

1875

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it's also difficult to fathom what the
questions should be.**

For those living with MS uncertainty is one
of its greatest challenges.

**LOOK
INTO
MY
EYES**

LOOK INTO MY EYES

With MS there are seldom answers; it's also difficult to fathom what the questions should be. For those living with MS uncertainty is one of its greatest challenges. Like this story MS is difficult to read in a straightforward manner. Like this story having this ambiguous disease forces a series of decisions. The choices range from the big, to the small, but all can seem equally stressful when the outcomes are so unknown. The MS'er is constantly searching for signposts which might direct them in the 'right' direction. Whilst there is often no correct path, people with MS need support and resources to be empowered by their decision-making, rather than overwhelmed.

As the protagonist of this story, we hope you can make it your reality for its few pages.

LOOMINGS

It's negligible, just a little odd.

Surely you are a hypochondriac.

When you walk for a while, or go for a run, the world around you loses its definition. It dissolves into a blur. The streets of the city resemble a painting by Monet, edges of buildings and buses are smudged, bleeding into each other. Back inside it's difficult to read, but once you've rested slowly things come back into focus. It's brutally cold outside and you wonder whether this has anything to do with it.

Tuesday brings an appointment with the GP, so you bring it up then.

The doctor looks at your eyes but is unconcerned. Now you are describing your occasional 'fuzzy' vision to a professional it sounds vague and irrelevant. Why are you wasting the GP's time when there are so many in the waiting room who're visibly ill?

But the haze persists when you are out and about.

You think it might be getting worse.

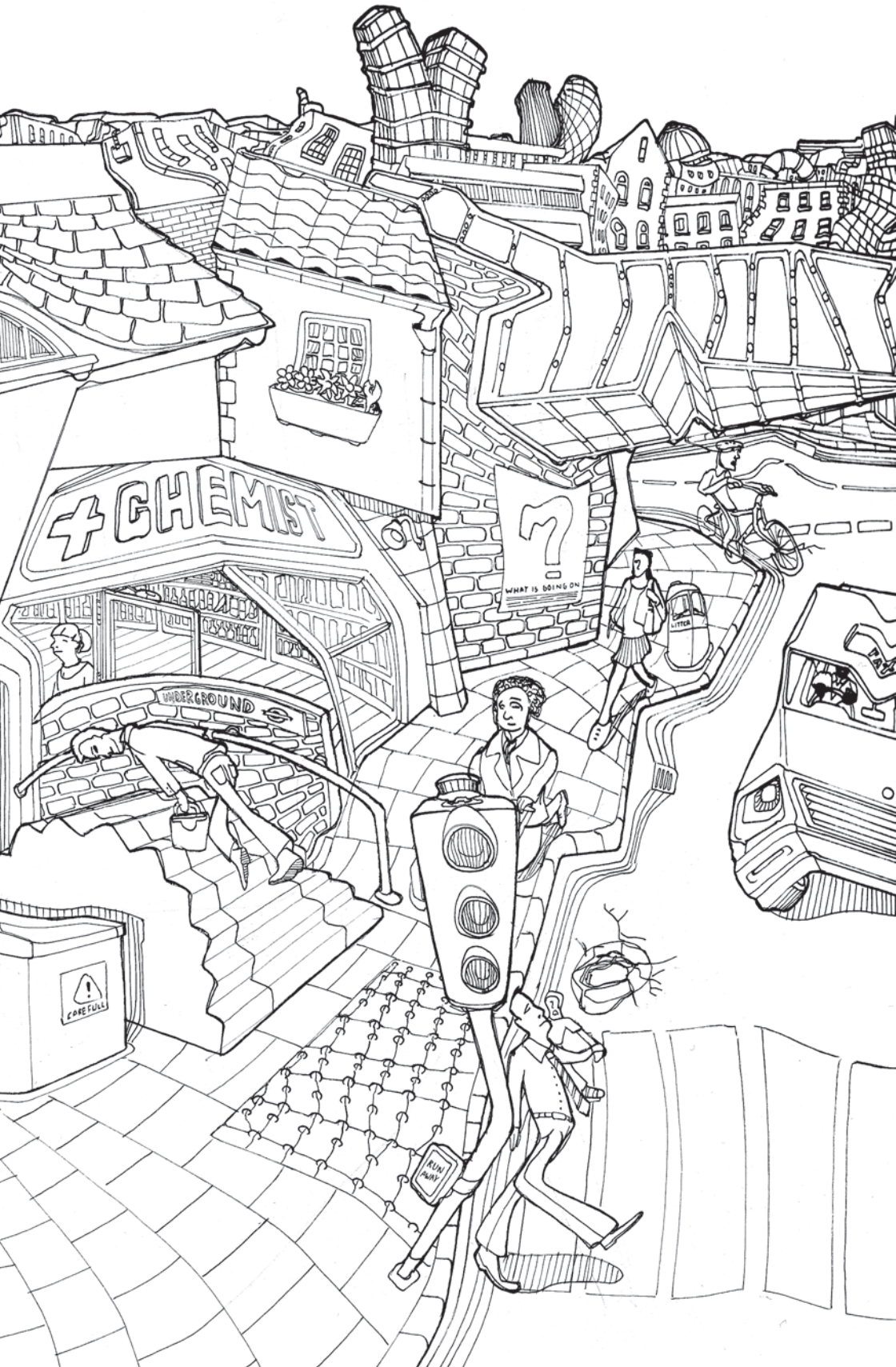
DO YOU

A/ DECIDE TO FOLLOW UP WITH YOUR OPTICIAN...

CONTINUE TO PAGE 16

B/ YOU RESOLVE TO STOP WORRYING AND TRY TO IGNORE IT...

CONTINUE TO PAGE 13



DELIBERATIONS

Even though your optic neuritis cleared up, the fatigue is crushing.

Most mornings by the time you arrive at your desk, having hurried around at home and then braced the city's rush hour, you are beat. It's as if the endurance needed to complete routine tasks has been mysteriously multiplied to the power of ten. The world as encountered by yourself and those without this invisible affliction, are radically different places.

A trip on the bus becomes an experiment in balance, a mad dash to get to your seat before it lurches forwards again leaving your now compromised vestibular system floored. You can feel the stares driving hard into your back as you sit in the seats up front for disabled people. People presume health if you're beneath 50. They have no idea. There is nowhere for these thoughts to be expressed on the anonymity of public transport, so they're incinerated internally in anger.

Stress at work is building. It's busy but you still have to leave the office exactly on time each day just to make it to the end of the week. This also draws funny looks. You are just about managing to get everything done, but there is less time, less energy, for chat and banter.

Then a bug breaks out in the office.

You are petrified of catching it and having the high temperature bring on an acute episode of symptoms. No one knows why you are acting so paranoid about your health, but you are consumed by the fear of a set back with your MS.



DO YOU

A/ STAY OFF WORK PRETENDING THAT YOU'VE GONE DOWN WITH IT...

CONTINUE TO PAGE 26

B/ KEEP ON GOING INTO WORK, YOU'VE HAD TOO MUCH TIME OFF ALREADY...

CONTINUE TO PAGE 28

OSCILLATIONS

“The blood tests are clear”
says the neurologist.

The doctors’ surgery is teeming.

Trying to steer clear of those who look worst afflicted with flu you are relieved to be called quickly in to the GP.

‘What’s the problem?’

Dr Ramsey swings herself round in her chair to face you as she asks.

You explain the reoccurrence of the blurred vision and mention that since you booked the appointment there have been some other strange incidences. You’ve been wobbly on your feet since having a cold last weekend. Dr Ramsey listens intently, the tenor of her face changing. She works through a routine that seems orthodox to her, but you can’t fathom the connections between. It is when you realise that you can’t walk heel to toe that you become unsettled.

Later that day you end up in A&E: the quickest route to a neurologist Dr Ramsey advises. You haven’t as yet quite fathomed why you need to see a neurologist. You studiously avoid thinking about it, especially when you are admitted to the hospital.

The defining moment of this day, this year, was sitting down in the wheelchair they brought to take you to the ward. The swift transition from being perceived a normal, healthy, going-concern in the morning to a hospitalised invalid by the afternoon is deeply shocking.

“That’s good news”

“Erm well not really,” she says.

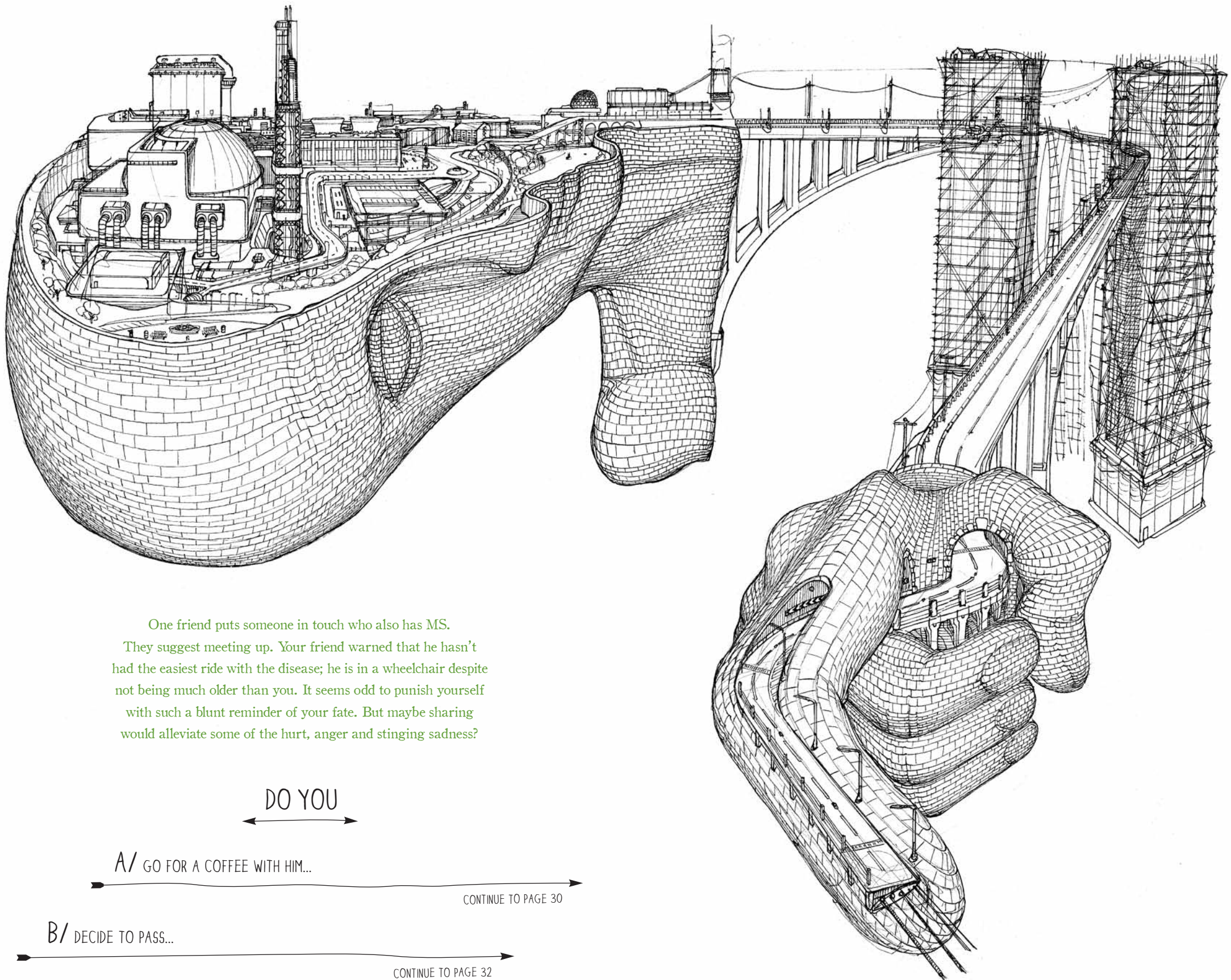
“Unfortunately the MRI showed clear signs of demyelination and this, with the spinal fluid results, leads us to a diagnosis of Multiple Sclerosis.”

A door shuts on the world of commonplace concerns you previously inhabited. Now your constituency is that of worst case scenarios, a dystopia you thought was meant for other people, not for you.

Siding yourself with the ‘have-nots’, rather than the ‘haves’, the expansive, ~~long lived~~ future envisaged, unbridled of any restrictions is relegated to elegy.

Instead, the immutable fact of your physical disintegration plagues you.

You stumble through some treatment. You are told that the outlook is positive for you. This seems an outrageous lie. Whilst the symptoms clear up, you are unable to resume normal life. Your relationships falter as you retreat from connections to your earlier self. Working seems improbable and you don’t return. The situation is irrevocable so why should things carry on as normal? Given the weight of the diagnosis, people don’t challenge your new behaviour, they seem uncertain of how to approach you now.



One friend puts someone in touch who also has MS.
They suggest meeting up. Your friend warned that he hasn't had the easiest ride with the disease; he is in a wheelchair despite not being much older than you. It seems odd to punish yourself with such a blunt reminder of your fate. But maybe sharing would alleviate some of the hurt, anger and stinging sadness?

DO YOU
↔

A/ GO FOR A COFFEE WITH HIM...
→ CONTINUE TO PAGE 30

B/ DECIDE TO PASS...
→ CONTINUE TO PAGE 32



REOCCURENCES

Spring arrived and slowly your blurred vision disappeared.

You returned to being a sharp-eyed flaneur, scouring the city on foot. Two years pass; busy ones in which new opportunities, long but satisfying working days, happy holidays and celebrations at home jostle comfortably alongside each other.

Then around winter solstice, almost exactly the same time of year as before, the haze over your vision returns.

You rack your brain for possible causes. Is it the lack of light in the short days of December or the cold?

What to do? Is there anything to do? The GP checked it out two years ago and said all was fine. Your family suggest you go back. But you're not sure. You don't really feel like explaining the situation again, when verbalised it just sounds odd.

DO YOU



A/ GO BACK TO THE GP SURGERY AND GET A SECOND OPINION...

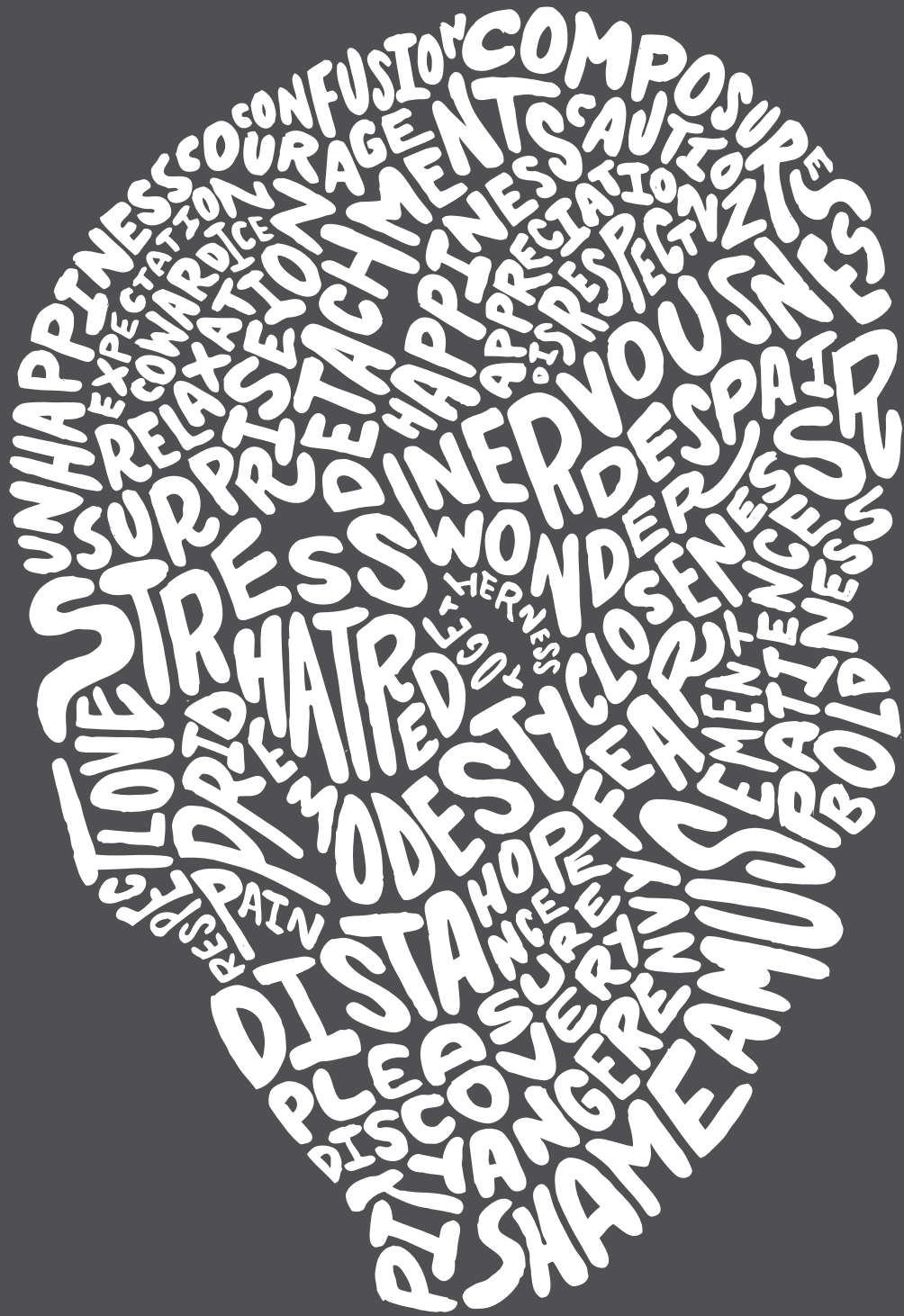


CONTINUE TO PAGE 8

B/ DO NOTHING...



CONTINUE TO PAGE 15



ESCAPES

You're always on the watch for it every year
as the days grow shorter and the weather colder.

You hold your breath as the winter solstice passes.

But it doesn't return.

Your eyesight has remained thankfully crystal clear.

After a while, those two episodes of foggy vision are
consigned to the past. Not forgotten though.

The incidences were a warning that the world
around you can be obscured by
malfunctioning senses; a reminder
your health is a fragile thing.

MIASMAS

Journeys through the city become an odyssey; signs, maps and bus numbers are blurred and unreadable once you're on the move. You stick to paths well trodden.

YOU'RE OFF TO THE OPTICIANS.

SURELY THE RIGHT PLACE FOR A
RELIABLE SECOND OPINION.

INSIDE, AMIDST THE REASSURING
ARMOURY OF OPTOMETRY EQUIPMENT
YOU UNDERGO EVERY TEST IN THE REPERTOIRE.

BUT INSTEAD OF AN EXPLANATION
THERE IS A REFERRAL TO THE EYE HOSPITAL'S
A&E DEPARTMENT.

THE OPTICIAN WATCHES YOU AS YOU LEAVE THE SHOP.

LATER YOU REALISE THAT UNLIKE YOU,
BLINDED BY IGNORANCE, HE COULD SEE
CLEARLY WHAT YOU WERE HEADED FOR.

THE SUBSEQUENT WEEKS ARE A BLUR,
FALLEN TO THE SAME DISORIENTATING
SMUDGES AS YOUR VISION, OR WHAT
WAS FINALLY DIAGNOSED BY THE EYE
HOSPITAL'S NEURO-OPHTHALMOLOGY
DEPARTMENT AS OPTIC NEURITIS.

Optic neuritis: a precursor to or symptom of Multiple Sclerosis. Soon you are bombarded by the disquieting deep bass sounds of an MRI scanner. You have a needle nudge between your vertebrae into your spinal cord to draw out diagnostic fluids. Until your consultant at the hospital confirms a diagnosis of MS, you have only the haziest notion of what this disease might mean. In health, you'd forgotten you were made of flesh and blood, and a nervous system pulsing with electricity.

The reliability of your health, had vanished for good.

The certainty you'd believed in vanished for good.

You're dreadfully humbled, as you'd presumed life would be plain sailing at least till middle-age. It's a shocking reminder that providence can play an implacable hand.

Later, you return to what used to be your life. You feel like an imposter posing as your former self. You return to work, heeding the advice of your MS nurses to be cautious about telling people. They are wary of prejudice towards MS in the workplace and you disclosing whilst the diagnosis is still so raw. In the office people treat you like 'normal', which is a comforting reminder that life can just carry on. But it is difficult: your colleagues care about you and you feel isolated by the secret you're keeping.

In some ways you are trying to maintain a normality that no longer exists.

Plus your optic neuritis seems only to be
getting worse and it is becoming
increasingly difficult to
read your computer
screen.

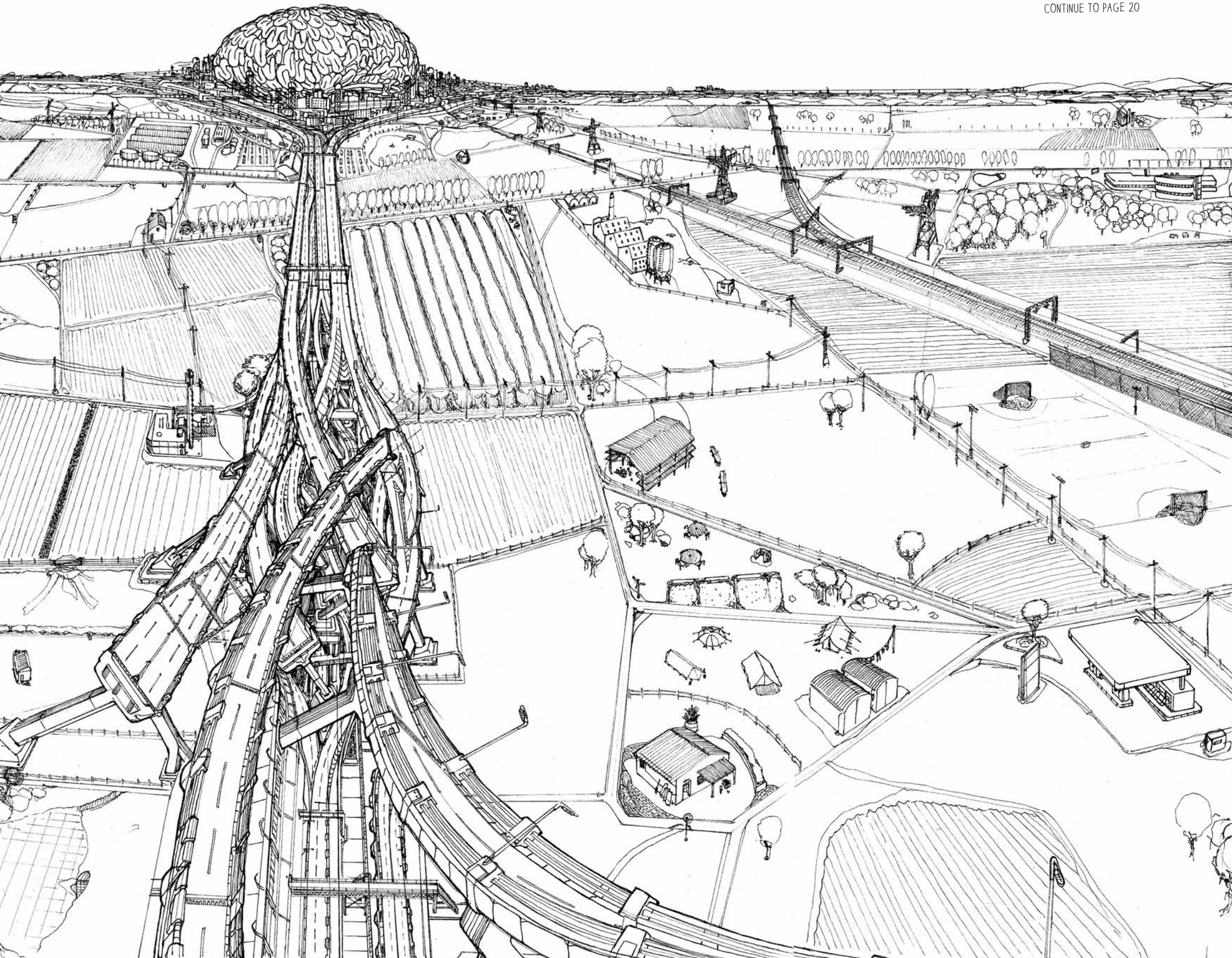
DO YOU

A/ 'COME OUT' TO YOUR MANAGERS AND COLLEAGUES...

CONTINUE TO PAGE 18

B/ DECIDE NOT TO DISCLOSE AT WORK...

CONTINUE TO PAGE 6



DISCLOSURES

The relief is enormous, this 'coming out'.

You're armed with booklets for all your team on 'MS in the Workplace'. This helps when the symptoms seem so vague; it's legitimizing. You explain about the diagnosis. That you're not really 'better' after your time off work, your vision is still blurred and that fatigue often hits you hard.

You can be 100% yourself again with colleagues and share pretty much everything, as you did before. Yet it is also still the office, so things comfortably continue as normal. The return of the commonplace is a welcome distraction, between 9 and 5 at least.

Whilst your health stabilises, you are still plagued by fatigue and your blurred vision is slow to improve. You're uncertain of whether the next day will bring a relapse or not, fatigue or not. Unable to sense where your new boundaries are, you often overstretch yourself doing the simplest things. To the outside eye you look a picture of health. But frequent visits to the hospital make you feel different, feel 'ill'. A forceful anger often and unpredictably detonates within you. It's triggered by little things, but it's about the big things. The short term and, even worse, the long term: that's what keeps you up at night.

Then one night, exhausted, you get a taxi to a friend's birthday dinner.

The restaurant is large and humming with conversation, muffled slightly by the weighty table cloths and thick carpet. Arriving late you take the only seat remaining, amongst people you do not know. Ten minutes later you are engrossed in conversation with the person to your left, sixty minutes on it's the same. They surprise you with their wit and their astute perceptions, their good looks accompanied by a generosity of spirit. You're intrigued by stories in which you glimpse a strong but not obdurate person, a sociable but not gregarious soul. You are giddy with the thrill of this unexpected meeting and thrilled this giddiness has nothing to do with a lesion this time.

Even better, on leaving the restaurant you make arrangements to meet the next week for a drink.

A little further down the line, things are going really well.

Buoyed up by the fact that the Gods, now in a more benevolent mood, have thrown a love affair your way, you've submerged the issue ruining all this, the typhoon about to wreak havoc on your parade. A longer term future with someone is surely impossible for you now? What partner would sign up to bear witness to your decline?

DO YOU

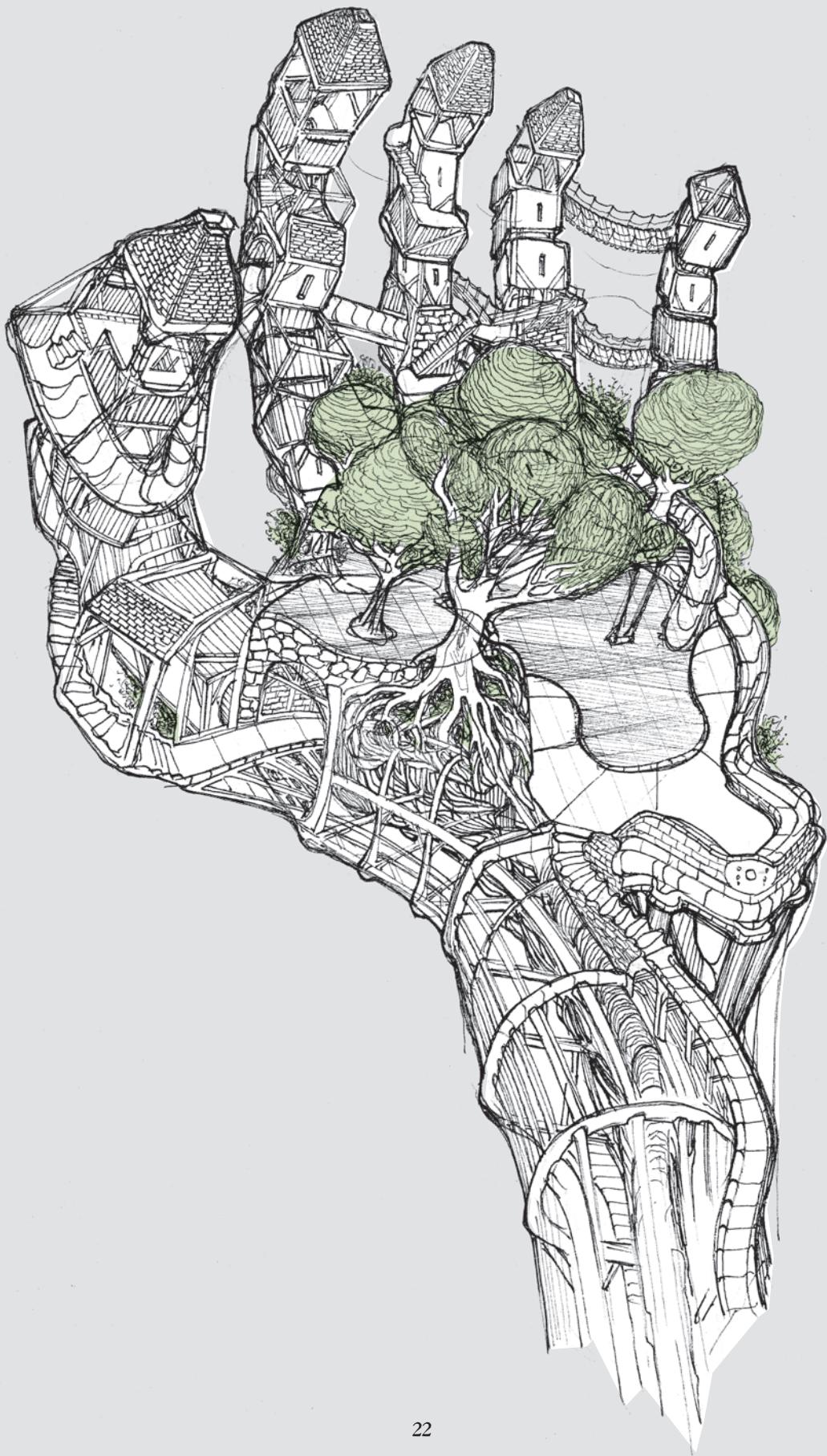


A/ KEEP THIS EXPERIENCE AS A HAPPY MEMORY. YOU BREAK THINGS OFF...

CONTINUE TO PAGE 23

B/ YOU DECIDE TO BROACH THE SUBJECT WITH THEM ON YOUR NEXT DATE...

CONTINUE TO PAGE 24



EFFLORESCENCE

During those post-diagnosis years that burgeoning romance was one of the first things you shut down. Its pre-emptive conclusion, likely unwarranted, felt like your only means of control. With no one in the same boat to turn to for advice it was impossible to imagine broaching the issue successfully. Now you have lots of people to ask for advice and know many positive love stories, not least your own. Then, in those shaky early days, it seemed improbable such fragile nascent feelings could survive the brutal revelations you were struggling with yourself.

Lying in the park in the powerful April sunshine, you are flooded once again with the reassurance of spring and the return of life. Now you know relapses, like winter, eventually end. The duress of the dark seasons makes the trees barren. But like nature, your nervous system has the capacity for new growth, the capacity to heal, at least at present.

The moment is increasingly potent.

Living with uncertainty means enjoying the health you currently have.

Not knowing what the future will bring means you have to flourish in the now.

CONSOLATIONS

“What’s up?”

You look preoccupied with something.”

“Well, there’s something I’ve been meaning to tell you. There’s just never going to be a good time, so I suppose I should just get it over and done with.”

“I’m all ears. Nothing serious, I hope?”

“Kind of. I mean no, not at the moment, but it will be. No that’s not how I wanted to pitch this, sorry I’ll start again. You know I mentioned that I had some problems with my eyes a few months back?”

“Yes, sure.”

“Well it turned out, that actually I was diagnosed with Multiple Sclerosis.”

“OK.”

“Do you know what it is?”

“Well to be honest, no, not really. It is serious though right? Disabling?”

“It depends. I have Relapsing/Remitting MS. The ‘best kind’ to have. My symptoms could go on being intermittent for the rest of my life or at some point, ten to fifteen years or so, it might turn progressive.”

“But you’re ok at the moment?
You don’t have any symptoms do you?
What was wrong with your eyes?”

“That was blurred vision, mostly it happened when my body temperature rose. So when I went running or walking, my vision would become fuzzy, it was difficult to read signs, bus numbers, all kinds of stuff. Aside from that, I’m lucky, I’ve just had sensory symptoms. Pins and needles in my left hand, occasionally. This all bodes well, I mean it could indicate the disease might not become that disabling in the long term.”

“Come here.”

“What?”

“Come here and give me a hug.
I can’t believe you’ve been dealing with all this, without letting me in on it.”

“I was scared you would run a mile.”

“From you? Not likely”

AMENDMENTS

It feels good to have some time off.

Your sleep seems bottomless.

Your body relaxes.

You need more time for this. More time to look after yourself.

Browsing for jobs online you find something good for three days-a-week.

It's financially feasible at a push. So you apply and surprisingly a month later it's yours.

With your extra time you read a lot of the literature on diet and exercise with MS that you couldn't face on diagnosis. You join a yoga class and start a meditation course. You pay more attention to what you eat. You begin to feel better than you have done in years, with or without MS.

You join a support group that meets every so often. You share stories.

People remark on how swift your diagnosis was, others have stories of years of misdiagnosis: repeated trips to the doctors, suspicions of ME.

Your new way of life becomes normalised and you build a network around you.

A network of people who can show you how they made it through or remind you that sometimes there simply is no 'right' path.

CONFESSIONS

“There is no obligation to tell me if something is wrong. But as an organisation we would like to help if we can.”

“Well...”

And so you divulge. Since being off work for a second prolonged length of time, it was fairly obvious to all your health is seriously compromised in some way. The bug, which you did catch, triggered a relapse. The weakness in your left leg was still visible in a slight limp when you returned to work.

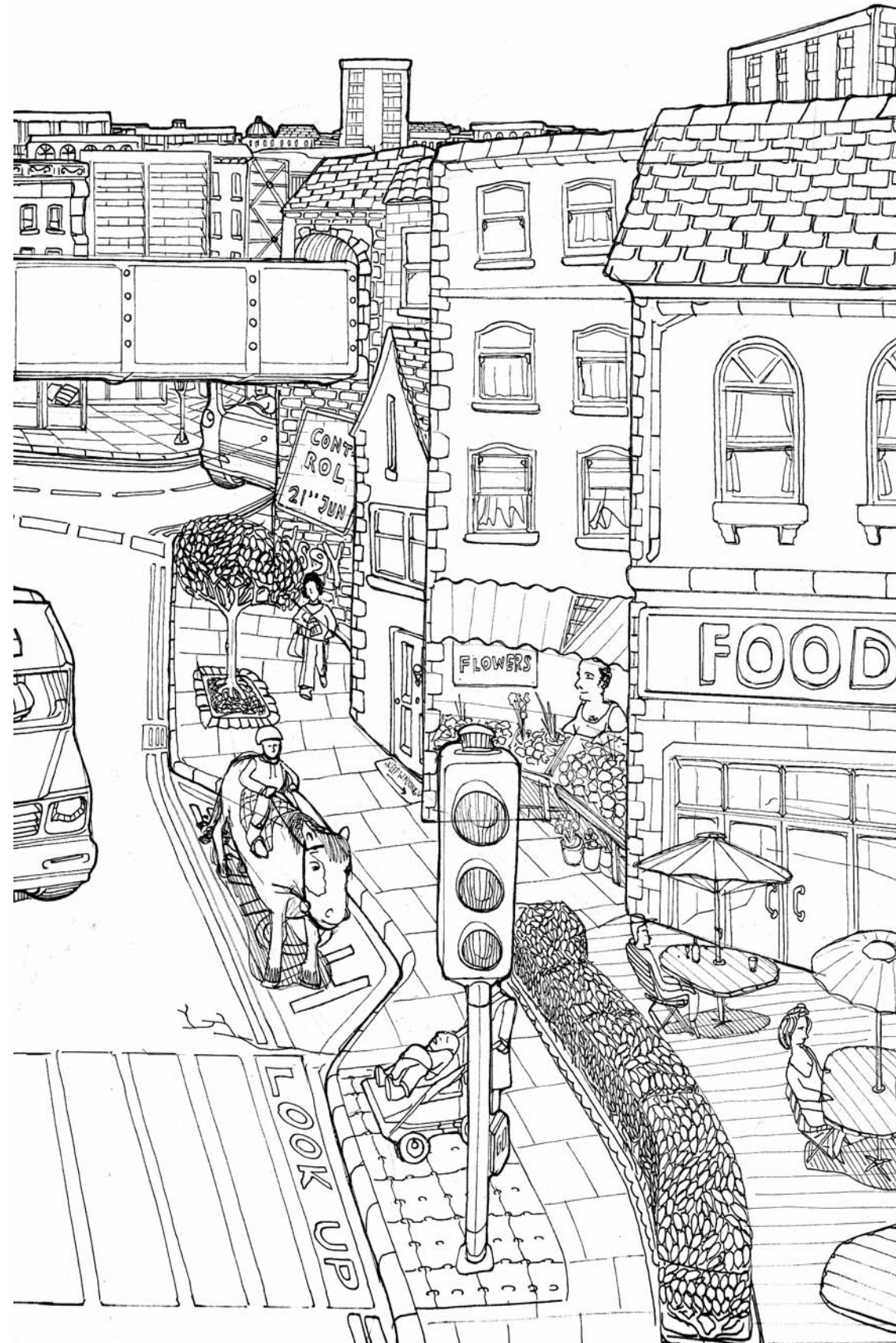
You’ve realised there is little point struggling on with this alone. There is help there and you are going to take it. It seems you are entitled to have things at work a little more on your terms. There is a scheme to provide taxis to and from the office. Now you arrive fresh. You reduce your hours for a period and this also helps you regain your strength.

Most importantly the changes enable you to work to your full capacity once again.

Your self-confidence and energy levels soar.

You have recovered some control in your life.

There are decisions still to be taken and you intend to make the best of them.



BEGINNINGS

It still comes and goes, that despondency.

Mainly stealing in, during the night and bothering you with heavy thoughts, upsetting your hard won equilibrium.

Meeting James was definitely a turning point. Talking with him, you begin to harbour hope.

He is permanently affected and his relapses severe.

But he is ceaselessly sanguine, with an unapologetic and unashamed attitude to the physical impact of his MS.

Whilst the disease may rampage through the brain,

James makes it clear that you can salvage dignity and a realistic optimism through your attitude.

And the talking does help.

Through James you get introduced to a couple of support groups.

It's here you find reassurance.

It's here you can build a rounded and healthier picture of what the future might look like for you, and how you might find paths to prosperity in it, despite your limitations.

Here where MS is normalised, you feel temporary rest bite from the ambiguity and loneliness of the day-to-day.

You can see paths ahead.

NAVIGATION

You were at the hospital again. It was unknown territory for years and now so familiar. The crowded clinic waiting room, with its stupefying heat, is a place of quiet dismay. Here you can't escape the fact of the disease you have. It's all around you and you nervously watch others for telling signs of the condition's progression. They in turn watch you.

Goldfish swim in a large tank in one corner. They enjoy a simple existence, with clear parameters, less room for disappointments and no choices to be made. You envy their sanguinity. You don't know which way to turn anymore. Now there is no clear path through life, only the obstacle of MS blocking your way. Your eyes are getting worse again. This terrifies you; especially during long nights when you lie awake thinking. The future exists only in the dark disorientating shadow of the disease's obstruction.

The MS nurse calls you in.
She studies you as you enter.

'How are you?' she asks, concerned.
You shrug and explain that after a brief rest bite your vision seems to be deteriorating.

'How are things otherwise?' she asks.
'Are you back at work yet?'
You shake your head.

'And how are you
spending your time?'

You tell her how you are currently getting by; not really going out much, sleeping a lot in the day. You apologise that you look so scruffy, but you've given up caring about your appearance; what's the point if no one will have you anyway because of the condition.

As soon as you've said this and you realise that you can't believe it completely, your composure crumbles. In vocalising your worst fear, a well of grief is unlocked within you. The anger you've been using as a buffer with the indifferent world dissipates. You sob, letting out in sorrow the utter hopelessness that's engulfed your mind.

During that appointment Siobhan, your MS nurse, rang your GP. Dr Ramsey ensured Siobhan she'd get you an urgent referral to a psychologist locally. Before too long you're seeing a Clinical Psychologist who actually specialises in chronic health conditions and MS specifically. She is part of an MS community team in your borough you didn't know existed before.

There is more crying in the sessions, but it feels healthy. It is with Maria that you begin to feel your anxiety about the future, about how you're going to survive and support yourself, is actually legitimate. Rather than the blithe dismissal of 'everything will be alright', you work through and rationalise your worries, discovering which are unfounded and which deserve further scrutiny.



Together you unpick your furious anger that had begun to erupt unexpectedly at strangers. Everything is less bewildering as you recognise and understand your reactions to diagnosis. From here you can edge forwards again in new directions. Now you have some means of making decisions about which way to turn and an ability to seek out those that can help you. You can now navigate through the darkness and around the obstacles thrown in your way.



NOTES

NOTES

NOTES

This book is part of a wider project by Northumbria University School of Design, which uses design approaches to create empathy with uncertainty and decision-making in Multiple Sclerosis (MS).

Freddie Yauner and Paul Robson who are leading the project, hope that the outputs will illustrate the ordinary, everyday decisions and triumphs of people carrying on with life and living with the disease.

With the help of freelance writer Cathy John the aim was to highlight the diversity of experiences in MS through the different trajectories the disease might take, the range of human reactions to life and illness, as well as the number of different roles people take within the MS 'Story'.

Cathy John Biography

Cathy John is a freelance writer and blogger. She's written articles about living with MS for The Independent and spoken about it on BBC Radio 4.

Her blog can be found at lickingthehoney.org. She won the MS Society Media Coverage of the Year Award 2011 for her feature on 'Coming Out' with the disease and her blog. Cathy is an advisor on two groundbreaking new online films about a young man's diagnosis with MS, Gallop and Belong.

She was diagnosed with Multiple Sclerosis in 2010

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Story:

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Ombro animation:

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