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CRAMB

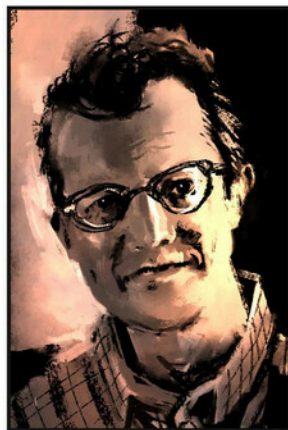


NOT THERE

A STORY OF FUNCTIONAL NEUROLOGICAL DISORDER

INTRODUCTION

Functional Neurological Disorder, or FND, is the second most common reason for a GP referral to a neurologist — doctors who treat brain and nervous system conditions. Yet it remains hidden and misunderstood. One of the main types of FND is called functional, dissociative or non-epileptic seizures. This describes episodes that look and feel like epilepsy or faints. About one in seven patients attending a “first seizure” clinic, and up to half of people brought in to hospital by ambulance with seizures, have this problem. But the events are not due to an electrical storm in the brain, as seen in epilepsy, or a problem in blood flow that causes faints. Instead the patient is involuntarily entering a trance-like state called “dissociation” where they are unresponsive and afterwards usually can’t remember what has happened. Their brain is not functioning properly — even though MRI, CT scans and brain wave tests (EEG) are normal. It’s terrifying for the person and for those around them.



When I started neurology training 25 years ago, people with functional seizures were routinely treated as if they were faking or making up their symptoms, especially in emergency settings. This is a horrendous experience for someone who is actually losing control during the events. We have learnt — and are still learning — a lot about this condition since then, including how to understand and treat it. Sadly, in many settings, ignorance persists.

Treatment begins with helping a patient wrap their head around this condition — it’s common and real, lots of people have it and it’s not “weird”. *Not There* is a wonderful and unique contribution to that process, literally illustrating what functional seizures feel like, frustration when health professionals don’t understand or help, and how there is a way forward with the right treatment. I’m looking forward to sharing this with my patients, their families and friends.

Professor Jon Stone, Professor of Neurology, University of Edinburgh
May 2020

Not There was created during the DCN Language and Cognition Fellowship, part of the Beyond Walls art and therapeutic design programme for the new Department of Clinical Neurosciences at Little France, Edinburgh.

Thanks to Tom Littlewood and Ginkgo Projects; Mark Daniels of New Media Scotland; Sorrel Cosens from NHS Lothian; Professor Peter Sandercock; Jen Collins and Stuart Jamieson from Western General MRI; Mat Stephenson; Jennie Higgs; Susana Camara Leret and Alex Menzies. And, of course, Professor Stone, who was incredibly generous with his time and enthusiasm for the project.



ONE MINUTE SHE WAS SITTING THERE.
THE NEXT SHE WAS ON THE FLOOR.



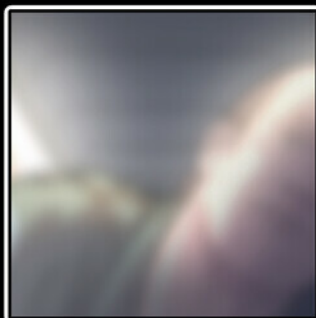
HAD THE BUS MADE A
SUDDEN MOVEMENT?

NO. WE WERE
SITTING IN TRAFFIC.

I THOUGHT SHE MUST
HAVE FAINTED. BUT SHE'S
BEEN OUT A LONG TIME.

SHE WOULD HAVE
WOKEN UP FROM A
FAINT BY NOW.

WOULDN'T SHE?



MMM.

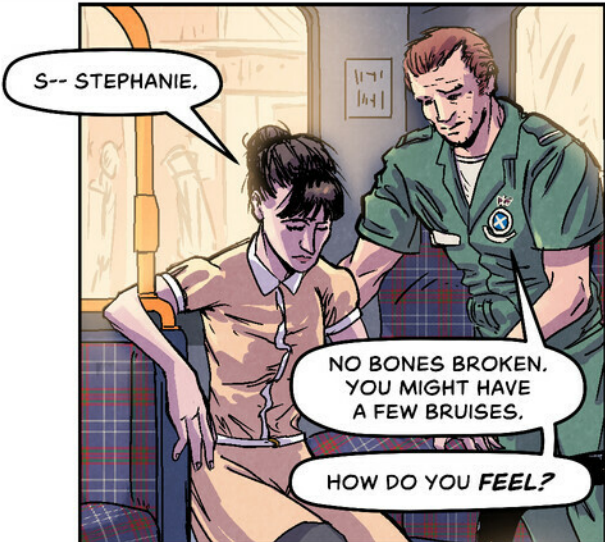
HEY. HEY.
CAN YOU
HEAR ME?



HELLO.



WHAT'S YOUR NAME?



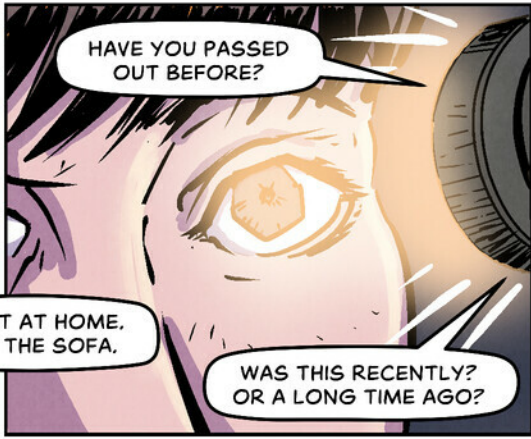
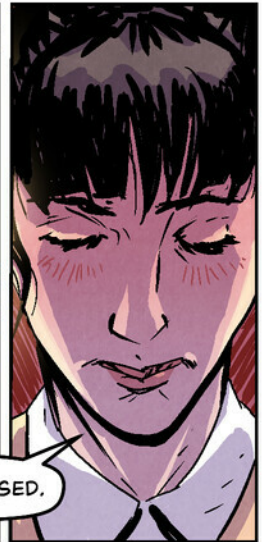
S-- STEPHANIE.

NO BONES BROKEN.
YOU MIGHT HAVE
A FEW BRUISES.

HOW DO YOU *FEEL*?



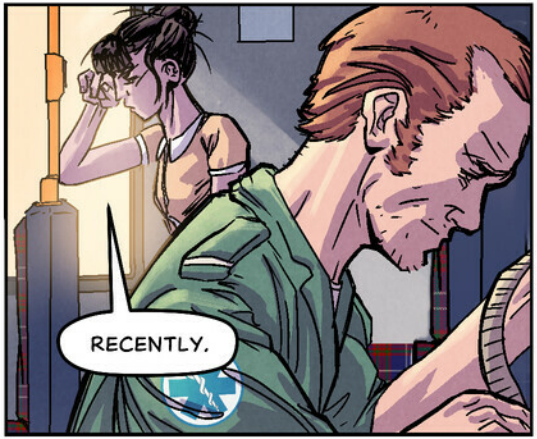
EMBARRASSED.



HAVE YOU PASSED
OUT BEFORE?

JUST AT HOME.
ON THE SOFA.

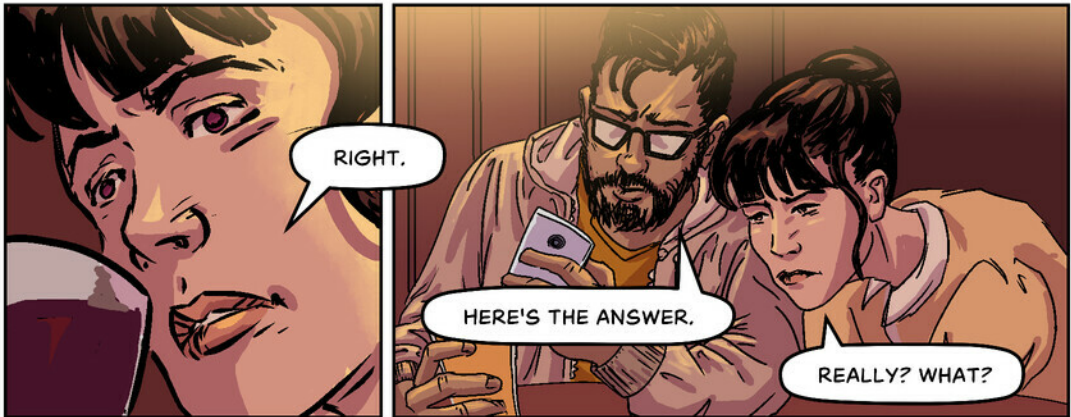
WAS THIS RECENTLY?
OR A LONG TIME AGO?



RECENTLY.









STEPH? CAN YOU HEAR ME?

ARE YOU *THERE*?

...MY GP **REFERRED** ME. I'M WAITING FOR AN APPOINTMENT WITH THE NEUROLOGIST.

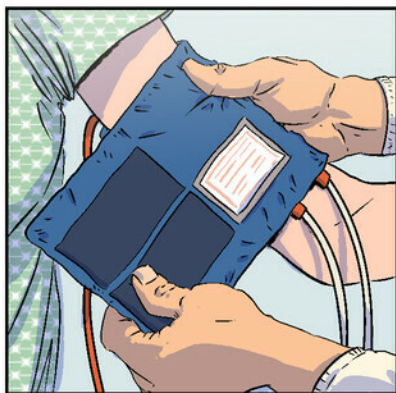
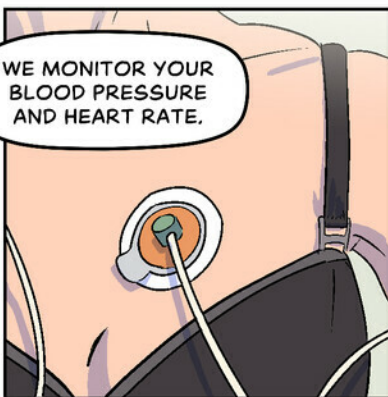
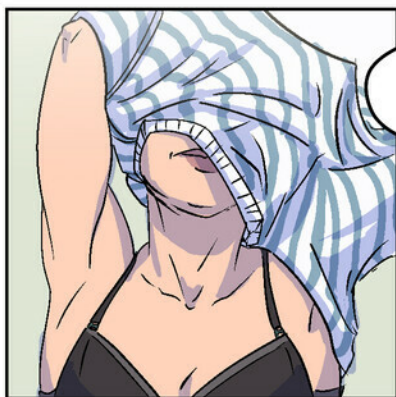
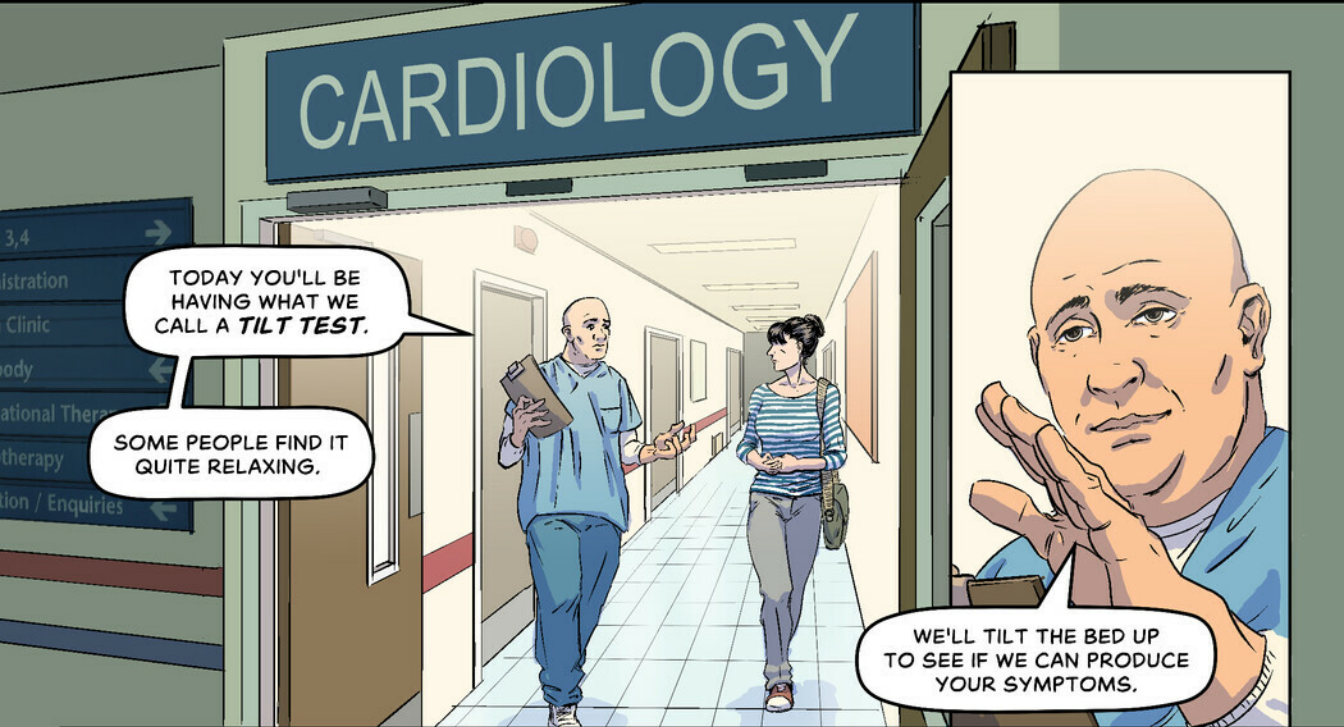
I-- **NO**, THANKS, BUT NO.

I'D GO **CRAZY** WITHOUT SOMETHING TO DO.

WOULD YOU LIKE TO TAKE A FEW DAYS' ABSENCE? SICK LEAVE?

WELL, THE OFFER'S THERE.

THANK YOU, I'LL BEAR IT IN MIND.



SO YOUR
CARDIOLOGIST HAS
REFERRED YOU.

THEY DON'T THINK
MY HEART IS
THE PROBLEM.

Dr A McAllister
Neurology



MMM. I DON'T
THINK THIS WAS
EPILEPSY EITHER.



I'LL SEND YOU FOR
SOME TESTS, AND WE'LL
SCHEDULE ANOTHER
APPOINTMENT.

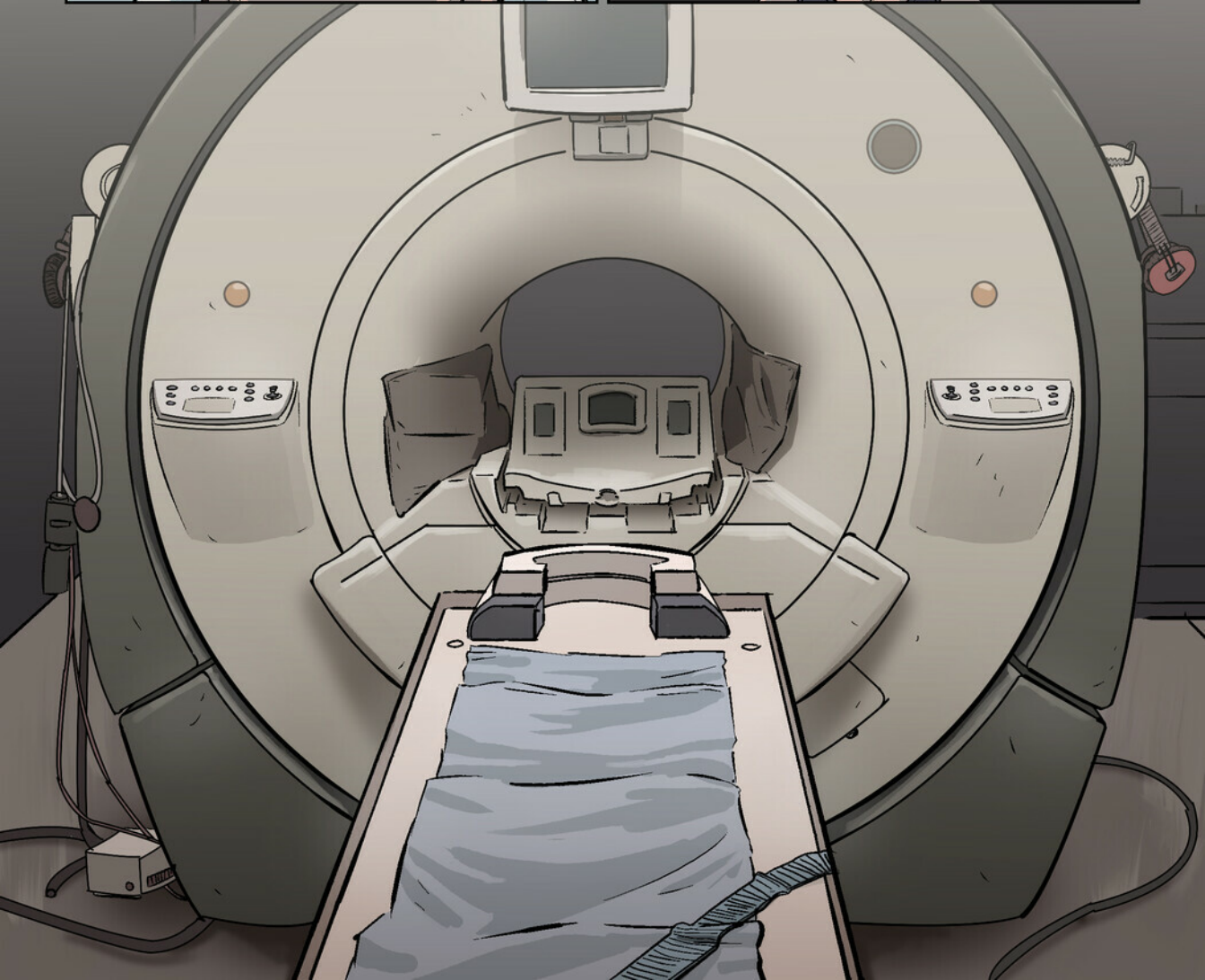


YOU'RE NOT
WEARING
CONTACT
LENSES?

OR A
HEARING
AID?

NO.

NO.



I'M GOING TO GET YOU TO LIE DOWN HERE, STEPHANIE.

THE SCANNER WILL SEEM **VERY LOUD**. WOULD YOU LIKE SOME MUSIC?

NO THANKS.

THE SCANNER WILL BE CLOSE TO YOUR HEAD.

IF YOU FEEL OVERWHELMED, SQUEEZE THIS AND I'LL STOP THE SCAN.

YOU'LL BE ABLE TO HEAR AND TALK TO ME WITH THESE.

THIS IS JUST TO MAKE SURE YOUR HEAD DOESN'T MOVE DURING THE SCAN. READY?

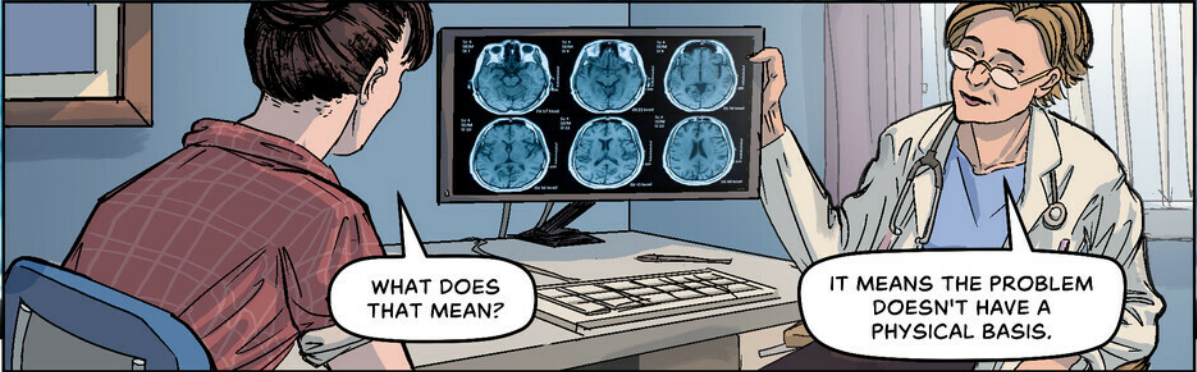
MMM.

DURRRRRRR



IT'S GOOD NEWS, YOUR MRI AND EEG HAVE COME BACK **CLEAR**.

THERE'S NO DAMAGE TO YOUR NERVOUS SYSTEM.



WHAT DOES THAT MEAN?

IT MEANS THE PROBLEM DOESN'T HAVE A PHYSICAL BASIS.



IT'S IN MY **MIND**?



THERE'S NO DAMAGE TO YOUR NERVOUS SYSTEM. THIS IS A GOOD RESULT.

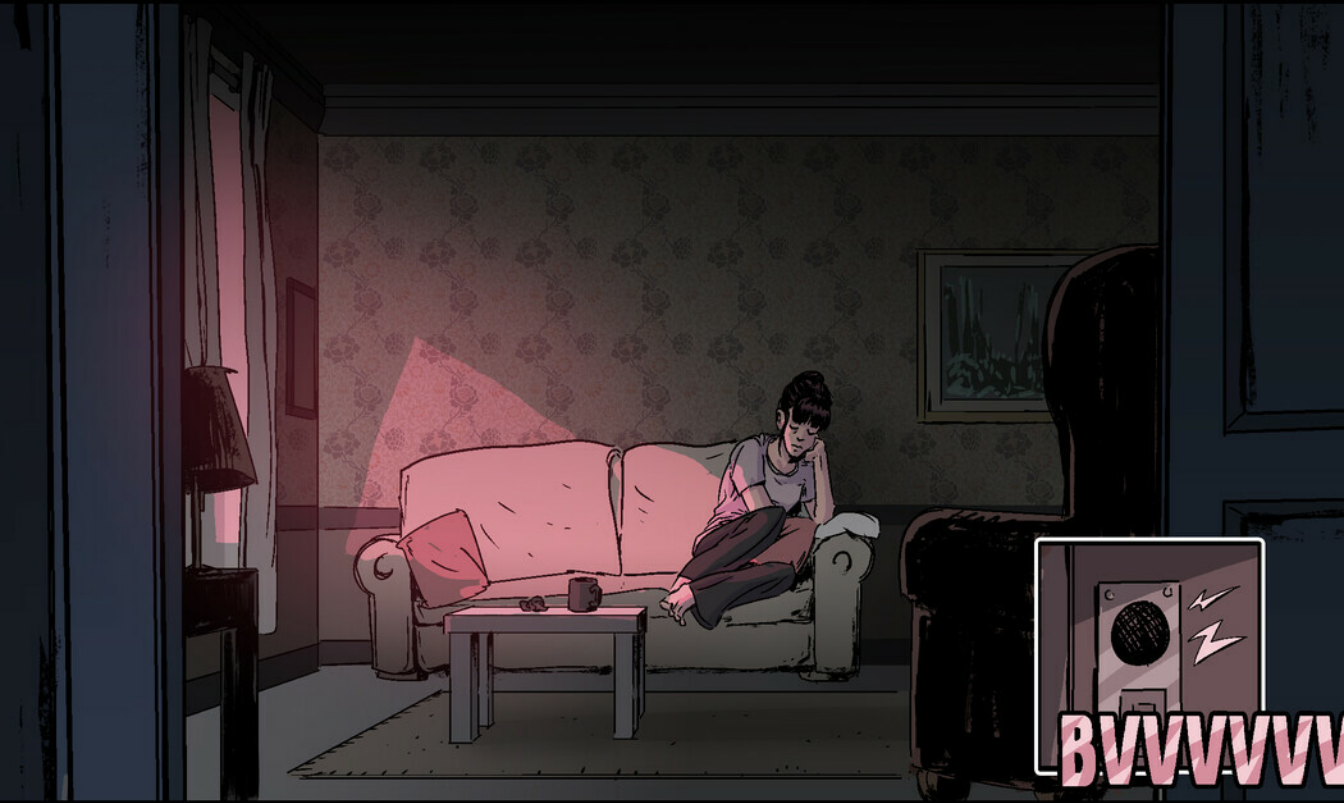


YOUR PROBLEM IS NOT NEUROLOGICAL.



I COULD REFER YOU TO A **PSYCHIATRIST**.





I ASSUME YOU HAVE TONIC.



WE STRUGGLED THROUGH THE MUSIC ROUND, BUT WE **DIED** ON GEOGRAPHY.

ANOTHER?

I'M FINE.



THERE'S A REASON WE KEEP YOU ON THE TEAM. WHERE'S YOUR RECYCLING?



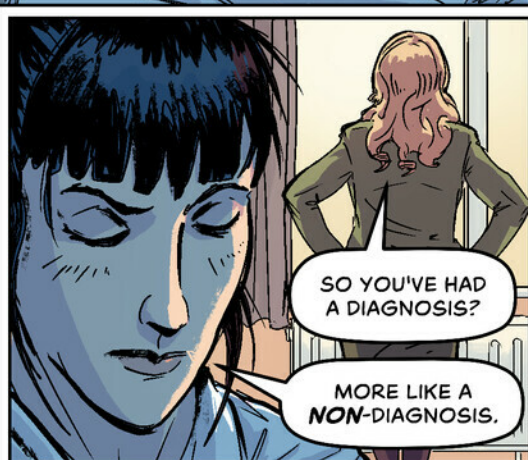
... NEVER MIND. I **FOUND** IT.



STEPH.



STEPH.



SO YOU'VE HAD
A DIAGNOSIS?

MORE LIKE A
NON-DIAGNOSIS.



THEY MADE ME AN
APPOINTMENT WITH
ANOTHER DOCTOR.



YOU'RE A STAR
IN THE OFFICE
AND I WANT TO
SUPPORT YOU.

BUT WE CAN'T HAVE
YOU COLLAPSING HERE.
THINK OF THE CLIENTS.



TAKE TWO WEEKS
SICK LEAVE ON
FULL PAY, THEN
WE'LL TALK AGAIN.

OK?



HELLO AGAIN.



WHAT IS **WRONG** WITH ME?

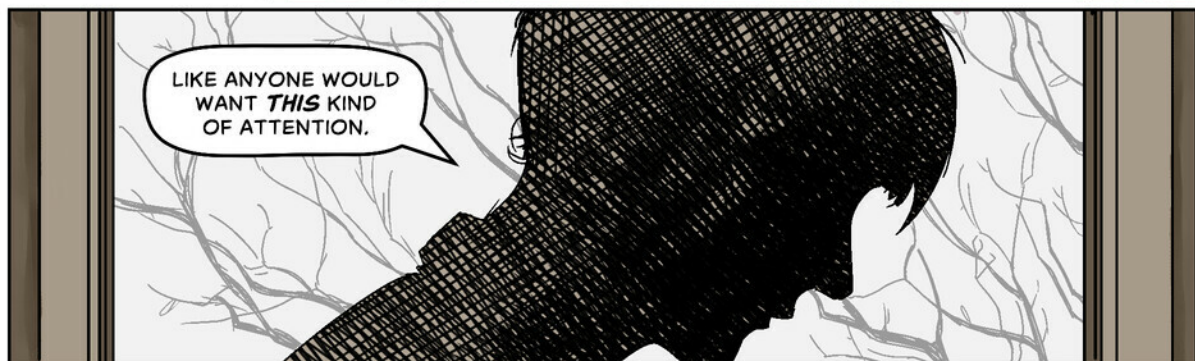
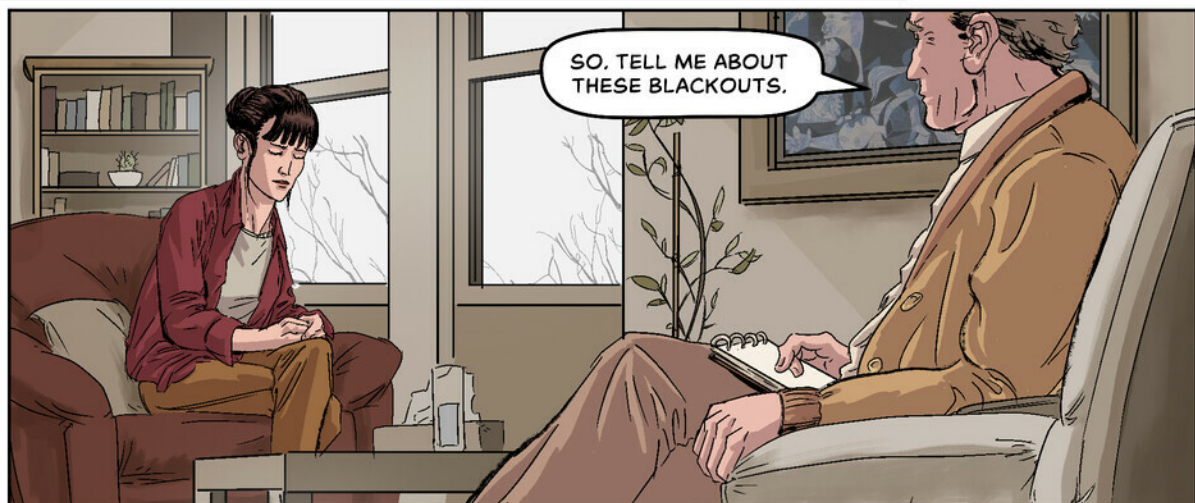
YES! AND A DAMN **NEUROLOGIST!**

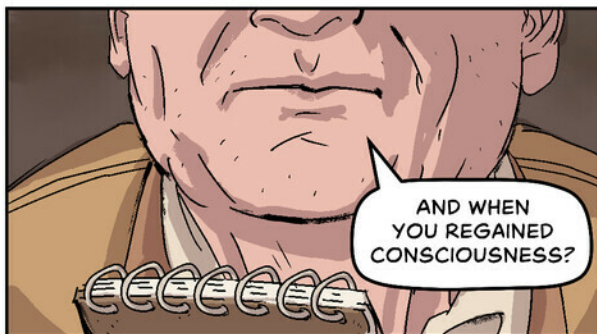
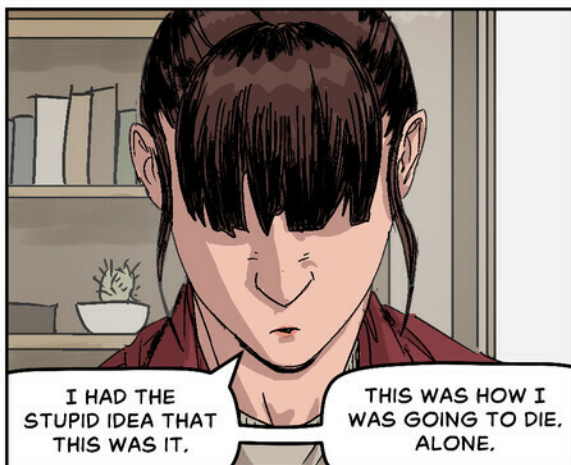
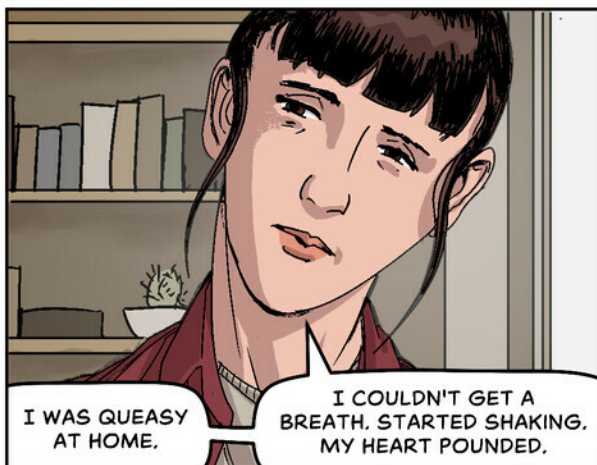
HAVE YOU TALKED TO YOUR **GP?**

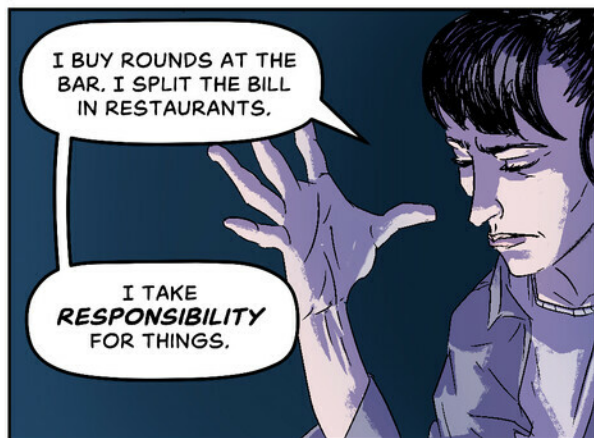
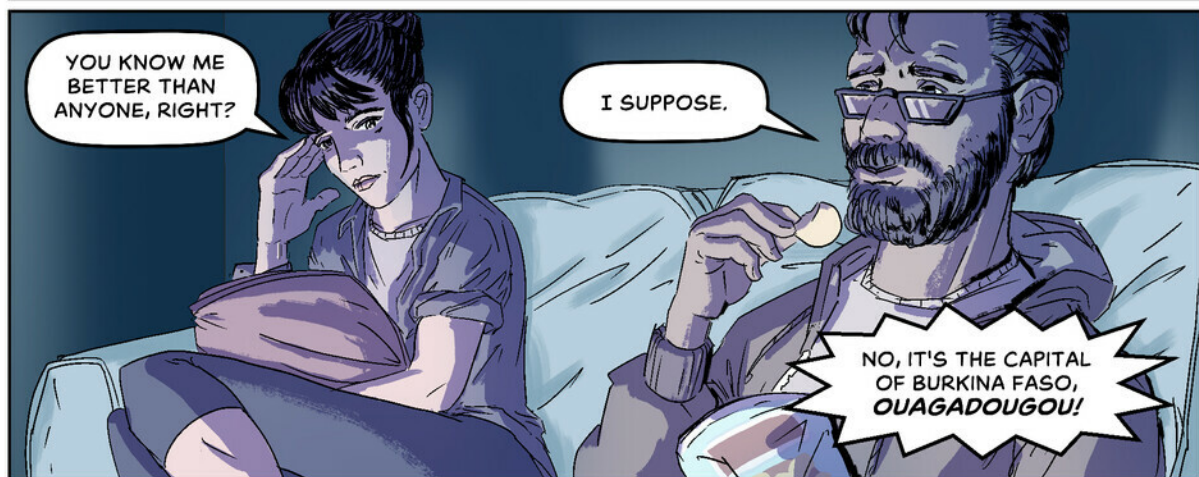
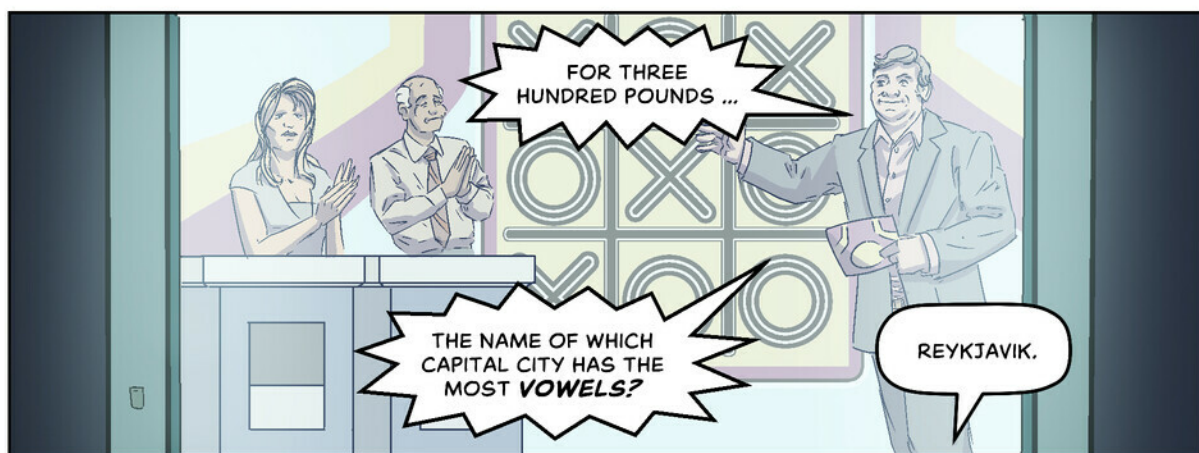


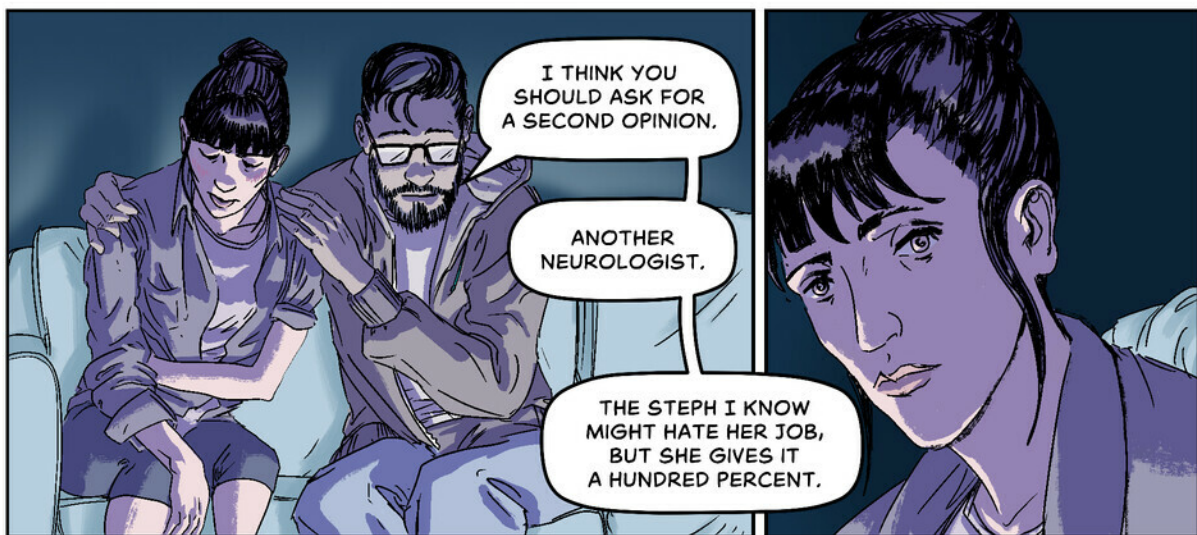
WE CAN'T KEEP BEING CALLED OUT FOR THIS.


I'M NOT DOING IT ON **PURPOSE!**











WHAT CAN YOU REMEMBER
ABOUT THE MOMENTS
JUST BEFORE YOU
HAVE A SEIZURE?

I DON'T ...
THERE'S NOT ...


I KNOW IT'S
UNCOMFORTABLE,
BUT PLEASE TRY.




IT'S *STRANGE*.



THE SENSATION IS
HORRIBLE. I FEEL
TRAPPED.



I ... DRIFT AWAY
FROM MY BODY, LIKE
I'M NOT THERE.



IT'S LIKE I'M JUST
NOT THERE.

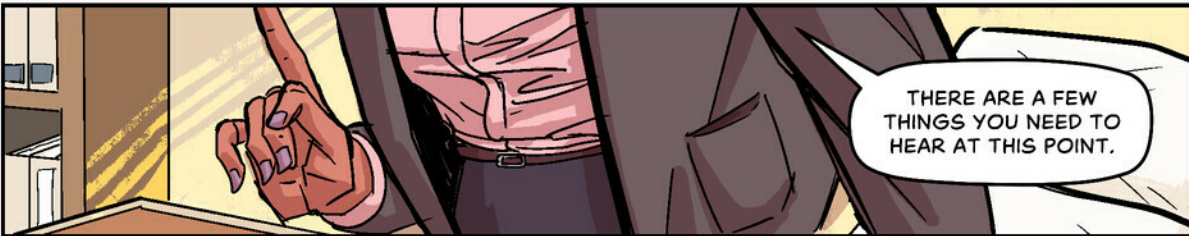


AND WHEN YOU
WAKE UP?



THERE ARE
BRUISES AND
HUMILIATION ...

BUT ALSO A SENSE
OF RELIEF THAT THOSE
FEELINGS ARE *GONE*.



THERE ARE A FEW THINGS YOU NEED TO HEAR AT THIS POINT.



THE SYMPTOMS YOU ARE EXPERIENCING ARE **REAL**.



YOU'RE **NOT** IMAGINING THEM, AND YOU'RE **NOT** MAKING THEM UP.

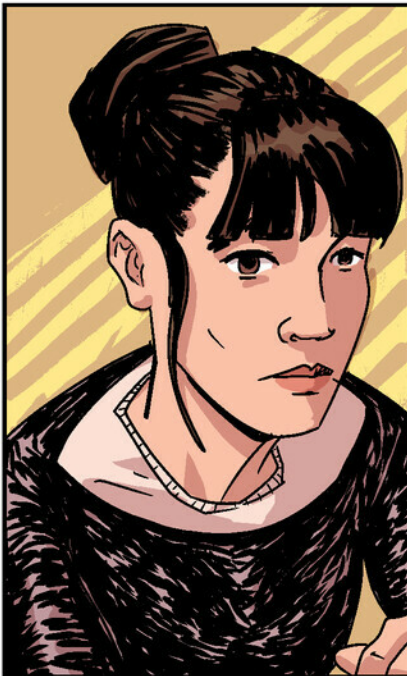


I THINK I KNOW WHAT'S WRONG.

REAL

NOT MAKING THEM UP


THINK I KNOW




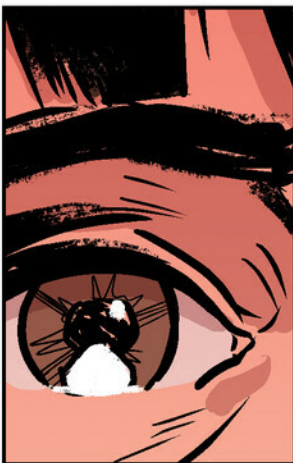
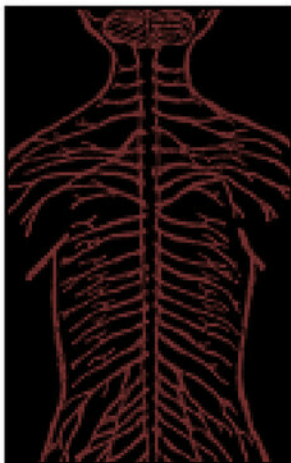
SORRY?



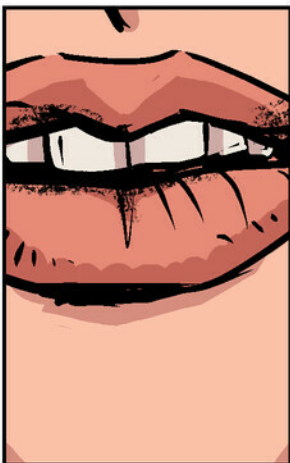
YOU ARE HAVING
WHAT WE CALL
DISSOCIATIVE
ATTACKS.



THEY ARE A TYPE OF **FUNCTIONAL**
NEUROLOGICAL DISORDER,
A PROBLEM WITH HOW YOUR
NERVOUS SYSTEM **FUNCTIONS.**



DR MCALLISTER WAS CORRECT
THAT THERE IS NO **DAMAGE**
TO YOUR NERVOUS SYSTEM.



AND THIS IS GOOD,
BECAUSE IT MEANS
RECOVERY
IS POSSIBLE.

Functional and dissociative neurological symptoms have been given many different names over the years.

Many of these symptoms are often linked to functional and dissociative disorders but the most experts believe that these symptoms exist at the interface between the brain and mind, between neurology and psychiatry, which makes it difficult when people (and professionals) are neurological or psychological. It suggests it is both, and the question doesn't really matter what we know about how movement pathways work in the brain.

This list does not include the most upsetting and distressing terms, it merely lists the most common.

Conversion Disorder - Sigmund Freud's classification (DSM-IV) 'conversion' symptoms are sensory symptoms. The principle may apply to these symptoms as there is little expert evidence in the majority of patients these symptoms are

symptoms of weakness, movement disorder, sensory symptoms and non-epileptic attacks.

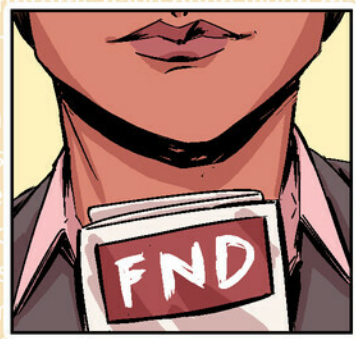
"Conversion" is something that a minority of patients but there is no real evidence for the idea of conversion. Patients (usually the worse these symptoms are, the more distressed the patient is). In the forthcoming revision of the DSM-5, the term may be replaced by a psychological symptom disorder. A psychologically stressful event linked to the symptoms will probably be included.

Dissociative Disorder - described in the DSM-5. See the page on Dissociative Disorders for more information.

Non-epileptic seizures - use for symptoms that are not identifiable disease. It implies the problem is purely psychological.

Psychosomatic - has come to mean the same as psychogenic although its original meaning was to describe the way in which the body affected psychological processes.

At the person has a lot of mental distress. The same as those for Dissociative Disorder. If someone has a lot of symptoms which are

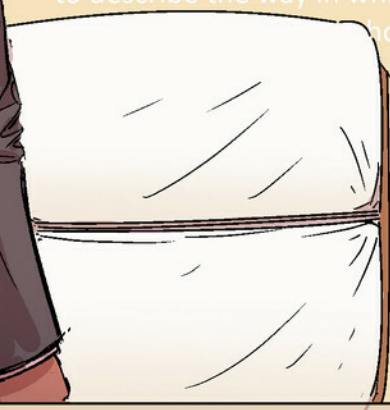


MANY PATIENTS IN OUR CLINIC HAVE SOME KIND OF **FUNCTIONAL NEUROLOGICAL DISORDER**, LIKE YOUR DISSOCIATIVE ATTACKS.

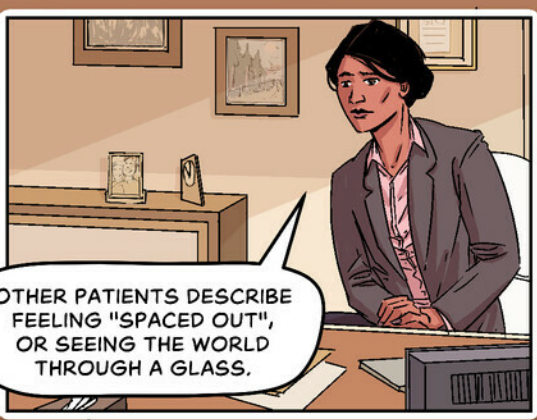
SOME PEOPLE EXPERIENCE UNCONTROLLABLE MOVEMENT, LIKE A TREMOR OR A SPASM.

OTHERS DEVELOP A **WEAKNESS** IN PART OF THEIR BODY, OR **LOSE SENSATION** IN A PARTICULAR REGION.

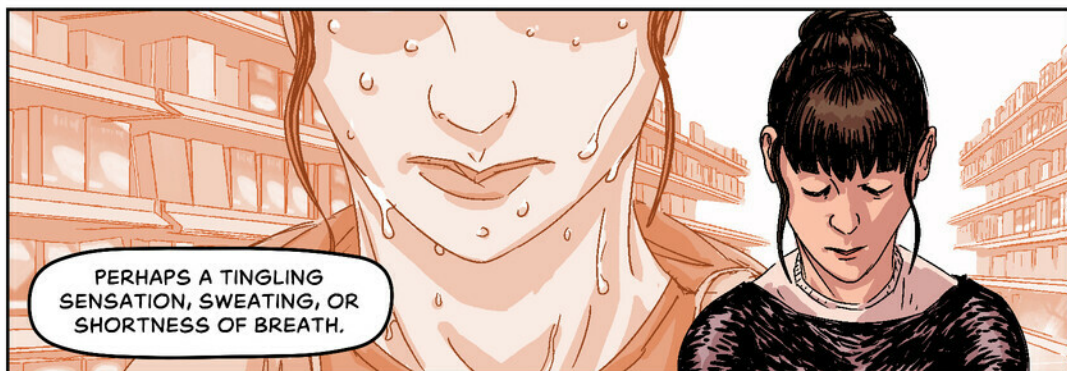
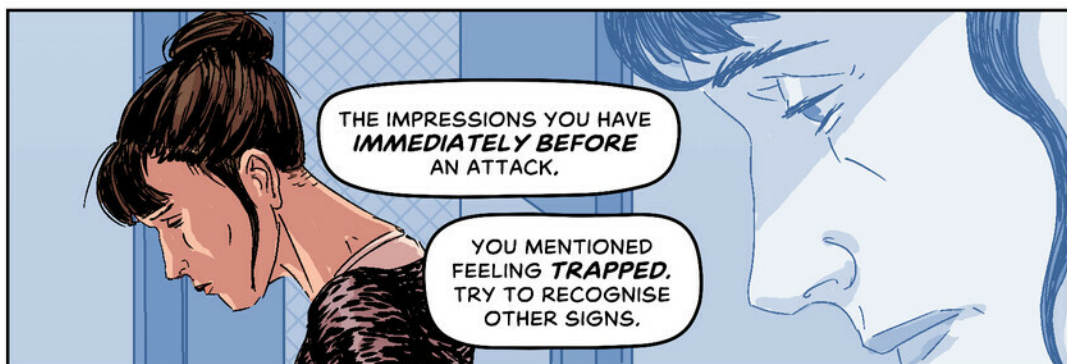
PROBLEMS WITH MEMORY, PAIN OR FATIGUE, OFTEN ACCOMPANY AN **FND**.



THAT FEELING YOU MENTIONED, OF DRIFTING AWAY, IS KNOWN AS **DEPERSONALISATION**.



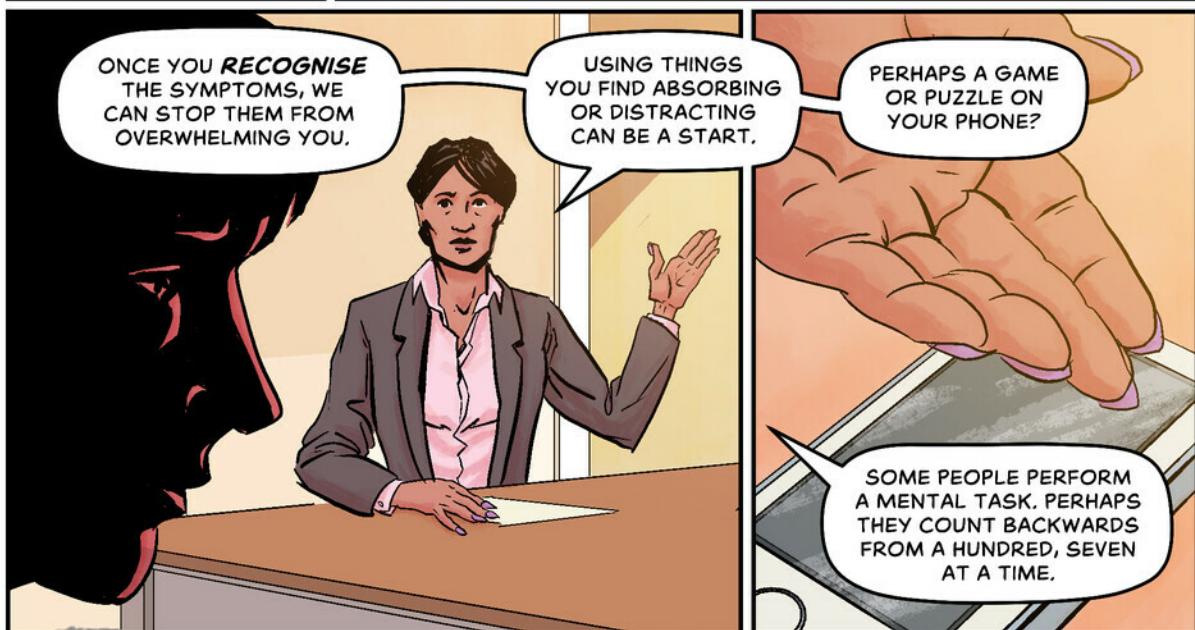
OTHER PATIENTS DESCRIBE FEELING "SPACED OUT", OR SEEING THE WORLD THROUGH A GLASS.





FOR SOME PEOPLE, THE ATTACK CAN BE A **RELIEF** FROM THE HORRIBLE, TRAPPED FEELING YOU DESCRIBED.

THIS IS A CYCLE WE CAN HELP YOU TO **BREAK**.



ONCE YOU **RECOGNISE** THE SYMPTOMS, WE CAN STOP THEM FROM OVERWHELMING YOU.

USING THINGS YOU FIND ABSORBING OR DISTRACTING CAN BE A START.

PERHAPS A GAME OR PUZZLE ON YOUR PHONE?

SOME PEOPLE PERFORM A MENTAL TASK. PERHAPS THEY COUNT BACKWARDS FROM A HUNDRED, SEVEN AT A TIME.



IT'S THAT SIMPLE? COUNT BACKWARDS AND IT GOES AWAY?

NO. IT'S **HARDER** THAN THAT.

BUT YOU CAN **DO** IT, STEPHANIE.

RECOVERY IS POSSIBLE FOR YOU.



STEPH!

I'VE BEEN RESEARCHING
YOUR FUNCTIONAL THING.

THEY USED TO CALL THIS
STUFF "HYSTERIA".

THEY THOUGHT THE WOMB ACTUALLY
MOVED AROUND THE BODY.



DAMIAN.

YOU'VE GOT IT
IN YOUR HEAD THAT
WE'RE GETTING
BACK TOGETHER.

THAT'S NOT
WHAT'S
HAPPENING.

I'M *ILL*, AND I NEED A
FRIEND I REALLY TRUST
TO HELP ME THROUGH IT.

I'D LIKE *YOU* TO BE
THAT FRIEND. BUT
WE'RE NOT GETTING
BACK TOGETHER.

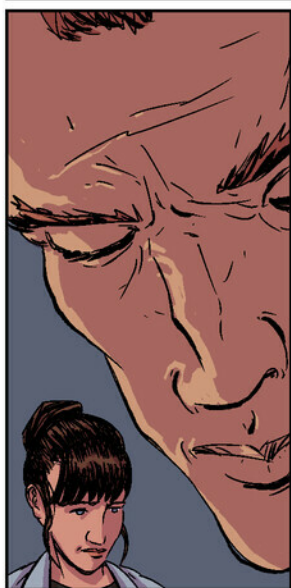
I UNDERSTAND THAT'S
DIFFICULT, AND YOU
CAN SAY NO WITH A
CLEAR CONSCIENCE.

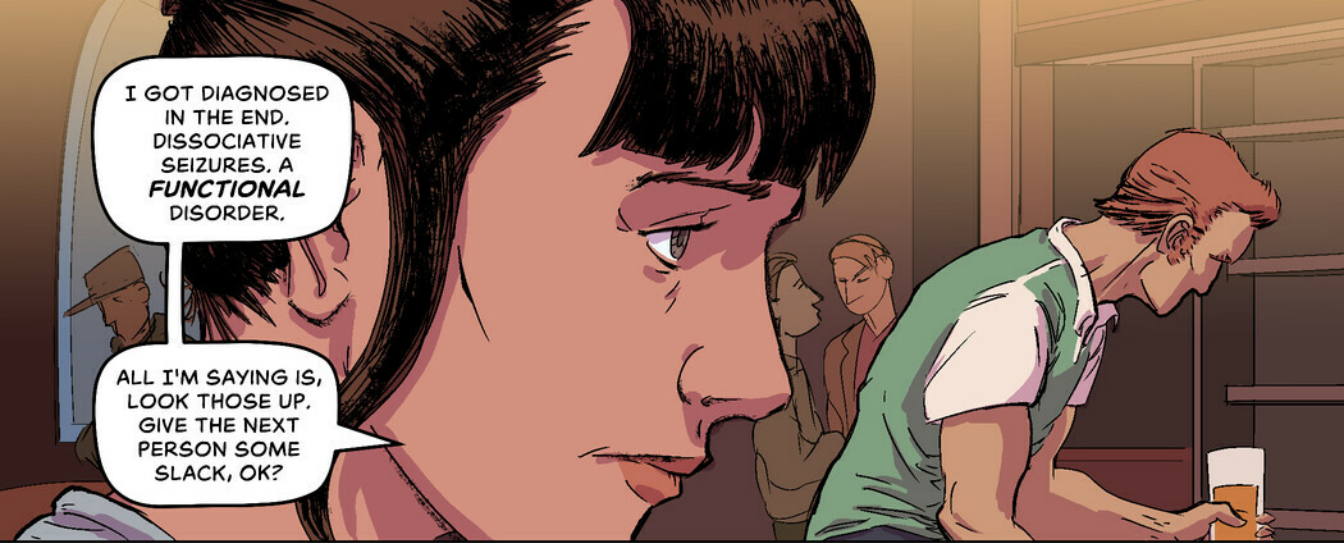


WHAT KIND OF
ASSHOLE WOULD
I HAVE TO BE
TO SAY NO?



A ***DIFFERENT***
KIND OF
ASSHOLE.





I GOT DIAGNOSED
IN THE END.
DISSOCIATIVE
SEIZURES, A
FUNCTIONAL
DISORDER.

ALL I'M SAYING IS,
LOOK THOSE UP.
GIVE THE NEXT
PERSON SOME
SLACK, OK?

RIGHT. SORRY
TO HAVE
BOtherED YOU.

I'LL LET YOU
GET BACK TO
THE FOOTBALL.

MY JOB'S ABOUT
PRIORITISING A
LIMITED RESOURCE,
RIGHT?

IT SHOULDN'T
BE, BUT IT IS.

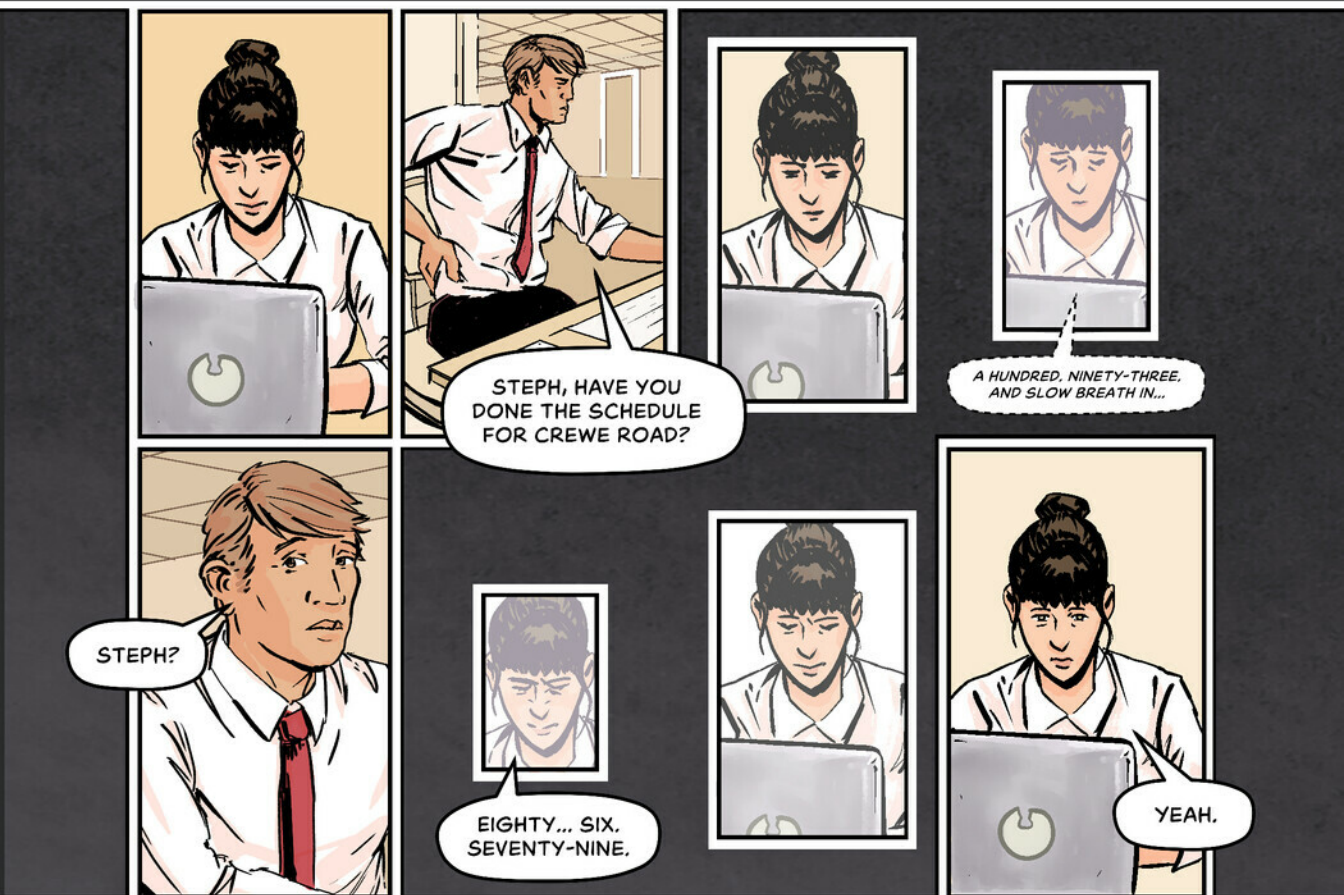
THERE'S NO POINT IN
PUTTING ON THE BLUE
LIGHTS AND RUSHING
YOU TO HOSPITAL.

YOU DON'T
NEED IT.

I DON'T ALWAYS KNOW
THE RIGHT THING TO DO.

BUT I **COULD**
TAKE ANOTHER
LOOK AT THE
FUNCTIONAL STUFF.





RESOURCES FROM HEALTH PROFESSIONALS

FND: A Patient's Guide

<http://neurosymptoms.org/>

A superb starting point and comprehensive collection of resources for anybody who wishes to learn more about Functional Neurological Disorders. Covers a wide range of symptoms, explores what is known about the bodily mechanisms and causes behind FNDs, and suggests positive steps to deal with the condition. Many videos and stories from patients — translations are available in several major languages.

FND Society

<https://www.fndsociety.org/>

An international multidisciplinary society for FND health professionals started in 2019. Has many educational resources, including webinars.

Non-Epileptic Attacks

<http://www.nonepilepticattacks.info/>

An information site with a useful list of Frequently Asked Questions.

PATIENT-LED RESOURCES

FND Hope

<https://fndhope.org/>

A global charity for people with FNDs. Offers peer support, information and advice.

FND Action

<https://www.fndaction.org.uk/>

Raises awareness, empowers patients and provides online support.

FND Dimensions

<http://fnddimensions.org/>

Developing a network of support groups across the UK.

FND Friends

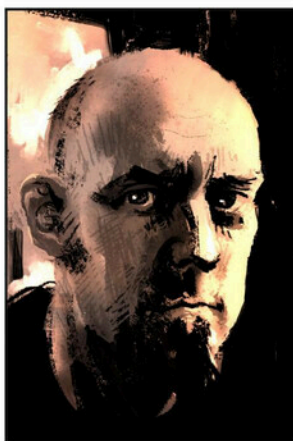
<https://www.fndfriends.com/>

Post-diagnosis support and education in southwest England.

In Our Words: Personal Accounts of Living with Non-Epileptic Seizures

Reuber, Rawlings et al. Oxford University Press 2018; ISBN 978-0190622770.

An accessible collection of patient experiences.



GAVIN INGLIS
script and lettering



FIN CRAMB
pencil, ink and colour



TONIC ARTS

PART OF



Edinburgh & Lothians
Health Foundation