CANCER CAR CRASH

In what is being called a national emergency, four times as many people are dying of bowel cancer as on the roads. **by SARAH CATHERALL**

A few weeks before Christmas, I stood in a Havelock North graveyard, watching my cousin Nick's coffin being lowered into a grave under a flowering tree. A month before, he had spent his 51st birthday in hospital after his bowel had blocked and failed.

Nick was 50 when he was diagnosed with bowel cancer. He was given little warning. When he began to have stomach pains, the disease had already metastasised and spread to his liver. Ten months later, he was dead, leaving his wife and son, six siblings and parents to deal with the loss.

Until I heard about Nick's illness, I had mistakenly thought that bowel cancer was a disease that usually struck older men; not a man like my cousin, otherwise fit and healthy and in the prime of his life.

As his brothers and my uncles picked up spades and shovelled dirt into his grave, I thought of my cousin's words to his sister, Rose. He was sad, he told her, that his disease wasn't picked up early enough to change the course of his life journey; that New Zealand didn't have a screening programme that might have detected the huge tumour in his bowel. Says Rose: "Nick was way too young. He had no symptoms right until the cancer had spread."

Bowel cancer is our second-biggest cancer killer, yet doctors say it is beatable if caught early. In 2015, 3081 people were diagnosed with bowel cancer and 1267 died of it. We have one of the highest rates of bowel cancer deaths in the Western world: in New Zealand, 40% of sufferers die from the disease, compared with 25% in Australia, where bowel screening has been gradually introduced over a decade.

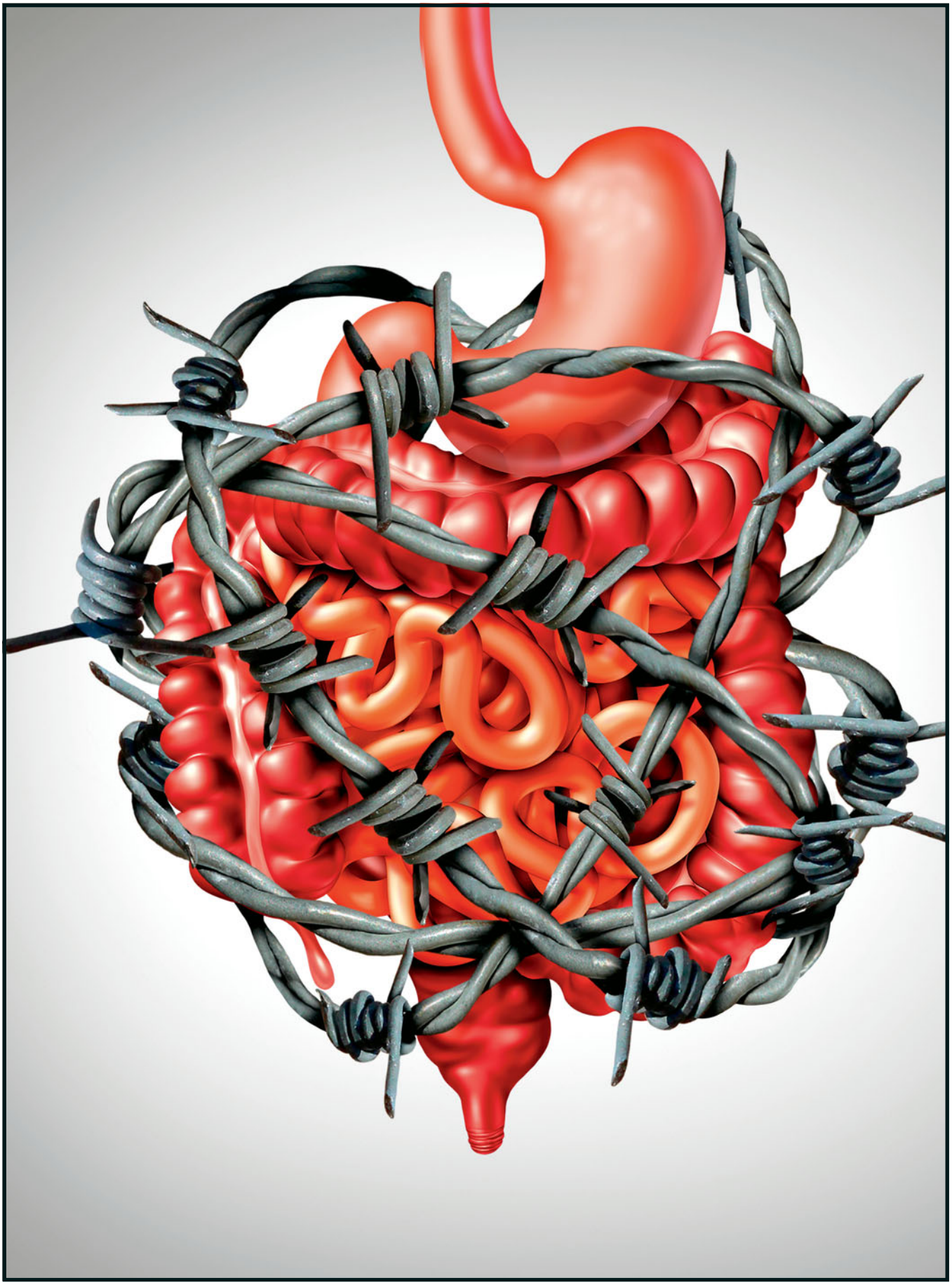
When screening is finally rolled out, the ministry expects 500-700 people will be diagnosed with bowel cancer each year.

In 2008, then Health Minister David Cunliffe gave the green light for a bowel-screening programme. That eventually led to a Waitemata District Health Board pilot, which ran from 2012 to 2017 and tested 198,000 people aged 50-70. Bowel cancer was detected in 375 of them up to March last year – the most recent results available.

However, a national roll-out of the programme will be delayed by a year and won't now be complete until June 2021, says Health Minister David Clark. The delay means up to 700 people could miss out on early diagnosis and treatment, according to Dr Chris Jackson, medical director of the Cancer Society, who says our annual bowel-cancer death toll, at four times the number killed on the roads, is a national emergency.

The hold-up springs from concern that 2500 people who should have been sent screening invitations last year as part of the pilot did not receive them. Clark says three people went on to develop bowel cancer. Tragically, one of those has died.

He has ordered an independent review of



GETTY IMAGES

Third time lucky

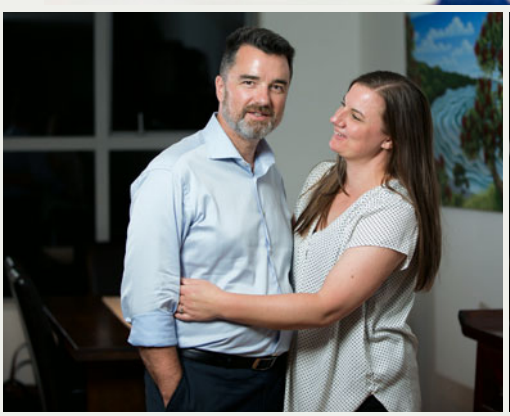
Lack of awareness that bowel cancer can afflict all ages means it is often misdiagnosed.

photographs by HAGEN HOPKINS

Stefan Corbett considers himself a lucky man. The public servant acted on his wife's hunch and was privately screened for bowel cancer. Sitting in a Wellington cafe, the father of two strokes his goatee beard and orders a Diet Coke. For a cancer survivor, he's young – 48 at his last birthday.

Three years ago, Corbett found blood in his stool. Fit and healthy, he had never been to hospital. A keen golfer, he thought he was bulletproof.

His wife, Sarah, pressed him to visit his GP, who suspected an infection, as Corbett frequently travelled to Asia for work. Four months later, when he was still noticing blood, a second GP diagnosed piles, sending him away with haemorrhoid cream. It took a visit to a third GP a few months later for the suggestion of a colonoscopy



to come up.

But Corbett's symptoms weren't serious enough to warrant a publicly funded procedure, so he would have to go private: he handed over his $3000 and prepared for the examination.

"The surgeon, John Keating, put a scope up, and he said, 'Oh, you've got a great big cancer. I can see it.'"

"It was a big shock."

"He said, 'It's nearly blocking your bowel. It's probably been growing for years.'"

He is keen that GPs – and men – get the message. "Men tend not to go to the doctor, and they particularly don't want a digital rectal examination."

Further tests revealed that the tumour was very close to breaking through the bowel wall. "It was all ready to go. The surgeon said, 'We've got to get it out fast.'"

Two weeks later, in April 2016, Corbett was on the operating table. The surgeon removed a 6cm-wide, doughnut-shaped tumour that he estimated had been growing for four years. The ideal time to catch a bowel cancer tumour is at stage one, but Corbett's had grown to stage three.

Corbett took three weeks off work to recover from the operation to remove a section of his ileum and get used to his ileostomy bag, before starting chemotherapy. The drugs caused nerve damage in his hands. "It was terrible. I spent three days in bed after every round. It was awful."

A year later, he had further bowel surgery to reconnect his intestine. But the procedure failed and he woke up five days later in intensive care after being operated on again.

"They were vacuuming stuff out. I had drains and tubes coming out of me. I had another scar – they had opened me up three times now. I was a mess."

A few months later, his surgeon made another attempt to rejoin his bowel. This time it was a success.

"It's been an absolute roller coaster for 18 months, my family not knowing what's going on."

For the next two years, Corbett has a high chance the cancer will return. After five years, he will be given the all-clear.

Does he worry? "No, I just get on with it. But the chance is there. I'm just celebrating that I'm cancer-free. I'm getting on with my life."

Corbett has put his experience to good use and is on the board of patient volunteer group Bowel Cancer New Zealand. He tells people that bowel cancer can strike at any age.

"I meet young people, people in their twenties, healthy women, ex-professional athletes [who are diagnosed with the disease]. They're middle class, upper class, working class."

He is keen for GPs – and men – to get the message. "Men tend not to go to the doctor, and they particularly don't want a digital rectal examination. They shy away from that stuff.

"The worst situation is one that many people find themselves in: when a tumour blocks their bowel and they get extreme symptoms. The bowel is obstructed and you have faecal vomiting.

"If you have a planned surgical intervention, it's done by a colorectal surgeon, rather than a general surgeon who happens to be working on the day. A lot of [acute-admission] operations end up with people having a permanent colostomy bag.

"Breast cancer is well advertised and warnings are issued regularly. But bowel cancer is insidious and under the radar."

Stefan Corbett with wife Sarah and, left, daughter Gabrielle Ryda: taking up the bowel-cancer message.

the national screening programme's IT systems; DHB staffing, equipment and capacity requirements; operational management; and clinical issues.

"New Zealand is behind many other countries in rolling out bowel screening. The intention to introduce a national screening programme was first announced in May 2008, but it was not until July last year that the first DHBs – Hutt Valley and Wairarapa – joined the national bowel screening programme."

The Waitemata pilot found that men were more likely than women to have bowel cancer, and the incidence increased with age.

Questions have been raised about DHBs' readiness to carry out the increased number of colonoscopies – the examination of the bowel by the insertion through the rectum of a camera inside a fibre-optic tube – screening will lead to. Across the Tasman, where a screening programme is being put in place, Bowel Cancer Australia has expressed alarm that only 40% of those referred for a colonoscopy get one within 60 days.

A Ministry of Health spokeswoman says New Zealand doesn't want the delays that are being reported in Australia of up to six months. "This is what New Zealand has sought to avoid with the considered and staged way we are introducing the national programme and building colonoscopy capacity at the same time. There is nothing more distressing for someone to get a positive screening test and not be able to get a publicly funded colonoscopy."

At present, screening for those without bowel-cancer symptoms comes down to where you live. Residents in Waitemata are getting screened, along with 60 to 74-year-olds in the Hutt Valley and the Wairarapa. That means just 16% of the screening age group is covered, or 107,510 of the estimated 700,000 who will eventually be eligible.

Jackson, who supports Clark's review, tries to contain his frustration at the hold-up in introducing national screening. The Dunedin-based medical oncologist, who specialises in colorectal cancer, says screening is the most critical element in fighting

the disease. "But we don't want a programme that is poorly funded, and we need a system that can cope. We hope the Government commits funds to allow this to happen as soon as is possible, and that the age range is extended to 50 to 60-year-olds as well."

In Australia, those reaching an even-number birthday from 50 to 74 are sent a bowel-screening kit; its national programme will be fully operational by 2020. In the UK, screening begins at 55, and Bowel Cancer UK is running a campaign, You're Never too Young, in response to a rising death rate from the disease among the young.

JUST A START

Doctors who have helped set up the New Zealand programme say we have to start somewhere and screening those 60-plus, where the bulk of cancers will be caught, is the first step. Ministry of Health figures show that 311 of the 1223 people who died of bowel cancer in 2013 were aged 65 to 74.

Bowel cancer can take off before any symptoms appear. It begins as a polyp, which appears either as a flat mass or like a mushroom attached to the gut wall with a stalk.

Susan Parry, an Auckland gastroenterologist, is clinical director of the programme. A week after speaking to the *Listener*, she was due to visit Hawke's Bay, to help the DHB there as it prepares to start bowel screening later in the year. The preparation "takes about a year", she says. "It's quite an intense process." People without symptoms of bowel cancer are being screened for the disease. "We need to ensure a DHB is ready."

Southern DHB – where more people are struck by bowel cancer than anywhere else in the country – will begin bowel screening next month. When deciding which regions get screened, Parry points to a few key factors: a DHB's capability and capacity, including meeting its colonoscopy targets; current rates of colorectal cancer; and rates in those most at risk. She is aware of the frustration at delays in national screening, and particularly the concern that cancers may now grow where they might previously have been detected and treated.

Aucklander David Vinsen: his surgeon said of his cancer, "Oh, I don't like the look of that fella."

Mike Hulme-Moir, a colorectal surgeon in Waitemata, can't say enough about the merits of bowel screening after five years of it in his patch. He had the job of contacting many of the 375 people in the pilot who showed signs of having cancer. Many had no symptoms. "They were usually shocked," he says.

One of those was Aucklander David Vinsen*. Now 69, he runs a property investment business and is chief executive of the NZ Imported Motor Vehicle Industry Association. In 2015, he was on a work trip in Germany when he noticed blood in his faeces. Returning to his West Harbour home, he had an annual check-up with his doctor, and at the end of the session happened to mention the blood.

His doctor sent him away with a bowel screening test kit, asking him to take three faecal samples over three days and send them off to the lab. Vinsen ignored it, as the blood had abated.

A week later, his invitation to join Waitemata's screening programme arrived in the mail. His doctor's nurse phoned to chase him up. "My GP had lost his mother at the age of 54 to bowel cancer, and he later told me that no one was going to suffer the same fate under his watch."

At present, screening for those without bowel-cancer symptoms is confined to Waitemata, Hutt Valley and Wairarapa.

Signs and symptoms of bowel cancer may include:

- A change in your normal pattern of going to the toilet that continues for several weeks (such as diarrhoea, constipation or feeling that your bowel doesn't empty completely).
- Blood in your bowel motion.
- Abdominal pain, especially if severe.
- A lump in your stomach.
- Unexplained weight loss and tiredness.

Vinsen sent off a sample for testing. At the time, he had no blood in his faeces and felt fantastic. He had no family history, although he wasn't a model eater, and drank a bit too much alcohol. Vinsen returned a positive test and needed a colonoscopy.

"I came to during the colonoscopy, and I remember the doctor saying, 'Oh, I don't like the look of that fella,'" he says. When a biopsy came back confirming cancer, Vinsen had surgery to remove the growth, along with 850mm of his lower bowel. He was one of the 39% whose cancer was caught at an early stage, and in his case, didn't need chemotherapy.

*A video about David Vinsen's cancer diagnosis and treatment has been published on the National Screening Unit website, tinyurl.com/NZLbowel.

1. Mike Hulme-Moir. 2. Dr Susan Parry. 3. Dr Chris Jackson. 4. Professor Ian Bissett. 5. Health Minister David Clark.

KEN DOWNIE; DAVID WHITE; MINISTRY OF HEALTH

Vinsen then wore a colostomy bag for four months, and had further surgery to reconnect his bowel. "I changed my job description at work, and thought, 'This is the year I'm going to be buggered,'" he says.

Clear of cancer for two years, Vinsen will be considered cured if he goes five years without its return. "The crucial thing is early detection. Screening is great, because it raises our consciousness that this can happen to anyone."

HIDDEN INVADER

Bowel cancer can grow and take off before any symptoms appear. It begins as a polyp, a growth on the intestine, which appears either as a flat mass or like a mushroom attached to the gut wall with a stalk. Some polyps are benign but others are malignant.

The evidence from the Waitemata DHB pilot is clear: 39% of the cancers found were at stage one, or localised; when a cancer is caught at that stage, patients have a 95% chance of survival. In the unscreened population, just 13% of bowel cancers are found at stage one, according to a 2015 Health Research Council report. And whereas

8% of cancers diagnosed during the pilot were at stage four and had spread to other organs, about a quarter of diagnoses in the unscreened population were in that category. At stage four, sufferers have just a 10% chance of surviving for five years.

Under the screening programme, 60 to 74-year-olds send in a stool sample, which is examined for traces of blood using the faecal immunochemical test (FIT). The Waitemata pilot found that men were more likely than women to have bowel cancer, and the incidence increased with age. The screening pilot's starting age of 50 has been raised by a decade for the national programme. The positivity test – the level at which a faecal sample triggers a colonoscopy – has also been lifted. The pilot programme found that 7% of those who had a colonoscopy had cancer.

FIT FOR PURPOSE

According to Ian Bissett, a colorectal surgeon who chairs the Government's bowel cancer working group, the FIT test is one of the best in the world. Bissett has been detecting and removing bowel cancers for two decades. Over that time, he says, survival rates have improved, which he attributes to better treatments, surgery, diagnosis and chemotherapy.

He says the other bonus from screening is that during the pilot, surgeons found and removed polyps, including some advanced adonomas (polyps) that would have become cancerous. "So we both diagnosed cancer earlier, and we possibly prevented some cancers from occurring."

He says other countries started with a narrow age band and then extended it. England started screening 60- to 69-year-olds, then extended the age range to 55 to 69. "That's what we will do."

He also says that the threshold at which a further investigation is needed is still lower than other countries' – half the level that triggers a colonoscopy in Scotland, for example. "That way, you only need to do half of the colonoscopies we did in the pilot to return 80% of the cancers."

Bissett talks about the need for a safe screening programme, referring to the importance of safe colonoscopies. When fully operational, another 8000 to 10,000 colonoscopies will need to be performed each year.

Data analysis from the pilot found 3.8 of every 1000 colonoscopies had a complication – bleeding, perforation, or tissue removal. Bissett says: "A colonoscopy has the risks of bowel preparation, sedation, the examination, biopsies and the removal of polyps. Complications can be rare but they can be life-threatening. We want to ensure those harms are outweighed by the benefits.

"I'm disappointed that it's been delayed, but I don't think it's the wrong thing to do. The roll-out is a major improvement for bowel cancer in New Zealand. It's good news, and maybe it's not as fast as we would like, but I believe we will have the best-quality screening programme in the world." It's a point backed by Hulme-Moir. "You don't want an endoscopist thinking they have to rush through eight colonoscopies in an afternoon," he says.

Key to a well bowel

- A Western low-fibre diet is linked to bowel cancer. High-fibre diets typical of Third World countries are associated with low rates of the disease.
- Eating plenty of fibre means the bowels are more active and less prone to constipation.
- Whole grains, foods containing dietary fibre, dairy products and calcium supplements are thought to reduce bowel-cancer risk.
- Kiwifruit is said to be good for bowel health.
- A family history of bowel cancer is a danger signal.

At present, just 16% of the screening age group is covered, or 107,510 of the estimated 700,000 who will eventually be eligible.

Ensuring DHBs can manage the extra colonoscopies necessitated by screening is a key reason for the delay in the programme's roll-out. Since 2013, the Ministry of Health says the gastroenterology workforce has been expanded to cope with additional colonoscopies. Four nurse-endoscopists are being trained to do colonoscopies and five gastroenterology trainees have been added to the workforce. The UK has nurse endoscopists, but they do only a small number of procedures, says Bissett.

BOGS AND SUNFLOWERS

Ian Foggo has bowel cancer and likens the experience to walking through a meadow. He might stroll past sunflowers along the way. Occasionally, he strikes a bog. But all the while, the 75-year-old retired orchardist knows that a cross and a cliff are waiting for him at the end. Whether he crashes to the bottom, or falls softly and gently, is the big unknown.

Foggo was diagnosed with advanced, incurable bowel cancer a year ago. By the time the stomach pains he mistook for gallstones alerted him that something was wrong, it was too late. The cancer had spread from his bowel to his liver and was already at stage four. His oncologist told him there was no point operating unless his bowel became blocked.

Since the diagnosis, the Tauranga father and grandfather has encountered several bogs and the occasional field of sunflowers. The first 21 days of chemotherapy were hell. He spent 14 days in hospital; after six weeks, he had lost 14kg. The chemotherapy dose was adjusted and he began to feel better. He had a joyous Christmas with his wife, Diane, two daughters, Penny and Suzie, and their partners and his grandchildren.

Until he was diagnosed, Foggo had been fit and healthy and a frequent gym-goer. He had retired in January last year, and two months later, he spent his first week in hospital. But Foggo is philosophical. Eighteen years ago, he survived a triple heart bypass. The years since have seemed like a gift. He is full of praise for his medical team.

Even so, he thinks that he would have got screened had the programme been in place. "I'm the sort of person who, if something like that is available, I would have done it. I would encourage anyone who has it available to do it. I had no prior warning."

Every eight weeks, he has a scan, and his oncologist thinks his tumour has remained static. "I get tired easily. It's been hell on the

Ian Foggo with wife Diane, granddaughter Scarlett and grandson Riley; fishing last year.

family. We now can't do things we planned to do in our retirement. It's hard for those around you."

When screening is finally rolled out, the ministry expects 500 to 700 people will be diagnosed with bowel cancer each year. It says the programme has been developed over a number of years with input from experts and advisory groups and it has received international endorsement. Says Bissett: "Ten years down the track, we will see that screening is a huge step forward."

A MATTER OF TRUST

The programme arrives almost 20 years after breast screening began in 1998. Cervical-cancer screening was introduced even earlier, in 1990.

It's coming much later than the Cancer Society's Jackson and others would like. The society made its first statement in support of screening in 2010, although it said it should happen only if the health workforce could cope with the additional colonoscopies and treatment. It is now calling for increased transparency, and milestone reporting showing where DHBs are up to as they prepare to screen the country's baby boomers.

Southern DHB – where more people are struck by bowel cancer than anywhere else in the country – will begin bowel screening next month.

"Some of the trials showing that screening reduces deaths from bowel cancer reported results in the 1990s, so it has been a long time coming," says Jackson. "As a country with one of the highest bowel-cancer death rates in the world, we would have liked screening to have been rolled out much earlier than it has been."

Says Parry, the programme's clinical leader: "The whole aim of screening, and why it saves lives, is that it picks up bowel cancer at an early stage, where the outcomes are better. My main concern is that the trust and confidence of New Zealanders in screening is not eroded.

"We do feel that this delay is in the best interests of the country. We would all – including me – like the roll-out to be sooner. But we have to live with what is achievable and safe." ▮

Revised screening targets:

- Southern and Counties-Manukau DHBs, by June
- Nelson-Marlborough, Lakes and Hawke's Bay DHBs, by December
- Whanganui and MidCentral DHBs, by mid-2019
- Five more, by 2019-2020; the final five by June 2021

FOGGO FAMILY COLLECTION