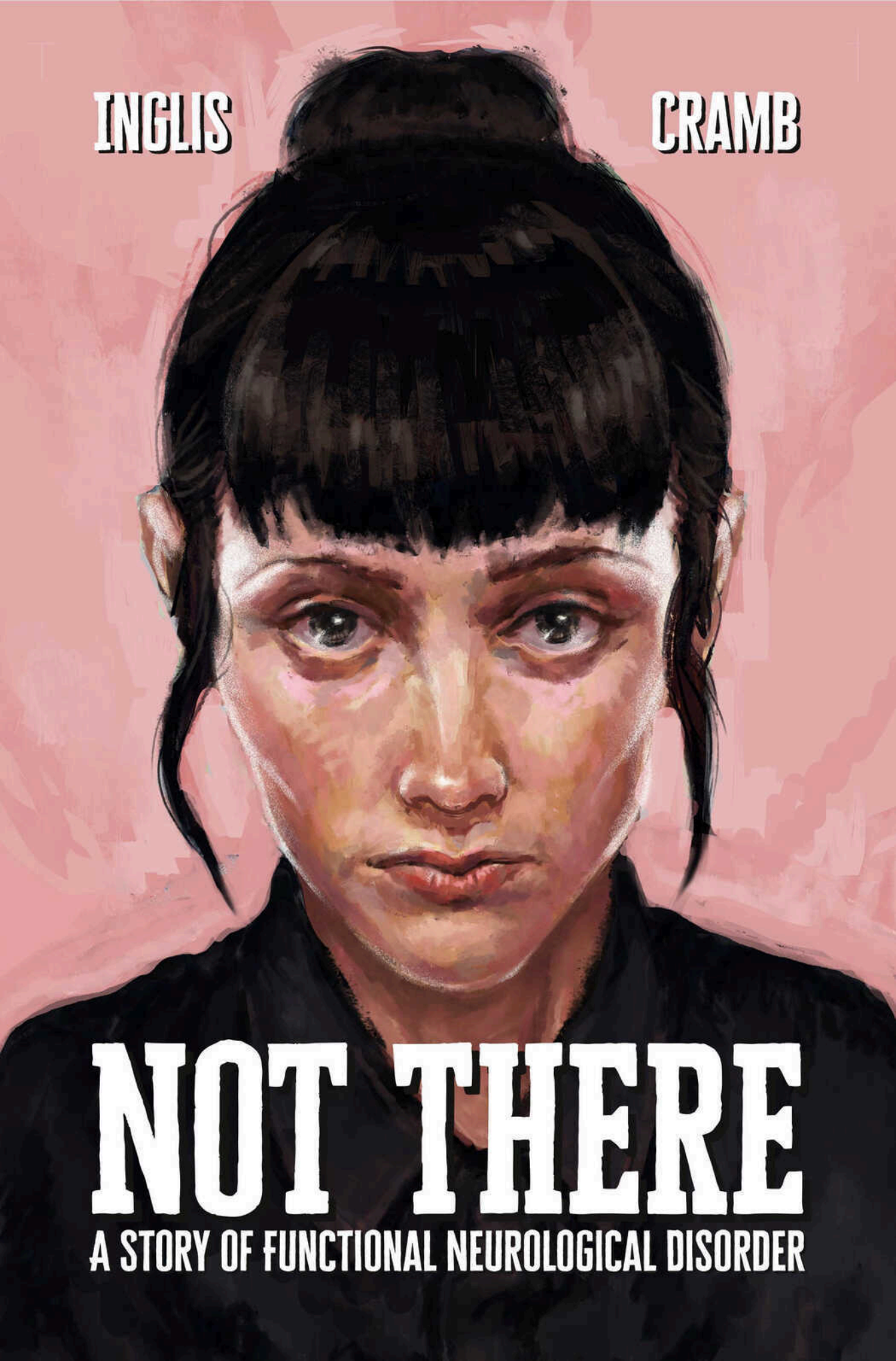
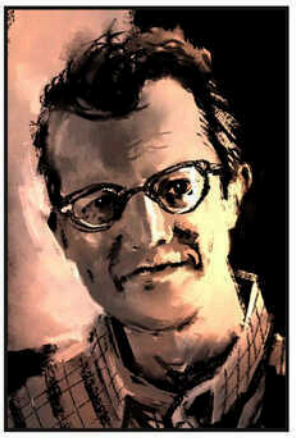
INGLIS CRAMB



# 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 un-responsive 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 people have it and it's not "weird". *Not There* is a wonderful and unique contribution to that process, literally illustrating what functonal 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.

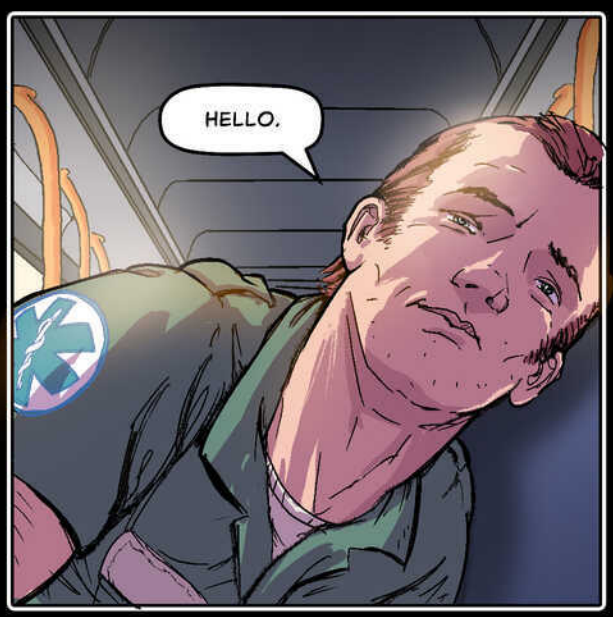
I THOUGHT SHE MUST HAVE FAINTED. BUT SHE'S BEEN OUT A LONG TIME.

SHE WOULD HAVE WOKEN UP FROM A FAINT BY NOW.

WOULDN'T SHE?

MMM.

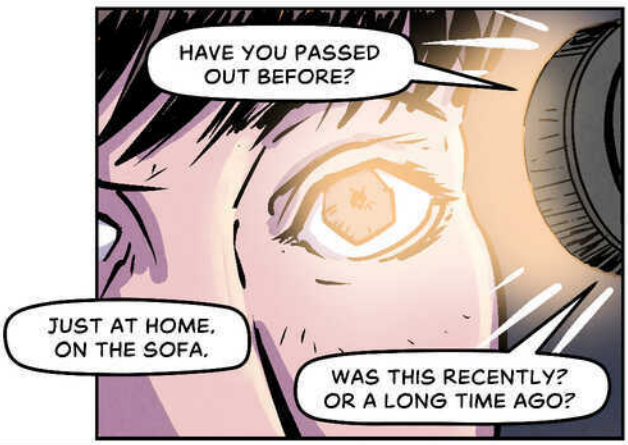
HEY. HEY. CAN YOU HEAR ME?

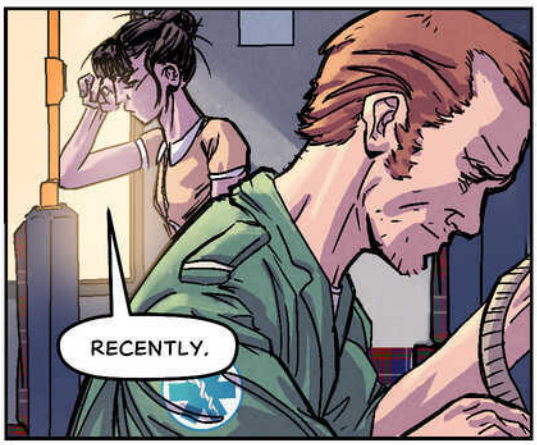


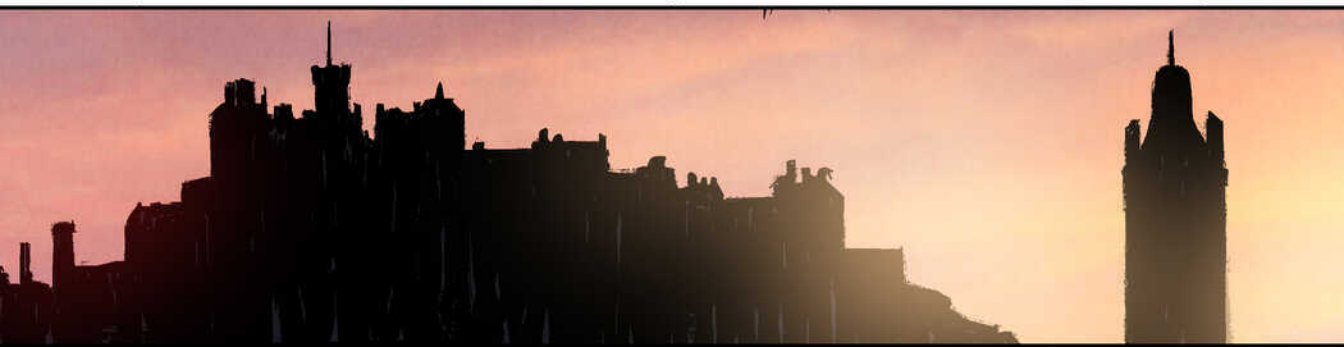

WHAT'S YOUR NAME?


S-- STEPHANIE.
NO BONES BROKEN. YOU MIGHT HAVE A FEW BRUISES.
HOW DO YOU *FEEL?*


EMBARRASSED.

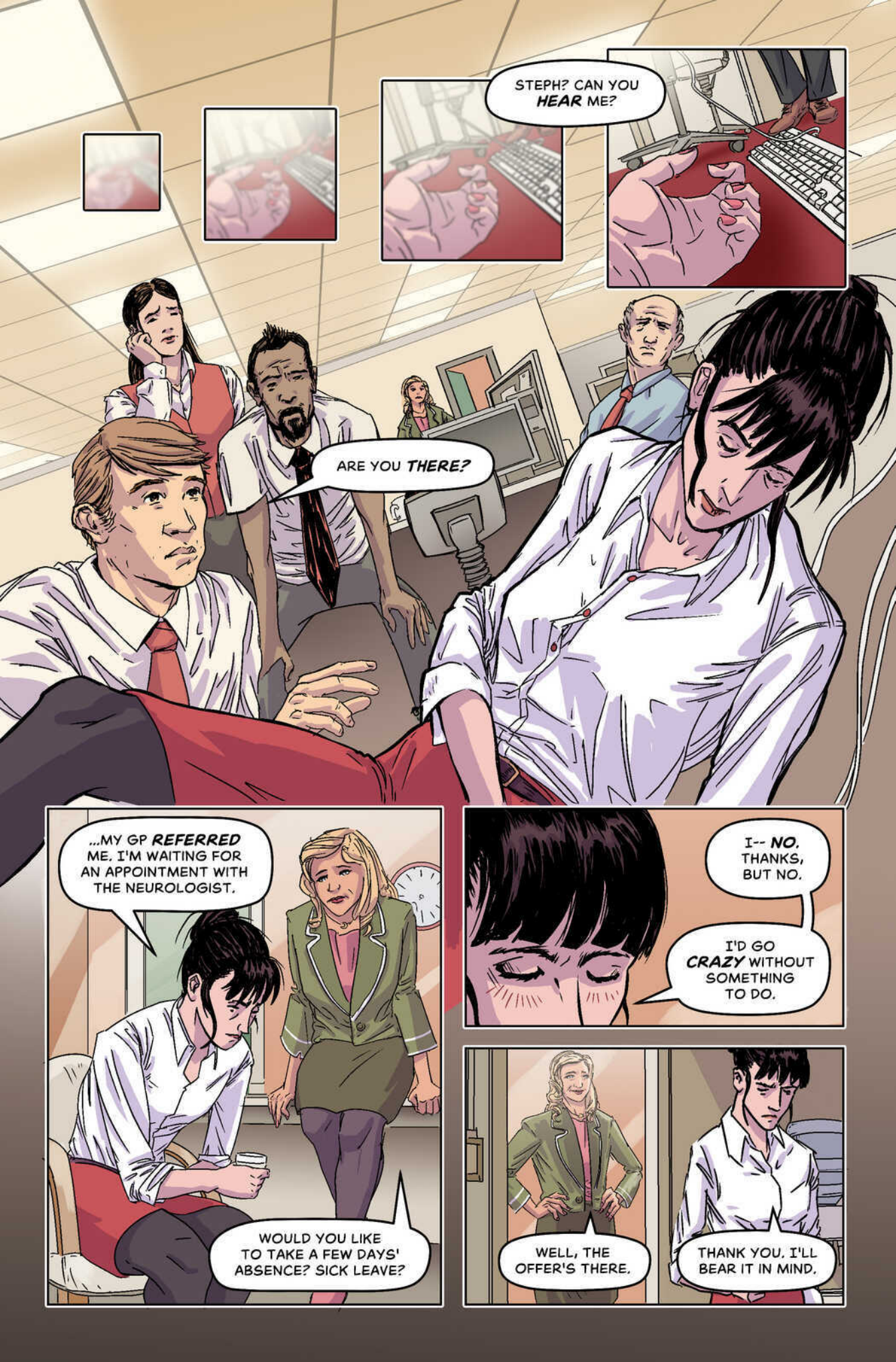

HAVE YOU PASSED OUT BEFORE?
JUST AT HOME, ON THE SOFA.
WAS THIS RECENTLY? OR A LONG TIME AGO?

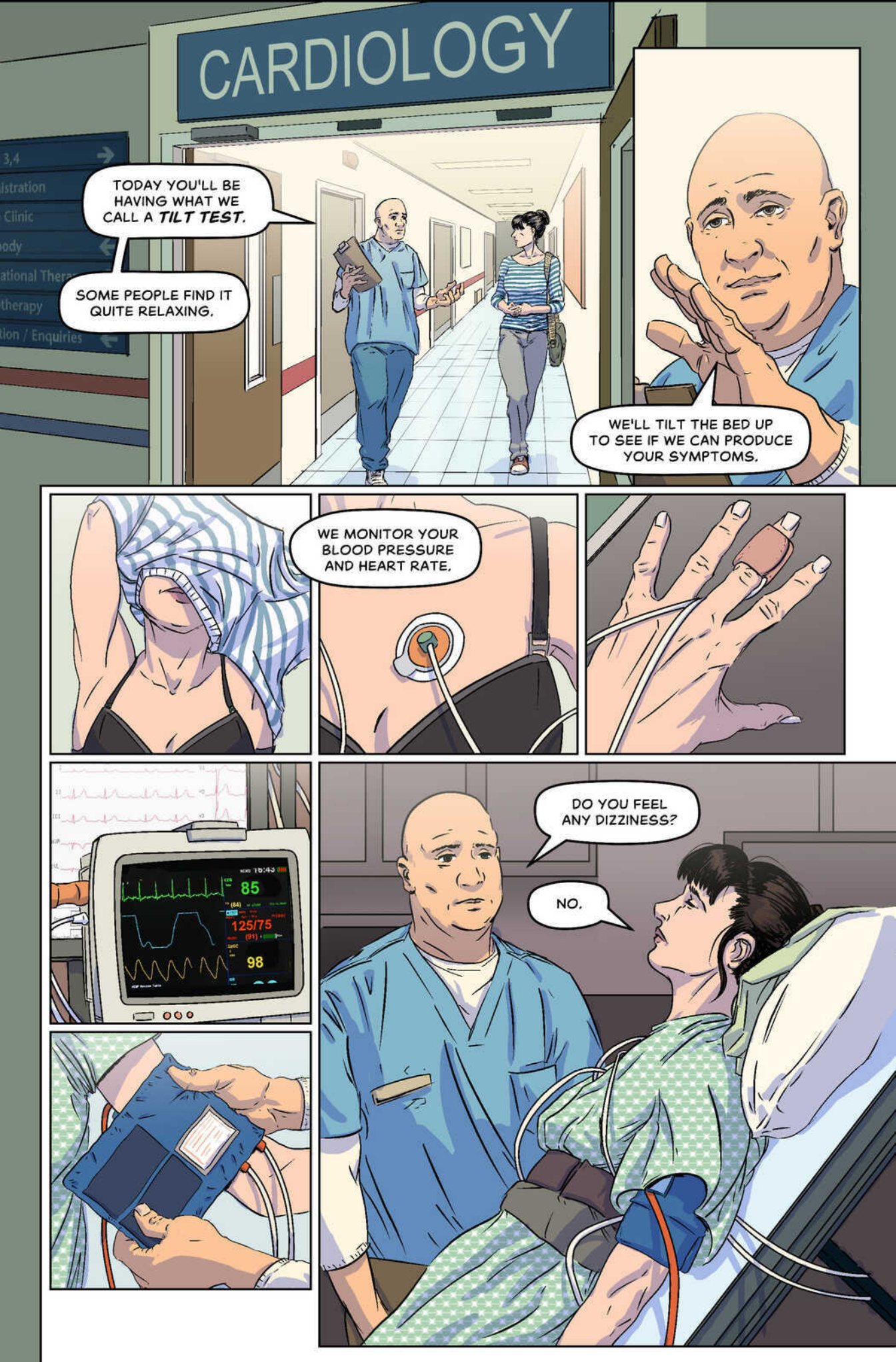

RECENTLY.

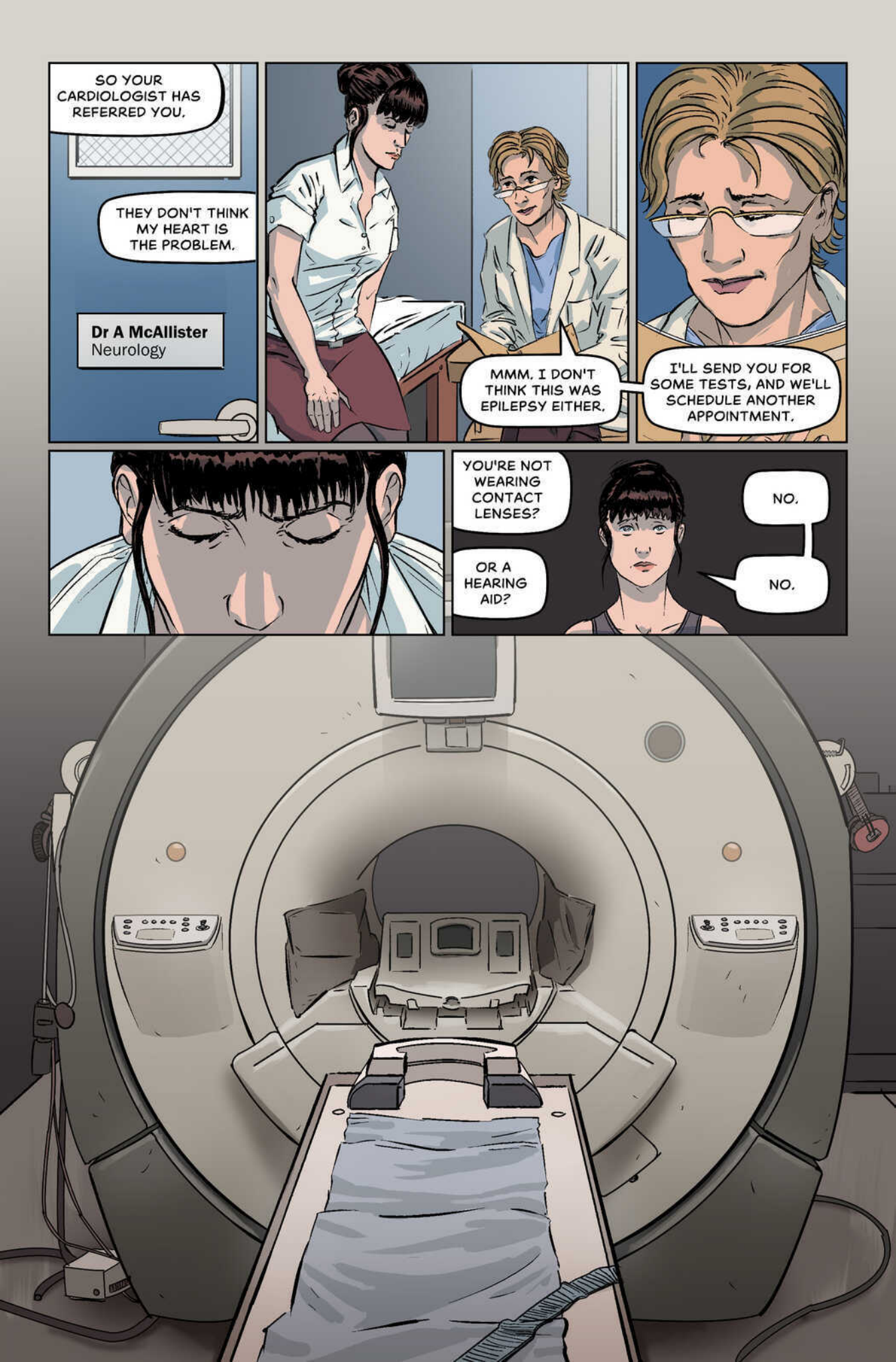



...WE'LL GET THEM NEXT WEEK.
NEXT WEEK.
QUIZ! 7:30
YOU WANTED TO TALK ABOUT SOMETHING?
IT'S JUST EASIER TO TALK TO YOU, BECAUSE, YOU KNOW...
BUT DON'T FEEL YOU HAVE TO--
IT'S FINE.
I NEVER FAINTED WHEN WE WERE DATING, RIGHT?
NOT THAT I REMEMBER.
WELL, I DO NOW.
A LOT.

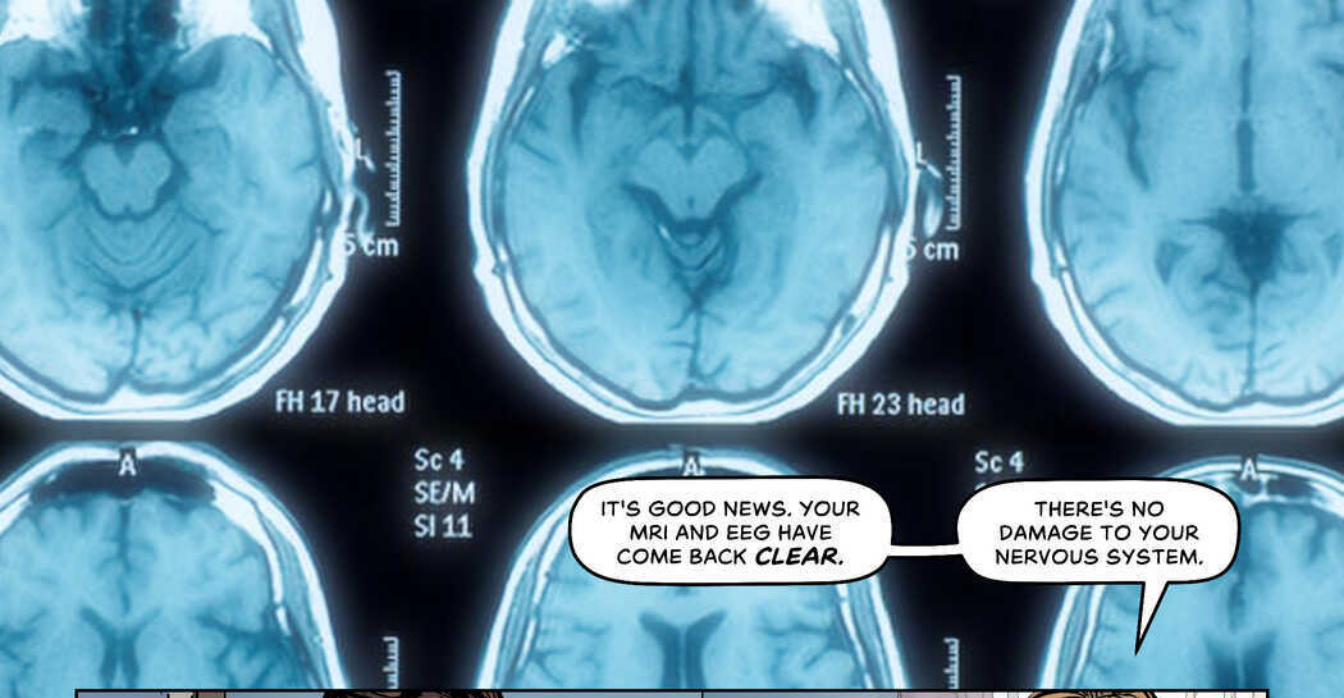

WHAT DID THE GP SAY?
HAVE I BEEN UNUSUALLY STRESSED? AM I PREGNANT? DID I STAND UP TOO QUICKLY?
HAVE YOU BEEN DRINKING AT WORK?
RIGHT.
HERE'S THE ANSWER.
REALLY? WHAT?
MICTURITION SYNCOPE.
A DRASTIC DROP IN BLOOD PRESSURE WHEN YOUR BLADDER EMPTIES TOO RAPIDLY.
DAMIAN, I NEED YOU TO ACTUALLY TALK TO ME. CAN YOU DO THAT?
... SURE.

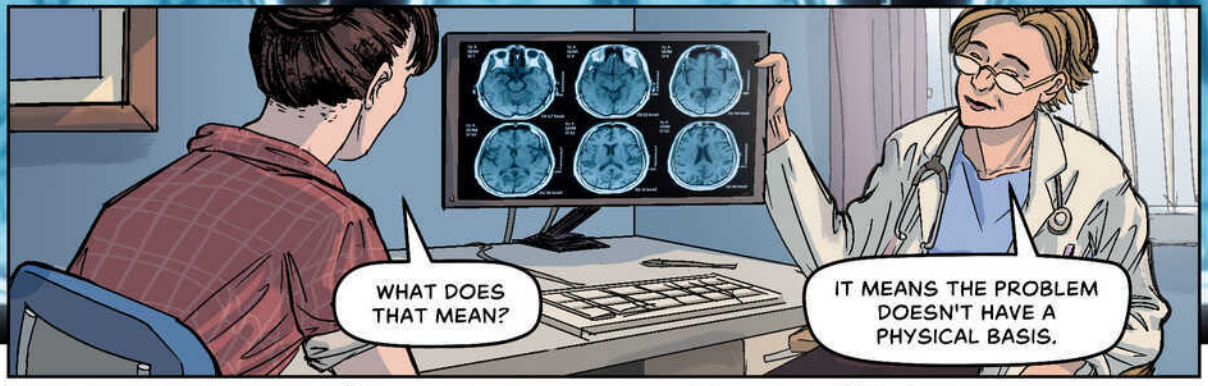

STEPH? CAN YOU HEAR ME?
ARE YOU THERE?
...MY GP REFERRED ME. I'M WAITING FOR AN APPOINTMENT WITH THE NEUROLOGIST.
WOULD YOU LIKE TO TAKE A FEW DAYS' ABSENCE? SICK LEAVE?
I-- NO. THANKS, BUT NO.
I'D GO CRAZY WITHOUT SOMETHING TO DO.
WELL, THE OFFER'S THERE.
THANK YOU. I'LL BEAR IT IN MIND.


CARDIOLOGY
TODAY YOU'LL BE HAVING WHAT WE CALL A TILT TEST.
SOME PEOPLE FIND IT QUITE RELAXING.
WE'LL TILT THE BED UP TO SEE IF WE CAN PRODUCE YOUR SYMPTOMS.
WE MONITOR YOUR BLOOD PRESSURE AND HEART RATE.
85
125/75
98
DO YOU FEEL ANY DIZZINESS?
NO.


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


FH 17 head
FH 23 head
Sc 4
SE/M
SI 11
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.

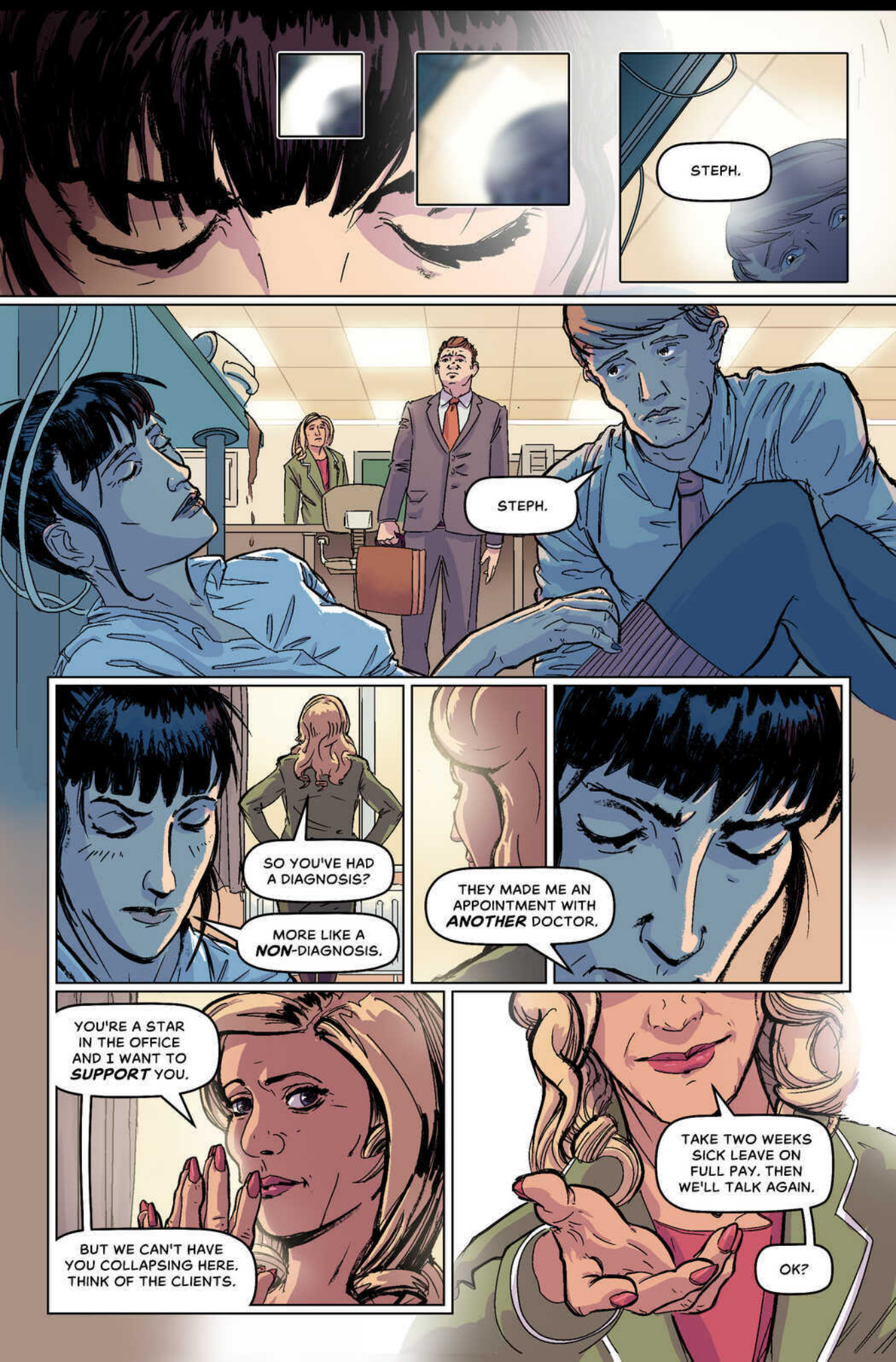

IT'S IN MY MIND?


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


YOUR PROBLEM IS NOT NEUROLOGICAL.

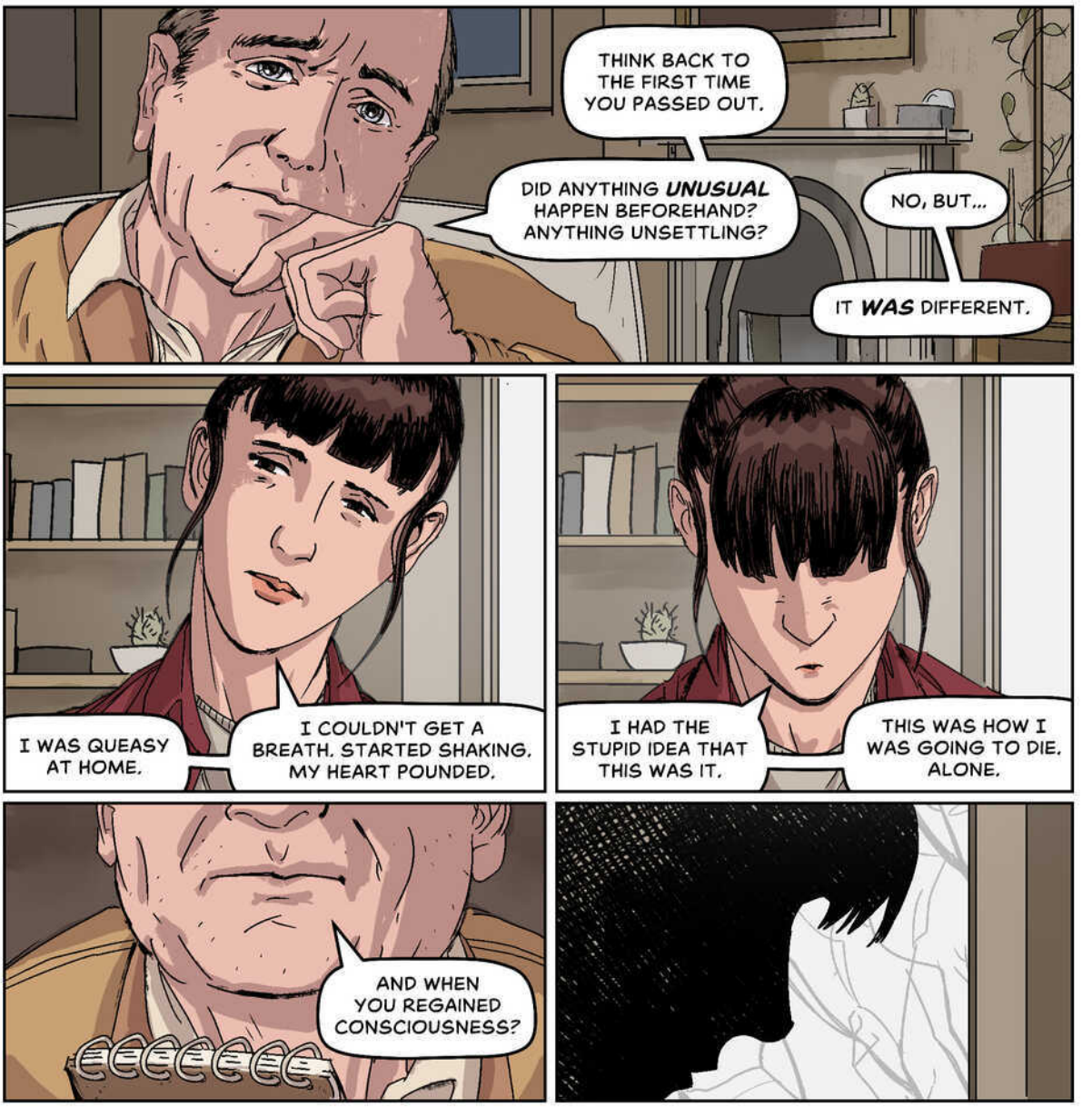

I COULD REFER YOU TO A PSYCHIATRIST.

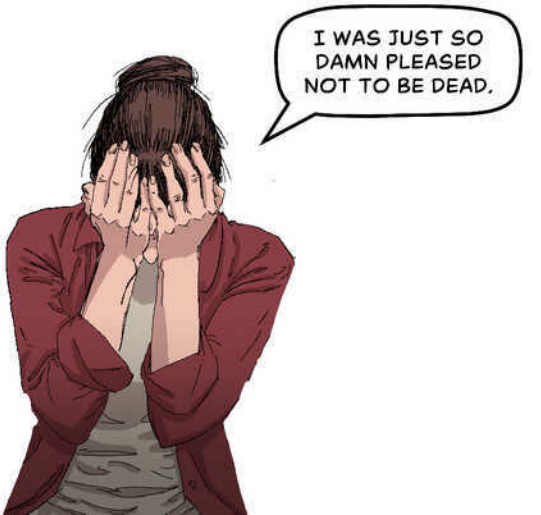

BVVVVVV
I ASSUME YOU HAVE TONIC.
GIN
WE STRUGGLED THROUGH THE MUSIC ROUND, BUT WE *DIED* ON GEOGRAPHY.
ANOTHER?
I'M FINE.
THERE'S A REASON WE KEEP YOU ON THE TEAM. WHERE'S YOUR RECYCLING?
... NEVER MIND. I *FOUND* IT.
PIZZA

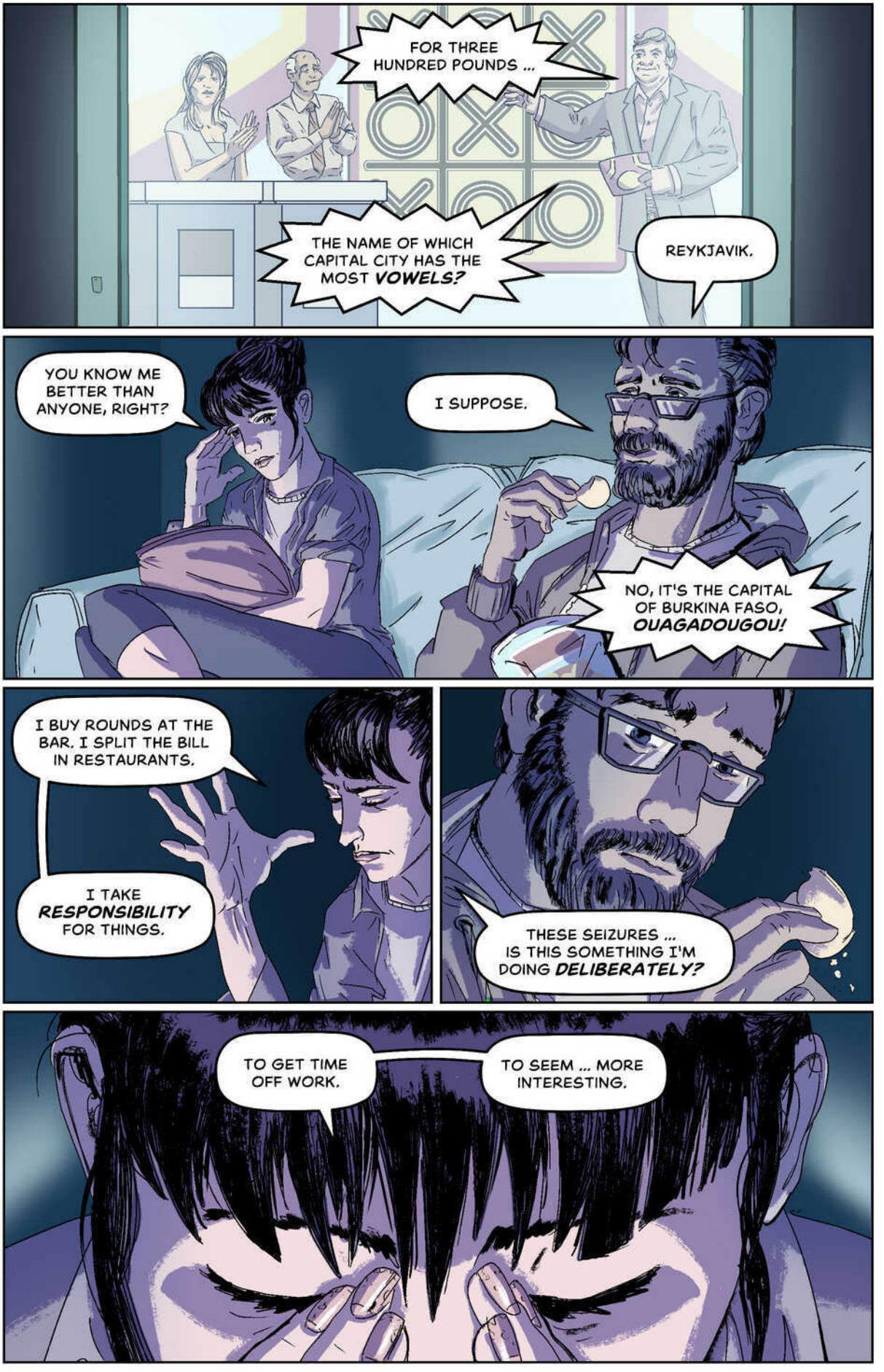

STEPH.
STEPH.
SO YOU'VE HAD A DIAGNOSIS?
MORE LIKE A NON-DIAGNOSIS.
THEY MADE ME AN APPOINTMENT WITH ANOTHER DOCTOR.
YOU'RE A STAR IN THE OFFICE AND I WANT TO SUPPORT YOU.
BUT WE CAN'T HAVE YOU COLLAPSING HERE. THINK OF THE CLIENTS.
TAKE TWO WEEKS SICK LEAVE ON FULL PAY. THEN WE'LL TALK AGAIN.
OK?

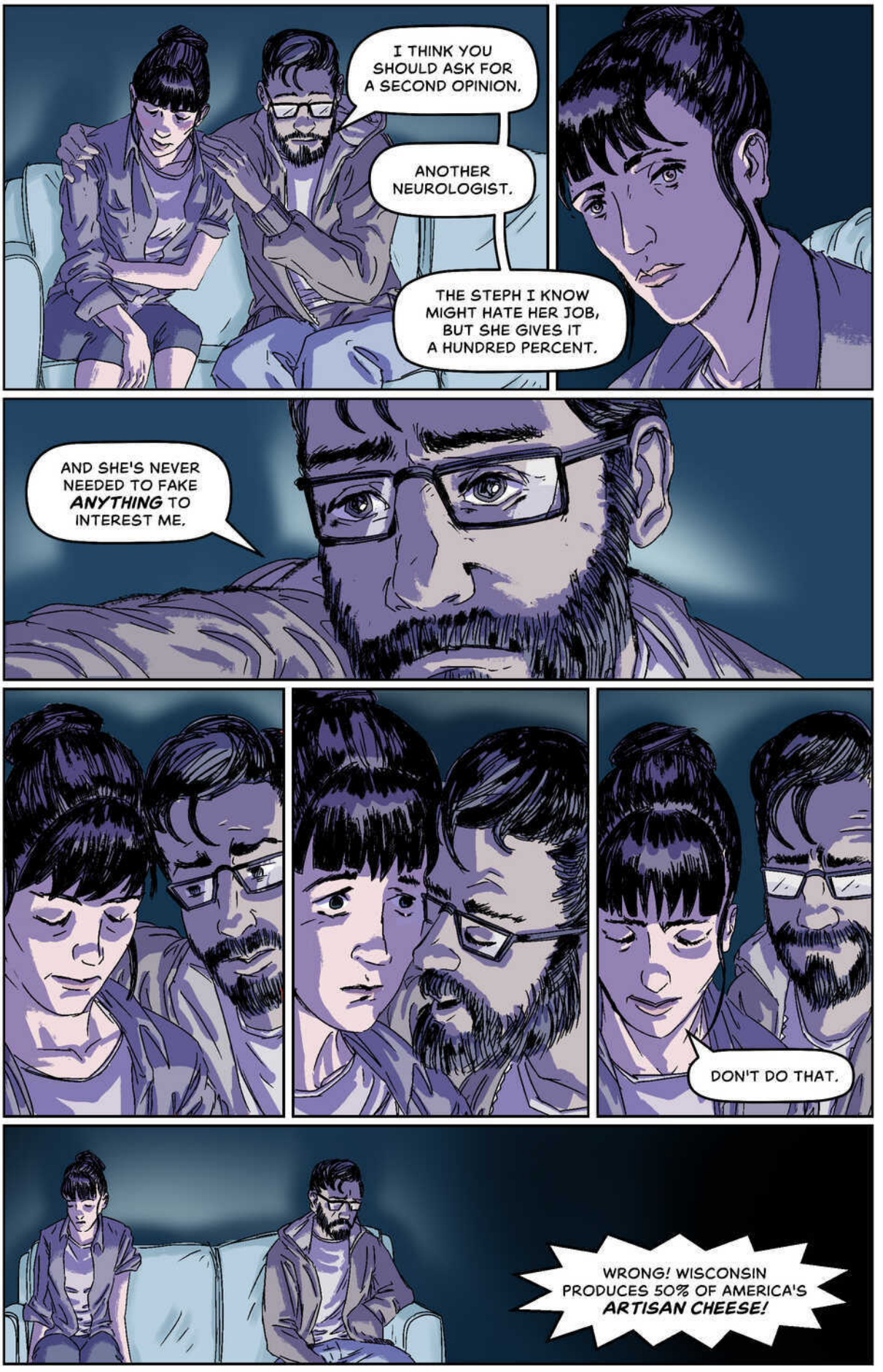

HELLO AGAIN.
WHAT IS *WRONG* WITH ME?
YES! AND A DAMN *NEUROLOGIST!*
HAVE YOU TALKED TO YOUR *GP?*
WE CAN'T KEEP BEING CALLED OUT FOR THIS.
I'M NOT DOING IT ON *PURPOSE!*


HELLO STEPHANIE, WOULD YOU LIKE TO COME IN?
OK.
SO, TELL ME ABOUT THESE BLACKOUTS.
THIS MIGHT SOUND PARANOID.
BUT I FEEL THAT PEOPLE LOOK AT ME *DIFFERENTLY* NOW.
AS IF I'M MAKING IT ALL UP FOR *ATTENTION*.
LIKE ANYONE WOULD WANT *THIS* KIND OF ATTENTION.


THINK BACK TO THE FIRST TIME YOU PASSED OUT.
DID ANYTHING UNUSUAL HAPPEN BEFOREHAND? ANYTHING UNSETTLING?
NO, BUT...
IT WAS DIFFERENT.
I WAS QUEASY AT HOME.
I COULDN'T GET A BREATH. STARTED SHAKING. MY HEART POUNDED.
I HAD THE STUPID IDEA THAT THIS WAS IT.
THIS WAS HOW I WAS GOING TO DIE. ALONE.
AND WHEN YOU REGAINED CONSCIOUSNESS?

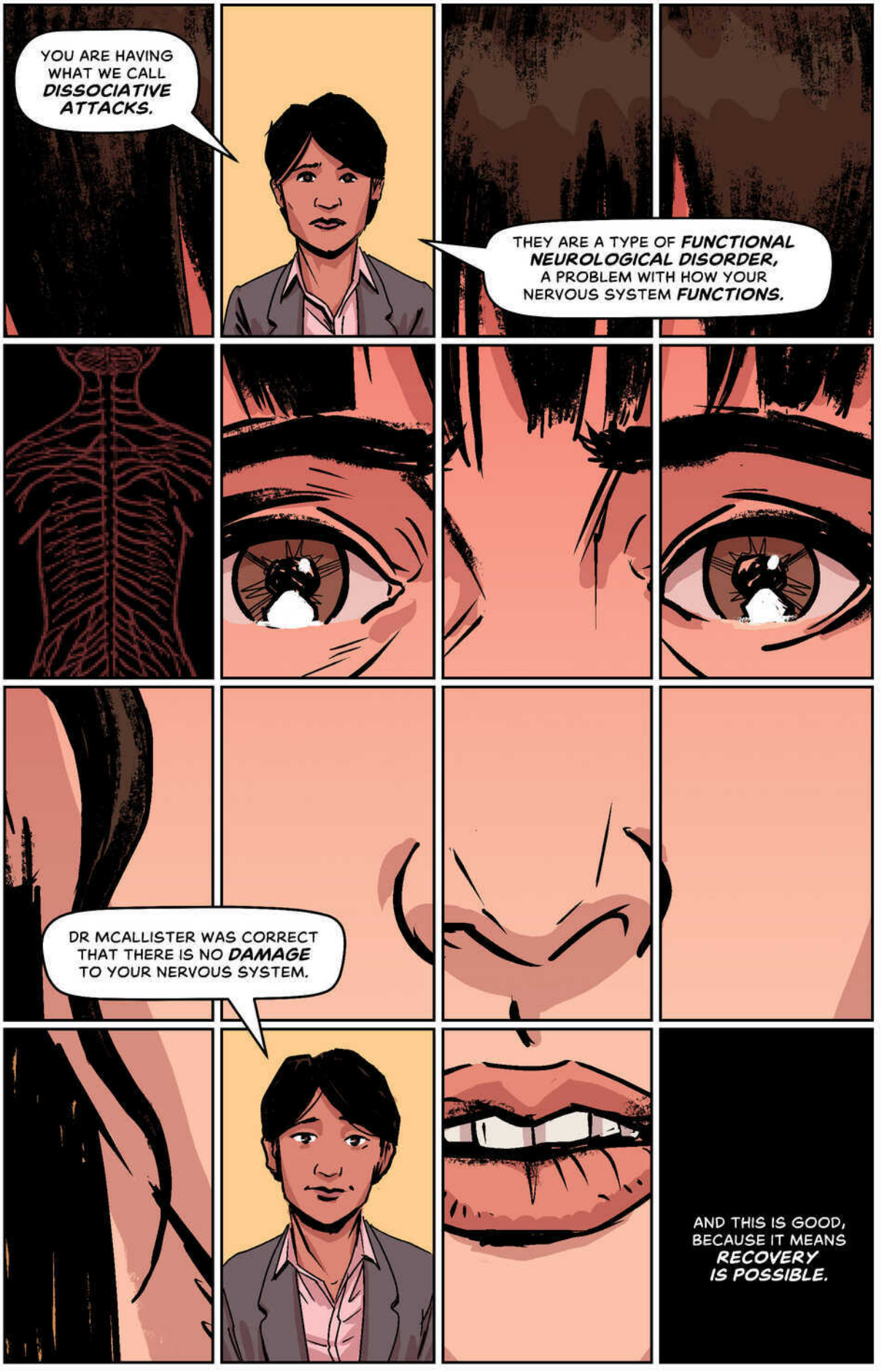

I WAS JUST SO DAMN PLEASED NOT TO BE DEAD.

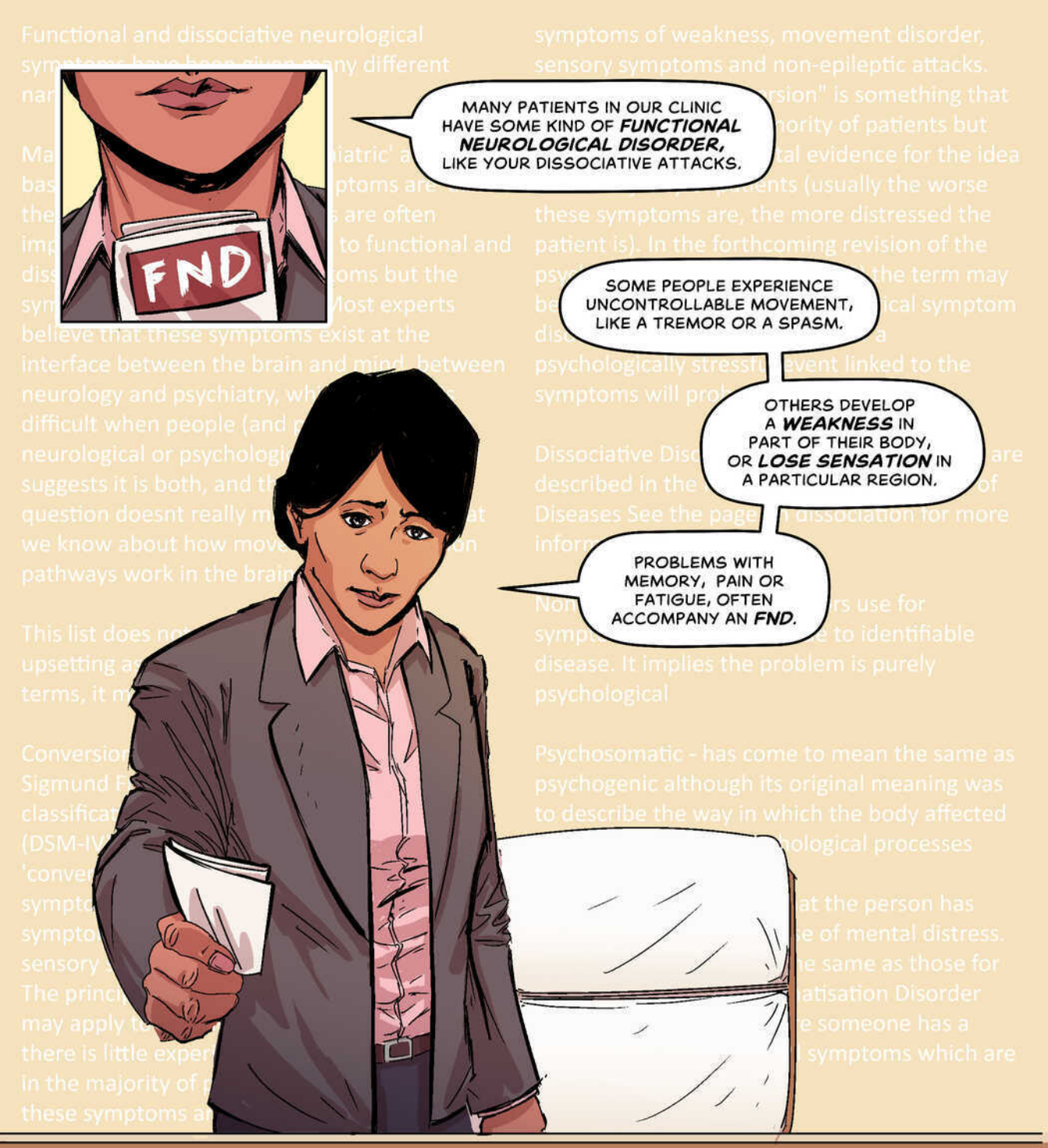

FOR THREE HUNDRED POUNDS ...
THE NAME OF WHICH CAPITAL CITY HAS THE MOST VOWELS?
REYKJAVIK.
YOU KNOW ME BETTER THAN ANYONE, RIGHT?
I SUPPOSE.
NO, IT'S THE CAPITAL OF BURKINA FASO, OUAGADOUGOU!
I BUY ROUNDS AT THE BAR. I SPLIT THE BILL IN RESTAURANTS.
I TAKE RESPONSIBILITY FOR THINGS.
THESE SEIZURES ... IS THIS SOMETHING I'M DOING DELIBERATELY?
TO GET TIME OFF WORK.
TO SEEM ... MORE INTERESTING.

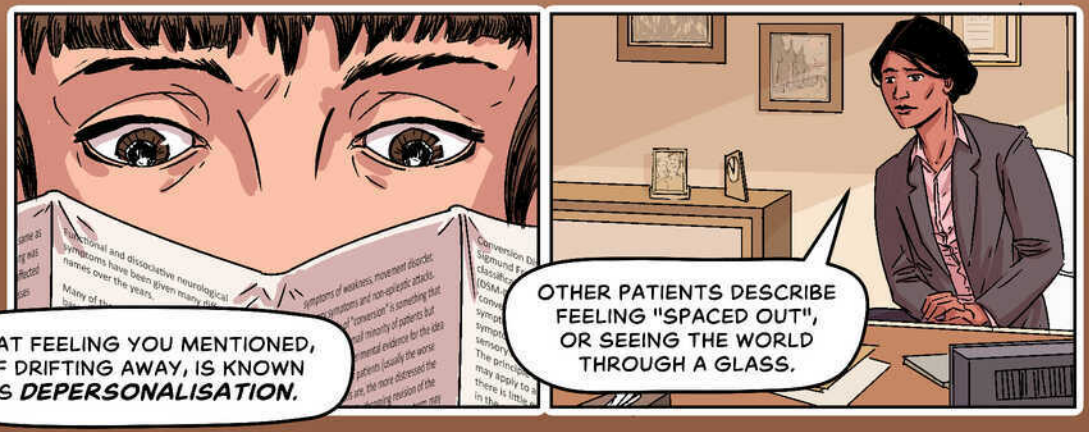

I THINK YOU SHOULD ASK FOR A SECOND OPINION.
ANOTHER NEUROLOGIST.
THE STEPH I KNOW MIGHT HATE HER JOB, BUT SHE GIVES IT A HUNDRED PERCENT.
AND SHE'S NEVER NEEDED TO FAKE ANYTHING TO INTEREST ME.
DON'T DO THAT.
WRONG! WISCONSIN PRODUCES 50% OF AMERICA'S ARTISAN CHEESE!


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.
FND
I THINK I KNOW WHAT'S WRONG.
REAL
NOT MAKING THEM UP
THINK
T 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.

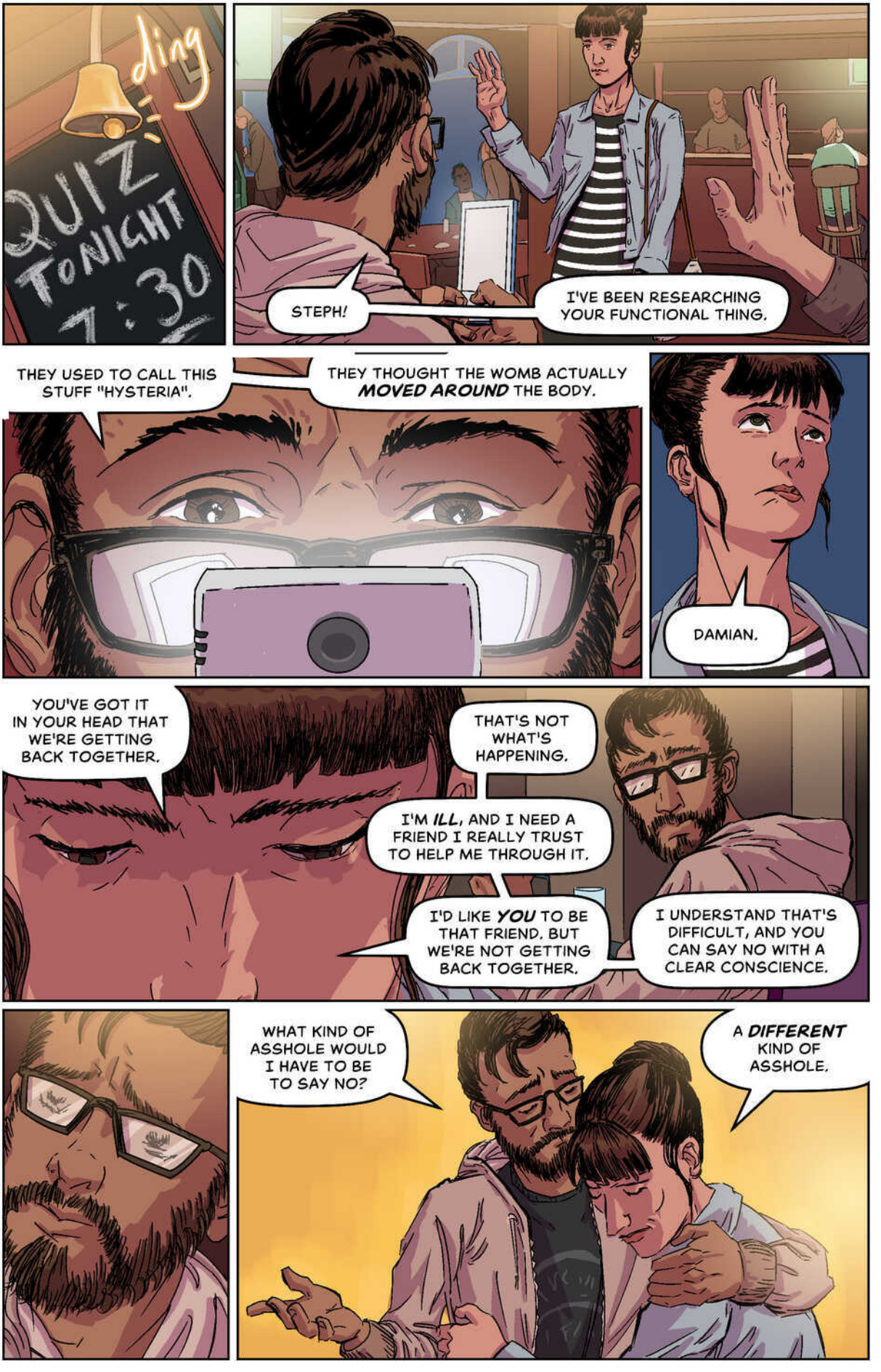

FND
MANY PATIENTS IN OUR CLINIC HAVE SOME KIND OF FUNCTIONAL NEUROLOGICAL DISORDER, LIKE YOUR DISSOCIATIVE ATTACKS.
SOME PEOPLE EXPERIENCE UNCONTROLLABLE MOVEMENT, LIKE A TREMOR OR A SPASM.
OTHERS DEVELOP A WEAKNESS IN PART OF THEIR BODY, OR LOSE SENSATION IN A PARTICULAR REGION.
PROBLEMS WITH MEMORY, 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.

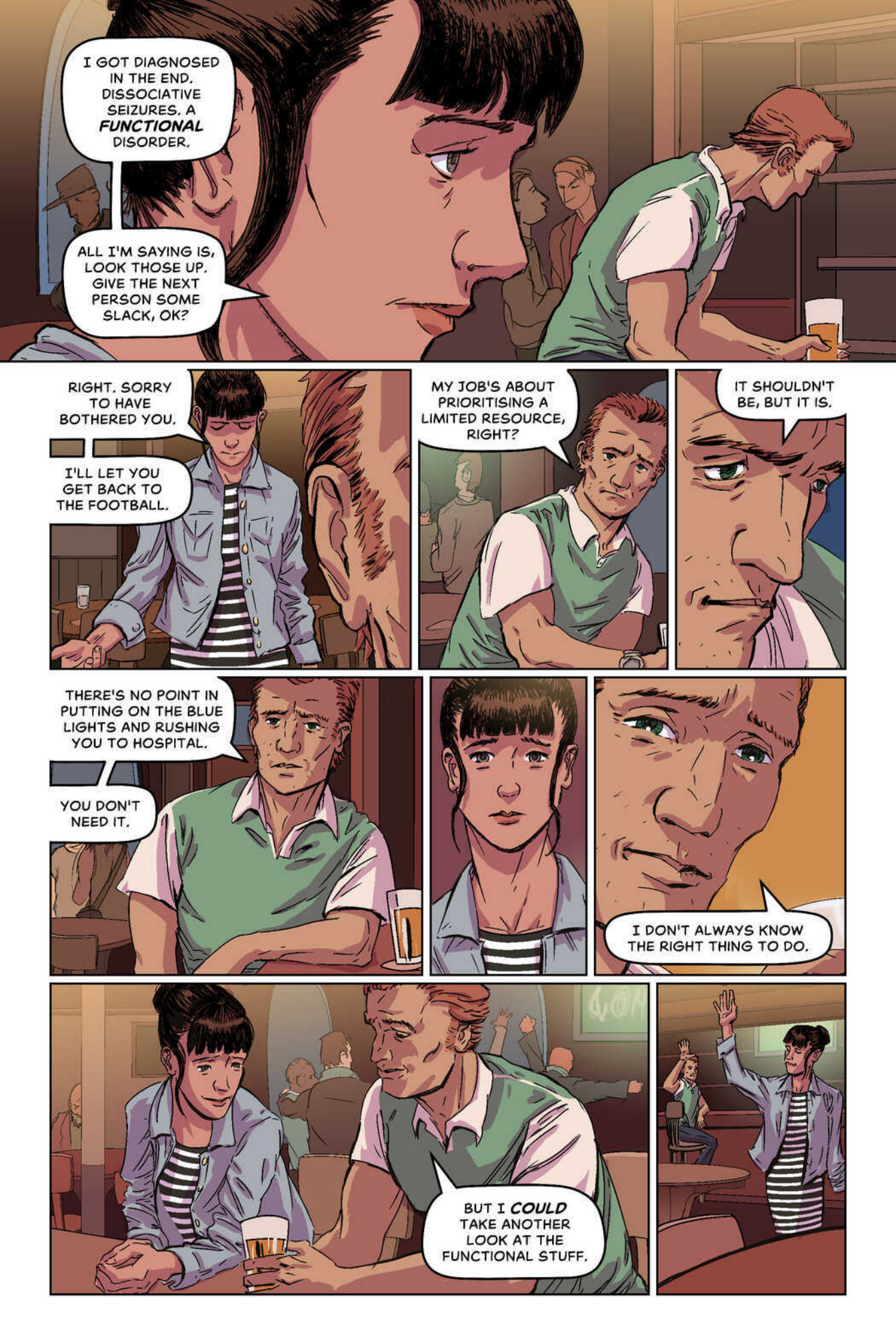

WHAT DO I *DO* ABOUT IT?
IT IS VITAL THAT *YOU* TAKE CHARGE OF YOUR RECOVERY, ALTHOUGH I WILL BE HERE TO HELP.
I NEED YOU TO LEARN TO RECOGNISE *WARNING SYMPTOMS.*

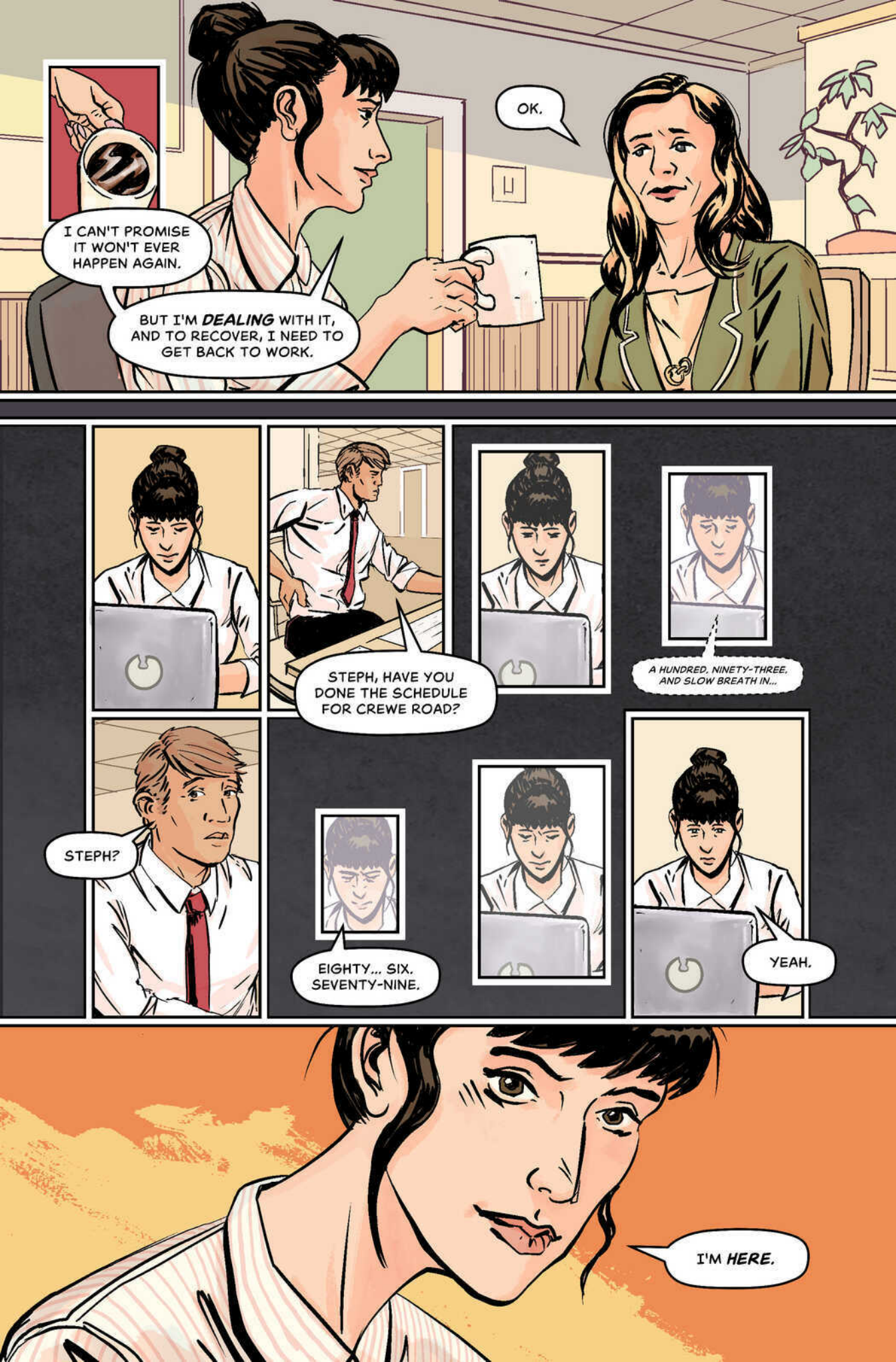

THE IMPRESSIONS YOU HAVE *IMMEDIATELY BEFORE* AN ATTACK.
YOU MENTIONED FEELING *TRAPPED.* TRY TO RECOGNISE OTHER SIGNS.
PERHAPS A TINGLING SENSATION, SWEATING, OR SHORTNESS OF BREATH.


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.


ding
QUIZ TONIGHT 7:30
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.


GIVE ME A MINUTE, WILL YOU?
EXCUSE ME.
HI.
LOOK, YOU NEVER CAME OUT AND SAID IT. I GUESS YOU CAN'T.
BUT I'M PRETTY SURE YOU THINK I'M FAKING MY BLACKOUTS.
I'M SURE YOU SEE A LOT OF SHIT IN YOUR JOB, AND DEAL WITH A LOT OF TIME-WASTERS.
WHATEVER YOU'RE THINKING, BELIEVE ME, I ALREADY ACCUSED MYSELF OF IT.


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.


I CAN'T PROMISE IT WON'T EVER HAPPEN AGAIN.
BUT I'M DEALING WITH IT, AND TO RECOVER, I NEED TO GET BACK TO WORK.
OK.
STEPH, HAVE YOU DONE THE SCHEDULE FOR CREWE ROAD?
A HUNDRED, NINETY-THREE, AND SLOW BREATH IN...
STEPH?
EIGHTY... SIX. SEVENTY-NINE.
YEAH.
I'M HERE.

# 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/

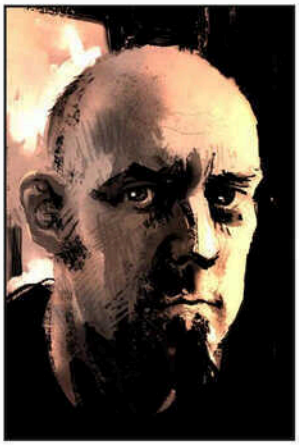
Developing a network of support groups across the UK.

**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

NHS Lothian

TONIC ARTS | PART OF Edinburgh & Lothians Health Foundation