

Foggy, Faint, Fatigued & Adrenaline

It's not in your head!



A manual for managing a malfunctioning body

CHRIS O'CALLAGHAN M.D.

Foggy, faint, fatigued & adrenaline: It's not in your head

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CHRIS O'CALLAGHAN

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Villains and heroes

Every good book has a villain, and this book is no exception. Its villain is low blood pressure.

Like most villains, low blood pressure has aliases. It is also called postural tachycardia syndrome (PoTS), orthostatic intolerance (OI), dysautonomia and neurally mediated hypotension.

People are often surprised to learn that blood pressure can be too low. But low blood pressure is relatively common – especially in young women. Low blood pressure can make you feel light-headed, fuzzy, foggy, faint and fatigued.

Every villain needs a hero. Our hero is a tiny molecule called adrenaline – your body's most powerful hormone.

When blood pressure falls, your body is flooded with adrenaline. This makes your heart pound and blood vessels contract. The result is that your blood pressure returns to normal, and a victim is saved from the clutches of the villain.

However, like every good hero, adrenaline also has a dark side. Adrenaline's dark side relates to the brain. Although low levels of adrenaline sharpen the mind, high levels can make you feel apprehensive. Very high levels make you look and feel anxious. Indeed, a vial of adrenaline can be described as panic-in-a-syringe.

The next twist in the tale is incredible but true: people with low blood pressure are often hypermobile – sometimes known as being double-jointed, or 'stretchy'.

'Stretchiness' is a genetic trait, which explains why these conditions often run in families. But stretchiness is not all bad – it can help you dance, sing, play music and excel at sport. So, just like adrenaline, stretchiness can be a hero, but sometimes it's a villain.

How to use this book

This is not really a book. Rather, it's a manual to help you understand how your body functions, and more importantly, how it can malfunction.

It includes 27 case histories. To see if the information in this manual applies to you, Kate's story (page 2) is a good place to start.

Few manuals are read from cover to cover, so each section in this manual is designed to stand alone. You can find topics of interest by browsing the contents page, checking the index or flicking through the pages.

Each section begins with 'Key Points' that summarise what follows.

Links to additional resources are listed in Further Reading (page 194). The websites of Dysautonomia International (www.dysautonomiainternational.org) and the Ehlers-Danlos Society (www.ehlers-danlos.com) are informative and accessible.

Further Reading also lists other resources that describe the links between inadequate blood pressure, hypermobility, fatigue, migraines, gut problems, crippling menstruation, troubled sleep, asthma, eczema and allergies.

The manual contains numerous stories and quotes from patients I have treated over several decades. Some of my patients might think they recognise themselves in the stories, but I have heard a similar narrative from many patients over the years. In fact, each case history is an amalgam of at least several patients, and each has been carefully modified so that no case history can be linked to a single individual. Any resemblance to actual persons should be considered purely coincidental.

Preface

A friend who immigrated to Australia many years ago once commented that, 'The thing I love about Australia is that you trust each other.' He gave the following example.

In his country of birth, he had never expected public officials to do their job. But in Australia, if his internet service is down and he calls the service provider, he is confident that the person at the other end of the line will genuinely try to help.

Trust is a wonderful thing but you still need to know something about who is providing your service or, in this case, information.

A unique perspective

All doctors learn from their patients. As a specialist, my expertise derives from the patients I have treated over more than 30 years in medical practice.

After graduating in medicine from the University of Melbourne, I trained as a specialist physician and was awarded a sub-specialist qualification in clinical pharmacology by the Royal Australasian College of Physicians. Later, I was awarded a Doctorate in Medicine for my research examining how adrenaline controls blood flow in the body. Then I spent three years in the laboratories of Professor Bryan Williams at the University of Leicester in the United Kingdom, where I studied how adrenaline modifies blood vessel structure by regulating the production of collagen – the microscopic fibre that holds the body together, and which plays a key role in the structure of blood vessels.

Upon returning to Australia, I applied what I had learned in the laboratory to patients who were in need of new treatments. The first of these patients presented with unusual symptoms related to high blood pressure. After caring for them for a while, my boss invited me to run a service using special devices to measure blood pressure over a 24-hour period. Being a dutiful lad, I did as I was told and, since he never told me to stop, I'm still doing it.

Unlike many countries, in Australia Medicare only funded our service if we consulted with the patients. This meant I saw literally thousands of patients who had just undergone this novel form of blood pressure measurement.

In medicine, writing about something new usually requires a particular kind of brilliance – or sheer luck. Thus, rather than representing genius, this manual was borne from being lucky enough to have had a unique clinical experience.

I hope you find it useful.

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30 June 2022

A disclaimer (you should read)

Disclaimers are like exercise – sometimes painful, but good for you.

Do not treat yourself

It's undeniable that some patients are poorly treated by the healthcare system, that some doctors may not understand your condition and that other doctors might think it's all in your head.

Nevertheless, you do need doctors. They manage other problems you might develop. They advise about the virtues and risks of self-treatment strategies (though they cannot stop you from using them). And even though they may not understand your problems, they can still be effective at treating them.

So, please, please, please ... keep seeing your healthcare professionals.

This book does not include all the information

A book of this size cannot include all the available information about a subject. Nor can it present all the theories.

To find further information on a particular topic, refer to the section on Further Reading (page 194).

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Introduction

Kate's story

2

Kate's story explained

4



1 Introduction

Kate's story

Case History No. 1

18 years old and cannot stand up

Kate's medical history is the typical story of a young woman with a moderately severe problem caused by blood pressure. Her story illustrates how:

- Low blood pressure can be difficult to diagnose.
- Problems with blood pressure can fluctuate over time.
- Lack of activity can worsen symptoms.

Kate's constant companion is a feeling of being light-headed, floaty, 'woolly headed', 'foggy brained' ... or something she just could not describe. She feels she might collapse when arising from bed and she struggles to stand for more than 10 minutes. Hot summer days suck the marrow from her bones. She has other issues: migraines, a lack of energy, bouts of excruciating chest pain and food-induced bloating, nausea, pain and diarrhoea.

Dominating Kate's life and tainting her every interaction with health professionals is a feeling of 'anxiety'. She has lived through years of inexplicable heart-pounding, shaking and sweaty fear that have destroyed her social life. Even worse, her favourite pastime of shopping has been reduced to a late-night snatch-and-grab from a small local supermarket.

Kate was like this before – between the ages of 14 and 16. However, her symptoms virtually disappeared after she completed an 11-week personal training program. By the time she started university, Kate thought her health problems were behind her.

But her symptoms returned just as she began studying for her first-year exams. Her family doctor called the first event 'glandular fever'. This time around she has seen more doctors, who have variously diagnosed anxiety, chronic fatigue syndrome and Lyme disease.

Education is the first part of treatment. Kate is relieved to learn that most of her symptoms are caused by a combination of low blood pressure and high adrenaline levels. Even better is knowing that her fainting is related to being 'double-jointed'. This means she can stop worrying about having a psychiatric condition, or a poison or virus lurking within her.

Relief rapidly transforms into questions. Kate begins by asking, 'So what do I have? Does it have a name?'

I sigh, anticipating an imperfect answer. 'The diagnosis is confusing. Some doctors call it postural tachycardia syndrome – or PoTS.'

She nods. 'Yeah, that's what the GP said.'

'But others call it orthostatic intolerance or OI', I say. 'I compromise and call it PoTS/OI.'

She nods enthusiastically.

'But hold on, it gets worse. Sometimes it's called dysautonomia and it might even be called "inappropriate sinus tachycardia syndrome".'

The nodding stops.

'Look,' I say, 'it doesn't matter what doctors call it. The problem is that you have a problem with your blood pressure.'

'Why did it come back?' Kate asks.

I explain that some people are genetically predisposed to developing a problem with blood pressure. Their symptoms can be unmasked by almost anything – from a viral infection to a psychological illness. In Kate's case, it appears that her symptoms were brought out by having forsaken physical activity for her studies.

'Oh my God, it all makes sense!' Kate exclaims. 'I didn't tell you but my dizziness didn't begin again until after an operation on my bum. I had to spend two weeks lying on my belly. Oh, and also, I had pneumonia just after that. It's been downhill ever since.'

Kate's next question is more sombre. 'Will I ever get better?'

I point to her family experience as a guide to the future. Both her sister and mother had longstanding problems with blood pressure and fainting. But their symptoms had improved dramatically by the time they were 25.

I go over it once more. ‘Kate, you do not have a toxin, a virus, a poison or a psychiatric condition. This is a physical and genetic problem. You were born with it, and you’ll die with it.’

I add, ‘But, as you have seen, your symptoms are dependent on your activity levels. So we’ve got to get you moving again.’

She looks wounded. ‘But I’ve tried exercise – I just can’t do it, and I think it’s making me worse.’

I should have remembered that Kate has been living with this condition for a long time. She has already tried everything to get herself going.

I grovel. ‘Sorry, Kate. I should have been clearer. Exercise and activity are great therapies, but I know you aren’t ready for them yet. The first step is to make you feel better. We’ll begin with baby steps.’

The consultation continues with me telling Kate how exercise and blood pressure interact. ‘Falling sick means people become less active and they stop exercising. This means your muscles lose their condition. The same applies to your blood pressure system. As your blood pressure system deconditions, you start to have symptoms of low blood pressure. Exercise therapy aims to reverse the process. The studies are very clear. Exercise therapy works reasonably well for some people.’

I don’t want to give false hope. ‘But there is also a truth about exercise you need to know. It doesn’t help everybody, and many people need to try other therapies before they are ready for exercise. I’m not making promises. But this is the best way forward.’

Kate’s story explained

Kate’s diagnosis

Kate’s problem is low blood pressure – sometimes called PoTS, OI, dysautonomia, neurally mediated hypotension or syncope. To keep it simple, in this manual I refer to it as ‘PoTS/OI’.

Why so many names? There are many reasons, but the simplest explanation relates to how medical research is performed. Individual research groups tend to work in isolation around the world. Any time a group discovers something new, they are obliged to name it. If different research groups are simultaneously investigating the same problem, it’s pretty easy to end up with a list of names that is longer than a sleepless night.

Is Kate anxious?

Kate thinks she has anxiety but she is probably wrong. The reason for Kate's incorrect self-diagnosis relates to adrenaline – the emergency hormone.

Surges of adrenaline make you shake and sweat. Your heart pounds and your brain feels like it might explode with activity. It's reasonable to mistake an adrenaline surge for a panic attack. And that might make you think your problem is anxiety.

But other factors can elevate adrenaline. In Kate's case, it is inadequate blood pressure. The flaw in Kate's diagnostic process is a failure to identify a problem with her blood pressure. But we forgive her for that – low blood pressure is easily missed.

As Kate learns about blood pressure, she begins to understand why she has 'panic attacks' at shopping centres, in crowds, in social situations or when riding lifts or escalators. These are situations where gravity has a chance to make blood pressure drop. And that can send Kate's adrenaline levels through the roof.

Why now?

Kate's story illustrates the classical timing for the onset of symptoms of low blood pressure, which include:

1. Just before or during adolescence.
2. Following lifestyle changes (e.g. stopping sport to concentrate on study).
3. After relatively minor events or illnesses that restrict your activity and make you lose your fitness (e.g. a viral illness, surgery or trauma).

But these are not the only times that low blood pressure can develop. It can occur at any time of life, and often without warning.

Why does Kate have PoTS/OI?

Kate's hypermobile joints provide a clue to understanding her low blood pressure. In brief, scientists think that people with 'stretchy' joints also have 'stretchy' blood vessels.

The link with joint hypermobility may explain why low blood pressure is seen in certain occupations. Many dancers, gymnasts, yogis and elite athletes are gifted with flexibility. But they may pay a price for this, by flopping, falling or fainting when the temperature exceeds 25° Celsius.

Oddly enough, studies show musicians may also have hypermobile joints. Are singers also hypermobile? Maybe. Artists might also be in this list.

Put another way, hypermobility is a gift that comes with a price.

Why is Kate hypermobile?

Joint mobility is genetically determined, so low blood pressure is often a family trait. Kate's mum was a semi-pro ballet dancer, and although Kate's sister is not hypermobile, she had inguinal hernias repaired when she was two, and she thinks she is developing varicose veins. Both mother and sister are regular fainters and both despise hot weather.

There is another genetic factor at play. Sadly for half of the population, low blood pressure affects women more than men.

Blood pressure, joints ... anything else?

Low blood pressure and joint hypermobility do not usually exist alone. Kate's other problems are intermittent gut complaints and a long history of difficulty with sleep. She has recently become debilitated by fatigue and her menstruation has always been more problematic than her peers. Other issues that can occur include asthma, eczema, allergies and migraines. These are not on Kate's list of complaints, but that is not to say they won't occur in the future.

How low blood pressure is fixed

Kate's big question is, 'Will I ever get better?' There are three common scenarios.

Scenario 1: Kate recovers spontaneously. This is the most common scenario. In this version, Kate might have become sick after a virus sent her to bed for a fortnight. For the next month she was sluggish and faint, even though the infection had resolved. But she slowly improved. Soon after, the improvement accelerated and it wasn't long before she returned to her usual activities. Healing was complete within a few months. Patients like this often do not come to medical attention.

Scenario 2: Kate needs help. Frustrated and a little bit scared, in this scenario Kate has tried everything. Several times she has improved but something always happens and she ends up where she started. She eventually concludes that nothing can help, not even exercise.

For many months, Kate remains stuck. Salvation arrives in the form of a clinician who recognises her problem. Education, medication and an exercise program help to control her symptoms. She is not cured but she is well enough to progressively increase her activity and re-engage with her old life.

Scenario 3: Kate is chronically ill. Thankfully, a prolonged illness is the least common scenario. Despite genuine effort and the use of miscellaneous medicines, herbs and other remedies, Kate cannot find a way to improve.

Time will be her salvation. Ageing is almost always associated with improved symptoms. However, until she grows older, Kate will need support to minimise symptoms and to help her cope with a disease that no one deserves.

Low blood pressure (PoTS/OI)

Blood pressure can be too low

9

How blood circulates

16



Low blood pressure (PoTS/OI)

Case History No. 2 Maria and her family

Maria's story illustrates the familial nature of a relatively mild case of inadequate blood pressure.

Maria (16) has 'low blood pressure'. She shares this trait with Connie, her mother. Doctors have told them their low blood pressure is 'very healthy'.

Connie has never had symptoms. In contrast, Maria 'always' loses patches of vision when she arises rapidly from bed. She struggles to stay upright during prolonged standing, such as school assembly. Maria does not feel faint – rather, she knows she must sit down or she will not be standing for much longer. She sometimes feels breathless from climbing a flight of stairs or even just standing and chatting.

Maria has experienced this problem for as long as she can remember, but it has only affected her lifestyle over the past few months. First, she fainted in the shower and fractured her wrist during the fall. Soon after she was forced to quit her part-time job on the checkout at the local supermarket – it was making her 'sick'. Now she works as a waiter on Friday and Saturday nights. Oddly, Maria says she feels fine when busy waiting on tables, but her symptoms return when she suffers the boredom of standing at the register. So, if the symptoms disappear when she is distracted, it must all be in her head ... mustn't it?

Maria's other major problem is concentration. She struggles at school, particularly in afternoon classes, and she drives her mother crazy by refusing to use her desktop computer. Instead, she uses her father's laptop while she is lying in bed.

Maria's grandmother also faints, but according to her that is 'because of high blood pressure'. Her grandmother is always complaining about having to take pills for high blood pressure – too many make her feel sick. At least she keeps something to herself – she hasn't told anyone that she has to get up four times every night to pass urine (the reason for that is discussed on pages 35 and 136).

Blood pressure can be too low

KEY POINTS

- Blood pressure can be too low.
 - When blood pressure is too low, you may be diagnosed with PoTS, orthostatic intolerance, dysautonomia or neurally mediated hypotension.
 - Low blood pressure can be mistakenly diagnosed as anxiety.
-

'I've always had low blood pressure, but the doctor has always said that's a good thing.'

Most people have heard of high blood pressure and its irredeemable though well-earned reputation. There is a clear relationship between high blood pressure and serious cardiovascular diseases such as stroke and heart attack. Put another way, the higher your blood pressure, the shorter your life expectancy.

At the other end of the spectrum is low blood pressure – which is often diagnosed as PoTS, orthostatic intolerance, dysautonomia or neurally mediated hypotension. Many people are unaware that their blood pressure can be too low. Even if they know of low blood pressure, it is usually regarded as a good thing. Again, this reputation is deserved. On average, people with low blood pressure live longer than the rest of us.

This does not mean that low blood pressure cannot cause trouble. Indeed, low blood pressure causes more symptoms than high pressure. A simple example of low blood pressure making itself known might be a 16-year-old collapsing at school assembly.

Fainting makes it easy for doctors to diagnose low blood pressure. But low blood pressure is not always simple. Sometimes it causes symptoms that are so vague that doctors struggle to make a diagnosis. Even worse is that low blood pressure produces symptoms that are similar to anxiety – meaning you might end up with a completely wrong diagnosis.

What defines low blood pressure?

KEY POINTS

- Low blood pressure is not defined by a number.
- Think of low blood pressure as pressure that is low enough to produce symptoms.

‘Probably the best diagnosis I can give you is low blood pressure.’

‘You mean ... Like, how do you know that? Is it low on the machine?’

‘Yes. Well, at least to some extent. Sorry, this is a bit confusing. But low blood pressure isn’t really diagnosed from the measurement. Rather, I know that’s the problem from what you’ve told me.’

Understanding the meaning of ‘low blood pressure’ is easy but a precise definition can be elusive.

Contrary to common sense, low blood pressure cannot be diagnosed by a single level of blood pressure. For example, 120/60 mm Hg can be incapacitating for some older folk, but this is a higher value than many 16-year-old females ever experience.

A more confusing example is when an older person has a disease of the blood pressure control systems. When lying down, their blood pressure could be 180/80 mm Hg. But within 60 seconds of standing, the pressure might plunge to 90/50 mm Hg. Thus, low and high blood pressure can exist almost simultaneously. Such a massive postural fall in blood pressure creates an enormous risk of fainting.

Rather than defining low blood pressure by a number, think of it as a pressure that is low enough to produce symptoms in a given individual.

What does 120/70 mm Hg mean?

Each heartbeat forces about one-quarter of a cup (60 mL) of blood into the circulation. This extra volume increases the pressure in the arteries and veins.

The unit of measurement for blood pressure is millimetres of mercury (mm Hg). Imagine a heartbeat that shoots the pressure to 120 mm Hg. The pressure falls before the next heartbeat – perhaps to 70 mm Hg. The following heartbeat drives the pressure back to 120 mm Hg, and so the cycle continues. In this situation, the blood pressure is recorded as 120/70 mm Hg.

Typically, blood pressure is considered ‘high’ if the first figure (the ‘systolic’ pressure) consistently exceeds 140 mm Hg, or the second figure (the ‘diastolic’ pressure) is more than 90 mm Hg.

Low blood pressure is more difficult to define but a systolic pressure of less than 100 mm Hg is considered pretty low for most people.