

# Six key things someone living with Long Covid would like you to know

*\*Insights gathered directly from people with Long Covid*

## 1 Accepting change can be difficult

I find it really tough to come to terms with how ill I've become and how many things from my old life I've had to give up. I know it might be hard for you too, and knowing what to say and how best to support me can be difficult.

Just knowing that you understand how my life has changed means a lot to me.

## 2 Being believed is important

Some people with Long Covid find that their doctors are dismissing their symptoms and think it's just anxiety. But often it's the other way round – I've experienced anxiety and depression since having Long Covid. It's so important to me that I feel believed by those around me and that my loved ones try to understand what I'm going through.



## 3 Pacing and rest are essential

I really want to try to do more and know that you want this for me too. But it's not that simple. There's no cure for Long Covid, and the only treatment is something called "pacing."

I have to avoid pushing myself too hard. If I do, it could make all of my symptoms worse, and make me feel unwell. This is called "post-exertional malaise," which might show up hours or even a day or two later. Using physical, mental, or emotional energy can take its toll – even just having conversations! I can judge how much energy I have to do things. So please understand if I have to say no to something – it's not personal.



## 4 The gift of listening

I sometimes find that I am not listened to by doctors, and it can be upsetting. Having the people I care about believe and understand what I'm going through would mean a lot to me. I really need your support as I go through this journey, hoping to get better or at least see a big improvement!



## 5 Should you invite me to events?

For some people with Long Covid, getting invites can make us feel sad about missing out on things. Some others are just happy to be asked and feel that they haven't been forgotten.

It would mean a lot if you asked me how I feel about going to big events like birthdays or family gatherings that I might really want to go to, but might not feel able to. If you're open to making some changes to help me join in, let's have a chat, and I can share some ideas.



## 6 Should you provide advice?

I know there's a lot of information about possible 'cures' for what I'm going through, thank you for wanting to share it with me. But when I can't try everything or if I don't get better, it makes me feel like I'm letting people down. It's tough when people think that I'm not trying hard enough. I really want to get better, and many do improve by taking it slow and steady.

Your understanding and support mean a lot to me during this journey.



Thank you for reading!



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