

This is the unedited version of a profile which appeared in *Australian Doctor* in 2000. The published version may have had minor changes.

The Profile: Hilda Bastian

CV

1996- present: Consumers' Health Forum chair

1993- present: Bastian has many roles with the Cochrane Collaboration, but her main one is as international convenor of the collaboration's Consumer Network, for which she runs workshops in many countries training consumers to evaluate and use health research

1984-89: Founding editor, Home Birth Australia Newsletter and author of consumer several publications and books surrounding pregnancy and birth

1987-1994: Founder and convenor of Maternity Alliance, a national coalition of maternity consumer groups across a broad spectrum of concerns and experiences

1986-1991: Coordinator, Homebirth Australia

Member numerous NHMRC and other health committees

A PASSIONATE WOMAN

Ask twenty different people to describe Hilda Bastian, and you end up with an intriguing diversity of views. Many call her an extremely courageous woman who has paid heavily for her principles. For some, she's pretty close to the devil incarnate.

Like a bull terrier biting at your leg that won't go away, says one prominent medico. The world's foremost consumer health advocate, says someone else. A British Medical Journal profile dubbed her "Australia's Consumer Champion" - a headline which made Bastian exclaim in one email, "oh SPEW!!!"

But there's a few things that just about everyone agrees upon. Bastian is brilliant, an independent thinker whose intellectual development didn't stop when she left school at 16. She holds strong views and is not backwards about arguing her case.

And she is a good talker. It can be hard to get a word in if the conversation touches one of the many topics about which Bastian is passionate and intense. She talks like she thinks - fast.

Fiona Stanley, director of the TVW Telethon Institute for Child Health Research, first met Bastian when both were appointed to the NHMRC's Health Advisory Committee some years ago.

"She was the best person on the committee in spite of being the least qualified in terms of specialist health training," says Stanley. "She always had read everything and often her comments were as relevant to the science we were considering as to the ethical or consumer issues."

The Commonwealth's Chief Medical Officer, Richard Smallwood, adds: "She's one of the very best examples of a combination of consumer advocacy and a very sophisticated understanding of health issues whether they're health care issues or public health issues, and [has] a very engaging personality and plenty of strength and plenty of courage."

After more than a decade of activism, however, Bastian is slowing down and changing directions. At 39, with two teenage sons brought up as a single mother on a low income while juggling dozens of hats, she is ready to concentrate her energies on the issues she feels most deeply about.

Rather than continuing to fight battles, she wants to put her efforts into supporting and developing other consumer advocates, particularly in developing countries.

Her term as chair of the Consumers' Health Forum ends this month. She will soon also relinquish some of her work with the Cochrane Collaboration, and has already given up much committee work, and withdrawn from the group she founded more than a decade ago, Maternity Alliance.

“I’m getting a bit long in the tooth to be a maternity consumer advocate - it’s been 15 years since I was pregnant,” she says.

She doesn’t plan to renominate for the Federal Government’s Medicare Services Advisory Committee (MSAC) - a role that symbolises her love/hate relationship with evidence-based medicine.

Years ago, when invited to help establish the Cochrane Collaboration, she agreed out of concern at its potential to become an authoritarian movement which could restrict access to care. “It’s great in theory but in practice is very flawed,” she says. “Despite saying it’s all about evidence, it’s absolutely value driven at every single stage.”

Bastian argues that many EBM devotees tend to share a common culture, values and social class. “They are not nearly so objective as they think,” she says. “They don’t see the extent to which their values are driving what they’re doing because their values are so similar.’

After giving several examples of how EBM can be out of touch with what is important to consumers, Bastian says: “That’s a very long way of getting around to why MSAC is important. I felt that seeing I was contributing so much to evidence-based health-care in a way, that I should accept the responsibility of being one of the people who sat there and said yes or no to what treatments will be available on the basis of evidence.”

Apart from wanting to take some time for self and a passion for sculpting, Bastian is keen to spend more time on global health issues. She plans to continue as international convenor of the Cochrane Collaboration’s consumer network, especially her work in Africa.

The other hats which Bastian will keep are also typical of her tendency to resist stereotyping. You can’t always predict what she will say or do - one reason why I have found her such a valuable contact as a journalist. She can usually be relied upon to give a fresh view, even of an old subject.

And so Bastian, who might not be regarded as the natural ally of private medicine, is keen to continue her work with Medibank Private, writing for its magazine and running workshops for consumers on how to evaluate research.

As a child, Bastian was surrounded by adults who spoke different languages. She was often the go between who acted as interpreter. It is a role she now enjoys, translating health research into useful information for consumers.

“In health care, knowledge is kept amongst a few people and communicated in ways that make it very, very difficult for anyone to understand,” she says. “That knowledge gap between consumers and the healthcare professional is so massive and in an information age, it’s not appropriate any more.

“It’s the same things that I battled with as a kid - how do you communicate in a very basic way between people with different levels of understanding.”

Chris Silagy, director of the Australasian Cochrane Centre, says Bastian can “deliver a session on how to do research and how to understand it better than almost any academic I’ve heard in terms of being able to engage an audience.”

Apart from her work organising consumer groups and representing them on committees and at conferences, Bastian has also been a prolific and influential writer in consumer and professional journals.

Many obstetricians still recall her article in the British Journal of Obstetrics and Gynaecology, called “Confined, Managed and Delivered”, which urged them to rethink jargon which was often pejorative. She highlighted the unquestioning use of terms such as “incompetent cervix”, “hostile mucous” and “failure to progress”.

Jeffrey Robinson, professor of obstetrics and gynaecology at the University of Adelaide, says the article also pointed out that when obstetricians spoke of “growth retardation” of fetuses, many women thought they meant mental retardation. That “growth restriction” is now more widely used reflects the impact of that paper, he says.

How do his colleagues perceive Bastian? “She’s liked and disliked, depending on who you speak to, because she does speak strongly and she argues her point of view well,” he says.

It is a measure of her standing, Robinson adds, that she was invited to give the annual oration at Adelaide's Queen Victoria Hospital some years ago, and spoke about how health services could better accommodate consumers' needs.

Georgie Stamp, a friend of Bastian and a former midwife, remembers that day well. "She started off on the obstetricians and they were looking very uncomfortable, and the midwives in the front row were tittering.

"And then she started on the midwives and their faces changed. Nobody's safe with Hilda - you just don't get away with it. She said to the midwives not to be complacent and think we are the answers for consumers, to think that we automatically know what women want."

Andrew Child, a vice president of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, agrees that his colleagues hold mixed views about Bastian.

"Obstetricians feel under attack from multiple directions," he says. "A lot of them respond to this by digging their heels in and becoming very resistant to criticism and may become very anti-midwives and anti-this and anti-that and feel that their way of doing things is the only right way. A lot of those people would not be terribly entranced by Hilda's views but I would hope there are a significant number who think a bit more broadly."

After working with Bastian on many committees, Child is a fan. He says it is often difficult for consumer representatives is to bring a broad view rather than simply reflecting own personal experience. Bastian is skilled at assimilating the medical literature, as well as crystallising committees' thinking, he says.

"I find her very stimulating to work with," he says. "She can appear to be very provocative on occasions. You need someone like that in a committee to actually head towards a solution rather than have a lot of people waffling."

Child says he is most impressed by the fact that Bastian is prepared to adjust her views according to the evidence - as happened with her stance on homebirth.

Bastian began her career as a consumer activist in the homebirth movement while living in the Blue Mountains, just west of Sydney. She had her two, much-adored sons, Adam, 17, and Nick, 14, at home.

Today, many in that movement consider her a traitor because of her role in drawing attention to the dangers surrounding high-risk home deliveries.

At a Homebirth Australia conference last year, an “Honouring of the Elders” ceremony was held to recognise the work of four homebirth practitioners - one GP and three midwives. That these practitioners had been de-registered was not a deterrent for the organisers.

Indeed, many homebirthers continue to see the de-registering as part of a conspiracy by the medical establishment rather than a sign of legitimate concerns about some homebirth practices.

One of the “honoured elders” was Maggie Lecky-Thompson, a midwife deregistered by the NSW Nurses Tribunal in 1998 for professional misconduct. She and Bastian were once colleagues, but are now bitterly estranged. Indeed, many of those who supported the honouring ceremony have few kind words to say about Bastian, who once lead Homebirth Australia and retains honorary life membership.

The push by Bastian and colleagues to air concerns about homebirth perinatal mortality rates, which began more than a decade ago, led to a deep split in the movement. It coincided with a push by her group to exclude midwives from running the organisation.

Initially, Bastian had started to teach herself about research methodology so that she could prove how wonderful homebirth was. “It was very hard for me to start seeing the problems,” she says.

When Bastian took the stage to present a paper titled “Perinatal death among planned homebirths” at an international perinatal conference in

Perth in 1990, some homebirthers were furious that the issue was being discussed publicly. Disputes also followed over who “owned” the statistics presented, and some midwives withdrew from the statistics collection.

The paper’s co-author was Paul Lancaster, the head of the Australian Institute of Health and Welfare’s National Perinatal Statistics Unit, now at the University of NSW. He and Bastian subsequently worked together on further investigations, culminating in a study published in the British Medical Journal in 1998. It concluded that babies were dying because of poor care surrounding home births, and warned against home delivery for high-risk pregnancies.

At the time, Lecky-Thompson, acting as spokesperson for the Australian Society of Independent Midwives, attacked the research, saying its conclusions were flawed because the circumstances of each death had not been fully investigated.

As Bastian continued to raise her concerns, she came under intense personal attack, to the extent that some critics accused her of being a bad mother. That she was once in a relationship with a prominent obstetrician is still cited by some as “evidence” that she had sold out to the medical establishment. Others accuse her of hijacking the movement for her own ambitions.

Lancaster, who admires Bastian’s intellect and principles, was shocked by how vicious the debate became. “I will never forget going to a meeting in Balmain on a hot February night,” he says.

“They’d called in a mediator to try to resolve the differences that Hilda was having with some of the independent midwives. They started off the night throwing a big ball around the room to get everyone calm. It was a very torrid night - lots of yelling, real animosity, personal vindictiveness was shown by some towards Hilda. Some were totally antagonistic to what Hilda was trying to do.”

He adds: “She was very much traumatised.”

Sue Cookson, the current national coordinator of Homebirth Australia, recalls another mediation session. “In the end, the mediators stood

around Hilda and protected her because there was so much anger in the room.”

Ann Saul, a former Homebirth Australia committee member now doing a PhD in sociology at Newcastle University, doesn't know Bastian well but has read the organisation's archives closely. She believes Bastian was wrongly “demonised”, but also that she failed to take her constituency with her.

Saul first saw Bastian in 1992 when she was giving a seminar at Newcastle University about the need for consumers to have good information about homebirth. “She was absolutely shaking because she was being given such a bad time,” says Saul. “Some of the personal abuse she was subjected to by the homebirth movement made her develop that rather tough skin.”

Maggie Haertsch, a senior research fellow at Flinders University and previously a homebirth midwife, was one of those who supported Bastian's push for better information for consumers. She admires how Bastian maintained her courage and principles in the face of sustained attacks.

She agrees with others' comments that Bastian tends to polarise people. “There's a bit of slash and burn,” she says. “But I like that about Hilda. I think that's very reflective of her passion.” She adds, laughing: “I've been fortunate I've never been on the bad side.”

There is no doubt that Bastian was deeply scarred by the homebirth fight - not least because the movement was such a huge part of her life. When she lived in the Blue Mountains, new mothers would receive cooked meals and help from what was then a tight, supportive community.

Before she moved to Adelaide several years ago, Bastian found it difficult to venture out of her home because she was so likely to run into angry homebirthers.

The experience helped change her view of the medical profession, she says. “I saw consumer advocates and midwives who would be willing to withhold information from consumers because they were being every bit as patronising as the worst I'd come across from a doctor. By the time

you've come across a few doctors who are more consumer oriented than a few midwives you start to question [your beliefs].”

The story goes that former Federal Health Minister Neal Blewett was more than happy to help fund CHF's establishment in 1987 because he was keen to have a voice to counter the medical lobby.

The Forum continues to receive federal funding, but relations with the Government are not as comfortable as in the past. As many community organisations who rely on federal funding have discovered, this is not a government which appreciates criticism.

The Forum's deputy chair, Lou McCallum, says he and Bastian are an effective double act in negotiations and lobbying; she ruffles the bureaucratic feathers and is not afraid to thump the table, then he comes in and helps to find a way forward.

“She's so passionate that that can be offputting for some people that she deals with because she argues her point really strongly and with great passion and intelligence,” McCallum says.

"Some of the bureaucrats are terrified of her. They don't like noise and confrontation and she can do both of those. So when the consumer rep gets angry about an issue they can find that terribly disturbing. It's a lobbyist's tactic and she does it beautifully.”

Many of the issues which have troubled the AMA of late are also familiar with the consumer movement, which is caught between trying to maintain a constructive engagement with government while satisfying the demands of a diverse constituency.

Bastian has been very good at maintaining that balance, says McCallum. “There are leaders who are effective because they manage everything - she's more the visionary leader out the front screaming, come this way. She's very good at identifying emerging issues.. and then it's up to the organisation to pick it up and she's on to the next issues.”

He adds that Bastian lives her values and can be quite uncompromising about them, which has promoted robust discussion in the organisation.

Others, however, find that Bastian's commitment to a cause can make working with her a difficult experience. Several colleagues comment that she is not a team player, and has a tendency to become involved in conflict. "Sometimes it's because the heart is in the right place that she will keep at it and at it and won't let go - I think partly it's that which gets her into a bit of strife," says one colleague.

Another says: "People are born with two ears and one mouth and they should listen twice as much as they speak. It's not that she doesn't want to listen, it's just that she hasn't got time to listen because she's so passionate about what she's on about."

Bastian says such criticisms don't acknowledge that her success in building and being re-elected to coalitions representing diverse groups - Homebirth Australia, Maternity Alliance and CHF - reflects that she is also a good listener. "I'm an advocate, there are many situations in which what I am doing is advocating and talking and trying to convince. That doesn't mean that is all I do," she says.

Coincidentally, I had read two novels - Lily Brett's *Too Many Men* and Richard Flanagan's *The Sound of One Hand Clapping* - before interviewing Bastian. Their themes - of the impact on first generation Australians of growing up with migrant parents who had been traumatised by wars abroad - are familiar to Bastian.

She grew up in Sydney but says it was like living in post-war Europe. Her mother had migrated to Sydney from Germany with her mother and aunt, who had both fallen in love with prisoners of war - a Serb and a Pole - who had been slave labour on nearby farms during the war. Bastian's father was Hungarian. (When she was 20, Bastian married a Czech-Australian, although they later divorced).

Bastian's childhood was dominated by the stories and language of Europe. "Other kids would get told fairytales and I'd get told stories of German atrocities or of Croat atrocities against Serbs," she says.

“When they all start slanging off at each other about the Eastern Europeans versus the Germans, when you’ve got both of them inside of you, you’re a bit of both, it’s a really difficult way to grow up.”

Once Bastian asked her grandfather why he took a nap every day after lunch, covered with jumpers and blankets, even when it was boiling hot. “He started to talk what it was like in the camps, how he had laid there through those really bad winters, how they had to eat cockroaches, had no blankets,” she recalls. “That he promised himself he would never be cold again.

“We were living out of time,” she says. “You didn’t fit in at home because you were so Australian and you didn’t fit in at school because you were not Australian enough.”

At school, she was painfully aware of persisting community anger against the Germans, knowing that a friend couldn’t play at her house because of it.

Elizabeth Bastian remembers that as a young girl, her sister read prolifically about Hitler and had a huge Anne Frank poster in her bedroom. She traces her sister’s passion for justice to that early awareness. “That disturbed us both a lot what had happened in Germany...and so you feel a real responsibility to never let things like that happen again.”

Bastian was made to repeat kindergarten because of language difficulties - for years she continued to discover words that she thought English belonged to another language. She hated school; apart from feeling an outsider, she didn’t trust a system that initially told her she was stupid because of her language problems, but a few years later sent her to a program for gifted children and then a selective high school.

When Bastian decided to leave school in year ten, the teachers asked Elizabeth to persuade her younger sister to stay. “The English master came to me and said, she’s the only person I’ve ever given 500 out of 500 to, you can’t let her leave school,” says Elizabeth, “but she just knew what she wanted to do and did it.”

Others who remember Bastian from her school days - including the Sydney Morning Herald's health writer Judith Whelan - say that she was always confident of her opinions and able to express them strongly.

After years of poverty, Bastian says she wanted to leave school to earn money.

After business college, she had a brief spell in a typing pool before finding a job that she loved as a court reporter. She also went back to night school, and no-one was surprised by her high marks in the HSC.

Bastian worked hard as a court reporter, earning lots of overtime, and Elizabeth remembers that she and her art student friends were often shouted plush meals by her sister. "She was very generous, she was very rich then, compared to now."

Bastian began her career as an activist as a teenager, no doubt influenced by her intensely political family. "Most of them supported political parties - but all different ones," she recalls. "When it came to elections, they'd all be campaigning for different sides. My mother supported DLP, my stepfather ALP and was a trade union rep. My grandfather for a while was national president of the Serbian Association and heavily, heavily Liberal. Pride of place was a photo of him next to Harold Holt."

Bastian started off in the Liberal Party, handing out buttons for Malcolm Fraser, then had a brief stint with the Democrats, then realised that political parties were not for her. She joined the Women's Electoral Lobby but didn't go back after being asked to spend meetings typing out envelopes rather than joining debate. Then followed a brief stint with Amnesty International.

But it wasn't until she discovered the homebirth movement that she found a cause which really captured her, at an intellectual, political and emotional level. She already had an aversion to the mainstream health system - having spent time in hospital as a child. She has scoliosis and, as a young adult, also suffered RSI and several back injuries.

"No two orthopaedic surgeons ever recommended the same thing," she says. "Most of them recommended surgery but on different body part - one wanted to cut off a part of my leg, one wanted to operate on my arm, another on my shoulder." She decided against surgery.

Bastian remains a voracious reader but has resisted any further formal education, influenced by the writings of South American Paulo Freire, who argues for the need for “organic intellectuals” to achieve social change. These are people who develop their political theory and knowledge from community involvement and action rather than institutionalised education.

Bastian says she feels that she has found a home in the consumer movement, partly because it values the things which made her an outsider as a child. “It’s a place where being of a lower SES, non-English speaking background is regarded as a good thing - you don’t have to apologise for it.”