

SURVIVING HEALTHCARE IN AUSTRALIA

Get the Support You Need

ANNE CRAWFORD, MPH

Foreword by Felicity Smith OAM

SAMPLE CHAPTER



Surviving Healthcare in Australia: Get the Support You Need

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This book is dedicated to:

My husband and daughter.

I have always wanted to write this book and they are the reason I have been able to. My husband has been my anchor, my partner, friend and mentor. My daughter has been my inspiration for this topic.

My ever-loving parents.

They have always been there for me and supported my development

Foreword

As a population, the health and health experiences of Australians compare well with those of other countries. And our life expectancy at birth remains among the highest in the world.

However, Australia's healthcare system is striving for efficiency. As a result, busy health professionals may tend to treat patient conditions solely on the basis of symptoms and scientific evidence. Unfortunately, this can lead to a reduced consideration of the patient as a person, who may be suffering from more than one condition or have other factors that should be taken into account before settling on a treatment plan.

The Australian health system is often too complicated for patients to navigate on their own. This issue is amplified by an ageing population and the anticipated rise in chronic disease. Therefore, we need to strengthen primary healthcare to better co-ordinate the care of patients and decrease the risk of medical errors that are unacceptable to patients and costly for everyone.

When health professionals, patients, families and carers work in partnership, the quality and safety of healthcare improves, costs decrease, provider satis-

faction increases, and the patient care experience is enhanced.

This book draws on Anne's experience as an industry healthcare professional, as well as being a patient and a carer for a child with a severe disability. It provides a compelling solution to improve a complicated system and is worthy of discussion well into the future. This book will present any reader with great insight into what is missing in the healthcare system.

I have known the author for a many years and am intimately acquainted the challenges she has faced. As Anne has dealt with each of these issues, she has always looked for ways to make things better.

As a mother of three adult sons with their own particular health issues, I too have dealt with my own challenges within the Australian healthcare system. Navigating a system that seems more intent on refusing you help when you most need it has been difficult and disheartening for me.

I commend the dedication of her determination in preparing this book, and highly recommend reading it.

Felicity Smith OAM
Chair, Board of Directors
Link Health & Community

Introduction

Healthcare systems around the world are constantly changing and developing, dependent on costs and demands like any service industry. In Australia, we have a world-class healthcare system, Medicare, that is the envy of most of the developed world. But it is still very confusing and inaccessible.

By profession, I am a nurse and midwife, and I have earned my Master's degree in Public Health. I have also worked in hospitals, aged care homes and in the community alongside general practitioners. I am currently on the board of several community health services. So, I have an intimate knowledge of Australia's healthcare system from a professional perspective.

However, I also have extensive experience with it from a personal standpoint. As a young adult, I cared for my grandmother in her final years, and I now have a daughter with special needs. In addition, a number of years ago, my eyes were injured in an accident and I came to experience how rare it is for our healthcare system to work to its full potential.

This exposure as a medical professional, patient and caregiver has provided me with an intimate

understanding of how our healthcare system is supposed to work.

In writing this book, I am motivated by the following concern: *If I can't negotiate my way around the healthcare system (despite my extensive education, experience and knowledge), how does anyone else do it?*

As you read, you will discover that this book is purposely not academic in nature. In it, I use real case studies to illustrate what can go wrong in healthcare and why.¹ Yet each story ends on a positive note and shares key points you can use to help you manage your own way through the healthcare system in Australia.

My hope is to convey some ideas about how to navigate through the system, as well as to provide an overview of where we have come from and how the system works today. Finally, I will provide some possible solutions to the current inequalities and frustrations that people experience.

While this book is intended for people who are currently going through diagnosis and treatment, or who are supporting a loved one with a health crisis, it is also relevant for lawmakers and policy changers. As world-class as our healthcare system is, there is still room (and need) for improvement.

The current system must begin to provide more well-rounded (or holistic) care for people and to acknowledge patients as the decision makers about their own treatment and ongoing care.

¹ Details and names have been changed to maintain privacy.

This approach requires that healthcare providers share enough appropriate information and guidance for their patients to make informed decisions. However, our current healthcare model works on the premise that the treating provider is the one who knows what is needed for the individual. This book challenges that viewpoint.

Although healthcare providers are starting to talk about partnering with patients, these professionals must understand that patients are not partners—healthcare professionals do not share in the problems these individuals are facing. There is no impact on the life of a healthcare provider when a patient is sick, except that it provides them with a job.

For example, if a patient requires surgery followed by a six-week recovery, the surgeon does not have to cope with the pain or manage home affairs while the patient is recovering. The surgeon performs the surgery and then prescribes the medication he or she believes the patient needs. The surgeon may suggest physiotherapy to ensure the recovery is as efficient as it can be, but it is the patient who is left to deal with the whole picture.

It is time that our healthcare system provides patients with the support they need, not just to recover from an illness, but to secure the best possible outcome physically, mentally, emotionally *and* personally.

Chapter One

The Missing Ingredient in Our Healthcare System

Healthcare in Australia is world-class and we are able to boast about equity and access. While we do have problems with access in our more remote regions, we have a fair system that caters well for most people. So why do people find the healthcare system so inhospitable and frustrating? If they are lucky, they will find support services by chance or word of mouth. But why is the system so confusing and why don't healthcare providers seem to know what is available for the community they support?

In my professional capacity, I am regularly asked how to access support services. Many people in our community do not know what is available to help them manage at home during an illness. There are also many people who don't know what to do when they are sick.

The health service system has become so specialised that there are practitioners who don't really understand how to help people outside their scope of knowledge. But people are not just a medical illness. They are breadwinners, parents, children, siblings,

partners or active members of their community. This means that when they fall ill, they need more than just medicine. They need a whole support system to get back to being themselves.

I have been to meetings of parents with disabled teenagers who did not know anything about support services for their children except for attending a special school. The families had missed out on so much. They were under financial strain that was causing tension in their partnership, and it could have been avoided had they known more about the services available to them.

There are many people in our country who struggle with mental health issues, alcohol and drug addiction, homelessness and social isolation. We are a rich country, but we still have many people who are struggling. And healthcare practitioners have become so specialised that they can miss the whole picture. We have made our healthcare system so complex and inaccessible that people often feel confused and unheard, and think their concerns are not being dealt with.

Australia's healthcare system has developed organically, beginning largely as charity or a service to those who could afford it. If people were sick and poor, they had to rely on charity or their families to act as carers. Many people went bankrupt trying to pay for their healthcare. Now we have a system that is capable of providing so much to the people it supports, if they only knew how to access those services.

When Australia entered the World Wars as part of the Commonwealth, it improved how healthcare was delivered. Most hospitals trained staff as if they were part of the army. It was very regimented, and patients and staff were designated into wards that became specialised in the areas of the body that were being treated.

Medical staff grew proficient in the treatment and care of people's illnesses. Research into healthcare also became specialised. Treatments improved, and hospitals became centres of healthcare excellence.

This evolution explains how gaps in healthcare began to develop—each specialty became adept at managing certain conditions but lost sight of the whole picture. As knowledge and complexity developed, the gaps grew.²

We have a healthcare system that considers itself the 'holder of special knowledge'. Healthcare providers believe they are the experts and should be the ones making decisions about the person they are caring for. However, although healthcare providers do have specialised knowledge, they may not know a person's particular circumstances and may not consider the implications of treatment options on that person's life.

Decisions about treatment should essentially be left up to the individuals themselves. They need to be the ones who make the final decision about whether to go ahead with a treatment that has been offered.

² To learn more about the history of this evolution, read 'Appendix: A Short History of the Australian Healthcare System' page 115.

There are many areas in the healthcare system where people are likely to fall through the gaps. Not having an understanding of the support they require or how to access such support means that people are being left to manage on their own. This puts them at risk of returning to the doctor or the hospital because they did not understand what they were supposed to do or what support they could access for help.

We have new ways to fund the Australian health system that have caused anxiety for both the patient and service providers. For example, the disability sector is transitioning to the National Disability Insurance Scheme (NDIS) and the aged care sector has recently transitioned to a similar scheme called 'My Aged Care'. Although there are many benefits to these changes, it has made an already confusing system even worse for both patients and healthcare professionals alike.

Dental care has never been well-funded by the federal government and is largely supported by state and territory systems. This has led to people simply not being able to access dental care, or having exceedingly long wait times to see a public dentist.

Finally, what happens when a patient goes to a doctor with a health complaint and there is no clear diagnosis? The healthcare professional will often label the person as a 'malingerer'. Thus, a person who complains when the healthcare provider cannot provide an identifiable answer is considered either psychologically impaired, lying or both.

In my experience, it is uncommon for the medical profession to acknowledge that medicine still has a long way to go in identifying many of the different conditions that can affect people. Instead, someone with an undiagnosed illness is often sent away feeling confused and unsupported. They become disillusioned and frustrated after being treated as if they are ‘putting on’ their symptoms, and it often has an impact on their personal relationships and ability to work.

Instead, the healthcare provider needs to consider the limitations of assessments and medical tests, and listen to the person’s concerns. If there is an ongoing health issue, treatment of the symptoms may be the best solution, even if the condition itself cannot be identified. This requires a deep knowledge of the treatment services available. Since the Australian healthcare system is so complex, this can be a challenge for any healthcare provider.

Olive’s journey through pain management.

‘Olive’ (as we shall call her) went to see her general practitioner (GP). She had many medical issues and was often mismanaged since her medical conditions interacted with each other. Olive had developed a good relationship with her GP over many years, and he was aware that Olive’s many conditions interact negatively.

One day, she was in significant pain. She had injured her shoulder and neck through repetitive and significant strain on her left arm

at work. In addition, she felt pins and needles down her arm and had lost strength in her left hand. A scan showed mild herniations in two of the discs in her neck. Not wanting to miss anything, the GP sent her to the hospital for further assessment.

Olive arrived at the hospital with a letter from the GP, and she was quickly assessed by a young emergency doctor. He was also concerned and admitted her to the hospital.

While she was still in the emergency department, Olive had a respiratory allergic reaction. Her symptoms were unusual and looked like a severe asthma attack. (Her allergy symptoms were respiratory in nature, not the usual anaphylactic reaction many people experience.) Her husband, Chris, was with her and he gave her an EpiPen treatment, as he had been taught to do by her GP and allergy specialist. The emergency doctor was not happy that Chris had done this and told him so.

Eventually, Olive was admitted to the ward and was seen by the senior specialist. He ordered a few tests and gave her some pain medication. As is often the case with Olive, nothing appeared in the tests they administered. Olive knew that one of her specialists, a rheumatologist, had visiting rights at the hospital so she requested to see him. He did not come to see her during the admission and Olive was referred on for rehabilitation.

When Olive went to the rehabilitation centre, she was admitted by a doctor who specialised in pain management. This pain specialist never performed a physical examination of Olive, but he still organised her pain medication. During her stay, Olive was largely left to manage herself with little interaction with the medical staff, while the centre only provided her with a small amount of physiotherapy. Given the level of care she received, she likely would have been better off at home.

When she was discharged four weeks later, Olive felt no improvement and was groggy due to the medications she had been prescribed. She decided to see her rheumatologist for a review. The rheumatologist was exasperated because the medications prescribed by the pain specialist worked against Olive's rheumatology regimen.

He was also angry that no one had let him know about her admission. Despite many attempts by Olive and Chris, their messages had never reached him. He told Olive which medications he recommended she take, but decided against changing her prescriptions.

Olive had an appointment with the pain specialist she had seen in the rehabilitation centre for an outpatient review. She told him what the rheumatologist had recommended, and he changed her pain medications accordingly.

The pain specialist wrote a letter to her GP that speculated about the psychological states of Olive and her husband. He assumed a lot, as his assessment wasn't made in coordination with Olive or her husband. He had not performed any physical examinations and had not discussed any of his concerns with her. He inferred her pain was associated with psychological distress, despite the swelling in the area of concern. He suggested that her home life was stressful, and her husband was encouraging her to be unwell. (Olive's husband was understandably concerned about her, but he was not encouraging her in her 'sick role'.) The pain specialist questioned her allergy, because it did not have the usual signs associated with allergies (despite Olive's allergy specialist's assessment and diagnosis). He also doubted her willingness to rehabilitate, as she was so focused on her 'sick role'.

If the pain specialist had discussed any of his concerns or performed a physical examination of Olive, then his appraisal may have had some basis for believability. But he had simply read the notes in her file for this particular episode and taken other health professionals' assessments as adequate. He made no effort to contact her regular medical providers or learn more about her health history.

He was not helpful, and Olive spent four weeks convalescing in a rehabilitation centre

when she could have used that time to heal and regain her physical strength.

On her last day in the hospital, Olive saw an inexperienced social worker and requested some help at home, but nothing was set up for her. Once she was home again, she became busy with her life. The social worker had given her a large bag of pamphlets, but they were too confusing, and Chris worked full-time and could not help her with more paperwork and phone calls.

Olive believed her time in hospital was not at all helpful, and that she had been left to figure out how to get better on her own. At home, she saw three different physiotherapists and continued to take her pain medications, which meant she could not drive. If she had to get to appointments, she had to rely on her family or take a taxi. It took six months for her to regain her strength and start to feel like her old self again.

She also saw her allergy specialist to discuss her allergy treatment, and he wrote a letter for Olive so that, if she went to hospital again, she could give them the letter for consistency of treatment. She did this because the hospital staff had not believed she had an allergy; instead they thought she was hyperventilating rather than having a reaction. Olive's immune system was so compromised, she had unusual signs and symptoms. Her immunologist was

happy with her progress, however, so at least she did not have to receive additional treatment there.

**Misdiagnosis, or a lack of diagnosis,
and the impact it has on the patient.**

Misdiagnosis happens a lot, as does a lack of diagnosis. This has an impact on a person's life and can affect their ability to work.

Olive's case study shows how those of us in the healthcare profession can miss important cues and make inadequate assessments when we use information from other providers. We are all human, and it is sometimes easy to copy others, which shortens the time spent gathering information. Unfortunately, if the information health professionals use is already tainted, the resulting diagnosis may be incorrect.

It is important for the health professional to assess people during their first meeting without relying on information gathered by others. Then if there is an inconsistency between their diagnosis and those of other medical professionals, it can be checked further.

I don't believe that Olive's case is necessarily a unique one, or that her doctors didn't care about what she was going through. But they each viewed her situation through the perspective of their speciality, rather than taking a holistic approach to her care and, in her case, that made her recovery more difficult than it needed to be.

Unfortunately, one of the most significant challenges that the medical profession faces is a lack of

time to make a proper assessment of each individual case they may see. To spend the necessary time with them to get them to articulate their needs and provide the right support can be more than they can afford to give. It's not a matter of being uncaring or insensitive. They have a number of patients they must see, and simply lack suitable resources to take the necessary time.

For the healthcare system to work effectively, we need to ensure that GPs and other healthcare providers can refer their patients to a local community professional who has a deep knowledge of the health and community welfare services available to people, and who is dedicated to the special task of helping individuals navigate these challenging situations, not just physically, but mentally, emotionally and personally as well.

We shall call such a provider a 'healthcare coach' (or 'coach' for short). And while they can't be found in many communities yet, having such an individual available would make healthcare and its related services more accessible to those who need it most.

Right now, Australia has many different referral pathways (healthcare services, IT systems and web-based systems) to help people find services, but negotiating the healthcare system is complicated to those not familiar with it.

There are very experienced nurses who work in general practices or in the community (in other words, the Royal District Nursing Service or 'RDNS'), as well as local social workers and case managers. But

unfortunately, they don't always have the training, experience or funding that allows them to spend the time required to provide the support individuals may need. Not because they don't want to, but because they may be limited by program parameters and, therefore, be unable to spend the time required to support patients until they are ready and able to manage their care on their own again.

Healthcare coaching is a role based on the concept of an executive coach, but for patients dealing with the healthcare system.

Medicare funds GPs, and also practice nurses in some instances, but there is no funding for a healthcare professional (or coach) who is adept at assessing a patient's requirements, and supporting and referring them appropriately. There have been projects periodically to support this process, but nothing to provide these experts with ongoing funding, either within a hospital system or associated with local GPs.

A solution could be to have healthcare coaches who are well-funded and resourced through Medicare working in both hospitals and the community. They could then support and direct people into appropriate individualised services.

These coaches may need to have a higher degree in nursing to be able to explain health conditions and their medications, and must have many years of relevant experience to bring to the role. Today, healthcare professionals suitably trained to act as a coach often end up in other roles, such as health

service management, policy roles, research associates or consultants to people who can afford them.

This is despite the fact that having coaches available would reduce the waste and distress that comes with inappropriate referrals, or having people going in and out of hospital as a result of their condition not being adequately managed.

The problem with evidence-based practice.

Another issue that we, as medical professionals, have to deal with is that medical conditions affect people in different ways. We are trained to rely upon evidence-based research, which is typically conducted with otherwise healthy individuals, so the condition or treatment can be analysed in a regulated way. Gender differences are not considered, nor are cultural differences or people with more than one illness. Thus, although evidence-based medical or health decisions are the gold standard of care, they may not be the best option for a given individual.

Ideally, you should develop a relationship with your primary healthcare provider so they can take other needs and medical concerns into consideration when providing treatment options. The best healthcare professional to have an ongoing relationship with is your local general practitioner.

About the Author

Anne Crawford (RN, RM, MPH, GAICD) has had a lifetime of training when it comes to how the Australian healthcare system works. She is a mother, daughter and granddaughter. She is also a nurse, midwife and public healthcare expert with an in-depth knowledge of the Australian healthcare system.



She has worked for thirty years in healthcare. Initially, as a carer, then as a professional nurse in hospitals, rehabilitation, aged care and finally in the community health setting working closely with GPs and allied health professionals. Anne now sits on the board of a community healthcare centre, private GP and dental practice. She has also set up a new and exciting business, Exploring Healthcare, providing guidance to people navigating their way through health, aged, disability and welfare services.

Anne was a primary carer for her grandmother through the aged care system at the end of her life. She also has a disabled daughter who has led her on a wonderful journey that included her need to access services in the community. Most recently,

Anne sustained a traumatic injury to her eyes that changed her professional trajectory, but also meant numerous hospital visits over the past three years.

As the premier healthcare coach in Australia, she hopes to one day see many more in the healthcare industry embracing the benefits of including a healthcare coach as part of their patient care team.

If you would like to interview Anne about health-care coaching, or to invite her to come speak to your organization, she welcomes such inquiries and can be reached at emeraldlakebooks.com/acrawford.

To read more visit
emeraldlakebooks.com.



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Praise for
Surviving Healthcare in Australia

The Australian Healthcare system has the potential to be world-class but is undermined by complexity, incongruity and a lack of systemic coordination. There is a need for patient-centric, holistic, value healthcare. In *Surviving Healthcare in Australia: Get the Support You Need*, Anne Crawford draws on her own extensive experience to provide insights and valuable tips on how everyday Australians can navigate the healthcare system to access better care and how our system can be improved to fulfil its potential.

Dr. Elizabeth Sigston
MBBS FRACS PhD

Surviving Healthcare in Australia is a 'must read' if you want to know about the support and care options available to you. Patient care doesn't have to be one dimensional, as it sometimes seems!

Rachel Johnson
Founder of HAAA and wSw

Overall, this book is a great introduction to the history and complexity of Australia's healthcare system, while introducing us to a potential solution or mechanism that will make this journey simpler.

Tom Voigt
Senior Policy & Research Officer,
Australian Association of Gerontology (AAG)

Anne Crawford's book demonstrates the need for modern approaches to remove the complexity that exists today in our healthcare system and restore trust back into the community. It highlights the importance for putting patients and their families at the centre of decisions and working alongside healthcare professionals to get the best possible outcome. *Surviving Healthcare in Australia* is a great book.

Paul Montgomery
Chair, MediSecure Limited and Wellways Australia,
Director, Melbourne Primary Care Network