

The last act of love

OUR PARENTS BRING US into the world and nurture us through the first part of our lives. As life comes full circle, it's only right that we should want to help them exit this world with love, comfort and dignity. But... what precisely does that mean for us?

The facts of our ageing population are no secret. More Australians are living longer – a child born today is likely to live a few years longer than one born just a decade ago – and the number of Australians aged

65 and over is projected to almost double over the next 20 years. Rising health costs for the elderly pose a serious long-term challenge for our nation. And, despite having few ground rules to follow, our society is hugely dependent on family members to care for the sick, frail and elderly.

That's the "big picture", but for a more personal perspective, you need only look around you. One in every eight Australians is a carer – and I happen to be one of them. ▶

IF YOUR AGEING PARENTS NEEDED FULL-TIME CARE, WOULD YOU STEP INTO THE BREACH? JOSEPHINE BROUARD INVESTIGATES THE EMOTIONAL AND PRACTICAL REALITIES OF LOOKING AFTER AN AILING PARENT

PHOTO: GETTY IMAGES



THE HARDEST CHOICES

After making the difficult decision to put my mother in care some years back, when Alzheimer's struck, my siblings and I recently began helping my father recover from open-heart surgery. At 81, he remained frail post-operation and admitted that he found it hard to make decisions. "I'd be lost without my children's help, and I don't feel strong enough to take care of myself," he conceded, encouraging us to move him into care alongside my mother.

In many respects, our family has been lucky; parents and children have tended to stare down the unpleasant realities of the situation, making decisions jointly and with a minimum of fuss.

Growing old is not pretty, as many geriatrics will attest, and it's often distressing for family

members to help loved ones make truly tough calls about their long-term healthcare. Typically, it's also very difficult to get everyone involved to agree on the appropriate course of action.

Trish Noakes, founder of Just Better Care, a provider of personal, palliative and dementia care in NSW, Queensland, Victoria and the ACT, believes that the issue of who will care for someone when they are old is a sensitive one. "Children can be motivated by a strong sense of duty to care for their parents, yet the arrangement can often place families under severe strain. There's also often a sense of guilt about the idea of putting Mum or Dad in a home."

Before facing the reality of a nursing home, families must come to terms with dealing with a family member with dementia at home. Mel

RESOURCES FOR THOSE LOOKING AFTER THE FRAIL

- Visit the Department of Health and Ageing website and click on popular page "Ageing", health.gov.au
- Alzheimer's Australia, alzheimers.org.au
- Catholic Health Australia is the largest non-government provider of health, community and aged care services in Australia, cha.org.au
- For a copy of *Caring for Your Elderly Parent* by Kate Sumner, visit caringforyourelderlyparent.com.au
- Protestant aged care provisions, upa.org.au
- Anglican aged care provisions, arv.org.au

Green, who has experienced it firsthand with her husband's parents as well as her own, says it's heartbreaking. "Watching one parent being swallowed by dementia and the other grieving, while struggling to cope with their new role as a carer, is difficult for everyone," she says. Denial, anger and frustration are common. "Often the best therapy is to be practical. For me that meant investigating what help was available. The Department of Health and Ageing became my No.1 resource, and arranging for an ACAT [Aged Care Assessment Team; see column far right] for my stepfather was an important first step towards getting support for my mother."

Green also found it comforting to create meaningful family moments. "My mother-in-law was a great cook and was aware that her memory was failing," she says. "So we organised a family day where we cooked all her favourite dishes and made a family recipe book." As time passed and the Alzheimer's worsened, "we created photo albums with pictures of her sons and their families, all labelled to help her remember." Green says in the end they were small gestures, but "they brought the family together at a time when we all needed support".

PLANNING AHEAD

Accountant David Sweeney was his father's primary carer for more than a decade. "Dad moved into a retirement village in 1997 on doctor's orders, and it was an awful time. He didn't want to go. We had to sell up the family home, put down his dogs and move him into a much smaller self-contained unit."

With his mother dead and his brother overseas, David made decisions with his father jointly, at first. "We both knew with certainty that things were only going to get worse, so we made sure that the retirement community had a nursing home for frail care in case we needed it," he says. The pair's forward planning paid off as Sweeney Sr's health deteriorated. By 2005, David accompanied his father to all his medical appointments ("Dad wasn't retaining information very well, and I realised it was time to interfere.") and two years later, when his father could no longer drive, David became de facto chauffeur for supermarket, medical and social trips.

In 2008, David took the important step – before his father became mentally deficient – of getting his father to sign two critical legal documents. The first was a Power of Attorney agreement, enabling him to access his father's bank accounts and manage his financial affairs; the second was an Enduring Guardianship agreement, enabling him to make decisions about his father's healthcare.

By June 2009, David had to change his work roster to further accommodate his father's needs. Luckily, his workplace was supportive. "I was driving Dad to the doctor three times a week for dressings to be changed, and I would visit

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every Friday to change his sheets, clean the kitchen and bathroom, do the shopping and prepare his meals for the week."

When his father passed away, in July of 2010, David was overwhelmed with relief. "He weighed 36kg, he was wearing a nappy and he was hallucinating. He just gave out in the end."

Despite the harrowing nature of caring for an elderly parent, David says he would do it all over again if required. "I know that there are a lot of children who wouldn't do what I did for my father, but it was easy to do. I simply wanted to preserve his quality of life for as long as I could."

DUTY OF AGED CARE

Kate Sumner, author of *Caring for Your Elderly Parent* (Woodslane, \$29.95) says Green and Sweeney are part of the first generation in human history that could spend more time caring for elderly parents than they do caring for their own children. "Many of us come to this role with little experience or knowledge of what it means to grow old, what kind of help older people need, what care is available in Australia and where to access it."

Alarming, statistics suggest that while one in every two Australians would like their children to personally care for them, only about one in three adult children would be prepared to do so. A survey commissioned by Just Better Care found that 30% of Victorians, 31% of people from NSW and 35% of Queenslanders would care full-time for parents. In WA, that number was 36%; in

ELIGIBILITY FOR AGED CARE SERVICES

Recent illness, disability, bereavement or simply the passing of the years may make it harder to manage at home without help. To access residential aged care or experience Extended Aged Care at Home (EACH), approval from an Aged Care Assessment Team (ACAT) is required. ACATs help older people and their carers work out what kind of care will best meet their needs when they're no longer able to manage at home without assistance.

Talk to your GP first to see if you need referring to an ACAT. A local ACAT member will then visit you at home or in hospital for an assessment. They'll discuss the results with you, and arrange referrals to community care services or a place in residential care, if this is appropriate.

Call 1800 052 222 for the nearest ACAT, or the Aged Care Information Line on 1800 500 853.



the Northern Territory, 46%; and in Tasmania, 50%. These figures, alas, fall short of what ageing parents would like, and sometimes even expect, from their children.

What would you do? Who knows? But if you suspect you may have to look after your parents in the future, heed these handy hints from those who have gone before you:

Do as your parent wants, not as you would do. "Don't apply your standards and values to a situation," says Sweeney. "Rather, tune in to what *they* want. If they don't care that a place is dusty, drop it and focus on what's important to them. And if they want a cup of tea and biscuits for dinner, instead of fresh fish and a piece of vegetable, the same applies. In a word: let go of your personal standards and expectations."

Expect people to have opinions, and shrug them away. "Only you as the primary carer know what it's like to care for another person around the clock. Concentrate on being selfish on their behalf; focus on putting their interests first. And if a neighbour or well-meaning relative thinks differently, too bad!" So says Sweeney, and Green agrees wholeheartedly.

If you need help, get it. Green and Sweeney stress that the first important step is to become familiar with the Department of Health and Ageing website (health.gov.au), and to book an ACAT assessment to arrange carer respite.

Manage your frustration as a carer. "As a parent becomes sick and frail, their memory will go and conversations will become repetitive.

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Expect this," says Sweeney. To thwart memory losses, Sweeney suggests carers leave visual reminders around the house, such as notes saying "Have you switched off the stove?" above the stove, or "Have you taken all six of your tablets this morning?" on the kitchen counter.

Decide when it's time to take control. Before a parent becomes too sick to make decisions for themselves, and while they're still of sound mind, get them to sign Power of Attorney and Enduring Guardianship documents. Both can be obtained from a newsagent and can be processed by a lawyer.

Start researching retirement village units with frail care facilities. Green says no matter how much or how often your parents might express the desire not to be moved from the family home they know and love, sometimes it's the best, or only, alternative. So be prepared.

Call the Aged Care Information Line (1800 500 853) to receive the booklet *5 Steps to Entry into Aged Residential Care*. "This booklet was my bible," says Sweeney. "It told me so much of what I wanted to know, from how things are calculated when you're on a pension to all the associations and support groups that can help." ●

FIND OUT MORE
about caring for frail
and elderly loved ones
at healthsmart.com.au