


# COVID-19

We are the  
'underlying conditions'

Ipsos MORI





# **HOW DOES PREPARING FOR A PANDEMIC AFFECT THE BEHAVIOURS AND LIVES OF THOSE WITH UNDERLYING CONDITIONS?**

Ipsos MORI's award-winning Ethnography Centre of Excellence has been spending time with people who have underlying conditions, exploring how they are adapting to life in the face of the COVID-19 pandemic.

Our Ethnographers seek an unfiltered view of people and culture to develop an empathetic understanding of in-situ behaviours and beliefs.

Participants' names have been changed.

“Am I one of the ‘underlying conditions?’ This is so confusing,” Lara says looking distraught. “Either way I’m reducing my immunosuppressants.”

On whose advice? “I’ve been talking to my friend and just decided. I’m bloody petrified.” Lara, a married mum of two living in a London suburb, has a rare chronic autoimmune condition. She hasn’t managed to speak to her specialist about what steps she should be taking to protect herself. Today she heard he was being diverted to help with the coronavirus effort.

Not far from Lara lives Mel, a secondary school teacher with Focal Segmental Glomerulosclerosis, a chronic condition that impairs the function of the kidneys.

“I hold my breath along the corridor every time I change class rooms,” she says.

Like Lara, she is on immunosuppressants. “I can’t stop taking them,” she says, “otherwise my body will reject my kidney.” She has talked to her doctor and knows she has an equal chance of catching COVID-19 as everyone else, “I just don’t know about my body’s ability to fight it.”

The news that it is the elderly and those with underlying conditions most at risk has reassured those outside this demographic. For Roberta, a mum of an immunosuppressed child with chronic Crohn’s, this process has been difficult to witness.

“I asked the headmaster of two of the schools in the local borough the other day if he thinks they will be shutting soon. He said no way. It’s just like the flu. It’s only a problem for the elderly or someone with an underlying condition. Fuck you! I thought. Don’t those with underlying conditions count?”

These experiences will be common to the millions of people in the UK already managing underlying conditions. They are likely to face confusion about which conditions are more problematic for this illness and have concerns around medication, medical supplies, doctors’ appointments and condition management. They face some potentially critical choices and trade-offs in the coming weeks.

Lara’s condition is called Relapsing Polychondritis. It is so rare, there is only one doctor in the UK who treats it. It took four years for her condition

to be diagnosed while she was passed from specialist to specialist. It is an autoimmune disease that affects the cartilage in her body. She is in constant pain but has today decided to reduce her methotrexate injections, which lower her immunity. With her doctor unavailable, this has been her own decision.

“I talked to someone else on the Facebook group who said the specialist said not to stop the immunosuppressants, but I’m too worried.”

She is anxious about not being able to access her doctor. “He is the specialist for Lupus too. I hope nothing happens to him.”

Lara is a ‘patient-expert’ with her illness, and works with the GP on what to do, but doesn’t necessarily follow all their advice (and nor do they necessarily give it, many not having heard of her condition prior to meeting her). This is why her specialist is so important to her.

“I was awake from 4am this morning just worrying,” she says.

It’s her birthday and she is debating whether to take her family out for dinner.

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"This could be the last time I leave the house for months, so I've got to do it. But it's a massive risk."

Roberta is already keeping Louise off school and, as of next week, will keep Louise's younger sister at home too. "I don't want Jenny there, touching things on the bus, and at school they're not following the hygiene procedures either," she comments. "Don't judge me, but I've gone into lockdown behaviour. I don't go out any more, I don't see friends. I don't want it to become an obsession, but I have to protect Louise. 2020 is bull shit."

Roberta is craving more information, specifically more targeted information. At the moment she is reading everything, some of which isn't that helpful.

"Like the Sun and the Daily Mail," she laughs. She says that she asked the Crohn's nurse by email two weeks ago what they should be doing, what the plan was for Louise. "I got back a cut and paste job for all the nervous parents out there. It just said: 'No, stay on the medication. We don't want to risk a flare-up.' I guess that during the middle of a pandemic they don't want people stopping their medications, getting a flare up and

going to hospital. It's a trade-off, but I'd like some more advice!"

Roberta's view is that she has to plan ahead to protect her family. She doesn't trust the Government's information. "It's very difficult. What you hear is it's only affecting the older people or those with low immunity. And it isn't affecting kids as much. But what about if your kid is immunosuppressed?"

Mel is anxious about her medication supply. "If India and China have a lockdown then I'm worried I won't be able to get my drug. If I stop taking it, my kidney will reject." This plays on her mind a lot.

"It's a nightmare right now, I am so stressed that I am not at all able to concentrate on the teaching," she says. "In this environment I see hundreds of children a day, there are no hand sanitisers in the dinner centre, nothing in the staff room. People are still sneezing and coughing without following the Government advice."

She says it's lucky she has so many antibacterial wipes from when she was on dialysis. She wipes down everything in the classroom before the kids come in and tries not to make physical contact with any of them.



Lara eventually decides she will go out for her birthday but, the day after, experiences regrets.

"Did I do the right thing? My husband is feeling guilty now because he wanted me to go out. He's worried it was a bad decision. We're second guessing everything now. But I won't be going out like that again."

One problem for Roberta isn't just the lack of information communicated to patients, but to the wider public about their responsibilities to protect the vulnerable. "How is it ok to 'other' people who are more vulnerable?" she asks. For her, the UK

isn't yet thinking in a group mentality. "As I walked up the street today there was a man spitting on the floor, and others just sneezing into the air."

One thing all these women have in common is the idea of their home as the safe house.

Roberta is both proud and slightly embarrassed of the fortress she has created at home. She will closely exert control over everything she can. She has made a disinfectant footbath for all visitors. Everyone takes their shoes off, dips their shoes in the liquid and then can proceed in socks only. She is also making her own hand sanitiser, having predicted a shortage she ordered stocks way before the shops ran out.

For Mel, while school feels like an environment she can't control, at home she feels safer. Once her family are inside with their hands washed, she wipes the front door, the door into the kitchen and all the surfaces. Her shopping habits have changed, everything is online, and she doesn't want to handle cash.

This was Mel's last week at school for the foreseeable future. "I'm not going in anymore now," she says. "It's too risky."

Lara's self-imposed lockdown measures have now started. Like Roberta, she has ordered the ingredients to make her own alcohol-based hand sanitiser. It was the only way she could access the amount she wanted. She will get visitors to wash their hands as they come in.

But while she does all of this, there is still an uncertainty. "Is it actually me? Am I one of the underlying causes they talk about? It's not in my throat or chest where other sufferers of RP have it."

In the absence of answers, she will take matters into her own hands and hope.



**During this pandemic, unprecedented in living memory, our research will help us stay close to patients, understanding their lived experience in troubled times.**

**We believe an empathetic understanding of those most at risk will be important in supporting public and official responses and to emphasise the importance of individual distancing and hygiene actions.**





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