CHAPTER 1

Pull the rug

You never forget where you are when you receive one of *those* calls. We spend our lives trying desperately to avoid them, but they are simply the price of being alive and loving other alive people. I was in an entirely unfamiliar holiday rental 4000 kilometres away from Dad when I received his call, but I can explain in detail the room in which I stood, sat and then slumped as I felt the blood drain from the top of my head to my toes while he delivered his news.

It was the first week of June in 2021, and I was riding high on a wave of media coverage, positive reviews and celebrity endorsements for my first book. And yet, unbeknownst to me, on the very same day my book was released, my dad was admitted to a hospital in Perth, the isolated but magical city I'd grown up in but had left some 15 years prior to carve out a media career and begin a serious love affair with the harbour city of Sydney.

My husband and I, as well as our two small children, had travelled to Wagga Wagga, a regional town a five-hour drive from our home in Sydney, to celebrate my husband's graduation from his master's degree. After three years of studying every weekend (and many hours on the tools myself either solo parenting or editing his assignments), I forced him into a gown and cap and gathered the family to celebrate. It was a happy day, a proud day, and one that would end in despair.

Dad had texted the day before to ask if we could have a quick chat soon, and — blissfully unaware of his plight — I had arranged to call him after the graduation, as always asking if he was okay before signing off. In retrospect he didn't really answer me, but he responded cheerily enough that it didn't ring any alarm bells. He was clever like that. I'm a firm believer anyone who can survive longer than two minutes after receiving a 'can we talk' message without speed-dialling the source deserves a medal. I am not that person. Yet, wanting to give my husband his rare moment in the sun, I allowed myself to remain caught up in what was in front of me, missing Dad's ninja-like avoidance of answering whether everything was, in fact, okay.

Which, when we connected later that evening, I would find out it was not.

Him: 'Sweetheart, I have some bad news.'

Me: 'About what?'

Him: 'About my health.'

Me: 'What's going on?'

Him: 'I have mesothelioma.'

Me, panicking and prematurely firing off a poor guess: 'Blood cancer?'

Him: 'It's cancer of the pleura — the lining of the lung…'

Dad's voice faded out and I felt hot and prickly, like I'd stepped outside of my body. I tried to orient myself in space and time by snapping into action, putting him on speakerphone so I could quickly google what we were talking about, and more importantly what sort of prognosis he was looking at. He slowly walked me through the details as I asked a million questions and tried to maintain some level of decorum, my eyes frantically jumping from link to link.

Fatal. Incurable. Six months. Eight months. Twelve months.

No doubt mustering every inch of courage he had and already looking for the silver lining, Dad insisted he felt 'wide awake' and

'blessed' for the wake-up call. And me? I cried all night, knowing deep in my bones that, sooner rather than later, I was going to lose my beloved dad.

If I think back to my childhood, I've always had an unquenchable thirst for a few things. The first is two-minute noodles. Even though they contain the nutritional equivalent of sand, I still love them and would eat them every day if I could get away with it and still be taken seriously as an adult. The second is pop song lyrics. I can't remember most people's names or my logins to pretty much anything, but I can remember every word to a wide array of 1990s R&B songs (which comes in less handy than you'd think). But the third is a thirst for knowledge, and it was always medicine and people that most piqued my interest. I probably should have been a doctor, but I was too busy studying the art of being a delinquent at high school to get the grades for medicine. Instead, I built a career out of asking doctors questions, and I think my hunger for answers was evident in me from when I was very, very little.

In 1988, Dad had a friend come out from the UK to stay with us. This wasn't uncommon — our house was a revolving door of Dad's friends, girlfriends and not-quite-girlfriends, as well as people brought in to help cover the rent. She was doing her PhD in something to do with the role of group therapy in adult education. One of the groups she observed and tested was men with HIV, which was — in the 1980s — pretty much a death sentence. She brought groups into our home so they could connect and talk about their illnesses and lives, and so she could watch what occurred.

This is an extract from her thesis:

> **The various members of the household, including Jack's four-year-old child Casey, moved in and out of whichever workshop was taking place with little apparent discomfort, listening, joining in the questioning and moving out again when a more pressing engagement beckoned. During the Body Positive**

> **workshop, Casey set up a miniature shop in her bedroom, and cajoled individuals into leaving the group in order to engage in trading according to her rules. At other times she joined in any group which took her fancy, taking readily to the turn-taking with questions, and occasionally pulling a question in her direction by sighing loudly and remarking to no one in particular that 'I haven't had a turn in ages'.**

This curiosity has remained with me my whole life. I vaguely remember those workshops; the memories must be stored in the same mental cabinet as the lyrics of the hot hits of the '90s. In subsequent conversations, I've learned my 'cajoling' of the participants basically meant taking them by the hand and pulling on their arm until they had no choice but to come with me. Bearing in mind this took place at a time when people thought you could transmit HIV by shaking hands or even touching the same surface, and people with the virus were largely shunned due to fear of transmission, I feel proud and grateful that I lived in a home where that sort of experience was available to me. Thinking about four-year-old me sitting in a circle with grown, sick men, asking questions and trying to be part of the conversation to understand the illness and the people living with it, feels like a very accurate representation of what I'd grow up to be. I'm fascinated by both clinical care and communication, and how knowledge and action truly are power when it comes to our health. This obsession served me well when Dad—and I, by proxy—were thrown into the fraught and fragmented medical system.

At that stage in my life, I'd spent 15 or so years reporting on, producing content for and facilitating conversations with key players in healthcare—a system I thought I knew intimately. Turns out the system and I were about to go from casual hook-ups to a shotgun wedding, for better or worse, in (mainly) sickness and (less so) health. My experience would give me a front-row seat to just how complex and challenging the system is to navigate, even with my high level of health literacy, communication experience and handy contacts.

I'd find myself scratching my head and imagining how much harder it would be if English wasn't your first language, you didn't have a family support network, or you couldn't read or write. This lit my desire to help others better navigate the system, so to orient you I'm going to start by sharing a bird's-eye, macro view—a YOU ARE HERE mark. If knowledge is power, then having a solid grip of the basics to work from is like taking the plug and sticking it into the electrical socket. It's step one of many, but every journey begins with the first step.

The care landscape

Australia is widely known to have one of the best healthcare systems in the world. It's not high-tax, high-return, topping-the-happiest-places-to-live-lists Scandinavia, but it's pretty good. It's by no means perfect, but show me a healthcare system—any system supporting a nation—that is. Unlike the US, where you pay or you suffer (making insurance benefits the holy grail of employment), Australia's healthcare system offers a two-pronged approach to medical care. Much like the UK's NHS, we have a public scheme called Medicare available to all, and a private system available to those willing—or able—to pay for it. An easy way to think about it is like when you travel with an airline. The public system could be thought of as economy and the private system is business class. It's an imperfect analogy because business class is considered better than economy, but the care you receive in the private system isn't necessarily better than what you'd receive in the public system—you just have more choice, shorter wait times and possibly a nicer seat.

Our public scheme, Medicare, is paid for by the federal and state governments (and therefore, by taxpayers). If you're an Australian citizen, permanent resident or applicable visa-holder, you can access free healthcare at bulk-billed medical clinics and public hospitals. Bulk-billing is where practitioners are paid directly by the government, so there's no out-of-pocket cost to the patient. The upside is that it

doesn't cost anything; the downside is that unless it's an emergency, you're likely to have to wait (sometimes years) for specialist care and you'll have little to no say in who delivers it. You might be able to choose your general practitioner (GP) but if you need more complex care, you'll get whatever surgeon or specialist can pick up your case — whenever they can get to it.

Our private system is paid for by industry (insurers) and individuals — people who choose to either pay for care directly to the providers, or to health insurers in return for coverage, and then any gap between what insurers will pay and what medical professionals choose to charge. The government pays too by covering some of the costs of care and providing a private health insurance rebate to policy holders (to help offset the cost), as well as paying for public hospitals in which private patients can still receive care. People who choose not to take out private health insurance are slogged with what's called the Medicare levy surcharge, designed to encourage us to take out private health insurance and take the pressure off the public system. The upside of the private system is that you have more control over who treats you, and in theory you shouldn't have to wait as long for care. The downside is that you'll pay fairly handsomely for the care you receive — whether that's paying for insurance or the price of treatment (or, more likely, both).

There are adjacent systems, services and schemes you may have to work with on the journey too, such as welfare (Centrelink), aged care (My Aged Care) and disability (the National Disability Insurance Scheme). These work alongside our healthcare system to deliver care (see figure 1.1).

Within the healthcare system, there are various subsystems, including:

- **Primary care:** This is usually what we call general practice — your first port of call when you're not well and the subsystem you'll likely interact with most. Primary care is the backbone of our healthcare system and arguably the subsystem under the most pressure.

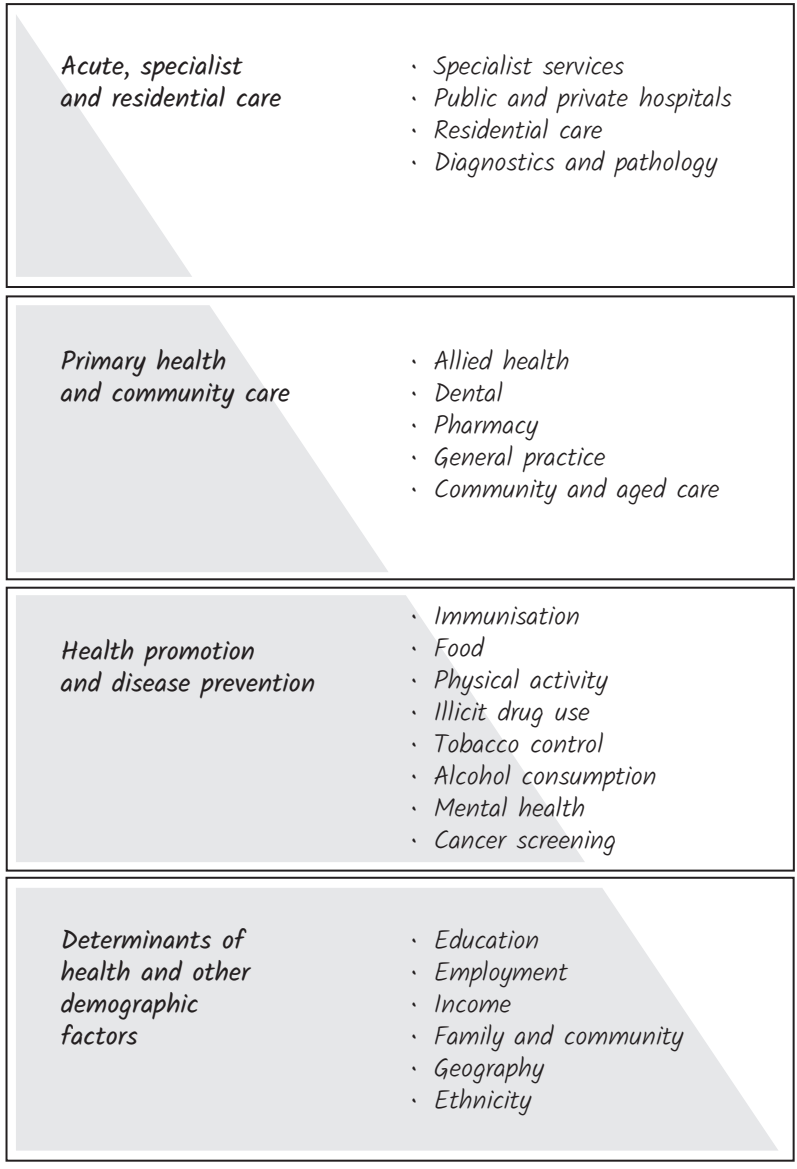

Figure 1.1 The layers of the Australian healthcare system

- **Secondary care:** The specialists we are referred to when primary care isn't enough—think cardiologists for our hearts, psychiatrists for our minds and orthopaedic surgeons for our bones.
- **Tertiary care:** The hospitals we go to when we need surgical or medical intervention (and little cups of jelly that make no sense nutritionally nor to anyone post-1994).
- **Allied health:** All the healthcare professionals who work alongside and support doctors and patients. Think physiotherapists, psychologists and pharmacists, for starters.

The subsystems are designed to fit together like LEGO—but *you* are the one playing with the colourful plastic blocks. It's up to you to come up with a design based on what game you're playing and make the pieces fit together. And if you've ever stood on a piece of LEGO in bare feet (hello, parents), you'll know that a rogue piece—while tiny—can cause all sorts of pain, drama and hopping around on the other foot while internally screaming obscenities at whatever tiny terrorist left it there.

In your Next of Kin era

So, what happens when someone you love is struck down with disease, disability or death, and you need to step up to the plate and play? You enter your Next of Kin era.

Next of Kin are defined as a person's closest living relative or relatives. Whether by birth or by choice, I believe Next of Kin have the opportunity to be much more than an emergency contact we write on a form and never expect anyone to call. In fact, I believe Next of Kin are one of the most powerful stakeholders in the healthcare setting. Next of Kin have a PhD in the patient; we are trusted by them, and we are one step removed from their experience. It's not happening *to* us, but in front of us. So, if there's anyone best positioned to provide support, it's Next of Kin. In the throes of illness, disability or mortality—whatever the patient is facing—their focus should be on the challenge in front of them. For that very reason and myriad others, it's hard for patients

to be their own advocates. In the same way lawyers handle divorces and real estate agents sell houses, sometimes we need an intermediary to think strategically on our behalf. And care is no exception.

So, let's talk tactics. Pretend you're in the army for a moment. I have about as much experience in the military as I do in the Ferris wheel industry (and I may or may not have streamed too many action series), but bear with me. In any mission, there's usually a couple of main characters: a target or asset (which in our analogy is the patient), and a captain (which in this case is you). Working with and around you are other special ops teams and services, but the captain is the one assessing all the inbound intel, reading between the lines, advocating for what the asset wants or needs, and helping devise a strategy that supports not just the management of the illness or injury, but the person who has it.

I'm going to level with you—being the captain can be about as much fun as doing your tax return while cleaning out your gutters. My nickname in our family while caring for Dad was Drill Sergeant Casey. While my ego bristled when I learned of my new moniker (because we all like being liked), in the end I responded with: 'Damn straight, and it's Captain Drill Sergeant Casey to you.'

Unfortunately, someone has to be in charge when someone else's health, happiness and, in some circumstances, life, is on the line. In an ideal world some helpful fairy godmother would assemble a team around you, brief you (like in the movies) and then give you some kind of lanyard, whistle or at least an official-looking hat. But in this world, the real world, you're going to have to assemble that team—and run it—yourself.

It's not what you know...

Bearing in mind the required team will look different depending on your situation, here are a few key players that were vital in ours and who you might find helpful to have in your corner.

- **A (great) GP.** Good GPs are worth their weight in whatever is the next level up from gold. Ideally, you'll have a relationship with

them already so they'll understand your history, but if you don't then you can build one. You might have to kiss a few frogs, but keep trying until you find the right fit. They'll be able to distil results to you if specialists prove hard to understand (or get an appointment with), and they can help escalate things if you aren't getting what you need. In short, they can crack proverbial skulls if needed.

- **Someone to support your person's mental health.** This could be a psychologist, counsellor or spiritual advisor. Having someone they can unpack things with that *isn't* you is vital for them, because there will be things they don't want to share with you, or anyone else they know—especially if they are facing their mortality.
- **Someone to support your mental health.** This could be any of those listed above but it could also be a skilled and trusted friend who knows when their level of support is no longer sufficient and you need professional support. Having someone who is trained and paid to support you is advantageous if you can afford it. Some hospitals, hospices and support services (such as Cancer Council Australia) have free counselling services and are worth exploring.
- **Someone who speaks fluent 'medicine'.** Got a friend who's a doctor or nurse? A second cousin who's a pharmacist? Get yourself someone who can decode for you beyond the guidance this book and Dr Google can provide. They can be invaluable at translating if they're willing to give you some of their time, and you'll struggle to get around if you don't speak the language.

My advice? Work hard on building solid relationships with all these people. You want them to like you so they'll be more likely to go above and beyond for you, and therefore for the person you're caring for. And if you find the right people, you'll learn fast that the old adage is true: it's not what you know, but who.

Hindsight

In our last interview, I asked Dad if there was something he wished he'd known earlier in the journey.

'I wish I'd known that the medical system is not well suited to managing complex diseases like this,' he told me. 'I've met some wonderful people but I think our health system has a long way to go in terms of really managing individuals well throughout the process from go to whoa, and leaves a lot to be desired in so many ways. I'm very lucky that I have a brain and some great advocacy and people I can turn to for advice when I'm stuck, and I really feel for people who don't have those things.'

If that's you, you're in luck. This book has been designed to hold your hand, sit with you while you have a cuppa and be a resource for you to turn to when you need guidance.

Setting an intention

Oh dear. 'Setting an intention' makes me sound like a meditation teacher. For the record, I'm not; and if I'm honest with you I can't bloody stand meditation. But I do think that when it comes to care (because it's often such a long and winding road), having a set of words to live by is smart. They'll become an anchor when seas get stormy, and the forecast shows a 100 per cent chance of wild weather.

My words came about while sitting in a café with one of my mentors. I lean on people when they've got direct experience with whatever I'm going through, and I'm always richer for their wisdom. I was speaking passionately (read: bitching) about Dad, for whom I had just moved my family across the country, from Sydney back to my hometown of Perth, so I could care for him in his time of need. Dad, grappling with his own grief around his diagnosis, as well as

all the other challenges that come with being an adult, was being (and I say this with compassion) a pain-in-the-ass. The same flawed, perfectly imperfect pain-in-the-ass he'd always been, but now with the added complexity of a terminal medical diagnosis. And he was, understandably, not handling it well.

Let me clarify here that I've obviously never been in his shoes, and I held (still hold) so much compassion for his situation. He was living anyone's worst nightmare in having to say goodbye to the people he loves most, sooner than he'd have liked to. So, there's zero judgement, just the experience of being on the receiving end of some of his discomfort — which is putting it mildly. Carers are usually compassionate, empathic people. They care, so they care. And as the closest person to the patient, they usually cop whatever mood, emotion or feeling the person in the hot seat is experiencing. Learning to protect yourself while supporting them is imperative to ensuring that you — as the carer — aren't left with too much residual scar tissue.

But back to the café. I was conveying to my mentor friend that I was a male bee's genitals away from putting us back on a plane — ready to tell Dad he could care for himself if this was how he was going to behave. That sounds callous, and I was no doubt talking a big game I wouldn't have ever followed through on, but it's a good example of how a Next of Kin relationship can be tested during these times, no matter how good and strong a foundation the relationship has.

'But you won't walk away,' she said, gently steering me back to the land of the rational. 'Because on the other side of this experience, when you're packing it away in yourself, you'll know you did absolutely everything you could to make this awful time a tiny bit better for him. You'll regret nothing, and it'll make living with the loss easier.'

These words became my North Star, the ones I said to myself frequently and professed to others when they were grappling with their own role in walking Dad home. They saved me numerous times because they reminded me this wasn't forever, and there *was* something on the other side of this. When I read those words back they make me feel as guilty now as I did thinking them then, because

between me and Dad, only one of us was able to say them. My inner world went to war with itself frequently—how could I look forward to the future when it was a future Dad wouldn't have? It's not that I couldn't live without him—I'd been through enough hard things to know I could, even though I really didn't want to—but looking forward felt like I was being disloyal to his experience.

The truth is, if you're going to dedicate your time to caring for someone else, you have to have something that is reserved only for you. Even if it's just a few words. They'll be your lifeline when you feel like you're drowning—and you will feel like you're drowning, no matter how strong a swimmer you think you are. You will find yourself well and truly outside of the flags, being sucked out to sea by rips and wishing you'd paid more attention to that CPR class you took once. This is the reality of trying desperately to save someone you love, while making sure you don't drown in the process.