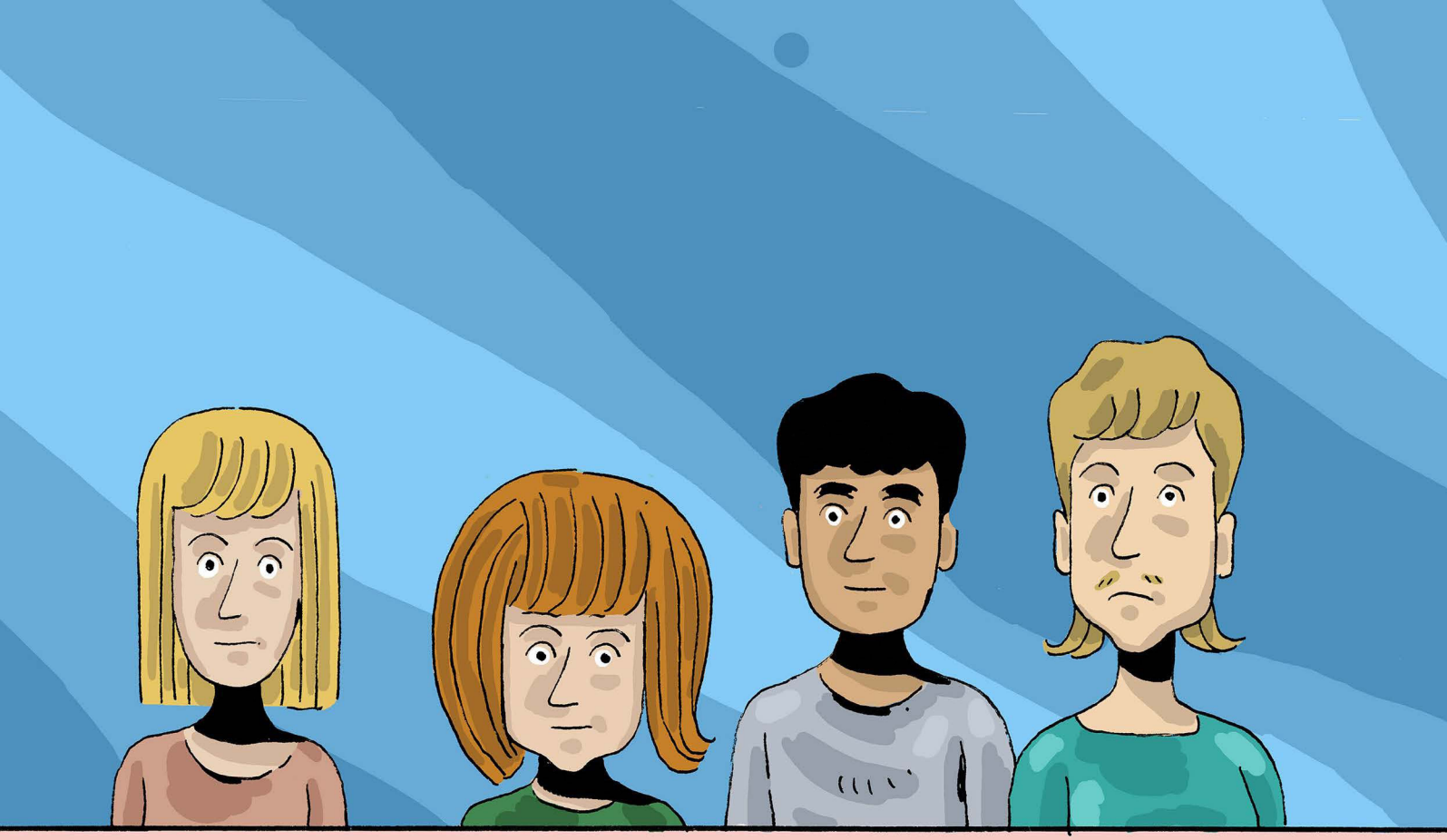


Long Covid Lives

An illustrated story series about young people living with Long Covid



LONG COVID LIVES

Chapter 1 of 3

Long Covid Lives

Chapter 1 of 3: A long way to diagnosis

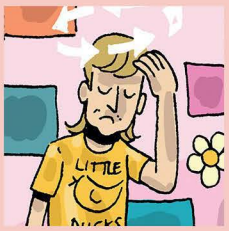
These are stories of what it is like to be a young person living with Long Covid, created in collaboration with those who have experienced it.

They are based on 72 young people's accounts generated through interviews with researchers. No individual characters represent one story – we have brought different people's stories together to represent multiple experiences.

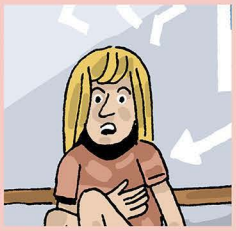
Introducing...



Santi: Santi (he/him) is a 19-year-old Asian British student taking a year out of university because he is experiencing Long Covid symptoms including chronic fatigue, increased heart rate, brain fog, and loss of taste and smell. Doctors tell him he is just having panic attacks, but he has experienced anxiety and panic attacks before, so he knows that something else is going on. He has a supportive family who help him find ways to get help outside of the NHS.

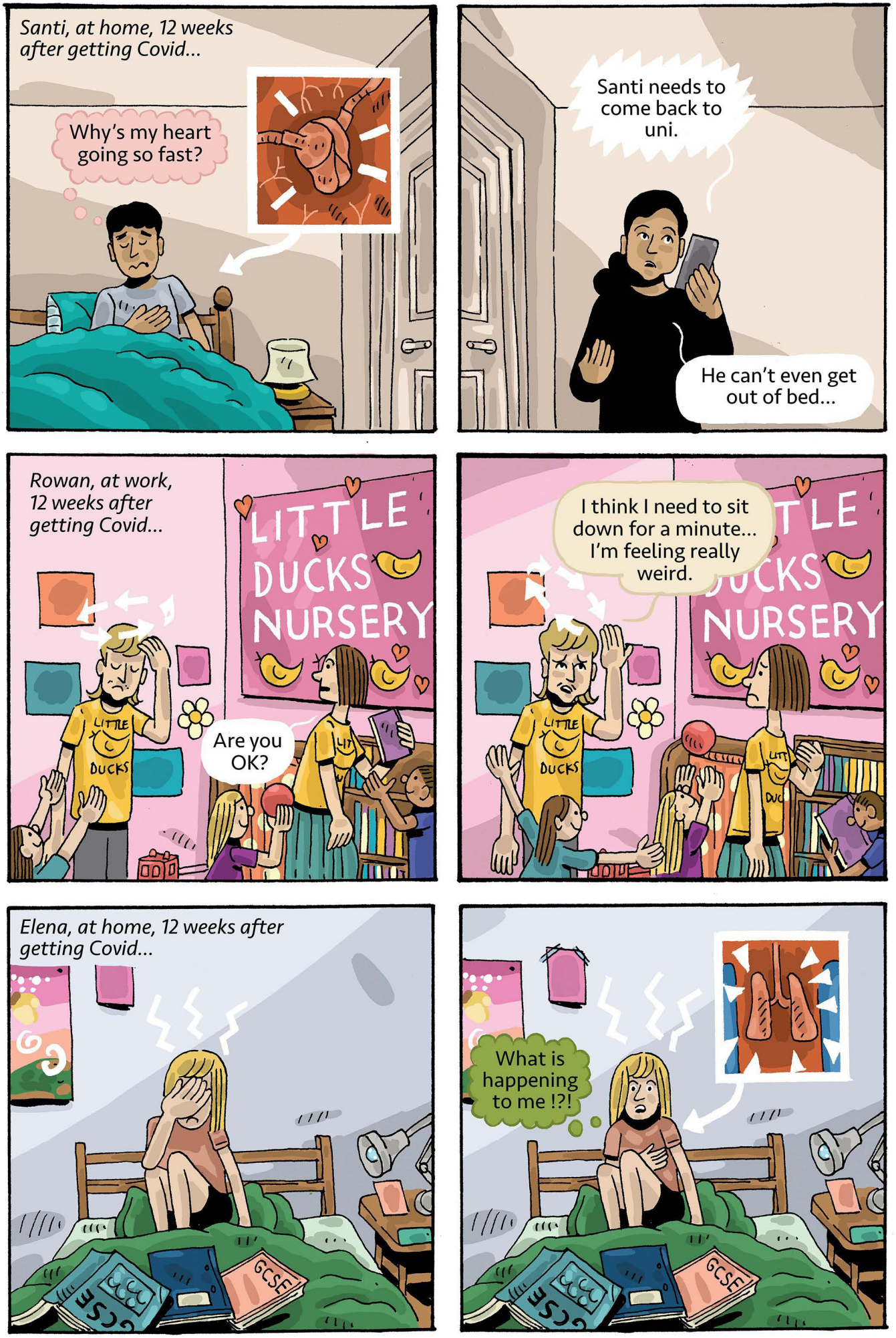


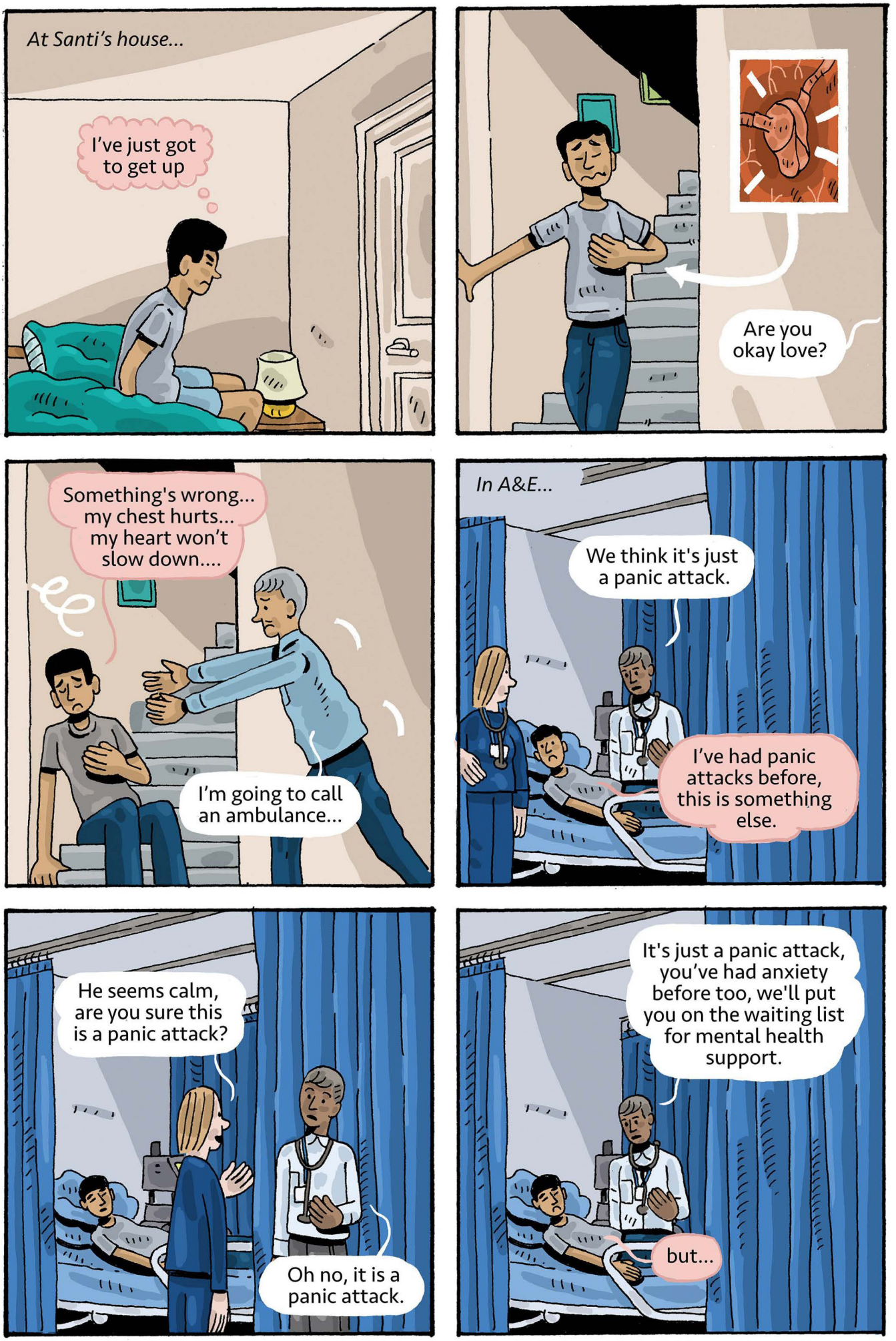
Rowan: Rowan (they/them) is a White British, 23-year old nursery practitioner living in shared housing. They are experiencing long-term symptoms from Covid-19 including chronic fatigue, dizziness, and nausea and face a high risk of getting ill again because of their work and living situation. They are struggling to access healthcare and when they finally get a GP appointment they have to decide whether to talk about Long Covid symptoms or accessing a gender identity clinic.



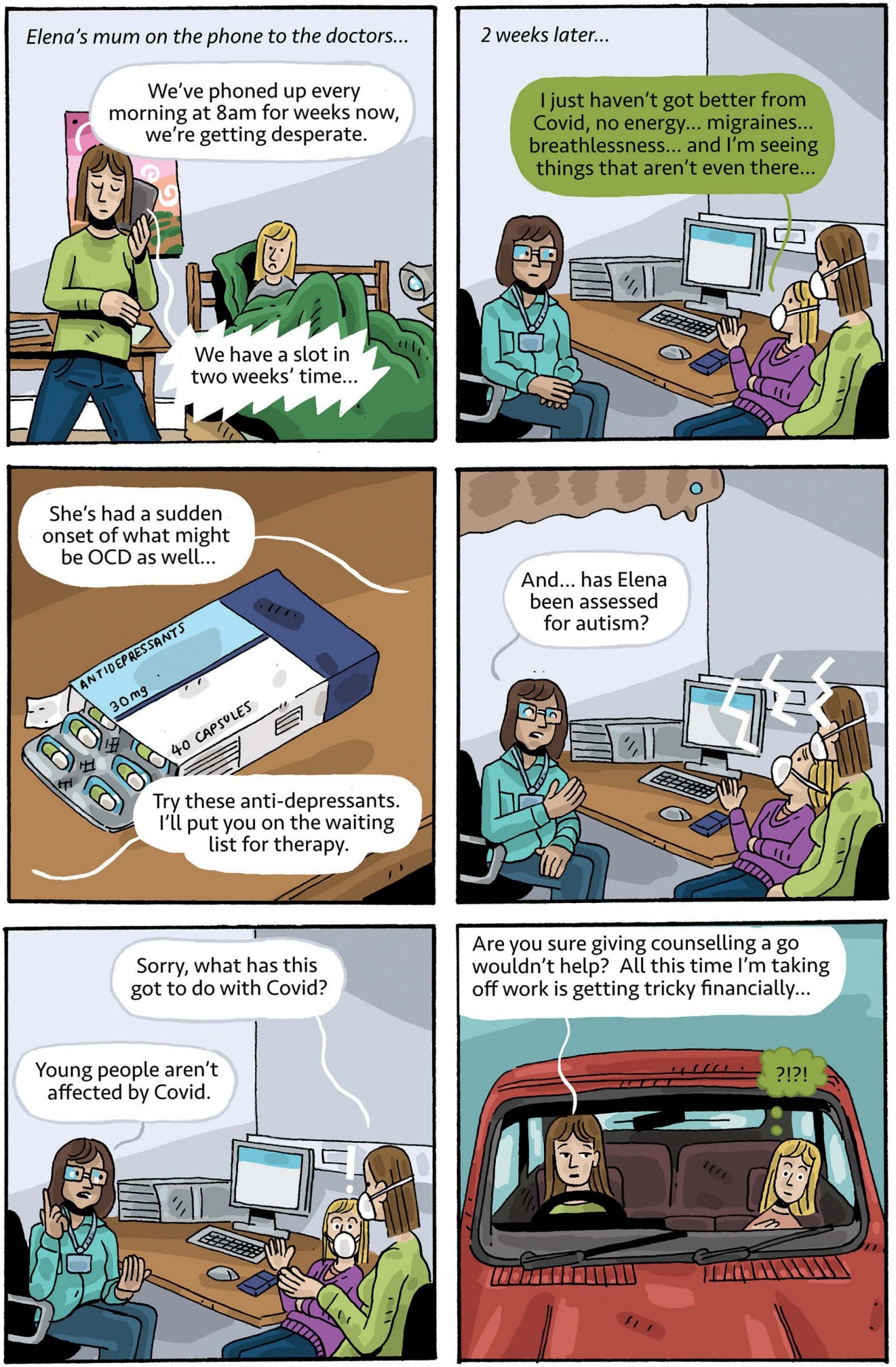
Elena: Elena (she/her) is a 16-year-old White British student who couldn't finish her GCSEs because of Long Covid. She goes to the GP with symptoms of chronic fatigue, migraines, breathlessness, and hallucinations, but doesn't feel taken seriously by her GP, who puts her symptoms down to depression and autism. She lives with a single mum who has to take time off work to support her. She sees people recommending private clinics but she can't afford them.

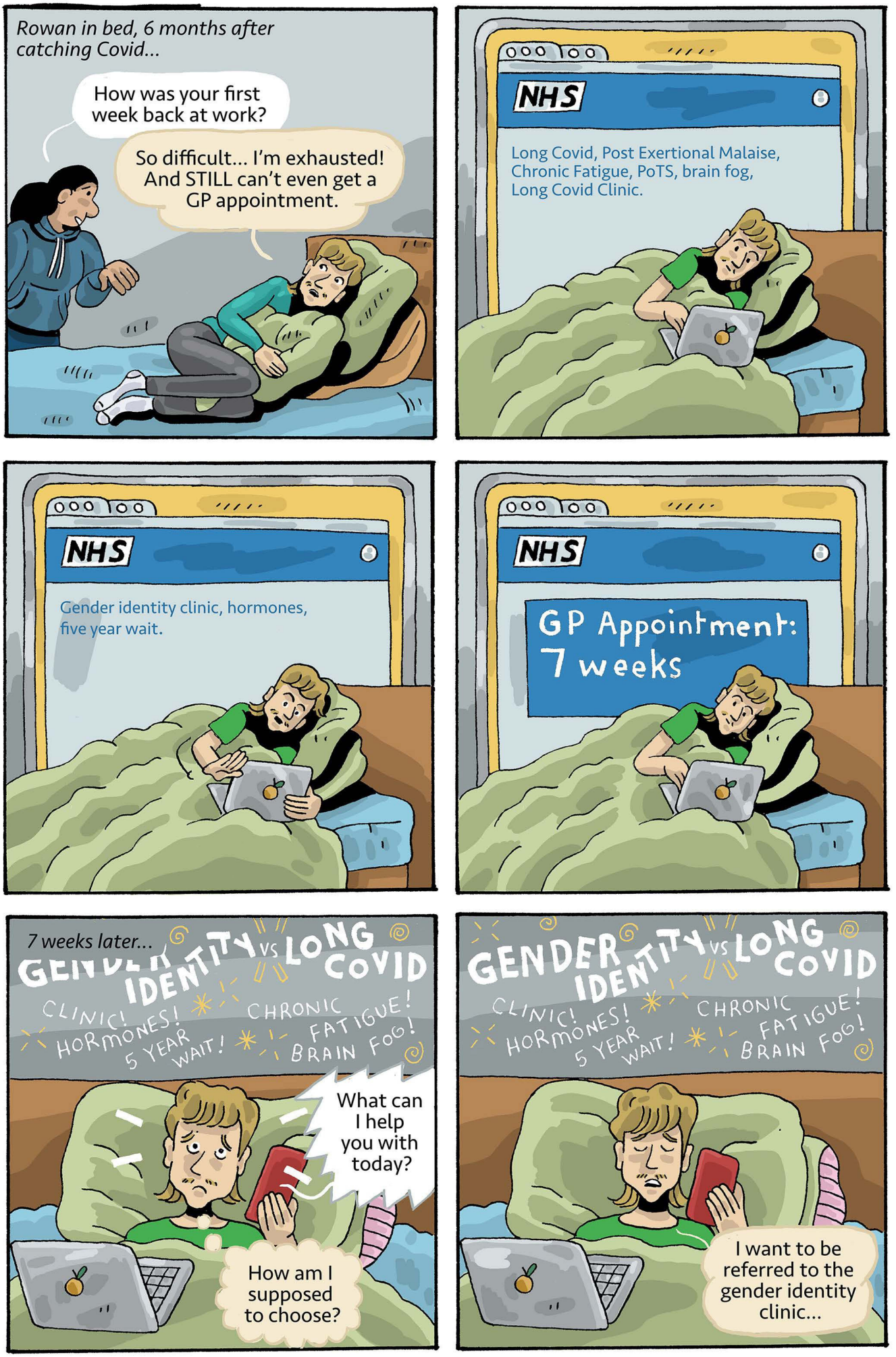
Content warning: *This chapter contains stories relating to illness experience, medical gaslighting, inaccessibility to trans healthcare, misgendering, and financial difficulties. The things said by characters (including doctors) relate to real experiences, but do not constitute medical advice. For advice on how to manage Long Covid, visit: www.longcovidkids.org. Scan the QR code on the back cover for a glossary of key terms.*

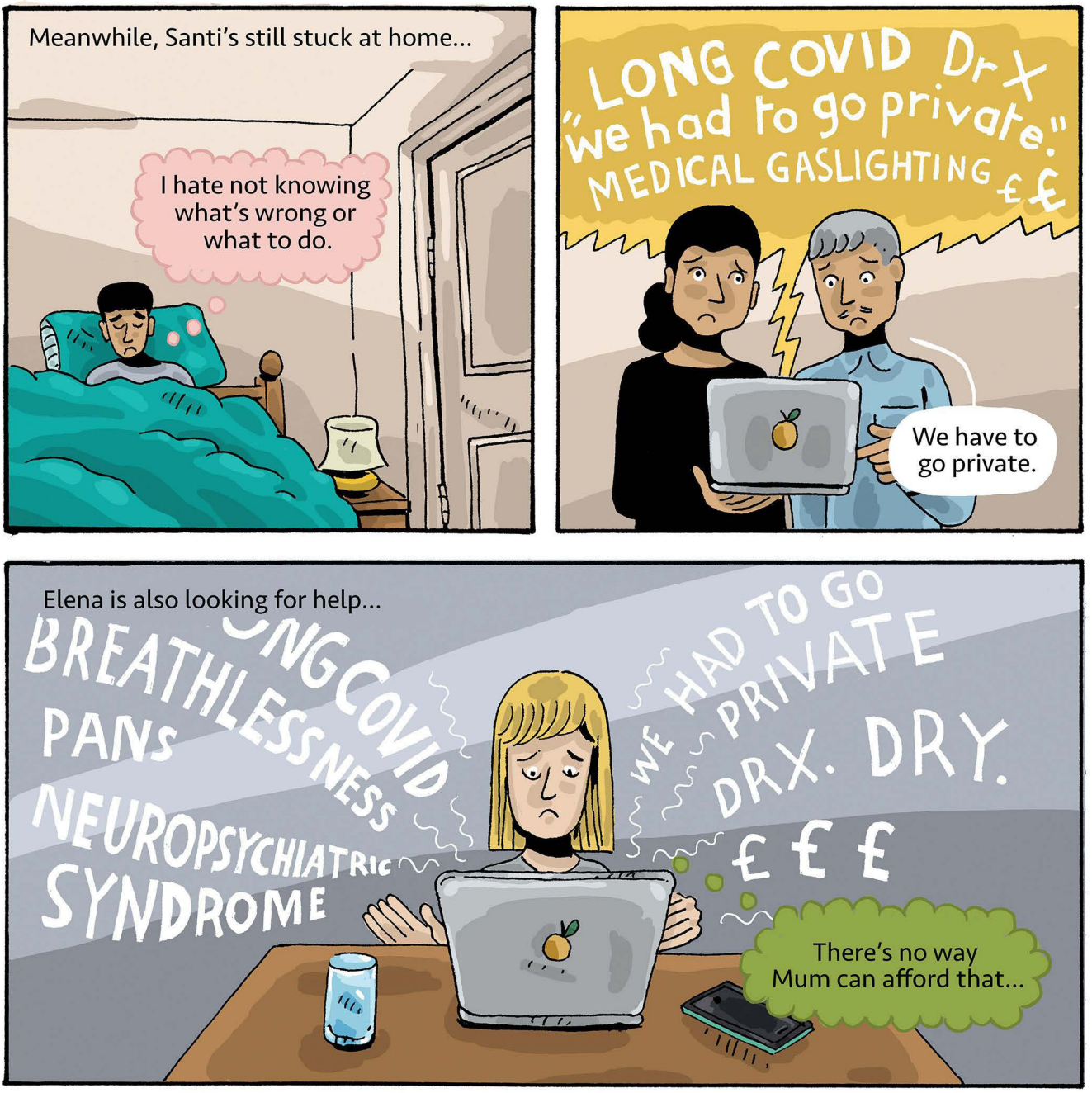

Santi, at home, 12 weeks after getting Covid...
Why's my heart going so fast?
Santi needs to come back to uni.
He can't even get out of bed...
Rowan, at work, 12 weeks after getting Covid...
LITTLE DUCKS NURSERY
Are you OK?
I think I need to sit down for a minute... I'm feeling really weird.
Elena, at home, 12 weeks after getting Covid...
What is happening to me !?!
GCSE

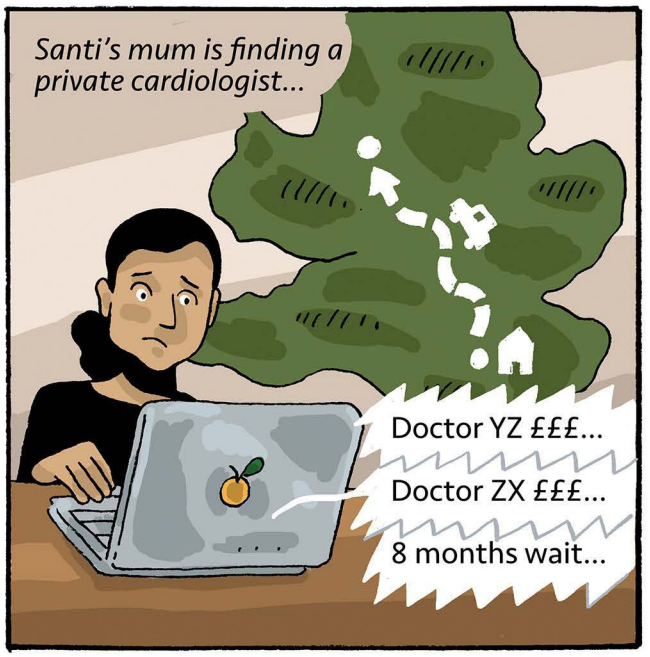

At Santi's house...
I've just got to get up
Are you okay love?
Something's wrong... my chest hurts... my heart won't slow down....
I'm going to call an ambulance...
In A&E...
We think it's just a panic attack.
I've had panic attacks before, this is something else.
He seems calm, are you sure this is a panic attack?
Oh no, it is a panic attack.
It's just a panic attack, you've had anxiety before too, we'll put you on the waiting list for mental health support.
but...

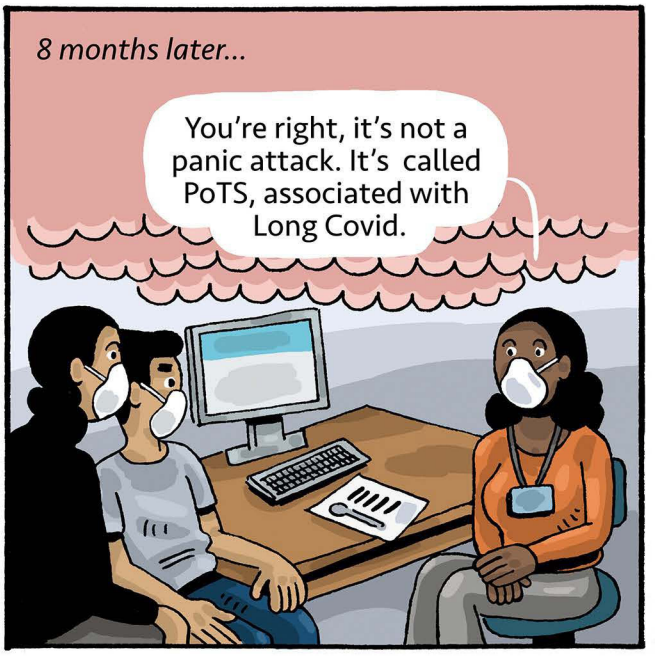

Will I ever feel normal again?
TACHYCARDIA
Dr XYZ
PoTs
LONG COVID
Meanwhile in Rowan's shared flat...
You literally can't stand up... don't they get that?
Work
Can you come in yet? We're desperate.
Sorry I still can't...
RENT DUE!
CHORES
6 months after getting Covid...
Are you sure you need to keep washing your hands?
I can't stop!
Mum what is that figure?
There's nothing there sweetheart...


Elena's mum on the phone to the doctors...
We've phoned up every morning at 8am for weeks now, we're getting desperate.
We have a slot in two weeks' time...
2 weeks later...
I just haven't got better from Covid, no energy... migraines... breathlessness... and I'm seeing things that aren't even there...
She's had a sudden onset of what might be OCD as well...
ANTIDEPRESSANTS
30mg
40 CAPSULES
Try these anti-depressants. I'll put you on the waiting list for therapy.
And... has Elena been assessed for autism?
Sorry, what has this got to do with Covid?
Young people aren't affected by Covid.
!
Are you sure giving counselling a go wouldn't help? All this time I'm taking off work is getting tricky financially...
?!?!

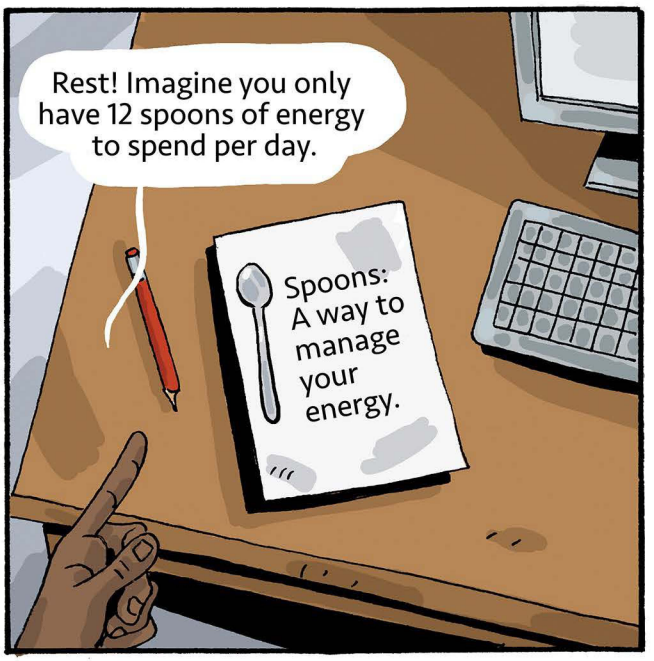

Rowan in bed, 6 months after catching Covid...
How was your first week back at work?
So difficult... I'm exhausted! And STILL can't even get a GP appointment.
NHS
Long Covid, Post Exertional Malaise, Chronic Fatigue, PoTS, brain fog, Long Covid Clinic.
NHS
Gender identity clinic, hormones, five year wait.
NHS
GP Appointment: 7 weeks
7 weeks later...
GENDER IDENTITY VS LONG COVID
CLINIC! HORMONES! 5 YEAR WAIT! CHRONIC FATIGUE! BRAIN FOG!
What can I help you with today?
How am I supposed to choose?
GENDER IDENTITY VS LONG COVID
CLINIC! HORMONES! 5 YEAR WAIT! CHRONIC FATIGUE! BRAIN FOG!
I want to be referred to the gender identity clinic...

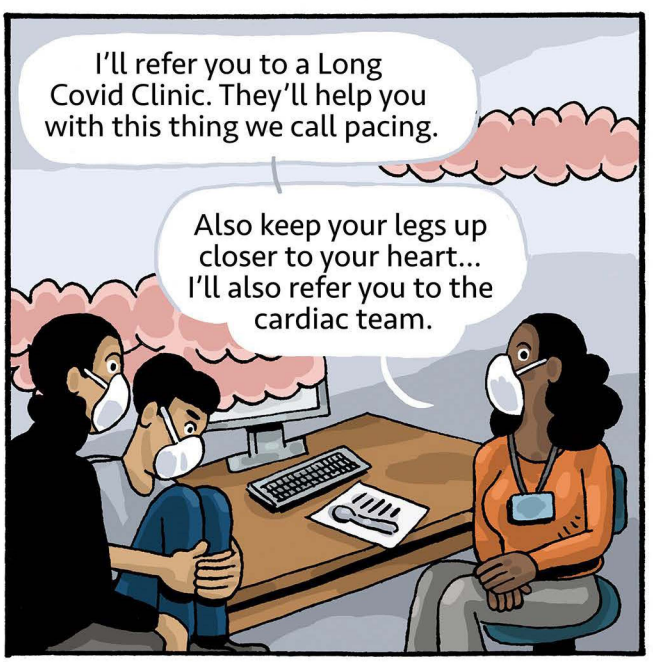

Meanwhile, Santi's still stuck at home...
I hate not knowing what's wrong or what to do.
LONG COVID Dr X
"we had to go private."
MEDICAL GASLIGHTING ££
We have to go private.
Elena is also looking for help...
BREATHLESSNESS
PANS
NEUROPSYCHIATRIC SYNDROME
WE HAD TO GO PRIVATE
DRX. DRY.
£ £ £
There's no way Mum can afford that...
Rowan has had to go back to work...
LITTLE
NURSERY
Will you help her out?
Her!?
I need the help, I'll have to let the pronouns go for now...


Santi's mum is finding a private cardiologist...
Doctor YZ £££...
Doctor ZX £££...
8 months wait...

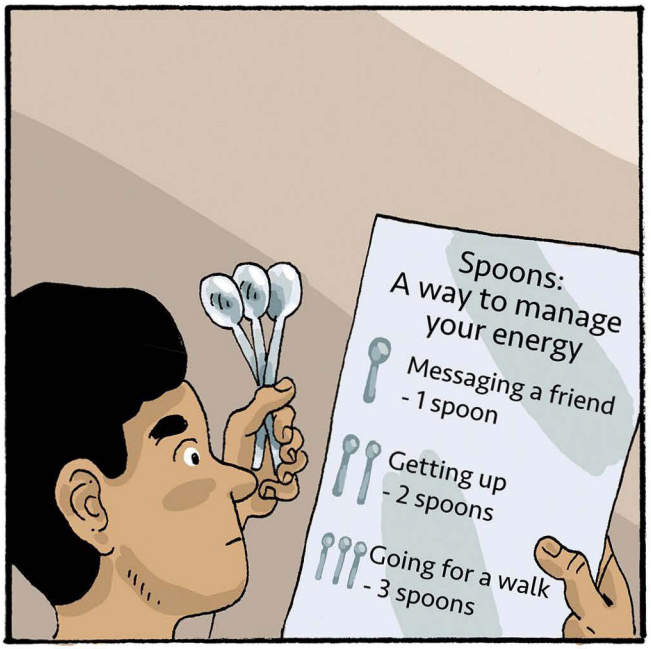

8 months later...
You're right, it's not a panic attack. It's called PoTS, associated with Long Covid.

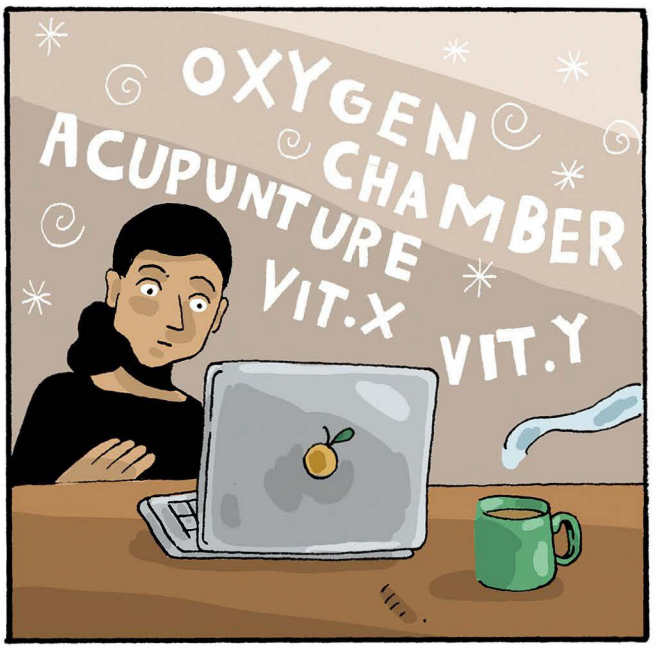

Okay, what happens next?


Rest! Imagine you only have 12 spoons of energy to spend per day.
Spoons: A way to manage your energy.

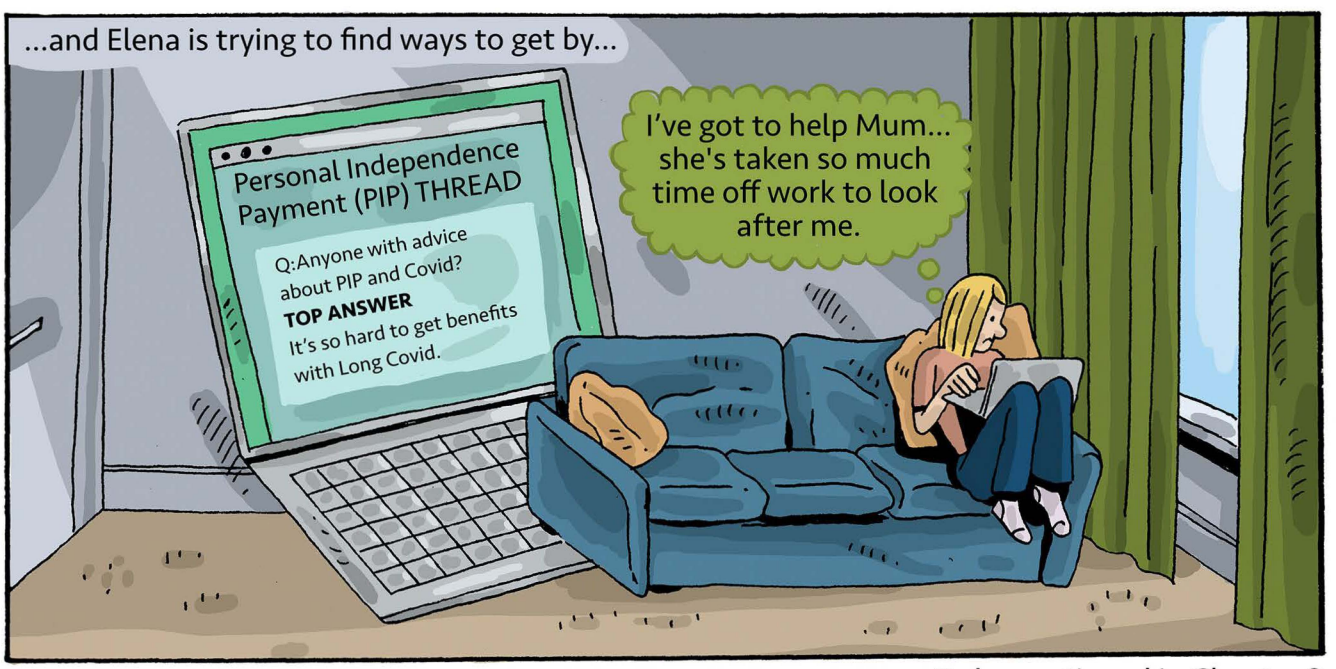

I'll refer you to a Long Covid Clinic. They'll help you with this thing we call pacing.
Also keep your legs up closer to your heart... I'll also refer you to the cardiac team.


Today was a lot... week to recover... overdone it.









To be continued in Chapter 2



LONG COVID LIVES

Chapter 2 of 3

Long Covid Lives

Chapter 2 of 3: Looping impacts

These are stories of what it is like to be a young person living with Long Covid, created in collaboration with those who have experienced it.

They are based on 72 young people's accounts generated through interviews with researchers. No individual characters represent one story – we have brought different people's stories together to represent multiple experiences.

Previously...



Santi: Santi (he/him) struggled to get support for Long Covid in the NHS. With financial and emotional support from his parents he finally managed to get a diagnosis and advice on 'pacing' from private healthcare. **This time** we see how Santi's experience of Long Covid also interacts with anxiety, disordered eating, and experiences of racism, as he goes back to uni on a reduced timetable. He is seen as "too complex" for NHS care.



Rowan: Rowan (they/them) also experienced ongoing health impacts from Covid-19 but struggled to get a GP appointment. They ended up prioritising accessing gender affirming care with the one appointment they managed to get with the GP. **This time**, Rowan is still trying to work out what is happening to them and joins an online support group to get some advice.

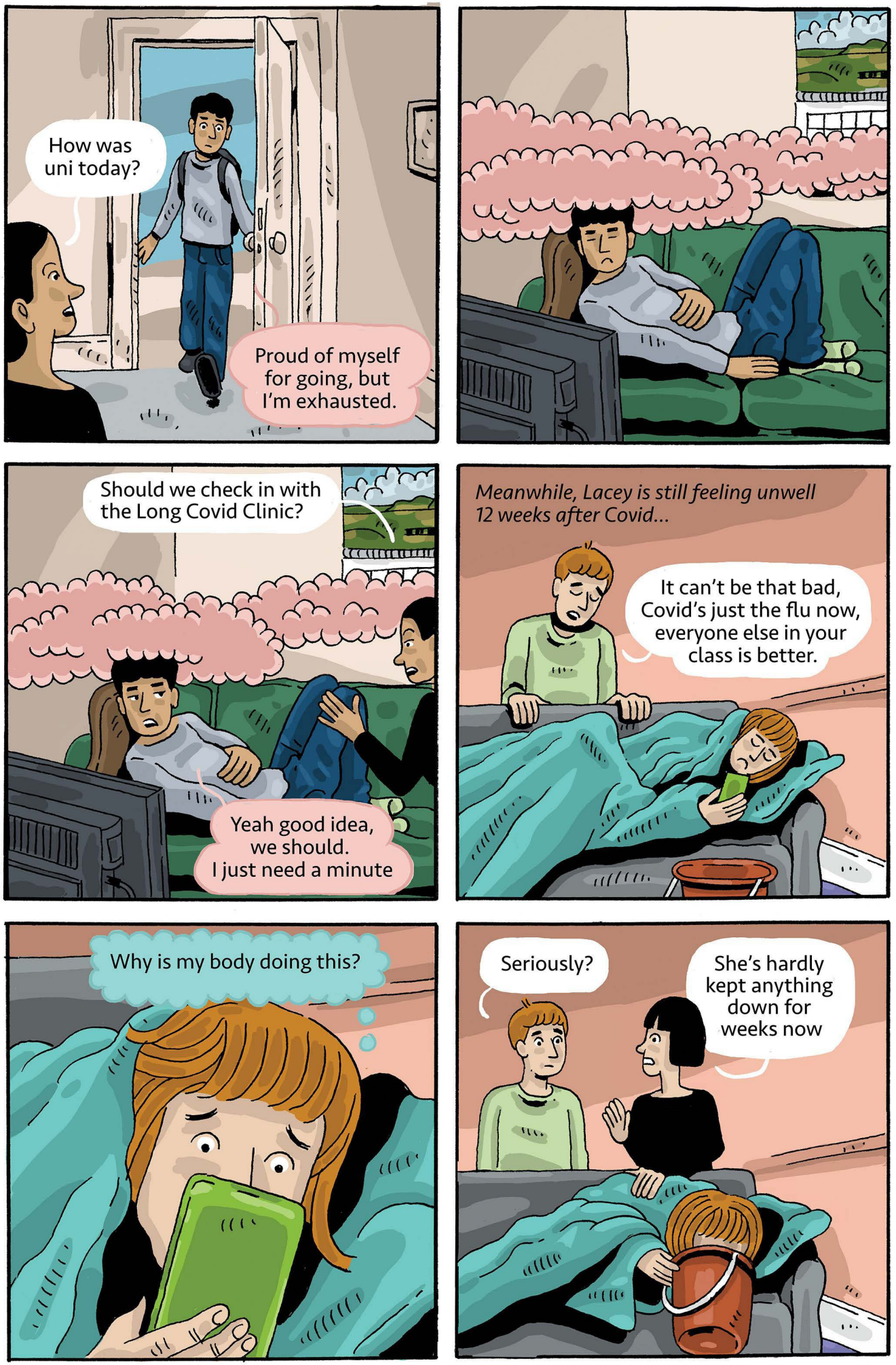


Elena: Elena (she/her) struggled to access any support for her experience of Long Covid, and her single mum couldn't afford to take her to private care. **This time**, Elena joins an online group of young people with Long Covid to gain some peer support.

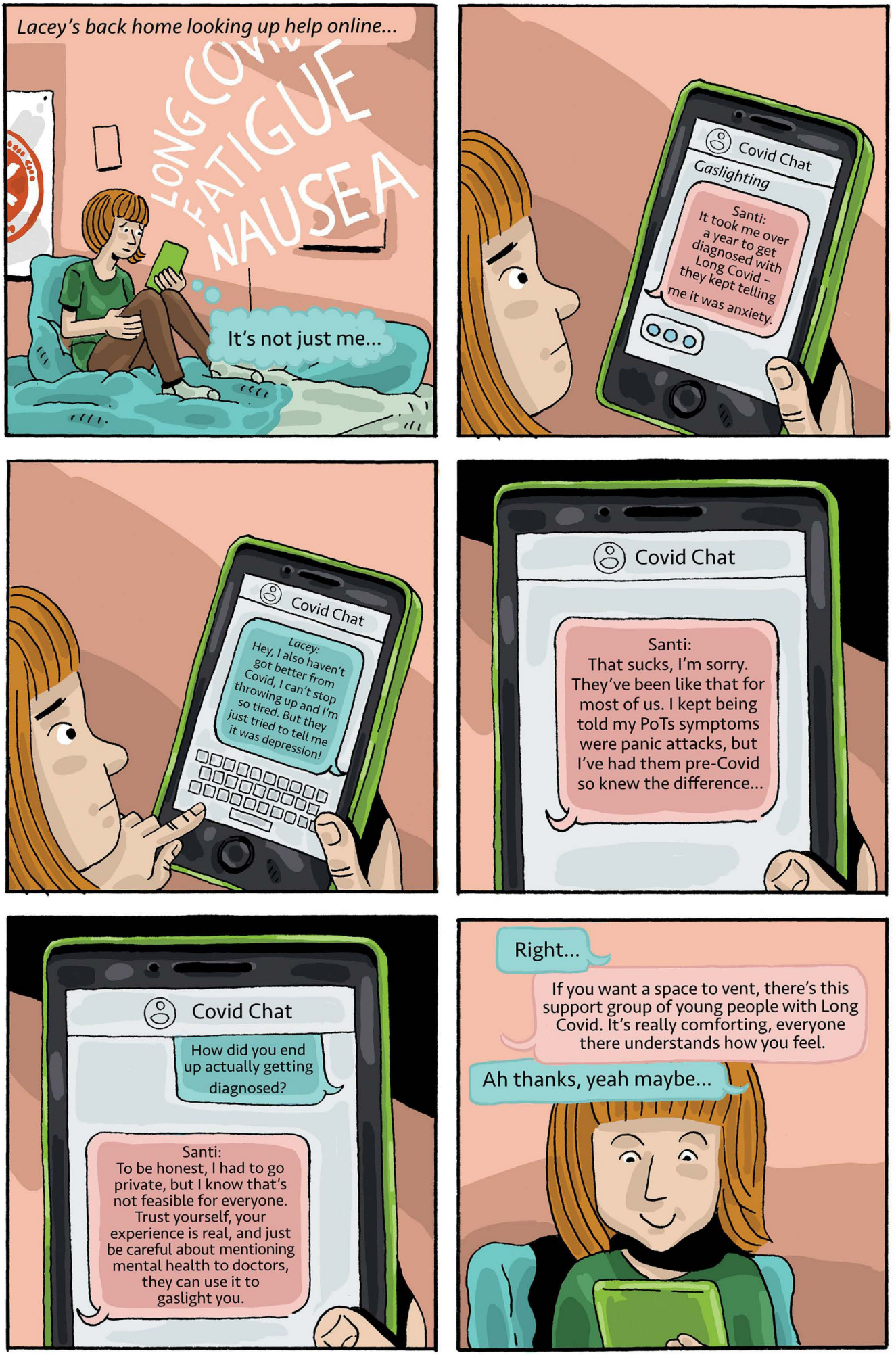


Lacey: This time we are also introduced to Lacey (she/her) who is a 17-year-old British European student who has taken time out of A-Levels because of long term symptoms from Covid-19, including chronic fatigue, allergies, and stomach issues which cause sickness. She feels gaslighted because the doctors say it's anxiety and depression. She wasn't feeling any of these things before she had Long Covid, but over time the isolation starts to impact her mental health.

Content warning: *This chapter contains stories relating to illness experience, declines in mental health, racism, and medical gaslighting. The things said by characters (including doctors) relate to real experiences, but do not constitute medical advice. For advice on how to manage Long Covid, visit: www.longcovidkids.org. Scan the QR code on the back cover for a glossary of key terms.*


How was uni today?
Proud of myself for going, but I'm exhausted.
Should we check in with the Long Covid Clinic?
Yeah good idea, we should. I just need a minute
Meanwhile, Lacey is still feeling unwell 12 weeks after Covid...
It can't be that bad, Covid's just the flu now, everyone else in your class is better.
Why is my body doing this?
Seriously?
She's hardly kept anything down for weeks now

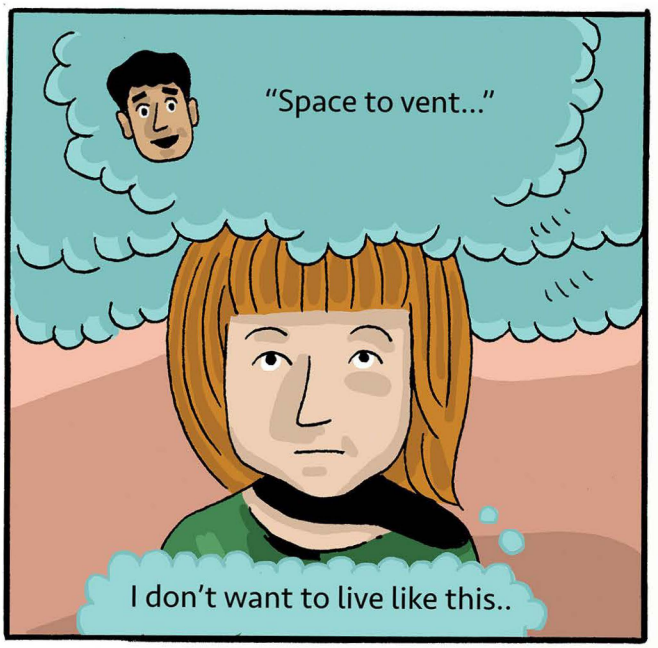

No football again today then.
July
I can't get through to the GP again, I'm calling 111.
We'll get a doctor to phone you back.
I'm taking you to A&E, this is ridiculous.
I've never seen anything like this. Are you sure you're not making yourself sick?
What on earth!
She's been like this since she got Covid 3 months ago. She's also had no energy whatsoever.
I'll give you some anti-sickness meds, but you also need to consider anti-depressants.
Depression?! How am I going to keep any of that down anyway...

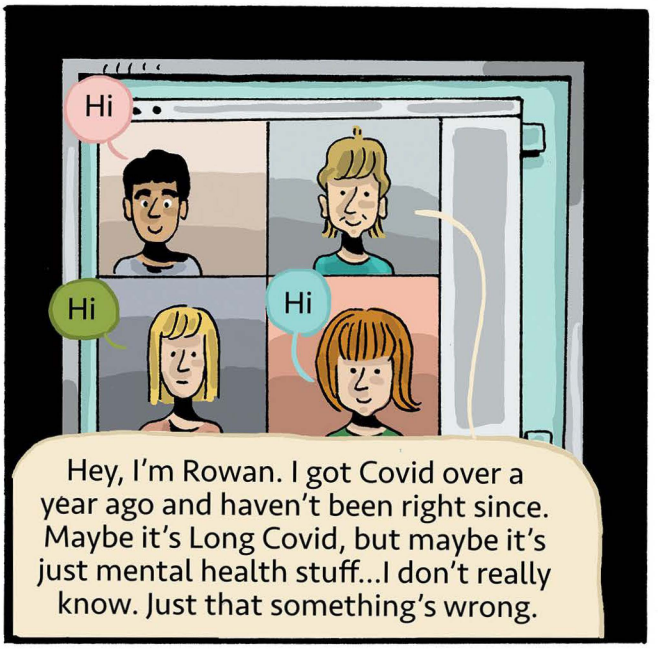

Lacey's back home looking up help online...
LONG COVID
FATIGUE
NAUSEA
It's not just me...
Covid Chat
Gaslighting
Santi:
It took me over a year to get diagnosed with Long Covid – they kept telling me it was anxiety.
Covid Chat
Lacey:
Hey, I also haven't got better from Covid, I can't stop throwing up and I'm so tired. But they just tried to tell me it was depression!
Covid Chat
Santi:
That sucks, I'm sorry. They've been like that for most of us. I kept being told my PoTs symptoms were panic attacks, but I've had them pre-Covid so knew the difference...
Covid Chat
How did you end up actually getting diagnosed?
Santi:
To be honest, I had to go private, but I know that's not feasible for everyone. Trust yourself, your experience is real, and just be careful about mentioning mental health to doctors, they can use it to gaslight you.
Right...
If you want a space to vent, there's this support group of young people with Long Covid. It's really comforting, everyone there understands how you feel.
Ah thanks, yeah maybe...


Meanwhile, Santi's gone back to uni...
How are you doing?
Yeah not bad, you?
I wish this question wasn't just small talk.
It's just a mask...
MEAL DEAL
Go back to China!
That's so racist, I'm not even from China.
You all right?
Yeah, just tired
She wouldn't understand...
Last night was so good you should have been there...
...still no taste...

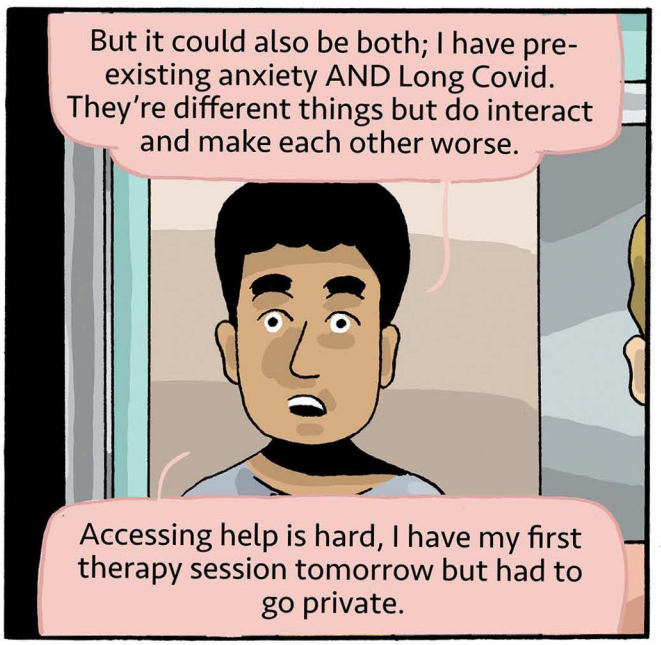

Lacey, 6 months later...
Get back to work, the pandemic is over.
Wish you were here.
When will this end?
ACHE
DEPRESSED
LOST
LONELY
ISOLATED
CONFUSED
OVERWHELMED
FEAR
SICK
"You heard what the doctor said, you're just depressed."
"What you're experiencing is real."
SANTI
I don't want to live like this.


Meanwhile, Santi's back home...
Uni Friends Chat
Hey are you coming into uni again soon? It's been a while!
ARE YOU OK?
Am I okay? I don't even know...
NHS
A message from NHS mental health services
NHS
We're afraid that your needs are **too complex** for our service...
TOO COMPLEX
ARE YOU OK?


"Space to vent..."
I don't want to live like this..

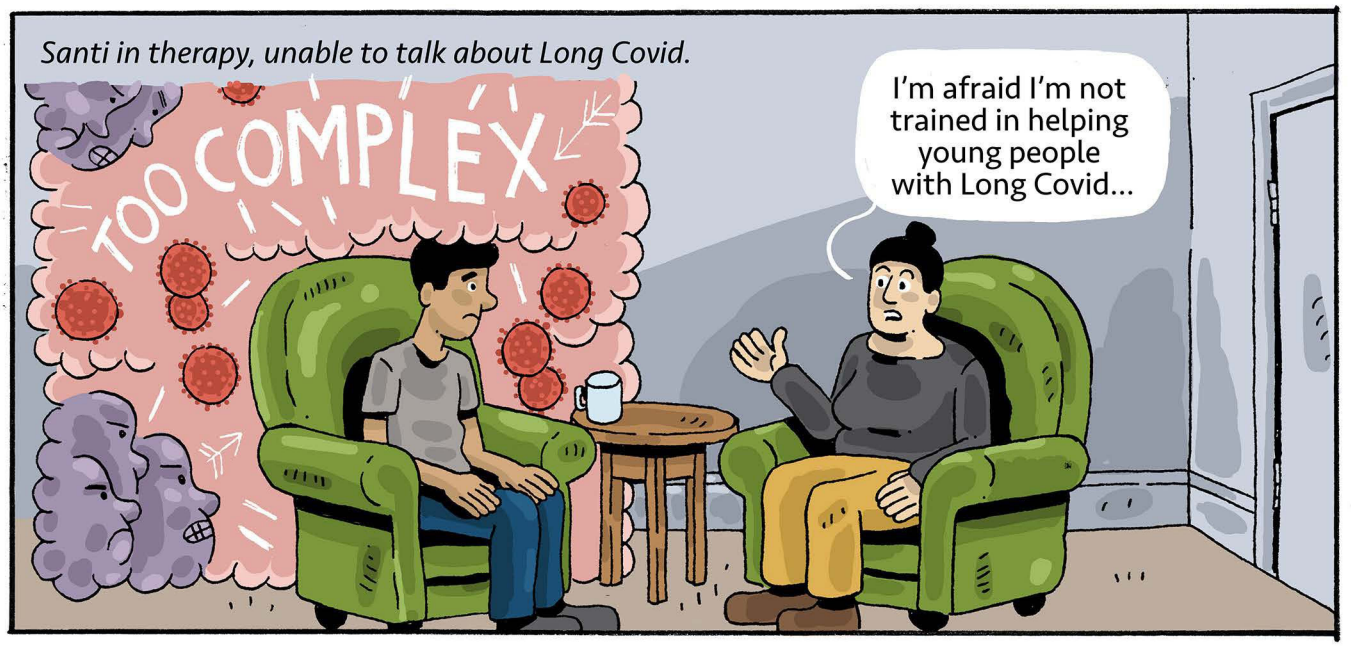

Hi
Hi
Hi
Hey, I'm Rowan. I got Covid over a year ago and haven't been right since. Maybe it's Long Covid, but maybe it's just mental health stuff...I don't really know. Just that something's wrong.


Don't let people tell you it's mental health, that's just a political tactic to dismiss Long Covid!

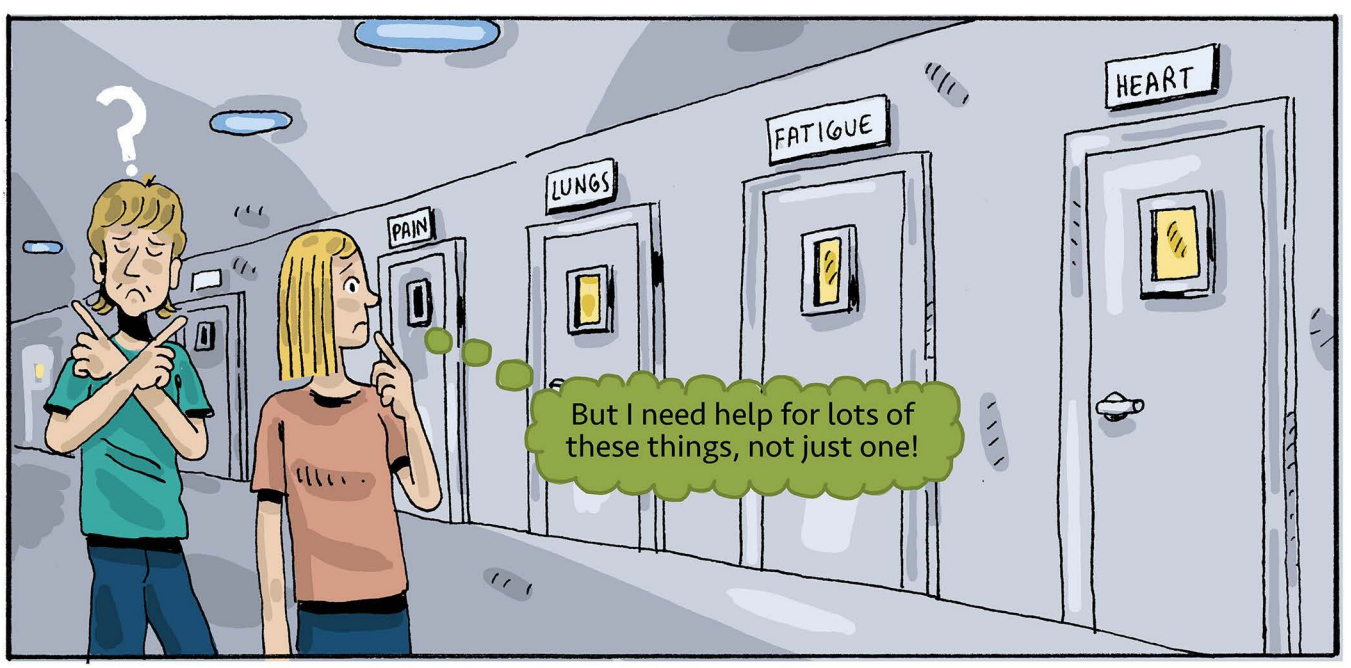

But it could also be both; I have pre-existing anxiety AND Long Covid. They're different things but do interact and make each other worse.
Accessing help is hard, I have my first therapy session tomorrow but had to go private.


I can't be honest about how dealing with Long Covid has affected my mood. If I bring it up, everyone just forgets my physical symptoms.
I never had mental health issues before, but how can I not now? My whole life's changed


Yeah I guess one thing doesn't discount the other, you can have both either together or on their own...
...they're different things but maybe sometimes one can make the other one worse?







To be continued in Chapter 3



LONG COVID LIVES

Chapter 3 of 3

Long Covid Lives

Chapter 3 of 3: Finding ways to live with it

These are stories of what it is like to be a young person living with Long Covid, created in collaboration with those who have experienced it.

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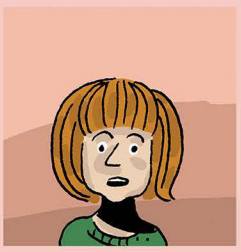
Previously...



Rowan: Rowan (they/them) is experiencing ongoing health impacts from Covid-19 but struggled to get a GP appointment so isn't exactly sure what is going on for them. They are still going to work as an early-years practitioner to pay the rent but have to use all their time off work to rest. **This time**, they find ways to adapt their life with little support. This includes working out which friends to keep close, and who to create more distance from.



Elena: Elena (she/her) struggled to access any support for her experience of Long Covid, and her single mum couldn't afford to take her to private care. **This time**, Elena tries to go back to school but finds that it is not very accommodating. After speaking with other young people with Long Covid, she finds some new things to try. It's not all a smooth ride, but these things help a little.

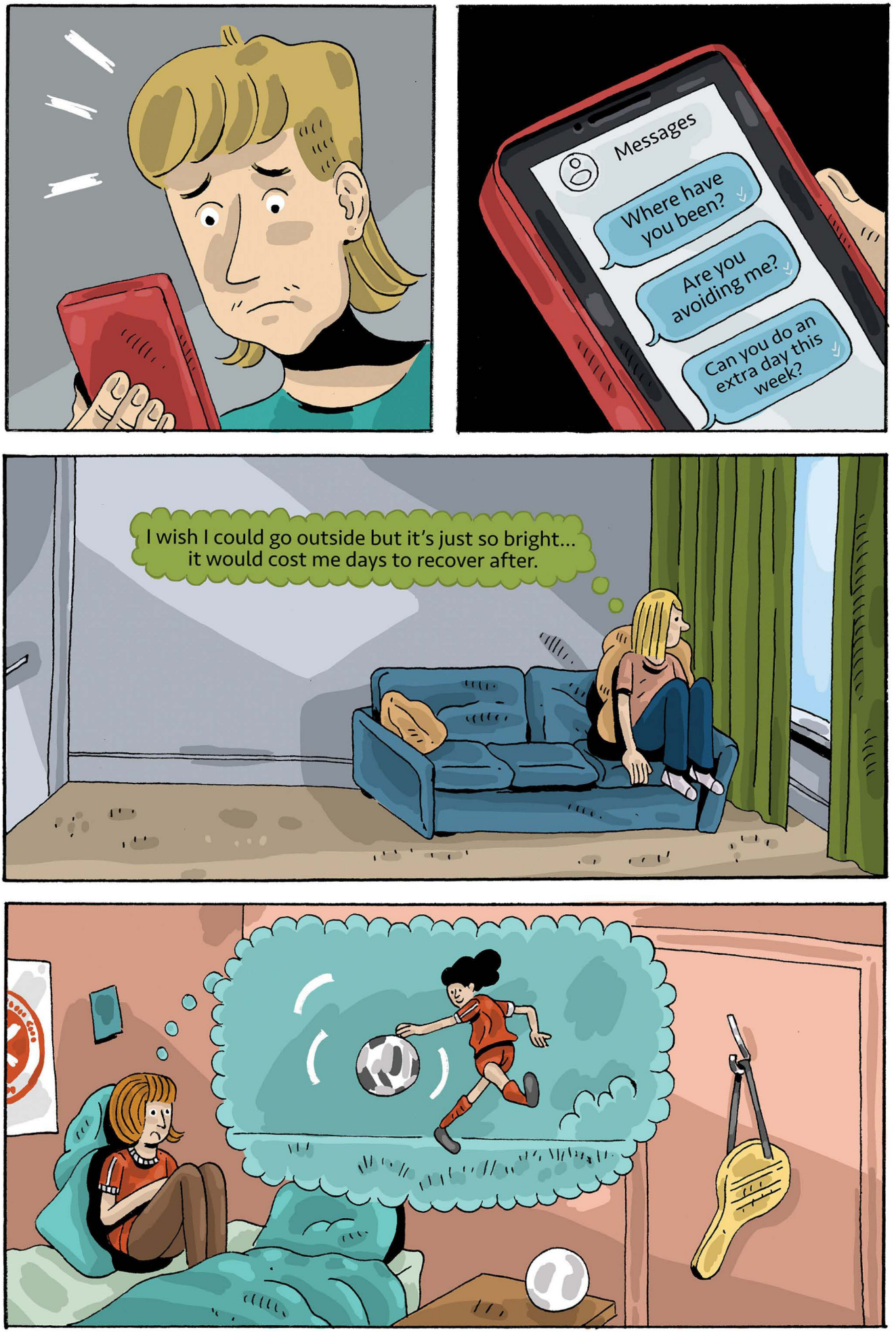


Lacey: Lacey (she/her) finally got a Long Covid diagnosis, but only after feeling gaslighted by doctors in A&E and having to hide any experience of anxiety and depression that came about as a result of experiencing chronic illness. **This time**, Lacey questions her identity now she can't do the things she used to do. After talking to young people with Long Covid online, she explores new hobbies that work with her health needs.



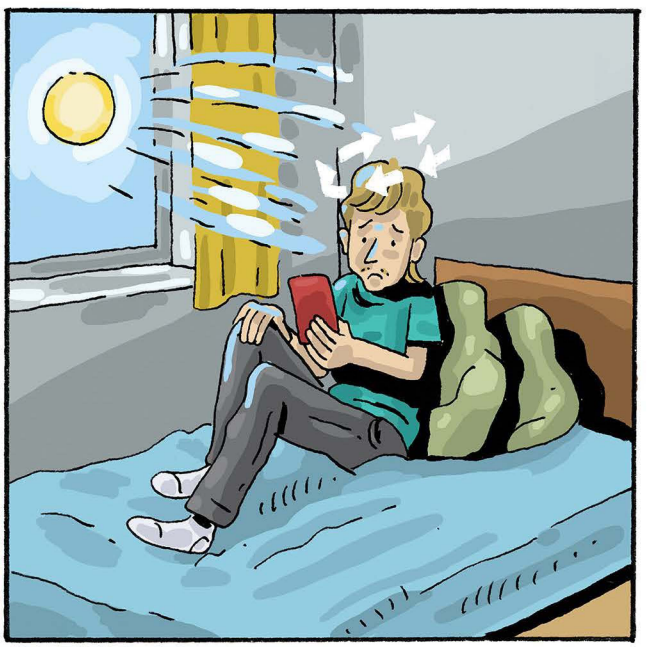
Santi: Santi (he/him) learnt the difficulties of managing the dual impact of mental health and chronic ill health and **this time** meets the others online and shares what he has learnt living with Long Covid.

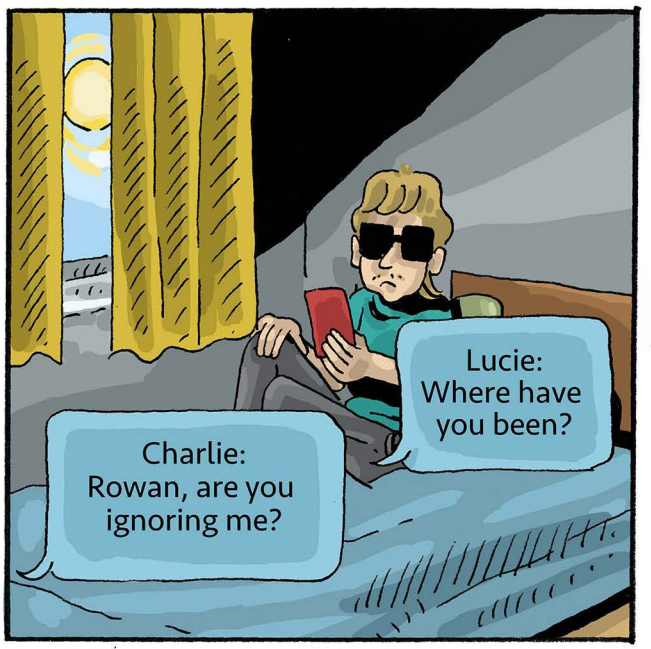
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Messages
Where have you been?
Are you avoiding me?
Can you do an extra day this week?
I wish I could go outside but it's just so bright... it would cost me days to recover after.


WINNER
Who am I anymore?


What if I'm never well enough to go back..
GET WELL SOON
we're all hoping you'll be back soon!




Lucie: Where have you been?
Charlie: Rowan, are you ignoring me?

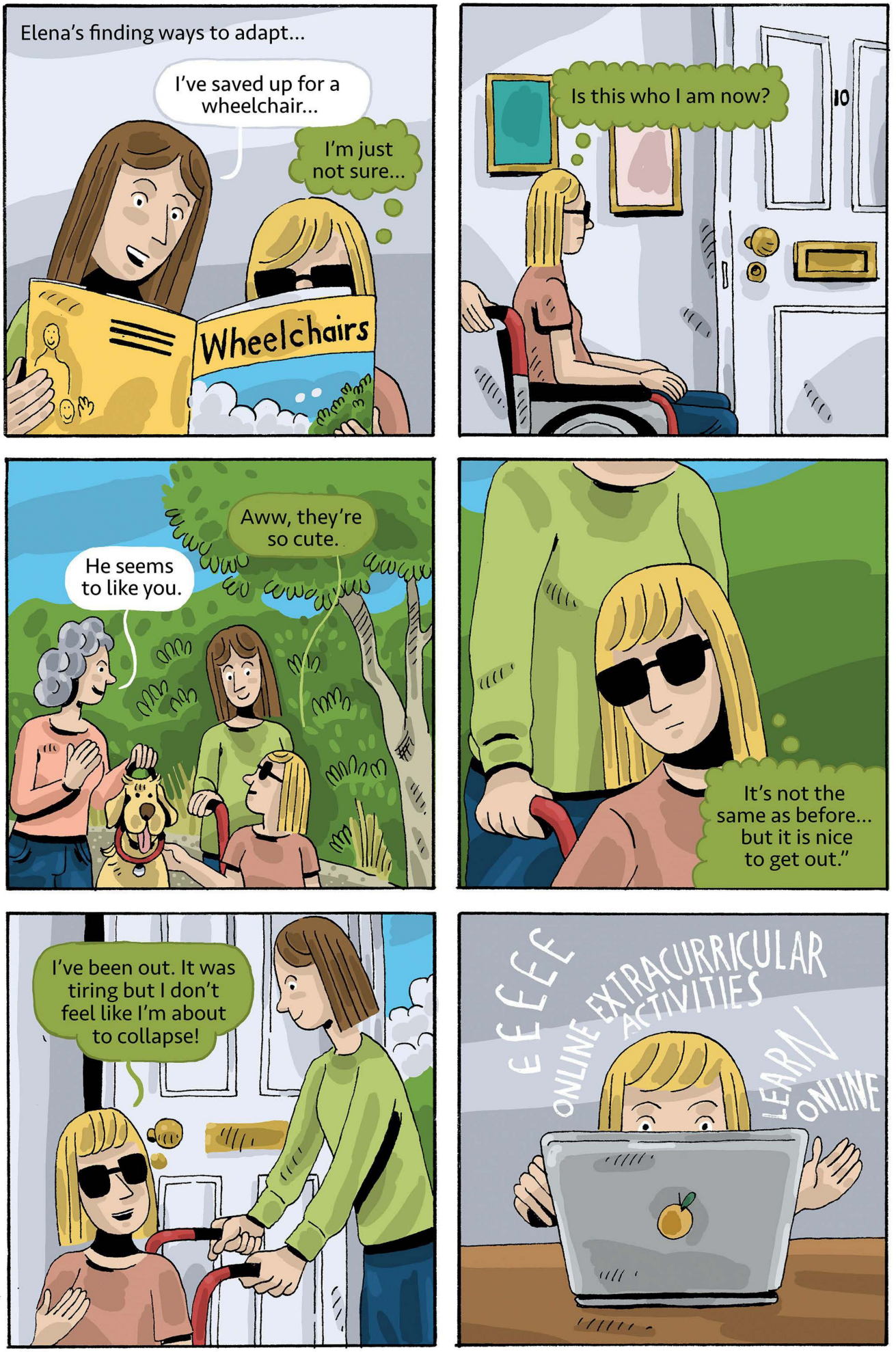

Rowan: Sorry, I don't know what is going on with me. I'm really not well.


Come on, you can't STILL be ill from Covid?


"You are legally obliged to attend school."
How am I gonna cope?
Dear tutor,
I will need:
• Ground floor lessons
• Online options
• Reduced and flexible timetable
• HEPA filters
• Reduced lighting
• To wear a mask
I can't get reinfected... last time it set me back months.
Achoo!
Cough
Could we close the blinds?
Sorry everyone, we have to shut out this beautiful sun.
SCIENCE
I'm seeing things now, I must be tired.
SCIENCE
11.30am
Mum, I need you to come and pick me up.


How is everyone?
It's so nice to see some people who understand what I'm going through.
Yeah, I love how low energy these calls are. I'm thinking of distancing myself from the pre-Covid friends who don't make the effort...
I tried to go to college on Monday but had to come home by 11.30. The brightness...the stairs...
I've started wearing sunglasses and closing curtains to block out the light.
Have you thought about online schools?
I'm just struggling to know who I am now, and what my future looks like.
I totally get that. It helps finding something you can do. Something more low energy


I guess I was into that for a bit.
SKETCH BOOK
Could this be the new me?
Meanwhile, Elena...
Did you say you're writing a blog on Long Covid?
Yeah! Do you want to post something?
Open letter to schools...
"CAN YOU STILL BE ILL FROM COVID?!"
ARE YOU OK?
Fred: Are you actually okay?
Rowan: It's so weird, the symptoms keep changing. Today everything smells of petrol.

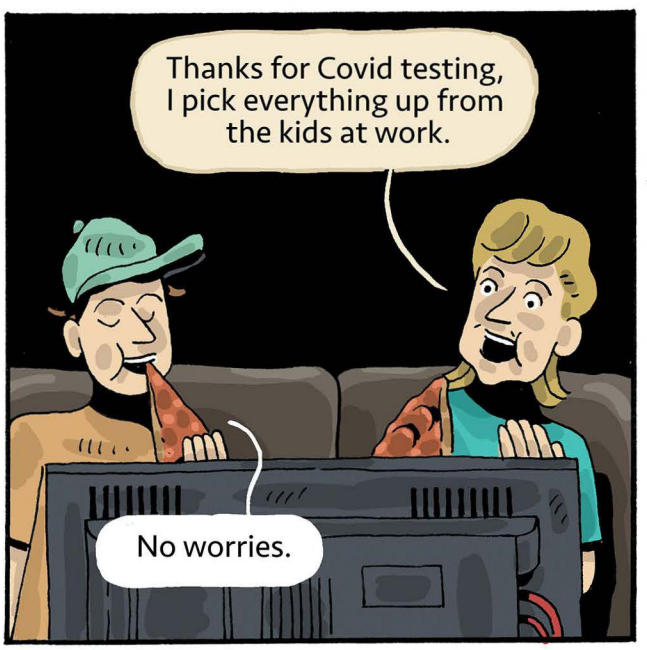

Elena's finding ways to adapt...
I've saved up for a wheelchair...
I'm just not sure...
Wheelchairs
Is this who I am now?
10
Aww, they're so cute.
He seems to like you.
It's not the same as before... but it is nice to get out."
I've been out. It was tiring but I don't feel like I'm about to collapse!
EEEEE
ONLINE EXTRACURRICULAR ACTIVITIES
LEARN ONLINE


Rowan is also finding ways to adapt...
So jealous of your half days.
LITTLE DUCKS NURSERY
Believe me I wish I didn't have to take them!

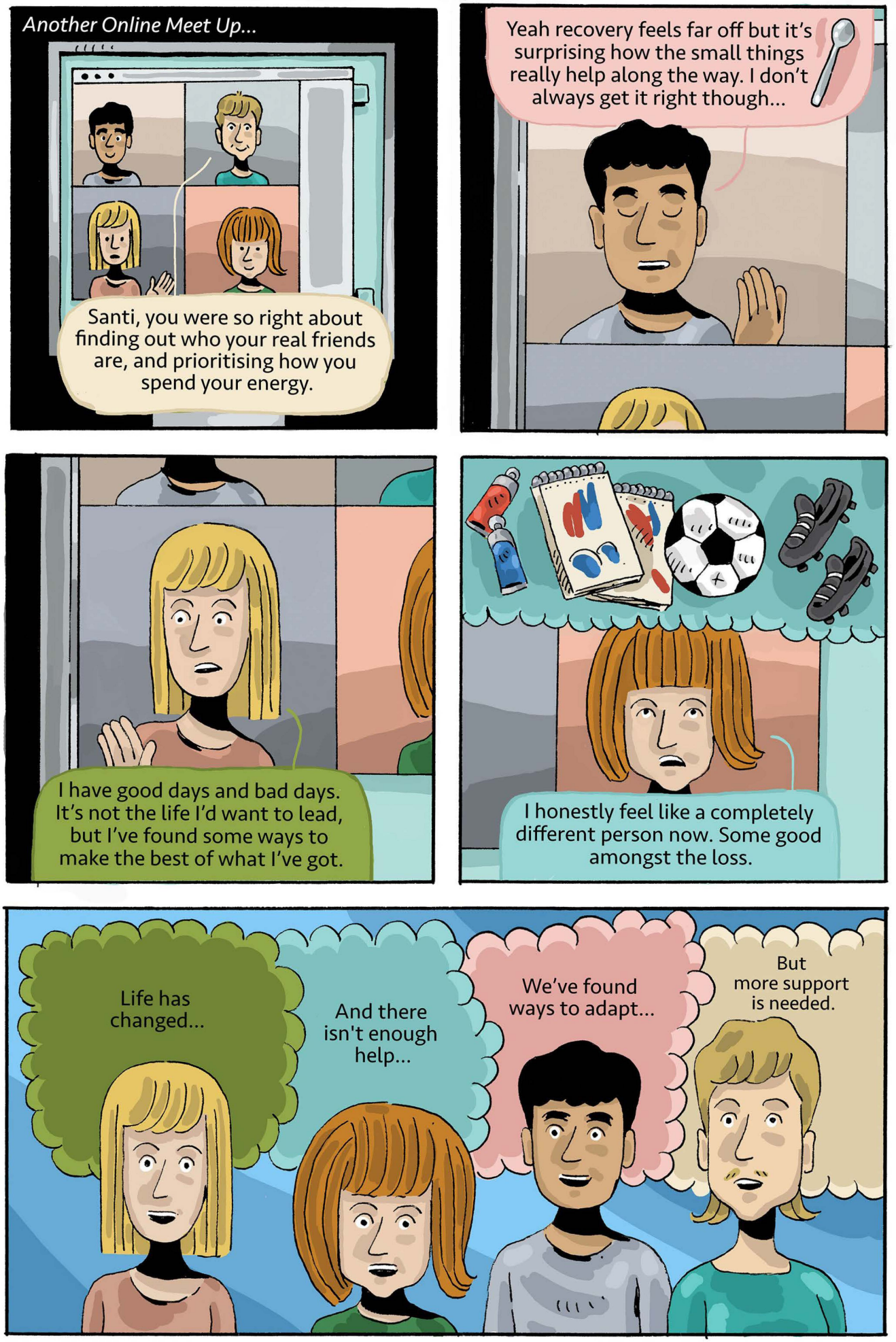

You'd better make it to my birthday party this weekend Rowan!


The weekend...
I'm so sorry...
Not even for a bit?

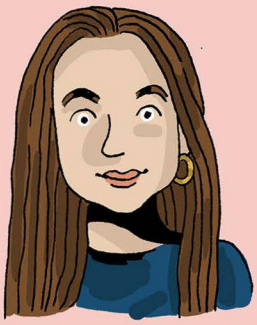

Later, Fred comes by...
Thought I'd come and see if you're okay...


Thanks for Covid testing, I pick everything up from the kids at work.
No worries.


Thanks for making the effort. Think I'll stop wasting time with people that don't get it.


Another Online Meet Up...
Santi, you were so right about finding out who your real friends are, and prioritising how you spend your energy.
Yeah recovery feels far off but it's surprising how the small things really help along the way. I don't always get it right though...
I have good days and bad days. It's not the life I'd want to lead, but I've found some ways to make the best of what I've got.
I honestly feel like a completely different person now. Some good amongst the loss.
Life has changed...
And there isn't enough help...
We've found ways to adapt...
But more support is needed.

Long Covid Lives was made with:



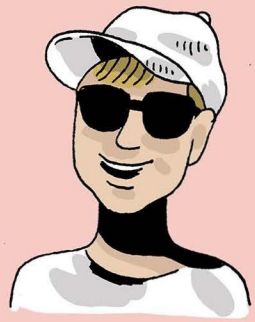
A.Haynes



Cal Bloodworth



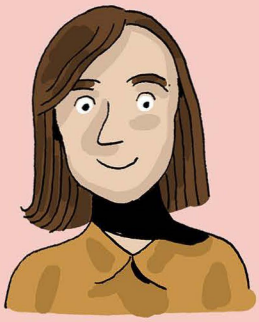
Eden Byrne



William George



Emily Miller



Hannah Cowan



Juliette Gunn-Roberts



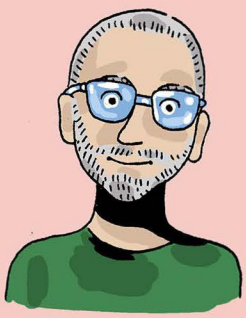
Zaira Clarke



Lucinda Leal



Praveena Fernes



Tim Rhodes



Daniel Locke



Benjamin Worku-Dix

Long Covid Lives

Credits

Produced from research by:
Covid Made Long Project, London School of Hygiene and Tropical Medicine

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Production
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Stories Drawn from Research
www.positivenegatives.org
@PosNegOrg

Long Covid Lives is a three-part graphic series which explores the lived experiences of young people living with Long Covid. It is based on a research project where young people were interviewed about their experiences. Our research shows that young people living with Long Covid can struggle to access care and support as well as to have their voices heard.

Part One explores the difficulties young people experiencing a range of ongoing symptoms face in being believed and accessing care and support. Part Two explores the multiple, varying impacts of Long Covid and the pandemic on young people's lives, and how the care available is often fragmented, failing to see young people's illness experience as a whole. Part Three explores how, despite the challenges of chronic illness, young people adapt and remake their worlds in order to live with Long Covid.

Long Covid Lives has been illustrated by Daniel Locke and produced by PositiveNegatives from research undertaken by the Covid Made Long Project at the London School of Hygiene and Tropical Medicine in partnership with Imperial College London, Long Covid Kids, and Long Covid Support.

Visit: www.lshtm.ac.uk/research/centres-projects-groups/covid-made-long
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See our lived experience glossary:
www.lshtm.ac.uk/research/centres-projects-groups/covid-made-long#lived-experience-resources

