



LONG COVID LIVES

An illustrated story series about young people living with Long Covid



LONG COVID LIVES

Chapter 1 of 3

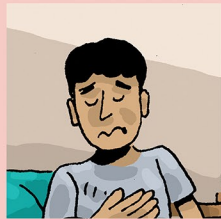
Long Covid Lives

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.



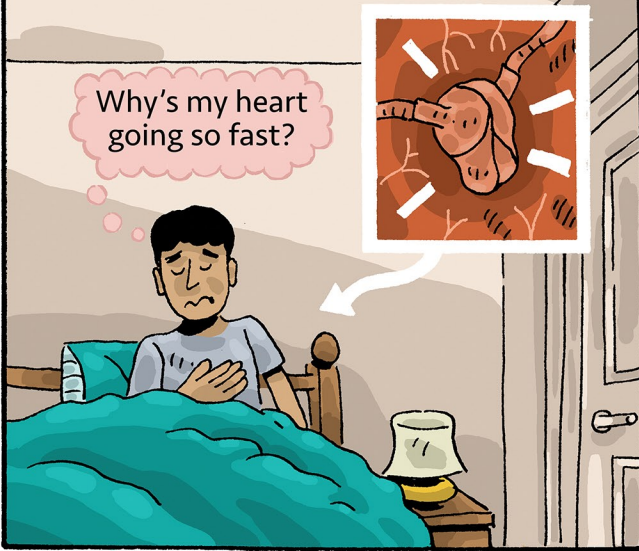
Rowan: Rowan (they/them) is a White British, 23-year old nursery practitioner living in shared housing. They are experiencing long-term symptoms from Covid-19 including chronic fatigue, dizziness, and nausea and face a high risk of getting ill again because of their work and living situation. They are 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.

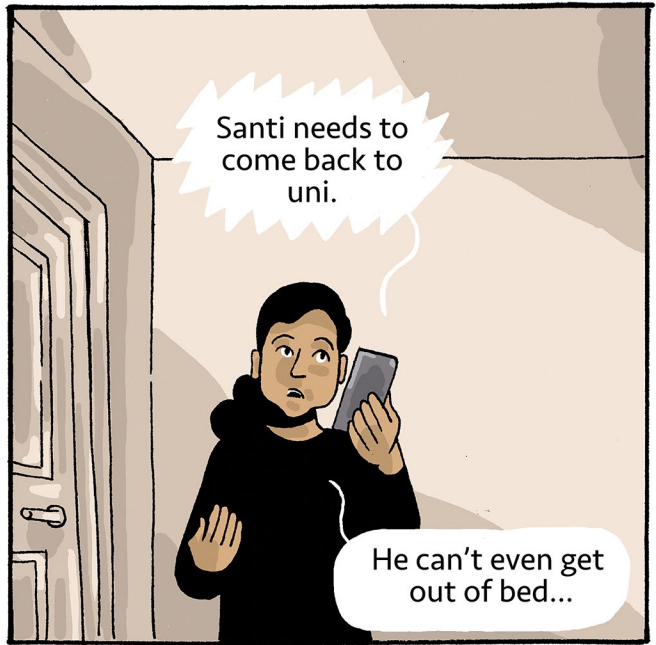
Content warning: *This chapter contains stories relating to illness experience, medical gaslighting, inaccessibility to trans healthcare, misgendering, and financial difficulties. The things said by characters (including doctors) relate to real experiences, but do not constitute medical advice. For advice 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...



Santi needs to come back to uni.

He can't even get out of bed...



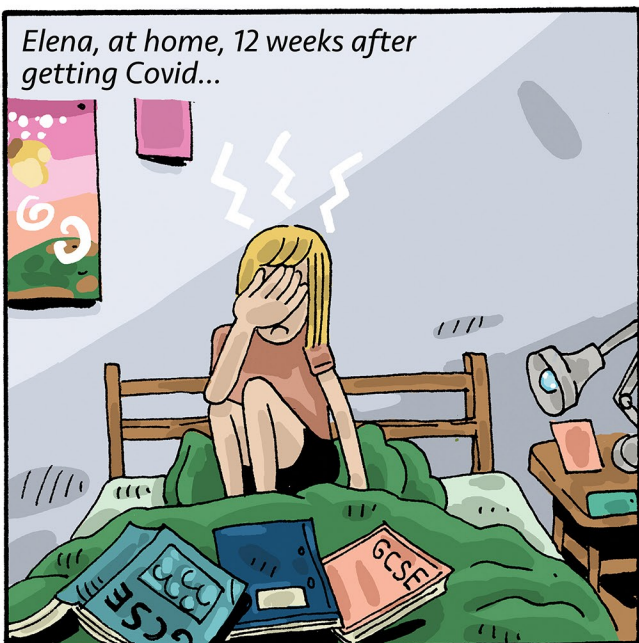
Rowan, at work, 12 weeks after getting Covid...



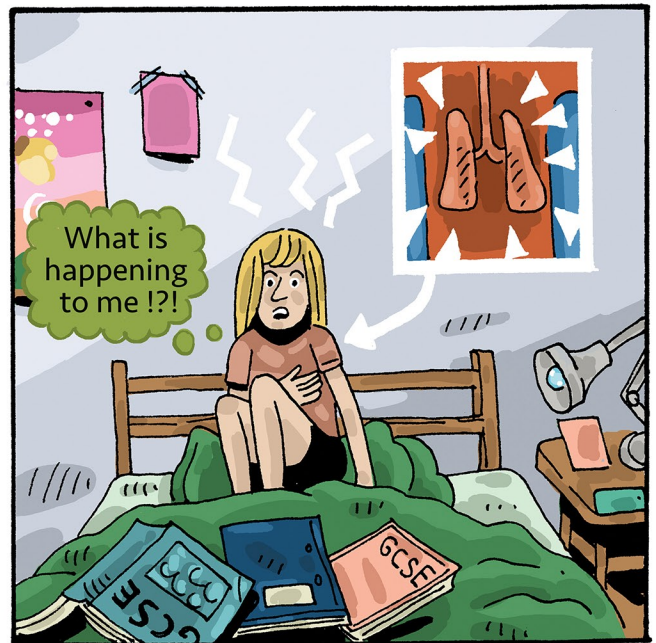
I think I need to sit down for a minute... I'm feeling really weird.

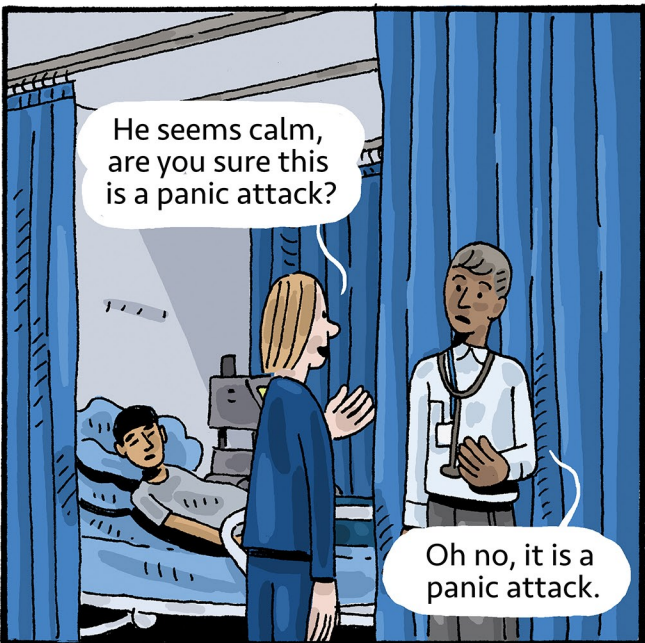
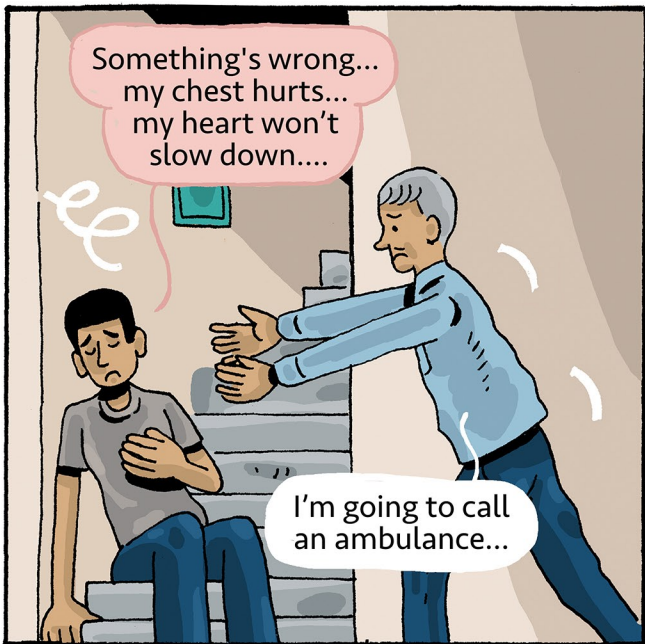
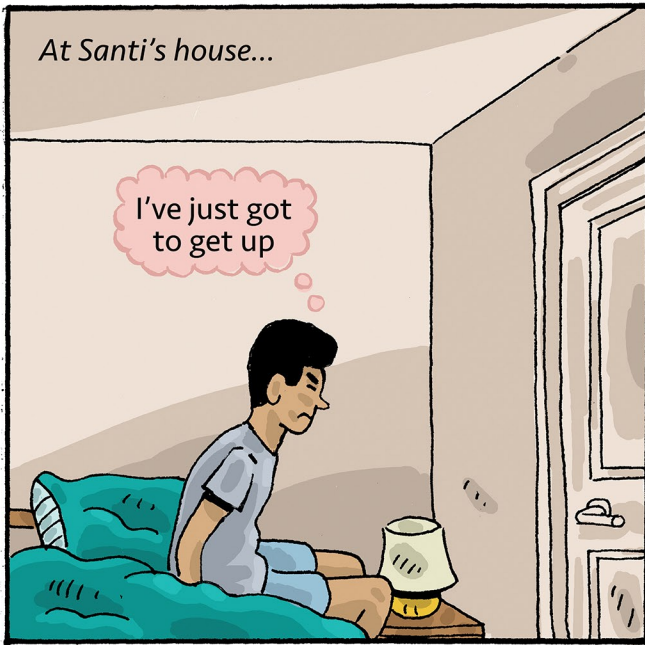


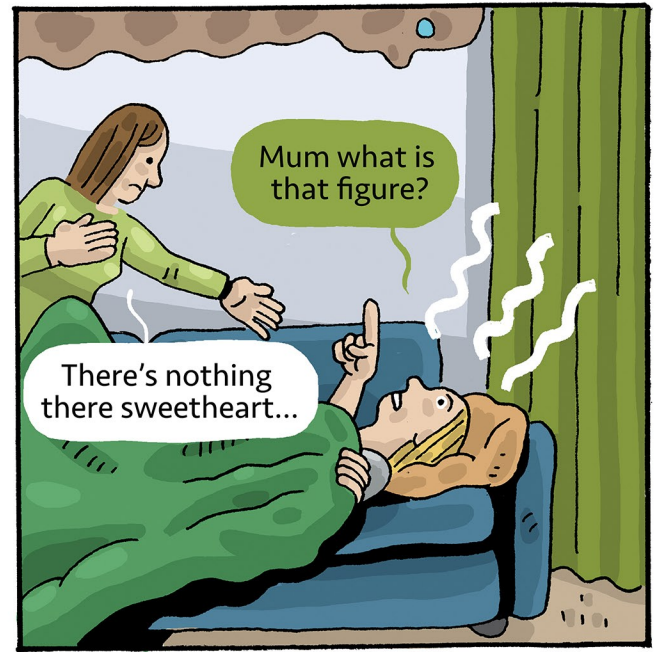
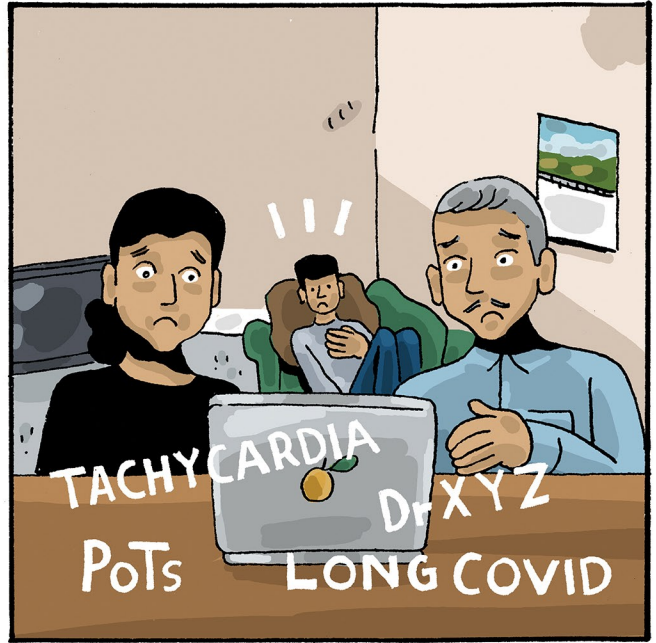
Elena, at home, 12 weeks after getting Covid...



What is happening to me !?!







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...

Try these anti-depressants. I'll put you on the waiting list for therapy.

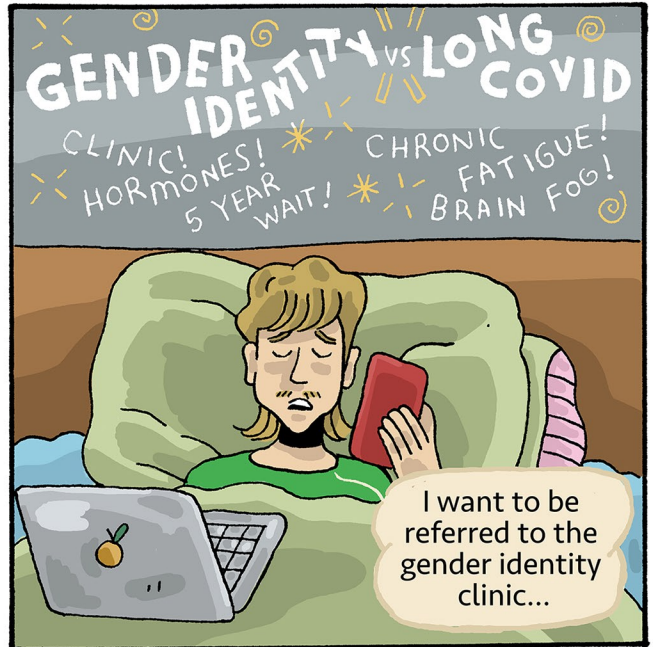
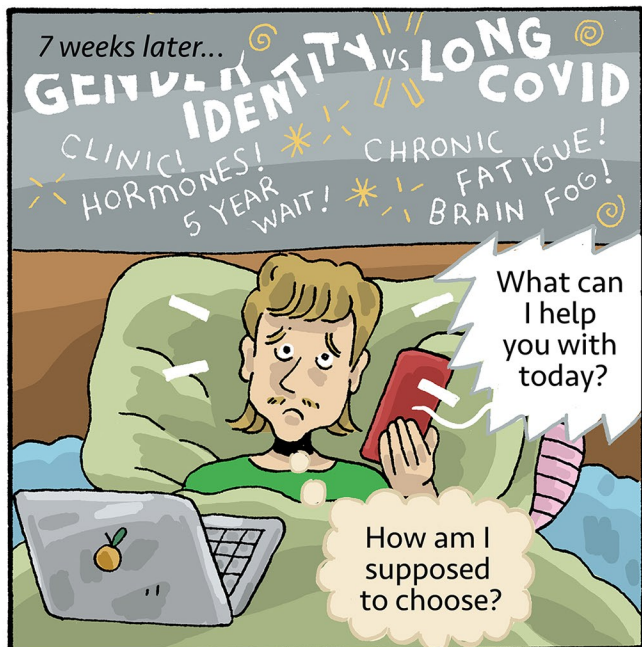
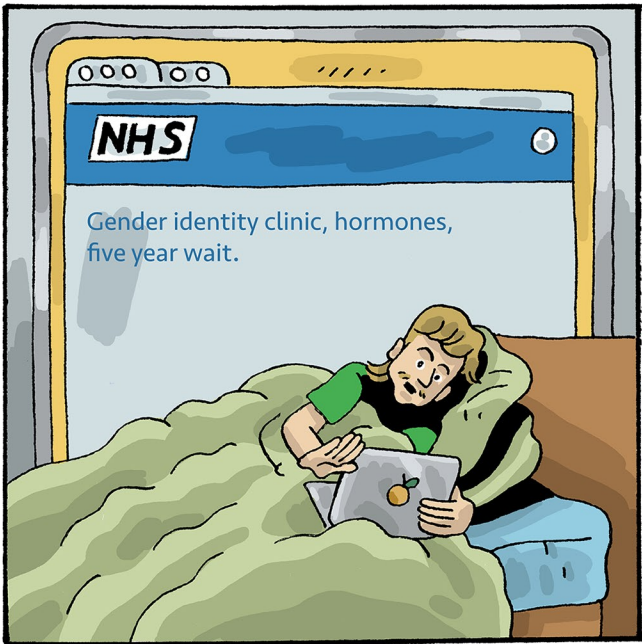
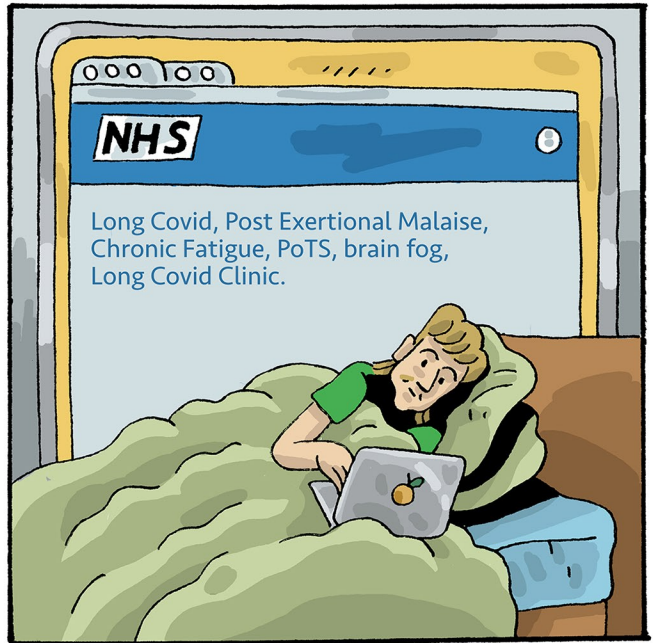
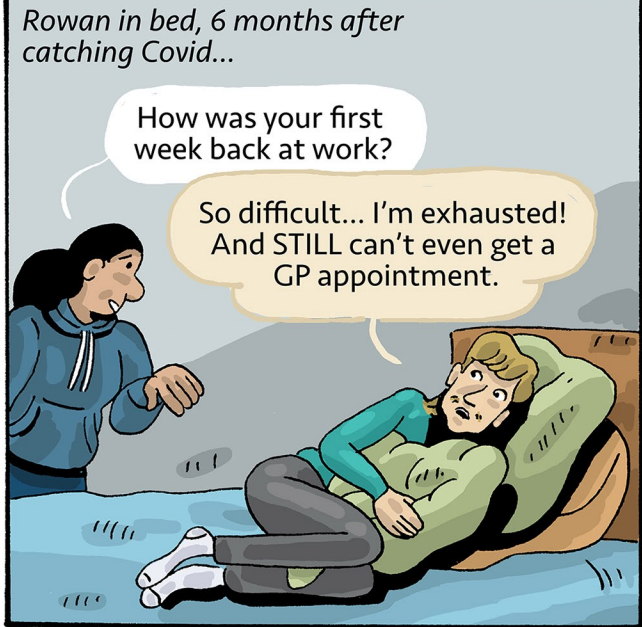
And... has Elena been assessed for autism?

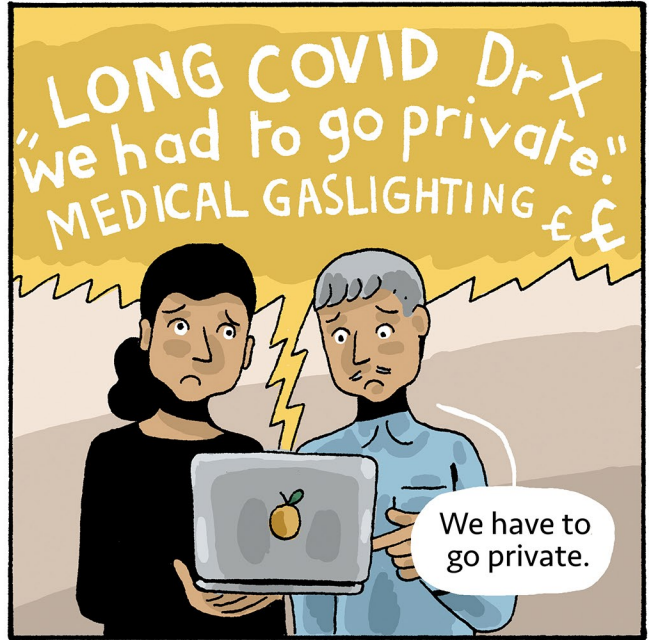
Sorry, what has this got to do with Covid?

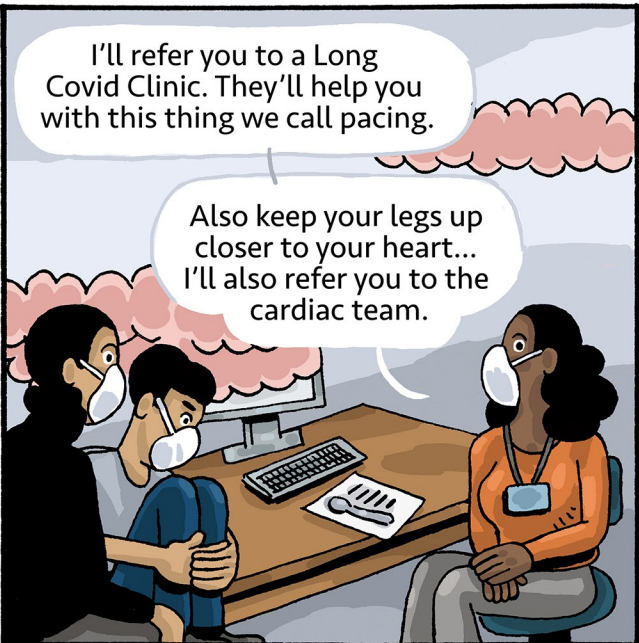
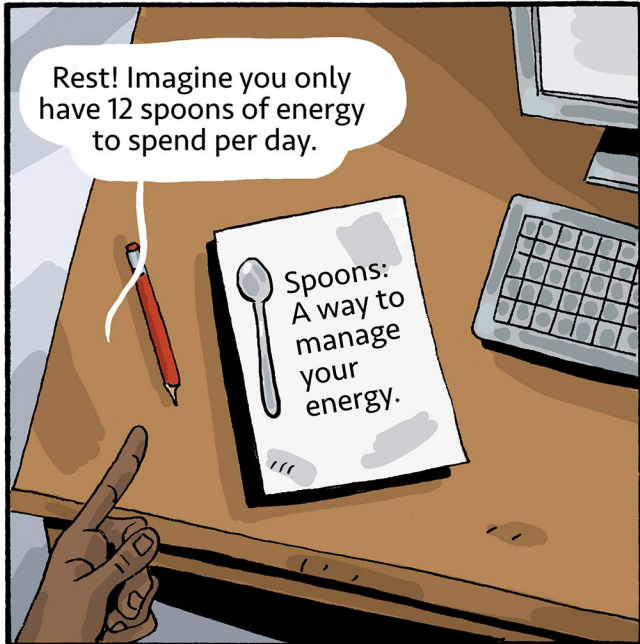
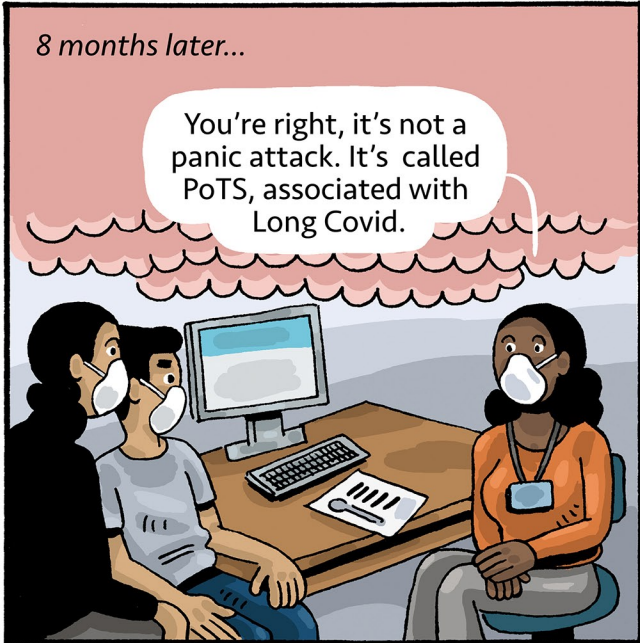
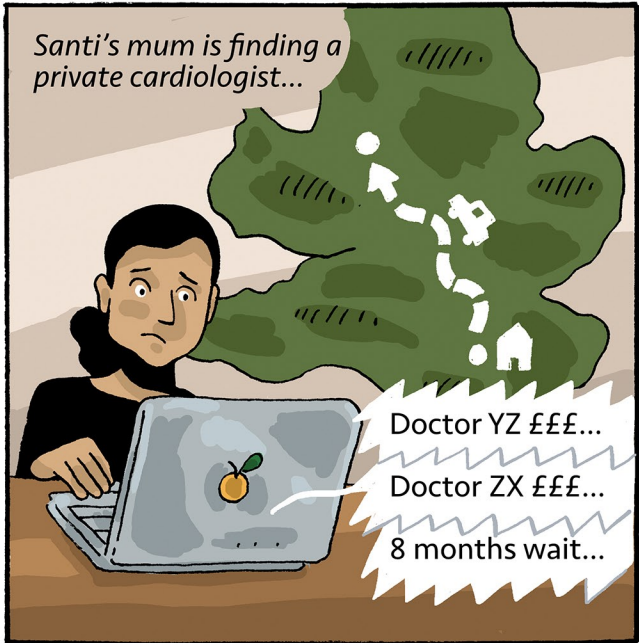
Young people aren't affected by Covid.

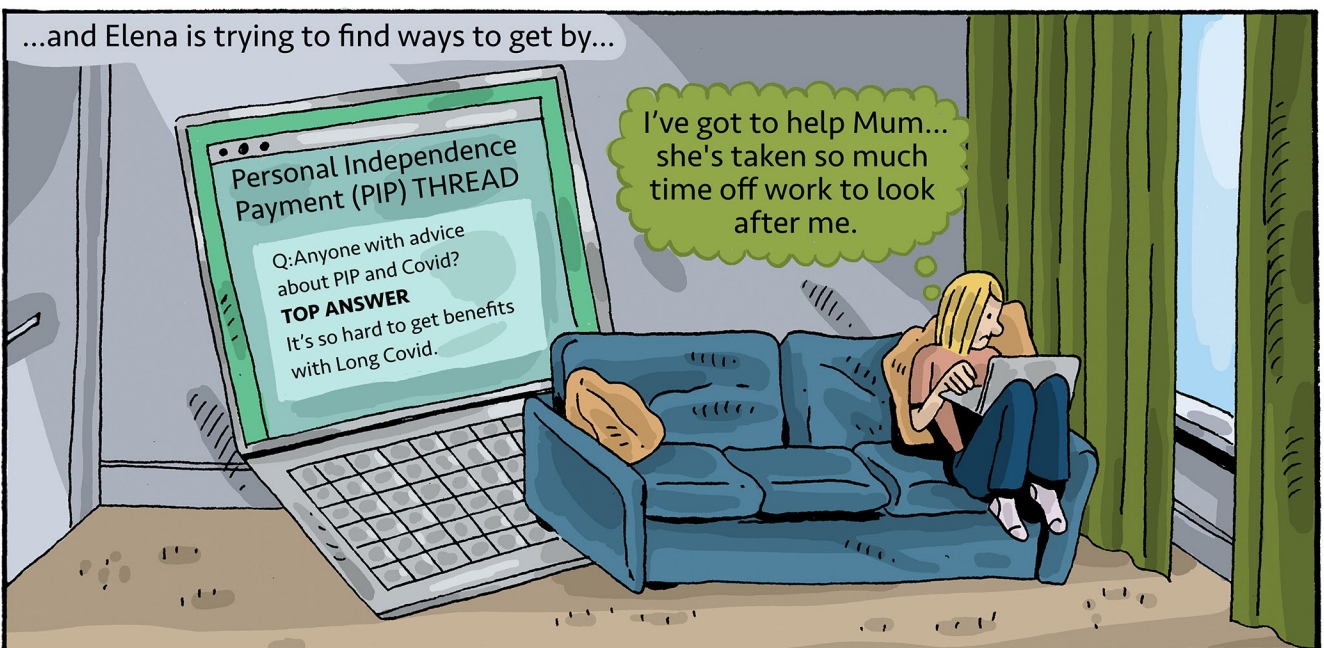
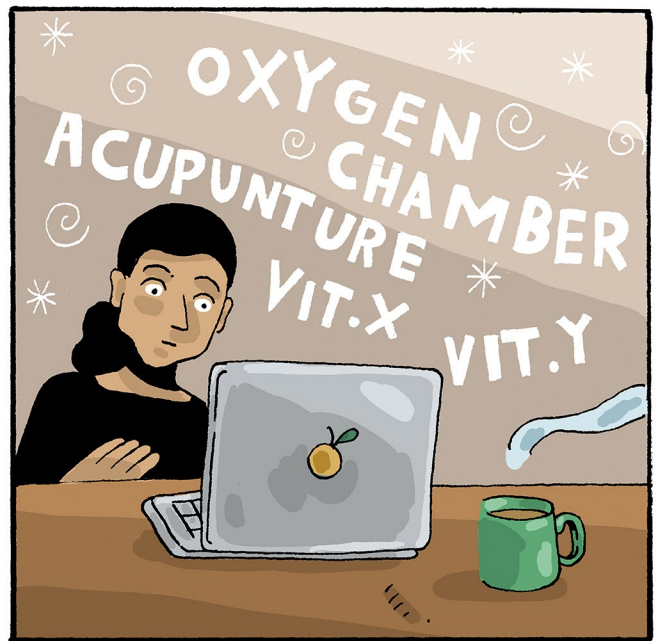
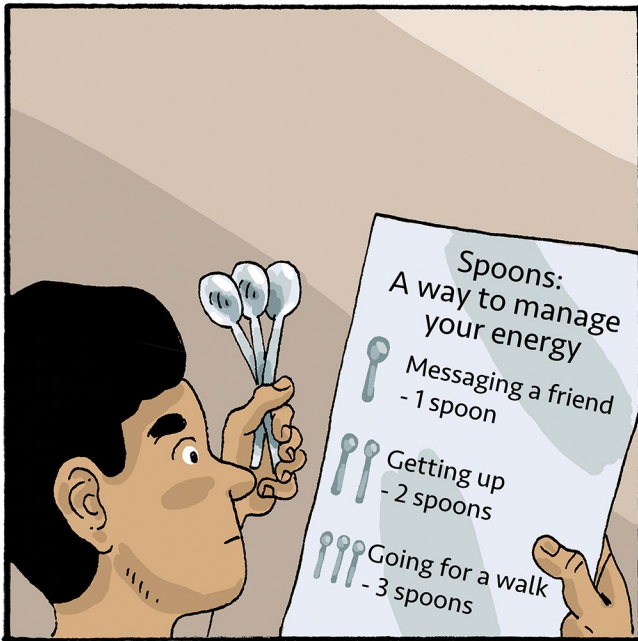
Are you sure giving counselling a go wouldn't help? All this time I'm taking off work is getting tricky financially...

?!?!?











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.

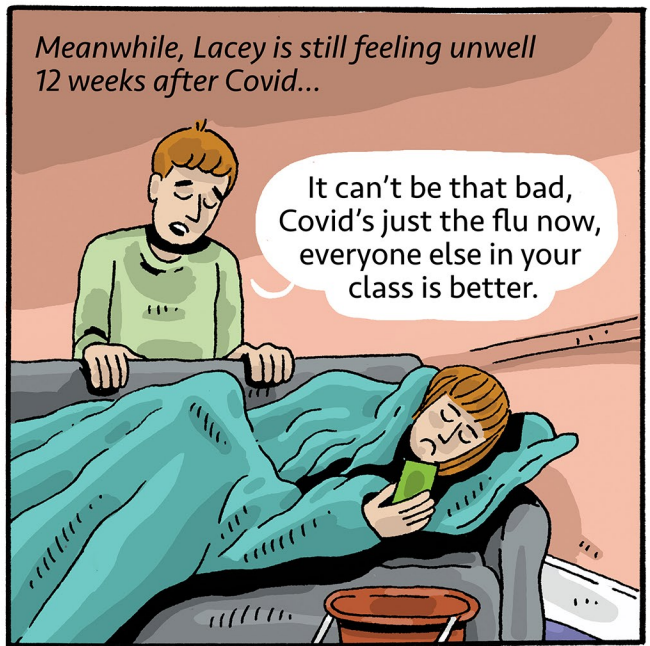
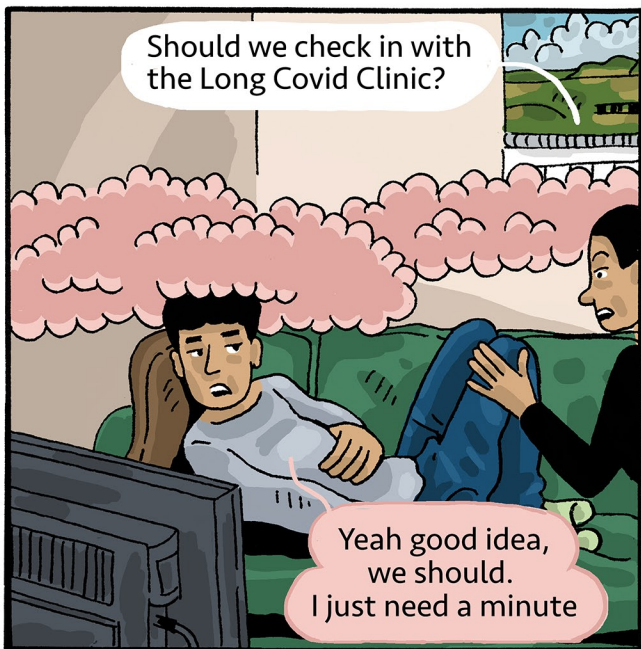
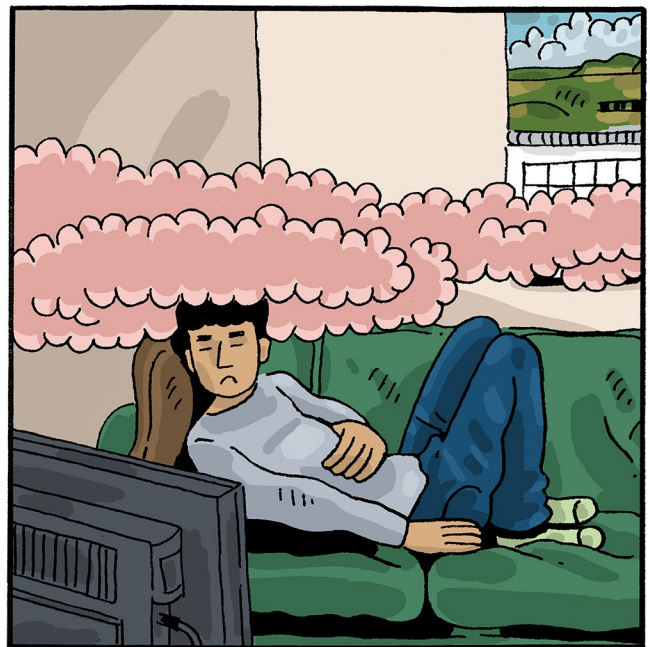


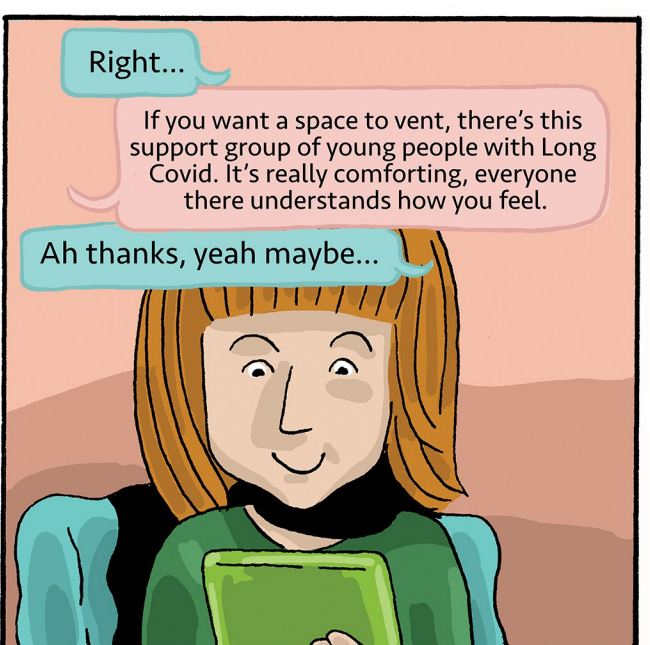
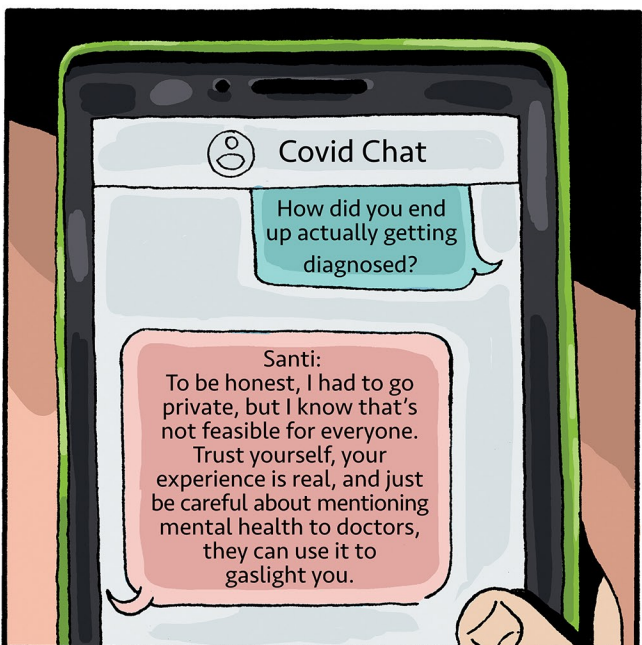
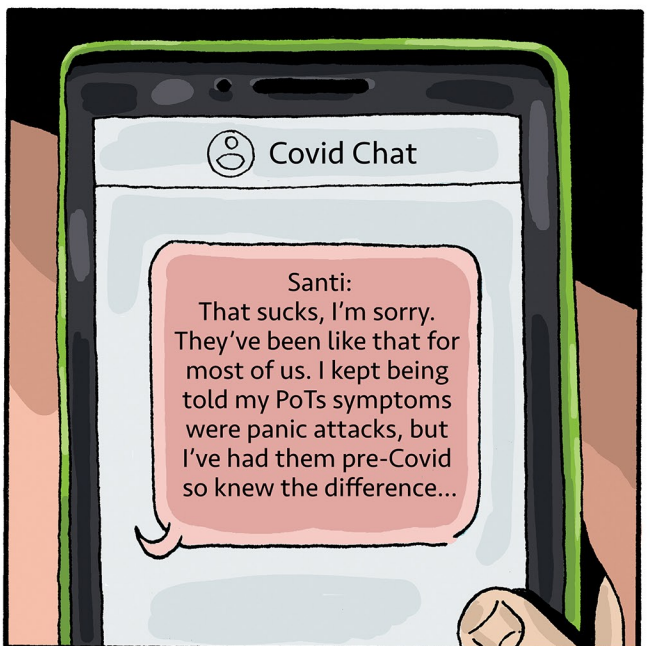
Elena: Elena (she/her) struggled to access any support for her experience of Long Covid, and her single mum couldn't afford to take her to private care. **This time**, Elena joins an online group of young people with Long Covid to gain some peer support.

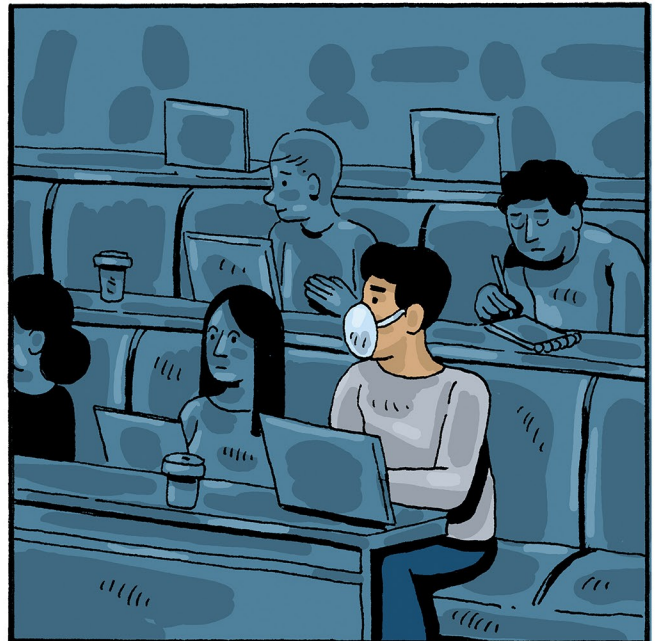


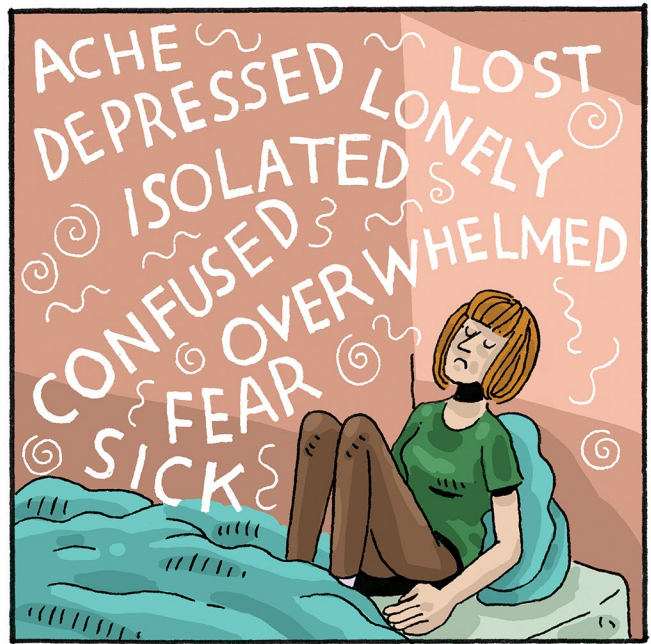
Lacey: **This time** we are also introduced to Lacey (she/her) who is a 17-year-old British European student who has taken time out of A-Levels because of long term symptoms from Covid-19, including chronic fatigue, allergies, and stomach issues which cause sickness. She feels gaslighted because the 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.*

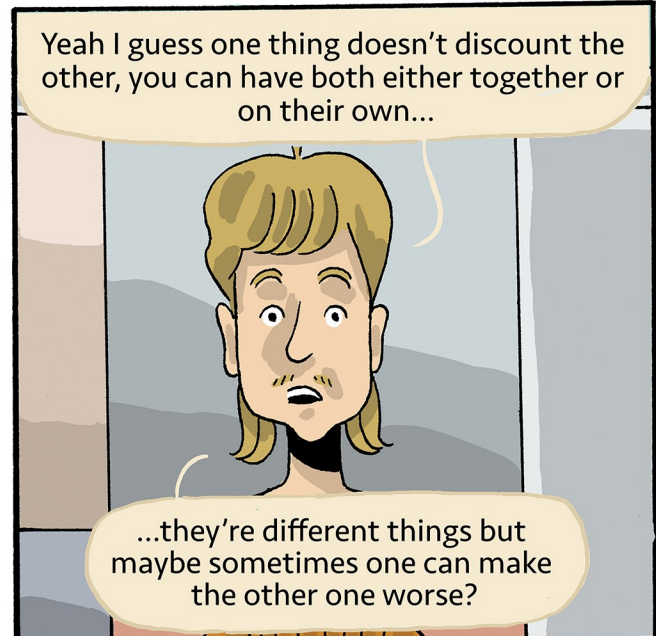
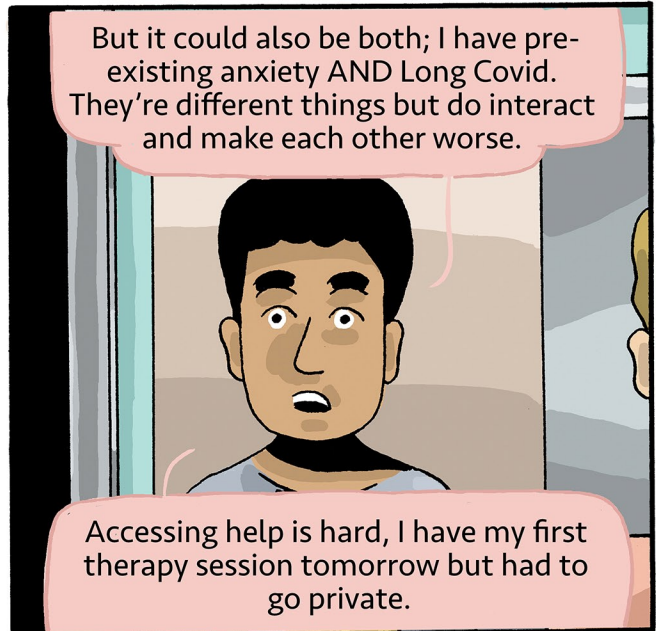
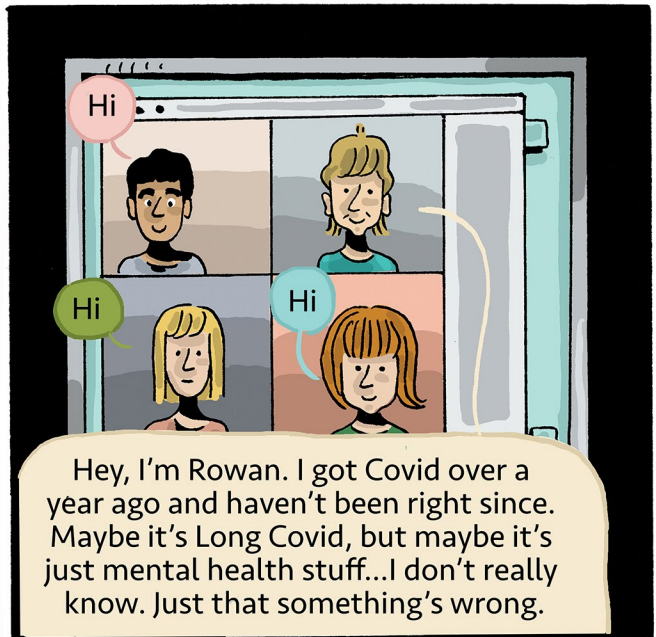
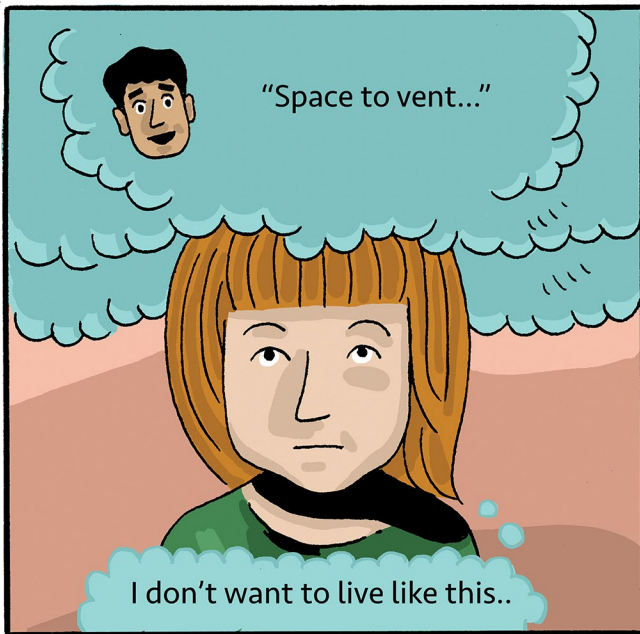




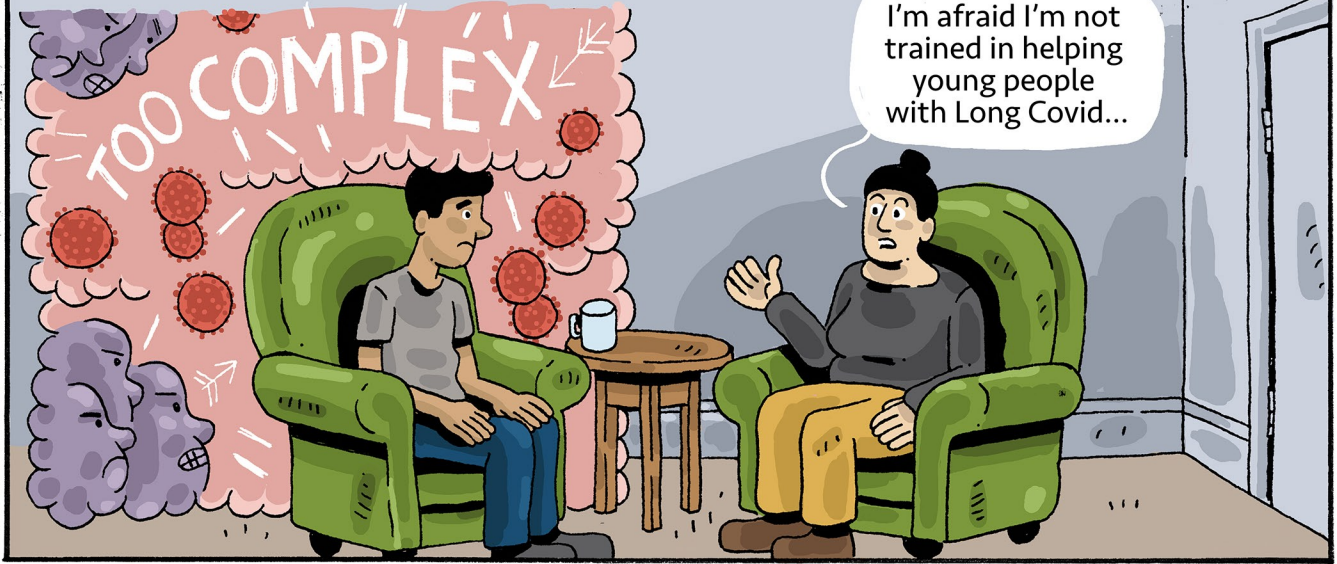




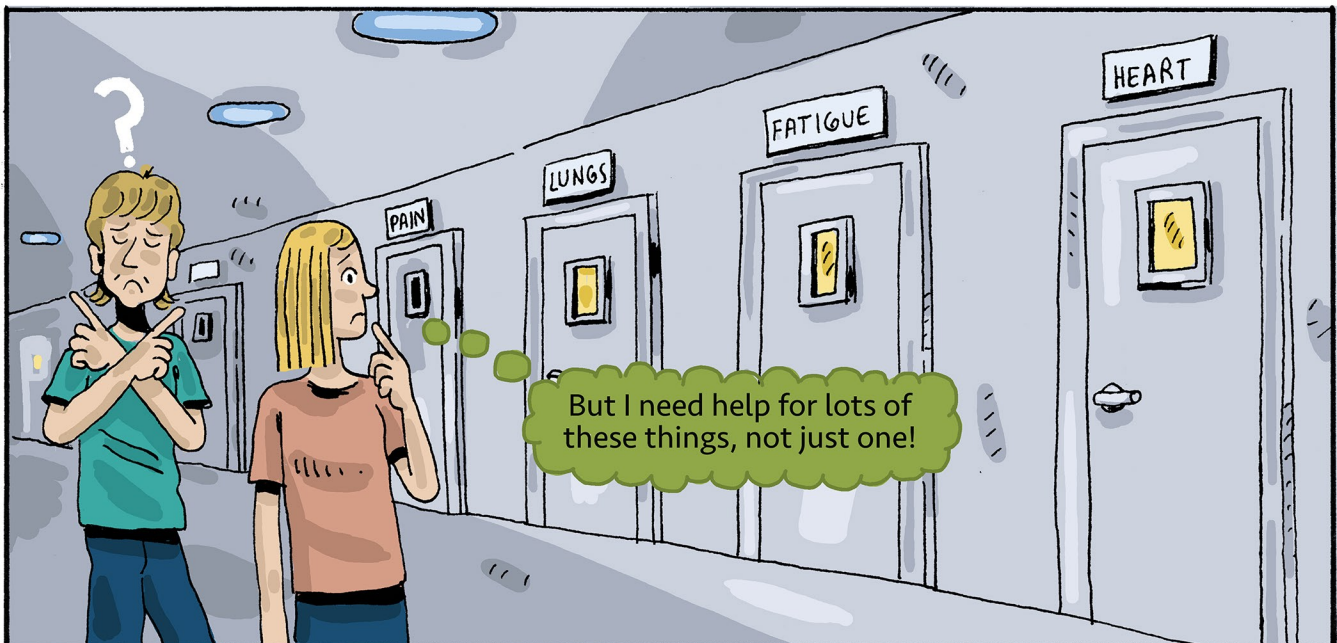


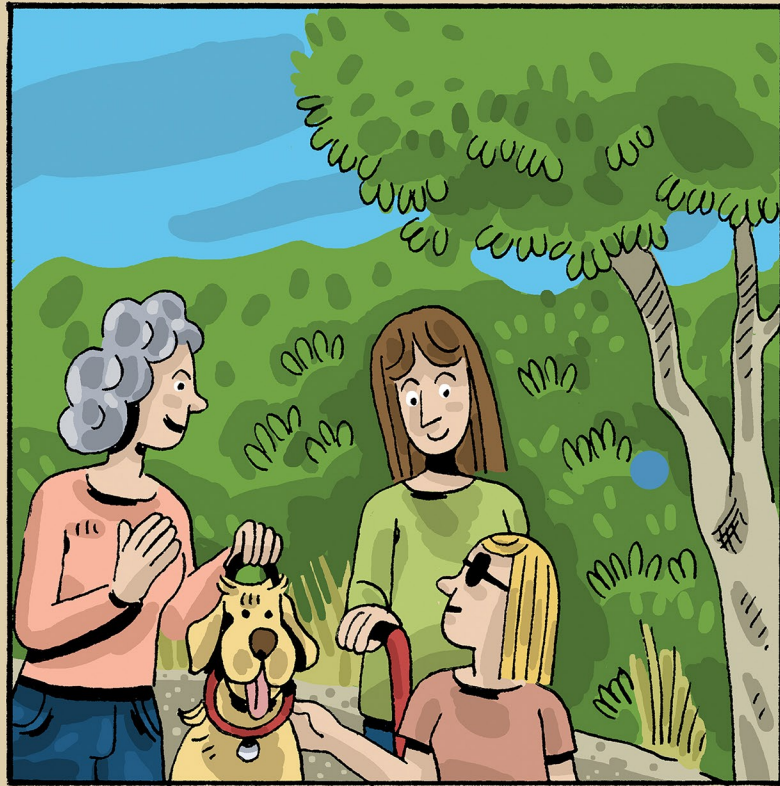


Santi in therapy, unable to talk about Long Covid.



Lacey in the Long Covid Clinic, unable to talk about anxiety and depression.





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.

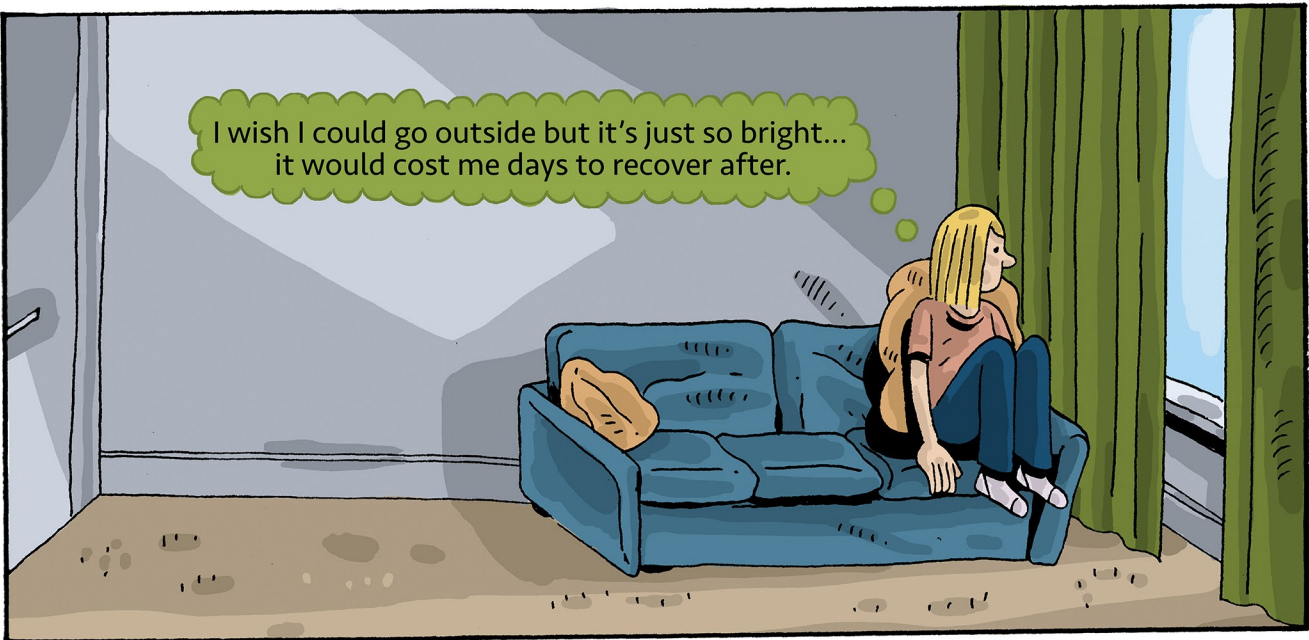


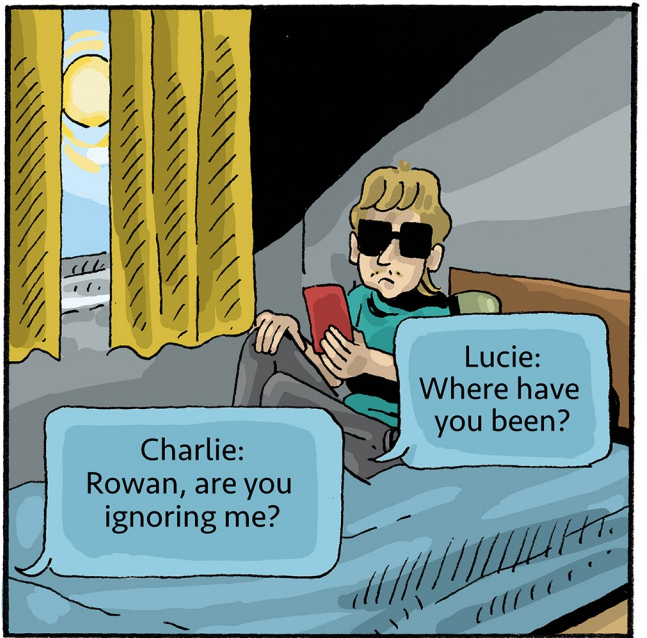
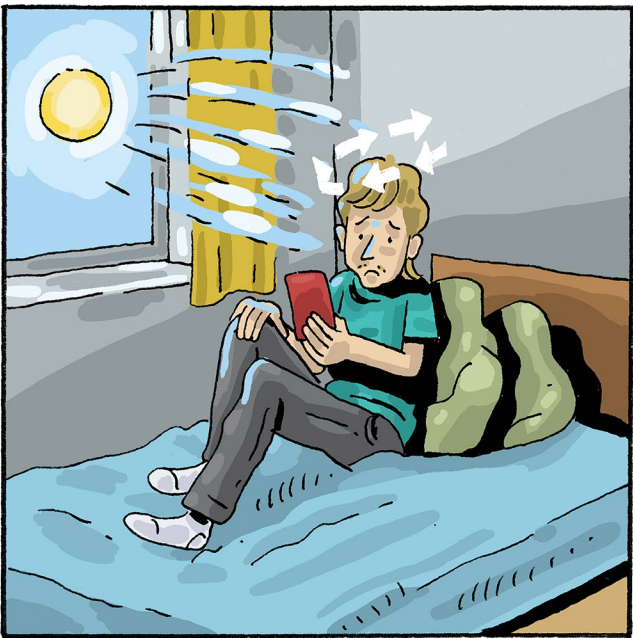
Lacey: Lacey (she/her) finally got a Long Covid diagnosis, but only after feeling gaslighted by doctors in A&E and having to hide any experience of anxiety and depression that came about as a result of experiencing chronic illness. **This time**, Lacey questions her identity now she can't do the things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

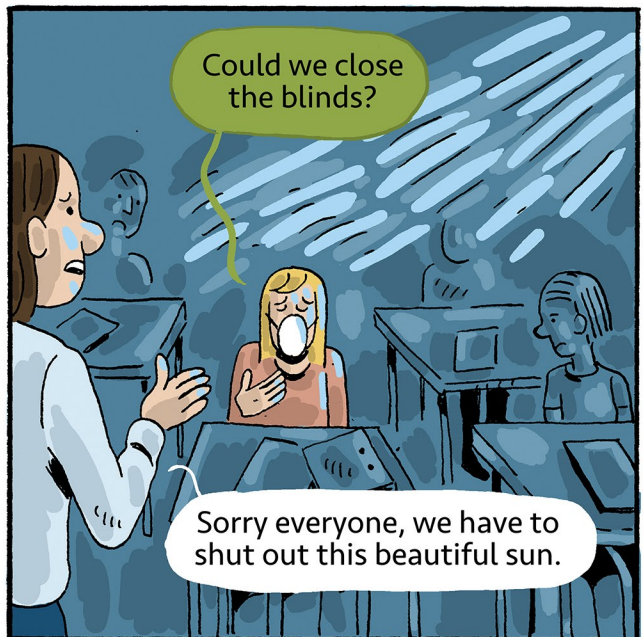
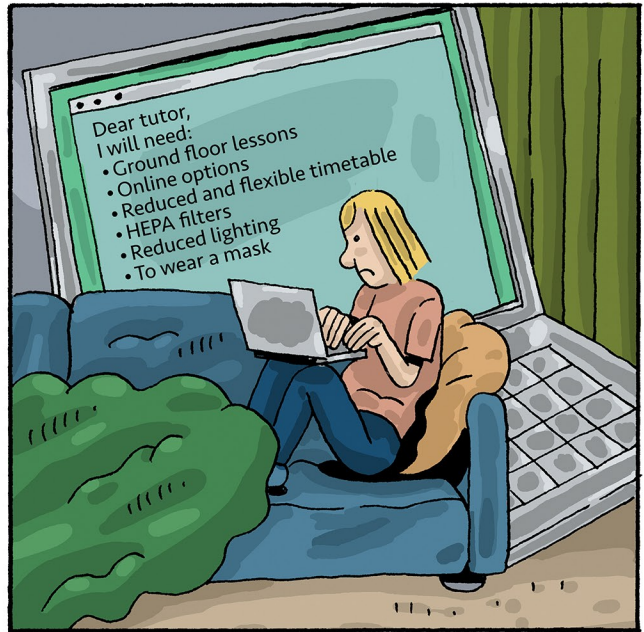
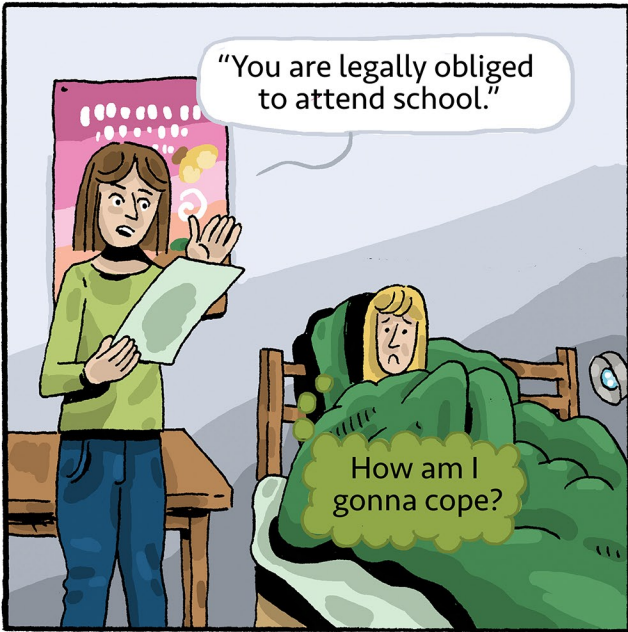


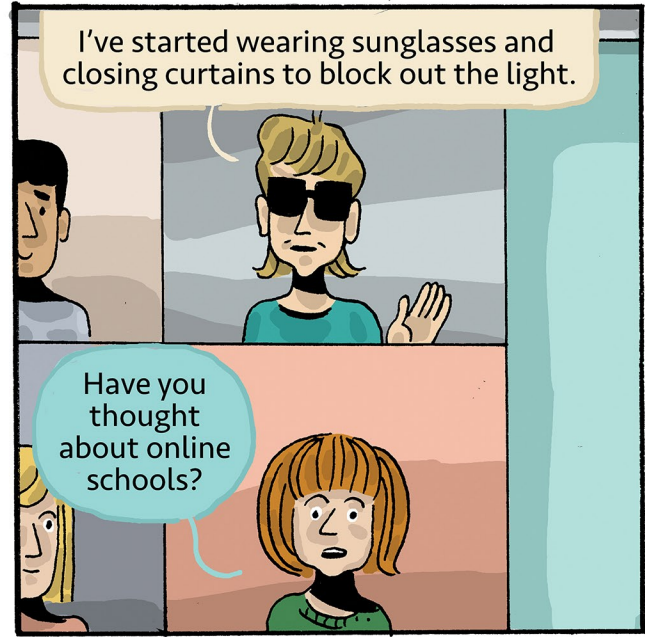
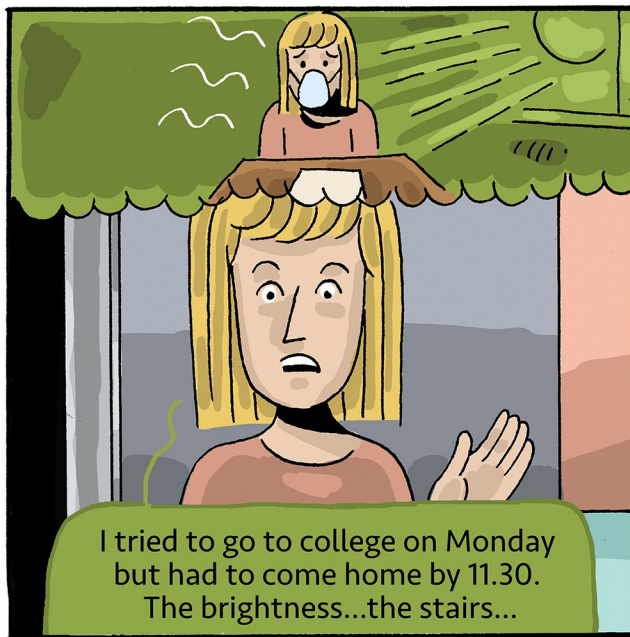
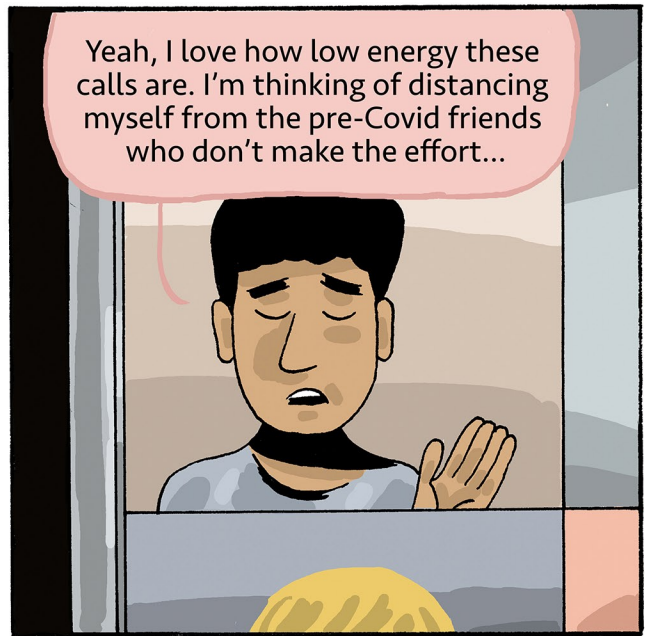
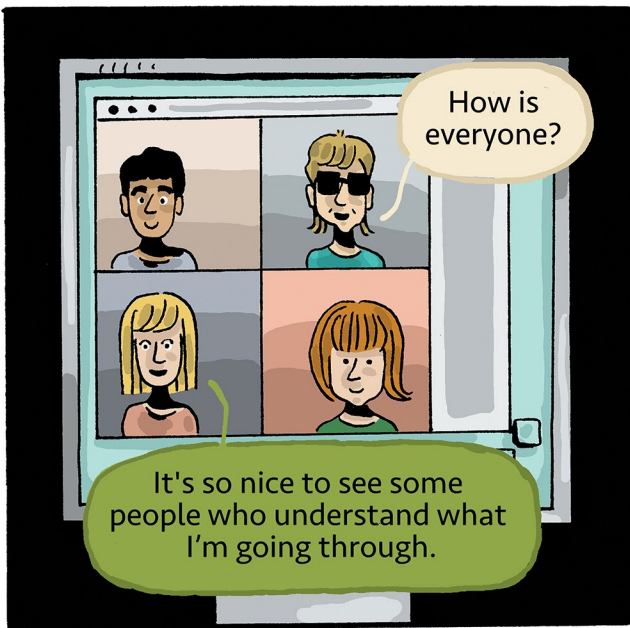
Santi: Santi (he/him) learnt the difficulties of managing the dual impact of mental health and chronic ill health and **this time** meets the others online and shares what he has learnt living with Long Covid.

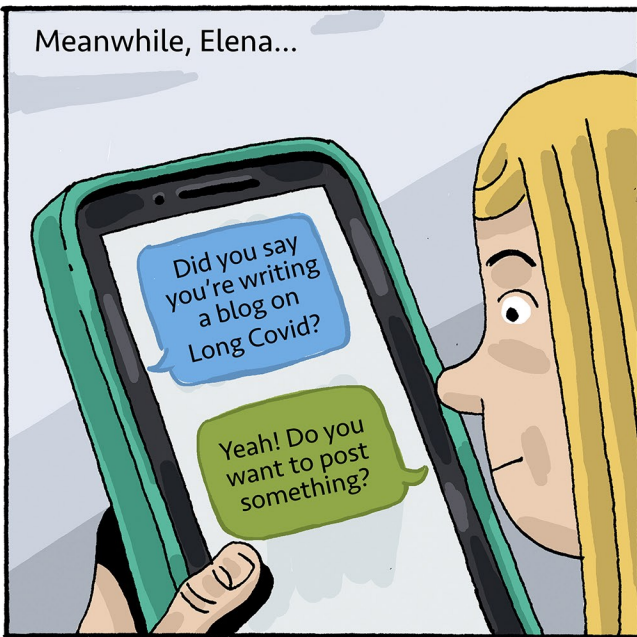
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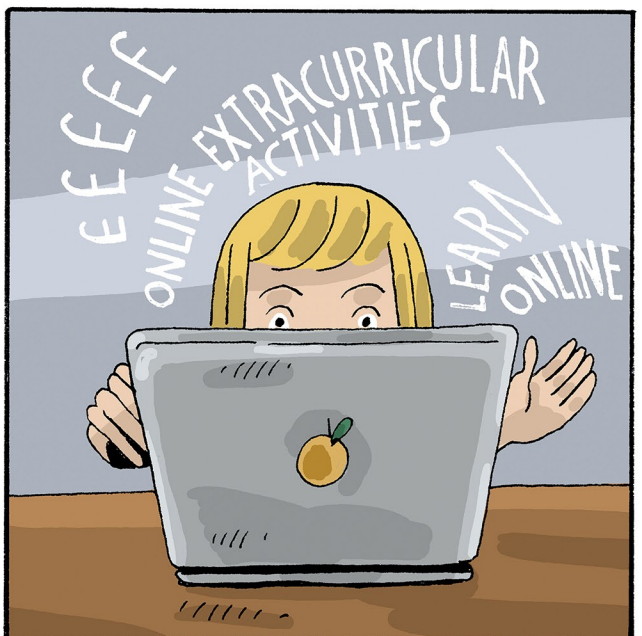
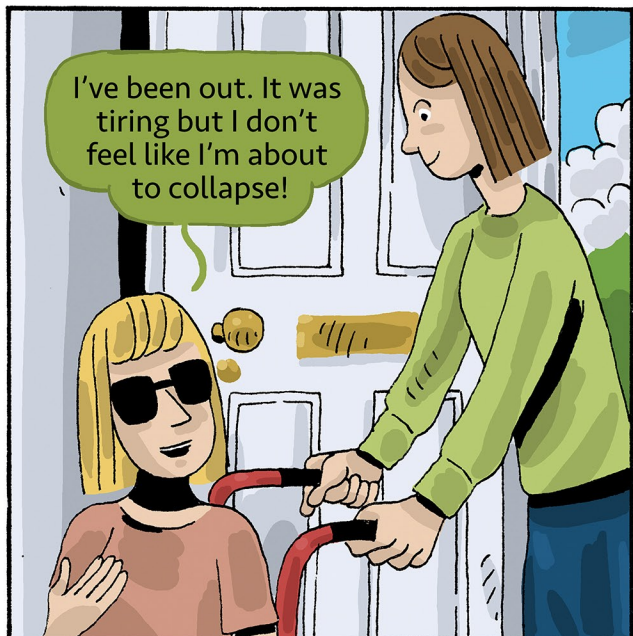
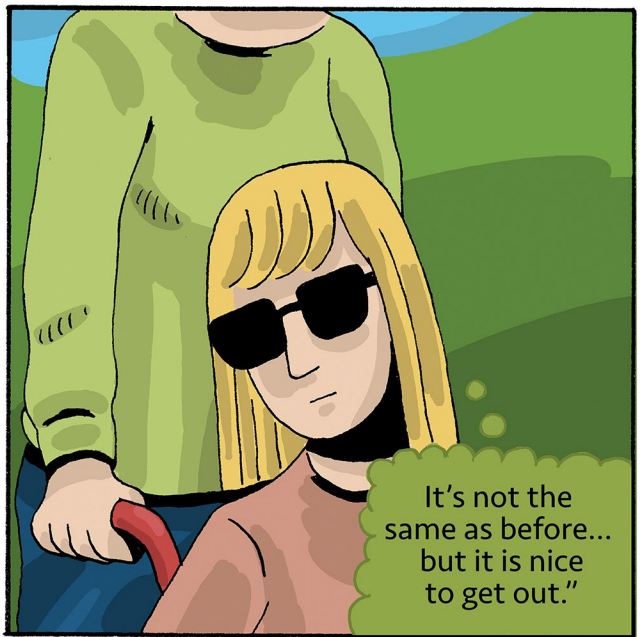
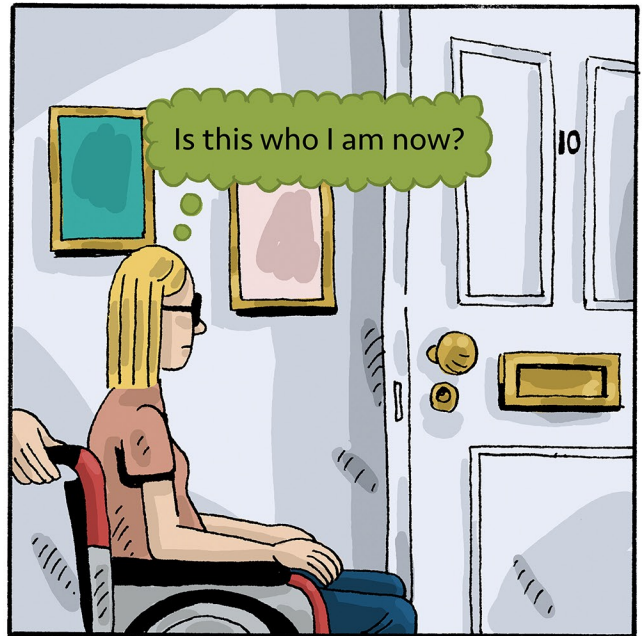


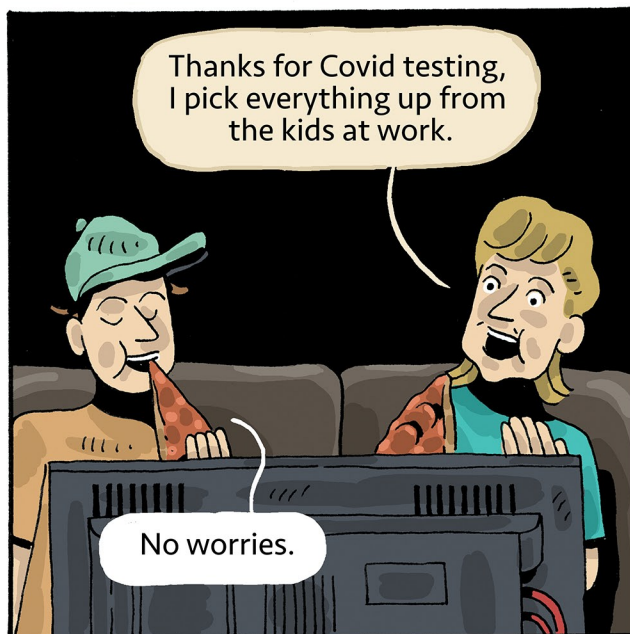




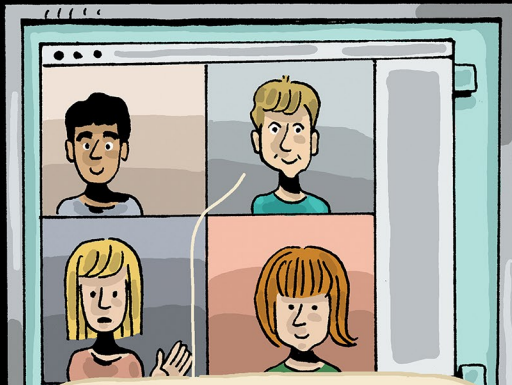






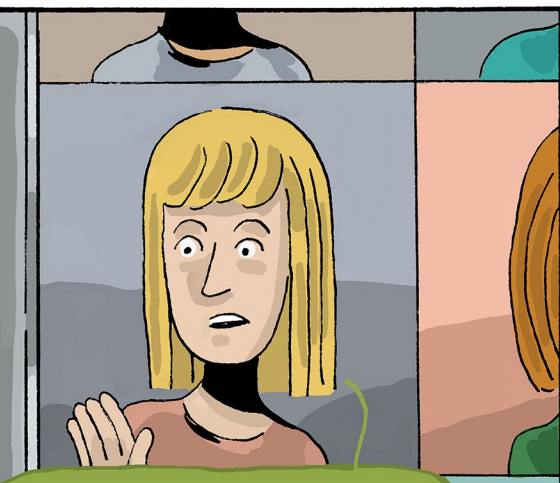


Another Online Meet Up...

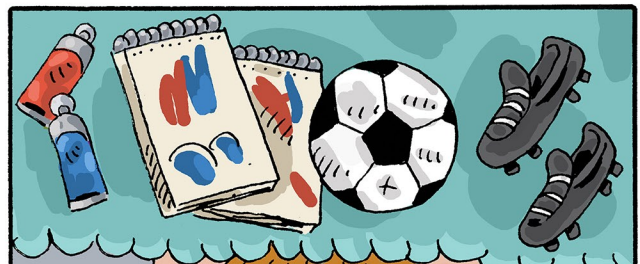


Santi, you were so right about finding out who your real friends are, and prioritising how you spend your energy.

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...

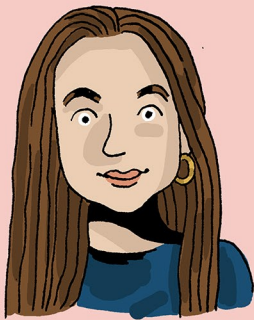


We've found ways to adapt...



But more support is needed.

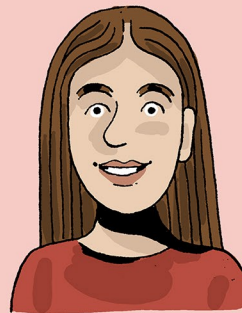
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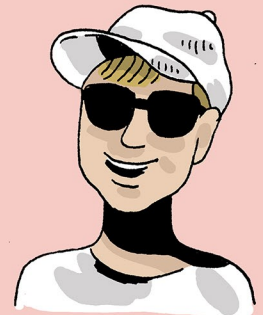
A. Haynes



Cal Bloodworth



Eden Byrne



William George



Emily Miller



Hannah Cowan



Juliette Gunn-Roberts



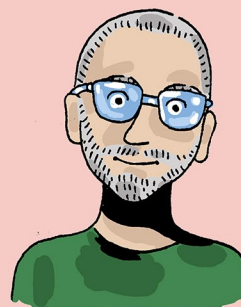
Zaira Clarke



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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Special Thanks to

Sammie McFarland and Kirsty Stanley at Long Covid Kids.

Funded by

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In Partnership with

Long Covid Kids and Long Covid Support, and Imperial College London



Produced By



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

Contact: Tim.Rhodes@lshtm.ac.uk

See our lived experience glossary:

www.lshtm.ac.uk/research/centres-projects-groups/covid-made-long#lived-experience-resources

