced the level of person-centred care offered at Starrett. This is a vibrant community full of people living their lives with

great joy and passion."

During her time at Starrett Lodge Cathy took over 800 photographs, while Corinne filmed hours of video footage. Corinne was later asked by UnitingCare Ageing to make a short film for Starrett Lodge. The film, *Finding the why; enabling active participation in life in aged care* features many of Cathy's best photos. It will be included in Cathy's later multimedia project *Side by side*, but its early production has already allowed it to be shown at the American Psychiatric Association's Annual Meeting in New York in May and to be circulated widely on the Internet, where it has generated great enthusiasm.

"It wasn't a planned project at all," Corinne explained. "Cathy and I had spent the morning meeting and capturing images of many happy Starrett residents... Then Colin McDonnell and I got chatting and came up with the idea to edit a video for Starrett Lodge using whatever footage I had time to capture that day. I simply held up my camera and captured what was happening. They provided all the magic! From a filmmaker's point of view, this is the stuff you can only dream of. You can plan and plan and plan and still never capture something as magical as this." ■

Finding the why can be viewed on the UnitingCare Ageing NSW/YouTube Channel at <http://youtu.be/hZN1CyEIFNM>



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Telling their own stories

A project that helps people with dementia share their life stories is proving so beneficial it is now part of routine care planning for Amana Living residents and will also be offered to its day club clients this year. **Fiona Calvert** reports

An understanding of individuals and their stories is essential to the delivery of quality relationship-centred care for people with dementia. Assisting those living with dementia to create and share their life stories with others has been shown to enhance communication and well-being (Moos & Bjorn 2006), as well as improve relationships between people with dementia and their carers (Woods *et al* 2009; Clarke *et al* 2003; McKeown *et al* 2006).

The use of life story interventions is a therapeutic tool related to reminiscence therapy. This involves the discussion of past activities, events and experiences, usually with the aid of tangible and sensory prompts such as photographs and music. It is recognised as an effective therapeutic tool in working with people with dementia, with evidence suggesting it enhances older people's mood and well-being (Chiang *et al* 2010). Similarly, the use of life story tools is gaining increasing interest amongst researchers and professionals working to improve the quality of care for people with dementia. While the use of personal stories within aged care is by no means a new concept, embedding such interventions within service processes is relatively uncharted terrain. Amana Living, an aged care provider in Western Australia, recognised the value of integrating life stories into

clinical practice and, in 2012, called on occupational therapy students from Curtin University to help staff move towards this goal. These tools are now being included in routine care planning for its residents with dementia.

Enhancing well-being

Amana Living dementia specialist Louise Jones said the use of life story tools can enhance residents' well-being in a number of ways. Helped by a structured process of reminiscence, the storyteller may be able to place him or herself emotionally and cognitively within an earlier time. The process of sharing one's life stories can also invite a greater understanding and respect from others, while relieving the frustration of people with dementia who struggle to find ways to communicate and connect with those around them. The benefit of sharing life stories may be enhanced through recording the stories in a way that is tailored to the person's sensory and functional needs. This allows the storyteller to revisit the memories, either for quiet contemplation or to regain a sense of calm and clarity during a period of agitation.

The life stories project

Amana Living's life stories project involved the university students doing seven-week placements in their final year of study, working across six