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Board walking and talking: DHB denizen gives the low-down

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NEWS

Lynda Williams is a self-described DHB junkie. She's been attending DHB meetings in the Auckland region since the mid-80s – a witness to the changes and also repeated mistakes of a health system grown increasingly complex and focused on money, she tells *Keira Stephenson*



Lynda Williams in her home in West Auckland. In two weeks, she'll celebrate her 66th birthday with her whole family at a bach in Muriwai

If there was an award for most DHB meetings attended, Lynda

Williams would win it. She started going to meetings in the mid-80s to find out what was up with the set of seemingly unwritten rules the women coming to her antenatal group were subject to when they gave birth, and never looked back.

Back then, there was a sort of press bench and half a dozen journalists at every meeting. Now, she says, she is one of the few constant attendees, and she struggles to pique the interest of reporters in what she considers to be fascinating and important stories.

Undeterred, she has continued sitting on various committees set up in the wake of the Cartwright Inquiry, advocating for patient rights and churning out reports in the Auckland Women's Health Council newsletter up to this day. Recently, despite her former disinterest in the form, she's even started blogging (<http://lyndasletters.nz/>).

The comments section on this is littered with recognisable names from the health sector.

For a period in the 1990s, the crown health enterprises prevented the public from attending their meetings, but when they opened up again under the newly formed DHBs, Lynda was right back in there.

At that time, she says, it was very much men in suits, used to meeting behind closed doors, and it took them a considerable amount of time to adjust to the meetings being back in public.

Auckland DHB was quite defensive at the start, but Waitemata was, and still is, much more open. Both Waitemata and Counties Manukau used to hold meetings in different areas around Auckland to allow members of the community to attend, but this has since stopped due to a lack of public interest. Allowing public submissions on strategic plans has also ceased.

Lynda has stopped going to Counties Manukau DHB meetings because they are secretive to the point of taking reports into exclusion sessions, which she has already sat through in open meetings at the two other DHBs.

However, when she did allow Pat Snedden to persuade her to join the Auckland DHB in 2007 as an elected member, thinking she could learn more by attending the public exclusion sessions, she was disappointed. The sessions were mostly just about money and protecting commercial interests.

That's one of the biggest changes she's seen in the health sector in the last 15 years – a growing focus on money, almost to the exclusion of anything else.

Being a nurse, a midwife, or a specialist used to be a calling, now everybody is focused on money, in a health system driven by international pharmaceutical and medical device companies, she says. "Medicine and how the health system works is changing so fast, it's hard for patients to stay informed and give true consent."

While she is considered an "honorary member" of Waitemata DHB, she did not relish her stint on Auckland DHB and she remains "intensely aware of my failure to achieve anything for women".

"It was like being a lobotomised flea on a runaway elephant," she says of the sense of impotence and powerlessness to change anything in an increasingly complicated hospital system, at board meetings where the decision outcomes seem largely predetermined.

The one thing she had set her heart on achieving – to make free emergency contraceptive pills available in pharmacies – has still not occurred to this day – despite a successful pilot and other DHBs, such as Waikato, taking the lead.

LYNDA IS far more comfortable and believes herself far more able to challenge the status quo and advocate for change, as an outsider in the public gallery where she is accountable only to her own conscience and no one can tell her what to do or say.

She says she learns something fascinating about the health system at every single meeting she attends.

The "professionalisation" of consumer representatives, where reps have to undergo an "indoctrination" course, strikes her as a ridiculous waste of money. Likewise, she sees publicly elected board members still being answerable to the health minister instead of those who elected them, as a travesty.

"The minister already has four appointed members. To insist the elected ones are also responsible to him or her is outrageous," she says.

It's another of the big changes she's witnessed over the years – DHBs and meetings have become controlled by the ministry. "There's less public input – the minister appoints a chair, cracks the whip and isn't open to feedback."

Fiercely independent advocates with a big picture understanding of local and international health systems is what is needed. Not people bound by short national election cycles at the mercy of drug company-led patient interest groups or focused on their own narrow professional interests and patch protection, she says.

This narrow, short-term focus has resulted in features like health targets, which, she says, every DHB has developed strategies for meeting, such as dropping people off waiting lists.

"I love hearing Lester Levy say 'health targets have unintended consequences'," she says. "It's a very simplistic way of the Ministry of Health trying to prove they are improving the health system, but I don't think it necessarily works well for patients."

The focus on child vaccinations is a good example – it's become the be-all and end-all for child health, but does nothing to address child poverty. "James Whakaruru was fully immunised, but it didn't save his life, did it?"

Over-treatment and diagnosis can be another unintended consequence of health targets. Lynda recalls a specialist at a DHB meeting giving a report into failure to meet spinal surgery targets. He had rung the GPs of patients who had not had their appointment to apologise and, overwhelmingly, the GPs told him not to worry about it – the patients' back issues had resolved.

Having attended two international "Preventing over-diagnosis" conferences, it's a topic she's hot on.

Lynda believes over-diagnosis and treatment are, to a large extent, driven by big pharma and medical device companies.

The definition of disease is continually being extended to the point that we now have pre-diabetes, and the bar is constantly lowered for symptoms like blood pressure and so more drugs are taken and sold, she says.

Even patient groups come in for criticism. The Breast Cancer Foundation pushed for Herceptin to be funded for 52 weeks instead of nine. In 2008, National agreed, which was a mistake current health minister Jonathan Coleman has admitted in hindsight. But, Lynda says, it is a good example of what can go badly wrong when patient-interest groups get co-opted by drug companies.

DESPITE HER criticisms, the self-proclaimed "DHB junkie" still encourages people to attend meetings. Even board members whose behaviour she disapproved of could be hugely entertaining. Former Auckland DHB chair Wayne Brown, for example, could be extremely rude and made no attempt to hide his contempt for some hospital processes or doctors who were totally resistant to change.

One time, he talked about "grumpy old doctors" and several grumpy old doctors turned up to the next meeting. A specialist who had come along said, very quietly, "I've been here for decades and survived many CEOs and will be here long after you've gone."

While public interest has generally dropped off, occasionally issues still rile the public sufficiently to see them attend en-masse. For example, when Waitemata DHB started charging for car parks at North Shore Hospital, a big deputation of old people and students turned up to volubly complain.

Closing the private postnatal ward in the mistaken belief the North Shore Hospital maternity ward could cope alone, also raised the ire of a bunch of mums. With babies and media in tow, they stormed the meeting and didn't know or care that they didn't have a right to speak. "They ranted and raved and interrupted and, within six months of closing the private ward, they were proved right," Lynda says.

THE 66-YEAR-OLD had thought she would be attending meetings and advocating for patient rights for another 10 to 20 years, but on Friday 9 October (she remembers the date exactly), her life "disappeared" when she received a diagnosis of pancreatic cancer.

Her terminal cancer, while making her acutely aware of the current arguments around melanoma drug Keytruda, has not, however, changed her high opinion of Pharmac.

She points out that, thanks in part to Pharmac, the palliative treatments she receives, of 12 sessions of four drugs, costs only \$2011, while still allowing the drug companies to make a profit.

She has it on good authority (from her ex-husband, cancer researcher Bill Wilson) that Keytruda costs only \$200–\$300 per patient per year to make. Journalists and the public should be challenging the drug company, not Pharmac, about the costs, she says.

Because Keytruda is not yet a targeted gene drug, it only works on 30 per cent of patients with specific genes.

"We can't afford to throw \$200,000 at everyone with only those odds."

She hopes in the future the odds will improve and predicts immunotherapy drugs, which actually work rather than concentrating on a one-size-fits-all approach, will be both cost and life-saving.

"I'm dying, but I don't believe I have the right to a quarter-of-a-million-dollar treatment, just because a pharmaceutical company is trying to make money."

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