

TEARS

While I was convinced the woman was afflicted not by a bodily disease, but rather that some emotional trouble grieved her, it happened at that very moment I was examining her, this was confirmed. Someone coming from the theatre mentioned he had seen Pylades dancing. Indeed, at that instant, her expression and colour of her face was greatly altered. Attentive, my hand laid on the woman's wrist and I observed her pulse was irregular, suddenly, violently agitated, which points to a troubled mind.

Galen, *c.* AD 150

I qualified as a doctor in 1991. For fledgling doctors their first great dilemma comes when they are asked to choose their specialty. Some parts of the decision are easy. You either want to operate on people or you don't. You can react quickly in an emergency or you can't. Some want to be a scientist in a laboratory. Others would prefer to spend their time with patients. Medicine has room for every type of person. It is sometimes harder to make the more refined career decisions that follow. You know that you want to be a surgeon, but which bit do you want to operate on? Are you fascinated by the heart, where a single missed beat can put life in immediate

peril? Or do you want to experience the highs and lows of the fight against cancer cells?

Despite all the possibilities, I knew from an early stage in my training what my decision would be. I wanted to be a neurologist. When I made that choice I thought I knew what it meant and where it would take me. I wanted to emulate the people I had learned from, the individuals who had inspired me. I enjoyed the detective drama of the job, unravelling the mysteries of how the nervous system communicates its messages, and learning all the things that can go wrong. Imagine a man who cannot move his right leg and cannot feel his left leg – where's the lesion? What's the disease? Or a woman who is otherwise well but finds she can't write and can't identify her fingers. Ask her to say which is the index finger and she will not get it right. What part of the brain, when damaged, causes that? Neurological disease manifests in elusive and strange ways. There is a sort of epileptic seizure that is triggered by brushing your teeth. There are strange temporary paralytic disorders that strike after eating salty food.

I started my first training post in neurology in 1995, expecting to look after people who had diseases of the brain and nerves and muscles; conditions like multiple sclerosis, stroke, migraine and epilepsy. I could not have predicted how far I would find myself drawn into the care of those whose illness originated not in the body, but in the mind.

Examples of how the mind affects the body are everywhere. Some are so commonplace that they are not regarded as anything out of the ordinary. Tears are only salt water produced by ducts in the eye. They are a physiological response to a feeling. I cry

if I feel sad, but happiness can have exactly the same effect. Sometimes tears are triggered by a memory or a piece of music or a painting. They occur in response to anger or laughter. The instantaneousness of it all has always amazed me.

The body has a multitude of ways through which it can express emotion. Blushing occurs when the blood vessels of the head and neck dilate and become infused with blood. It is an instantaneous physical change seen on the surface but reflecting a feeling of embarrassment or happiness that is held inside. When it happens I can't control it. That point is important. My blushes betray a feeling and, even when they increase my embarrassment, I cannot stop them.

Sometimes the body's reactions are more dramatic than a brief blush or the odd tear. Even quite exaggerated bodily responses to emotion are easy to accept if the circumstances are right. In the early nineteenth century in *Naples and Florence: A journey from Milan to Reggio* the French novelist Stendhal described how he felt when he first encountered the great frescoes of Florence. 'I was seized with a fierce palpitation of heart, the wellspring of life was dried up within me, and I walked with a constant fear of falling to the ground.' Perhaps what Stendhal described seems extreme to some of us, but to others it may seem absolutely obvious that, on the day one first encounters the frescoes of Giotto, one's legs will weaken and one's heart will miss a beat.

There are many modern examples of the tendency to collapse in response to excitement. Think of young people fainting at pop concerts, for example. Of course, many such collapses are easily explained by the physiology of the body. A young girl is

overcrowded in intense heat, her blood vessels dilate to cool her, venous pooling draws her circulation downwards away from her head and, for just a moment, her brain is deprived of oxygen, she collapses and consciousness is lost. She has fainted due to nothing more than the body's physical response to a physical trigger.

And yet when scientists examined just this phenomenon, they demonstrated that not every swooning, swaying teenager could be accounted for in this way. In 1995 the *New England Journal of Medicine* published an article in which young people who had collapsed at a music concert were interviewed. Of the 400 brought to medical attention, forty were examined. Sixteen of those forty lost consciousness in a faint that was felt to be entirely explained by physical triggers – heat and dehydration leading to falling blood pressure, circulation drawn away from the brain and subsequent collapse. Others had panicked when they found themselves trapped in a crowd, leading to hyperventilation that constricted the blood vessels going to the brain and, again, a brief blackout followed. But the doctors also observed that not every collapse could be attributed to heat or dehydration or the crush of the crowd; some had occurred in the context of only one trigger: an overwhelming surge of emotion. An emotional collapse, with no physical cause to account for it.

Most of us readily accept these common phenomena. We are familiar with the shake in our hand as we pick up the pen to sign the marriage register or the bead of sweat on our brow as we stand up to give the presentation we do not want to give. These are the body's physiological responses to stress. They serve

a purpose even if that purpose is not always obvious. They belong to the impulse that made the caveman's heart beat faster so that he could run away from the woolly mammoth. But what if this type of normal physical response to emotion ceases to work properly? After all, every function of our body that supports us can malfunction. Any cell that is alive can overgrow so that tumours form. Or they can stop growing, as with hair loss, for example. Any chemical that is produced can be overproduced, or underproduced, as happens in the overactive or underactive thyroid gland. In just the same way, sometimes the physical response of our organs to stress goes too far. When that happens, something that was normal is no longer so and illness occurs.

The word psychosomatic refers to physical symptoms that occur for psychological reasons. Tears and blushing are examples of this, but they are normal responses that do not represent illness. It is only when psychosomatic symptoms go beyond the ordinary and impair our ability to function or endanger our health that illness results. Modern society likes the idea that we can think ourselves better. When we are unwell, we tell ourselves that if we adopt a positive mental attitude, we will have a better chance of recovery. I am sure that is correct. But society has not fully woken up to the frequency with which people do the opposite – unconsciously think themselves ill. Certainly, there are several medical disorders that are already commonly associated with stress. Most of us know that stress puts our blood pressure up and makes us more vulnerable to stomach ulcers. But how many are aware of the frequency with which our emotions can produce serious disability where no physical disease of any sort exists to explain it?

Psychosomatic disorders are conditions in which a person suffers from significant physical symptoms – causing real distress and disability – out of proportion to that which can be explained by medical tests or physical examination. They are medical disorders like no others. They obey no rules. They can affect any part of the body. In one person they might cause pain. Think of the child who gets a pain in the stomach when they are being bullied at school. In someone else they might affect the heart. It is not unusual for somebody going through a period of stress to be troubled by palpitations. These sorts of symptoms are quite common but psychosomatic illness can also manifest in more extreme ways: as paralysis or convulsions or almost any sort of disability. They are disorders of the imagination restricted only by the limits of the imagination. Think now of any physical symptom and, at some time, in some person, the mind has reproduced it.

On any average day perhaps as many as a third of people who go to see their general practitioner have symptoms that are deemed medically unexplained. Of course, a medically unexplained symptom is not necessarily psychosomatic. Some of these people have transient illnesses that do not reveal themselves in common investigations. Lots of viral infections, for example, do not show up on routine tests. They come, they go, we never know exactly what they were but, once we feel better, the exact cause doesn't really matter. Other people are clearly unwell and this is demonstrated through abnormal results of physical examinations or abnormalities on tests, but still the cause is not determined. There will always be diseases that stretch the limits of scientific knowledge. Every year scientists discover the cause

for previously unexplained medical complaints, so some will get their diagnosis in time. But amongst those with unequivocal, but undiagnosed, physical symptoms is a large group in whom no disease is found because there is no disease to find. In those people the medically unexplained symptoms are present, wholly or partially, for psychological or behavioural reasons.

Psychosomatic illness is a worldwide phenomenon with little regard for any culture or system of health care. In 1997 the World Health Organization carried out a collaborative study to look at the frequency of psychosomatic symptoms in the primary care setting in fifteen cities across the world. Included were cities in the USA, Nigeria, Germany, Chile, Japan, Italy, Brazil and India. At each centre the frequency of 'medically unexplained symptoms' (i.e. where a psychosomatic cause is suspected) were quantified. The study showed that while the severest form of psychosomatic disorders are rare, the milder forms are not. The conclusion was that as many as twenty per cent of those attending their doctor had at least six medically unexplained symptoms, a sufficient number to significantly impair their quality of life. Interestingly, in this study, rates of medically unexplained symptoms were similar in both developing and developed countries. Differences in availability of health care did not affect the prevalence of the disorder. Sufferers in every country were high utilisers of medical services and had a high rate of disability resulting in lost work hours.

Disorders that are this common – that occur in twenty per cent of patients worldwide – must have a financial impact on the health service. This is very difficult to quantify. Those who have tried to do so have come up with some quite startling

figures. In 2005 a study carried out in Boston revealed that people with a tendency to develop psychosomatic complaints cost the health care system twice as much as those who do not. These results were extrapolated to estimate the yearly cost of psychosomatic disorders in the USA – \$256 billion. To put this into perspective, in 2002 diabetes, a common disease with multiple life-threatening complications, had a yearly cost of \$132 billion.

Psychosomatic disorders are not neurological disorders. They belong to the fields of psychology and psychiatry. I am not a psychiatrist, I am a neurologist. At first my interest in, and exposure to, psychosomatic disorders may seem to make little sense. Until, that is, you realise that it is precisely because I am not a psychiatrist that I have come to see so many patients who suffer in this way. After all, if you collapsed or suffered a severe headache why would you ask a psychiatrist for help? Psychosomatic disorders are physical symptoms that mask emotional distress. The very nature of the physical presentation of the symptoms hides the distress at its root, so it is natural that those affected will automatically seek a medical disease to explain their suffering. They turn to medical doctors, not to psychiatrists, to provide a diagnosis. Those with abdominal pain see a gastroenterologist, those with palpitations a cardiologist, those with visual blurring an ophthalmologist, and so on. And because every type of specialist sees a different form of psychosomatic illness, and labels and treats it differently, it can be very difficult to fully appreciate the extent of the problem.

The two most common psychosomatic symptoms are fatigue

and pain. They are difficult symptoms to assess because they cannot be objectively measured, they can only be described. Psychosomatic illness for a neurologist, however, will often manifest as a loss of function, such as paralysis or hearing loss. These sorts of deficits are subjectively experienced by the patient but there are ways in which they can be objectively verified and quantified, at least in part. The neurologist can fairly reliably differentiate disability due to organic physical disease from that which has a psychological cause. As a result the neurologist is faced with a diagnosis of psychosomatic illness more often than other specialists, and that is how my interest arose.

Up to one-third of people seen in an average general neurology clinic have neurological symptoms that cannot be explained and, in those people, an emotional cause is often suspected. It is very difficult for a patient to be given the news that their physical illness may have a psychological cause. It is a difficult diagnosis to understand, let alone accept. And doctors can be reluctant to offer it up, partly for fear of angering their patients but also for fear of what they might have missed. Patients often find themselves trapped in a zone between the worlds of medicine and psychiatry, with neither community taking full responsibility. Those who struggle with the diagnosis may seek the opinion of doctor after doctor in the hope of finding a different explanation – and validation of their suffering. Repeatedly normal test results begin to seem a disappointment, so desperate is the patients' search for another answer. Some find themselves pushed into a corner where they accept the role of the undiagnosed, someone who cannot be helped, because anything is better than

the humiliation of a psychological disorder. Society is judgemental about psychological illness and patients know that.

When my medical career began my own views on psychosomatic illness were little different. Compared to *real* illness these patients did not make the grade. My interest grew slowly, at first through gradual exposure and later more quickly when I found myself thrown in at the deep end in a new job.

Like most doctors my first experience of psychosomatic illness came when I was a medical student. When you meet the first patient who is physically ill, but with no disease to explain it, you dismiss them. You are there to learn about disease and they have nothing to teach you about that. Then you qualify and become a junior doctor and you act as a sort of triaging service. You are often on the front line, trying to make a diagnosis and then presenting it to your senior doctor for their approval. You prioritise the patient you view as the sickest. The person in the waiting room with chronic unexplained pain finds themselves at the bottom of your list. If nobody else has been able to explain the pain it is unlikely that you will. You grade illness not by how distressing the patient finds it, but by your own ideas about what constitutes a serious illness. On this matter doctor and patient do not always agree.

Once I had started my training in neurology my relationship with psychosomatic disorders began to grow. I became increasingly aware that a large number of people coming through the door of our clinic had symptoms that were more likely to be related to stress than any brain or nerve disease but I, like so many of my colleagues, saw my role as one of ruling out neurological disease.

After I had done so I absolved myself of further responsibility. The rotating nature of training jobs meant that I might see a patient once and never again, so it was an easy stance to take. *Good news, we have not found a brain tumour, your headache does not have a serious cause.* And goodbye.

Then I met Brenda. She was unconscious that first time and for most of our meetings that followed. Brenda had come to the casualty department following several seizures. The on-call doctor had seen her and arranged for her to be admitted. We were on the ward when she arrived. Everybody stood back in fright as a trolley came speeding up the corridor towards us. Brenda had been stable in the casualty department but, as the porter transported her to the ward, her next seizure had started. The porter and the nurse who was with him had broken into a run. On the ward an oxygen mask was quickly clamped to Brenda's face, while two nurses attempted, and failed, to roll her on to her side. The trolley had come to a stop by the nurses' station and all the other patients and their families strained to see what was going on. A nurse appeared with a syringe filled with diazepam and handed it to me to give to Brenda. I tried to catch Brenda's flailing arm but it kept slipping from my grasp.

Another doctor came to help and we managed to pin down the arm even as it fought against us. I slowly administered the injection. We stood back and waited for it to take effect, but nothing happened. I could feel the heat of all those eyes on my back and it was a great relief when the registrar shouted for the anaesthetist to be called. Brenda had been convulsing on and off for ten minutes by the time the intensive care team

arrived; the only drug that could be given safely on the ward had been given twice and failed. The whole ward breathed a sigh as we watched the porter and anaesthetist turn Brenda's trolley around and wheel her quickly away again.

I barely recognised Brenda when I saw her the next day. She was in the intensive care unit, intubated, her breathing under the control of a ventilator. A second tube threaded itself through her nose down into her stomach. Her eyes were closed with tape and her hair was pulled back tightly. Her seizures had not come under control so she had been put into a medically induced coma. Every time the intensive care doctor tried to withdraw the sedation and wake Brenda the seizures immediately started again. Over the next two days epilepsy drugs were given at escalating doses. In those two days Brenda became increasingly unrecognisable. Her skin became waxy and pale, her stomach dramatically distended, but her seizures were not improving.

On the fifth day we all stood around Brenda's bed watching her. The neurology consultant had asked to be present the next time the sedation was being withdrawn. It took only ten minutes for the first signs of Brenda's waking to show. She coughed against the breathing tube and her hands began to clutch at anything within reach.

'Brenda, how are you feeling? You are in the hospital but everything is okay,' the nurse squeezed Brenda's hand.

Brenda's eyes flickered open and she pulled at the breathing tube again.

'Can we take it out?' the nurse asked, but the intensive care doctor said not quite yet.

Brenda stared into the eyes of the nurse, recognising immediately

the kindest person in the room. She coughed and tears began to run down her face.

‘You’ve had a seizure but you are perfectly fine now.’

Brenda’s left leg was beginning to shake.

‘The seizure is starting again. Should we re-sedate?’ someone asked.

‘No,’ the consultant answered.

By now the shaking had spread to the other leg and had become more violent. Brenda’s eyes, which had been open and alert, were slowly closing again. As the shaking moved up through her body the machine that measured her falling oxygen levels began to beep behind her.

‘Now?’ a tense voice asked, syringe filled and held in preparation.

‘It’s not a seizure,’ the consultant said.

Glances were exchanged.

‘Take out the ET tube,’ the consultant, again.

‘Her oxygen saturation has dropped.’

‘Yes, because her breath is held. She’ll breathe again in a moment.’

Brenda’s face reddened, back arched and limbs shook violently. We all stood around the bed, our breath held too, in sympathy.

‘It’s not an epileptic seizure, it’s a pseudoseizure,’ the consultant said and, as she said it, to our immense relief, Brenda took a large gasping breath.

Half an hour later Brenda was awake and sitting up in bed, with large tears coursing down her cheeks. That was the last time I saw her and the only time I ever saw her fully awake. Brenda and I never spoke.

Later that day when I was back in the hospital coffee room with the other junior doctors I told them about Brenda. 'You know that woman who has been anaesthetised in intensive care for most of the week? She doesn't have epilepsy, after all. There was nothing even wrong with her!'

It would be several years before I fully realised the danger that Brenda had faced. It would take longer still for me to really understand the disservice I had done her with my words. During my subsequent training I did become more understanding of psychosomatic disorders. But I would need to complete my training to mature as a doctor.

In 2004 I was appointed to my first consultant post and with this came the greatest change in my medical practice. As a senior registrar I thought I had known responsibility, but when the final decisions became mine alone I saw that I hadn't really. The weight of decision-making is very different when there is nobody above you to say what you did was right or wrong. Only the patient getting better or worse will tell you that.

The specific job I had chosen helped too, even though, at first, I did not fully know what I had taken on. I was trained in two specialities, neurology and clinical neurophysiology. Neurology qualified me to care for patients with diseases of the nervous system, and clinical neurophysiology taught me how to carry out specialist investigations on the nerves and brain. My first consultant post straddled those two areas and saw me running a service whose main purpose was to investigate people with epilepsy who were not getting better with standard treatment. It transpired that approximately seventy per cent of the people referred to me

with poorly controlled seizures were not responding to epilepsy treatment because they did not have epilepsy. Their seizures were occurring for purely psychological reasons.

Suddenly I was seeing a greater number of patients whose illness could be more fairly classed as psychological than neurological. And each person I encountered had a story to tell, and too often that story was one of a journey through the hospital system that led them to no satisfactory understanding of what was wrong. Few received treatment and few recovered. I witnessed suffering that had lasted for years, and it was clear to me that it would no longer be acceptable for me to tell my patients which diseases had been ruled out and to consider that my job was done. If I was ever going to make anybody better I would have to start being more proactive. For the first time I saw clearly the seriousness of this disorder, how people struggled to recover – and how they rarely did.

Since those early days I have met many people whose sadness is so overwhelming that they cannot bear to feel it. In its place they develop physical disabilities. Against all logic, people's subconscious selves choose to be crippled by convulsions or wheelchair-bound rather than experience the anguish that exists inside them. I have learned a great deal through working with people who battle on despite the hardship and judgement that the world throws at them. I have found myself astounded by the degree of disability that can arise as a result of psychosomatic illness. In the beginning I sometimes fought against feelings of suspicion towards my patients, questions about their insight and their motives. So dramatic were some of the disabilities that it was not always easy to hold on to a belief in their

subconscious nature. I have shared my patients' struggle to accept the power of the mind over the body. I have felt their frustration at how the system fails them and their anger at how they are perceived. In this book I will tell the stories of some of the brave people I have encountered. I have been very careful to protect the identity of my patients. All names and personal details have been changed completely, without altering the vital components of the stories. I hope to communicate to others what my patients have taught me. Perhaps then, future patients – people like you and me, our friends, families and colleagues – will not find themselves so bewildered and alone.

Before I begin, I need to clarify some terminology. So far, for simplicity I have used the term *psychosomatic* to refer to any physical symptom which cannot be explained by a disease and is suspected to have a psychological cause. But to say somebody has a psychosomatic disorder is not a distinct diagnosis, it is an umbrella term that encompasses several different diagnoses. That is also the case for the term *medically unexplained symptoms* – this is shorthand that the medical community uses to refer to symptoms that are thought to be stress-related and which cannot be accounted for by any physical disease. I will continue to use the terms psychosomatic and medically unexplained symptoms in this umbrella sense throughout the book. I will also use the term *psychogenic* when I am referring to symptoms where there is a strong conviction that they have arisen in the mind, as a result of stress or psychological upset.

However, the terms psychosomatic and psychogenic will not always be appropriate. These labels make assumptions. Each

contains the prefix *psycho* which presupposes that a symptom arises in the mind, usually through emotional or mental distress. For some patients, particularly those who are wholly unaware of a psychological trigger, these terms are both alienating and potentially incorrect. In their place I will sometimes use the term *functional*. This is a purely descriptive term that implies that a symptom is medically unexplained but which makes no judgement about any particular cause.

To further clarify the difference in these labels, imagine a woman who suffers a serious sexual assault and soon after develops unexplained paralysis of her legs. In light of the known trauma, once medical disease has been ruled out, the paralysis could reasonably be described as either psychosomatic or psychogenic. On the other hand if a woman develops medically unexplained paralysis where there was no known preceding trauma, her paralysis would be better referred to as functional in the first instance. This term says that her neurological system is not functioning as it should, that no disease has been found, but it does not presume to know why. Many doctors use these labels almost interchangeably, but to the patient the distinction means a lot.

The *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) is the bible by which psychiatrists diagnose psychological and psychiatric illness and in it the term *psychosomatic disorder* does not appear. The conditions I describe in this book now more accurately fall into the *DSM* classification of *somatic symptom and related disorders*. Within that category there are several subclassifications. Each of those are designed to help the doctor make a diagnosis, but they are labels that cannot be

offered easily to a patient. Included under this heading the *DSM* describes the following distinct conditions: somatic symptom disorder, conversion disorder, psychological factors affecting medical conditions, and unspecified somatic disorder.

A *somatic symptom disorder* is defined by the prominent presence of somatic (bodily) symptoms that cause significant distress and disruption to normal life for which there is no, or little, medical explanation. Pain is the most prominent symptom. It can be accompanied by almost any other sort of symptom, tiredness or diarrhoea or pretty much anything. The behaviour surrounding the symptom is key, not the symptom itself. There is disproportionate worry, anxiety and excessive energy spent on health concerns. It isn't enough just to have pain, what's important is how the person is disabled by that pain. They may stop exercising first. When the pain continues they stop working. Then they begin to avoid the normal activities of daily life.

There is an important distinction to be made here between the terms *somatisation* and *somatic symptom disorder*. Somatisation refers to the tendency of a person to have physical symptoms in response to stress or emotions. So, for example, if I get a headache when I am under pressure then I might be said to be *somatising* or to be a *somatiser*. But somatisation does not necessarily lead to a somatic symptom disorder. To somatise is a common, almost normal, feature of life. It is a basic mechanism through which the body demonstrates mental distress. If the symptoms are transient and not excessively disabling then they do not indicate illness and do not constitute a somatic symptom disorder. Only when they are chronic and disabling can this diagnosis be made.

A somatic symptom disorder is a rare and devastating medical problem which represents one extreme of a spectrum of diagnoses. It describes the person who is chronically severely disabled with multiple symptoms and has little chance of recovery. At the other end of the spectrum are the *unspecified and brief somatic disorders* that dip in and out of a person's life, wreaking havoc for shorter periods and to a lesser degree. Illness of this sort is common. An example of this would be somebody who develops joint pain that cannot be explained, it causes disability, interferes with life but isn't accompanied by multiple other symptoms and eventually disappears.

A *conversion disorder* is the neurological form of a somatic symptom disorder. Most of the same rules apply – it is still a condition where disability outstrips any disease that can be found – but in this particular case, the symptoms are neurological. So rather than pain being the most disabling symptom, there is loss of strength in a limb, or convulsions, or loss of sensation.

Conversion disorders are also known as *functional neurological disorders* and, in a small number of cases, as *dissociative disorders*. Conversion disorders were once also referred to as *hysterical conversion* or *hysteria*. When I use the term hysteria I will be using it in the historical sense, not in the way we use it now. Currently hysteria is used to describe an outburst of irrational emotion but in the past it was a medical diagnosis of unexplained, largely neurological symptoms. In this book the words hysteria and conversion disorder will be used to refer to the same illness in different eras.

It is important to point out that in a somatic or conversion

disorder an organic physical disease may or may not be present. Such disorders do not presuppose *no* disease. Sometimes there is a medical diagnosis of a disease but the disability is out of proportion to it. That is where the classification of *psychological factors affecting medical conditions* comes into play. Imagine somebody who suffers with asthma. Their asthma is well treated and stable and for that reason lung function tests are normal and, when the doctor listens to their chest, there is no wheeze and the air can be heard going into the lungs. There is a disease present which is deemed under good medical control but the person still feels disabled by shortness of breath. If the asthma is well controlled and fails to explain the ongoing symptoms then those symptoms may be fairly considered as potentially psychosomatic or functional. Or, imagine somebody who has an underactive thyroid gland, a disease that causes fatigue. They are taking hormone replacement tablets and blood tests show that the treatment has returned their thyroid hormone levels to normal. We might expect that person to have minimal symptoms of thyroid disease. If that person suffers with ongoing crippling tiredness which the thyroid disease does not fully explain, then that tiredness might be called psychosomatic even though there is a known underlying medical problem.

In actual clinical practice all of these diagnostic terms are used in a fairly indiscriminate manner. It would not be unusual for a single patient to see several doctors and receive a different diagnostic label from each; conversion disorder from one, functional neurological disorder or psychosomatic disorder from the next. Sometimes a doctor uses the term that they perceive to be the least pejorative, or the one that the patient is most likely

to understand and to accept. To a degree I will reflect that practice in the stories I tell.

Finally I need to clarify the terms *disease*, *organic* and *illness*. A disease is a biological dysfunction of the body. It implies a physiological abnormality or anatomical structural abnormality. The terms *disease* and *organic* refer to pathological disorders of the body, as opposed to disorders of the mind.

Illness is not the same as disease. Illness is the human response to disease. It refers to the person's subjective experience of how they feel but does not assume any underlying pathology. Illness can be either organic or psychological. A person can have a disease but not be ill. For example a girl with epilepsy has a disease, but if she is not having seizures and the epilepsy is asymptomatic she is not ill. A person with a psychosomatic disorder, on the other hand, is ill but does not necessarily have a disease.

Everybody's experience of illness is their own, and that is where illness becomes distinct from disease. I recall a non-medical friend of mine wondering why it was not possible to define all the characteristics of a single disease. Then a map or a formula could be created for all the common ailments and doctors might even find themselves obsolete – tap your symptoms into a computer program and a diagnosis pops up on a screen. That friend had failed to understand the human condition. He could not see the ways in which the individual patient impacts on their own disease. A person's personality and their life experience moulds the clinical presentation, the response and the outcome of any brush with illness. If you take one hundred healthy people and subject them to the exact same

injury you will get a hundred different responses. That is why medicine is an art.

Many of the people I will tell you about in this book suffer from illnesses so severe that their lives have been destroyed. But most of them do not suffer from a disease. That distinction will prove very important to them. It will decide how their disability is perceived, both by themselves and by those around them. That, in turn, will determine everything that happens from that point onwards.

For most sufferers acceptance of the diagnosis is dependent on how the illness is viewed. Those who can accept it have the best chance of recovery. But for that to happen, some of the common preconceptions and judgements levelled at those with psychosomatic illness need to change. Those preconceptions and judgements mould every patient's story, and form a crucial part of this book.

PAULINE

At one time or another, we will try to silence painful emotions.
But when we succeed in feeling nothing we lose the only means
of knowing what hurts us and why.

Stephen Grosz, *The Examined Life* (2013)

Pauline was easy to spot. She was half the age or less of any other patient in the ward. The cot sides of her bed were up and each was covered with a layer of soft padding. To the right of her bed there was a wheelchair. In a high-backed chair to her left sat a woman who was staring intently at me. I saw her whisper something to Pauline and then their two similar faces turned back in my direction. Similar but different, in Pauline's face I saw only fear, but in the other I saw hope. Curtains were partially pulled around the bed, shielding the women from the neighbouring patients. Or the other way round, I didn't yet know which.

I had received a call the previous evening asking me to see Pauline as soon as possible. She had been admitted to the ward with pain and swelling in her leg. She had undergone a series of investigations but no explanation had been found. This was Pauline's third admission with the same problem. That morning

the team looking after her told her that they had exhausted all possible tests in the search for a cause. Pauline was told that nothing further needed to be done and she could go home.

'It is not possible for us to find an explanation for everything. There is nothing more that I can do for you,' the consultant had said.

One hour later Pauline was in the bathroom when she lost consciousness. A nurse had heard a loud noise and had run in to find Pauline lying on the floor, convulsing. The emergency medical team was called and Pauline was resuscitated and carried back to her bed. In the hour that followed she was witnessed to have two more convulsions. After the on-call neurologist had seen Pauline and heard her story, I was next on the list.

Before going to talk to her I went in search of her medical records. I found them on the bottom of the trolley, where files are kept that are too bulky to be stored elsewhere. Pauline's notes came in two large volumes. These were the sort of notes that more commonly belonged to the elderly or people troubled by a lifelong incurable and serious condition. But Pauline's notes were different, they spoke of a lifetime in hospital but they did not contain any definitive diagnosis or satisfactory explanation of any kind.

I read through the file thoroughly, starting with her first admission to hospital and leading to the present day. How an illness evolves is of great importance if you are ever to find a cause. Only when I was familiar with the version of the story that existed in the records did I approach Pauline. I introduced myself and started as I always did.

'How old are you now, and when were you last completely well?'

'I am twenty-seven,' Pauline answered, 'and if you really want

me to go back to the very beginning I haven't been well since I was fifteen years old.'

So I asked her to start there, at the point where one life ended and another began. This is the story she told me.

'I was just like everybody else – normal.'

'You were more than just normal, darling,' Pauline's mother rested her hand on her daughter's arm. 'She was very sporty, good at everything, in the top set at school. She could have been anything she wanted to be.'

'That was twelve years ago. Now look at me.'

In the year leading up to her GCSEs Pauline had begun to complain of feeling generally unwell. She was tired and plagued by aches and pains. Her doctor had run some tests, told her that she might have a urinary tract infection and put her on a course of antibiotics. That seemed to help for a while but the problem soon recurred. Pauline received four courses of antibiotics in only three months; each time she improved for a brief period but then deteriorated again.

'After the first infection I started to experience burning pain every time I used the toilet. Antibiotics only ever helped for a week or two. And when the infection came back I could barely get out of bed, I felt so weak.'

In the end Pauline was referred to a urologist, a bladder specialist. Numerous tests were done but all the results were normal. A camera was passed up into her bladder in the hope that an explanation lay there. There was nothing out of place. In the end the urologist put Pauline on a low-dose antibiotic which she was told to take every day to prevent future infections. She had taken the antibiotic almost continuously ever since.

'I got a bit better after that,' she said.

Pauline had got better but she had missed so much school that she could not sit her exams and was forced to resit the year. That meant that she was in the same class as her younger sister. Her old classmates had moved ahead of her. It was difficult, but Pauline was resourceful and able to make new friends and seemed to settle into her studies again. Pauline was soon at the top of her class.

'I didn't feel the same as I had before the infections but I acted the same so nobody could tell.'

'She was a driven child,' her mother told me.

For one whole term Pauline remained in school without missing a single lesson.

'I was always tired but I fought it. I could even play netball, that's how good things got for a while.'

Pauline's recovery was incomplete and short-lived. During the Christmas holidays she began to notice that her joints felt increasingly painful and swollen. She went to see her doctor and he wondered if this might be a side effect of the antibiotic. Pauline stopped taking it on his advice. Almost immediately she contracted another urinary tract infection. The antibiotic was restarted and Pauline was referred to a rheumatologist.

'When they saw how bad things were for me they thought I might have juvenile arthritis and started me on a course of steroids. But when the tests came back everything was normal, nothing was wrong,' Pauline recounted.

'I'm sure that when they said that everything was normal that they did not mean that nothing was wrong,' I ventured.

'Are you *sure*?' Pauline replied.

No, I wasn't.

While taking the steroids Pauline's weight increased dramatically, but her joint pain did not get better. She had difficulty walking and spent most of her time at home. Isolated, in pain, concerned about her appearance, she became depressed.

'Her depression was a wonderful opportunity for all the doctors to say that her illness was all down to that,' her mother told me, 'but she wasn't depressed when it all started. That came after.'

Pauline stopped taking her steroids. She also stopped eating. Her weight fell rapidly. At the same time her joint pain also got a little better.

'It was odd,' her mother said, 'when she stopped eating it almost seemed that she was improving in other ways. She even had a couple of weeks when we thought she would get back to school.'

But it was not very long before it became plain that Pauline's weight loss was in itself a problem. She became worryingly underweight. Her periods stopped. Her hair began to fall out. Yet it was difficult for Pauline to start eating again when this was as close as she had felt to being pain-free in over a year. Seeing how Pauline improved just as a result of a change in diet, her mother wondered if she had a food intolerance. She took Pauline to be tested for allergies. After a series of tests Pauline was told that she could not eat wheat, dairy products and a variety of fruit and processed foods.

'I was a bit doubtful,' Pauline said, 'I'd been eating most of the things they listed all my life. But I didn't have much choice so I followed the diet they gave me and I put on weight, which

was good. The pain did come back but it wasn't quite as bad as it had been.'

Although Pauline gained weight she never fully returned to how she had been. She had missed so much school by then that her mother was concerned that she would struggle to catch up with the other children. A private tutor was hired. Pauline studied at home and only went back to school to sit her exams. She did well, her scores placing her in the top ten per cent of her class.

Pauline remained on a restrictive diet. She was taking regular painkillers. She could no longer play sport, but she could usually walk. She had also started going out with friends again, and even had her first boyfriend. It was a short-lived, lukewarm affair, but Pauline was happy to have had her first relationship. It made her feel normal again for a while.

Pauline was keen to take her A levels but was scared too. She did not want to get caught in the cycle of missing classes and catching up and falling behind that she had known for the previous two years. The decision was made to continue with tutors at home. She was glad of the decision in the years that followed. Her joint pain came and went in bouts. Every now and again she thought she saw a pattern develop, but almost as soon as one had been discovered, it disappeared.

Sometimes the pain was so severe that Pauline could not walk. She described how she would crawl on her hands and knees to the bathroom if there was nobody there to help.

'Sometimes I didn't drink anything all day just so I didn't need to make the trip.'

In time Pauline's mother had to leave work to care for her. 'I couldn't bear to be apart from her at that time. If I left the

house for too long I had visions that I would come home to find her dead in her bed, or collapsed on the floor. That's how weak and pale she looked, like a girl who would die at any moment. And she was only eighteen years old.'

Pauline lived with her mother and her two younger sisters. Her parents had divorced when she was twelve. After the divorce she had regular contact with her father at first. Their meetings had only tailed off as she had grown older and had wanted to spend weekends with her friends instead of with her younger sisters and father. In time her father had started a new relationship and he had remarried shortly before Pauline's first illness. Her mother had remained single. When Pauline was first hospitalised with the urinary tract infection her father had rushed to be by her side. When Pauline's mother had to give up work her father supported the family financially and paid for tutors. But as her father's life moved forward and as Pauline's illness became more and more normal to the whole family, his visits had become less frequent too.

'Everybody forgot about how much pain I was in after a while. I didn't want to be the girl who was always complaining so they began to think I was better. My sister saw me taking my painkillers one day and asked me what they were for.'

Diet and rest had only partially controlled Pauline's pain. As she got older, it got worse. Simple painkillers were no longer effective and she had been prescribed morphine. Even that did not fully eradicate the pain, but to Pauline pain had become a normal part of life.

'I could have lived with the pain if it were not for what happened next.'

During the summer holiday in the lead-up to her final A-level year, Pauline's next illness struck. Her mother heard her calling out from her bedroom and came into the room to find her lying on the floor, doubled over and clutching her stomach. An ambulance was called and she was rushed to her local hospital. The admitting doctor diagnosed her with acute appendicitis and she was taken directly to theatre for an emergency operation. Her mother and sisters paced the floor of the hospital waiting to see if she would recover. They were by her bedside when she woke from the anaesthetic and cried out that the pain was no better. Two days later the surgeon told her that they had been mistaken in the diagnosis. When they had microscopically examined the appendix they had removed, they discovered that it showed no signs of inflammation and no evidence of appendicitis.

That was the beginning of a chain of events that would last over a year. A relentless and fruitless pursuit of the cause of her abdominal pain had begun. At first the doctors thought she might have a stomach ulcer caused by years of taking painkillers. A camera at the end of a long flexible scope was passed down into her stomach. No ulcer was found but her stomach lining seemed inflamed so she was given antibiotics and antacid drugs. They helped, but just a little and not for long. Next they wondered if the pain might come from chronic constipation caused by morphine and poor diet. A barium enema failed to provide an explanation. So a camera was passed through her back passage and into her bowel. Polyps were found, small out-pouchings of the bowel wall. Pauline was told that polyps were unlikely to be the cause of her pain but they might be a

precursor for bowel cancer and they would need to be monitored for the rest of her life.

If Pauline had not noticed constipation before, she noticed it now, and it alternated with crippling abdominal pain and diarrhoea. Soon she had undergone multiple scans, one of her gall bladder, another of her liver, and then her ovaries. Whenever she thought the doctors had exhausted the operations they could do, it turned out they had not. She agreed to each operation thinking that she would do anything to get better and believing that it was not possible for things to be any worse. She was wrong. On the day that her younger sister sat the last of her A levels, Pauline awoke from her latest exploratory operation and discovered just how bad things could get.

‘My mum was there when I woke up. I didn’t notice anything wrong at first. After a while the nurse came and asked me if I had been to the toilet since the operation. I hadn’t so she told me to give it a try. Mum pulled the bedclothes aside and I moved my body in the way that you do when you think your legs will follow. But my legs did nothing. Mum and I started laughing. That’s how ridiculous it was. We thought the anaesthetic hadn’t worn off fully. We stopped laughing when we saw the look on the nurse’s face.’

From that day on Pauline had been in a wheelchair. She had lost all strength in her legs. A neurologist was called and he had arranged for her to have a series of tests.

‘What was the outcome?’ I asked Pauline.

‘He couldn’t explain it. I was a medical mystery once again.’

‘Did he suggest any cause? Any treatment?’

‘No, he just left her like that,’ Pauline’s mother answered.

Her voice was edged with frustration. When Pauline spoke it was more dispassionate. Sometimes it felt as if she was telling me somebody else's story.

After that the investigations stopped for a while. Pauline saw a physiotherapist and learned to move her legs a little but could never stand or walk. The joint and stomach pains continued and Pauline survived on a cocktail of drugs. The family home was converted so that Pauline had a bedroom and bathroom on the ground floor.

Life moved forward in many ways. When sports and other activities were no longer possible she found new ways to socialise and make friends. Always a keen reader, she set up an Internet-based book club specifically for people with disabilities who could not travel to meet in person. She began writing and kept a vivid diary of her experiences which she shared online. She eventually sat her A levels and easily qualified to study English literature at her local university. And she met her second boyfriend.

Mark was a student physiotherapist at the hospital that Pauline attended. They had become friendly during her treatments. One day Pauline was waiting outside the hospital for her mother to come and collect her when Mark appeared beside her. They started talking and discovered that they shared a love of books and films. By the time Pauline's mother arrived they had arranged to meet that weekend to see a film. They had been together ever since.

Pauline was twenty-one when she met Mark and started university. She had been ill for six years but at last she felt that she was experiencing some of the things that she had missed out on. While her pain and disability continued, everything else improved.

‘While I was at uni I barely needed to see my doctor. I knew he had done all he could and it felt as if the problem, whatever it was, had burnt itself out.’

Pauline spent four years as a student. She required a small amount of help to allow for her disability – she was given extra time in exams because she could not write for prolonged periods, and friends brought her notes if she could not attend a lecture – but she did not allow her health problems to hold her back. She became a vital member of her university. She was secretary of the student union. She was the girl on campus that everybody recognised. For practical reasons she remained living at home with her mother but she socialised regularly and lived her life as any other student did. Pauline was no longer dependent on her mother, so her mother could return to work. Both her sisters had left home to go to university in other cities. Mark qualified as a physiotherapist and two years into their relationship he moved in with Pauline in her family home. They planned to get their own flat and marry when Pauline had finished studying and they both had jobs.

‘I think that almost having it all made it worse when I began to lose everything again.’

Pauline sailed through her final exams and found a job in a junior position at a publishing company. She and Mark began flat hunting. She was close to many of her goals when she fell ill again. It started when several people in her office caught a flu bug. Pauline was also affected but worse than most.

‘I have always had a weak immune system. I catch every bug going.’

She took a few days off work and stayed in bed. The day

before she was due to return to work she noticed that one leg was unusually painful.

'I always have pain in my joints but this was a new pain.'

Her doctor feared that her immobility had led to a clot forming in her leg and advised that she go to the local casualty department for some tests. Pauline was admitted to hospital and, while awaiting the investigations to explain her leg pain, she developed the familiar symptoms of a urinary tract infection. Passing urine became so difficult that the nurses inserted a catheter that would empty her bladder until she felt better. She had suffered yearly bladder infections despite taking daily antibiotics but she had never been catheterised before. Initial tests did not reveal any definite infection but three days later she was found to have a high temperature and her condition acutely deteriorated. Further microbiology tests showed that she had a hospital-acquired infection which was resistant to normal antibiotics. She was moved to an isolation room and was subjected to high doses of toxic drugs. It took a week to bring her temperature back down.

Pauline and her family were greatly relieved when she recovered. She was moved back to the general ward and the nurses removed her catheter. Four hours later Pauline was crying out in pain. Her bladder felt full to bursting but no amount of straining on the toilet would empty it. The nurses reinserted her catheter. The same thing happened the next day. Multiple further tests were ordered but it became obvious that this was another problem that would remain unexplained. Ultimately Pauline met with a bladder-care nurse who removed the indwelling catheter and taught Pauline how to empty her own

bladder using a small rubber tube. After that Pauline never used the toilet in a normal way again.

In the six months that led up to my meeting with Pauline the quality of her life had once again stalled before slowly declining. Pauline felt that she was on the brink of losing everything that she had fought so hard for.

‘For years I had limited sensation in my legs. It was all so cruel, the only feeling I ever experienced was pain. Not pain from the outside. You could burn me with a match and I wouldn’t blink. The pain was on the inside.’

Twice more Pauline went to the casualty department with calf pain that no amount of morphine would quieten. Each time she was doubled over by it. Twice she was sent away. ‘Your tests are normal. There is nothing we can do.’

‘Something had to be wrong. There had to be something causing the pain, but I got the feeling that they thought I was imagining it,’ Pauline said.

I agreed with her. To be in pain is not normal and there is always a reason.

The third time that Pauline presented with calf pain she was finally readmitted. The doctor had wanted to discharge her again but her mother had refused to take her home.

‘If I have to bring my daughter back to the hospital in this state one more time and nothing is done, I will make a complaint.’

Four days later the consultant told her that she had no choice but to go home; he had exhausted everything he could do for her. That was the day her convulsions began.

‘I knew I wasn’t ready to go home,’ she said.

Pauline had packed her belongings and was in the bathroom when she collapsed. She had been sitting in her wheelchair and brushing her teeth when she started to feel unwell. The room was suddenly spinning and she sat back in her chair to steady herself.

'Suddenly my vision closed in as if I was entering a dark tunnel. I knew something terrible was going to happen. I tried to call out, but I couldn't.'

After that Pauline remembered nothing for a while. Time passed in which she did not play a conscious part. When she awoke she was still in the bathroom but no longer in her chair. She was lying on the ground and strangers towered over her. Somebody had opened her pyjama top and she was aware that she was bare underneath it and she felt warm hands touching her, applying sticky pads. There was a sharp pain in her arm as a doctor she had never seen before stabbed at her with a needle. The floor underneath her felt wet. She would realise later that she was lying in her own urine, that her bladder which so staunchly disobeyed her conscious commands had emptied itself while she was unconscious. In the crowd she sought a familiar face and found a nurse who had cared for her on the ward. Reflexively she tried to push her attackers away and begged the nurse to help cover her up.

Once she was fully awake Pauline was carried back to her bed. But almost as soon as she arrived there she felt it begin again.

'I felt I was being sucked down into the bed. It was as if my life was being drained out of me. As soon as my vision began to get dark I knew I was going to lose consciousness and I

willed it to stop. I tried to tell the nurse but no sound came out. I could feel my body stiffening. Someone put an oxygen mask on my face. It hurt. I knew the doctors thought I was unconscious but I could feel everything they did and hear everything they said. One nurse said she couldn't feel a pulse. Eventually my whole body began to shake and then I blacked out. I don't know how long it lasted but when I woke up my mother was with me. I was so relieved to see her.'

Pauline's mother had come to take her home. She was there when the third convulsion struck.

'She just went very pale and very still. Then she sort of flopped back on to her bed like a rag doll. She started to shake. The shaking was just in her arms at first but it spread and became more and more violent. She wasn't breathing. It felt like it lasted for ten minutes but I think it was probably shorter than that. At the end she let out a horrible gasping breath. When the shaking stopped she just lay there. It was if she was asleep but it wasn't a normal sleep. Nothing I did or the nurses did would wake her up.'

Pauline could not remember that attack, nor any that followed during the evening and night before we met.

'I forget everything after the third seizure,' Pauline reported. 'Was my mother with me last night? I don't know.'

And now I have forced Pauline to recall everything, to tell me in detail about what had led her here. And all the questions have been answered. No, there is no family history of epilepsy. Yes, my parents are divorced but it was a long time ago. I love my job, I can't wait to go back.

At times her mother became upset. 'Can't you read all of this

in her notes? Is my divorce really important here? Is a bladder infection that happened when she was sixteen really relevant to what's happening now?'

'I think that everything that has happened is of great importance and I can understand the story better when I hear it from Pauline rather than just read it in the notes.'

There are always two realities, the one which exists in the notes and the one which lives in the patient's memory. I needed to know both and I knew that neither version could be wholly relied upon.

'Is this going to be yet another undiagnosed problem that I will have to live with?' Pauline asked.

'No, I believe that there is a very good chance that this will be different. We have very sophisticated tests to diagnose the cause of seizures. I am hopeful that this is something that we can diagnose and from which you can recover.'

At the end of the conversation I explained to Pauline that it was too early for me to say for certain what was wrong but that I would transfer her to the neurology ward under my care where she would undergo some further investigations. I ended the conversation as I always did:

'Is there anything important that you think I have left out or anything further that you want to ask?'

Pauline said there was nothing else, but just as I left she called me back.

'Have you seen anybody like me before?'

Too many to count, I thought. But other people's stories would be of no help to Pauline at that moment.

'I have seen people with similar problems to yours but no two people are ever the same.'

As I walked away I felt the guilt that I always feel when I have not been completely honest. I was certain that I knew what was wrong with Pauline but I had withheld that information. That I had been down this road before, and that it had not always ended well, was also withheld. But I knew that I was not the only one with secrets. Pauline's story had not been complete. It was our first meeting and it remained to be seen whether we would find a place where we could each be entirely honest with the other.

There is only one way of knowing with absolute certainty why a person has lost consciousness, and that is to witness the event. Otherwise a diagnosis is based entirely on interpreting the story that the patient and the witness have provided. That way is confounded by errors. People are not good witnesses. Distressed, frightened people are more unreliable still. Descriptions of seizures are influenced by what people expect to see as much as by what they have really witnessed. In the imagination of every mother watching her child convulse her child becomes deathly pale and moribund and foaming at the mouth. One minute always feels like an hour. And yet most of the time that description is all that doctors have to go on.

It's rare for a doctor to have the opportunity to witness their patient's seizure. Most seizures that recur do so infrequently, often only once a month or even once a year, and each attack only lasts for a minute or two. Admit that person to hospital to witness their seizure and you will have a long wait, and when it finally happens, blink and you'll miss it.

But there are circumstances in which it is possible to see a

blackout and, in doing so, to make a definitive statement about the cause. For example, sometimes blackouts have a trigger. In epilepsy this might be flashing lights or sleep deprivation. If this is the case, and a diagnosis is needed, the patient can be brought to the hospital and exposed to the offending trigger so that a seizure happens in a safe environment in front of trained witnesses. Similarly, people who faint might notice that sudden changes in posture provoke their symptoms, so they are placed on a tilting table to induce an attack. Controlled monitored exercise might be used to provoke cardiac symptoms if that is the suspected cause of the collapse. In a small number of unfortunate people their collapses are so frequent that even a short hospital admission will allow you to see the attacks for yourself.

Where triggers are less clear, video-telemetry units are an invaluable facility for observing seizures. In them, patients ostensibly sit around waiting to collapse and staff sit around waiting for it to happen. Of course it is actually more sophisticated than merely waiting and watching, and it is all thanks to a trainee German doctor called Hans Berger.

At the end of the nineteenth century, Berger was riding his horse in a military exercise. For an unknown reason the horse reared and Berger was thrown to the ground. He landed perilously close to the rolling wheels of an artillery cannon. The horse that pulled the cannon came to a halt just in time to stop Berger coming to a grisly end. Berger was greatly relieved by his escape. That evening he received a telegram from his sister wishing him good health. She reported that she had been overwhelmed by concern for him that day and had felt

compelled to send him her good wishes. Berger could not believe that his sister's impulse to send a telegram was just a matter of coincidence. It seemed clear to him that in his moment of greatest peril, he had somehow communicated his distress to his sister many miles away. He would make it his life's work to understand how this telepathy had occurred.

In the nineteenth century it was already widely known that the organs of the body produced electrical activity. Berger took this knowledge and tried applying an electrical discharge to the head in the hope that it would reveal the mechanism for psychic energy. This gave no useful information. So instead he attempted to measure the existing natural animal electricity present on the surface of the head using a galvanometer. He made a startling discovery: even through the skull he could make reproducible recordings of electrical activity that, he surmised correctly, must be coming directly from the brain. He was never able to prove the existence of telepathy but by 1929 he had published his first scientific paper on the recording of brainwaves in a human via the scalp, and had invented the electroencephalograph, or EEG.

Understanding the characteristics of the electrical activity of the brain would prove very useful. Most importantly Berger showed that the brainwaves were ever-changing and each change in pattern reflected a change in the state of awareness of the subject being tested. Drowsiness, light sleep, deep sleep and waking all had a pattern of their own. Brainwaves, as measured by an EEG, could therefore determine if a person was awake or asleep, conscious or unconscious, at any given time. An EEG came to be the definitive means of assessing consciousness and

is used to this day as one of the primary tools in understanding why a person has suffered loss of consciousness or coma.

In a video-telemetry unit patients are restricted to a single room where they are under constant video surveillance. Small painless metal discs attached by paste to the head make a round-the-clock recording of the brainwave, or EEG pattern. A cardiac electrode takes a similar recording of the heart rate. A group of nurses rotate to watch the video stream of the patient at every moment of every day, with only the bathroom remaining private. When the convulsion or blackout under investigation finally occurs the nurse is ready to run into the room to assess the patient, check their blood pressure and blood sugar and keep them safe and reassured until they recover.

Through this type of monitoring, based on the principle that all our brains generate an electrical pattern and that the brainwave pattern reflects the level of awareness of its owner, it is possible to determine the cause of a large number of seizures with a high level of confidence. There are many reasons that a person might have a seizure or lose consciousness and video-telemetry monitoring distinguishes one cause from another.

If a healthy person faints, because they are dehydrated or overheated, for example, the first physiological change will be a fall in their blood pressure. Their heart detects the problem and tries to compensate with an increase in heart rate. The person feels weak and dizzy and they know something is wrong. They may be aware of their heart rate increasing. The blood literally drains from their face and they appear pale. If the increased heart rate is not enough to compensate for the fall in the blood pressure then, just for a moment, vital blood is

drawn away from the brain. As the brain becomes deprived of oxygen the brainwaves slow dramatically and the patient loses consciousness. In a healthy person the blood pressure usually recovers quickly and, when it does, oxygen is restored to the brain. The normal waking brainwave pattern is immediately restored, the patient awakes and no harm is done.

But not all faints occur in healthy people for simple reasons. Some occur in people with heart problems. In those collapses the first change may be that the heart rate slows down dangerously. So the heart changes first this time and, if it is not beating sufficiently to support the blood pressure, that drops. With the fall in blood pressure the brainwaves slow and with that the patient loses consciousness. Only when the heart starts beating at a normal rate again does the patient, and their brainwaves, recover.

Or the cause of a blackout might lie not in the heart or blood pressure, but in the brain itself. This is the case in diseases like epilepsy. The sequence in epilepsy is different again. First the epileptic seizure produces a burst of unwanted electrical activity in the brain. The patient only loses consciousness as that electrical discharge spreads and takes over the brain. The heart rate and blood pressure may or may not be affected as the patient blacks out.

Blood pressure falls – heart rate increases – brainwaves slow; heart slows – blood pressure falls – brainwaves slow; brainwaves change – consciousness is lost; each of these patterns combined with a video recording of the collapse suggests a specific diagnosis that is usually reliable. The overarching principle on which each diagnosis rests is always that you cannot be

unconscious – neither asleep, nor anaesthetised, nor in a seizure – if your brainwaves do not change.

These are the principles that I will use to determine the cause for Pauline's seizures.

Three days after Pauline and I met she was transferred to the neurology ward. On each of those days she had multiple seizures. On her first day and night in the video-telemetry unit she had six more. The following morning I reviewed the video and watched each seizure in turn. Each collapse was the same.

Pauline is lying in bed chatting to her mother. She suddenly stops talking. Her mother doesn't notice at first and continues with the conversation. Pauline is sitting very still, staring into the distance, when her mother realises something is wrong. She reaches to press the nurse call button and just as she does Pauline folds in on herself and drops loosely back on to her pillow. As the nurses run into the room Pauline begins to shake. At first it is a shivering but quickly it builds in intensity becoming more and more violent with every second. Soon her arms are flailing so wildly that the nurses cannot get near enough to help. Her arms are hitting against the padded sides of the bed. Pauline's mother is a foot away from her daughter, her hands covering her face.

In one minute the shaking stops. Pauline's whole body sinks back into the bed as if deflated. The nurses take the opportunity to roll Pauline on to her side. They have barely done so when the shaking begins again and it is just as violent as before. Another nurse enters and ushers Pauline's mother from the room. The shaking starts and stops five more times before it is

over. At the end Pauline lies still on her side where the nurses have placed her. Her eyes are closed and her breathing is rapid. The nurses try to wake her to check that she is alright but for ten more minutes they cannot rouse her. When she does wake her mother is back by her side. Pauline doesn't say anything, she just starts to cry. Her mother comforts her.

I watched the video of each seizure and I reviewed the brain tracing and heart tracing for each and then I made an appointment to meet with Pauline and her family.

When we met again Pauline's mother was with her and this time Mark was also there. They sat like sentinels on either side of her, each holding a hand. I asked Mark to move to sit beside Pauline's mother. I didn't want my attention divided.

Before Pauline had moved to the video-telemetry room I had explained the purpose of the test in detail. Pauline understood the changing nature of brainwaves but I explained it again because it was of vital importance to what I would say next.

'I have reviewed each of your seizures carefully. I have looked at the video and at the brainwave tracing and the heart rate for each. The first piece of good news is that I have not seen the pattern that I expect in an epileptic seizure so you definitely do not suffer from epilepsy. The heart tracing was normal, so the heart looks healthy which I hope will also be a relief to you.'

'That's good news isn't it, darling.' Pauline's mother squeezed her daughter's hand. Pauline and Mark stared blankly in my direction. I saw no sign of relief.

'When I looked at the brainwaves during your seizures I saw that they showed the pattern I might expect in somebody who is conscious, a waking pattern.'

Mark tried to interject and I heard myself speak louder and faster.

'This is a very difficult thing to understand so please just let me finish and then ask as many questions as you want. The brainwave pattern looked normal and there is only one reason that a person can be unconscious, completely unaware of their surroundings, with the brainwaves still looking normal, and that is if the loss of consciousness is caused by something psychological rather than a physical brain disease.'

Mark shook his head and pressed his lips tightly together. I was aware my voice had become more emphatic.

'Let me first explain that all of our bodies produce physical symptoms in response to emotional distress. But we have become so used to the common ways that this happens that we have stopped noticing it. If I am nervous my hands shake – that is my body changing physically in response to an emotion. When we are frightened our hearts race. When we are upset tears flow from our eyes. These are all examples of the ways in which each of us have experienced physical symptoms when there is nothing physically wrong. These sorts of physical responses to distress are normal everyday responses to normal everyday fears and upset. But for some people physical reactions to emotion can be more dramatic and more disabling than these simple examples. One extreme way that the body can respond to upset is to produce blackouts and convulsions. This sort of convulsion is known as a dissociative seizure.'

I couldn't hold back Mark's questions any longer.

'You're saying that she's not really unconscious.'

'No, Pauline's unconsciousness is real. Think of the example

I gave of the heart racing in response to fear. The heart rate has really doubled, I can feel it in my chest and you could measure it. It's not imaginary. But it's not happening because I have a heart disease. My heart is healthy. My heart is just responding to distress.'

'You think it's all in my head.' As Pauline spoke she stared past me.

'No, Pauline, I know your seizures are real. They are real, but they are arising in the subconscious rather than being due to a brain disease. Dissociation means that a sort of split has occurred in the mind. Your conscious mind separates from what is happening around you. That detachment means that one part of you doesn't know what the other is doing. But it's not deliberate. You cannot make yourself unconscious any more than I can deliberately blush or produce tears.'

I wanted Pauline to look at me, but she wouldn't. I couldn't read her response.

'Pauline, is anything I'm saying making any sense to you? How do you feel about what I've said?'

She shrugged her shoulders. 'I just feel tired.'

'Do you understand what I'm trying to explain?'

'I understand. I just don't see how any of this applies to me. I'm not stressed. My life has never been better.'

Pauline is right, of course.

'I know. The examples I've given you are all ones in which stress is felt and the physical symptoms are experienced alongside it. Dissociative seizures are often different. Often the physical symptom is there in place of the emotional upset. So, for example, if there is a memory or emotion that is too painful

for a person to experience, that emotion is converted into a physical disability as a sort of protective mechanism. In a convulsion it is as if your brain is shutting down for a minute to keep you safe.'

'Safe from what, though?'

'I don't know the answer to that. But even if it isn't possible to know the answer now it may be possible in the future.'

For a moment I thought of how Pauline's illness had behaved. How it struck her down when she was facing a challenge or when her life was about to change.

'So I'd rather have a convulsion than face something unpleasant from my life? Why would I do that to myself?'

'It's ridiculous, is what it is.' Mark was furious now.

'I know this is all very hard. You are not doing this to yourself, Pauline. If everything else I say seems ridiculous, then just remember one thing: the seizures are real, whatever they consist of. They are real and disabling and out of your control and they must be taken very seriously. The cause only helps to indicate a treatment; it shouldn't detract in any way from how awful these seizures have been for you.'

'What is the treatment?'

'I would like to refer you to a psychiatrist.'

'After all you said, you are just saying I'm mad.'

'No. These seizures are your body telling you that something is wrong. The psychiatrist might help you work out what that is. I think that these seizures are curable, Pauline. I think a psychiatrist might help you to see that.'

'Isn't there a medication that would help?' Mark asked.

I knew that Pauline was already taking seven medications.

None had resulted in any great improvement in her life. Two were there purely to counteract the side effects of the other five. Pauline was twenty-seven years old. I needed her to recognise a pattern that wasn't working and find a new one.

'Medication won't help dissociative seizures.'

'You think they're curable.' Pauline's mother interjected this time.

'I absolutely believe that these seizures can go away completely and I hope the psychiatrist will help speed up that process.'

We sat in silence for a while and when it seemed all the questions had been asked I ended the consultation as I usually did, 'Is there anything else you would like to ask? Is there something that you think that I have left out?'

'Nothing.'

As I said goodbye I felt that I had failed to connect with Pauline. She had agreed to see the psychiatrists but her acquiescence had felt empty. I was relieved when two days later Pauline kept our agreement and had her psychiatry assessment.

Few people will ever endure the scrutiny that Pauline had endured. Most of us get to put our childhood selves behind us but Pauline had been called upon to recount her story over and over, not just the story of her illness but of her life. The psychiatrist had been thorough. Pauline had told more of her story. Some of the information was new but much I had already gleaned from Pauline's notes the first time we met. Perhaps if you have a lifetime of illness in twelve years you forget some of your own story. Or perhaps Pauline had withheld information because she did not want me to be prejudiced by things that had happened in the past. Or maybe the subconscious was at play again, choosing what to tell me and what to hide.

It was true that Pauline had had a happy childhood but it was no more free of traumas than anyone else's. When she was nine years old she had developed an eating disorder. At that time a family dispute was tearing her father's family apart. Her immediate family became estranged from her paternal grandparents, aunts and uncles. Pauline took it badly. She stopped eating and only recovered with the support of her family and the help of a child psychologist. It was a short-lived illness.

Trouble resurfaced when she was twelve years old and her parents divorced. Pauline stopped eating again briefly. The psychiatrist thought that Pauline must have feared losing her father, just as she had lost his family before. Her mother promised her that would never happen and Pauline appeared to recover when that proved to be true.

Another striking omission from Pauline's story was that I was not the first doctor to raise the issue of psychosomatic symptoms with her. When her legs had become paralysed at the age of twenty-one a diagnosis of hysterical paralysis was offered as an explanation. Pauline had rejected it outright. She had seen the psychiatrist once and had never returned, nor had she accepted the advice that was given in that single session. I had known this when Pauline and I met but I didn't raise it with her. For Pauline and I to work together I needed to give her space and time to decide what she wished to discuss and when.

The psychiatrist thought that Pauline needed help but was concerned about her ability to accept treatment. In particular she wondered how her relationships might hinder her recovery. Was it possible that she was too well looked after? Would others miss her if she was not always dependent on them?

The psychiatrist had also discovered that, while Mark and Pauline's relationship was loving, it had never been consummated.

'I wonder if she is so focused on, and in control of, her own body that she could not possibly allow another person inside her in such an intimate way. She controls her intake of food in the same way. That sort of control is difficult to relinquish to others,' the psychiatrist told me.

I went to see Pauline after her session. For the first time her mother was not with her. The sight of her alone caused a hollow feeling inside me that I did not fully understand.

'How did it go with the psychiatrist?'

'It was okay.'

'I hope it made some sense to you,' I said ineffectually. 'Was there anything new you wanted to ask me? Did she raise anything that wasn't clear?'

'No.'

I needed to move Pauline forward but without alienating her.

'I think you had a chat about your leg weakness?'

'Yes, she says you think that's imaginary too.'

'I hope you know that I don't think anything is imaginary.'

There was a pause. I wondered what she might be thinking.

'Did the psychiatrist tell you what happened when I was nine?'

'She told me you were unwell for a while but we didn't discuss the details.'

She turned her head and looked away from me and towards the window.

'Did she say why?'

'Only that there were some problems in the family.'

The conversation had become stilted; I was not sure where it was going.

'Now that I'm officially mad everyone will think I was abused but I wasn't.'

Was this a statement? Or a question? Or an invitation?

'Why do you think we would think that?'

'I read it on the Internet. Dissociative seizures happen to girls who have been abused as children.'

'Sometimes, yes, but just as often it's nothing to do with anything like that.'

'It's not like that for me.'

'I know.'

I followed her gaze to the window but there was nothing for her to see there but grey sky.

'My uncle was accused of abusing a girl who lived next door to him. Dad wouldn't let us see him after that, even though they didn't prove it. Dad's family were furious. They said Dad should have taken his brother's side, not some stranger's.'

'That must have been very difficult for you.'

'He never touched me.'

'Good.'

I waited a while, not sure if our conversation was over.

'Do you think that my other medical problems are like the convulsions?'

I had been waiting for this question. I was glad it had come.

'I think there is a strong possibility that your other symptoms are psychosomatic, yes.'

‘But you’re not a gastroenterologist or a rheumatologist. Are you even qualified to say that?’

‘No, I’m not, but I have read your test results and I have read what your other doctors have written in your notes. None of your other symptoms were ever explained and this would explain them. And, if I’m right, something could be done about those too.’

Pauline looked directly at me again. She was crying.

‘For twelve years, Pauline, you have been in and out of hospital, having invasive tests, trying new tablets that never work. Every time you’ve had an operation, instead of getting better, you’ve ended up with a new problem. You go into hospital with a stomach pain and you come out in a wheelchair. I am asking you to try a new approach because the old one isn’t working. The very least I can promise you is that it will not make things worse.’

‘I want to talk to Mark.’

I could not shake the feeling that Mark inadvertently bound Pauline to illness, and this made me afraid that she would refuse to see the psychiatrist again. If you have asthma and the first inhaler doesn’t work, you don’t abandon the diagnosis, you ask for something stronger. And yet psychiatrists seem to get only one chance. It was hard to ignore the idea that six years ago Pauline might have chosen a wheelchair over a psychiatric diagnosis. I knew this thought was unfair to Pauline – if such a choice had ever been made, it had not been a conscious one. Pauline was right, nobody would choose what she had suffered. This was an illness out of anyone’s control.

Pauline was due for discharge. Her tests had been completed.

We had a diagnosis. She had seen the psychiatrist. There was no reason for her to stay. She had only to agree to the next step. I told her she could go home the following day and that after that she would be seen by the psychiatrist and a series of psychological and physical therapists who would help her move forward.

But Pauline and I would have one more eventful night ahead of us before that happened. Just after midnight my phone rang. It was the on-call neurology junior doctor. 'Just a courtesy call to let you know that Pauline has threatened to kill herself. We've locked away her medications and given her a one-to-one nurse and have called the on-call psychiatrist, but we thought you'd want to know.'

'Thank you.' I did want to know. But there was nothing I could do. I went back to bed but I didn't sleep.

The following morning Mark greeted me at the entrance to the ward. There was no preamble.

'She has polyps and gastritis and recurrent urinary tract infections. Are you saying she's making those up too?'

I suggested that we speak again once I had seen how Pauline was doing and had talked to the doctors who had seen her the previous night. Mark's agreement came through gritted teeth. When I received the outcome of the previous night's consultations I was relieved to learn that Pauline's distress was felt unlikely to be linked to a real intent to harm herself. I would ask the liaison psychiatrist to see her again before I would allow her home. But first I went to see Pauline. Mark and her mother were present, positioned as sentinels once again.

'How dare you say that all her medical problems are

psychological? The only distress Pauline has ever had in her life has been because of her illness. If these convulsions are due to madness, it is all due to the pain she has suffered. Did you ever think of that?’ said Mark.

It occurred to me for the first time that there could be things that Mark did not know.

‘I’m sorry this has been so difficult. I know there are points on which we don’t agree so I think it would be more useful to Pauline if we stick to addressing those things that are definite.’

‘Pauline needs to pass a catheter to empty her bladder. That’s definite. How could that be psychological?’ A little spray of spittle accompanied Mark’s words. Pauline’s and her mother’s eyes were cast downwards.

‘We can’t unravel all of this here and now.’ I turned to Pauline. ‘*Pauline*, I don’t have all the answers but I know one thing and that is that your convulsions did not occur as a result of a brain disease. That is what I know for certain and that is where I think we should focus our attention.’

The room fell completely silent. Pauline would not look at me. Her eyes were fixed on Mark who was gripping her hand. I looked at how their fingers intertwined. I could hardly tell one hand from the other and I thought of my discussion with the psychiatrist. Here was a girl who had, in a sense, lost one side of her family, and now illness bound her tightly to those who remained. I thought of her threat to harm herself and saw a girl who knew only one way to be heard.

‘If you are feeling better later it will still be possible for you to go home. Do you think you will be able to come back to see the psychiatrist again and have the treatment she suggested?’

Now all three faces turned in my direction, one blank as usual, one adversarial, but I thought I saw something hopeful in the third, in the face of her mother.

'I feel that at least some of what you are suffering can be relieved. I ask that you just give the treatment programme some consideration.'

Did her mother give an almost imperceptible nod?

It has been through trying to treat people like Pauline that I have come to realise that not all suffering is the same. It is not necessarily the greater suffering that receives the greatest consideration and sympathy. Illness is not scored in that way. Deadly disease obviously scores higher than others. After that there is an unofficial ranking system for illness in which psychiatric disorders are the out-and-out losers. Psychiatric disorders manifesting as physical disease are at the very bottom of that pile. They are the charlatans of illnesses. We laugh at them. If all of Pauline's problems are indeed psychosomatic in origin then no matter how hard I tried to convince her, she knew she would be judged and she was right. Pauline and her family were fighting to preserve her dignity.

I had tried to make Pauline see that physical manifestations of unhappiness are something we all experience, it is not a personality flaw or a sign of weakness, it is a part of life. Life is hard sometimes. It is harder for some than for others. We all manifest that hardship in different ways: some cry, some complain, some sleep, some stop sleeping, some drink, some eat, some get angry and some suffer as Pauline does. But I made a mistake with Pauline. Over time, the more patients I have

met like her the more I have come to understand it was not Pauline or her family who needed to be convinced of the reality and legitimacy of her suffering, it was the world outside.

After talking to the psychiatrist again Pauline was allowed home. I was on the ward as she left. Mark had gone to get their car and Pauline and her mother only nodded in my direction as they left. But, just as I thought I would never see either of them again, Pauline's mother suddenly turned around and came back towards me.

'She hasn't had a single seizure since you told her the diagnosis, you know. I don't think she's realised it yet.'

After her first night on the neurology ward Pauline's seizures had indeed completely disappeared. But what Pauline's mother had not yet registered was that the leg pain for which Pauline had been admitted had also just as silently melted away. As I watched them leave I suddenly felt hope for Pauline, if only she could bring herself to make it to the next stage.