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Your details

1 What is your name?

Name:
Rhyssa Cathro

2 What is your email address?

Email:
[redacted]

3 Are you submitting as an individual, or on behalf of an organisation or group?

I am submitting as an individual

4 How did you hear about this consultation?

Select from the following options:
Through my job

If you selected other, please specify below:
Through my Support workers job

Questions for individuals

[redacted]

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Questions for organisations/groups

1 Name of your organisation or group (if applicable)

Organisation:

2 Type of organisation/group (if applicable)

Organisation - type of organisation/group/ropū :

Please feel free to provide any further detail below:

Share ‘one big thing’ or upload a file

5 Are you here to tell us your ‘one big thing’?

Your one big thing::

Once Upon a time, long long ago (about the early 1980’s), New Zealand/Aotearoa (NZ/A) had no Health and Disability Commissioner and had no Consumers Right’s code.

In those days, it seems, broadly, medical ethics amounted to “What a good chap did/would do”: an era of “Doctor knows best” (D.K.B) D.K.B. is both a burden and a privilege:

The burden: exhorting from professionals their absolute utmost efforts.

The privilege: what doctor decided was best derived its “bestness” status from the very fact that the doctor had identified it. A doctor’s choice had to deviate strikingly, momentously from the customary attitudes before it would be viewed as “not okay”.

When the choices and actions around the “Unfortunate Experiment” transpired, ‘we’, of NZ/A realized that it was emphatically not okay that it happened, furthermore, nor was it okay that it was able to happen.

So: the creation of the role of the Commissioner and the Code of Rights. The triad of values on which the code is based, and which resonate throughout the whole code:

-Respect for the patient

-Respect for their dignity

-Respect for their autonomy

These shift the crucial value choices from the doctor to their patients: D.K.B. to - what? – Patient’s Values Prevail (P.V.P.)? It may well be that a patient’s choice, having reviewed the information and options described by their doctor in terms of their own values, that their conclusions (from the risk/benefit, expectable outcomes/ quality of life scenarios), coincide with the preference the doctor would have chosen.

Well and good. However, there is a persisting problem when the patient’s choice is unpalatable to their doctor.

It is hardly surprising that doctors, confident of their conclusions, may not be comfortable with supporting what they believe to be a “wrong” path forward – but no longer does doctor “know best” for their patient: an informed autonomous patient (or their informed previously chosen attorney) does. If a doctor finds this situation to be untenable, maybe an adaptation could be made of the existing medico-legal strategy which allows doctors who are government funded to “opt out” of providing terminations of pregnancy so long as they refer on, in a timely manner, to a doctor who will provide this service. This seems like a workable pathway, at least as a temporary measure, to provide patients access to their choices of care plans with a doctor who is supportive of their choosing.

At present I am aware of two areas where this difficulty in progressing from D.K.B. to P.V.P. is creating real strife, life and death, quality of life issues:

A) Reluctance to invoke an ending power of attorney for patients with an advance directive in place. [Foot note 1. As detailed in an article in the New Zealand Listener: Stroke of Courage Peter GRIFFIN pp20-25, Feb 25th- Mar 3rd 2023, (copy included) also a few pages from Barbies Bill website.]

B) Patients who prefer the risk/benefit (/likely outcomes quality of life/) scenarios. [2. Once other options have been dually explored.] of effective pain management to that of the pain.

It is true that there are certain valid reasons for patients to be refused, quite properly, some options they may seek. However these "proper" refusals are based soundly upon ulterior responsibilities and duties the doctors have [3. E.g: a) extravagant amounts of plastic surgery for a patient who is neither disfigured nor dysfunctional- a misuse of taxpayers resources. B) similarly, taxpayers resources sought for "treatment" which have not been demonstrated in scientific peer- reviewed studies to be clearly therapeutically effective- laetrile, mega-dose vitamins, green lipped mussel extract. C) antibiotics for viral conditions- endangering the whole population by increasing resistance.], not based on their practitioners' feelings about the merits or otherwise of the patients chose(s).

To "protect” a competent informed patient from their own choices by withholding resources cannot be held to be a valid option to the practitioner, surely, if the concept of “autonomy" is to be a meaningful concept. A doctor may explain their position, their reasoning- but if they do not convince, surely they have no right to enforce it. [4. For a doctor to have a respectful, dignified interchange with a patient on such an issue (when doctor and patients risk/benefit assessments and consequent choices do not coincide) will hardly be possible when the patient is overwhelmed by their symptoms, therefore, the first step, surely, should be to get the symptoms under control.]

It is not surprising that doctors, confident of their conclusions, maybe uncomfortable supporting what they believe to be a "wrong’ path forward- but no longer does doctor "Know best” for their patient; an informed autonomous patient (or their informed previously appointed attorney) does. If a doctor finds this situation to be untenable, maybe an adaptation could be made of the existing medico-legal strategy that allows doctors who are government funded to “opt out” of providing terminations of pregnancy so long as they refer on, in a timely manner, to a doctor who will provide this service this seems like a workable pathway at least as a temporary measure, to provide patients access to their choices of care plans with a doctor who is wholely supportive of their choosing.

Given that the code was created nigh on three decades ago (July 1996), yet we still have this disturbing hiatus in progress, it seems we need some focused effort presumably best to come from the commissioner and then collegially through the institutions training the next generation of practitioners to achieve a professional environment wherein a patients can expect to have their autonomous, informed choices, in particular when their practitioner disagrees with their choice(s), rather than the practitioner simply arrogating the choices to themselves, overriding the patient's intended autonomous decisions, or simply overriding the patient's awareness' of possible choice. [5.

How many of us would choose to pass kidney stones over several days while cramped, sweating, vomiting and anguished by pain? After the prescribed dose of pain reliver, demonstrating its inadequacy but no change was instigated.]

And when those choices have been arrogated by a practitioner there is at presents nowhere/ no one to whom one might appeal the situation- even a request for a ”second opinion” would very likely be the first one over again, as what practitioner would want to challenge a colleague "publicly on what is going to be seen as a “Judgement call”, measured against what is seen to be the customary treatment approach.

Autonomy is not autonomy which is refused when it difference of opinion finds?

Autonomy by any other name would make life rosier?

Neither an arrogater nor an abdicator be?

If you can maintain your autonomy, when all about you are losing theirs...?

To grant or not to grant autonomy – that should not be in question!

Autonomy, autonomy, wherefore art thou autonomy?

It is a truth universally acknowledged, that a competent person with a health condition must be in need of being told what to do.

AND THE ULTIMITE GOAL IS TO IMPROVE QUALITY OF LIFE.

6 Upload a file

File upload:
Stroke of courage.pdf was uploaded

Not Answered

Topic 1: Supporting better and equitable complaint resolution

1.1 Did we cover the main issues about supporting better and equitable complaints resolution?

Please add your response below:

1.2 What do you think of our suggestions for supporting better and equitable complaint resolution, and what impacts could they have?

Please add your response below:

1.3 What other changes, both legislative and non-legislative, should we consider for supporting better and equitable complaint resolution?

1.3 changes - supporting better and equitable complaint resolution:

Topic 5: Minor and technical improvements

5.1 What do you think about the issues and our suggestions for minor and technical improvements, and what impacts could they have?

Please add your response below:

5.2 What other minor and technical improvements, both legislative and non-legislative, should we consider?

Please add your response below:

5.3 What are your main concerns about advancing technology and its impact on the rights of people accessing health and disability services?

Please add your response below:

With huge thanks to the support from Reece Fisher from Stepping Stone Trust, whom without this would never have developed from the gem of insight through to a real submission,

5.4 What changes, both legislative and non-legislative, should we consider to respond to advancing technology?

Please add your response below:

Publishing and data protection

May we publish your submission?

Yes, you may publish my submission

Please note any part(s) of your submission you do not want published::

Reasons to withhold parts of your submission

Yes, I would like HDC to consider withholding parts of my submission from responses to OIA requests.:
No

I think these parts of my submission should be withheld, for these reasons: :

If needed, can we to contact you to follow up for more detail on your submission?

Yes, you can contact me

Would you like to receive updates about the review?

I'd like to receive updates about the review, I'd like to receive updates from the HDC about this and other mahi

Stroke of courage

What's the point of having a 'living will' if doctors ignore it? That's the question driving a new campaign for a law change.

by PETER GRIFFIN • photograph by HAGEN HOPKINS

Draining and surreal. That's how Louise Duffy describes the experience of watching her mother, 78-year-old Barbara Duffy, slowly become a skeletal figure in her rest home bed.

Barbie was rushed to Christchurch Hospital in October 2021, in the depths of the Covid-19 pandemic, after suffering a major stroke at her home in Methven, Canterbury. As emergency doctors worked to stabilise her, Louise, a marketing executive who lives in Martinborough, Wairarapa, sat nervously by the phone awaiting updates from Barbie's partner, Peter Harper, a former teacher her mother had met later in life.

> **Barbie feared suffering a major stroke more than any other illness that commonly afflicts the elderly.**

The word from the hospital was to wait 24 hours while doctors determined how serious the stroke was. Strokes affect about 9500 New Zealanders every year and are the most common cause of adult disability. Most people survive a stroke, which occurs when blood flowing to a part of the brain is interrupted by a clot or haemorrhage, depriving the brain of oxygen. But survivors can be left with a range of physical and cognitive disabilities.

Barbie feared suffering a major stroke more than any other illness that commonly afflicts the elderly.

"[Having a stroke] is her biggest nightmare," a senior nurse at Christchurch Hospital wrote in Barbie's medical notes on the afternoon of October 7, after talking to Duffy and other family members. It was the day after Barbie was admitted.

FORWARD PLANNING

Barbie had prepared for this grim eventuality. She'd already appointed Duffy as her enduring power of attorney for personal care and welfare, giving her decision-making power if she was ever deemed "mentally incapable" by a medical professional.

She had also written up an advance directive in 2005. This type of document, sometimes referred to as a living will, went into detail outlining her wishes if she was ever incapacitated.

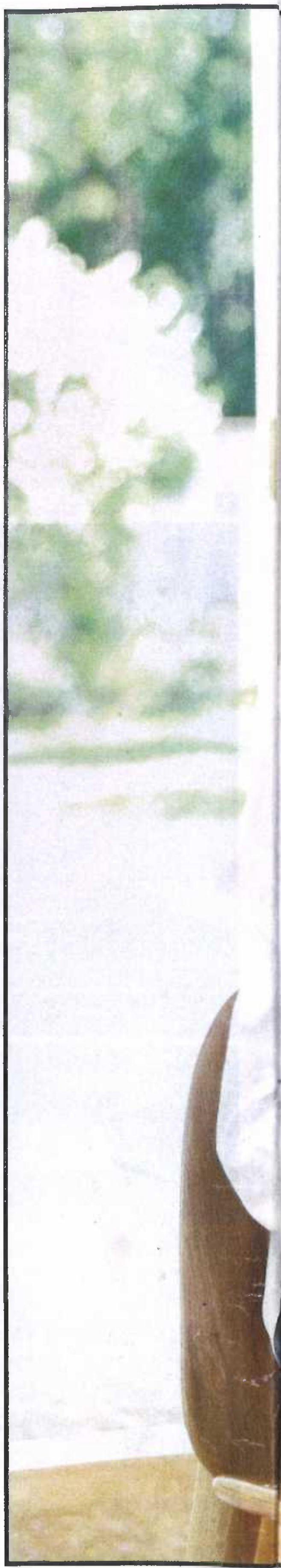
"I read the document on the way to the hospital," says Duffy. "I didn't know or had forgotten she had one."

That one-page document, signed by Barbie, her GP and witnessed by Harper, asserted her right to refuse life-saving treatment should she suffer a "serious loss of mental or physical capacity ... [where the] condition is unlikely to be reversible or [to] improve".

Lying in a hospital bed, semi-conscious, unaware of what exactly had happened to her, Barbie had certainly suffered serious loss of mental and physical capacity.

The blood clot that caused the stroke was successfully removed, but blood flow did not recommence to the affected section of her brain.

What was less clear was the extent to which she would recover and once again enjoy her daily



Louise Duffy: "Barbie's Bill (named after her mother pictured in the framed photo) is about following the patient's informed consent."

Party support: Act's Brooke van Velden and David Seymour back Louise Duffy's petition.

GETTY IMAGES

Time to act

David Seymour wants Parliament to clarify 'living wills'.

Louise Duffy believes that not following advance directives can lead to "untold emotional and physical suffering".

David Seymour, leader of the Act Party and the man instrumental in bringing the End of Life Choice Act 2019 into existence, firmly agrees.

"The treatment options are more complex. The illnesses are more complex," he says.

"The chance of winding up incapacitated and having decisions made for you, as happened with Barbie, keeps increasing."

The petition to introduce Barbie's Bill into Parliament, he points out, is not a right-to-die campaign. That fight was won with the introduction of the assisted dying regime in November 2021. By the end of September, 214 terminally ill patients had ended their lives with the assistance of doctors under the law.

Instead, Seymour wants to see Parliament codify in law what an advance directive involves.

"It would give it huge authority," he says. There's no guarantee that Louise's internet-based petition will result in a bill, even if the 100,000 target for signatures is reached. The petition will be presented to Act's deputy leader and health spokesperson, Brooke van Velden, in April.

"I certainly hope that the petitions committee will decide to conduct a full inquiry or have the health committee do one," says Seymour who is "wary" of the medical community's reaction, given the heated debate over the end-of-life legislation.

"Sometimes the medical profession will take Parliament's intervention as a criticism or an attack on their autonomy.

"But this is Parliament trying to empower citizens and bring clarity in a specific part of the doctor-patient relationship."

10-15km bike rides, gardening and visits to friends in her neighbourhood.

The doctors and nurses at the hospital knew Duffy had enduring power of attorney (EPOA) status and the medical notes reveal how clearly Barbie's wishes were expressed by her concerned family members.

"Louise is clear that her mother has said many times: no life-prolonging treatment, no resuscitation/CPR, no forced eating/[nasogastric tube], no antibiotics, just painkillers and some dignity," they read. So why didn't the senior doctor invoke Duffy's attorney status, which is a legal requirement for the accompanying advance directive?

Advance directives are technically legally binding and recognised by the major medical bodies and the Code of Health and Disability Services Consumers' Rights, which sets out your "right to be fully informed, make an informed choice and give informed consent". But the decision to follow it ultimately rests with a clinician.

"I believe they were too optimistic about her prospects for recovery," says Duffy. "If the directive, which stated 'no food or fluids are to be administered by any artificial means' had been followed, she would have died medicated and semi-conscious 7-10 days after her stroke."

But Barbie's medical notes suggest her doctors and nurses were sufficiently satisfied that she was willing to receive treatment.

"It is not ideal or perfect to decide how lucid or cognitively intact to make a decision about feeding for her," a nurse wrote on October 11, five days after Barbie's stroke. "We can use simple cues to help. She does not object to inserting [a tube]. It also suggests that she accepts that."

But the same set of notes included this jarring line: "We have to sight her EPOA [enduring power of attorney] and her care plan."

Despite Duffy giving nurses all the advance directive and EPOA documentation when she arrived at the hospital on October 8, it was clear these hadn't been read. It was October 11 before Duffy was even able to speak to the doctor about her mother's condition – all previous information had come via nurses in the stroke ward.

Several weeks later, Barbie, now a patient of the Burwood Hospital rehab team, had recovered enough to consider her situation. She faced, as Duffy puts it, "years of residential care, unable to move her right side, speak, read or write and with limited comprehension. She needed 24/7 help to dress, feed, bath and toilet".

CHOOSING TO DIE

Back in Martinborough, and with Burwood restricting visits due to Covid, Duffy would hold lengthy FaceTime sessions with her mother, who simply nodded or shook her head in response to her daughter's questions.

Duffy canvassed Barbie's options, including moving in with the family in Martinborough or entering a residential care facility. But she also raised another option. "I told her, 'Your advance directive said that in a major change in life where you felt the quality was gone, you wanted care withdrawn. You still have that right,'" she says.

A couple of days later, now in a care home in Ashburton, Barbie stopped eating. Finding herself in the nightmare scenario she had wanted to avoid, she chose to make the decision she had expected to be made on her behalf as she was lying in Christchurch Hospital.

It took 58 days for Barbie to die. "She tried to stop taking fluids, but she had some kidney issues and it got too painful," Duffy says.

"There was no pain relief. She got morphine in the last three or

DUFFY FAMILY COLLECTION

Barbie Duffy was an avid traveller and led an active life up until her stroke at age 78.

four days. She never lost her temper. She never seemed distressed. I think she was comfortable with her decision and wanted us to be comfortable with it, too."

Duffy isn't seeking to "relitigate" what happened in those critical days after her mother was admitted to hospital. Her family has not pursued legal action. She believes there's a systemic problem with the process around advance directives and how EPOA rights are invoked. Utilising a "rusty law degree" gained decades ago, she has researched potential law changes and started a petition, hoping to secure 100,000 signatures, to pave the way for a bill to be introduced to Parliament that would make advance directives legally binding documents.

"Barbie's Bill is about making directives to withhold care effective when it is clear the quality of continued life is seriously impacted," says Duffy. "It is about following the patient's informed consent."

The principles of informed consent and patient autonomy are fundamental to medical treatment, says Greg Martin, who runs the Ashburton-based law firm Arrowsmith Law. "Western medicine and the ethics that medical professionals operate under are very much about the preservation of life," says Martin, who studied medical ethics as part of his law degree. He has helped many clients prepare EPOA documents.

"On the other side, you have a fundamental basis for civilised society, which is autonomy. While you are competent, you are the person who should make decisions for how you get treated."

The advance directive is designed to maintain that autonomy on behalf of a patient who is incapacitated. But adherence to advance directives varies considerably.

"There's a gap in the middle where there's no one talking to the patient, because they can't talk themselves, but the power of attorney is not appointed yet," says Martin.

That requires clinicians to make hard calls on behalf of patients, including assessing their mental capacity and deciding whether to invoke the EPOA status that can result in a medical team withholding treatment, resulting in the death of the patient.

> **"There's no advance-directive policeman, there's no structure around this stuff."**

SURVIVAL AT ALL COSTS

That's anathema to most medical professionals who have signed the Hippocratic oath. As American surgeon, writer and public health researcher Atul Gawande writes in *Being Mortal*, "Hospitals are designed to ensure survival at all costs."

Martin supports Duffy's campaign for change, but feels wholesale legislative change isn't necessarily required.

"There's no advance-directive policeman, there's no structure around this stuff. The only structure that exists legally so far as I'm concerned is the power of attorney structure," he says.

Advance directives have status in common law so are, in theory, legally binding. A key change to that legal structure, says Martin, would be to allow an independent doctor to review a patient's medical records to assess whether the EPOA should be invoked.

"In a hospital, it could be somebody whose sole job is to make those calls."

The other problem is that there's no central registry of advance directive documents. If an Aucklander has a heart attack in Queenstown and arrives in the Lakes District Hospital emergency department, there's no guarantee that the document outlining the patient's care plan can be quickly accessed. In that crucial window when a patient requires life-saving assistance, decisions can be made that go against the notion of informed consent.

It's hard to know exactly how serious the issue of advance directives being ignored really is. The watchdog for patients, the office of the Health and Disability

Commissioner, told the *Listener* just five complaints have been received since 2015 relating to advance directives.

Patients and their families have the legal right to sue medical institutions in civil court, but there's little relevant case law relating to advance directives not being followed. More often, says Martin, legal disputes emerge over decisions made by the person with the power of attorney. Family feuds are common.

A survey commissioned by Auckland public relations agency Pead PR to support Duffy's petition found that just 47% of 500 respondents making up a demographically representative sample knew what an advance care plan was.

"My mother told us if she ever ended up what she termed a 'vegetable', to put her out of her misery."

Only 16% had an advance care plan in place for themselves, according to the survey completed in January by Octopus research platform, and just 13% had one in place for their parents. But 78% of those surveyed prioritised quality of life and the right to die with dignity if they "suffered a severe and irreversible loss of mental or physical capacity".

LIVING WILL

"We need to talk about death more," says Wendyl Nissen, whose experience of the health system during her own mother's final months is outlined in harrowing detail in her bestselling 2021 memoir, *My Mother and Other Secrets*.

On Good Friday in 2019, Nissen's mother, Elis, aged 85 and suffering from dementia and diabetes, had a stroke at her cottage on Nissen's property in the Hokianga. Several mini strokes followed, with a major stroke on May 1 leaving Elis paralysed on her right side, needing to be spoon-fed and unable to be understood.

"I no longer thought she might die, I hoped she might die," writes Nissen, a journalist and broadcaster.

Like Barbie Duffy, Elis had written down her wishes for end-of-life care many years before.

"My mother had her living will, which she had written more than a decade ago, and she told us over and over again that if she ever ended up what she termed a 'vegetable', to kill her and put her out of her misery," Nissen writes.

Elis' husband of 65 years, Cedric, was her "attorney" under her EPOA. But the living will turned out to count for little. Days of "will she, won't she" followed as Nissen and her family waited for doctors at Whangārei Hospital to determine whether Elis would go into palliative care, indicating she likely had just weeks to live, or residential hospital care, where she could linger on for months or years.

The doctors noted a long list of debilitating ailments and care requirements. Nevertheless, hospital-level residential care was recommended and Nissen had to scramble to find a bed in a rest home for her mother. When Elis died three months later at Jane Mander Retirement Village in Kamo, north Whangārei, it was after coming down with pneumonia.

Wendyl Nissen, whose mother Elis, pictured with Nissen in earlier days on the opposite page, died three months after a major stroke.

JANE USSHER

The care staff had signed an agreement with Nissen and her family that antibiotics would not be given to Elis. Finally, she was at peace, not that Nissen, who had a difficult relationship with her mother, could find much herself.

"I didn't really like my mum. But the daughter in me cared for her. It's a horrible thing to live with that. I did not save

NISSEN FAMILY COLLECTION

my parent from that humiliating, horrible three months," she says.

"Am I angry that some doctors played god and decided to push mum off onto a care home to be kept alive, instead of letting her die as was her wish? Absolutely, I am furious," she concludes in *My Mother and Other Secrets*.

Would a detailed advance directive taking account of Elis' various ailments have made a difference? "I feel like it would have been ignored anyway," says Nissen.

Which is why she also supports Louise Duffy's campaign for legislative reform.

MEDICAL OPPOSITION

Many clinicians push back against that. A study published in the journal *JAMA Internal Medicine* last year reviewed 29 cases of patients' experiences with advance directives in the US. It found they "often act as an obstacle to meaningful conversations around patients' goals of care and future decision making".

If advance care planning is approached with a "set it and forget it" mentality, the authors argue, it will likely fail to improve the delivery of care that aligns with the patient's goals.

Barbie was fit and healthy up until the day she had her debilitating stroke. Her retirement days were full of activity, with plenty of biking and walking and volunteering for Meals on Wheels and the Red Cross shop.

An avid traveller, she spent part of the 1960s hitchhiking around Europe and the US. In 1967, she met Irish lawyer Francis Duffy at a party in London. They married and had two children, Justin, then Louise, who was born in 1971. They relocated to Paris then the US. But when Barbie's step-father had a major stroke in 1972, it was one of several factors that spurred a parting of the ways between the couple. Barbie returned to Christchurch with the children to help her family.

She took a job as personal assistant to the general manager of ABC Cables, but left the corporate world to become a teacher, moving to Methven in 1979.

> **"Speaking to clinicians and people in white coats who are really clever and busy is quite intimidating."**

The career change allowed the solo mum to spend more time with her kids. She took early retirement aged about 60. She kept travelling and was due to visit Duffy, her husband and son in Martinborough when she suffered the stroke.

GAME OF CHANCE

We all hope for a quick and painless death. We are encouraged to watch what we eat, to exercise regularly, to lessen our chances of being claimed by a chronic disease. Our genetic make-up and random events such as car crashes or a bad fall can cancel out all our decision-making.

Healthcare is also vastly complex, which is why Martin has sympathy for the frontline medical staff who make life and death decisions every day.

"There are practical limits to this kind of preloading consent to treatment with an advance directive," he admits. "There are always going to be situations where doctors and emergency workers aren't going to be able to download the patient's notes to see whether they want their coronary artery patched to keep them alive."

But clearly expressing your wishes in a detailed care plan, and telling your family members about it, can only help foster the shared decision-making that many families feel is lacking in hospitals.

"Speaking to clinicians and people in white coats who are really clever and busy is quite intimidating," says Helen, a Wairarapa-based general practitioner the *Listener* has agreed not to name. Helen is also an assisted dying doctor, helping terminal patients who have six months or less to live to cut short their suffering.

Having practised as a GP in the UK and New Zealand since 1988, Helen estimates that about 10% of her patients have an advance care plan in place.

She believes the English system, which sees a central register of care plans and EPOA contracts maintained, speeds up the decision-making process and can lead to better outcomes.

She sees a valuable role for GPs in helping patients complete advance directives because of their intimate knowledge of their circumstances. "Out in the swamp of primary care, we see our patients in a more holistic way.

"We're the only people that look at someone as a whole rather than the person with rheumatoid arthritis in bed four who has just had a stroke."

She also supports Barbie's Bill and hopes the petition will, if nothing else, raise awareness of the issues people who suffer a catastrophic illness or accident face.

The proposed bill would seek to establish a GP-based system with simple, standardised advance directive forms, and a centralised database that holds directives.

It would allow for registered doctors or medical bodies to provide "timely and objective patient prognoses" and, most importantly, legislation would make directives binding, "as per the patient's informed consent".

Visit www.barbiesbill.nz to find out more about the proposed law changes and to view the petition.

Saturday, January 1, 2022, was the last time I saw my 78-year-old mum, Barbie. In early October 2021, she'd had a severe stroke at home. Medical notes show I called the hospital a day later to say this was mum's worst nightmare, and to stop everything and let her pass.

The day after, the hospital had my EPOA (enduring power of attorney) and her advance directive (also known as an advance care plan or living will) with her clear instructions to withdraw care, including artificially administered fluids, if she'd suffered a "severe loss of mental or physical capacity".

We weren't medical experts and thought we'd get a quick, objective prognosis from the hospital. Instead, it was delayed and included best-case scenarios, so it wasn't clear what was probable. Stroke rehabilitation was the only option presented by mum's doctor, who didn't sight her directive. Even though we questioned it, mum was kept on a drip while she couldn't swallow post-stroke.

Mum had loved travelling, the outdoors, family and sometimes golf. She enjoyed weekly 10km tramps, daily walks and visited family here and overseas often. She volunteered and would pop in on older locals for a drink, to keep them company.

After the stroke, Mum was unable to speak, read or write. With limited comprehension and movement, she needed 24/7 care. When she could understand more, she took the only bit of control left and refused food, then fluids. It took her 58 days to die.

Our family supported her directive and choice — it was invaluable and comforting to know what was important to her — which was being able to enjoy life, not living as long as possible.

Feeling "it doesn't have to be this way, we can do better" and with advice from a nurse, doctor and lawyer, I put together the idea for Barbie's Bill to bring certainty to people, their families and medical teams.

Advance care plans are something the health sector will deal with more and more. One in four Kiwis will be 65-plus by 2030. Nurses are at the coalface so know the stats — strokes every 55 minutes, five-plus serious brain injuries a day and many other serious, debilitating illnesses and conditions.

The proposed bill aims to create a national directive database accessible anywhere, anytime; set up clear standardised forms for advance care plans; and provide legal backing to follow directives.

As Barbie was an organ donor, we hope the database can be an organ donation register too. Perhaps it could also be the foundation or catalyst for the much-needed centralised national medical database.

Barbie's Bill will only deliver if it is actively supported. You can sign a petition to go to Parliament requesting this bill be drafted, and then share it with someone else, in under 30 seconds at www.barbiesbill.nz.

Barbie started life in 1943 as the youngest of three sisters. Born and brought up in Christchurch, she left for her OE when she was twenty, travelling through America and Europe. She met her husband in London and returned to New Zealand with their two small children, Justin and Louise, in the 1970s.

After the couple parted she threw herself into bringing up their kids and become a teacher, in part, so the family had more time together. They lived in rural Canterbury where she remained, after they left home, with Peter her partner of 25 years.

Always interested in people and change she volunteered in the community, looked out for other locals and took up local environmental issues. She also continued to travel and tramp…a lot. Put simply, Barbie loved family, the outdoors, travel, people and sometimes golf!

On the morning of Wednesday, 6 October 2021 Barbie had a major stroke at home. She had a clear, valid advance directive in place withdrawing care, so she could be allowed to die, should she suffer a serious loss of mental or physical capacity.

Her directive was not followed and she was kept alive. The stroke left her unable to speak, read or write. With limited comprehension and movement she needed 24/7 care, possibly for many years.

Weeks later, when she could understand more, Barbie refused food and, in the end, fluids. She passed 58 days later, unmedicated until the last few days

It came about because Barbie's wishes were not followed, and it took a distressing 58 days for mum to starve to death. It does not need to be this way.

The family had talked about what happened with Barbie's directive and Louise (daughter) came back to this midway through last year. With Peter (partner) and Justin's (son) support, she put together Barbie's Bill based on Barbie's medical records and input from a doctor, nurse and lawyer.

Having read journalist Wendyl Nissen's book about her mother, Louise contacted her. Wendyl got in touch Deborah Pead of Pead PR, who wanted to be involved for her mother. Between them, they put together the Barbie's Bill campaign.

Louise also sent the Barbie's Bill proposal to David Seymour of ACT, who agreed the party would take a Bill to parliament and suggested a petition.

Barbie's Bill will ensure advance care plans count and that a person's wishes, their informed consent, must be followed.

It's about giving people choice and control over their care, which can include the right to refuse care to allow them to control how they die.

The House of Representatives is being asked to put in place a national register so medical teams can instantly see if patients have advance directives and to adopt the Barbie's Bill advance care plan template to create clear, effective standardised directives, with a mandate that directives are followed.

Other things we think should be included are

– making the national register a centralised database to allow for instant access, anywhere, anytime

– having advance directive doctors to provide timely, objective consultation about the application of a directive

– where care has been withdrawn, have more and better end of life care options

– have an online end of life planning site with planning steps, directive templates and tools like letters at med.stanford.edu/letter