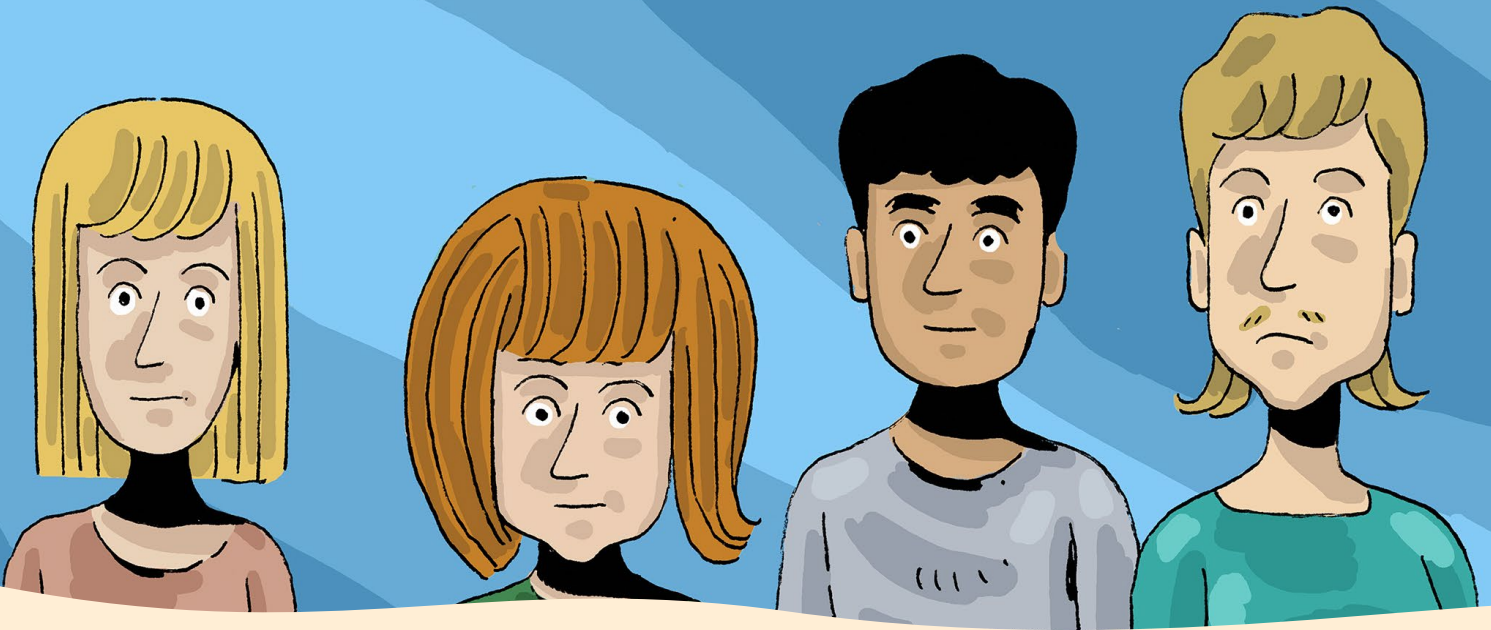


# Living with Long Covid: *A Young Person's Guide*



# About this guide



## Why did we write this guide?

**We are a group of young people living with Long Covid who have worked with health researchers to develop a guide on Long Covid from a young person's perspective.**

Long Covid is an ongoing chronic condition following a Covid-19 infection. It can involve a wide range of symptoms and affects everyone differently. As it is a relatively new illness, knowledge about it is still developing and lots of people don't realise that young people get Long Covid too.

Younger people are discredited from having a chronic illness because it's not something that young people are viewed to have. There's just like super denial that illnesses can affect any age.

**Rilee, Aged 25**



**We have produced this guide for young people with Long Covid, and the people in their lives.**

Young people affected by Long Covid today face a lot of uncertainties and challenges. This can make us feel alone and misunderstood. But we want young people experiencing it to know that this is a real illness and that other young people out there are finding ways to navigate Long Covid. We want other people to understand how Long Covid affects us, and what they can do to make things easier.

**This isn't a medical guide but focuses on what it's like to live with Long Covid as a young person.**

This guide is written in the words of young people, drawing on research interviews and consultation sessions with Peer Researchers with lived experience of Long Covid. All the anonymised stories and examples in the guide are based on the experiences of young people aged 15-25 who have participated in the 'Covid Made Long' study.

**Our experiences of Long Covid are not all the same, and this is part of the challenge.**

This guide represents a range of perspectives and experiences but doesn't cover everything there is to know about Long Covid.

You can find places for more information about Long Covid and support on the **Resources** pages at the back of this guide (28-29).



# The things that we want people to know are...

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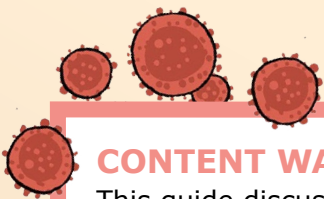
Access to support and  
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\* *An ally is someone who supports and stands up for young people with Long Covid, even if they haven't personally experienced it or the challenges that come with it.*



## **CONTENT WARNING**

This guide discusses some of the challenges of living with Long Covid, including lack of access to care and support, as well as mental health, social and financial impacts. Each section contains tips and tricks to help address these challenges. If you need additional support, see the Resources pages at the back of this guide (28-29).

# Long Covid is overwhelming

I was throwing up, I was passing out, I couldn't even speak because my stutter was so bad. So I actually went to the doctor, like, 'why is this happening in the first place?' and he was like, 'So, it's Long Covid'

*Kelly, Aged 23*

**"I have a miniscule amount of energy per day to work with"**

Long Covid is a constellation of ongoing symptoms following a Covid-19 infection. Common symptoms can include brain fog, fatigue, joint and muscle pain, breathlessness and stomach issues. This can feel like an overwhelming and confusing set of symptoms to navigate. People's experiences of Long Covid vary. It's a dynamic condition, so symptoms can come and go and change over time.

A lot of us experience fatigue or reduced energy levels. This feels like extreme tiredness, where you need to curl up and rest after doing everyday things which wouldn't have a big impact on most people's energy levels. This can make it difficult to balance daily activities, social life, and getting enough rest.

You can find out more about Long Covid symptoms, described in young people's own words, in our Lived Experience Glossary.

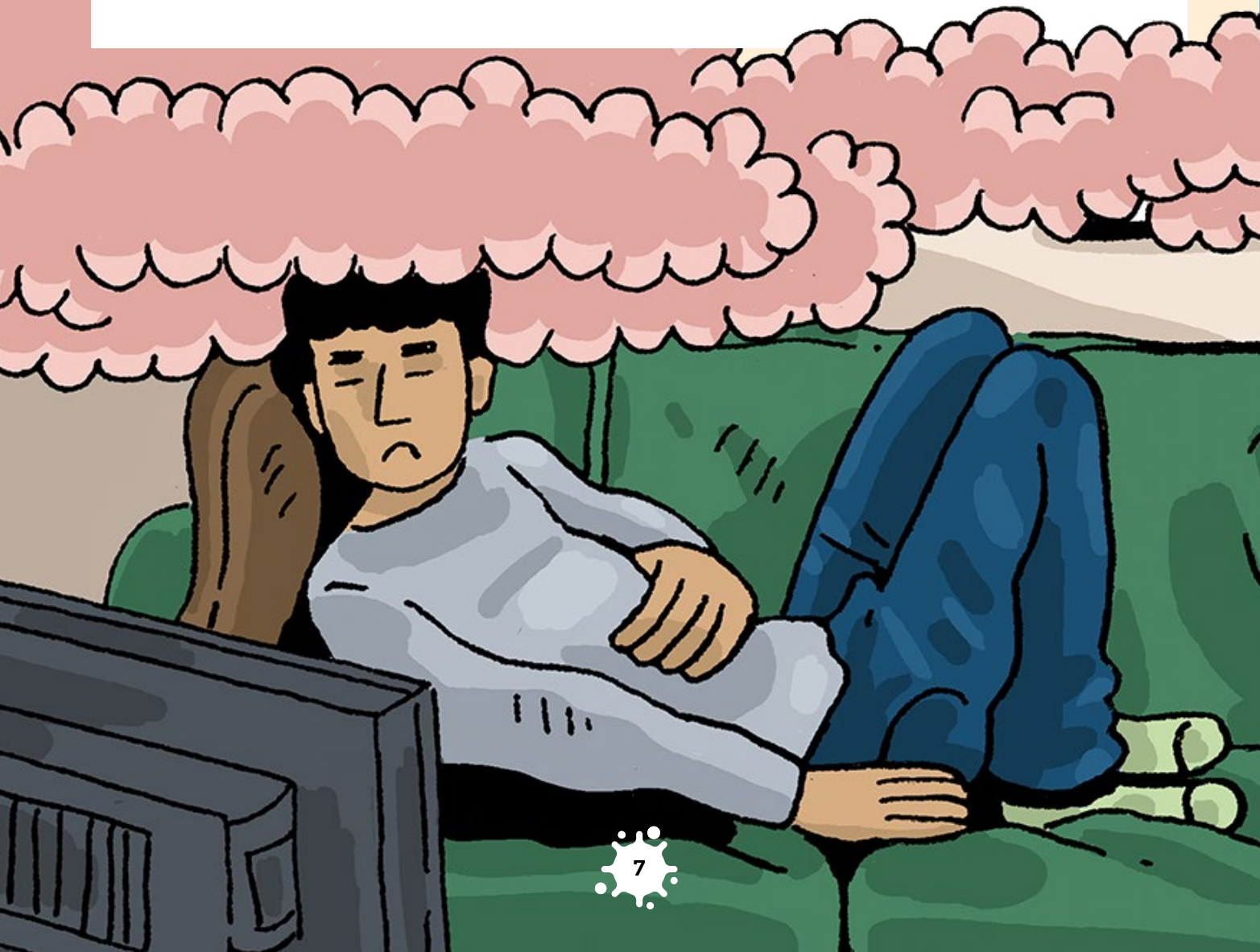
[www.lshtm.ac.uk/research/centres-projects-groups/covid-made-long#lived-experience-resources](http://www.lshtm.ac.uk/research/centres-projects-groups/covid-made-long#lived-experience-resources)

## EXPERIENCE

I'm Rilee, I'm 25 and I was travelling in Europe when I caught Covid-19. I thought it was just like a cold at first, but then I started experiencing strange symptoms like tiredness, blackouts and nosebleeds. It was like a domino effect where different things kept occurring in my body.

I had to go home to rest and couldn't get out of bed for several months. I wasn't aware of how bad Long Covid could be, I felt like I was dying. I had a really severe fatigue which feels like trying to walk straight under water but loads of waves are pushing you in different directions. It was just so intense. For me, Long Covid has been a catalyst for so many new problems including a high heartbeat, blood flow issues, and chronic fatigue.

One of the hardest things is the invisibility of my symptoms, because I'm young and I don't look sick. People struggle to understand what I'm going through and don't believe that young people can get as poorly as I feel. Connecting with other people with Long Covid online really helped me figure out my symptoms. It's been two years, and I feel like I'm slowly feeling better. But progress with something chronic, it isn't overnight.



# Long Covid can make life uncertain

People my age don't really understand Long Covid. They kind of go, 'Ooh, you look perfectly healthy, what are you on about? There's nothing wrong with you!'

*Taylor, Aged 18*

## "It can take time to figure out"

One of the difficulties of Long Covid is that there are so many symptoms which can change over time. And it can affect everyone differently. This makes it different from many other illnesses. No one will ever have *your* Long Covid. Some people feel better quicker, and for other people

it is ongoing. A lot more is known about Long Covid now, but it can be difficult to get a diagnosis or the right advice. This can make it confusing for us and for other people in our lives to understand. But finding the right support can make this easier to manage.

## "It isn't all in our heads"

Long Covid is a physical illness that affects all aspects of your life. But a lot of people don't really believe in Long Covid. There's not much public awareness and when there is, it focuses on older people. People ask things like, "Are you sure that is what's really happening?". This is sometimes called 'gaslighting' and

can come from friends, family members, medical professionals, or people at school, uni, or work. The isolation of feeling that people don't believe you is at times as damaging as the illness itself. Being made to question your own experiences can have big impacts on your mental health.

# “I can look a lot better than I feel”

You might see us doing alright one day, but things look different when we get home, or the day after. Even when we ‘look’ well, that’s almost

never the case. The problem with invisible illnesses is that people can’t actually see the symptoms.

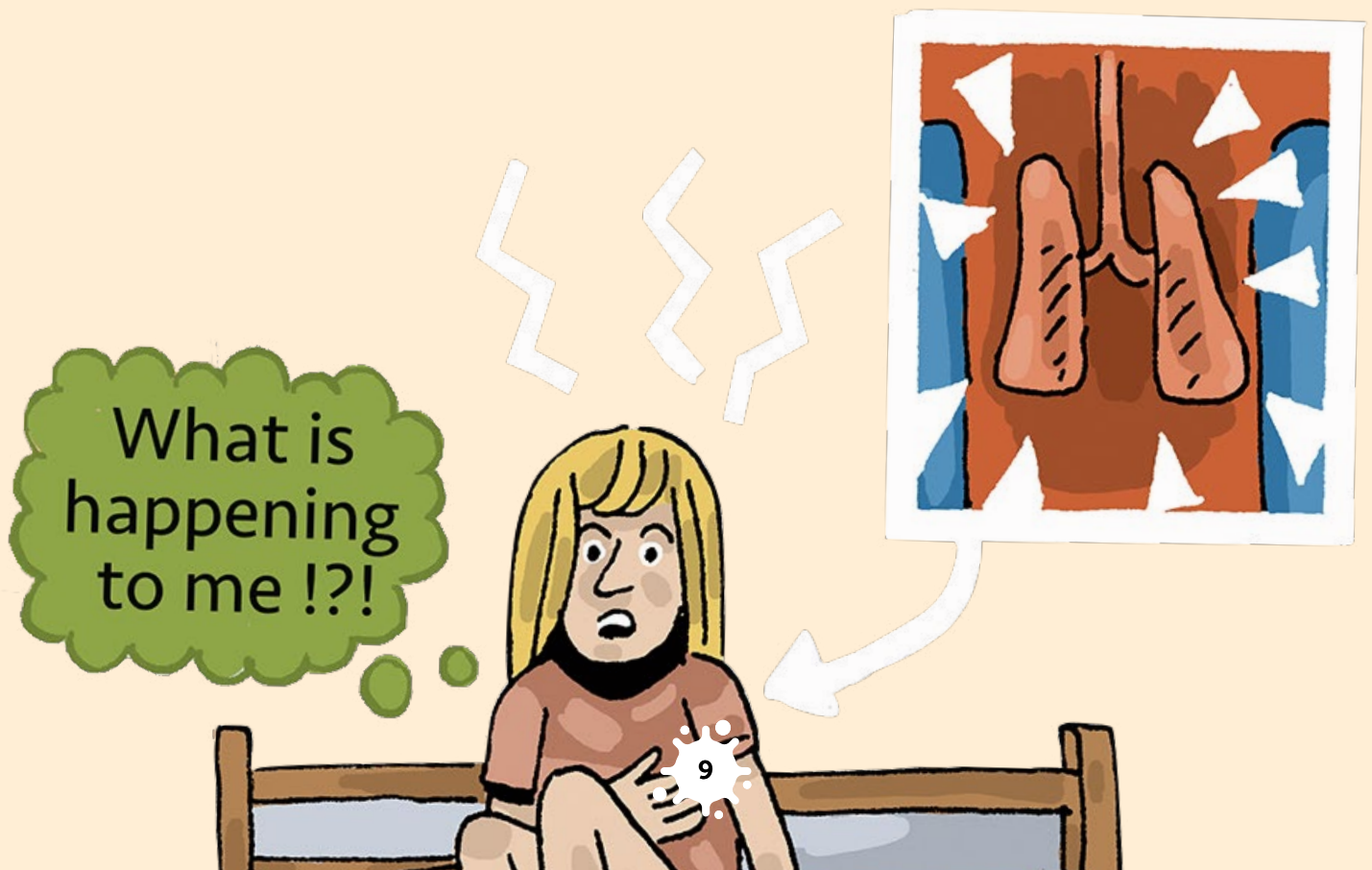
## TIPS AND TRICKS:

### If you’re a young person with Long Covid...

- Know that you are not alone: see the resources pages (28 – 29) at the back of this guide for spaces you can meet others with Long Covid.
- Take things one day at a time.
- If someone doesn’t believe you, find others that do.

### If you want to be a good ally...

- Take what we’re saying seriously.
- Listen to us and work with us to find out what is really going on.
- Read up on Long Covid yourself (read this guide, and see the resources on page 28 – 29).



# Pacing is really, really important

I have to really pace my life now, like if you're going upstairs, just get everything you need in one go. The hardest thing to work through in therapy was accepting that I was sick, I kind of refused. I would go up and down the stairs ten times a day until I was passed out on the floor because I didn't want to accept that I had to change my life.

*Isabella, Aged 18*

I purchased a ping-pong set because I thought that that would be like a low energy thing and I could play it against a wall. And that's given me a bit of joy back, to be able to have sport in a small way.

*Rilee, Aged 25*

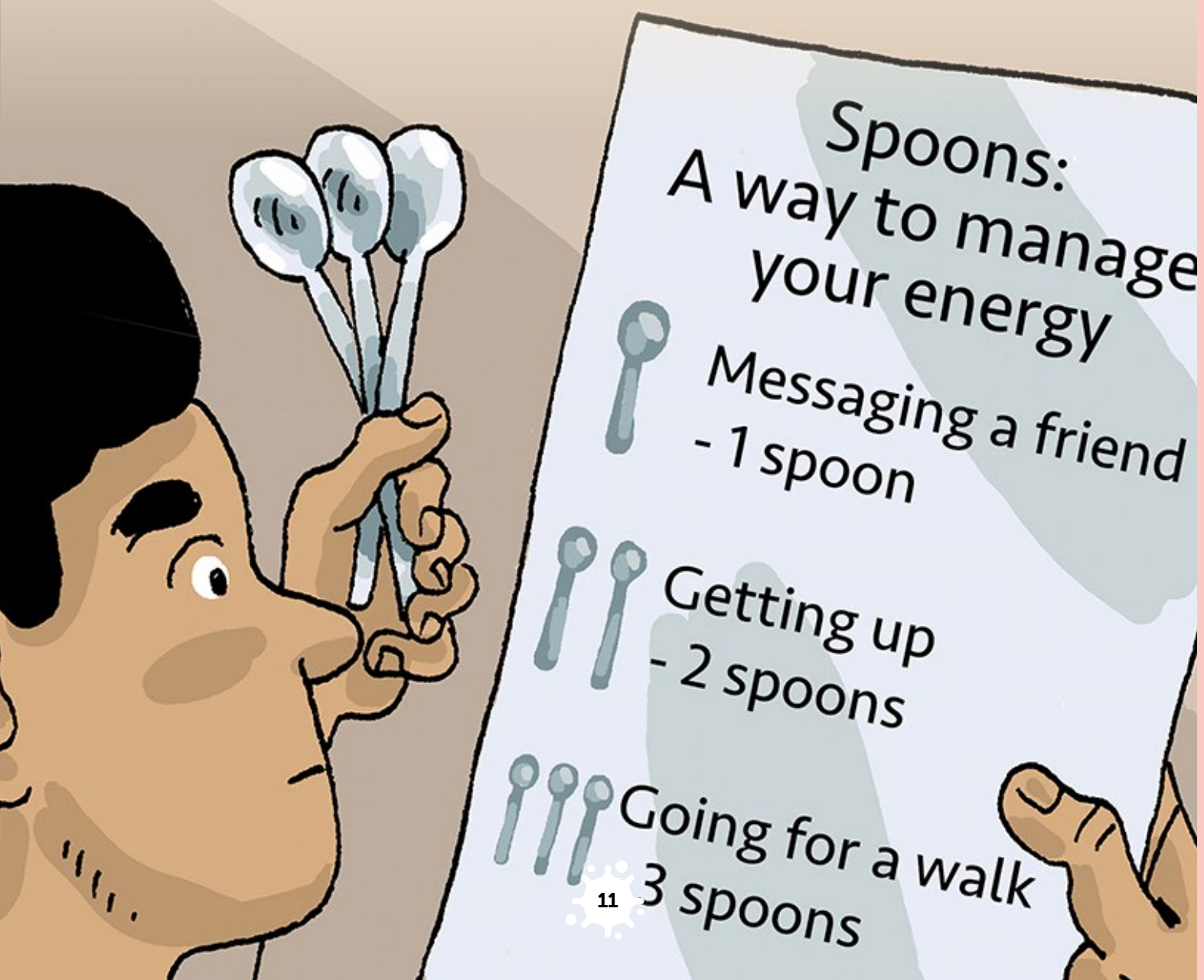
## "I've got to pace and prioritise"

People with Long Covid don't start the day with as much energy as most other people. We have to be more careful with how we use our energy, and 'pacing' is vital. This means not taking on too much and prioritising what we do so that we can build in time for rest. Pushing yourself too hard or trying to do too much can result in crashes, where we feel like we can't move for days.

Pacing can feel bittersweet when you have to let go of things that you used to enjoy. Resting can feel boring and frustrating at times, but it's important to do it anyway.

**Spoon theory** is an easy way to communicate the challenges of managing energy for people experiencing disability or chronic illness. It came about when Christine Miserandino was explaining her experience of chronic fatigue to a friend over dinner. She used spoons from the dinner table to show the limited amount of energy, or 'spoons', chronically ill people start each day with, compared with others. All activities 'use up' some quantity of your spoons, meaning that you have to carefully consider how to use your spoons. Energy levels can go up and down, and you might not start with the same amount of spoons each day.

If you use more spoons of energy than your daily allowance, this means going into your 'spoon overdraft', like spending money you don't have in your bank account. This can lead to a 'spoon debt' which can have 'interest', meaning you will start with less spoons on future days and need to rest more to 'repay' the energy 'debt' over the following days or weeks.



## EXPERIENCE

I'm Jack and I'm 17. Before Long Covid, I did lots of things after school like Explorers, rugby and cricket. When I got ill, I didn't know much about Long Covid so I carried on doing sports, but I would get really tired after. Gradually I had to stop all sports, because of my fatigue. I continued going to school, but I had to use breaktimes to try and conserve my energy for the rest of the day. This really impacted my friendships, as I didn't have the energy to explain what was going on for me.

I got referred to the Long Covid Clinic and they taught me about pacing activities and making time for rest. They helped me get a reduced timetable and breaks in exams. I started using a quiet study space to rest. I put headphones on and listen to a big playlist I've made which helps me to switch off from the noise and busyness of school.

Now I am slowly getting better, although recovery is like a wobbly rather than a straight line. I've managed to go back to cricket and Explorers and balance this with A levels. But if I'm having a tricky week, I skip things sometimes. I try not to put too much pressure on myself, cut back when things get too much and prioritise resting.

## “Different forms of fatigue need different types of rest”

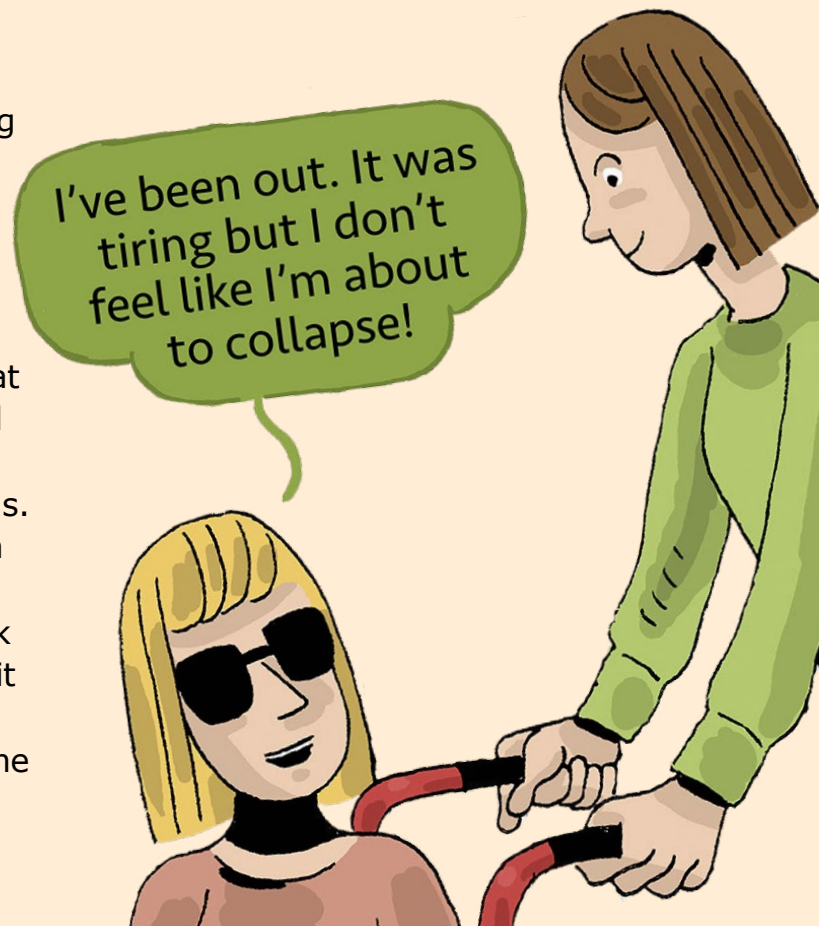
Different activities use different types of energy. Walking takes physical energy, reading takes mental energy, and experiencing things like frustration or sadness takes emotional energy. You might have different amounts of energy per day for different activities and need different types of rest. For example, watching TV might rest your body but tire your mind. So, it can help to balance different types of rest.

For some of us, mobility aids can help to conserve energy when going out and about, or gadgets that might help at home, like a slow cooker or robot Hoover. It can feel like an identity shift, but these things can help you access things that you want to do in new ways.

# “Pacing is not an exact science”

Pacing is vital, but it's not an exact science. It's about give and take, making sacrifices and trying to mitigate for the things you do. It can mean having to make hard decisions, like balancing energy with work commitments.

Sometimes you have to think about what is important for your mental health, and prioritise things that bring you joy, even if it means having less energy afterwards. But having a crash after doing too much is no joke, and it can have long term consequences. This is always in the back of your mind. Everyone is different and it can be an internal battle to figure out if you're pacing enough, or when to test the waters. It's impossible to pace perfectly.



## TIPS AND TRICKS:

### If you're a young person with Long Covid...

- Reflect on what matters most: Prioritise things you have to do like appointments, learning, or work, but try and make time for fun things too.
- Try scheduling breaks: If you want to have the energy to do something one day, you might have to plan not to do too much on the days around it.
- Think about using mobility aids and gadgets to conserve energy.

### If you want to be a good ally...

- Understand that sometimes we might have to cancel plans. It isn't fun when we have to rest all day instead. It can be boring and frustrating.
- Help us pace. Don't encourage us to push ourselves beyond our energy limits, listen to us and accept how we're feeling on the day.
- Don't question how and when someone uses priority seats on public transport or a mobility aid – it fluctuates with our symptoms.

# Long Covid affects all aspects of your life

Who I was prior to Long Covid and who I am now are quite different things. I was just a normal kid, and then when I got ill, that's when like everything changed. It is tumultuous, up and down. It has been a real ordeal, life changing, life upending, like nothing has remained the same.

**Emma, Aged 17**

I have kept in contact with a couple of people, but it's sort of difficult to socialise because they talk about stuff that they've done. And I just couldn't relate, because there is not a lot that I had been up to.

**Taylor, Aged 18**

## “Long Covid is life changing”

As young people with Long Covid, we have to make a lot of changes to function at a base level. Everyday things can take a lot of effort and sometimes we miss out on things other people our age are doing. It can be hard, or even impossible, to access education or work, stay connected with friends, or do

fun things that we used to enjoy. Needing to rest can feel like a lot of monotony, like your world has gotten smaller and you've lost some of your freedom. Before getting ill, our lives were mostly about going out, doing things, and hanging out with friends. But living with Long Covid, things have to change – at least for now.

## “People don’t always know what to say”

It can be really hard to navigate social life when you have Long Covid. People often don’t know much about it and find it hard to understand. And it’s tricky to explain to others when you’re trying to figure it out yourself. Trying to explain it over and over again can be exhausting

when you have limited energy and struggle to find the words. It feels like lots of people want to ‘move on’ from the pandemic and don’t want to hear about Long Covid anymore, which makes it even harder to be understood.

I feel like people get annoyed at me, because I’m constantly saying like, ‘Oh my God I feel so exhausted Today’, or ‘I can’t concentrate very well’, or ‘I’ve gone dizzy’. I feel like they’re like, ‘Why do I need to know this information? I don’t really care.’

**Taylor, Aged 18**



## “Prioritise the people who get it”

It's important to focus on the friendships or connections that show understanding, are supportive, and adapt with you. Connecting with people with similar experiences through online support groups and sharing tips and tricks can

be reassuring and really help. People who haven't had Long Covid might not know what it's like to live with it, but they can listen, come to understand what we're going through, and do things to help.

## “So, is this a forever thing?”

People always ask “when are you going to get better?”. This question is difficult, because we don't know. It can feel overwhelming and sad to think about. Getting better isn't a linear progression and sometimes people don't get it when

you feel worse again, after a period of feeling better. A common misconception is that if someone has been ill for a long time then they must be used to it, or that it doesn't affect them as much as when it first started. But it does.

Someone who's chronically ill, they've got no secure future, they're unsure if they're going to be well tomorrow. If you can find someone like that who's like in a perfectly good mental state 100% of the time then I will applaud you.

**Ben, Aged 16**

## “There are mental health impacts, too”

People suggesting that Long Covid is “all in your head” can make us really hesitant to talk openly about mental health. Some of us struggled with mental health before, but some of us were at our happiest and never had any challenges with mental health before getting Long Covid. It's not that we're anxious and that is causing us to be

ill; it's that being ill for a long time can impact your mental health. Being isolated from friends, uncertainty over the future, and trying to avoid getting reinfected can produce an anxiety of its own. It's only when people acknowledge that Long Covid is a physical condition, that we feel safe talking about how this huge life change is making us feel.

# “There’s been an awful lot of learning curves”

Living with Long Covid is a new experience for the people in our lives, too. It can take time for friends and family to understand that we might need to adapt how we spend time with people, like taking more breaks, wearing a mask, or meeting outside to avoid getting ill again. It can take time to figure out how to navigate social life, but trying out ways to stay connected can help, even if they feel small.



## TIPS AND TRICKS:

### If you have Long Covid...

- Try finding ways to connect with friends in a different form, like keeping in touch virtually via message, videocall, gaming, or meeting up once-in-a-while.
- Lower-energy hobbies can help pass the time, like art and craft, modelling, playing guitar, reading books, writing, crochet, cooking, watching films, playing video games or spending time with pets.
- Or, try adapting old hobbies to be more low-energy, like watching sport instead of playing it, or finding accessible clubs, like Virtual Guiding.
- Finding someone you trust and who validates your experience of Long Covid can make it easier to talk about mental health.

### If you want to be a good ally...

- Social life is still a really big thing for us, even if we have to spend more time resting. Making an effort to check-in helps us to feel less isolated.
- We need you to understand that our physical symptoms are real before we will feel safe to talk about how that impacts mental health.
- Help us to adapt - like finding places we can take a break, going to less noisy, bright, or crowded places, or thinking about how we can stay in touch remotely.

# Accessing care and support can be challenging

I put so much work into trying to educate different groups. The problem is, the people that don't want to hear it, don't want to hear it! Even if you come with evidence, they don't care.

*Theo, Aged 25*

The doctors were kind of like, 'this is probably a resurgence of your anxiety'. So they just didn't do medical investigations for six months, and then panicked when they did and found that something was actually wrong."

*Rose, Aged 23*

## "Getting help is like a constant battle"

Finding support to adapt to life with Long Covid often feels like a battle. Whether that's healthcare, finding ways to access education or work, or financial support. Systems are often inflexible and lots of people don't know what Long Covid is,

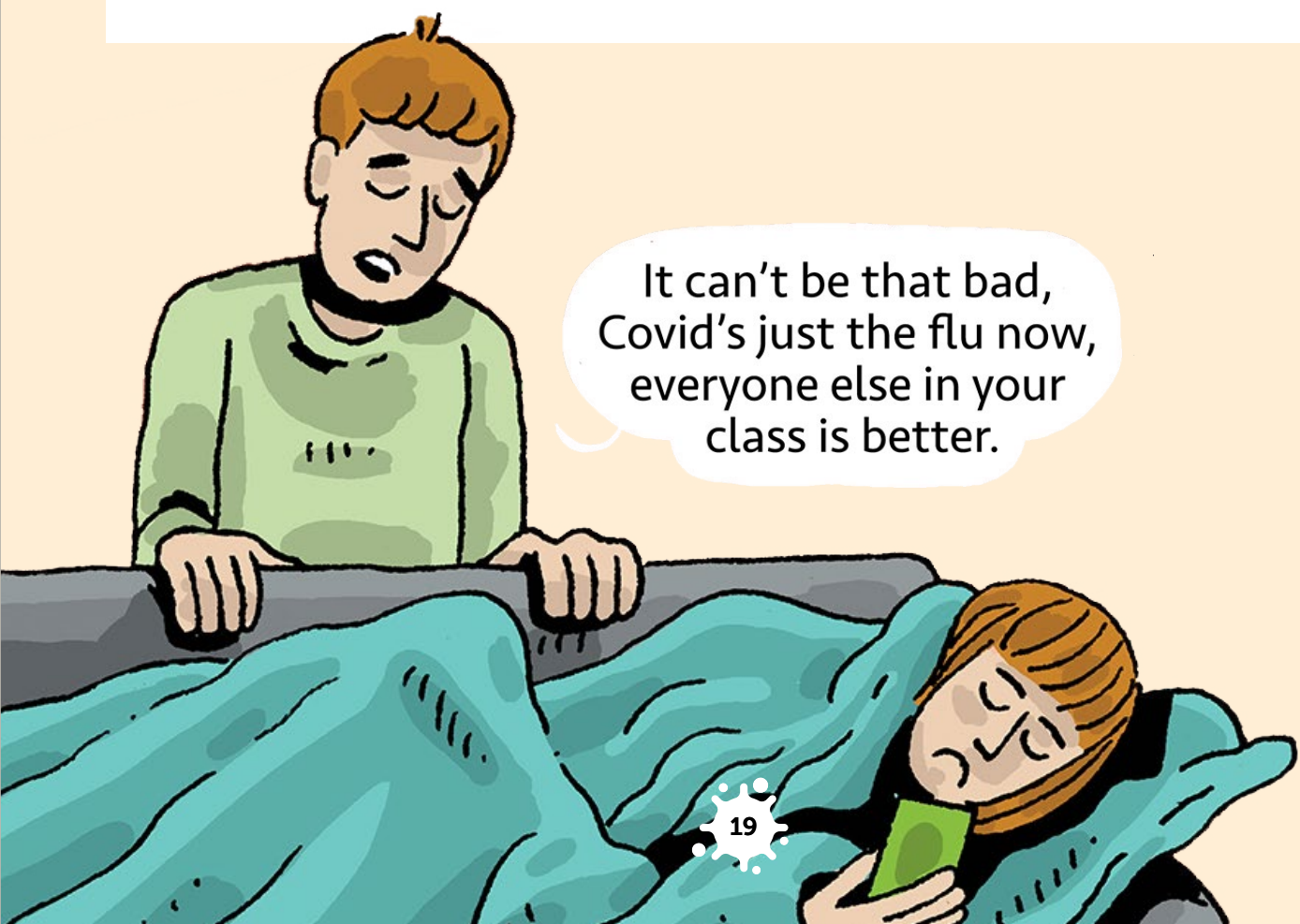
which means spending a lot of time advocating for yourself to get the help that you need. Having to repeatedly explain what's going on for you and fight to get help is exhausting, especially when you're ill and have limited energy.

## EXPERIENCE

I'm Elias, I'm 25 and I was at university when I became ill with Covid-19. It began as your classic flu-like symptoms, but turned into chest pains, difficulty breathing and fatigue. I ended up going to A&E where they did an ECG and X-ray and then sent me home. But the pain continued and never left.

I play trumpet but every time I tried to play I felt a burning shooting pain in my chest and could barely breathe. Lots of doctors suggested that if I practiced trumpet and exercised more it might help me recover, but then I obviously crashed and the pain got worse. For a long time I struggled thinking that maybe I was imagining my symptoms. But then I was given advice through the Long Covid Clinic and a lung function test showed that I have 50% of the expected lung capacity for someone my age.

The Long Covid Clinic also offered the opportunity to speak to a psychologist to help me process it all. But despite doctors telling me it was a physiological issue, the therapist told me that my symptoms were completely psychological. She offered me EMDR therapy and said that she could cure me, because it was all in my mind. I was taken aback, because lots of tests I've had have shown things that are wrong, and I've been diagnosed with Long Covid. Luckily my family are really supportive and always told me that what I was going through is real, and I found some doctors within the system who were helpful too.



## “I ended up having lots of referrals, but was always bounced back”

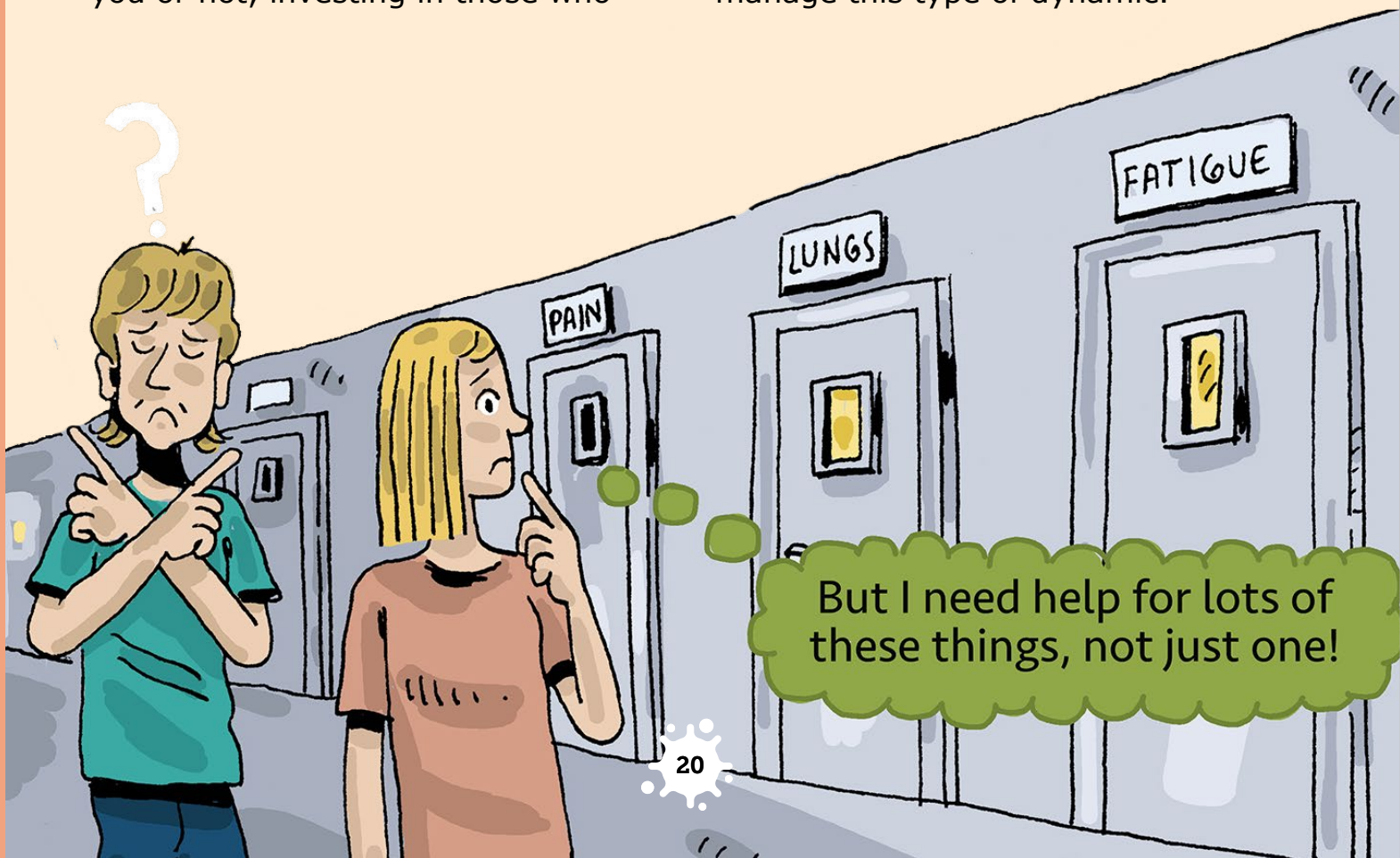
There are often long waits to access care. GPs are important because they can refer you for specialist help, but they don't always know about Long Covid. When you do get referred, it can involve being bounced between different departments, rather than getting care which responds to how

Long Covid can affect different parts of your body at once. Where you live also shapes what services you are offered, so some of us are left with limited care unless we can travel long distances or can afford private healthcare.

## “It's felt a lot like me and my family against the world”

Social connections like friends, family, or partners really matter, especially when healthcare and other support can be so difficult to access. It's not always the people you expect who are the most supportive, people can surprise you. The key is recognising when someone is actually helping you or not, investing in those who

are supportive, and being ok with moving on if a relationship becomes unsupportive or one-sided. If someone is important to you, it can be hard to disconnect from them completely, even if they aren't being helpful. It can help to talk to someone that you trust about how to manage this type of dynamic.



### **Some of the ways that friends and family have helped are..**

- Providing emotional support while we navigate stretched and fragmented health services.
- Validating that what we're experiencing is real, listening and allowing us to vent - acknowledging what we're going through can be a huge weight off our shoulders.
- Helping with day-to-day things like organising appointments. This really helps us to conserve energy.
- Still treating us like ourselves by not making a big deal of it when we're affected by symptoms or need to adapt things.
- Supporting us to support ourselves, like not encouraging us to do things which take a lot of energy when we're not feeling up to it.

I recently got into a relationship. I wasn't supported by my mum, so to now have someone in my life that does support me has, I think, helped with my healing. Maybe that's how I've had the confidence to go out more.

**Rilee, Aged 25**

## **“It takes effort to keep support going over time”**

It can be challenging to support someone with Long Covid, and we know the people in our lives might have mixed emotions. Taking on additional caring responsibilities can affect your time and energy and there can be financial impacts, like needing to take time off work to provide care.

It can be hard to keep relationships going when someone is ill for a long time, because it changes things. We know that continuing to be there takes a lot of effort, and we want the people in our lives to look after themselves too.

## TIPS AND TRICKS:

### If you're a young person with Long Covid...

- Some doctors and teachers don't accept that Long Covid exists and this can feel like a constant battle. But remember Long Covid is real. You can find people who get this, and they can be really helpful.
- Sometimes you need to take one battle at a time, and it can help to go stage-by-stage to get diagnoses or accommodations at school or work.
- Bringing someone else into your appointments can make a huge difference. We get listened to more, and taken seriously, when someone else is in the room with us. It also helps with the cognitive and emotional labour of accessing support.
- Build in self-care after appointments, because advocating for yourself can be exhausting.

### If you want to be a good ally...

- Listen to us and collaborate with us to work out what's going on and how our lives can be made better or easier.
- Help us find workarounds to make sure that we can actually attend or join in with things.



I receive quite a lot of comments about wearing a mask at school, because a lot of people don't want to be told that Covid is still a thing. But my friends always stick up for me.

*Joe, Aged 16*

## What we want young people with Long Covid to know...

### **You are not alone:**

Long Covid is real, and other young people out there are experiencing it, too. It can help to talk to other people that have been through it.

### **Prioritise people that get it:**

Some people might dismiss or not understand Long Covid. Invest your energy in the supportive people, they're the people you want to keep around.

### **Figure out what works for you:**

Finding ways to adapt your life to manage your illness, like pacing, can be really important. But, there's no perfect way to do this. Everyone is different and you might need to test things out along the way.

### **Be open:**

Talking about how you feel and how Long Covid affects you can help other people to understand and adapt things.

### **Find low-energy things you enjoy:**

Being ill can be hard, but it can really help to find doable activities to help you get through the day-to-day. And maybe this will become something you're genuinely passionate about.

### **Do what feels right for you:**

We all take our own approach to limiting the chances of getting reinfected with Covid-19. Understand the risks, do what makes you comfortable, and don't worry if other people don't get why you might want to wear a mask or socially distance.

# How to be a good ally...

## If you're a young person who doesn't have Long Covid...

### **What you say makes a difference:**

Talking about being ill can be a sensitive subject. If you want to understand what is going on for us, think about how your question might feel from our perspective. Ask from a place of genuine care, rather than out of curiosity.

### **Hear what it's like for us:**

It would make life easier if we could just say "I've got Long Covid, I need to rest" and people got that, rather than having to explain it every time.

### **Covid-19 affects us every day:**

We understand that lots of people want to 'move on' from the pandemic, but for some of us this isn't possible.

### **Help keep people with Long Covid safe:**

If you are ill, make efforts to stay at home and wear a mask until you are better. What might be a mild illness for you could impact us much more and take us a long time to recover.



Thanks for Covid testing,  
I pick everything up  
from the kids at work.

## If you're friends and family...

### **You might need to make extra effort:**

It can be hard to maintain relationships when we're ill and energy is limited. The people in our lives might need to put in extra effort, too. Things might look different, at least for a while, but our relationship can still be good.

### **Things can change from day-to-day:**

Understand that symptoms and recovery can fluctuate. Just because we could do something last week, it's not guaranteed that we'll be able to do that same thing this week.

### **We might need to say "sorry, not today":**

When we make plans, we might need to cancel last minute. If we can't go, we can't go and it's nothing personal.

### **What you say matters:**

As important people in our lives, the things you say can have a huge impact. Encouraging us to 'push through' symptoms or suggesting that it's 'all in our heads' is really detrimental. It can make us question our own experiences.

### **Knowledge is power:**

It's ok to be unsure, but lots more is known about Long Covid now. Educating yourself will help you support us, and yourself, better.

### **Look after yourself, too:**

We know that supporting someone who has Long Covid can feel all consuming. But it's important to find support for yourself too through support groups, accessing carers allowance, or finding time to do something for yourself.

### **Stick around:**

We don't know when we're going to get better, which makes the future uncertain. But keep being there, because this makes a big difference.

### **Help keep people with Long Covid safe:**

Try and keep your distance or wear a mask if you are unwell with something we could catch. What might be a mild illness for you could impact us much more.

## If you work in health and social care...

### **Listen to us:**

Understand that we aren't making it up, it isn't in our heads. The symptoms we are experiencing are real and we want to be better. It can take ages to get a diagnosis, so even if we don't have a diagnosis yet, we should still be taken seriously.

### **Learn from us:**

Because Long Covid is a new thing and we want to get better, we've often done a lot of research into it. This means we might know things that doctors might not. We want to pool our knowledge, but we don't want it all to be left up to us.

### **Collaborate with us:**

We want to get better, and we want to work collaboratively with you to do that. It's ok not to know everything right away. We'd always rather you say 'sorry I don't know... can I find out?' than try and hide a lack of knowledge with unhelpful advice.

### **It's all connected:**

Because you can often only bring one issue to your GP at a time, it's hard to get help for a multi-symptom condition like Long Covid. Helping us work out how all the different symptoms connect to each other really helps.

## If you work in education...

### **Be open and adapt:**

Supporting someone with Long Covid to participate might mean doing things a bit differently, like enabling us to join classes remotely, exam concessions, having a reduced and flexible timetable, access to space to rest, online learning, ground-floor lessons, and additional support.

### **Advocate with us:**

Education systems can be inflexible, so when we ask for adaptations, we can end up feeling like an inconvenience. We have to do a lot of

advocating which can be exhausting. Staff that help by advocating for our needs make a huge difference.

### **Include us:**

Sometimes students and teachers can make negative comments about the adaptations we need to access in-person education, like needing classes downstairs or wearing a mask. This can make us feel excluded, targeted and unsafe. More understanding from staff and other students would make it easier for us to be involved.

## If you work with someone with Long Covid...

### **We want the opportunity:**

It can be almost impossible to find work that is accessible. If we share our health needs in interviews people can seem understanding, but then we often aren't offered jobs. This makes it hard to share that you might need reasonable adjustments like reduced working hours, additional breaks, or support with workload.

### **There's lots of pressures:**

Lots of us need to balance our health needs with the cost of living. This means sometimes feeling pressured to work when we're not well, or 'pushing through' symptoms at work when we need to rest. Doing what you can in your position to help us, makes a big difference.

### **Don't assume young people aren't affected:**

Because we're young, some people assume we aren't really affected by getting ill. But when you have Long Covid, getting ill can have a huge impact on your symptoms for a long time. When illnesses are going around, don't assume we'll be fine coming to work just because of our age.

### **Help us to adapt:**

People that we work with can help us to adapt, for example, explaining things in clear and accessible ways, swapping roles for the day, having the option to work remotely, providing accessible equipment, or having a part-time or flexible work schedule.

I think chronic illness in general shows you what's important to you, and what you can and can't live without. And I've definitely found friends that I feel understand me a lot better, and I've definitely learnt. When you get so much taken away from you, you kind of have to look at what you've got left, and think what means a lot to me.

*Emma, Aged 17*

# Resources

## Support for Long Covid

**Long Covid Kids:** A charity that advocates for families, children and young people affected by Long Covid and related illnesses. They offer online peer support services for young people to connect with others who understand their experiences. See their 'Educational Toolkit' for teachers (Videos 1-4) and peers (Video 5) to learn more about Long Covid.

[www.longcovidkids.org](http://www.longcovidkids.org)

[www.longcovidkids.org/educational-toolkit](http://www.longcovidkids.org/educational-toolkit)

**Long Covid Support:** A peer support and advocacy group for people living with Long Covid. They offer a private online peer-support group on Facebook for people with Long Covid and their carers.

[www.longcovid.org](http://www.longcovid.org)

[www.facebook.com/groups/longcovid](https://www.facebook.com/groups/longcovid)

**Long Covid Physio:** An international peer support, education and advocacy, patient-led association of Physiotherapists living with Long Covid and allies. See their website for education outputs for anybody living with Long Covid and people wanting to learn more.

[www.longcovid.physio](http://www.longcovid.physio)

**NHS:** The latest NHS advice on Long Covid is available on their website.

[www.nhs.uk/conditions/long-covid](http://www.nhs.uk/conditions/long-covid)

**WHO:** The latest World Health Organisation advice on Long Covid is available on their website. See this factsheet for advice on Long Covid self-management for young people.

[www.who.int](http://www.who.int)

[www.who.int/news-room/fact-sheets/detail/post-covid-19-condition-\(long-covid\)](http://www.who.int/news-room/fact-sheets/detail/post-covid-19-condition-(long-covid))

## Support for young people

**Childline:** A free 24-hour counselling service for children and young people up to 19 years old. You can get help and advice about a wide range of issues, call Childline on 0800 1111, talk to a counsellor online, via email, or post on the message boards.

[www.childline.org.uk](http://www.childline.org.uk)

**The Mix:** If you are under 25, contact The Mix for free by phone, text, email or webchat. Use their phone counselling service or get information on support services for all areas of life. Text 'THEMIX' to 85258.

[www.themix.org.uk](http://www.themix.org.uk)

**Papyrus:** Confidential, crisis support for suicidal young people aged 13 and below. For help and suicide prevention advice (24/7) call 0800 068 4141, text 07860039967 or email [pat@papyrus-uk.org](mailto:pat@papyrus-uk.org).

## Welfare support

**Citizen's Advice:** Offer free confidential advice online, over the phone, and in person. For information on financial support for sick or disabled people or carers, see the Benefits page on their website.

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service):**

Offer free, impartial, and confidential information to young people with special educational needs and disabilities (SEND) and to their parents and carers. Find your local SENDIASS service here:

[www.councilfordisabledchildren.org.uk/about-us-0/networks/information-advice-and-support-services-network/find-your-local-ias-service](http://www.councilfordisabledchildren.org.uk/about-us-0/networks/information-advice-and-support-services-network/find-your-local-ias-service)

## Support for related conditions

**PoTS UK:** A charity that supports and educates patients, family, friends and healthcare professionals by sharing up-to-date evidence and resources about PoTS.

[www.potsuk.org](http://www.potsuk.org)

**PANS PANDAS UK:** A charity offering information and resources about PANS/PANDAS and a parent-led virtual support group.

[www.panspandasuk.org/](http://www.panspandasuk.org/)

**Action for ME:** A charity that provides support for everyone affected by ME/CFS. They offer free support services for children, young people and adults.

[www.actionforme.org.uk](http://www.actionforme.org.uk)

**Mast Cell Action:** A charity supporting people affected by Mast Cell Disease. They offer virtual peer support sessions and supportive resources.

[www.mastcellaction.org](http://www.mastcellaction.org)

## Support for carers

**Carers UK:** The leading national charity for unpaid carers. They support, advocate for, champion and connect carers across the UK. If you have a question about caring you can contact their helpline on 0808 808 7777 from Monday to Friday, 9am – 6pm (including Bank Holidays), or email [advice@carersuk.org](mailto:advice@carersuk.org).

[www.carersuk.org](http://www.carersuk.org)

**Carers Trust:** Run a network of local carer organisations across England, Scotland and Wales. They offer information, advice, practical support and/ or care in the home to unpaid carers of all ages. See their website to find your local carer service:

[www.carers.org](http://www.carers.org)

# Credits

## Produced from research by:

Covid Made Long Project,  
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## University Researchers

Hannah Cowan, Zaira Clarke,  
Tim Rhodes, Praveena Fernes

## Peer Researchers

Alex, Eden Byrne, Lucinda Leal,  
Jenny, Cal Bloodworth, William George,  
Juliette Gunn-Roberts, A. Haines,  
Emily Miller

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## Illustration

Daniel Locke, in collaboration  
with *PositiveNegatives*



## Stories Drawn from Research

[www.positivenegatives.org](http://www.positivenegatives.org)  
[@PosNegOrg](https://twitter.com/PosNegOrg)

## Graphic Design

Will Mower

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The logo for Imperial College London, featuring the word 'IMPERIAL' in a bold, blue, sans-serif font.

Long Covid Kids and Long Covid Support

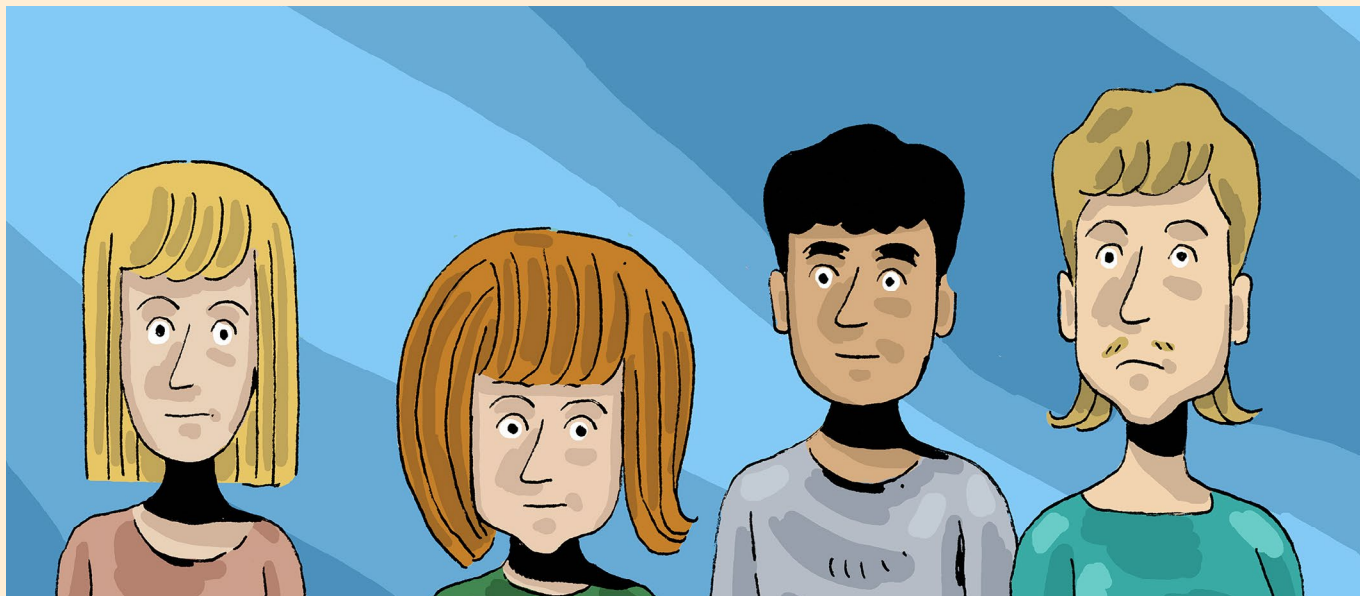
The logo for Long Covid Kids, featuring the words 'LONG COVID KIDS' in a bold, sans-serif font. The 'i' in 'KIDS' is red.

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This guide explores what it is like to live with Long Covid as a young person, told from the perspective of young people who have lived it. This is based on a research project where young people were interviewed about their experiences. The guide is written in the words of a team of 11 Peer Researchers who have experienced Long Covid; and the 72 young people who have participated in qualitative interview research as part of the Covid Made Long project.

The guide has been illustrated by Daniel Locke 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](http://www.lshtm.ac.uk/research/centres-projects-groups/covid-made-long)

**Contact:** [Tim.Rhodes@lshtm.ac.uk](mailto:Tim.Rhodes@lshtm.ac.uk)