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Good **Weekend**

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## For the love of Niki

How the life of his beautiful girl drove a father to win a massive compensation deal for thalidomide survivors.  
By Andrew Rule

### Plus

#### Winning ways

Martina Navratilova bounces back

#### Operation Focus

Stop multitasking: it's less useful than you think

His daughter's battle with the terrible legacy of thalidomide is over. Now Ken Youdale has teamed up with an unlikely ally to persuade a multinational giant to pay millions in new compensation for those who are still suffering.  
By Andrew Rule.

# ENDURING

# LOVE



**"An extraordinarily beautiful girl who had one of the toughest of lives to lead":** (above) Niki Youdale with Monty, in about 2001; (opposite) Ken Youdale (at left) with his fellow campaigner, lawyer Peter Gordon.

**W**HEN KEN YOUNDALE VISITED THE *VOGUE AUSTRALIA* office in the 1960s, the most glamorous women staffing the most glamorous magazine in the land would flutter around him as if he were a star, not just another "suit", there to talk business with their boss.

"The girls all loved him," muses his then business contact – now an old friend – Bernard Leser, the Condé Nast publisher who founded the magazine in Australia on the way to becoming an international publisher of renown. "The *Vogue* editors all thought he was the best male around."

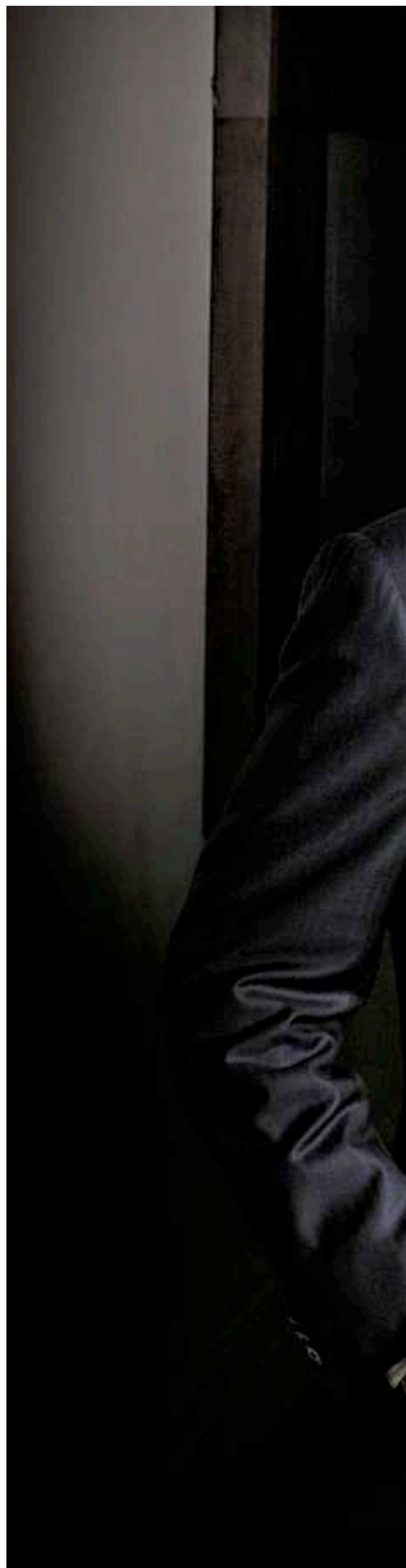
Part of the attraction, he says, was that Youdale was not only dashing and handsome but radiated decency. "A gallant man – both a gentle man and a gentleman," murmurs Leser, whose international publishing credentials might qualify him as a tough judge of human nature. "He was very modest about what he'd done. It was like drawing teeth to get him to talk about himself. There are not so many of his quality around. But beyond the charm was a very analytical mind. He had an extra-persuasive tongue and he was sensitive."

He pauses, framing his next sentence carefully. "And there was tragedy in his life. But there was never any self-pity about it." Then he talks a little of what happened to Ken and Janet Youdale's little girl.

AT 86, KEN YOUNDALE, DFC, OAM, STILL LOOKS AS IF HE HAS JUST STEPPED from a yacht for a hit of tennis – a game he is known to play dangerously well for his age. Youdale inherited athleticism from his natural father, an international rugby player for South Africa. His stepfather was a shrewd businessman who played Davis Cup tennis for Australia and taught young Ken winning ways in both. His mother was a cultured and well-travelled woman who ingrained a love of the arts in her handsome only son.

In 1947, as a poor law student with a distinguished war record and a flair for writing musical comedies, Youdale borrowed the airfare to New York and bluffed his way into meeting the musical theatre giant, Oscar Hammerstein II, to pitch a show he'd written. He got the advice he wanted – "Take it to the West End" – and Hammerstein got to improve his tennis game.

As it turned out, Youdale didn't bother pitching his musical in London because his "serious" business career was taking off. Along the way, the Hammersteins would introduce him to contacts who would license his company to sell Perrier water in Australia, one of the coups that would turn





the tennis-playing, musical-writing lawyer into a prosperous businessman – independently, as an executive with Amatil and, later, starting a successful consultancy that he still runs.

Youdale's life story is full of these lucky breaks. He calls it "karma". Others might call it "charmer". He is a charming man who has in most ways led a charmed life. Even when he went to war as a teenage airman in 1942, his luck held. He flew dozens of raids over occupied Europe when the odds of surviving or dying were like tossing heads or tails.

As a navigator, he says, he was painstaking and pragmatic, always trying to plot a course that placed his aircraft in copybook formation, minimising the constant danger of being shot down by German night fighters. He describes the terrifying experience of flying 36 missions as calmly as if talking about a far-off football season – one in which half his team was killed. The year Youdale turned 20, his mates were being shot down every week and he knew the odds were he might be next. It left many survivors shattered but Youdale survived with body and nerve intact.

Like many of his generation, he is not given to public displays of emotion. He is guarded about his feelings and offhand about his achievements, which are many. Before the war ended he was awarded a Distinguished Flying Cross by King George VI at Buckingham Palace.

He was just 21; ahead was the law, the theatre and financial and social success. And marriage to a beautiful woman, Janet Hayes. The Youdales seemed blessed, but their life changed on May 9, 1962, when their first child was born.

Early in the pregnancy, Janet had asked a Sydney pharmacist for something to combat morning sickness. He produced a new product a drug company was marketing as Distaval. The drug was supposed to be sold by prescription only, but because the chemist knew Janet he waived the rules and gave her the bottle. She took two of the pills over the next few days and thought no more about it until much later. By the time the baby was due, the Youdales were living in Melbourne, where Ken was starting a business.

Janet's labour was far shorter than predicted, and Ken was in their apartment when he got an urgent telephone call from the maternity hospital. Could he come immediately? The baby had been born and his wife was hysterical because the nurses were refusing to show it to her "because it is deformed".

Youdale rushed to the hospital. The nurses apologetically produced his tiny daughter. She had no thumbs. Apart from that, she looked perfect but she wasn't. Internally, her body was malformed as well. One sign of this was that she vomited breast milk and had to be artificially fed.

A doctor immediately identified the cause of the missing thumbs – because he and his wife had just had a severely handicapped baby son after the mother had taken thalidomide. It was the first time the Youdales heard the proper name of the drug sold under the trade name Distaval, and about its ghastly effects.

They christened the baby Nicole and called her Niki. When she was six months old, they took her to the Mayo Clinic in the US and "in five minutes" discovered that missing thumbs were the least of her troubles. Baby Niki was alive only by chance – a freakish impediment that stopped blood leaking into her lungs. A congenital heart condition known as truncus arteriosus, meaning she had one blood vessel pumping blood from the heart, not two, effectively starved her blood of oxygen. Many babies with her condition drowned in their own blood.

Niki would grow up to face the fact her parents



“  
‘I love you so very much, Daddy,’ she said, and in a second she was gone – back on the hospital trolley – waving over her head.”

**Living in hope:**  
(above, from left)  
Manon, Ken,  
Romaine, Janet and  
Niki Youdale.

had lived with from that day: that without a heart-lung transplant and a lot of luck, she would die young. The wonder is that she would survive as long as she did.

**N**IKI YOUDALE WAS ONE OF THOUSANDS of “thalidomide babies” who survived birth around the world between 1960 and 1962. Estimates that there were 7000 physically handicapped survivors have been published but recent research suggests many more “thalidomiders” went unacknowledged for reasons only now starting to be revealed. Whatever the real tally of survivors of the greatest medical disaster in history, many more thousands died in the womb or shortly after birth. Alive or dead, many were grotesquely malformed, born without arms or legs and sometimes neither, and often suffering internal deformities as well.

Compared with many other thalidomiders, as they prefer to be called, Niki looked relatively “normal” and used her considerable abilities to help others as long as her heart and lungs allowed. “She grew up to be a fabulous daughter,” says her father. She became a make-up artist in television and theatre and did volunteer work to help others, many with an outlook less grim than her own.

As Niki reached her 30s, her family nursed the hope that a lung-heart transplant would be possible if she got to the head of the donor list in time. In 2003, her time ran out.

Last month Ken Youdale wrote a letter to a new friend in which he describes what happened to his daughter. The friend is a seasoned plaintiff lawyer, but he admits he choked up when he got to this part of the letter:

“Janet, Romaine, Manon and I were all gathered at her room at St Vincent’s Hospital only days after she had been taken off the heart/lung transplant program (she had been put on to the program after months of exhaustive tests and was waiting for a heart/lung of the correct size for her chest) as she had suddenly, and unexpectedly, been diagnosed with a brain tumour. That’s a cancer, of course – so there was now no longer a possibility she could ever have such a transplant, no matter how successful the operation for the tumour.

“As she was wheeled out of her room on the hospital trolley, and was about 20 feet down the corridor leading to the lift, she suddenly told the two orderlies to stop pushing, jumped off the trolley, came running back to me, put her arms around me and gave me the hardest hug and kiss on the cheek. ‘I love you so very much, Daddy,’ she said, and in a second she was gone – back on the trolley – waving over her head. Three hours later she died, undergoing the operation.”

In the same letter, he writes that Nicole “was an extraordinarily beautiful girl who had one of the toughest of lives to lead. She had to conquer each day to stay alive and get enough oxygen in her lungs to keep breathing. She lived to make other people happy and at her funeral, not only was the church, St Mark’s, in Darling Point Road [Sydney], full to capacity, the aisles were completely full and there were as many people outside the church as in ... Janet and I saw dozens of people we had never seen before, and in many cases only learnt the connection much, much later.

“One of her many contributions to others was to participate in Lifeline – a telephone service for men and women in distress – that, on the 10.30pm shift, or any other, she would counsel desperate people with no money, no food, no home, with two or three children, and about to commit suicide. She would get them into somewhere for the night, with food, blankets, and safety ...”

Niki’s school, Ascham, gave her a prize the year she left. After her death, the school made it an annual award in her name. It is given for courage.

KEN AND JANET YOUDALE WERE IN THEIR 70S when they buried their girl. They had endured 40 years of cruel uncertainty and Ken had devoted 24 of them to the Australian Thalidomide Foundation he had helped set up in 1974.

An honorary governor, he had the business acumen to handle the modest compensation given by the British company Distillers, which had sold thalidomide-based drugs around the world after obtaining rights from its German inventors. The foundation held the money in trust until each of the (then) 39 identified Australian and 10 New Zealand victims turned 25.

## A medical catastrophe

No one knows just how many thalidomide victims have made it to middle age, only that the original estimates of “something like 7000” who survived birth were probably too low. In the 46 countries where the drug was sold under various trade names as a morning sickness treatment, thousands more babies died at birth or in the womb.

The official line is that thalidomide was invented in the early 1950s by a German company, Chemie Grünenthal, but recent research indicates it was probably developed by Nazi military scientists as an antidote to sarin gas. Either way, Chemie Grünenthal’s chemists assured a credulous world it was non-toxic, had no side effects and was safe for pregnant women. Such claims would prove criminally negligent but doctors and pharmacists accepted them at face value, and it would take years to sheet home responsibility for what became the world’s greatest medical disaster.

When women took the drug in early pregnancy, when foetus limb buds form, it produced babies with a wide range of deformities. Some had no arms, just flippers from the shoulder; some no legs, just toes; some had limbless trunks. Some appeared normal but were injured internally or were deaf, blind, autistic or epileptic.

The link between a rash of birth defects and the new drug was made by an Australian doctor, William McBride, in 1961. But until the UK *Sunday Times* newspaper campaigned in the 1970s to reveal the full story, it was covered up for years by the best legal advice drug companies could buy.

The Youdales had two other daughters, busy social lives and broad interests; no one would have blamed them for stepping back from the thalidomide cause once Nicole was gone. The foundation had been wound up in 1998 because the last of the victims had long since received the last of their compensation. Youdale had earned the right to spend his last years in peace.

Which is what might have happened if the thalidomiders, in 2008, had not held a conference in Sydney. The gathering marked a decade since the foundation’s winding-up, which had ended any formal reason for the group to get together. Niki Youdale had been popular among the others and as a tribute to her – and her father’s long service – they asked him to speak about the foundation’s work. It was, in a sense, a reunion.

But Ken Youdale, still the diligent navigator, did his homework. At 84, he was still running his corporate consultancy and was a keen internet user. He found things were changing. After decades of benign neglect and grudging “charity”, the thalidomiders’ cause had found new life.

In the UK, two shrewd activists, Nick Dobrick and Guy Tweedy, had embarrassed the British government and struck a spark of generosity from the giant multinational Diageo, which had taken over the company that marketed thalidomide as a morning sickness drug nearly 50 years earlier.

One of the protests had thalidomiders staging naked “sit-downs” outside the British Parliament. And they were getting results, to the benefit of disabled people who had lived longer than doctors had predicted in the 1960s – but who now needed more support as their malformed and overworked bones and muscles broke down.

For instance, Diageo had increased its annual voluntary payment to the UK-based Thalidomide Trust from about \$5 million to more than \$13 million a year. The trust pays a small yearly “pension” to each victim.

As the biggest alcohol company in the world (with annual revenues of \$25 billion), Diageo had inherited a monstrous wrong perpetrated a gener-



ation earlier by one of its subsidiaries, the Distillers company. Diageo could afford to support every thalidomide victim on earth, but was under no legal obligation to do so. The only hold over the company was moral: its subsidiary, having unwittingly perpetrated an unspeakable tragedy, had ducked responsibility for it until *The Sunday Times* in the UK broke down formidable legal barriers to expose a cynical corporate cover-up.

Youdale had spent his life spotting opportunities and knew this was one. When he gave the speech to the Australian Thalidomide Foundation two years ago, it could have marked the end of his devotion to a cause to which he’d given much. Instead, he plotted a new course, getting himself elected as honorary special adviser to the foundation to fight for just compensation for surviving thalidomiders in Australia and New Zealand.

The World War II airman had a plan: to return to Europe, 65 years after his previous campaign, for one last raid.

YOUDALE KNEW IT WOULD BE A WAR OF TACTICS, and that he would have to gather ammunition and intelligence. He worked “seven days a week”, from early 2008, to wangle an audience with Diageo’s decision-makers. He sensed he had to act fast because of the looming retirement of the company’s chairman, Lord Blythe, who had trebled its voluntary payments to UK thalidomiders.

Youdale wrote to the Australian prime minister’s office and to the new Health Minister, Nicola Roxon, to the Parliamentary Secretary for Disabilities, Bill Shorten, and to Senator Jan McClucas. It worked. Each wrote back, with Roxon promising the prime minister would back the thalidomiders’ campaign for compensation from Diageo. Youdale guessed that the Australian Government letterhead would get him a seat at the high-rollers’ table in London. Meanwhile, there were other obstacles.

“I realised no one had ever costed how much thalidomide victims needed to live, because each case was different,” he says. “One girl had no arms

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“A fabulous daughter”: (above) Ken and Niki Youdale in about 1998.

and no legs. One man had no arms. One had shocking scoliosis [curvature of the spine].” But how to compare them in dollar terms?

He drew up a questionnaire for the thalidomiders. Their answers charted the plight of people worn out from living with a range of crippling handicaps, many unique to that individual.

Trying to act for people scattered all over Australia and New Zealand was potentially a legal nightmare. He needed unanimous agreement from the 46 surviving thalidomiders – a decision often involving anxious relatives and family lawyers – and a legally watertight authority to act on their behalf.

Youdale knew some big commercial lawyers but none had an easy solution to the question of how a single voluntary “envoy” could act for each claimant in such a complex claim. He was pondering this problem in a coffee shop in Edgecliff when a local solicitor asked what the trouble was.

When he explained, the solicitor suggested that each thalidomider simply sign a power of attorney document giving Youdale authority to negotiate on his or her behalf in London. It was the right answer – but not everyone took it at face value. And that was lucky, because when a Victorian thalidomider wary of signing the document went looking for advice, he stirred the interest of one of the toughest class-action lawyers in the business.

PETER GORDON WAS JUST FINISHING THE epic Vioxx personal-injury trial against the global drug company Merck, in May 2009, when his office took a call from a man whose name he vaguely recalled: Tony Speccio. Speccio is a thalidomider – and a builder in outer Melbourne’s bush and bayside suburbs.

A couple of years earlier, Speccio had sold a beach house to Gordon, who had made his name and his fortune as a plaintiff lawyer with Slater & Gordon. The Vioxx case was the latest in a series of headline-grabbing class actions against huge targets ranging from mining companies to the Catholic Church, dodgy breast implant manufacturers and “Big Tobacco” firms.

Gordon had been impressed with the craftsmanship of the house, all the more so because Speccio had overcome big physical handicaps to master his trade. So when the little builder asked for help, the big lawyer invited him home.

Speccio brought the Youdale document requesting power of attorney. It so happened that Gordon, after years of building his firm into a class-action powerhouse, had just decided to step aside to devote time to cases that interested him. He could afford to work pro bono for good causes.

At first Gordon was wary of Speccio and the others giving power of attorney to a man in his 80s who had not practised law since the 1950s. He also doubted their chances of winning compensation when they had already received a settlement in the 1970s, albeit a modest one. But after Gordon called Youdale, he changed his mind. He advised Speccio to sign up. And he offered to help, for nothing.

Youdale thought it a splendid idea. He had charmed Gordon – and the tough lawyer had impressed the older man. And so two men who had never heard of each other quietly united against the richest distillery company in the world.

They make an odd couple. Youdale, the unruffled establishment figure, a one-time executive with a company that sold tobacco. And the pugnacious Gordon, former hardscrabble Footscray kid, who carved a career in so-called “ambulance-chasing”, notably against Big Tobacco. Once, they would have been natural enemies: Sydney-old-school-tie-capitalist versus Melbourne-



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Two men who had never heard of each other quietly united against the richest distillery company in the world.

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union-lawyer-from-hell. But on thalidomide they had common ground.

“Peter was direct and strong. I liked him straight away,” says Youdale. Gordon was won over by the older man’s calm conviction that he would get a result, and his good grace in accepting help.

Months earlier – in late 2008 – Youdale had gone to London armed with his Australian government “letter of support” and ample spare time. He stayed at the East India Club for a month, determined to smoke out Diageo executives who, he guessed, were stalling for time. “I sat on my bum for three weeks before they realised I wasn’t going away,” he recalls, chuckling. At the second meeting, the Diageo man said he was bringing a company lawyer. Youdale, keen not to be outnumbered, invited a friend to the meeting.

It happened to take place on November 11. At 11am precisely, Youdale and his friend stood and asked for two minutes’ silence to honour the Allied war dead. “Of course, they had to stand, too. That threw them,” says Youdale, who relished wrong-footing the London men on their home turf.

The deceptively polite meetings in London were the beginning of a long-distance, slow-motion dance that would persuade Diageo to send two of its top people to Australia last August. Again, the Diageo executives got more than they had bargained for. When they met for three days of talks at the Blue Hotel in Wollomooloo, Youdale produced his new best friend, Peter Gordon. The third person in the Australian delegation was Lance Fletcher, a thalidomider born without ears. His condition underlined the suffering of the people Youdale and Gordon spoke for.

It worked. Diageo’s corporate relations director, Ian Wright, opened by saying that although the firm’s current leadership had nothing to do with decisions made by others in the 1960s and 1970s, he wanted to apologise for the great wrong suffered by thalidomide victims.

The war hero and the hard-edged litigator were both moved by his sincerity, and the gesture set the tone for the meeting. Gordon was able to persuade Diageo to change its model of doling out money over victims’ lifetimes, in favour of paying larger amounts up front to bring greater comfort to people whose life expectancies are not always long. “The idea is to benefit all of them, not just those who live to be 90,” he explains drily. The corporate wheels turn slowly. It has taken another nine months for the \$50-million deal to gestate. It is an astounding win. But it might not be the last.

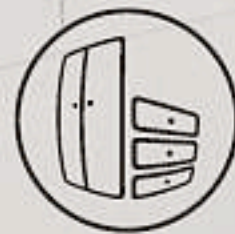
The plight of the survivors has motivated Peter Gordon. He suspects there are many more people affected by thalidomide than have been acknowledged by the drug companies and health authorities – both those with deformities always known to be thalidomide-related and those with deformities that medical science is only now starting to see might have their roots in the drug banned so long ago.

He has spent months poring over obscure documents and cultivating sources around the world. So far, he says he has found that the Nazi-era German company that recklessly oversold the merits of thalidomide to the UK firm Distillers has never been sued.

“Somewhere in Germany,” he says, “there’s a big company that can expect a writ for a new class action in Australia in the not-too-distant future.” **GW**

*A POSTSCRIPT. IN APRIL, A DOCTOR ASKED KEN YODALE: “IN CONFIDENCE, have you done all this work on thalidomide to make yourself look good or do you really do it because you just want to help others?” Youdale described his reaction in a letter two days later: “I was stunned. The man had never seen my daughter; it’s now been seven years since Nicole died and somehow this man thought that my Order of Australia ... was political payback for working for the thalidomide cause for the last couple of years – as simple as that.” It wasn’t.*

“Peter was direct and strong. I liked him straight away”: (above) Ken Youdale found an unexpected and powerful ally in lawyer Peter Gordon.



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