

Dianne Pendergast, Queensland's Adult Guardian

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Picture a not-so-pleasant family future. Your 70-something father, beset by Alzheimer's disease, has had a serious fall at his nursing home.

For two weeks he's been comatose in an intensive care unit, the hospital's specialists diagnosing extensive brain and internal injuries. Tubes feed him. A machine breathes for him. And the doctors are united: your dad will not recover. Adhering to principles of "best medical practice", they wish to remove life support.

Your mother has passed away. You and your siblings love your father - that has never been in dispute. But longstanding bickering within the family over his health, financial and accommodation arrangements has led, some months earlier, to the appointment of an outsider as his primary decision-maker: a public official, known as the Adult Guardian. So now the ultimate decision must and will be made. By a stranger. Even if she is not alien to these circumstances.

During the past 12 months, Dianne Pendergast - the state's incumbent Adult Guardian - has elected to "withhold or withdraw life-sustaining measures" from 22 Queenslanders. "I've been accused of killing people and ruining people's lives and all sorts of things," says the 45-year-old strawberry blonde lawyer. "I've been accused of playing God. I've been told that I'm quite mad. (Families) will say things like, 'if this was your father ' or 'if this was your daughter ' They try to personalise it for me.

"But I don't terminate lives. It's not euthanasia. A decision like that has got to be something the medical profession recommends; it needs to be medically and ethically viable."

Pendergast pauses over coffee that has long gone cold. We're in a bistro in the plaza of the avant-garde Brisbane Magistrates Court building in George St. Her office is on the third floor. At surrounding tables, police officers and legal eagles are huddled in lively debate over this matter or that.

Pendergast's tough, contentious job brings a certain perspective, too. For instance, as we both look across to the blur of people and cars outside, she homes in on the potential for crippling head injuries. "People hanging off corners in the CBD it makes me absolutely shudder. I feel like getting them and pulling them back," she says. "If they came to an acquired brain injury unit with me one day, they would really start to do things differently."

Her voice softens: "You know, it doesn't get any easier. I find making end-of-life decisions incredibly sad."

THE OFFICE OF THE ADULT GUARDIAN HAS BEEN awash with controversy almost since its inception in 1998. Nonetheless, the founding premise of the OAG was noble: to establish a last line of protection for the rights and interests of adults with "impaired decision-making capacity". The majority of Pendergast's "clients" have either an intellectual or psychiatric disability, an acquired brain injury or dementia.

An independent statutory officer chosen by the Attorney-General, she is currently the legal guardian of 720 such citizens aged 18 and above from around the state. She has overarching responsibility for them, with day-to-day management delegated to a team of 15 principal, senior and junior guardians.

Hearings before the quasi-judicial Guardianship and Administration Tribunal may award guardianship to Pendergast when an impaired decision-maker has no apparent family or friends. Or where evidence of abuse, neglect or exploitation is produced. Or where family conflict over decisions concerning the person has become so intense, the GAAT decrees that an external guardian is the best option.

The trouble is, Pendergast's patronage is often imposed against the wishes of family members who do not accept it is necessary or just. Two years ago, following fervent lobbying by a coalition of advocacy groups and a series of adverse reports in *The Courier-Mail*, then attorney-general Linda Lavarch instructed the Queensland Law Reform Commission to review the state's guardianship laws and procedures. That evaluation is ongoing.

But Pendergast assumed stewardship of the OAG from predecessor Paula Scully only in May last year. At the halfway mark of her three-year tenure, she says she is striving to change the agency's reputation for being insular and defensive. "We have a very big responsibility to question ourselves and to have a strong dialogue with people about what we're doing and why," she says. "You can't do that by battenning down the hatches."

The stakes are enormous: Pendergast is sanctioned to conduct all personal and health decisions on behalf of clients. And from time to time, when one of them becomes terminally ill, is in a coma or vegetative state or has a sickness or injury so severe that he or she is not expected to survive without life support, the "healthiest" determination can result in death.

"The predominant group of people we make end-of-life decisions for are people who have no-one else in their life," she says. "Generally it's someone who's 65-plus. An incident has occurred and the doctors don't want to give that person CPR, assisted ventilation or anything like that.

"If you're a young, fit person, you might have the strength to withstand what's done to preserve your life. But if you're frail-aged, those sorts of interventions (for example, CPR, which may inflict damage such as broken ribs) are huge assaults on people's bodies.

"So you're prolonging life in a way that makes negative outcomes more likely. And the more negative the outcome, the less the medical profession can provide comfort."

Pendergast stresses that when her edict is that life support be withdrawn or withheld, it must line up with the tenets of "good medical practice". But when divided or rancorous family members are involved too, the pressure intensifies. "We're often placed in a situation where someone who loved someone enormously and has got unfinished business with them doesn't want this to end," she says. "We do look at the (patient's) values and morals and what decision they would have made. And we do take into account the opinions of all the important people in that person's life.

"But ultimately, the person I'm responsible to is not the family. It's the person in the bed."

A shearer's daughter brought up in Charleville, Pendergast could not do what she has to do without an iron resolve. However, there are surprising elements to her. A thunderous laugh, for one - and a heart of glass. Twice, when describing the suffering and abuse experienced by some of those in her care, she abruptly stops and chokes back tears.

"I'm sorry," she says. "I've learnt that a lot of people in this sort of work employ their intelligence a lot. I guess it's more a forensic experience. That's not the way I engage with anyone. You need to use your intellect and advocacy to effect change for people. But I don't have the capacity to separate my emotional and intellectual responses. It is part of what makes me very good at my job and it is part of what makes me very bad at my job. My biggest strength is also my biggest weakness."

THE OAG EMPLOYS SEVEN INVESTIGATIVE STAFFERS who launch more than 140 new probes a year, acting on tip-offs from relatives, friends or neighbours, banks, hospitals, aged-care facilities or other agencies. More than half the alleged victims are aged 75 and over, 59 per cent of them with dementia. The majority of complaints and concerns are about financial abuse from family members.

Challenging a son or daughter who is fleecing an ailing, elderly parent tends to be nasty business. Especially with the extraordinary powers at Pendergast's disposal. Her investigators have the legislative authority to sequester records and accounts; gain access to medical files; suspend Enduring Powers of Attorney; and remove people from homes and care facilities where there is a suspected immediate risk of harm.

At the most despicable end of the financial abuse continuum is what Pendergast has dubbed "granny napping". "There was one where a (family member) separated a husband and wife and ripped (the husband) off - took all his money," she says. "We were appointed to pick up the pieces and we got (the husband) back. But then, in all of this kerfuffle, there was an accident and he died from a brain injury. If he'd been left in a stable situation with proper nursing support in place, it's unlikely any of that would have happened. So what (the family member) did was unforgivable."

When money is misappropriated by Enduring Powers of Attorney, criminal fraud prosecutions are typically hard to prove, she says. Traditionally, attorney agreements are signed before incapacity so that in the event of later illness or accident, someone "trusted" can make decisions for another.

"Attorneys are often a loved son, sister cousin," Pendergast says. "The problem is they may have a bad record of (financial) decision-making. Or they could be extremely foolish or extremely bad. Often, the way we find out about this is that we get a phone call to say nursing home fees haven't been paid. We look into it and find assets gone, the money gone.

If we think people are being ripped off, we will suspend powers of attorney immediately and step in. We don't dilly-dally because often the money goes into poker machines or failed businesses and you just can't get it back."

In the backlash - particularly if it entails her taking over as guardian - Pendergast and her staff may be taunted and intimidated: "It can get really heated." But for the older client, the pain is redoubled. "Not only do they lose their resources, but they lose hold of their family's support because one group of the family is absolutely appalled by what the other group has done. At a time in your life when you should be enjoying your family to lose that because someone has behaved badly, it's just irreplaceable."

Pendergast has also identified a swelling clientele in the 18-25 age bracket: chiefly young people who've moved out of the care of the Department of Child Safety without suitable family or friends to take over. And most of the sexual abuse her investigators uncover is committed against younger women with an intellectual disability. Commonly, the alleged perpetrators are fathers or grandfathers. These matters are automatically referred to police. But frequently it is the police who have come across the initial allegations and, having not found sufficient evidence to press charges, moved the case on to Pendergast. Although the customary evidentiary tests might have failed, Pendergast can run the sort of interference that splits families and sparks hostility.

"Because of the difficulty for police (of eliciting admissible evidence from the intellectually disabled) because they have to prove something beyond a reasonable doubt, they are often never going to be able to bring criminal charges," she says. "So they'll refer it to us, and our role is to protect the adult."

She cites a couple who were outraged when (a family member) was removed from their care and placed in secret accommodation. Pendergast, who has become the young person's guardian, is unapologetic: "They are continually demanding that we tell them where she is. It was never going to be the case that we could prove (sexual abuse), but there were allegations. And when we relocated (the person) she started talking, eating, putting on weight. She's happy. Since we've moved her, she's changed remarkably."

Occasionally, she adds, people are the architects of their own demise. These are the "squalor cases" in which elderly hermits have gradually stopped looking after themselves and their homes. "There was a house earlier this year that an investigator and a nurse went out to see for us. And it was that bad, when they opened the front door they vomited from the smell. The gentleman living there had collected human excrement in buckets and had gangplanks going over the tops of them so he could walk through the place. He had ulcers. He wasn't eating properly. He was demented. And he was alone."

Another shocking scene involved a woman's neglect of her aged mother, who had dementia. "A woman was living in a Queenslander," Pendergast says. "And the mum lived underneath it. (The ceiling) was so low that she couldn't stand upright. She didn't have baths or showers and when we took her to the hospital, her watch was embedded into her skin. So, over time, they had to apply saline solution to her skin to get the watch off "

EMPATHY FOR THE ADULT GUARDIAN AND HER work is a long way off Barbara Sobczak's radar as she struggles to come to terms with the death of her 83-year-old father on June 24 this year. Stanislaw Sobczak took 16 days to pass away in hospital after Pendergast, on doctors' recommendations, consented to the removal of his hydration drip.

"My father's been dead for five months now," says Barbara, 44, "and I believe (Pendergast) might have even forgotten about his existence."

Stanislaw had been living with his wife Maria, also in her eighties, at their Brisbane home when he lost his speech and movement down his right side as a result of a stroke a year ago. He spent more than two months at Logan Hospital, and a dispute over his future needs developed between Barbara and her elder sister. "I wanted to take him to my house in Townsville and look after him there," Barbara says. "But my sister wanted him in a high-level-care nursing home." She went to the GAAT to seek guardianship at a February 16 hearing. Taking into account the depth of family conflict, the tribunal appointed the Adult Guardian instead.

Stanislaw was housed in Carindale Court nursing home, in the Brisbane suburb of Mt Gravatt, where in late May he had a second stroke and fell into a coma. He was transferred to Princess Alexandra Hospital, and the prognosis was grim. He was hydrated but denied a feeding tube. "The doctors said my father had less than a one-in-1000 chance of getting any better," Barbara says. Nevertheless, she says she and Pendergast concurred that he would keep receiving fluids until a certain time, when treatment would be reassessed.

The hydration tube was removed almost two weeks before the agreed date, Barbara says. The next day, when she sought reinstatement of the tube at a GAAT hearing, the tribunal dismissed her appeal on the grounds that "the continuation of hydration to Stanislaw Sobczak is inconsistent with good medical practice". Barbara says her father, who as a 23-year-old migrated from Poland, was a tough nut. While his ability to communicate was devastated by the first stroke, his mind "was still working. He just couldn't verbalise what he thought." She believes his chances of recovering from the second stroke were worth fighting for.

"He needed more time," she says, "but no-one listened to me. If you're a daughter and he's got one chance in 1000, you're going to give that to him. That's the difference between a daughter and an outsider who's weighing the odds. She's listening to doctors and logic. For her, it was just a mind decision. For me, it was a mind and heart decision."

Carers Queensland, a non-government agency providing information and support for half a million Queenslanders who look after incapacitated relatives or friends, worked closely with

Barbara Sobczak during her ordeal. CQ's regional services manager, Brendan Horne, says Stanislaw Sobczak's fate underscores the OAG's "anti-family" regime. "I've got no problem with people taking away artificial supports to people's lives," he says.

"But I don't think it's the doctor's choice or the Adult Guardian's choice. It's a family decision."

Some vulnerable family members are undoubtedly abused by their carers, says Horne, and "there needs to be a mechanism to support those people". But he adds that over the past two years, his agency has counselled more than 100 families that have objected to the Adult Guardian's interventions.

"A service provider (such as a hospital or nursing home) might report a family member to the Adult Guardian and say they are obstructing the best interests of (their relative). Or when a person becomes incapable, you might get differences of opinion between family members as to who wants to be top cocky in terms of making decisions.

"In these circumstances, we argue that there needs to be a far greater emphasis on mediation - not to make some quick formalised legal order, focused on the individual, which leaves families as collateral damage. The net's been cast too broadly. Too many good families, who only need a little bit of support and help to solve situations, are caught up in a very coercive approach."

Horne portrays as "incredible" the OAG's clout and the lack of avenues for complainants: "You won't find another authority that can operate with the kind of power that this body's got." As one indignant family member puts it: "(The OAG) is a fascist little cell."

A FAMILY COURT REGISTRAR FOR 14 YEARS UNTIL applying for the Adult Guardian post, Pendergast counts her own family ties as close. Her dad Ken has grown wealthy from horticulture. Her mother Edna, still "focused on family, work ethic and the idea that you've got to put something back", is one of ten children from Irish-Catholic stock. Pendergast has two siblings and "something like 65 first cousins".

"But some family members, who I love dearly, have said to me, 'I don't know why you're doing this. Why don't you just go somewhere and open up a practice and make lots of money?' There's nothing wrong with that," she says, "it's just that it doesn't interest me. You know, you can't you can't "

It's not who you are?

"No."

Pendergast is prepared to touch on the Sobczak controversy, despite the confidentiality provisions governing the Guardianship and Administration Act. While not regretting her handling of the case, she nods when I conjecture about "miracle recoveries".

"You hear those sorts of stories and you think " she says. "And that was one of the things (Barbara's) view was that if there was a one-in-1000 or one-in-100,000 chance But if a doctor advised me that (patient recovery) was a medically and ethically likely outcome that we should aim for, then I wouldn't make the decision to withdraw or withhold life-sustaining measures."

Speaking generally about mediation, she is resolute. "It's got a place," she says, "and decisions rightly rest with healthy, functioning families. But not all families are functioning in a way that can protect (her clients)."

She insists appellants have opportunity to seek redress through an internal OAG review or return appearances before the GAAT. Other forums are the Ombudsman, the Crime and Misconduct Commission and the Supreme Court. When I suggest the first two options have the hollow ring of Caesar judging Caesar, she won't abide it. "No," she says, "the reviews (are carried out) with much angst. And we do overturn decisions on internal review."

Our meeting has stretched into lunch. Pendergast has picked at a plate of nachos, but now it's time to move on. There's work to do, issues to decide. Tonight, after catching up with her husband Greg Lee, a senior communications officer with engineering firm Sinclair Knight Merz, and their nine-year-old son Bader, Pendergast will lace on joggers and hit her neighbourhood pavements.

Given the earthy reality of her days, she can't purport to be any guardian angel. And so she must run, chasing the calm that she needs to make her decisions fly. "It's the coolness and it's the rhythm of running - and it's the blackness," she says. "It's how I churn stuff through and somehow get this order in my head. By the time you've completed five kilometres, you've advanced your decision-making on a matter.

"I don't mean that you've finalised it. But you've thought it through. You've really challenged yourself about a lot of things."

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