My Pancreatic Cancer Journey

A Patient's Perspective, Written to Help Others Recently Diagnosed

By Gary Murphy

Diagnosed February 2026 — shared in the hope it helps someone else

Why I Wrote This

I'm sharing my pancreatic cancer journey in the hope it helps other patients who have just been diagnosed.

There have been moments of despair, frustration, relief and joy along the way, and I've learned things I wish I'd known much earlier. My hope is that by sharing my experience, I can help make what is a genuinely tough journey a little smoother and more manageable for you.

There's a lot of excellent information out there for newly diagnosed pancreatic cancer patients, but most of it is written by clinicians and medical professionals rather than patients. I think the patient perspective matters too, because everyone's experience is different — not everyone will have the same side effects, or react to treatment the same way.

Medical literature has to list every possible side effect, and to someone who's never been through it, that list can be daunting and scary. The truth is, you really don't know what will happen to you until you start treatment.

This is my story, not a prediction of yours. I hope it helps.

Key Takeaways

If you read nothing else in this document, read this page. These are the lessons I'd most want a newly diagnosed patient to hear.

If You Only Read One Page

- Your journey will be different from mine. Medical literature lists every possible side effect — treat it as a guide, not a forecast.
- Trust your instincts, and your support person's. My wife pushed for an earlier gastroenterologist appointment, and it mattered.
- Ask for a single point of contact early. A dedicated cancer care coordinator made a huge difference once my chemo started — I wish I'd had one from day one.
- If you want a prognosis, ask directly. Clinicians may not volunteer one unless you insist.
- Side effects change over time, and treatment can be adjusted. Report every new symptom to your team — for me, dropping one drug (oxaliplatin) made a big difference.
- Look after the whole you. Diet, exercise and mental health need to be coordinated with your treatment, not managed in isolation.
- Check your insurance early. Income protection and TPD claims take time and paperwork — start as soon as you can.
- Mindset matters. A positive outlook alongside good medical treatment made a real difference for me.
- Look after your supporters too. This is hard on them as well — they need care, breaks and thanks.
- Use reputable sources, such as the Cancer Council and Pankind, rather than general internet searches.

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About Me

I'm a 59-year-old man, happily married to Michelle for 33 years. We have two adult daughters and two granddaughters.

Before my diagnosis, I considered myself reasonably fit and healthy. I ran 5km every day and did Park Runs on Saturday mornings. I loved getting out on the water in my kayak and spending time at the beach, and I'd recently taken up cycling on the local trails. I also enjoy reading, painting, spending time with family and exploring new places.

I've never smoked, drank alcohol in moderation (a glass of wine on weekends, nothing during the week), ate healthily and avoided junk food. I wasn't on any prescribed medication and would only see a doctor for a flu injection or antibiotics.

My mum had bowel cancer and my father had diabetes, but there was no strong family history of cancer.

Why this matters

There's no single profile for who gets pancreatic cancer. I was fit, healthy and had no major risk factors — yet here I am. If something feels wrong, don't dismiss it just because you're 'healthy'.

The Early Signs

A Timeline of Symptoms

- Early January 2026 — Heartburn, bloating and loss of appetite began. Running became difficult and uncomfortable.
- Around the same time — I caught a cold that turned into a lung infection; my GP prescribed antibiotics.
- I wondered if I'd developed a sudden intolerance to gluten or lactose, so I changed my diet. It didn't help.
- I went back to my GP and asked to see a gastroenterologist.
- Late January — During a morning run, I had a lot of discomfort, trouble breathing and tremors in my arms. My wife called an ambulance. At hospital, an ECG and blood tests ruled out a heart attack but showed elevated lipase levels. I was discharged that afternoon.
- The wait to see a gastroenterologist was around six weeks, but my wife found a cancellation and got me in sooner.
- 5 February 2026 — My GP had already booked a CT scan. That morning I saw the gastroenterologist, who requested a CT scan with contrast, done that afternoon. That evening, feeling unwell, I struggled to breathe while walking the dogs, began dry retching, and my wife drove me to hospital. A large vomit brought some relief.

- That night — an emergency doctor took us to a private room and explained the CT scan had found a significant mass in the head of the pancreas. It was too soon to be certain, but it was most likely cancer. A nasogastric tube was inserted and a lot of fluid drained. I was admitted to the ward a few hours later.

Trust your instincts

My wife is a nurse, so she has a lot of medical knowledge — but not in oncology. I knew almost nothing about the pancreas beyond that it produces insulin. If a specialist appointment is weeks away and something doesn't feel right, it's worth asking about a cancellation list or another way in sooner.

I asked the doctors how long I'd had the tumour. They said it could have been growing for quite some time, which surprised all of us.

Getting Diagnosed

My initial diagnosis came in the emergency room. My wife was understandably very upset; I was surprised at how calm I felt. As an engineer, I'm quite rational and analytical, and I was strangely relieved just to know what was causing me to feel so unwell.

I'd expected a longer, more uncertain process of tests, so having an answer — even a hard one — felt like something to work with. I'm aware of the stages of grief: denial, shock, disbelief, anger, depression and acceptance. I went almost straight to acceptance. There didn't seem much point asking “why me” — millions of people get cancer every day, and I'd simply joined a club nobody wants to join.

My immediate thoughts turned to treatment: what it would involve and how long it would take. Nobody could answer those questions yet.

Treatment Experience

Hospital Stay

I was admitted to hospital on 5 February 2026 with a nasogastric tube and put on a saline and nutrient drip. An X-ray checked the tube's position, followed by further tests and scans — MRI and PET — because the CT scan alone wasn't conclusive.

The tumour had blocked my duodenum, so I went to theatre to have a feeding tube inserted. I then had a gastroscopy and biopsy. During the gastroscopy the feeding tube was disturbed, so I had to go back to theatre to have it replaced.

The surgical team told me the tumour was inoperable because of its size and location — the risks of surgery outweighed the benefits. They said oncology would most likely recommend 6 to 12 weeks of chemotherapy to try to shrink it. I was also told they'd found spots on the peritoneum.

I asked for referrals to the oncology team and to Peter Mac.

I was still on clear fluids and had lost about 12kg, down from 88kg to 76kg. The surgical team considered a gastric bypass to relieve the blocked duodenum; I asked whether a stent was possible instead, and after some discussion we agreed a stent was the less risky option.

The Stent and Going Home

- 26 February — the stent was fitted.
- 2 March — discharged after almost four weeks in hospital.
- 4 March — first appointment with my oncologist, who recommended 12 cycles of chemotherapy, one per fortnight. I asked for time to reflect and consider (I still hadn't heard back from Peter Mac).
- 11 March — follow-up appointment. I asked for a prognosis; the oncologist was initially reluctant, but I insisted. He said that without treatment I had 3 to 6 months, and with treatment 9 to 12 months, possibly longer depending on how I responded. My wife was very shocked. We shared the news with our daughters and family — there were a lot of tears. We agreed to proceed with treatment.
- 13 March — baseline CT scan, and that afternoon my chemo port was installed.
- 15 March — first chemo session.

As of writing, I've had 10 chemo sessions.

What I'd Have Changed

I didn't feel particularly supported during my hospital stay. I rang the Cancer Council and spoke to someone who was fantastic — full of encouragement and information. I also rang Dianne at Pankind, who was similarly empathetic and full of practical support.

The nurses in hospital were wonderful and caring. Being a training hospital, I saw so many different doctors, interns and trainees that I was never quite sure who was making decisions, which was frustrating at times. I'd hoped for a single point of contact to discuss my care. I'm very fortunate that my wife, a nurse, was at my side every day and often asked the right questions and challenged decisions on my behalf.

I was disappointed that I didn't see anyone from the oncology team until 4 March — almost four weeks after diagnosis. I feel we lost valuable time, and some of those discussions could have started earlier, especially once surgery had been ruled out.

Now that I'm in chemotherapy, I feel much better supported. My cancer coordinator has connected me with nutritionists and physiotherapists, and organised medical statements. I wish I'd had someone like her from the very start — it would have helped me feel far more reassured.

If you take one thing from this section

Ask early and often for a single named contact person on your care team. If a coordinator isn't offered, ask if one is available.

Chemotherapy and Side Effects

My Regimen: Modified FOLFIRINOX

I was prescribed 12 sessions of modified FOLFIRINOX chemotherapy, one every second week. It combines four drugs:

- **Oxaliplatin** — a platinum-based drug that damages the DNA of cancer cells so they can't replicate. It also affects some normal cells, which is what causes side effects like neuropathy.
- **Irinotecan** — blocks an enzyme cancer cells need to copy their DNA, causing breaks that can't be repaired.
- **Calcium folinate** — a vitamin B supplement that treats certain anaemias and boosts the effectiveness of the other chemo drugs.
- **Fluorouracil (5-FU)** — disrupts DNA and RNA production in cancer cells so they can't grow or divide.

A Typical Chemo Day

My first visit to the cancer centre was daunting because I didn't know what to expect. The staff were considerate and put me at ease — I was shown to a reclining chair, connected to my port, and given pre-medications for nausea and diarrhoea control. Staff came around regularly offering drinks and snacks.

I brought an iPad and a book, but found the open-plan ward noisy — nurse and patient conversations, the constant alarms from infusion machines, general hubbub. My wife stayed with me the whole time, which I valued not just for company but so she could follow what was happening and ask questions.

It was a long day — 8.30am to 3.30pm. I was then hooked up to a Baxter bottle infusing fluorouracil over 48 hours. It's far better than being admitted to hospital for two days, but it does restrict movement, and sleeping and showering with it takes some getting used to.

After 48 hours, a nurse visited my home to remove the bottle and give me a pegfilgrastim injection to boost my white blood cell count. I also took two dexamethasone tablets a day for the two days following each session — a corticosteroid that helps control the immune and inflammatory response.

Side Effects — What I Actually Experienced

- Diarrhoea, starting the same day as my first session.
- Peripheral neuropathy, mainly in my fingers and tongue — including taste changes and slight swelling that affected my speech. I couldn't touch anything cold without pins and needles.
- No nausea or vomiting, which was my biggest worry given my stent.
- Feeling “wired” from the steroids for a couple of nights, followed by fatigue once they wore off. I learned to nap in the afternoon and still sleep 8–9 hours overall.
- Constipation once we reduced the anti-diarrhoea medication (managed with Movicol), and haemorrhoids from my hospital stay that made this worse.

- Mouth ulcers that were painful and affected my eating — treated with prescribed mouthwashes.
- A low blood platelet count, which showed up first as blood in my urine, then later as a severe nosebleed that left blood on my pillow. My platelets had dropped to 13 (should be over 100) and I needed a transfusion.
- Worsening neuropathy — a friend going through treatment suggested glucosamine (normally an arthritis medication). Neither my oncologist nor the nurses had heard of this use before, but they were happy for me to try it; it didn't eliminate the neuropathy but made it more manageable for a while.
- Cumulative fatigue — early on I'd recover within 3–4 days of a session; later that stretched to within 2 days of the next one. As a normally active person, I found this frustrating — my home exercises and bike rides dropped away, and I struggled with fine motor tasks like Lego or painting.

A hospital lesson learned the hard way

Twice I had urgent issues on a weekend: blood in my urine, and later a chest infection. Both times, the Emergency Department and a Medicare urgent care clinic were slow, or a doctor unfamiliar with chemotherapy was reluctant to prescribe antibiotics. Both times, going straight to my cancer centre on the next weekday got me seen and treated fastest. If you can, find out in advance what your cancer centre's after-hours advice line is, and use it before defaulting to a general ED.

Monitoring and Adjusting Treatment

Before each chemo session I had a blood test and a check-in with my oncologist. I also had a pre-chemo CT scan, follow-up scans after 6 and 9 sessions, and monthly CA19-9 blood tests to track the cancer marker.

My cancer marker fell rapidly — from 4,989 in March to 132 in June (a healthy level is under 38) — showing the chemo was working. A CT scan also showed the tumour hadn't grown, and may have shrunk slightly.

Because of the toll on my nerves, my oncologist and I discussed taking a break from chemo, and we removed oxaliplatin from my regimen. That single change made a huge difference to my neuropathy and fatigue.

I was referred to a Cachexia Clinic, where I saw a physiotherapist, nurse and dietitian together at the same table (the doctor was unfortunately called away). I'd previously had separate conversations with a dietitian about my nutrition and an exercise physiologist about a home exercise plan, but I was worried these weren't coordinated with each other. The joint round-table discussion was genuinely useful — I just wish I'd had it sooner.

Coordinate the whole picture

Weight, diet and exercise need to be actively coordinated with your oncology treatment, not managed in isolation. Ask if a joint clinic or coordinated review is available.

Mind and Body

While the physical side has been the focus of this chapter, the mental side matters just as much. I have a strong Christian faith to draw on, a positive mindset, and a wonderfully supportive family and friends who encourage me and pray for me.

I've chosen to be open about my diagnosis and post regularly on social media. It's been cathartic for me, and by the feedback I've received, encouraging for others too.

I know that for many people, a cancer diagnosis — especially pancreatic cancer, given its low survival rate — is frightening and upsetting. If you're struggling mentally, please actively seek help. I believe effective treatment happens when a positive mindset works alongside the physical treatment, not instead of it.

The Financial Cost

Most of the resources I've read offer generic financial advice — pointing to financial advisors or support services — but few talk about the actual costs involved.

We're fortunate in Australia to have an excellent public health system. I spent almost a month in hospital with 24/7 care, several procedures, and a multitude of CT, MRI and PET scans, gastroscopies and daily blood tests. I estimate that cost at tens of thousands of dollars — research puts the average burden-of-disease cost per pancreatic cancer patient in 2023 dollars at over $70,000. I didn't pay a cent of it.

However, my diagnosis meant I had to resign from my full-time role due to medical incapacity, and my wife — a registered nurse who was about to start a new role — chose to become my full-time carer instead. On top of the stress of the diagnosis, treatment and an uncertain prognosis, we now faced the added stress of how we'd manage financially.

Fortunately, I'd taken out income protection and total-and-permanent-disability insurance through my superannuation. I made an income protection claim in February, which required numerous forms, including reports from my GP and oncologist. My GP charged $880 to complete these and took over a month to do so — which shocked and disappointed me.

My claim was approved, and I received my first payment in late May. Going four months with no income and living off savings was very stressful, and even now, income protection payments are 80% of my previous income, so managing on an immediate 20% pay cut has been a struggle.

Beyond direct treatment (which I haven't had to pay for), there are indirect costs:

- A blender and juice maker, needed because my duodenal stent put me on a liquid, then moist, then semi-moist diet.
- Protein supplements such as Ensure, which aren't cheap.
- Travel costs — fuel, parking and vehicle wear and tear — for appointments and treatment.

These costs add up and add to the stress. For anyone without insurance, the financial side of a diagnosis like this is a genuinely scary prospect.

Act early on insurance

If you have income protection or TPD insurance through your super, start the claims process as early as possible — it can take months to come through, and the paperwork (and your GP's fee for completing it) can be a surprise.

Support and Connection

Without question, my wife and daughters have been my biggest supporters — making sure I have smoothies and protein drinks, that I rest and don't overexert myself. I've also been genuinely touched by hundreds of messages from family and friends around the world.

One unexpected upside is that people are sharing sentiments with me now that they might otherwise only have shared after my death — sentiments I wouldn't have been able to hear. I'm grateful for that, and grateful for my faith, which lets me put my trust in God. I'm not angry, and I'm not asking “why me” — I'm looking for ways to use my situation to help others.

Changing the Narrative

Sadly, pancreatic cancer isn't well known or understood. Most people — myself included, before my diagnosis — know a story about breast, lung or prostate cancer. These cancers are well known, well researched, and have active fundraising behind them. Pancreatic cancer doesn't have a known screening program, and for those of us unfortunate enough to get it, survival rates are very low. I'd like to help change that.

Messages for Others

To Fellow Patients

It's understandable that people say “I know what you're going through” or “I know how you must be feeling” — but honestly, 99 times out of 100, they don't. Even fellow pancreatic cancer patients I've spoken to have had different symptoms and different reactions to chemo than me.

Educate yourself. There's a lot of good information available, but stick to reputable sources like the Cancer Council and Pankind — not everything you read on Google is helpful. The more you know, the more questions you can ask, and the more you know what to expect.

My advice — easier said than done — is that while it's natural to get angry and ask “why me,” wallowing in self-pity won't help you. If you want to fight it, or simply make the most of the time you have, you need a positive mindset above all else. We all die at some stage; some of us get longer than others. Don't measure life in years — measure it in memories. Some people live to 100 and are miserable; others live to 30 and pack in enormous joy and fulfilment.

Be positive and focus on the good things. Live in the moment — treasure sunrises and sunsets and the small wonders of nature that others take for granted. Let yourself laugh. Look after your mind and body. Control what you can — your sleep, nutrition, exercise, connections and mindset. You can't control the cancer, and you can't control how you respond to treatment, so focus on what you can control.

Accept that it won't all be rainbows and unicorns, and that you'll have bad days. Just like the sun comes up again, those times will pass.

Don't be selfish. Most of us are fortunate to have cheerleaders and supporters — and I believe it's actually harder for them. The focus is on the patient: you get the care, the treatment, the support. Nobody's really looking after the people looking after you. They're likely feeling angry, maybe a little guilty for thinking about a future without you, frustrated and helpless because they can't just hand you an aspirin and have it all be fine in the morning. Tell them you appreciate them. Thank them. Acknowledge that this is tough for them too. Give them space, and make sure they get a break and their own support.

To Supporters

To anyone supporting a pancreatic cancer patient: thank you. Thank you for being there, for doing the simple things, and for putting up with what will be major changes in demeanour, activity, communication and appearance. It must be hard watching someone you love change so drastically. Be patient and tolerant — patients can get grumpy or stubborn.

Remember to put your own oxygen mask on first. Look after yourself, because if you don't, you won't be able to look after the patient. Get enough sleep, nutrition, exercise and time for yourself. Don't feel guilty about it — you don't want to crash and burn.

Looking Ahead

For myself, I'm hopeful I can do more than simply exist in the time I have left. I want to create lasting, positive memories for my family and help build awareness of pancreatic cancer. I've set up a fundraising page for pancreatic cancer research — I'd love to see better screening, earlier intervention and more targeted treatment. My dream is a future where nanobots can be released into the bloodstream to attack cancer cells without touching the healthy ones.

For my family, I wish that they can focus on the positive. I've been fortunate to live a full and wonderful life with few regrets — a loving wife, a beautiful family, and so many memories made together. I'm sad they'll be cheated of what might have been another 20 years with me, but I'm also grateful I won't suffer in other ways I always feared, like dementia, or becoming so incapacitated that I'd be wholly dependent on others.