Out of the Blue

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CASSLAND BOOKS

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Out of the Blue was commissioned by the Institute of Neuroscience at Newcastle University and funded by the Wellcome Trust. Scientists at the institute are developing experimental treatments for epilepsy that use brain implants and light-sensitive gene therapies. To a lay person, this research – involving neuroscientists, computer scientists, engineers and clinicians – is bewilderingly complex. My role was not to illustrate or explain what they were doing, but to bring a different perspective to the project.

What is epilepsy? There are several answers to the question. For the scientists, pharmacists and doctors seeking an effective treatment, it's a neurological conundrum that might have a solution. For most of us, by contrast, it's just a word. Although it affects one in a hundred people, it gets few headlines and we know little or nothing about it. In many ways it's a hidden condition.

But for those who have epilepsy, it is something else. It is a lived and living experience. For them, the question is more personal: what is it like to live with epilepsy? Only they can answer it.

This was my starting point. Before responding in some way to the science of these radical treatments I wanted my work to bear witness to the experience of those who live with epilepsy.

The Epilepsy Society agreed to circulate a questionnaire for the project. It asked a number of questions. What does epilepsy mean to you? How do you feel at the onset of a seizure, and how do you feel afterwards? Are there any positive words to describe your epilepsy? Is there anything else you would like to say?

Almost a hundred people responded. They described with candour and in detail the reality of how they – and their families – are affected by the condition. Their words were extraordinarily powerful, moving and illuminating. They form the foundation of *Out of the Blue*.

How best to embody this record of a condition so intimately stitched into the lives of those who have it, and yet so hidden from the public eye? I imagined an installation in which the words were embroidered into antique undergarments – chemises, nightdresses, bloomers. Like epilepsy, these garments were worn concealed beneath the surface; in their vintage, too, their very fabric would contain hidden histories.

The Royal School of Needlework offered to set *Out of the Blue* as a first-year BA embroidery project: thirty-five of its staff and students took part. Other embroiderers heard about it from a range of sources. A total of 106 signed up to sew.

Each volunteer was sent an individual garment as their canvas, together with a selection of embroidery threads in ultraviolet yellow and light blue, and black. They were given an edited testimony for the front and a single word for the back. The instructions were simple: keep to the colour scheme; sew the single word on the back; the testimony on the front was to be legible.

Embroidery is a slow, contemplative process: many of the embroiderers spoke of the impact the testimonies had on them and their design. Their skill, craft and imagination transformed each of the original garments into a uniquely responsive embodiment of the words they carry.

The resulting installation consists of 106 antique garments embroidered with the words of people living with epilepsy, suspended from the ceiling of Newcastle's Hatton Gallery in a single block of one hundred, lit by natural and ultraviolet light. The garments move on pulleys programmed by computers to correspond to the algorithms of electrical activity in an epileptic brain.

The photographs of the embroidered garments were taken in the Royal School of Needlework's apartment at Hampton Court Palace. In this rich historical setting they are presented as portraits whose very formality heightens the intimate drama of the words stitched into them.

Each copy of the book, which forms part of the installation *Out of the Blue*, also includes a set of unique, signed cyanotypes printed on fine Japanese paper. Cyanotypes are made using ultraviolet light, a process which mirrors the use of light in the optogenetic therapies being developed by the scientists. These prints explore, through pattern, the synchronization that occurs in the brain during an epileptic fit.

Susan Aldworth

Out of the Blue

Willow N

I think I'd be very different if I had never had epilepsy. Less brave that's for sure. I got diagnosed at fourteen, right before everyone started going to house parties and stuff. It felt like my teenage years were gone already, and that all the nights I was meant to spend out with my friends had been called off, replaced with early, low-stress nights in to prevent seizures.

It didn't really feel fair. That's one of the things I've been trying to get over in the three years since my diagnosis, I was so hung up on how 'unfair' it was, that I let it control me. I spent so long being angry that I had this thing that I couldn't control, and that I'd done nothing to deserve. But at the end of the day, everyone has things they can't control, and anyone can die at any moment. Car crashes and freak accidents kill healthy people my age every day. So, I shouldn't follow the saying 'live every day like it's your last' any more than anyone else, but I'd be lying if I said that epilepsy hasn't made me more appreciative of all the good things I have in my life.

My friends and I make a lot of jokes about my epilepsy. Humour helps, I've always found that. If you can make it funny, then it's not as scary. If there's one thing that epilepsy is, it's scary, so I need a lot of jokes to get through the rough patches. I guess that's it overall. I've faced something this scary at my age and still managed to make a laugh out of it, so anything else the world has to throw at me should be manageable.

At the start of a seizure my shoulders start creeping up towards my ears, just like I'm a bit tense or something. I'll relax and it'll go away for ten seconds or so and then come back, I'll relax again and then it'll come back faster, and so on. Then my jaw starts wobbling and I realise what's happening. Before most of my seizures I can remember being able to fight it off for a while. It reaches a stage where it feels like my entire body is shutting down. Everything is so tense, it's terrifying.

brave

safe overloading headache wooliness overwhelming pills brave wizardry déjà vu

stuck challenge

The worst part is that no one else notices. It feels like I'm going to explode but no one else sees a thing, and I'm focusing so hard on trying to fight it off that I can't talk. I'm just stuck there for what's probably less than a minute, but what feels like an hour in this 'in-between' phase. I'm still there, I'm still conscious. I can see, feel, and think. But I can't do anything. I'm trapped in a body that won't listen to me.

It feels like I'm stuck in someone else's body. It doesn't feel real, it's like I'm watching it all from a distance. All the fear vanishes in the last second and I'm not scared anymore; I guess it's kind of peaceful. I don't like to dwell on the idea that that could be my brain trying to make me feel better before I die.

The feeling of an aura is the same feeling I get right before a seizure, but I don't lose control this time. It's the same feeling as fighting against my brain, but it's like I'm winning. I'm in control. I know of course that it's not me doing that, it's the medication. But it still feels pretty good to be in control of your own brain. I can only recognise it as an 'epilepsy' feeling because it's kind of like déjà vu. I know I've felt it before. It's not an emotion, or even a physical feeling. It's just this thing that seems to take over my entire head for a few minutes. It starts with feeling a bit faint, then dizziness, then the aura feeling sets in and I realise what's happening. Then I am absolutely terrified. I'm more scared of that feeling than I am of anything else in the world.

Then I start hearing a noise, but it's like it's coming from inside my head. It's like radio static and it starts off really quietly; I'm not sure how fast it builds up because I get confused, but before I realise it I can't hear anything else but this static. I'll tell someone what's going on and they'll keep trying to talk to me and ask me questions and I just have to say over and over again that I can't hear them, I'm not sure how loud I'm talking.

It just feels like everything's overloading, like my brain is firing everything it's got all at once and it's spilling over. It starts to calm down and then the static noise gets quieter, but it stays as this low buzzing noise for about ten minutes more. And I'm left really tired, and all I can think about for the rest of the day is how quiet everything seems, and how strange it is to be able to hear my own voice again.

I wake up twice, I regain consciousness a few minutes after a seizure, but it's not really me. It's just the parts of my brain that make me seem awake. My personality, my memories, my emotions – none of that's there. My mum says that it's like looking at a newborn baby again, I'm just empty. I don't talk or follow instructions, but I can walk, and apparently I just sit there and smile for about forty-five minutes. Doctors spend ages trying to get me to say something or communicate in any way, but I just smile, which is a bit creepy and I don't like to think about it because it's weird to be told how you act when you're not really there. No wonder people used to think epileptics were possessed.

Then I just snap out of it after a while. I'm just completely awake. Everyone's asking me questions like what date it is and if I can count backwards from ten, and I have to answer and do everything they ask before they'll believe that I'm awake properly. My brain just fuses the last thing it remembers with where I am when I wake up, and if no one tells me what's happened then I just believe whatever it tells me. It does it so well that once I just stood up from a tonic-clonic seizure with a broken nose pouring blood everywhere and carried on with my day for half an hour before someone sat me down and rang an ambulance. I don't feel any pain. I feel kind of happy, and although I know it's just fake happiness from my brain rebooting, it's still quite enjoyable. The happiness wears off quickly, twenty minutes at most, and then I'm exhausted. It's not a normal kind of tired, it's a kind of tired that knocks you down and sends you off

overloading

withdrawal

for ten straight hours and then hangs over you for two more days. Then the pain from whatever injuries I've given myself – generally a whack to the head of some sort – start hurting after I wake up from being asleep, which is always fun.

I've been free of tonic-clonic seizures for almost three years to the day (from when I'm writing this), and my recent EEGs have cleared me to start withdrawing from medication in September 2019 if I remain seizure free until then. Although my seizures have stopped, I constantly have reminders that my brain isn't quite working as normal. The auras come and go in patches: sometimes I have a few in weeks when I'm stressed, sometimes I'll go months without them. My neurologist says they could be due to the medication itself, or they could be seizures being prevented by the medication; there's no way to tell apart from trying to come off the medication – which is a terrifying idea.

If I no longer have epilepsy, withdrawal from medication will be life changing. The drugs gave me a vitamin D deficiency so severe I was exhausted 24/7, and although I'm now on supplements, I still feel like the drugs are holding me back. Their job is to suppress everything. When I went onto them in 2015 I could almost feel them pushing everything in my brain down, which was good because it stopped my overactive brain giving me seizures, but bad because it made me feel less energetic and alive. The issue is, if I don't have epilepsy anymore, then the drugs are just pushing down the normal things, and I can't help but wonder what it'd feel like to have everything bounce back again.

I have a thirty to forty percent chance of being seizure-free after withdrawal from my medication. That's not a fun statistic to be faced with, but I'm going to give it a go because if there's even a tiny chance that I can live without epilepsy, then I'll take it. The real test of my bravery will be during withdrawal. There's a fair chance I could have seizures during withdrawal even if I don't still have epilepsy, but there will be no way of knowing if these are caused by withdrawal or epilepsy until I'm completely off the medication. This means I could be faced with the decision to carry on withdrawing and face more seizures, or to run back into the arms of the medication that'll stop it and stay living not knowing if I do still have epilepsy. I just hope I make the right decision. Either way, my gap year before uni will be a little different to most people's; no driving, no drinking, no way of affording travel insurance. But oh well, I've put up with all of that for this long.

Evie

Epilepsy is so unpredictable; it looms over you. When you wake up and see everyone staring down at you, it is the worst feeling and it ruins the day.

Paige Rannigan

My epilepsy is a burden and a constant weight on my shoulders. And although it's part of what makes me who I am, for me it means constant worry and feeling ill.

I'm asleep when I have tonic-clonic seizures but in the days and hours beforehand I feel unexplainable anxiety and immense exhaustion. Before my myoclonic seizures, which are very regular, I feel like my brain is tripping or skipping a beat, all while feeling cloudy and dizzy.

After a seizure I feel scared, confused and nauseous, with amnesia. My body hurts and aches and overall I'm exhausted for days afterwards.

Scary, inconvenient, inconsiderate, cruel, persistent.

It's constant and something you never get a break from. Even when I'm not having a seizure, there are always symptoms present and overall it's just a dark cloud over my head.

cloudy headache looms

nauseous

constant

can't empty

Lily Crank

There are lots of things you can't do when medication is controlling your life. You can't socialise or you don't want to. You can't exercise. You can't go to work. You can't eat properly, you can't sleep properly, you can't drink alcohol. There is a myriad of things, that you want to do, that you feel everybody else is doing, that you can't do.

Gordonnay Gaines

invisible illness

it's important people know
i am a person with epilepsy
that i support everyone with epilepsy

my initial seizure
as a high school senior
happened in front of my classmates
& the last?
my father had to physically knock down the bathroom door

explaining the emotions associated
with such a confusing experience is completely senseless to anyone
who has no clue what it's like

going through such trauma
that creeps up at the most inopportune times
when happiness and joy are the
only things on one's mind

sometimes i wish i won't wake.

side effects
anxiety
wondering when's the next one
everyone surrounding you in the hospital
asking do you know who they are, is scary

what if you woke,
not to recognize a single face
ever again?

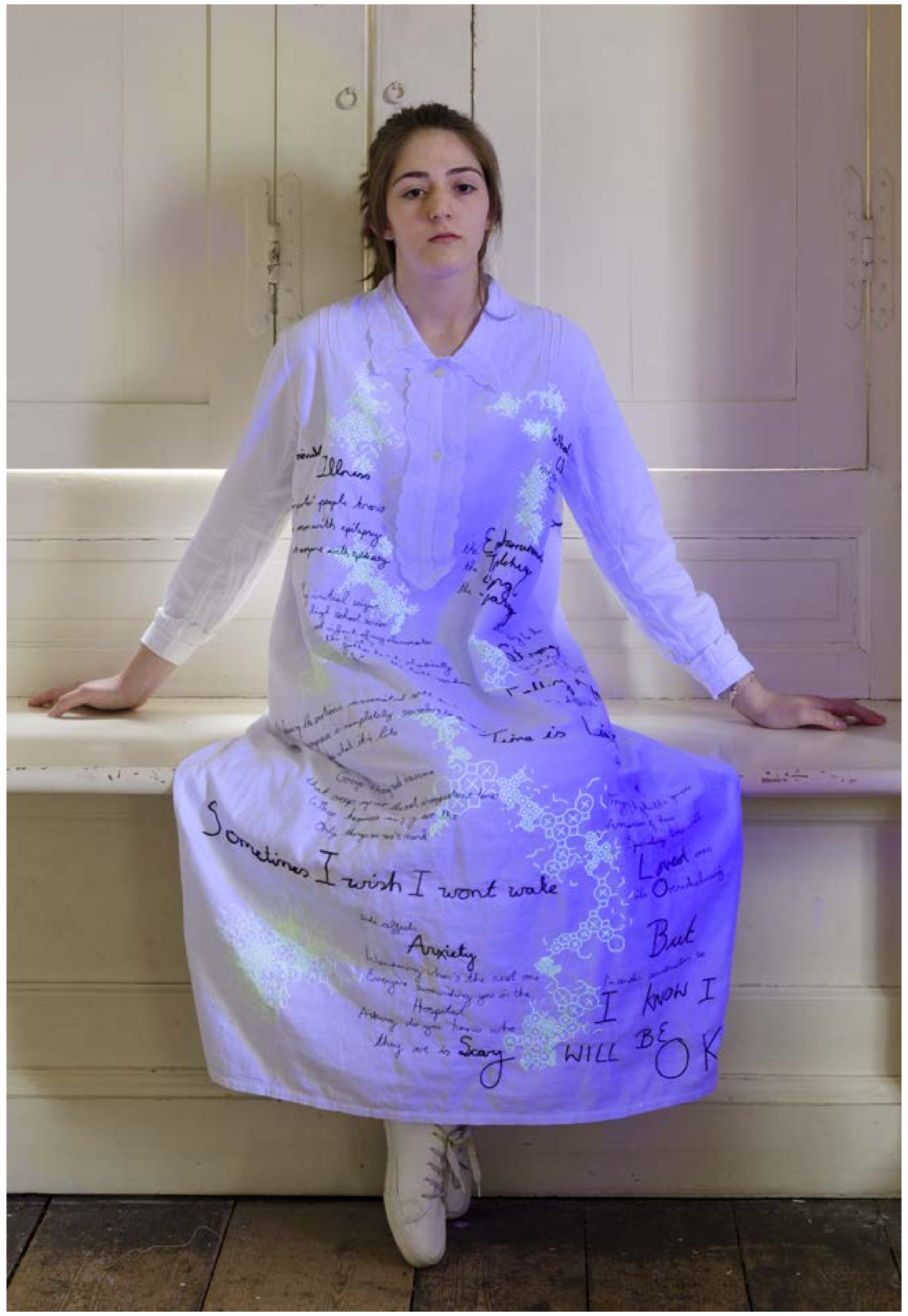
the embarrassment due to
the twitching
the staring
the passing

attempting
to be strong
when it truly feels as if
your entire world is falling apart
it's difficult.

time is limited.

school
work
trying to get the proper amount of sleep
spending time with loved ones
it's overwhelming

but i'm under construction
so,
i know i will be okay.



overwhelming

Elizabeth Reid

The brain of a person with epilepsy has a unique quirk and can have a hiccup with or without any warning during circulation. No two brains are exactly identically affected, so each person affected by epilepsy acts, responds, reacts differently.

> Aura inside top of ribcage
> Tingling toes
> Scared, imaginary man in black coming up close
>   behind me, need to stand with my back against
>   something for protection.
> Worry what kind of seizure may come.
> Aura, complex partial or worse?
> Imagine hospital/ambulance, flashbacks of
>   previous seizures.
>
> If no seizure comes – relief, but also worry of
>   another episode coming soon.
> If the seizure does come – mind is blank, tired,
>   upset, embarrassed.
> Usually back to 'normal' next day.
>
> My epilepsy is complex partial (mesial temporal
>   sclerosis), since childhood – I've not known life
>   without it. It's on my mind 24/7.

I was diagnosed with epilepsy when I was seven years old, and have been on medication since then. My epilepsy has been well controlled with new medication since 2003. I take fifteen pills a day. I choose to float in my bubble without seizures as opposed to reducing pills and having seizures. I was employed as a civil servant for twenty-seven years, but had to take medical retirement in 2014 due to the side effects of the medication.

difficulties   aura

Jayne Shipley

Now that you are still, others
are all arms to tame you. They press
beads into your scalp, to read
the patterns of your mind. I want
to be the one
to soothe you; to be the one
to brush your knotted hair, to pull you back,
to whisper the name I gave you.
I think of the moon and wait …
whilst nurses cast spells
in the negative space between us.
Doctors perform their wizardry.
Now that you are still, I take
the time to breathe.

Max Eilenberg

If you're blind, you're blind. You don't have blindness. If you've got a cold, you've got a cold. You are not cold. I have got epilepsy and I am epileptic: it's one of those things where you have a condition and that condition defines you.

When you ask what epilepsy means to me I think of it as being a constituent part of what I am. There's no getting away from it. It's a constituent part of me in the same way as if I'd been born with one leg.

Being epileptic means a combination of things, some good, some bad. The bad thing is that it's a life challenge. To put it into modern day language, it's a disability. And yet it's also something that's seriously good. It used to be associated with magic, so mad men and wise men could be epileptic. However, I know that on balance I would prefer not to have epilepsy, not to be epileptic.

wizardry

epileptic

born self brain

brain

Epilepsy also means that you have to take medicines and drugs for all of your life. It means trying to find in my life a balance between the medication and what it liberates you to do because epilepsy prevents you doing certain things. And the disabling consequences of the medication… that is the whole problem of ‘cure’ and its consequences. It means a whole constellation of things.

It is very, very difficult for me to make swift decisions. If I am really thinking about something, I like to hold all the possibilities in my mind before saying ‘Let’s do that.’

I feel as if something happens in my brain, and that what happens is an insult – an insult to everything I would like to think of as myself, an insult to self. And of course, myself is lodged in my brain.

There comes a moment during an epileptic fit when my *self* ceases to be, as a result of some activity in my brain. I can’t say therefore that my brain and myself are identical. I have to say that my brain wipes my sense of self clean, and that then my sense of self re-emerges from somewhere else in my brain.

Stephen Hagon Hood

Epilepsy has made me look at life differently. It puts me on edge wondering when my next seizure might be or how bad it will be, or even if I will come round again after it. But it has become part of me because it also makes you think ‘fuck it’. Why let anything stress you out? – because if I get too stressed it can happen, so I suppose it makes me care less about some things, as if they are not important. I wouldn’t say it has stopped me enjoying life but I have had to adapt my life around my epilepsy – so that takes me back to the point. Just say ‘fuck it’. It is what it is.

I believe the medication is more of a mind game as it makes me think it can't happen when in fact it can at any time, any place. And it was hard at first but now it's okay. If it happens, it happens. Nothing no one can do will stop it. That's epilepsy… if it happens, it happens. It is what it is.

Anthony Williams

As a seizure looms there is a sudden intense feeling of fear with a horrid sensational metallic taste around the throat. The stronger the taste the more severe the seizure is. Quite often if the taste is weak it lingers around causing clusters of smaller seizures, but if the taste is really strong it can make me unconscious immediately.

If I had a severe seizure, there was a good chance there'd be no lingering auras afterwards, but my muscles would often be very achy, sometimes for weeks after. When seizures were small there was a good chance the aura would linger around until I had a more severe seizure when it might disappear for a bit before returning again without warning.

Epilepsy is horrid, frustrating and soul-destroying.

Epilepsy completely hid my true self because it was so frustrating and gave me thoughts of suicide. It was soul-destroying with not many people around me who understood what I was going through.

Once diagnosed, life went from reasonably happy to very depressing. I tried to find employment and other useful things to do with my time but all failed as my seizures worsened which made me more depressed. After years of frustration I was offered surgery which revealed who I was really meant to be. Now my seizures have finally ceased!

fuck it   depressing

clusters frustrating

soul-destroying alarmed

Emma Roy-Williams

I was diagnosed officially with juvenile myoclonic epilepsy when I was eighteen years old. This is after having two grand mal seizures in one night in a beer garden in New Cross, South London, in front of all my university friends. It wasn't my first seizure; I'd had one in bed when I was still living with my mum in Manchester. It was after a pretty heavy night clubbing and my stepdad, who is a doctor, told my alarmed mum: 'That's an epileptic fit'. But I have always preferred calling them seizures – it sounds less Dickensian.

I have taken three different types of medication but I still have grand mal seizures and absences. I am taking Keppra at the moment, a drug which I hate. It makes me angry very quickly – known as 'Keppra rage'. I am slowly introducing Lamotrigine into my life, which I've taken before, which has fewer side effects. Epilepsy has affected me in so many ways and I have suffered from a lack of self-esteem a lot – but now, as an older woman I am not ashamed to say: I have epilepsy.

Tom and Louise S

I have worked with my daughter Louise on these words. She has a mutation in the DCX gene that resulted in her being born with epilepsy. In fact, she was having seizures even before she was born.

DCX

It's what I'm made of
It makes me who I am
It makes me swim faster
It makes me row longer
It makes me a winner.

headache self-esteem

Louise has lived with epilepsy all her life and so to her its ‘normal’ as she does not know what it is like to not have seizures. Sometimes Louise gets upset about having epilepsy and learning difficulties as it impacts her life, not being able to be independent.

After a seizure Louise is confused. It takes about thirty minutes to recover, to be aware of where she is and who is about her; after that she is fully chatty and can continue (though not swimming as it’s a bit risky).

If it’s a grand mal, recovery could take longer: it’s like swimming two thousand metres, she’s so exhausted and needs about twelve hours’ sleep.

Sometimes she can be injured and need a lot of reassurance as to where she is and who is there. She is known at the local A&E so that helps her feel comfortable with maybe having an X-ray and being stitched quickly.

Ashley Warwick

To me epilepsy is like my own personal monster that never leaves. I can see the destruction it causes but no one else can see it so they don’t always understand what’s happening or why I struggle so much.

After a seizure I often feel a bit like I’m drowning. I can’t make sense of where I am or what’s what. All I want is to go to sleep so that it will all stop.

There is so much involved in fighting epilepsy and sometimes the medication that controls the seizures is as bad as the seizures themselves. It can be like a never-ending battle. I’m just thankful that I can still lead a relatively normal life. My experience of epilepsy has helped me to raise awareness of it in the workplace, so I suppose I would say it has created a unique opportunity and ability to understand what others may not.

struggle

controlled winner rebooting constellation aftermath battle

disappointed resilient

Shona McIntyre

My epilepsy has been controlled by Tegretol since 1985. I feel very lucky and am able to put it out of my mind.

I felt out of the room while medical people talked to my mum about my first seizure.

I have become understanding as to how other people with conditions suffer. I felt different, but hated to be called 'Epi'.

Rebecca M

What does epilepsy mean to me? It means I'm emotionally and physically drained. It means the absence of my freedom and independence. Isolated. Fear of death and stabbing sadness in my heart.

After a seizure, my body feels as if I have drunk a bottle of whisky, then decided to run a marathon, tripped down a hill while hitting my head off a rock. Emotionally, I'm disappointed at my body and saddened by other people's reactions towards me due to their lack of empathy/understanding.

On the positive side, it's character building. It's helped me to learn to access inner strength. I am trying to get on with life while dealing with this long-term illness and I don't let my condition stop me.

On the other hand, I'm hugely disappointed by the lack of research into the condition and the lack of support from the NHS. It's disgusting that CBD isn't actively offered to sufferers instead of drugs filled with side effects. Epilepsy is hardly ever reported in the media but it affects so many people. Empathy and understanding of others are so rare. I take twenty-four hours to recover after a seizure, yet my work would still expect me to get up and come in. They think I'm lying – due to their lack of knowledge. Just because I'm young they believe I'm perfectly able to recover instantly. I can feel very isolated and misunderstood.

Hollie McBride

confusing madness strange heartbreaking terror
blank scared shaken worried emotional embarrassment

different understandings of others strong fighter serving

Epilepsy isn't just about the fit itself it's the aftermath
that follows to yourself and loved ones and people
around you people standing back as their first impression
is drink drugs never judge a book by the cover until you
know how it is to stand in my shoes then don't judge

Florence Collingwood

There, then not there
So momentary it is almost unnoticeable
But left, like a dream
Is that real, I am here, or there?

Fiona N

An absence is like watching an old movie in a cinema when suddenly the screen just goes blank as if the film had broken or torn or melted. Absences are like a break in projection. There is a millisecond when the screen just goes blank.

Sometimes people notice it; sometimes if you are in the middle of a sentence you won't make it to the end. Sometimes you can cover it up… People often have moments when they ask, 'What did I just say?' It is not total loss of consciousness; you don't faint and you don't drop to the floor. It is just that your mind goes completely blank for a millisecond. Then you regain consciousness and you simply continue what you were saying.

I also have photosensitivity where the absence is triggered

embarrassment

absence

unnoticeable disability?

isolated possibilities millisecond

by an external stimulus: light. Last year I was on a train and it was a really bright, sunny morning. The conductor asked for my ticket at exactly the same moment a ray of light hit my face and I could really feel not being able to respond – and then covering it up as you do. He probably didn't pick up on it at all; you find ways to cover it up.

The condition itself I can't do anything about. It is simply part of me, who I am. But I do have choices about what, if any, medication I take. Some drugs might work better for me than others. I sometimes wonder if I would have had fewer fits without taking any medication.

And then you have problems like, for example, pregnancy. I talked to someone recently who is epileptic and pregnant: there are huge choices about medication to be made. It sometimes takes decades for the side effects of drugs to become known. You are damned if you do and damned if you don't.

Would you say that epilepsy is a disability? When you define disability it probably doesn't feature as one. I think you could interpret it as such because it gets in the way of being able to do things. What is a disability? The perception of the epilepsy can be more disabling than the condition itself.

Kendra Krupp

I've been fighting with epilepsy my whole life. The worst I've ever been is over three hundred seizures a day. I'm twenty-seven, soon to be twenty-eight. When I was twenty-one I was told I'd have full-blown Alzheimer's by thirty. I'm doing better now, not seizure-free but I can function. When I get sick or stressed they're much worse. When I was having hundreds a day it'd take me over four hours just to get dressed, brush my hair, put on socks and shoes. I lose time, sit up in my sleep, scream, laugh, cry, see feel and smell stuff that isn't there. I've been suggested surgeries but I turned them down. Epilepsy isn't just shaking and falling down. I got picked on in high school, no one understood.

Jane B

I was thirty-five when I had my first grand mal. I was walking with my husband and daughter. I started to say 'I feel funny' but I never finished. I came to with my husband and daughter kneeling over me. My daughter looked sad and scared, my husband looked worried. I didn't know why. I didn't know anything. When I woke again I was in an ambulance. My husband and daughter weren't with me, I was afraid. I didn't understand what had happened. I became very anxious and agitated. Weeks later my husband told me that when I came round, I said 'I want my mum'. My mum had died nineteen years previously. It upsets me to know that deep within my psyche, I want my mum.

Sophie

I am twenty-one, a university student living with temporal lobe epilepsy.

Epilepsy means restrictions on what I can do. I was a competitive swimmer and can no longer do the one thing that I cared most about. It also means last-minute changes to plans and feeling isolated because of this. Most of all, epilepsy leaves me in a constant state of anxiety over when the next seizure is coming. Epilepsy now controls my life.

After a seizure my head feels like it has been smashed against a brick wall and my whole body aches. My epilepsy nurse once told me she had a patient who was hit by a bus and they said that was less painful than a seizure. I am usually completely confused, I don't know where I am or who is

stressed

agitated

ache

around me. If I have a seizure in public, the worst feeling is embarrassment. People stare but I think I probably would too if I saw someone lying on the ground.

Epilepsy has made me resilient, stronger, more determined and appreciative of the good days.

It doesn't just affect me but my whole family. My brother has missed out on holidays, been left at a friend's whilst I'm in hospital and had my parents leave his important sports matches because of me having seizures. My parents are constantly worrying about SUDEP – sudden unexpected death in epilepsy – and what lies ahead for me.

Claire O'Hara

I started having tonic-clonic seizures when I was fourteen years old. No family history, no other illness/difficulties, they just came out of the blue. I was massively scared as the cruel thing with my kind of epilepsy is you never know when the next seizure is going to strike. I was studying for my GCSEs at the time. My greatest sadness was I had to stop swimming and riding a bike. At fourteen this was a big deal.

Epilepsy to me is frightening, no less frightening at forty-four, my age now, than at fourteen. It's the last thing I think about as I go to bed, wondering if the next seizure will be tomorrow, and the first thing I think about when I wake. Stress and lack of sleep are the triggers for me to have a seizure, I try to live as stress free a life as possible but when I get inside my head too much I end up stressing over how to be stress free!

At twenty-four I went through a medication change which left me with panic attacks as the frequency of my seizures rose. I wanted to start thinking about a family but the medication I'd been on since fourteen was sodium valproate – a disaster basically for the foetus. It can cause spina bifida,

sudep medication

amongst other complications; hence the change. The panic attacks left me feeling very low. I wouldn't leave the house for fear of having a seizure in public.

It has always struck me that it was worse to witness a seizure than actually suffer from one as you really don't have a clue what is happening.

After a seizure, it is like a light being switched on and off over and over again inside my brain. Those who are most familiar to me, my family, my children, are for a short time strangers. My mouth is sore as I bite my tongue and the muscle pain is excruciating. A seizure is the equivalent to running a marathon.

My epilepsy has taught me to keep things in perspective. I am one of the lucky ones, I have a great close family network around me and my husband is unbelievable in his support. He is proud to tell people about the condition and how I deal with it. My children, both girls, are growing up with a clear understanding about epilepsy and have much empathy for others they may meet with the condition. Epilepsy has, in my opinion, built my sense of humour and made me more strong-minded.

My seizures are fairly well controlled – I was averaging perhaps one a year and I am currently seventeen months seizure free. It never leaves you, though; you just never know where or when the next one will be.

The most important part for me living with epilepsy is I have and never will let it define me, it's just part of me and I wouldn't be me without it.

Rachael Hepton

I am twenty-six years old and I was diagnosed with epilepsy when I was fourteen. To me, epilepsy is an unseen piece of me that only shows itself when I have a seizure. It's taken my life away and given me something completely different.

confusion frightening

assumptions repair witness

excruciating drained soul uncertain

robbed cloudy

headache looms disorientated

blank soul-destroying define me

surgery

persistent void worry

After a seizure I feel burnt out, just walking without anything left inside. Aching, usually have a headache as well, and need a sleep.

I was fourteen when I was diagnosed with epilepsy. I had my life planned out, I was going to go to uni, get a flat and have a really good job. Then bang! This happened. The life I had planned dropped and went into sawdust. My GCSEs turned out bad. I couldn't get a job as I was constantly having seizures. In and out of hospital. I was twenty and had surgery for a VNS for my seizures. Yes, they've reduced but I'm not fit free. Wouldn't wish it on anyone. Constantly taking pills just to stay out of hospital. That's epilepsy.

Alison Armshaw writing about her daughter, Laura

My daughter Laura is eighteen years old. She has epilepsy, along with cerebral palsy. She can't write, so I'm doing it for her from both of us.

Laura was born with cerebral palsy. She developed severe epilepsy, having sometimes hundreds of cluster tonic-clonic seizures a day. This dominated her life, our lives, as you never know when it's going to strike. Laura had surgery which was successful in eradicating her seizures for some years. It completely changed her life – she started learning more, absorbing more. She was much happier, more confident and life was much better. The worry is always there that she will have a seizure. But none of this stops her being the loving, bright, funny, charismatic and charming young woman she has grown up to be.

Mariz Lerona

My epilepsy was a wakeup call. Before it I wasn't paying attention to my health – poor eating habits, driving myself to exhaustion, and lack of sleep. When I first had epilepsy, it compelled me to review my lifestyle and change. Sadly it has affected my whole life as I am a student, and have to work and study long hours. Since lack of sleep and exhaustion are triggers, I have to choose between work and study.

> Exhausted, muscles are hurting especially in my legs, arms, and neck. Migraine, continuous 'ting' sound in my ear, sensitivity to light and sudden movements. My stomach and chest feel void.
>
> Reminder to take things one at a time, to be humble, to appreciate every moment, and to live consciously.

There will be times where I'll be confused as to why I've had an epileptic episode. I've looked for the cause so as to avoid it or minimize it, but I am having a hard time pinpointing it. It's difficult to accept the disorder when I feel healthy and then I'll fall all of a sudden.

> Feeling empty sometimes happens but think that it shall pass. Engross in activities that feeds the soul.

Manveer K

I am twenty-one and had petit mal from ages five to nine. The absences caused me to fall behind during school and the medication caused weight gain which has never left me. After ten years of being well I was diagnosed with epilepsy in my second year of university aged nineteen following further absences.

exhaustion fuddle

sudep medication empathise

lifestyle

My epilepsy makes me constantly anxious as I have no control over my seizures. This causes me stress which may help trigger a seizure. I hate that I have to take medication daily. WHY ME?

Beth and Hannah Savage

On guard
Hyper alert
Researching
Researching
Drugs don't work
Researching
Researching
Lifestyle change
Researching
Researching
Cannabis claims.

Epilepsy, migraine
Triggers – the same
Flashing lights
Screens
Fuddle the brain
Illness, and stress
Late nights
Some foods
Hormones, excitement
They do us no good.

Going out to work each day
Epilepsy hidden away
Until the grand mal
Exposé.

Catherine Youngs

I like to pretend that I haven't got it and that I can prove them wrong. So I guess by that that I see my epilepsy as a form of weakness or attach some level of shame to it. I remember when I was diagnosed at the age of nineteen my mother told me not to tell my grandparents as they would be too upset. I'm not sure if my brothers know. It's become a bit of a family secret. I don't tell many people.

When I was diagnosed in 1984 I had had a particularly bad attack after a series of jerks and falls whilst studying a B.Ed. at polytechnic in Newcastle upon Tyne. I put it down to partying hard and keeping a full-on life of late nights and a full teaching and studying timetable. In a panic, fearing lateness, I had rushed to teaching practice with really bad carpet burns on my face and was told to go home by the headteacher. The nurse on site referred me to the Royal Victoria Hospital in Newcastle and I was seen straight away. They diagnosed me there and then. The consultant told me that I might as well forget teaching as a career, that I wouldn't be able to drive, that I should forget swimming and certain sports. Subsequent consultants and obstetricians have told me that I would be unable to have children or neurotypical children, or a home birth.

I have proved them all wrong – I am a senior teacher at a learning support service in inner London specialising in the inclusion of children with complex learning needs (driven by my history and experience). I have two neurotypical daughters (I stopped taking my medication when trying to conceive and pregnant due to fears of potential sodium valproate syndrome); both were born at home. I have not only taught but have had a full and rounded professional history leading to high level of responsibility. I have a full and healthy life and lifestyle that includes a range of sports, including swimming!

I don't get full blown seizures – my epilepsy is called

secret fall

dizziness

myoclonic epilepsy. It starts with a small involuntary jerk which can be quite minor, which can lead to a stronger one/ones, which can sometimes lead to a fall. It feels frightening. I get in a panic – which probably doesn't help.

Afterwards I feel shaken and disorientated. And a bit frightened. I often get them when I've got up early for something, am stressed and have been rushing around. I will get them when I am in the shower or getting out of the shower or getting dressed, so I am often naked when they occur. I guess this makes me feel particularly vulnerable. Because the jerk/fall is involuntary and brings such a force with it, I can drop to the floor unable to put an arm or hand out to prepare or break the fall, leading to painful scrapes and bruising.

I have to respect my epilepsy and take heed of it. I have to keep it in check by medication and how I maintain my health and lifestyle. But it is not me; it doesn't rule or define the pathway of my life. It's something that I have.

Abba Baba

I am from Nigeria and a nurse by profession. I'm currently an epileptic patient on anticonvulsant medication. To me, epilepsy is an abnormal electrical discharge of the brain resulting in its signs and symptoms.

Prior to the episode my vision tends to become dummy and somehow I am not perceiving reality at which point then I fall unconscious. The precipitants associated with my spell are severe hunger, sleep deprivation and over-ventilation. Afterwards I feel headachy, dizziness and my body aches. I also have temporary loss of memory.

Those whose have witnessed my spells tell me that I jerk my whole body, then my upper and lower limbs become stiffened and I bite my tongue as well as shouting for at least five to six minutes.

I have undergone EEG and it shows that I have a generalized seizure disorder. I'm currently on a low dose of Tegretol because the frequency of my spells relates to my own negligence of the precipitating factors I have stated previously.

Annette A

'Medicines aren't going to help you
There's no therapeutic value in what you take.
Learning to manage your condition
That's what you've got to do,' I was told.

My consultant doesn't know me,
My life's all topsy turvy.
How can I make anyone understand
The pains, strains and torment
My body endures daily and nightly?

Sixty percent of the time I am fine
You really would think that nothing is wrong,
But my brain has other ideas.
Misfiring electrical circuits
Make my body contort and shake, violently.

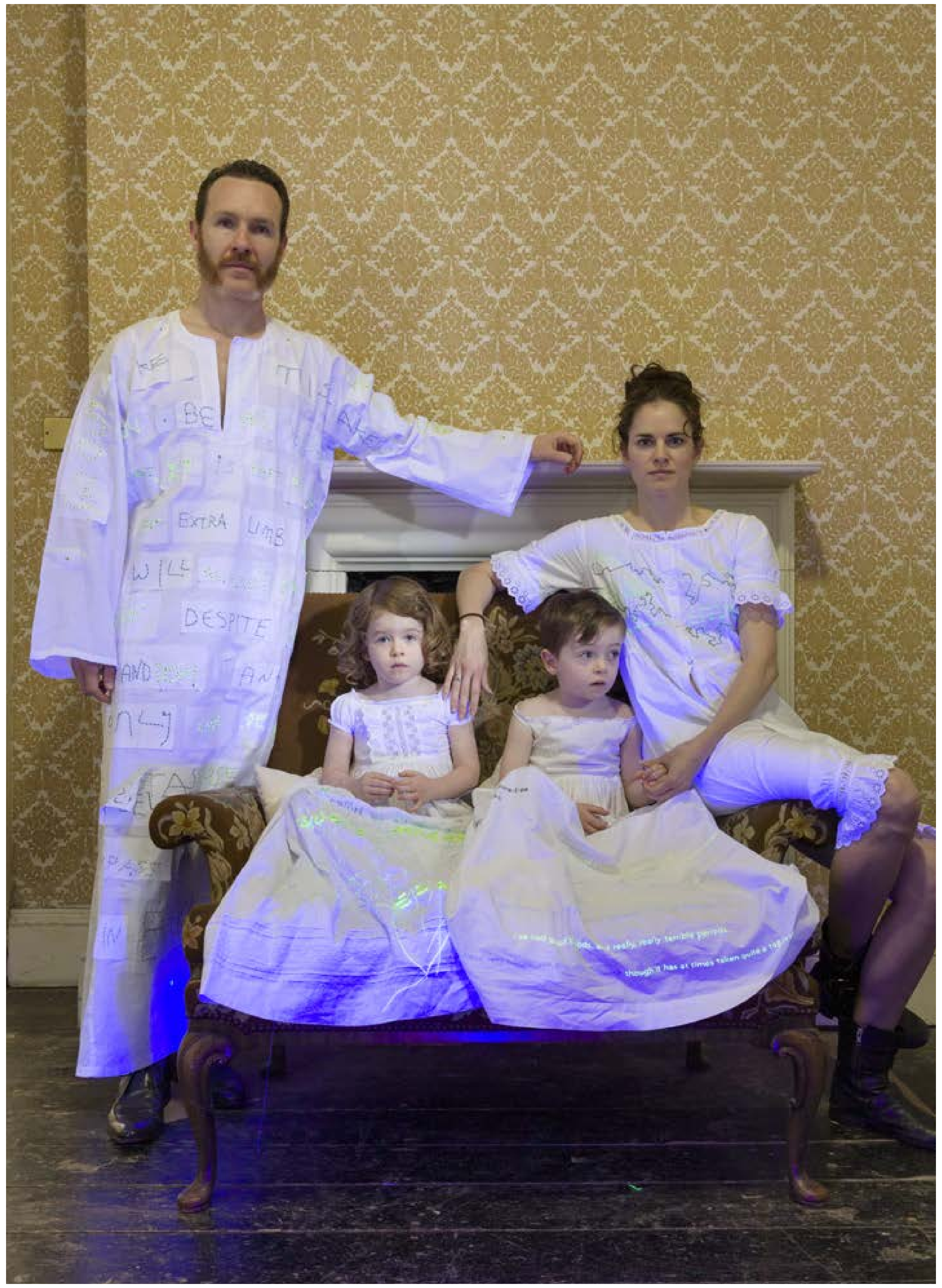
Scary to behold, powerless to help.
MUCH much much worse to experience,

At that moment *anything* could happen...
It's so overwhelming you don't see an end.

But it does end.
And you are ok.
Maybe battered and bruised,
But the only way to cope is to forget how bad it was.
Until the next time.

bruised

malfunction baffled soul-destroying stop unseen persistent drowning



accept nic's painting understanding empathy

Deborah Bassett

Epilepsy.
Such a small word.
It came like a thief in the night.
It robbed me of my dignity, my independence,
my confidence, my memory, my energy, my driving licence,
and the holiday of a lifetime.
It reminded me how much I love my family, not to take life
for granted, and to live for the moment.
Its legacy is my resilience, patience and empathy.

Vicky Chadwick

I wrote this poem to describe how I feel about my daughter's epilepsy and how I see it as a battle.

The Seizure Fairy

It's just a malfunction she professionally said,
of the wires, components that reside in her head.
We have no idea why we can't explain the reason,
it's not the weather or her age or the change in the season

But you see it's so simple to describe it this way
when you're telling a parent this news every day
When the charts and the graphs show the fairy inside
playing tricks with the buttons inside my child's mind

When you're curled on the hard floor beside as she sleeps
When you're listening intently to make sure she breathes
When she wrestles a bad dream and tosses and turns
When you pray for her safety and her future you yearn

It feels hopeless controlling as medicines take hold
When you think they are working and the seizures unfold
The appointments the test the opinions advice
The desire for answers, you would pay any price

Then in time with a pardon we start to get bold
To tackle the bitch fairy and lessen her hold
With plans and with strength and with courage we fight
To restore life to the time before the fairy took flight

Now she lives in the background she rarely comes out
Her vindictive poison we are mostly without
We have slain that bitch fairy her power we've smothered
Dear bitch fairy heed this and don't take on A Mother.

Steven Connelly

It was a typical and normal Saturday morning routine of emerging from bed, relishing in a ravishing bath with intentions of preparing to get organised for meeting my friends in town. I was on my bathroom floor surrounded by paramedics and my father, I was baffled and overwhelmed at the circumstance. When they told me that I had had a seizure I was distressed, completely bewildered.

After a seizure it takes a long time for me to become fully conscious and back to normal. I often feel disoriented and unconnected from the world for several hours. I also experience a massive pounding in my head which goes on for days. Vertigo, my whole world is spinning. It's extremely frustrating and frightening. There's nothing I can do apart from resting and sleeping; most times this is impossible due to the injuries I have sustained. I feel persistent torment and anguish as I dislocate my shoulder every time I suffer a tonic-clonic seizure.

invisible

Tatjana Keane

My son Luke was twenty-three when he had a strange event one morning in March 2015, while asleep in his bed. This was the first of three focal epileptic seizures to happen over six months. He was put on medication and is now on a third type. He has developed some other types of seizures which are not noticeable but annoy him a lot. He was a brilliant young graduate about to do a PhD in psychology at Cambridge. Life became uncertain, disturbed, worrying… He has since embarked on a Master's course and is doing well. We are waiting for a surgery as that might be the only way to control or minimise his condition.

Epilepsy is often an invisible blight. It can strike suddenly and with huge impact and consequences. Our family was devastated. We couldn't sleep worrying every night if he would be ok. As with anything else though, one learns to live with it, we are all 'coping'. Luke is doing as best as he can. The medication has changed him. His confidence, his personality traits have altered. He is stoic. He doesn't like talking about it.

I can't think of any positive words or sentences connected with epilepsy. It is all about loss, upset, crying and fear. Hopes dashed. Unknown future. And a loss of it. SD, sudden death. I know there are worse illnesses. But when it happens to you, when is not controllable, there is fear. No sleep. It's devastating.

Silences… how to tell and who to tell.

I would like to embroider the phrase 'MY SON' on one side. On the back I would embroider 'Desperate want for a repair'.

Judith and Nicola

I am Nic's mother and so I am not able to describe how she feels but at fifty she has battled with this condition since she was four – with intractable epilepsy; the psychosis came later. Treatment has not helped this situation although she tries hard to not to be affected by the voices. I find it interesting that she is able to express so graphically how she feels even if she finds verbalising how she feels very hard. In Nic's painting she tried to explain a seizure.

Lessa Liggat

I've had epilepsy for thirty years. My record of being seizure free is two and a half weeks. It's had a significant impact on my life, and that of our family, but I've been married for nine years and have two children, both on the autistic spectrum. My mother has also developed epilepsy in the last few years. I've had good periods, and really, really terrible periods. Sam has always been very supportive and understanding, though it has at times taken quite a toll on us both.

I often write, but when my epilepsy is bad that is impractical and frustrating. I repeat sentences, miss words or phrases, misspell things ridiculously or cannot force my hands to obey. When they are too bad to write, but not relentless I'd crochet instead, but this requires the ability to count accurately. So when that breaks, I would paint instead. My carpet is ruined courtesy of paint because my coordination is shot and I dropped the brush so often, but it's a way that helped my autistic son to begin to identify feelings when words don't suffice. Due to the effects of my temporal lobe epilepsy and multiple seizure types, I have experience of 'not having the words' and being frustrated by that or feeling trapped.

Seizures and postictal periods, with drug side effects,

nic's painting understanding

nic's painting

trapped

uncertain drained soul excruciating

cloud things. They blur all of my emotions, and often intensify any negative ones such as fear. It breeds a gallows-esque style of humour, and I have lost friends due to having severe periods. For me a flare up isn't a week or two. They usually last months. The ages of twelve to nineteen are pretty much a blank for me. I am not bitter about that; I do wish that I remembered some things though. Like how my husband and I got together in the first place, and which exams I sat (I remember a few).

Alasdair Wilson

My epilepsy is a real pain; it knocks you down when you least expect it. My head feels like it is going to explode. I feel completely drained physically and mentally and it takes two days to recover.

Go out live your life make mistakes learn be all you can be. Accept it is part of you like an extra limb and you will accept and thrive despite it. Resent and deny it and you will only ever be able to exist as those feelings will encompass and hold you back in everything you do.

Anonymous

Epilepsy is a life-robbing, soul-destroying, terrifying part of my life. It is very infrequent, which in turn makes it more terrifying, not knowing when it will strike. In the long periods between I eventually become complacent, thinking maybe it won't happen again, or maybe not thinking of it at all. Then I suddenly get ambushed by it and am robbed of all sense of dignity.

I am panic stricken and experience an extremely high sense of awareness of myself and my surroundings. I focus on controlling my breathing so I don't become hysterical. I find ways to make myself safe for the duration of the seizure, knowing I may die. Within seconds – if there are others around – I find someone to help, I find a space to lie down, inform the 'helper' what to do before launching into a grand mal seizure.

To the onlooker, I am unconscious, but for myself I have a sense of my arms being directed in different directions, of my left hand contracting so much it's extremely painful, and I feel pain although I appear unconscious. I have a sense of my legs stiffening, of the terror, the lack of control I have of my own body. I can't stop it.

During my first seizure I felt dizzy and rather cruelly before losing consciousness had hallucinations of a brain with light bulbs lit up within it. I was unconscious and unaware to start with, then I became aware of my 'consciousness' lifting part-way out of my body and that I couldn't breathe. I heard my husband saying, 'Shall I get an ambulance?' I was screaming in my consciousness, 'Yes! And tell them I can't breathe!' I still felt the panic, before becoming unconscious again. All through that my body was in a state of unconsciousness. Apparently I had turned blue. In a seizure, I usually do regain consciousness just in my awareness, not my body, but the first seizure was the only time I realised I couldn't breathe.

I am usually incontinent during a seizure, which is highly embarrassing. It's also distressing that the ambulance crew inform you that you have been incontinent. I understand why they do that, but it sounds like an accusation, and creates acute embarrassment in me. After all, it's not something I am aware of or have control over.

After the first one I had the mother of all headaches – it was difficult to lift my head for a week. Subsequent seizures have differed in recovery. Sometimes I become aware that I am screaming and yelling, 'I am not going to do that again!' I have a feeling I mean not take a seizure again. I think this must be like a fugue state as I am not aware at the beginning of the shouting.

ambushed

terror me

headache wooliness

robbed disorientated

I am not in charge of when seizures occur, which is bloody annoying. After a seizure I feel disorientated, acutely afraid and embarrassed, on edge – sometimes for weeks afterwards – and exhausted.

I experience different sensations in my head, wooliness, pain, clouded over like some part of my brain has switched off. Post-seizures I become agoraphobic and experience panic attacks when I go out shopping.

I make myself go out because rationally I don't have seizures in quick succession – they're usually months, if not years apart. It doesn't stop the terror of the possibility of it happening again. My hands start tingling and I get panicky and hyperventilate, so I talk myself down whilst taking longer breaths and practicing mindfulness techniques.

It's exhausting, and I am invariably fatigued and anxious. After my last seizure I avoided going out as much as I could for months; my husband had to get most of the shopping.
I eventually started seeing a therapist to reduce the anxiety and to put things in perspective as I was due to start college in the next academic year, so something had to be done.

My epilepsy is infrequent but still terrifying even when it's not happening. The possibility of a seizure continues to cause anxiety, albeit not so debilitating as before. It has been two and a half years since my last grand mal, but almost every day a muscle twitches. I get migraines which can present with some of the same symptoms, and I have to tell myself, this is not a seizure.

The seizures robbed me of my first career, and for years they robbed me of my self-worth, self-belief and self-confidence.

I worry if my children will 'inherit' this disease and the symptoms I experience. I don't take medication because medication can induce seizures, and as mine are very infrequent, it's not optimum. At a time of extreme anxiety I did start taking one of the medicines, as I thought it would help reduce the anxiety if I 'eliminated' the possibility of taking a seizure.

However, even on the very low doses I was getting very worrying side effects – limbs doing weird things, strange sensations in my head, a burning sensation on my hand which took months to go after stopping the tablets. I am aware that I could die at any time I take a seizure, but I don't tend to dwell on that. It's more the anticipatory anxiety that I suffer with, except when I *do* take a seizure.

Shannon McCarthy

Epilepsy is the scar that keeps speaking. After a seizure? Mind and body are beaten, my heart is raw. God help me. It hurts.

I feel union with the human heart that suffers. There is a light.

Nick Martin

I was diagnosed in 2016 at the age of twenty-eight, which was difficult to come to terms with. Living life without any kind of problems then BAM! I have my first couple of seizures/episodes. Driving licence gone for a year, people asking if I'm going to fit in front of them, people making assumptions about it, repeating the same shit jokes about it. Doesn't really bother me anymore but the first year was hard.

It's quite a lonely disorder to have. It's not visible. No one else understands how you feel when you've had a seizure. So I'd say immediately after a seizure is the worst I have ever felt. I wake up not knowing where I am, wondering why I feel like I've been for twelve rounds with Mike Tyson. Then I realise what's happened.

Epilepsy doesn't mean much to me, it's just a part of me now. Something I have to live with and something that I'll probably never understand.

lonely raw

insecure

drive

empowering

I find living with epilepsy not much different to before I had it; but it is something that is always at the back of my mind. It doesn't affect my day to day routine apart from having to take a pill twice a day and not being able to drive each time I have a fit. I can still do everything I did before. I still play rugby at a decent standard, ski and hike.

Vanessa Day

Frustrated. Disappointed. Insecure. Upset.
Sore, it hurts to move, hurts to talk, hurts to think!
It's hard for a few days, maybe a week.
But it will pass.
Awareness of my epilepsy is an everyday thing
but I don't allow it to control my life.

Simon Privett

I have been living with epilepsy since my diagnosis aged fourteen – twenty-two years ago. I spend much of my spare time doing charity work for Epilepsy Awareness. Epilepsy has become my driving force. It's made me stronger and more resilient, quicker to empathise and more determined to support and educate others. I want to inspire people. I want someone to look at me and say, '*Because of you, I didn't give up*'.

After a seizure it feels like the world's worst tiredness. An overwhelming desire to sleep combined with a physical exhaustion that leaves me unable to stand unaided. Unparalleled confusion. Like being very drunk – but worse.

It's also empowering, affirming. My epilepsy has made me a stronger, more empathetic person with a more defined, focused desire to help medical and research professionals in developing better and faster tools for the diagnosis and treatment of epilepsy.

Mark S

‘The darkness swallows me and cares not where I am pulled into this tunnel. I must let go and float away...’

Gabriella Brusatto

Multi-focal epilepsy. My brain misfires consecutively at various, independent locations in my brain. Epilepsy and I have been together since 1993. For the longest time, I was just angry. Angry at everything and everyone. I couldn’t understand why me, what had I done wrong so young? I didn’t want anyone’s pity and refused to tell anyone who was not close to me about my epilepsy. It was a silent suffering. I knew that I needed my sense of humour to help me through the life I would know. However, I could not step out of my own sorrow to see what good I could turn my own experience into. It was not until my epilepsy had turned my world upside down that I decided to take some dirt and grow a beautiful flower from it. Last year I decided to begin a blog to share my story with the world, and to be an advocate.

Danielle Townsend

For me, epilepsy has been a catalyst. I’ve struggled with it for most of my life, and there have been a lot of ups and downs, but it has ultimately made me a better person.

Epilepsy means losing a core sense of control over your own body. Having epilepsy since childhood meant brushing up against mortality at a very young age, while not really having the emotional maturity to process what was going on. This, coupled with the shame and stigma I felt, caused me to keep my diagnosis and everything I was going through a secret.

darkness stigma sadness devastating

misfires

misfires

distance side effects

I didn't know anyone else with epilepsy, and I also didn't see any positive portrayal of people like me, and I felt isolated. But feeling like a weird, lonely kid ultimately made me develop a strong sense of empathy towards people who are seen as 'other'.

After an episode, I feel really, really tired and dazed – but I wouldn't change anything. Learning how to deal with the stigma, the side effects of medication and the physical effects of epilepsy has clarified my perspective and values, and I am grateful for every day. I've also found humour to be a fantastic coping mechanism.

I buried it for a long time, but a sexual assault a few years ago brought back to the surface similar feelings of shame and loss of bodily autonomy. It forced me to deal with emotional baggage that I hadn't really unpacked, and galvanized me to advocate for the epilepsy community and people's rights in general.

I only started becoming more outspoken about my experience with epilepsy within the last few years. I am thankful that my seizures seem to be controlled with medication, but the side effects are difficult to deal with, and there aren't a lot of treatment options available. We need more research funding to develop affordable, alternative and newer treatments for people with epilepsy. We need more outreach to the general public about the condition and educational campaigns to fight the stigma that people with epilepsy still deal with every day. It's time for epilepsy to come out of the shadows.

Out of the Blue was commissioned by the CANDO project at the Institute of Neuroscience at Newcastle University as part of the exhibition *Illuminating the Self* shown at the Hatton Gallery and Vane in Newcastle in January 2020.

CANDO – Controlling Abnormal Network Dynamics using Optogenetics – is a multi-site cross-disciplinary project to develop treatments for certain kinds of epilepsy using brain implants and light-sensitive gene therapies. The exhibition, funded by the Wellcome Trust, forms part of the project's public engagement activity: I am grateful for their support.

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Finally I am happy to thank Arts Council England for the grant to make this book.

Susan Aldworth

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