# Disconnected

The state controls her mother's life. Katelyn's fighting desperately to get it back.

#### By Cason Ho

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Katelyn holds back tears as she walks into the hallway of her mother's home. She hasn't been allowed here for two years.

Her mother Ava has dementia, and has been put under the care of a state guardian.

The guardian controls almost every aspect of Ava's life, from where she lives to who she can contact.

The family has raised serious allegations against the state, which they say has failed to ensure Ava receives adequate care, including medical services.

The state guardian has denied the claims of neglect, saying it has only worked in Ava's best interests.

But on one occasion, the family says they were told Ava's guardian had more than 100 other cases to manage, and was too busy to immediately respond to their concerns.

Names in this story have been changed as it's illegal to identify people under state care in almost every state and territory.

## A final visit

Ava now lives in a nursing home. Her house feels empty, but is still cluttered with belongings, as though it's been left in a hurry.

Katelyn's been allowed in to collect sentimental belongings before the house is sold.

"I was born here, and I grew up here. I went to university when I was living here," Katelyn says.

Katelyn looks through her mother's vanity table. ABC News: Cason Ho

She finds her mother's favourite perfume. ABC News: Cason Ho

She finds a bottle of her mother's favourite perfume.

"Maybe I can take a little bit to her. Can't get this one anymore," she says.

In the corner of the room, there's a small white device emitting a green light.

It's a monitor for Ava's heart that's meant to transmit important pacemaker information to her cardiologist.

Katelyn received a call from the cardiologist's office two weeks ago.

They told her the monitor hasn't worked for more than 18 months.

Her mother has been under state care the entire time.

Katelyn scrambled together an email to Ava's state guardian.

The remote heart monitor is crucial as mum has a pacemaker, which needs to be monitored.

[The doctor] is very worried about mum and wants to see her and wants the remote control heart monitor set up.

The guardian responded late the next day.

This matter is acknowledged and discussed with [Ava's] medical team.

Two weeks later, the monitor still hadn't been connected to Ava's heart.

Katelyn found it sitting on the bedside table of a room Ava hasn't been in for a year.

The cardiologist has since contacted the guardian asking to have the monitor reconnected "as a matter of urgency".

The Office of the Public Advocate, which oversees state guardianship, said it can't share confidential medical details, but told the ABC that Ava "is receiving all medical care as required".

## Under pressure

Trustees and guardians manage the assets and lives of people considered incapable of making their own decisions, including where they live, who they talk to and what medical treatment they receive.

Those without any loved ones willing — or deemed appropriate — to take on the responsibility are placed into state care.

In Western Australia, where Ava lives, the number of people under the guardianship of the Office of the Public Advocate (OPA) has ballooned more than 13-fold, from 232 in 2005 to more than 3,000 in 2022.

Over that same period, the number of full-time equivalent staff has increased less than four-fold, from 24 to 85.

Giving evidence at the Disability Royal Commission in late 2022, WA's Public Advocate Pauline Bagdonavicius conceded the growing workload was unsustainable.

## Faceless agents and faceless Australians



A phone call spiralled into a chain of events that landed Louise in state care. Amid widespread allegations of mistreatment and exorbitant fees, her family is raising concerns.

"The caseload ratio that has been considered by treasury in terms of allocations to our office is at 55 per guardian on average," she said.

The average caseload at that time, however, was 71 cases.

"Demand for OPA's statutory service of 'guardian of last resort' continues to increase," Ms Bagdonavicius told the ABC.

"OPA has secured additional resources through state goverment budgets, however workloads remain high. Recruitment and retention efforts continue to be a priority."

Nationwide, the number of people under state guardianship has grown 23 per cent in the past five years, according to the Australian Guardianship and Administration Council.

An ageing population and increasing cases of dementia, mental illness and intellectual disability have been cited as contributing factors.

## **Turning point**

Katelyn sobs quietly as she opens a jar containing her father's ashes.

She's overwhelmed by a flood of memories as she makes her way through the home.

Katelyn feels nostalgic. One memory, however, is tinged with sorrow.

"We all knew mum was losing her cognitive ability, losing her memory, from 2018," she says.

Around this time, Katelyn alleges a maintenance man started spending more time at the home and often visited with his partner as Ava's cognition declined.

The family became worried Ava was being exploited, prompting Katelyn and her fiance to try to film evidence on a phone of the maintenance man receiving cash payments.

Katelyn claims the maintenance man did minimal work. ABC News: Cason Ho

Ava's backyard is dishevelled. ABC News: Cason Ho

The garden is littered with dead plants. ABC News: Cason Ho

A messy stack of gardening pots piled on top of each other. ABC News: Cason Ho

At the time, Ava shouldn't have been paying cash for maintenance work as her assets were under the care of the Public Trustee.

Any payments should have been made by the Trustee from Ava's account on her behalf.

The maintenance man attempted to stop Katelyn and her fiance filming and get them off the property, pushing Katelyn repeatedly while they fought for the phone.

The worker has since been convicted of assault over the incident.

Katelyn didn't know it at the time, but being assaulted was the least of her worries.

## Kept apart

A police report of the incident, seen by the ABC, has since been used to prevent Katelyn from seeing her mother.

The report details Ava's account, which shows her daughter Katelyn, and her fiance, were aware of Ava's declining cognition.

[Ava] is concerned as they are telling people that she has dementia and can't think properly.

They are trying to make her look like she cannot care for herself and cannot be responsible for her own assets.

The report states Ava appeared lucid and had no history of cognitive impairment or mental illness.

However, just three days later, the State Administrative Tribunal deemed Ava incapable of making her own decisions.

She has since been formally diagnosed with severe dementia.

"There is no way that in three days my mum's cognitive ability declined that much," Katelyn says.

She claims the maintenance man took advantage of Ava's declining cognition by sowing doubt about whether she could trust her own family.

"It's extremely upsetting. I don't need my mum's money ... I've only ever tried to protect her," Katelyn says.

The incident report shows Ava told police her daughter Katelyn was attempting to take control of her finances.

[Ava] is aware that [Katelyn and her partner] are going to the Public Trustee to try to gain control over her finances and her house.

Worried about both her mother's deteriorating condition and the influence of the maintenance man, Katelyn says she initially applied to take control of her mother's assets and guardianship.

She denies she was trying to exploit her mother, and insists she was trying to protect her.

When Katelyn realised the approval process would take too long, she instead asked for the state to take over her mother's finances immediately.

She argues it's proof she wasn't interested in her mother's money.

Katelyn is retired and lives off rental income from two properties. She's named as the executor of Ava's will, which leaves her entire estate to Katelyn — who is her only child — and Katelyn's two children.

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Ava has been paying the Public Trustee thousands of dollars in asset management fees. ABC News: Cason Ho

Her daughter Katelyn is appauled at the state of the home. ABC News: Cason Ho

Rat droppings are littered throughout. ABC News: Cason Ho

The garden is overgrown. ABC News: Cason Ho

When police attended the home after the assault and heard Ava's account, they suggested she seek a restraining order against her own daughter.

Katelyn was put under an order which prohibited her from seeing her mother or visiting her home.

Records from the Public Advocate show it had concerns Katelyn was manipulating her mother.

But the records also show Ava would ask to see Katelyn, and missed her when she wasn't allowed to visit.

It's unclear how Ava truly felt when she was lucid. The state guardian leaned towards minimising risk by keeping them apart.

Strict measures are in place within state guardianship systems, which are intended to protect clients from abuse.

However, the Disability Royal Commission revealed an overwhelming theme of people in state care "feeling trapped" and "overly protected".

It's a delicate balance to keep vulnerable people safe in the least restrictive way possible.

It's even more difficult when you're managing more than a hundred lives at once, as Ava's guardian allegedly was.

## Desperation

While Katelyn wasn't allowed to visit her mother, Katelyn's daughter was and often did.

She also had concerns for her grandmother, and told the Public Advocate Ava wasn't taking her medication properly.

The family has also claimed other parts of Ava's care were negligent, including incidents of her sleeping in soiled sheets, eating rotten food and being left in a home full of potential hazards.

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Katelyn says there was rotten food in Ava's home despite having carers visit twice a day. Supplied

Ava's soiled bed sheets. Supplied

Ava's home had fall hazards and poorly maintained structures. Supplied Both the care provider and the Public Advocate investigated the claims and said they were unfounded.

A transcript of a state tribunal review of Ava's guardianship shows her granddaughter pleading for help.

Nothing is being done and we're being told that we're liars and our allegations are false.

It's very frustrating, because we can see that my grandmother is not getting proper care.

She argued for guardianship of her grandmother without administration, which means she would have cared for Ava, but not have had any access to her money or assets.

We don't want to be trustee. If there was a family member appointed as her guardian, she would be able to get the care that she needed ... by people who love and care about her.

The request was denied, with the state tribunal deeming the state guardian the most appropriate carer.

Katelyn has since taken the state guardian to court to fight the restraining order preventing her from visiting her mother.

Instead of going through with a prolonged trial, Katelyn settled for an agreement that allowed her to visit Ava at the nursing home where she now lives.

"I'm sure that they [the guardian] have an astronomical workload, and I sympathise with that — like a lot of people, they are probably overworked," she says.

An ABC investigation into public trustees and guardians across the country has revealed numerous accounts of people receiving questionable care.

## Prisoner of the state



When Dan started suffering from memory loss and anxiety, it kicked off a chain of events that left him living in a nursing home against his will with little say over his future.

The system which cares for the community's most vulnerable people has been found to charge exorbitant fees, forced them to do things against their will and arguably acted against their best interests.

It's illegal to identify people under state care — with penalties ranging from hefty fines to imprisonment — making it difficult to publicly scrutinise state trustees and guardians.

Katelyn reflects on the past few years of dealing with the system as she wanders through her mother's home.

Rat droppings and cobwebs are scattered throughout a cupboard filled to the brim with food.

Katelyn looks through a cupboard full of food. ABC News: Cason Ho

Cob webs and rat droppings in a cupboard full of food. ABC News: Cason Ho

Katelyn opens a cupboard full of food. ABC News: Cason Ho

"They have done things — forbidden me from having contact with my mum ... forbidden me from helping my mum, from seeing my mum," she says.

"All these things are just not based on what's best for my mum."

She feels confused about claims she's exploiting her own mother, and angry about the care the state has provided.

"If this is happening to me — and I've never been charged or convicted of anything in my life, I'm an only child and did everything to help my mother ... I know there are so many other people that it is happening to," she says.

"The most vulnerable people, the people that we love the most, are being so badly treated by the government agencies we entrust."

#### **Credits**

• Words, photos and digital production: Cason Ho

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