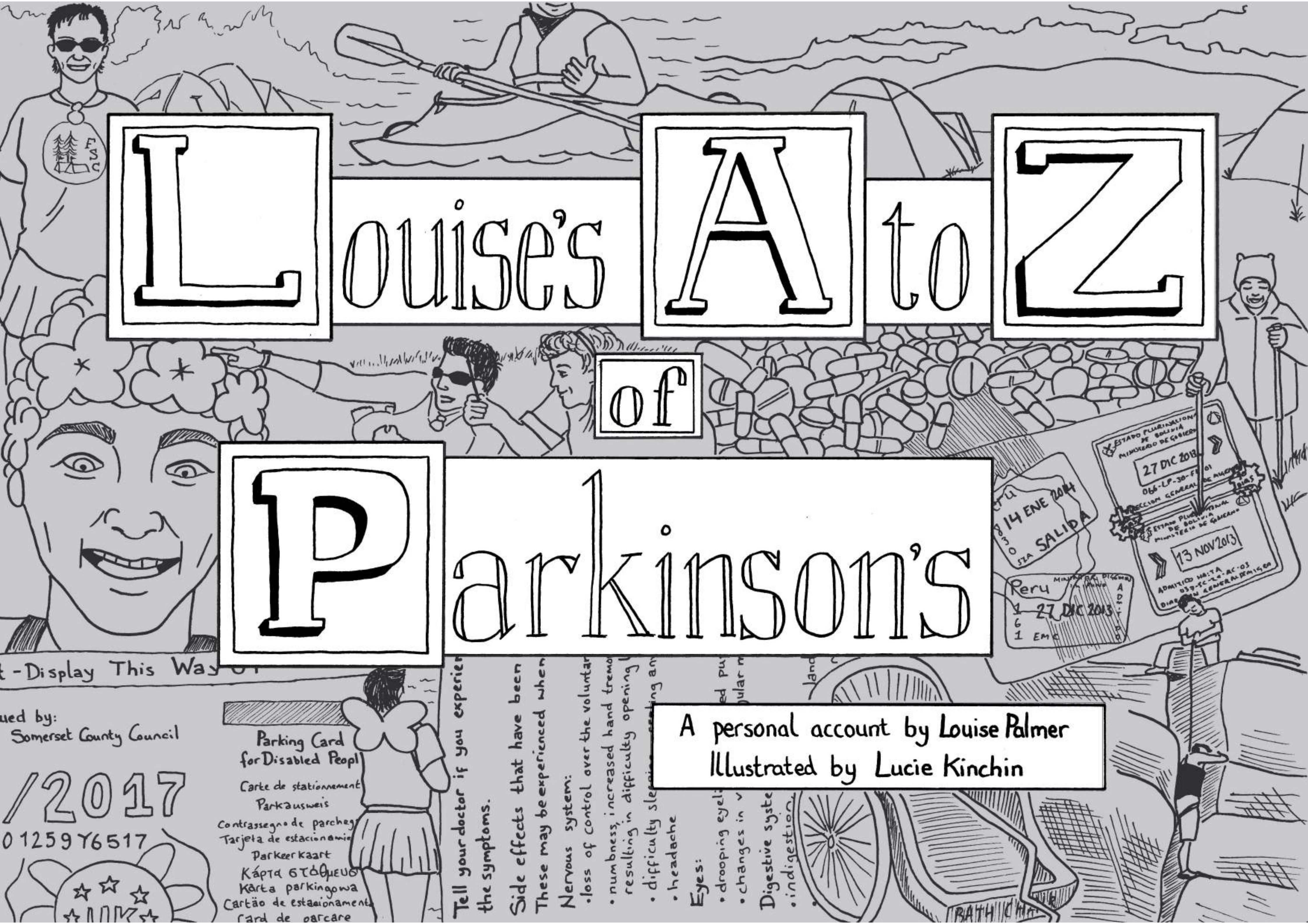


Louise's A to Z of Parkinson's

A personal account by Louise Palmer
Illustrated by Lucie Kinchin

Introduction

With my hands firmly shoved into my jacket pockets and all of my fingers and toes crossed, I silently repeat my mantra, "Please don't find the drugs, please don't find the drugs, please don't find the drugs..." The Bolivian customs officer, waylaid by my selection of dry bags, becomes bored with trying to find his way into the contents of my rucksack. He gives up, smiles sweetly and indicates that I should move on. Shoving everything back into my bag as best I can, I swing it onto my back and head out of the airport towards the taxi rank. What a relief.

This is not a tale of international drug smuggling. I am not about to embark on a different version of Orange is the New Black. Rather, as I entered Bolivia, a large portion of my luggage was made up with the numerous boxes containing the Parkinson's medication that I would need while travelling around South America. As advised by many websites, I had brought a copy of my prescription, a doctor's letter of my diagnosis, and had carefully ensured that all of the labels on the packaging were secure. However, given that my Spanish lessons wouldn't start until the following morning, I was not convinced that I could explain my way out of the sheer volume of medication I was carrying. Even though I've had four children and am therefore fairly accustomed to the indignities of being rummaged, it was not something with which I particularly wanted to begin my trip.

You might be wondering why this story begins with me arriving with a rucksack full of Parkinson's medication in a South American country when I don't really speak the language. Well, having been diagnosed with Parkinson's Disease in the spring of 2013, I was in a tent in the Hebrides when I received a phone call from my daughter, Lucie, saying that she had split up with her boyfriend, but still wanted to complete the trip to South America that they had been planning. I had read accounts by Michael J Fox (diagnosed with Parkinson's in 1991) that his symptoms had been lessened by the altitude in Bhutan; and with an average elevation above sea level of around 3000 metres in a lot of Bolivia, if altitude was going to benefit my condition, Bolivia would be the right place to go. Therefore, in a moment of madness, I suggested to Lucie that we spend the winter travelling together.

So, what are these symptoms I was hoping to alleviate? The medics refer to a long list of changes that may indicate the onset of Parkinson's, but people could easily associate many of them with getting older: I certainly had. General muscle stiffness and persistent neck pain are common onset symptoms, and can demonstrate themselves as increasingly poor posture. Sleep problems may include uncontrollable movements, difficulty in turning and restless legs. I had found that more recent photos never showed me smiling, even though I was happy. This is called 'masking': the movement and control of facial muscles becomes difficult, so you may a have blank or serious expression without realising why everyone thinks you are always grumpy. As the brain's signals to muscles are disrupted, your voice may soften or inflection may reduce. Constipation and other bladder or bowel problems are also common, with excessive sweating or hot flushes occurring… the list goes on. But how many middle aged people have no complaints about 'getting old': stiff, forgetful, menopausal, grumpy or constipated? Even my GP (now ex-GP) was convinced my symptoms were a result of 'my age' or the menopause. It had eventually taken an abrupt comment from the surgeon operating on my damaged shoulders for me to book an appointment with a neurologist, who made the diagnosis.

Lucie had been studying away from home, and had not fully understood the impact that my diagnosis had had on my life, nor the decline in my abilities. I was much less able to climb mountains: I think that she had expected; but fiddly little tasks like getting money out of my purse had also become more difficult. Luckily, she spent some time most days drawing in her journal which gave me time to relax. We were away for about three months and therefore there was not the mad rush to explore and move on that many travellers feel: we spent a long time in each of the places we stayed, which gave me time to recover from overnight bus journeys and recover my strength for our next adventure. Plus, Lucie was very good at the massively important, practical job of prompting me when my watch alarm went off reminding me to take my medication. This ensured that I was able to function at a reasonable level.

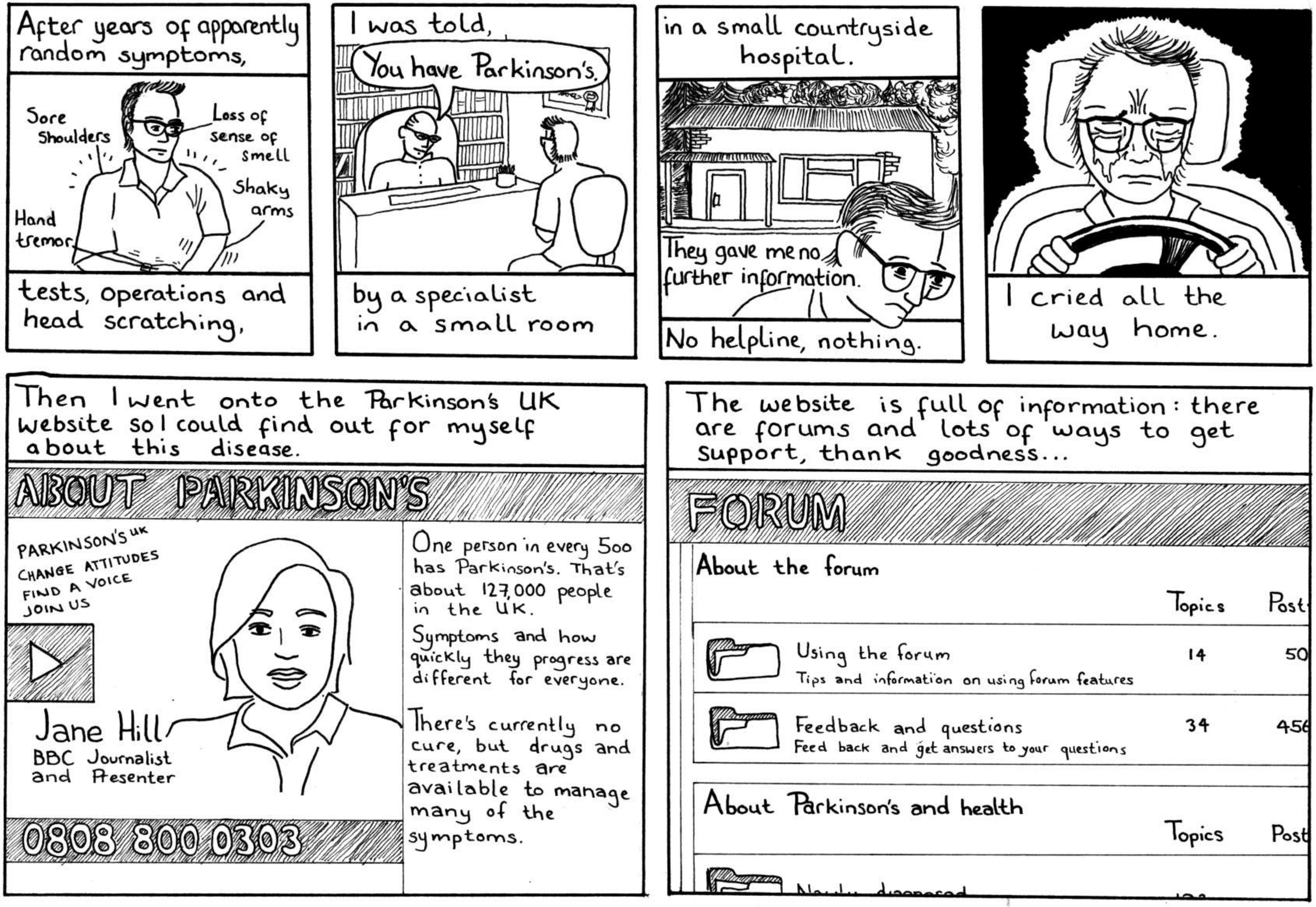
As we travelled, Lucie was writing an illustrated journal (see Appendix), and since managing my Parkinson's was a part of our experience, she asked if we might work together to make a comic about it. She didn't know much about the disease, but what she did know was that everybody is different, and not everybody that is diagnosed is old. Everyone has different symptoms which appear at different rates, some people have very few symptoms, whilst others have many. We chatted long into the night about my experiences, and what kind of 'travel equipment' I would find useful: a spare leg for when mine stops working, nimble fingers to help with packing, and so on. The following day her head was bent over her sketchbook as she put my words onto paper.

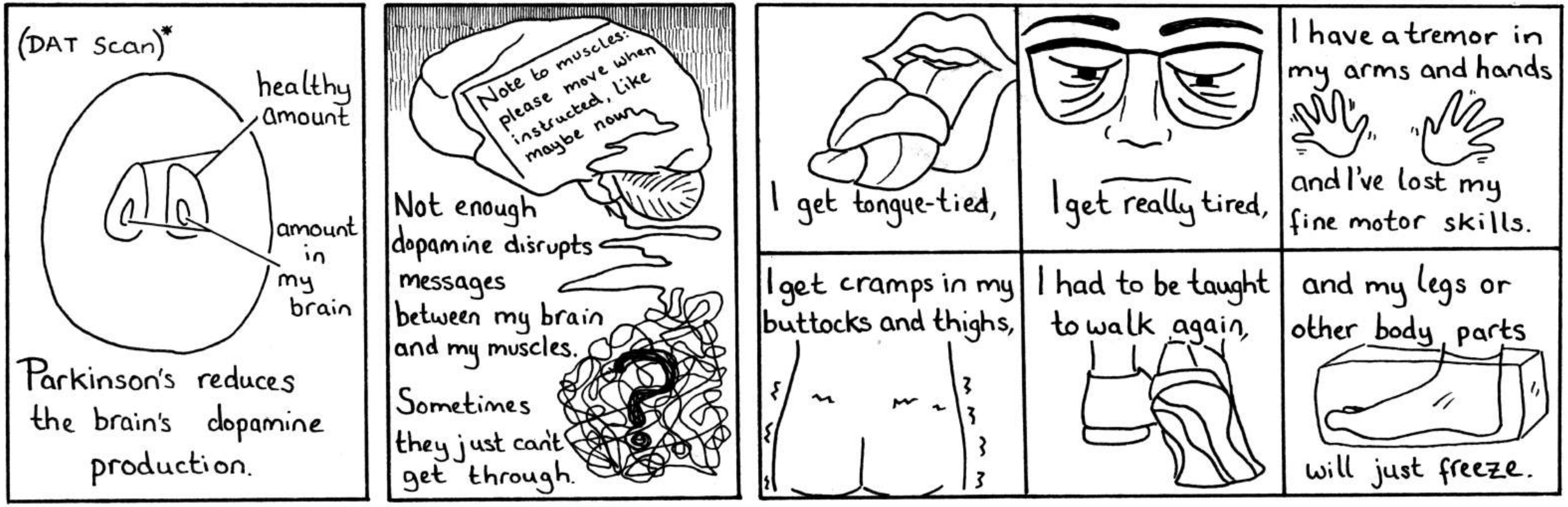
The feedback from the comic was amazing. It quickly became clear that most people we spoke to think Parkinson's is something that only happens to old people. Not only that, but actually, other than thinking it involves some element of shaking, very few people have any idea what having a progressive, degenerative neurological disease could mean to a person and to their friends and family. Given that Parkinson's affects one in every 500 people in the UK - that's about 127,000 people - and over 6.3 million worldwide, we thought that more people would benefit from education. When we came home, we discussed how we could get the message out there about Parkinson's, in particular to highlight that it does not only affect old people: about 10 – 20% of those diagnosed with the disease are under 50, and half of those are diagnosed before 40. Younger patients tend to experience a slower progression than older people, possibly because they have fewer general health problems. Unlike many other degenerative diseases, Parkinson's doesn't develop in a straight line. Sufferers' motor (movement, co-ordination, physical tasks, mobility) and non-motor (digestive, cognitive, emotional and social) symptoms appear at such different rates, and are so broad in severity and range, that it is almost impossible to offer a meaningful scale as to which stage or level of the disease each individual is experiencing. There is currently no cure for Parkinson's, but there are a range of treatments to control the symptoms and maintain quality-of-life.

After the success of the previous comic, we decided that a good way to get this information out into the world would be in comic form.

And so we began *Louise's A to Z of Parkinson's.*

- *Louise Palmer, 2015*


After years of apparently random symptoms,
Sore Shoulders
Loss of sense of smell
Shaky arms
Hand tremor
tests, operations and head scratching,
I was told,
You have Parkinson's.
by a specialist in a small room
in a small countryside hospital.
They gave me no further information.
No helpline, nothing.
I cried all the way home.
Then I went onto the Parkinson's UK website so I could find out for myself about this disease.
ABOUT PARKINSON'S
PARKINSON'S UK
CHANGE ATTITUDES
FIND A VOICE
JOIN US
Jane Hill
BBC Journalist and Presenter
0808 800 0303
One person in every 500 has Parkinson's. That's about 127,000 people in the UK.
Symptoms and how quickly they progress are different for everyone.
There's currently no cure, but drugs and treatments are available to manage many of the symptoms.
The website is full of information: there are forums and lots of ways to get support, thank goodness...
FORUM
About the forum
Topics
Post
Using the forum
Tips and information on using forum features
14
50
Feedback and questions
Feed back and get answers to your questions
34
45
About Parkinson's and health
Topics
Post



*(measures dopamine production capacity)

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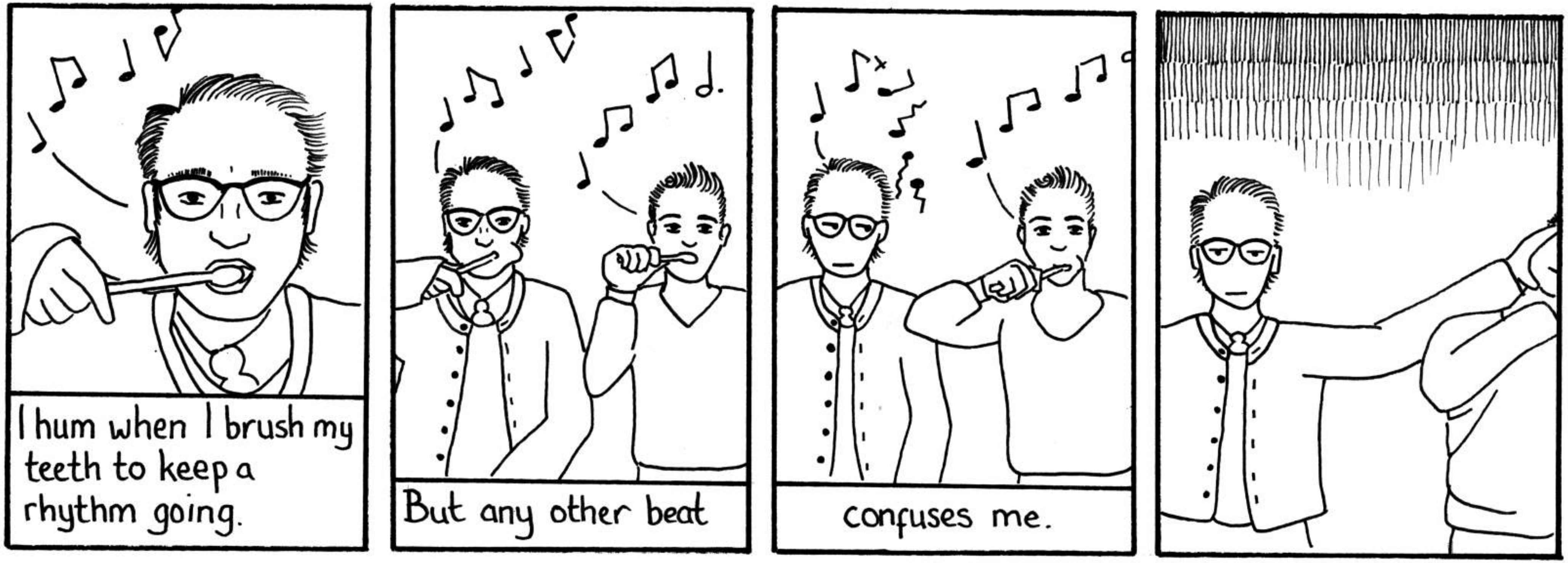
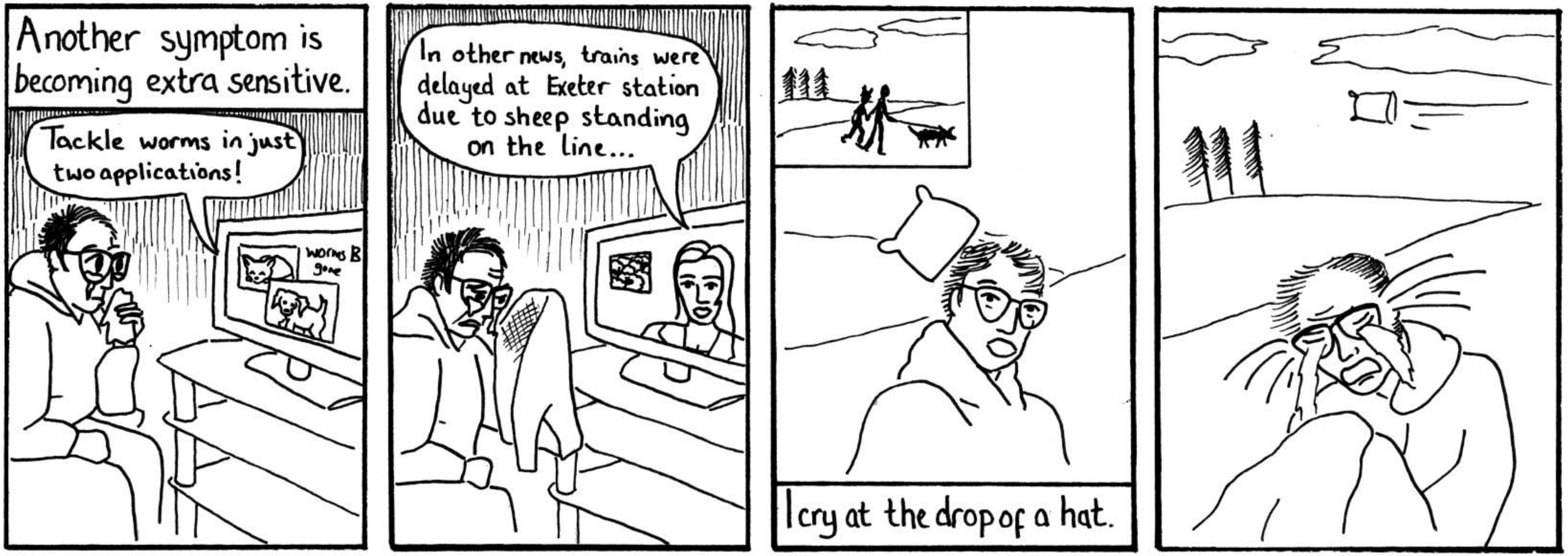
* see Appendix

Always look on the Bright Side

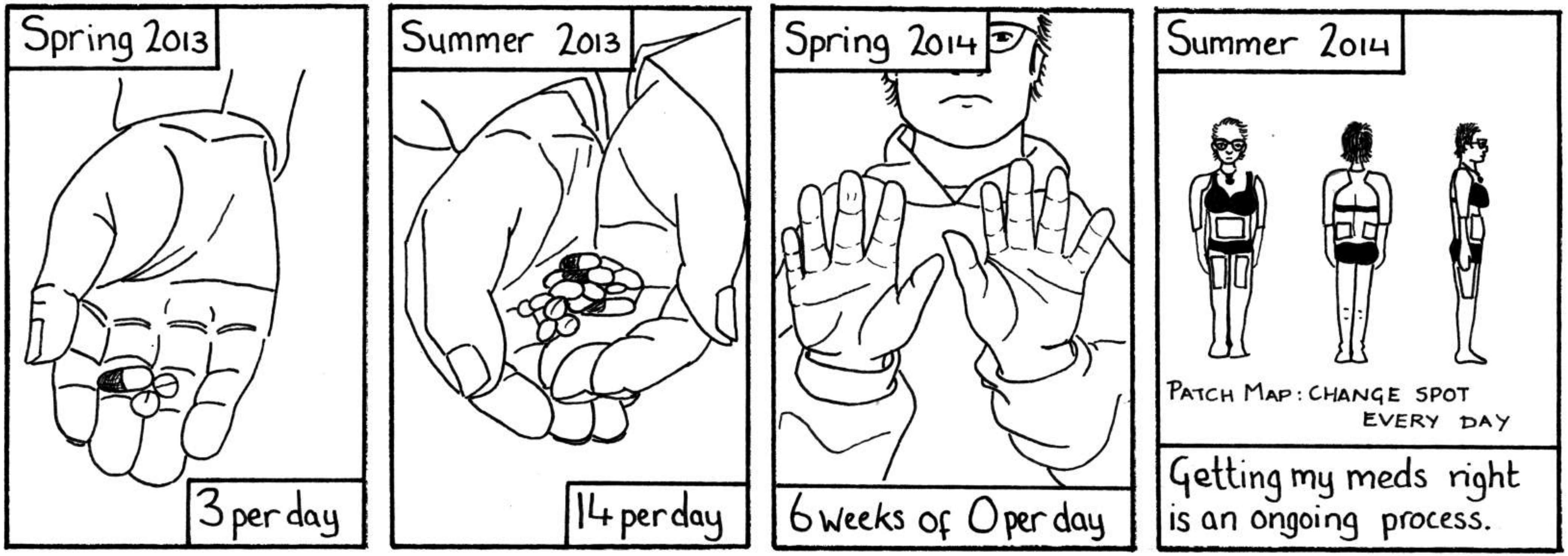
Brushing my teeth



Crying

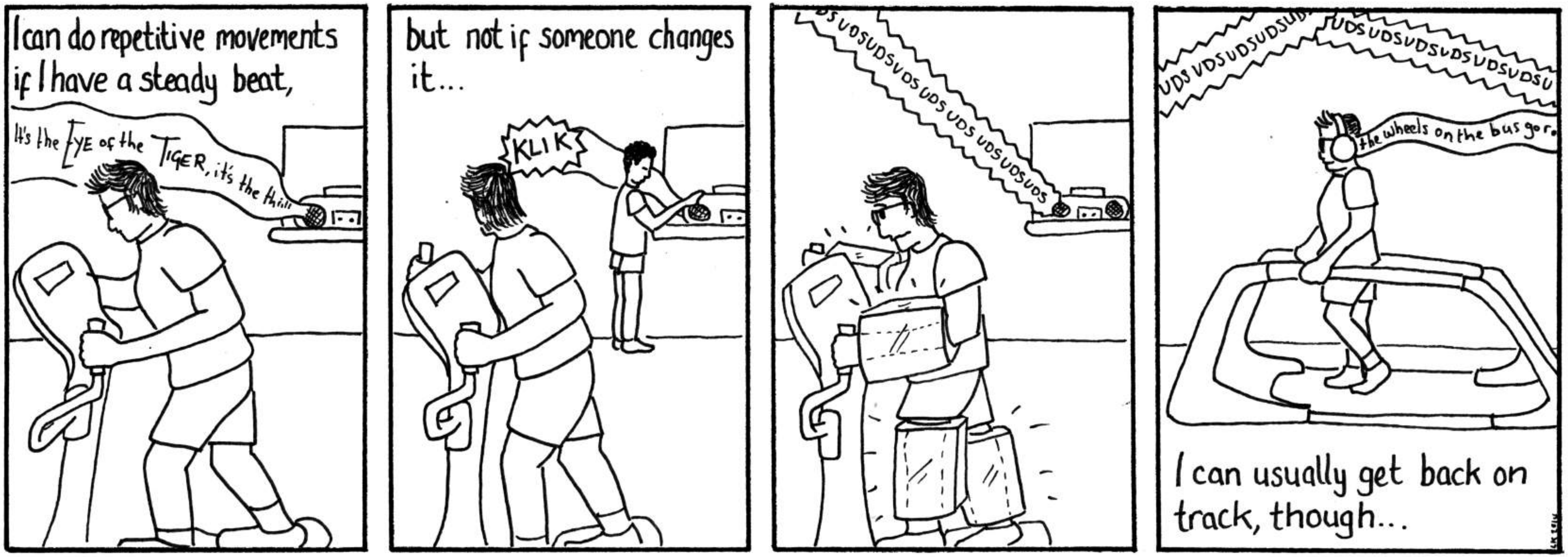

Another symptom is becoming extra sensitive.
Tackle worms in just two applications!
Worms B gone
In other news, trains were delayed at Exeter station due to sheep standing on the line...
I cry at the drop of a hat.

Drugs


Spring 2013
3 per day
Summer 2013
14 per day
Spring 2014
6 weeks of 0 per day
Summer 2014
PATCH MAP: CHANGE SPOT EVERY DAY
Getting my meds right is an ongoing process.

Energy levels

Freezing


I can do repetitive movements if I have a steady beat,
It's the EYE of the TIGER, it's the thrill
but not if someone changes it...
KLIK
DSUDSUDSVDSUDSUDSUDSUDSUDS
UDSUDSUDSUDSUDSUDS
UDSUDSUDSUDSUDSUDSU
the wheels on the bus go r.
I can usually get back on track, though...
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Galloping


SPORTS DAY PARENTS RAC
Galloping sideways is the only way I can move fast without falling.
FINISH
LK 2014

Hair

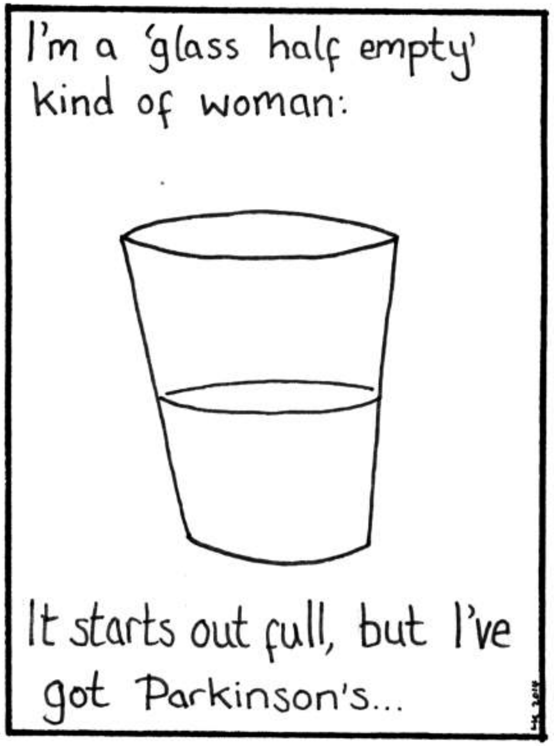

Parkinson's forces you to make decisions about your appearance.
Maybe not.
(it's too easy to burn yourself with shaky hands)
Not great either.
Much better.

Ignorance

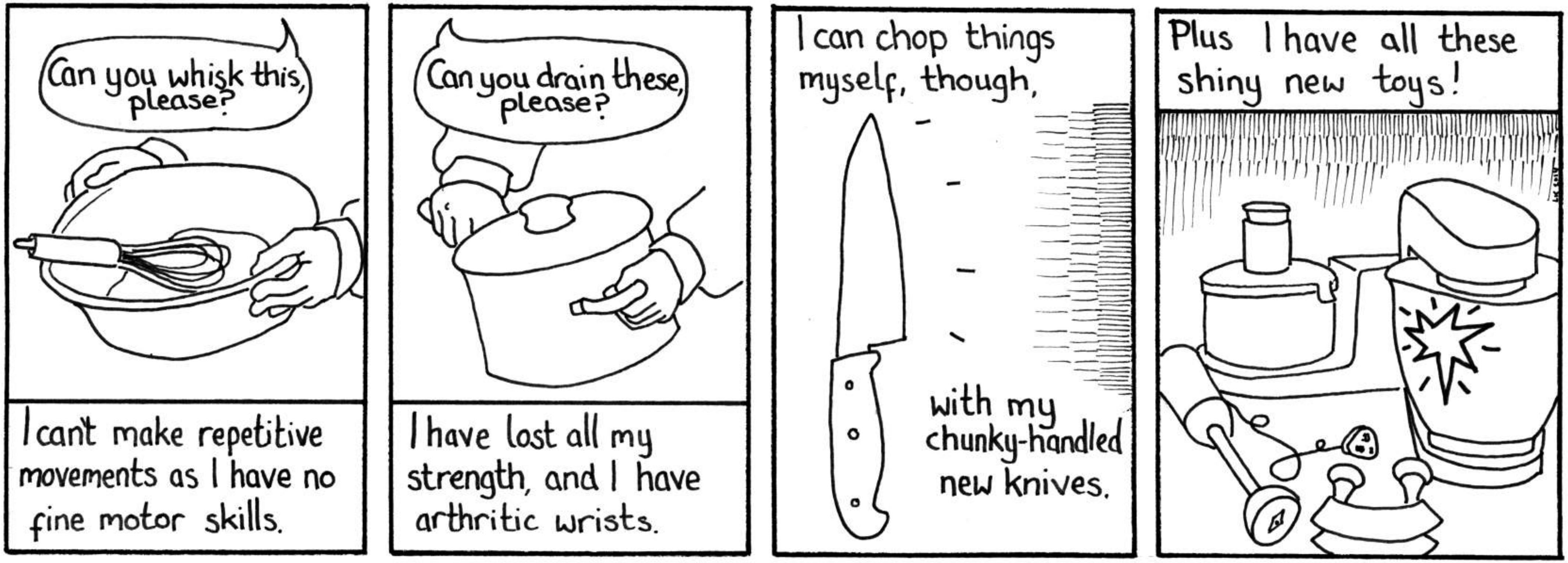

People can have very little patience.
My fingers often don't work very fast...
(2 minutes later)
(5 minutes later)
sometimes they just stop.

Jokes

They say laughter is the best medicine. We've been laughing for months and I haven't got any better, but it's worth a try...

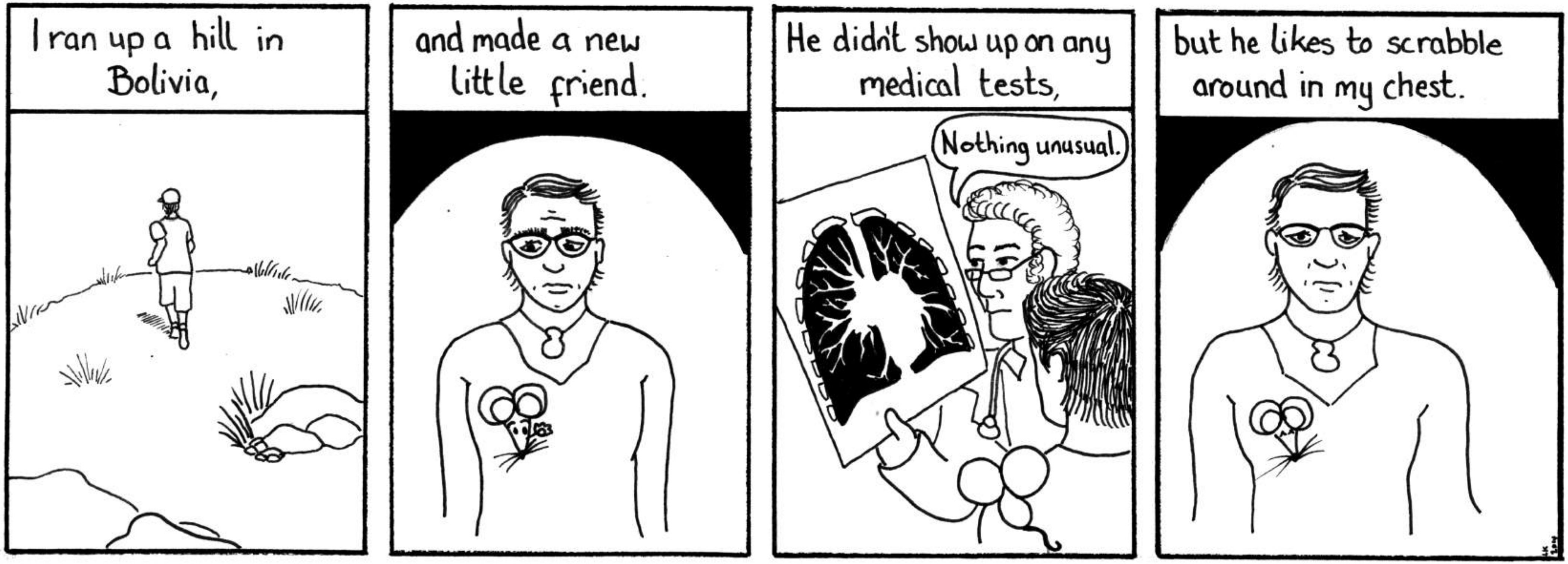


Kitchen


Can you whisk this, please?
I can't make repetitive movements as I have no fine motor skills.
Can you drain these, please?
I have lost all my strength, and I have arthritic wrists.
I can chop things myself, though,
with my chunky-handled new knives.
Plus I have all these shiny new toys!

Little friend

discomfort, muscle spasms, hallucinations: they're all symptoms, take your pick...

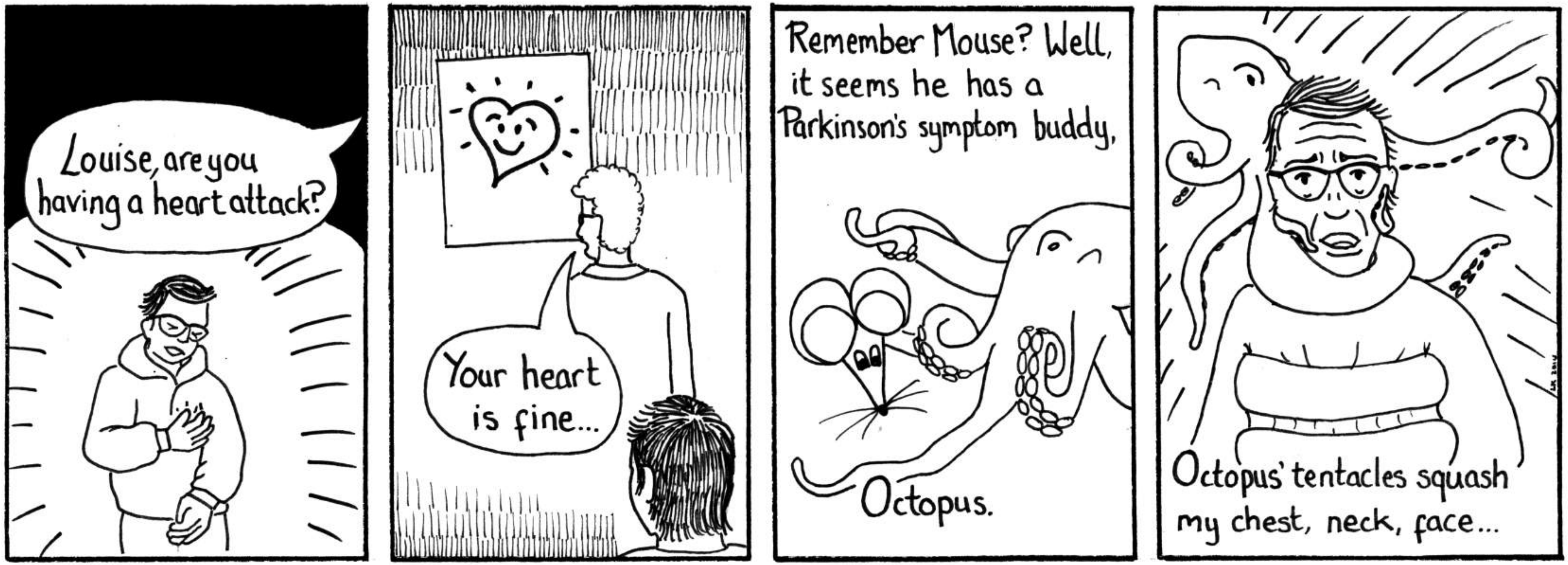


Learn more about the little mouse scrabbling in my chest on Lucie's blog in the Appendix...

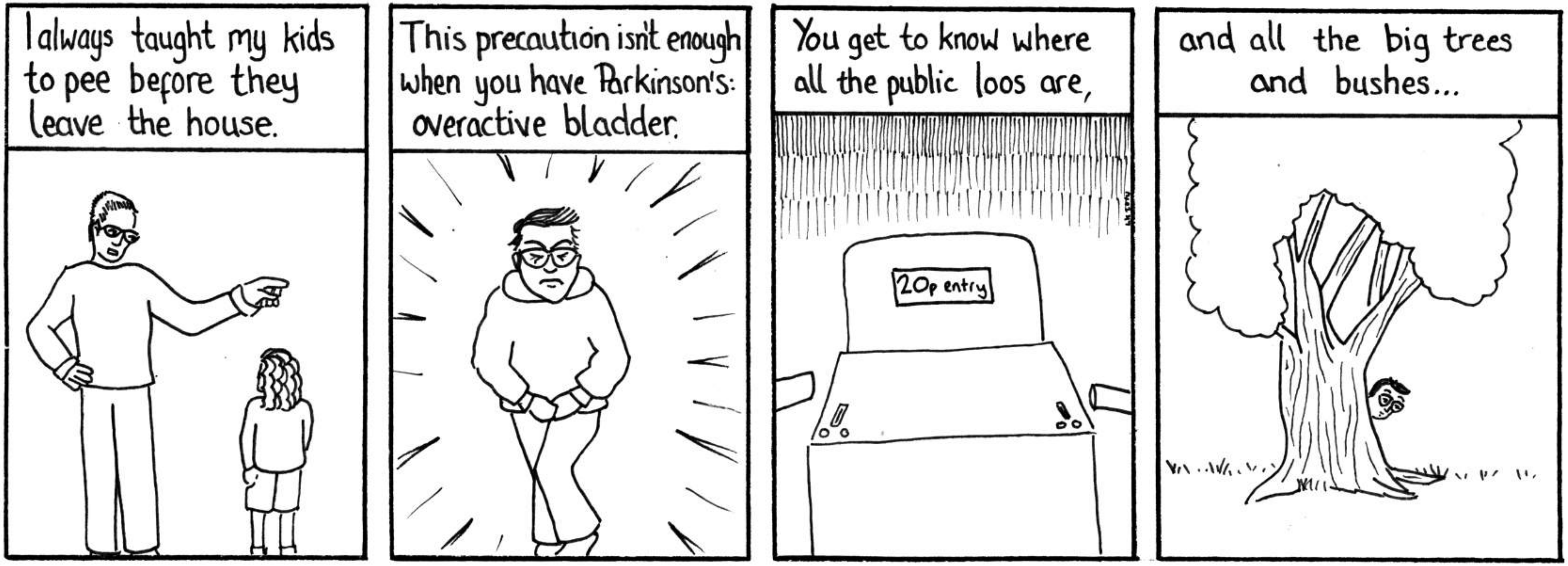
Makeup

Not really there?

Octopus

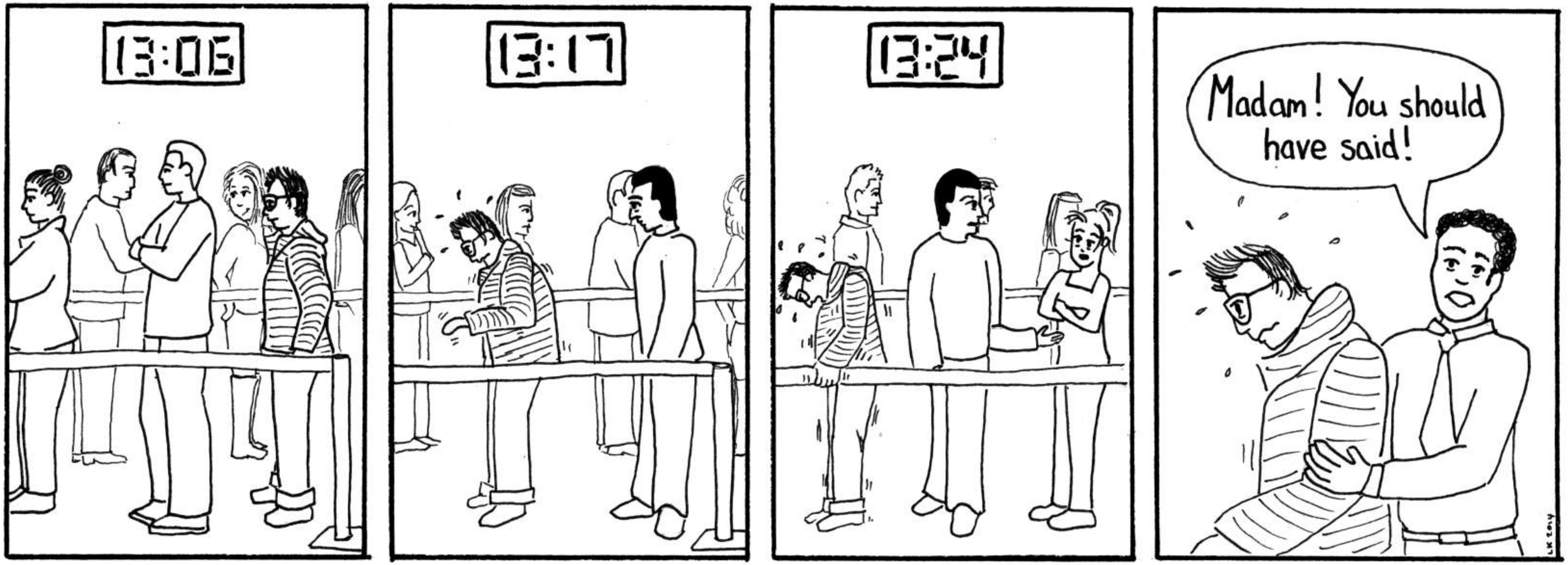

Louise, are you having a heart attack?
Your heart is fine...
Remember Mouse? Well, it seems he has a Parkinson's symptom buddy,
Octopus.
Octopus' tentacles squash my chest, neck, face...

Peeing


I always taught my kids to pee before they leave the house.
This precaution isn't enough when you have Parkinson's: overactive bladder.
You get to know where all the public loos are,
20p entry
and all the big trees and bushes...

Queue jumping

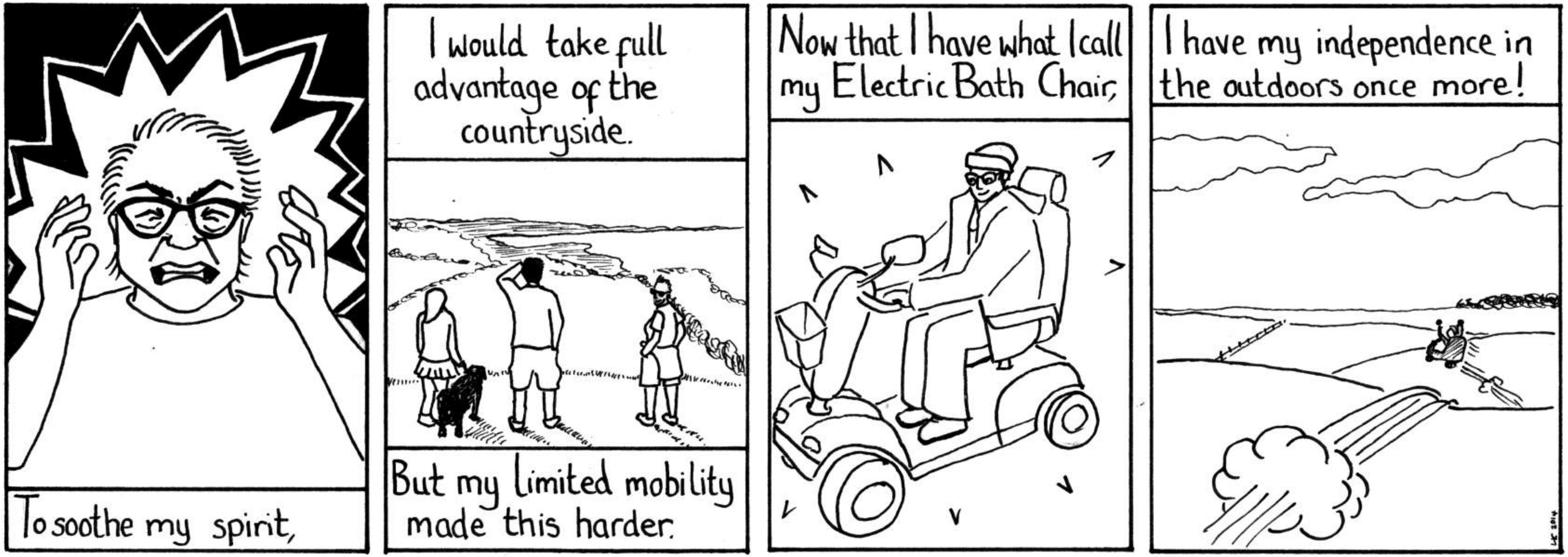
Sometimes it takes a while, but people do help me, and let me jump queues...



Rambling

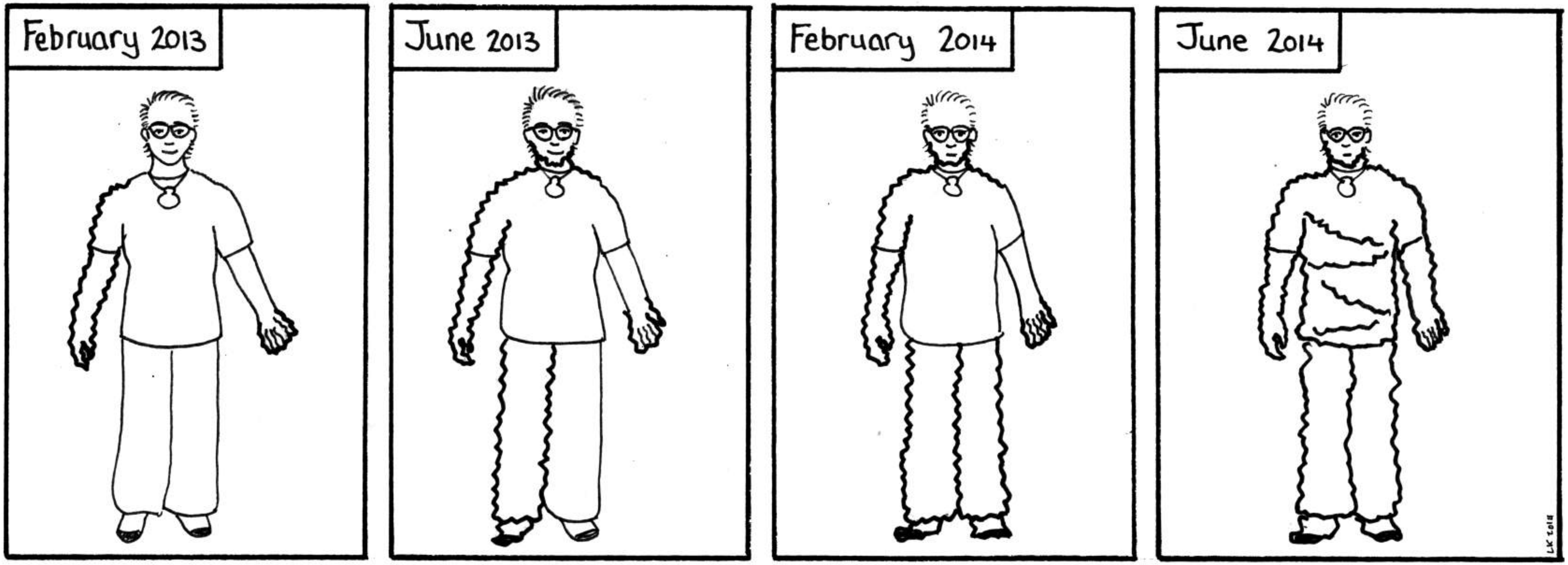

I used to walk up mountains
but now, with my tippy toes
and tiny steps,
I have to hold Duncan's hand on my 20 minute stumble.
But at least I get out in the fresh air...

Soothing

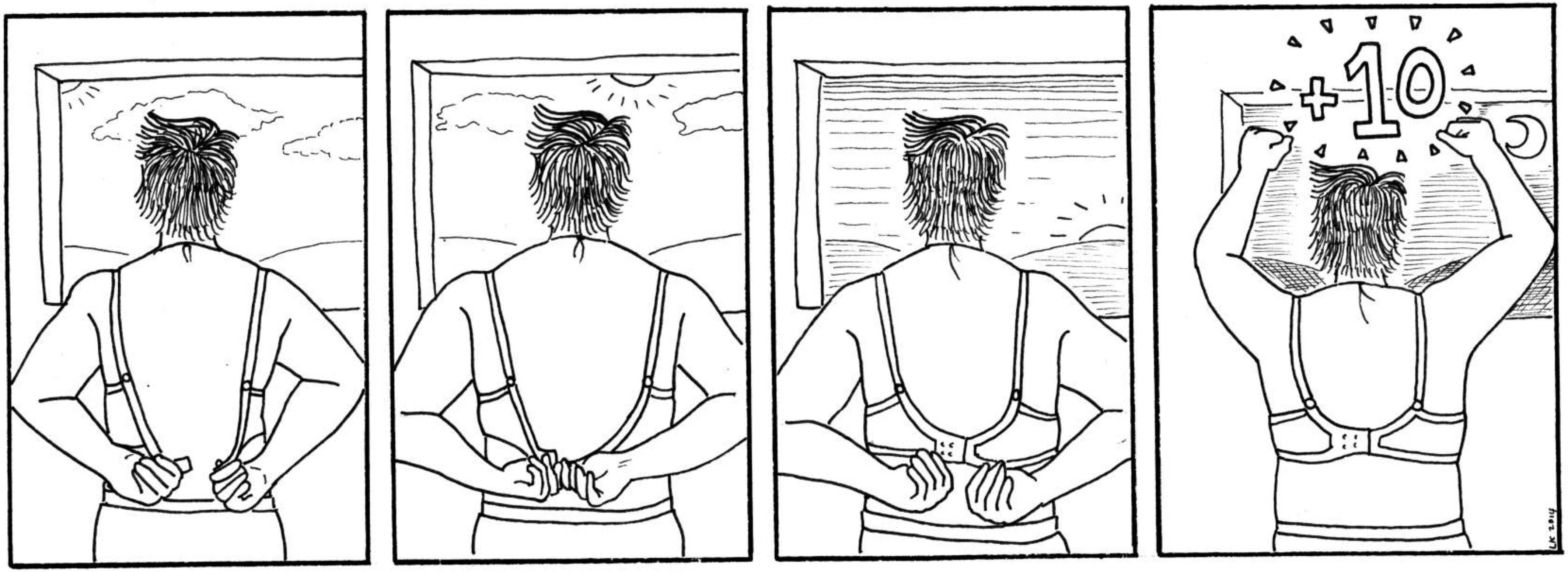

To soothe my spirit,
I would take full advantage of the countryside.
But my limited mobility made this harder.
Now that I have what I call my Electric Bath Chair;
I have my independence in the outdoors once more!

Tremor

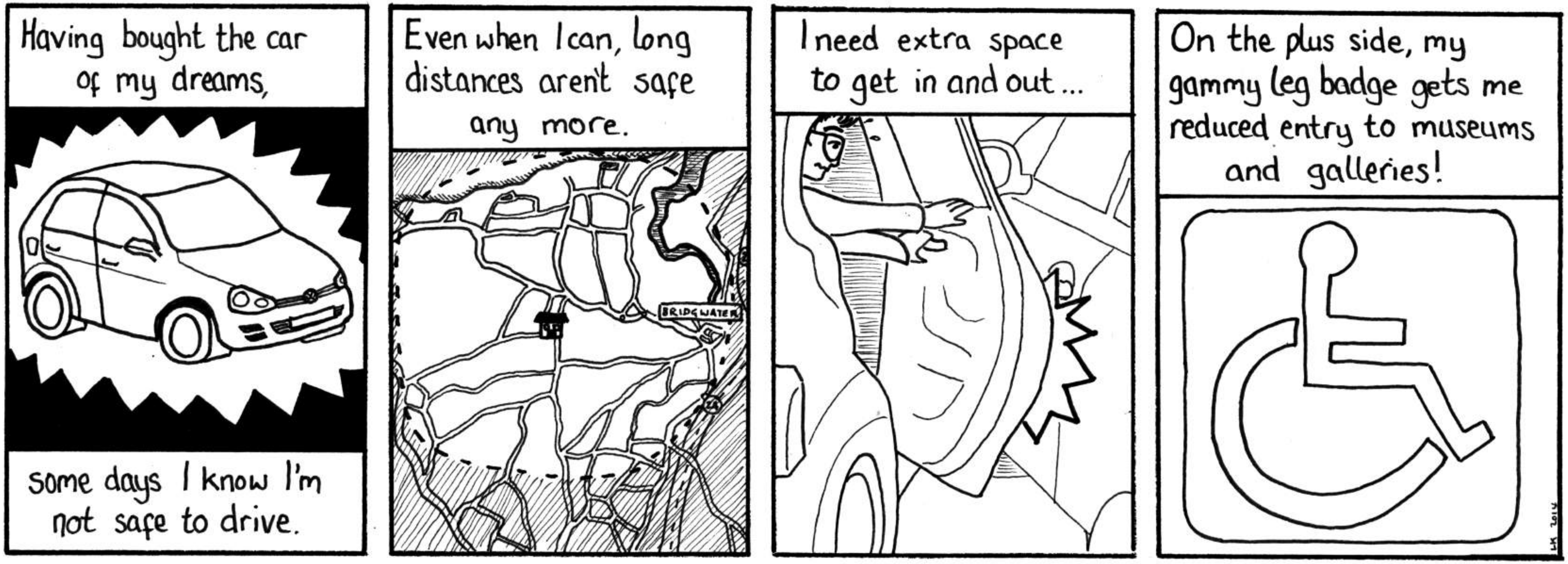
This has been the progression of my tremor over the last 15 months



Underwear



Vehicle


Having bought the car of my dreams,
some days I know I'm not safe to drive.
Even when I can, long distances aren't safe any more.
BRIDGWATER
I need extra space to get in and out...
On the plus side, my gammy leg badge gets me reduced entry to museums and galleries!
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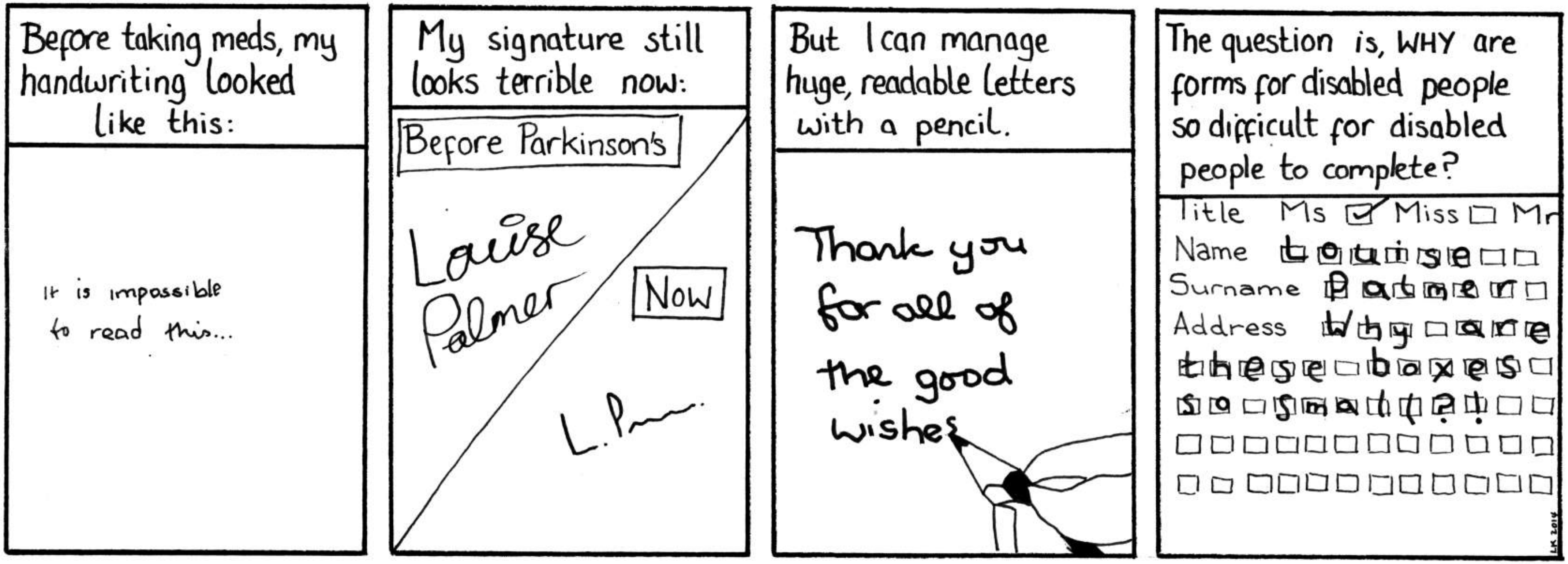
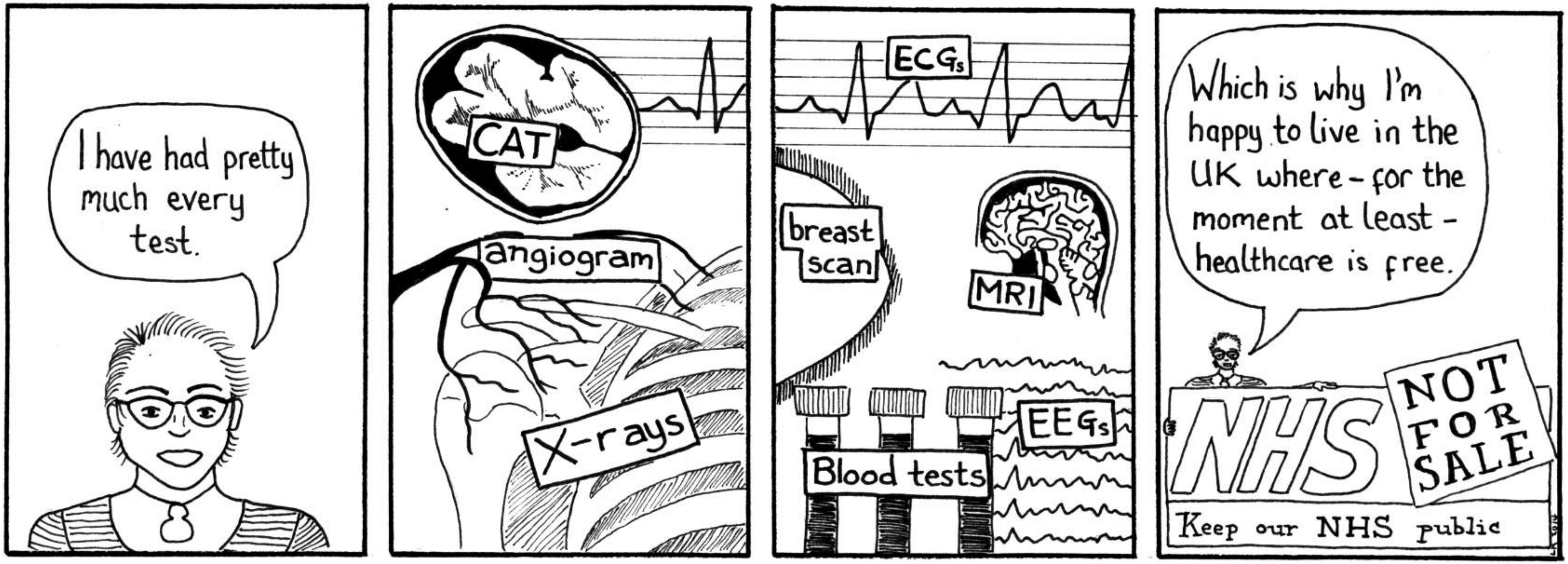
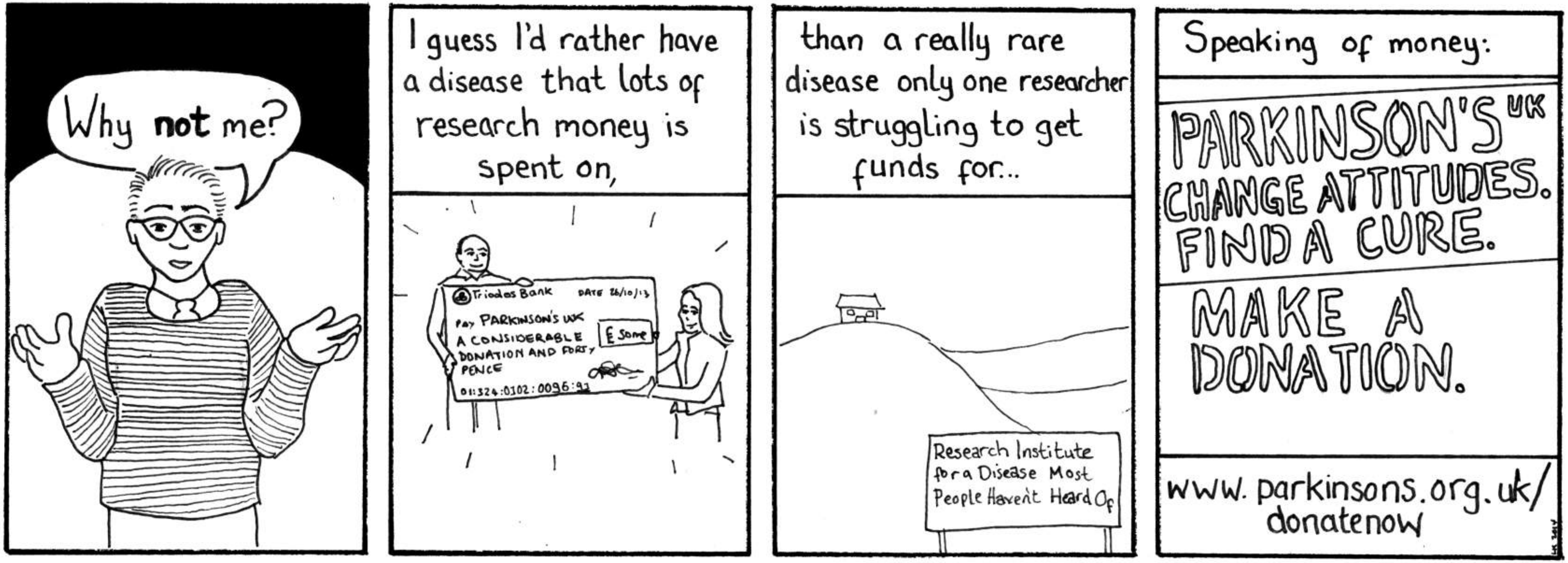
Writing


Before taking meds, my handwriting looked like this:
It is impossible to read this...
My signature still looks terrible now:
Before Parkinson's
Louise Palmer
Now
L. P
But I can manage huge, readable letters with a pencil.
Thank you for all of the good wishes
The question is, WHY are forms for disabled people so difficult for disabled people to complete?
Title Ms ☑ Miss ☐ Mr
Name Louise
Surname Palmer
Address Why are these boxes so small?!
LK 2014

X-rays, etc.


I have had pretty much every test.
CAT
angiogram
X-rays
ECGs
breast scan
MRI
EEGs
Blood tests
Which is why I'm happy to live in the UK where - for the moment at least - healthcare is free.
NHS
NOT FOR SALE
Keep our NHS public

Y me?


Why **not** me?
I guess I'd rather have a disease that lots of research money is spent on,
Triodos Bank
DATE 26/10/13
PAY PARKINSON'S UK
A CONSIDERABLE DONATION AND FORTY PENCE
£ Some
01:324:0102:0096:91
than a really rare disease only one researcher is struggling to get funds for...
Research Institute for a Disease Most People Haven't Heard Of
Speaking of money:
PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
MAKE A DONATION.
www.parkinsons.org.uk/donatenow
LK 2014


Z
zzzz...
It's hard work
making comics.
zzzz...
So, as Lucie draws,
...zzzz
I snooze.

Appendix

While we were travelling, Lucie was illustrating a journal.

Included here are her pages about my Parkinson's symptoms:

'Shakin' a Path Through Bolivia & Peru' – the comic we wrote together about my Parkinson's.

'The High Altitude Pathology Institute' – about my 'mouse'.

Shakin' a Path Through BOLIVIA & PERU

Hi pals. This is my mum.

She has Parkinson's.

(This is what everyone says, except the doctor we met in La Paz who noticed a hell of a lot quicker than any of mum's doctors...)

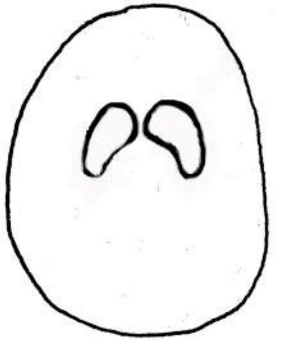
I asked her to come to the blog to tell you a bit about it.

When they think of Parkinson's, most people think of old people who shake a lot.

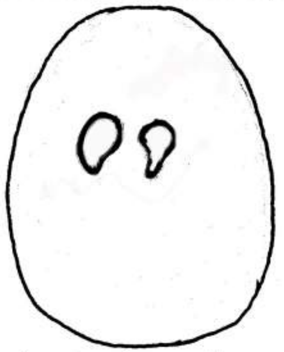
But anyone at any age can be struck by it, and the quicker it's diagnosed, the longer you've got function for.

Parkinson's is a degenerative neurological disease that affects **dopamine** production in the brain.

Let's look at some brains to illustrate! (these are from DAT scans)

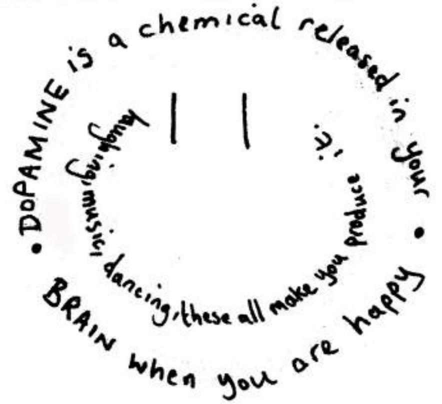


This is a normal brain, showing big areas where dopamine is produced. The areas look like big eyes.



This is my brain. I only have tiny little eyes. This is all that's left producing dopamine in my brain.

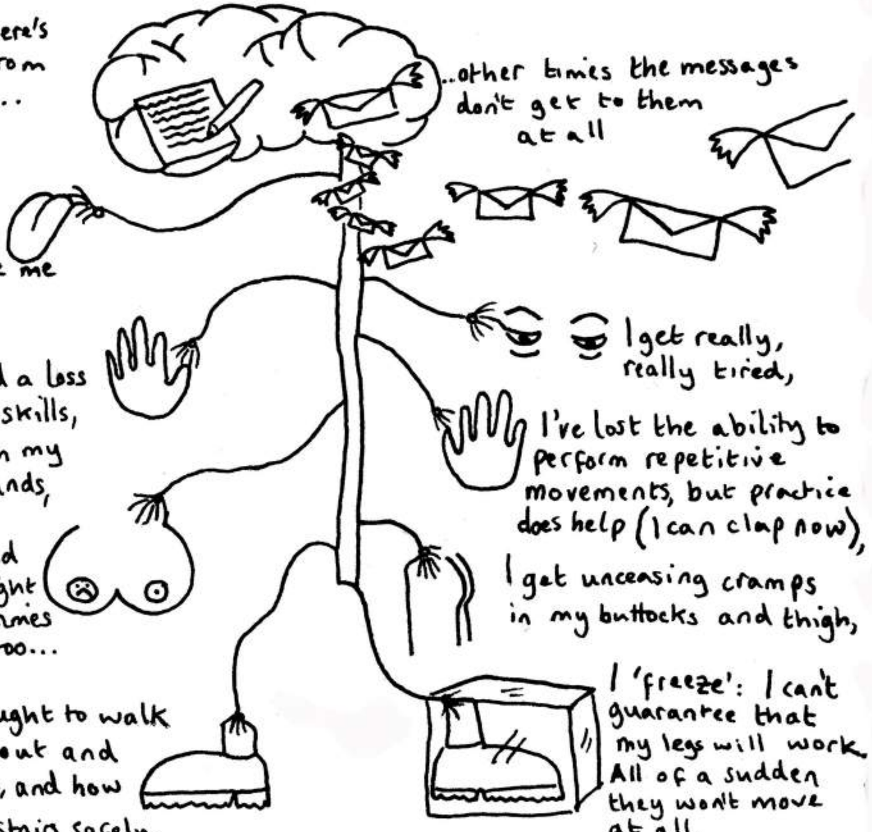
So, what is DOPAMINE? Why is it important to have massive eyes in your brain?



• DOPAMINE is a chemical released in your BRAIN when you are happy •

laughing, music, dancing, these all make you produce it.

For me, not having enough dopamine disrupts messages from my brain to my muscles.



Sometimes there's no feed back from the muscles...

...other times the messages don't get to them at all

This can make me tongue-tied,

I get really, really tired,

it has caused a loss of fine motor skills, and a tremor in my arms and hands,

I've lost the ability to perform repetitive movements, but practice does help (I can clap now),

I have a weakened muscle in my right breast, so sometimes that tremors too...

I get unceasing cramps in my buttocks and thigh,

I had to be taught to walk again, to stride out and swing my arms, and how to come down stairs safely,

I 'freeze': I can't guarantee that my legs will work. All of a sudden they won't move at all.

Given that I'm travelling through Bolivia and Peru with all this going on, what did I bring with me, and what do I wish I'd brought?

IDEAL TRAVEL EQUIPMENT

#1: Nimble Fingers

These would be useful,

...for stuffing things into rucksacks,

...and for putting things into/taking them out of purses, bumbags...

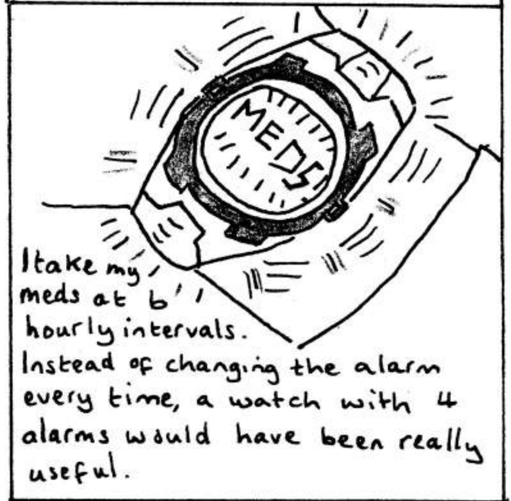
Luckily, I brought a Lucie who is an adequate replacement for my own spare hands.

#2: An extra 3 hours in the day

For napping.

Luckily, I brought a Lucie who spends hours a day painting and drawing, so I have time to doze.

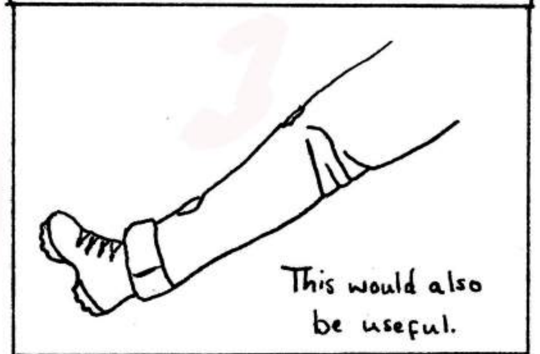
#3: Adequate Digital Alarms



I take my meds at 6 hourly intervals.
Instead of changing the alarm every time, a watch with 4 alarms would have been really useful.

Luckily, I brought a Lucie, who has a "your alarm's going off" jabby finger to prompt me.

#4: Spare leg



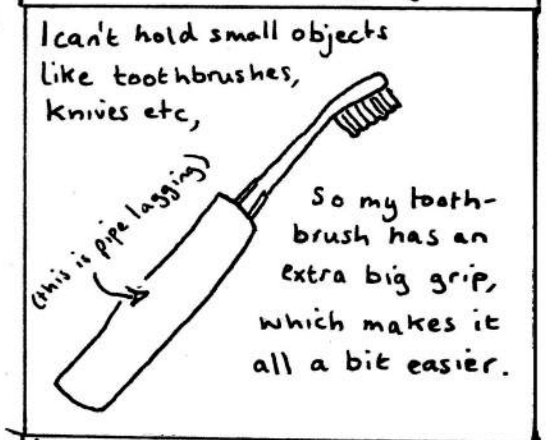
This would also be useful.

I was so busy concentrating on making my leg work in the jungle I kept banging my head on branches. A spare leg would've helped.

Climbing on and off boats and buses would be easier with a foot I could guarantee would reach where I want it to go...

Luckily, I brought a Lucie, so in times of crisis I had a hand to hold and give me support.

#5: More pipe lagging

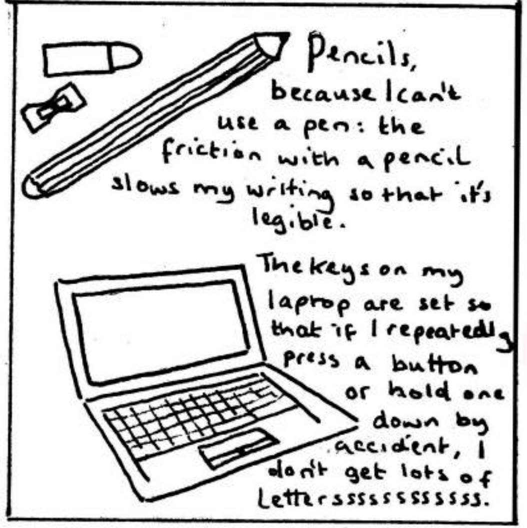


I can't hold small objects like toothbrushes, knives etc,

So my toothbrush has an extra big grip, which makes it all a bit easier.

If I had spare, I could've helped more with food preparation, and wouldn't have spent 10 minutes shaki after cutting up a mango...

What I did bring was writing implements:



Pencils, because I can't use a pen: the friction with a pencil slows my writing so that it's legible.

The keys on my laptop are set so that if I repeatedly press a button or hold one down by accident, I don't get lots of Letterssssssssssss.

In conclusion, while it would be nice to have spare, functioning body parts, really all you need is a Proactive travelling companion who is fitter and stronger than you are. Unluckily, I only had a Lucie, but you get what you're given, don't you? xxx

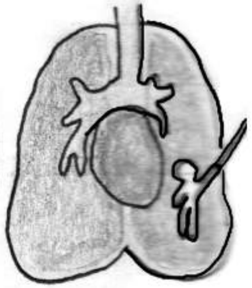
My mum ran up a hill
when we went on
the Salt Flats
tour near Uyuni.

Afterwards, she coughed **alot** and had a bit of a sore chest.

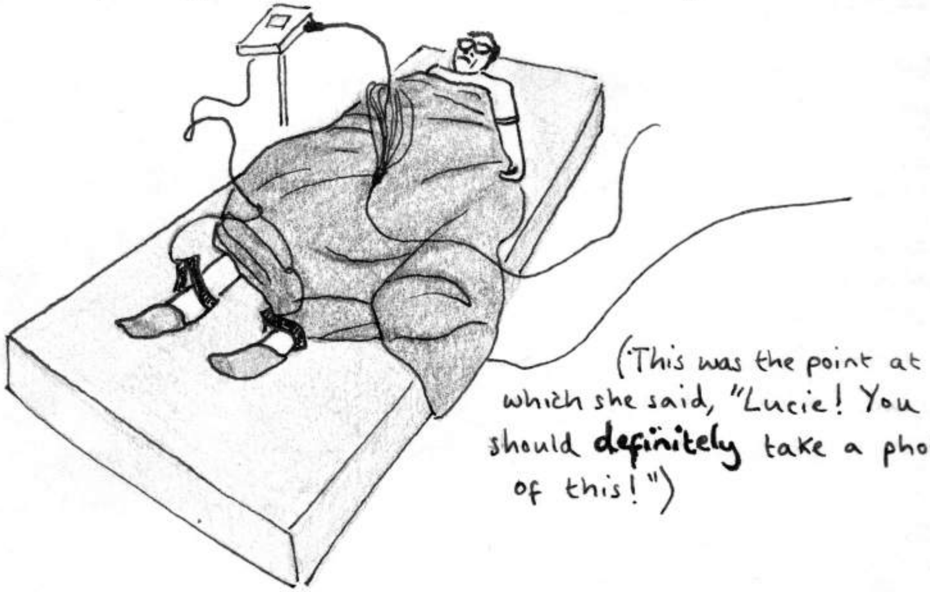
Since then she's had a little mouse on her chest, scratching away inside.

It was getting worse in La Paz, so we went to the

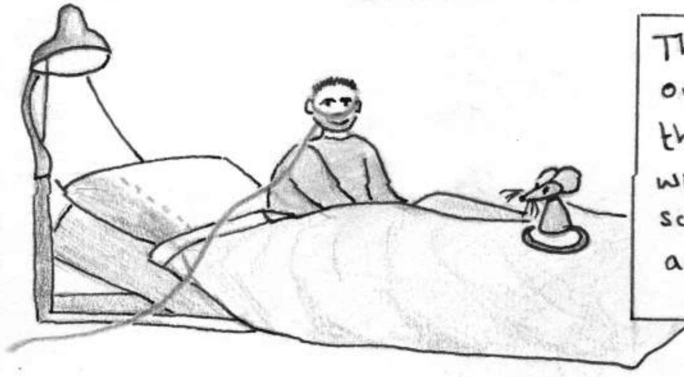
High Altitude Pathology Institute, La Paz



After an initial assessment which established **very** high blood pressure and possibly something on her lung, they poked and prodded her for some hours, doing x-rays, blood samples, heart sonograms, the lot.



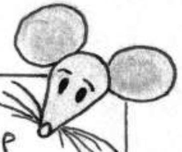
(This was the point at which she said, "Lucie! You should **definitely** take a photo of this!")



They kept her in overnight because they couldn't work out what this little mouse scratching around actually was...

At 9pm, after she'd been tapping oxygen for a while and it hadn't helped her blood pressure, they decided to put her in the 'adaptation chamber' to simulate different altitudes to see if it would affect her blood pressure or the little mouse.

Apparently the chair was uncomfortable, but how cool is this piece of equipment?!



In the end, the doctor realised that running up the hill must have weakened a tiny bit of muscle in my mum's chest, which gave her the little mouse that is prone to Parkinson's tremors. Nothing wrong with her heart, nor her lungs, nothing serious at all. Although she'll get her blood pressure checked out at home.

Links

Parkinson's Resources online

Parkinson's UK: www.parkinsons.org.uk

Parkinson's US: www.parkinson.org

Michael J Fox's website: www.michaeljfox.org

Young Parkinson's: www.youngparkinsons.org

Louise and Lucie's blogs

Louise's blog: www.onlysize3feet.wordpress.com

Lucie's blog: www.drawnoutthinking.net