

This is the unedited version of a profile which appeared in *Australian Doctor* in 2001. The published version may have had minor changes.

The Profile: Margaret Kyrkou

CV in Brief

1978-present: Medical Officer and manager in School Health (now Child and Youth Health)
1996-present: Part-time lecturer and tutor, School of Special Education and Disability Studies, Flinders University
1999: Master of Disability Studies, Flinders University
1984: FRACGP
1967: MB.BS (Adel)

HER TIME HAS COME

The lovely young bride, with her dark hair piled high on her head, looks even more Greek than her new husband, who actually is Greek. The faded wedding photos show Margaret and Steven Kyrkou as a radiant couple with a world of possibilities ahead of them.

Then come the photos recording the arrival of their beautiful Catherine, who is all chubby smiles. And then baby Nicole, also as pretty as a picture.

There is also a photo of an older woman with a strong, handsome face, cuddling her grand-daughters. Eleftheria Kyrkou, who gave birth to Steven in a stable while German soldiers were burning her village in Greece, spent her last 18 years living with her son and his family in Adelaide.

But then the photos stop. The remaining pages in the album are bare. Suddenly there was no time for such things. It became hard enough for the Kyrkous just to make it through the everyday.

When she was about eight months old, their Catherine had a seizure. Viral meningitis, the doctors thought. By the second seizure, her parents knew that she had a major intellectual disability. As she grew up, it

became clear that Catherine also had autism, severe epilepsy and mild cerebral palsy.

It is difficult for an outsider to imagine what life must have been like in those early years. Catherine was quick, so quick that she could take a biro out of your pocket and put it in her mouth before you even knew it was missing. If the front door was left unlocked, she would be halfway down the street before anyone realised.

She needed constant watching, especially during her regular stays in hospitals, which are not designed to be safe or comforting for people like her. The seizures occurred so regularly that the long ambulance trip to hospital became part of Margaret's routine. As did the sleepless nights.

Growing up, Nicole was never sure that her mother would be there to pick her up from school. She was so often at the hospital instead.

Although medically qualified herself, Margaret saw that some doctors assumed that because her child was disabled, she must be a bit slow herself.

"Some of the treating doctors weren't willing to mention intellectual disability - they'd just say, 'don't expect great things of Catherine,'" remembers Margaret. "They didn't want to have to put the label to it. The first time I saw it written down was in a teacher's report. She was about 11 or 12 then."

And finances were tight; it was just impossible for Margaret to continue working as a locum for local GPs when there were so many other demands on her time.

Life must have been tough. Really tough. But Margaret doesn't dwell too much on that side of things on the Sunday afternoon we meet in the family home at Toorak Gardens in Adelaide's leafy eastern suburbs.

The house is in the midst of long-overdue renovations. It is quite bare, because things have to be kept out of Catherine's reach and because there hasn't been much time or energy left over for the house.

On the mantelpiece are photos of two attractive young women, Catherine, 28, and Nicole, 25. They jostle for space with a mass of congratulations cards.

“It was hard, but you get resigned to it. You just had to cope with it,” says Margaret, now 60. She speaks so quickly that I wonder if she is nervous, but later realise she always does; force of habit perhaps when there is so much to do.

But didn’t you ever get burnt out or ask, why me? “I was too tired to think of that actually,” she says. “You just keep on going because Catherine is our daughter and we will do the best we can for her.”

Catherine, who is developmentally a two or three-year-old, continues to keep the family on their toes as she finds ways to express her “wicked sense of humour”.

“She has got a bright bubbly personality that people take to,” says Margaret. “She will take the mickey out of you at the drop of a hat. She relates to people quite well in her own autistic way.”

Margaret didn’t expect Catherine would develop attachments to particular people but realised otherwise when she went overseas several years ago for some weeks. Catherine was more restless than usual when her mother was away. “When I rang, her face lit up,” says Margaret. “It was quite a surprise because I didn’t think she’d be that attached to me.”

Nicole, who now works in disability services with Margaret and is undertaking study in disability, says she has learnt from her mother the philosophy of doing the best with what you have.

“I’ve been told that not many people survive having a sibling with a disability,” she says. “I’m not saying that it hasn’t been hard. But mum’s just got an attitude that it’s got to be done, you can’t change certain things and you’ve just got to work around them.

“Dwelling on how things should have been or could have been isn’t really in our nature. Looking back now I really appreciate how hard it was and how good a job she’s done in keeping everything together. She

just always had time and managed to put my priorities and Catherine's priorities side by side, not one outweighing the other."

You sense, though, that there was not much time for looking after Margaret.

Earlier this year, Nicole and her mother had arrived home from work and were busy in the kitchen preparing for dinner. After opening the mail, Margaret stopped what she was doing and went unusually quiet.

Nicole thought something was wrong. Instead, her mother had just received a letter asking if she would accept a Medal of the Order of Australia in the General Division, for her services to children with disabilities.

The award was publicly announced in the Queen's Birthday Honours List in June.

And Margaret has hardly stopped smiling since. Her delight in the award is touching. Not that she was one to get on the phone and skite to friends. Most say they only found out by reading about it in the paper.

Kate Kohler was one of three colleagues to secretly nominate Margaret two years ago. Kate works in the Access Assistance Program, funded by the SA Education Department and based in the State Department of Human Services' division of Child and Youth Health. It supports staff who work with about 300 disabled children in schools in country and urban areas. Margaret has managed the program for eight years.

"If our workers weren't there, the children would be in institutions," says Kate. She has worked in the disability field for more than 25 years and says programs such as this have made a huge difference.

"The kids I used to work with were in wheelchairs and unable to talk," she says. "Now they are getting the interaction and social skills and laughing."

Kate says Margaret has had a great impact in changing attitudes and opportunities for the disabled because of her experience as both a mother and a doctor. Margaret is known for taking phone calls at all

hours from families, and for being generous with her time in offering advice and support.

Kate is thrilled about the award and that at a recent child and youth health conference Margaret received a standing ovation: “The fact that she’s been recognised has brought her out a little bit more; she’s been slogging along helping everybody and not been really rewarded herself. In a way, people needed to say thank you to her for her time and energy.”

Margaret first became involved in the disability area as a parent active in Catherine’s school and in parent groups, including Mothers of the Disabled and the Autism Association of SA. She moved into the area professionally when invited to join the School Health Service, assessing children with disability and learning problems and later training doctors and psychologists in assessments.

She also worked part-time in occupational medicine, at an abattoir run by the SA Meat Corporation. There she worked with the Institute of Medical and Veterinary Science’s Professor Barrie Marmion in the early 1980s on trials of a vaccine for Q-fever. She also helped investigate an outbreak of brucellosis.

Marmion says Margaret helped make “a substantial contribution” to the vaccine’s development. He remembers her as “a very pleasant, helpful person, very shrewd, and a very good organiser.”

Friends say that Margaret often went to work on very little sleep after being up all night with Catherine. But Marmion is surprised when asked about this. It was not something Margaret ever complained about.

Over the years, Margaret has spoken at many conferences on disability, and also lectures to Flinders University students. Her longstanding professional and personal interest led her to undertake a Masters project examining premenstrual syndrome in disabled women.

She had seen how badly PMS affected Catherine, who was unable to express her suffering but showed it in her behaviour, and responded well to analgesic treatment. Margaret’s survey of women and their families led to strategies for managing what had been a neglected problem.

Margaret, who is now undertaking a PhD on disability-related issues affecting women from menarche to the menopause, cites a dentist's comment that he wouldn't give pain relief to a young disabled woman before a procedure because "she wouldn't feel pain".

Catherine was at home until she was 18, and now lives in supported share accommodation, but returns home most weekends. Margaret takes her to netball on Saturday mornings, helping her daughter on the court.

Margaret Asche, as she was then, grew up near Adelaide, the eldest of four. Her parents were born during the depression and had to leave school early. They struggled financially, but were determined their children would have a good education. They also imbued them with a sense of community service.

Margaret's father was a small businessman who started off making garages in the 1950s. Realising that some people were living in them, he and his brothers moved onto making houses, before opening a hardware shop.

Margaret, a shy child but an enthusiastic Girl Guide, wanted to do medicine from when she was about seven but wasn't confident of her academic abilities so began teacher training. After six months, she decided to go back to her first love, and had to pay back her teaching scholarship.

She went to the local employment service looking for part time work to support her studies, but got a job there instead. That experience, interviewing and placing workers, proved invaluable in later years, she says.

Margaret was attracted to general practice as a medical student because of its wholistic approach to families.

Shirley Saint, an Adelaide GP who studied with Margaret, describes her old friend as genuine, conscientious and humble.

“She sells herself short if anything,” adds Shirley. “I really don’t know how she’s coped; I just think she’s wonderful. I’ve always felt that she’s someone I could rely on if I had any problems.”

Margaret met her husband Steven while working in Victoria. She had been taking Greek classes and met him through friends.

Steve, now a partner in a agricultural manufacturing firm, says he first noticed Margaret as a “very down to earth, very kind person”. She is also very calm, he adds. “I don’t think I’ve ever since her angry, maybe once or twice. I’m the one with the short fuse.”

The only drawback is that “sometimes she volunteers too much and volunteers me as well,” he says.

While many couples who have children with disabilities break up, Nicole believes the experience has brought her parents closer. She says it probably reflects the Greek sense of family and looking after each other.

Margaret’s sister, Janet Lothian, also works in disability, as a psychologist with the SA Education Department. She says having Catherine has had a huge effect on her sister’s life - “in the way that she’s risen to make it a strength.”

Another sister, Judith Rudland, an international development consultant based in Canberra, says Margaret was from her earliest years someone who looked outwards in terms of helping others.

“In a way she’s been a mother figure in a lot of the organisations she’s been in and the work she’s done. She’s someone who’s been steadfast and comforting; she’s a quiet leader.”

Nicole hopes that her mother’s award will mean that more people appreciate that “she has made a huge impact on a lot of peoples’ lives”. She says: “Until now a lot of her work has been unrecognised.”

It seems that after all these years of hard labour-of-love, Margaret Kyrkou’s time has finally come.

