

# Let's talk about **COUGH**

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# Introduction

**Chronic cough is a cough that lasts longer than eight weeks, doesn't go away and doesn't respond to treatment. Chronic cough affects one in ten people.**

Everyone is different, every cough is unique. This book invites you to walk in the shoes of people who live with chronic cough. These experiences might be very familiar to you, or very unfamiliar, or somewhere in between.

**Part 1** of the book is a collection of 50 anecdotes and reflections that have been shared by people who live with chronic cough. They are about everyday experiences and social encounters.

**Part 2** of the book is a list of 10 social tips and tricks for people who live with cough and for people who respond to cough.

**This pocket book does not offer medical advice but it does offer real-life insights from people who have decades of experience living with cough.**

**Part 1**

# Living with chronic cough

1

You just can't relax. You're always waiting. Even when you're not coughing – like when I was at the cinema last week – you're just hoping it won't start.

2

People stare at you in the supermarket. They think you shouldn't be out. I want to tell people it's not contagious.

3

It used to be that if you were sat on a bus or something like that, then someone would tap you on the shoulder and say, "are you alright? Would you like a sweet – or I've got a drink, would you like a sip?" And that was really reassuring just to know that some people did understand. But I can't honestly say that anybody has been like that since Covid. People just stare at you in disgust and there's no sweets or anything like that – nothing at all.

4

I remember one time where the cough was so bad. I was in a shopping mall, which wasn't very airy, and I had a coughing fit. It was so bad that I felt like I was going to pass out.

5

I'm aware of certain foods that I know will trigger me. At the theatre, I'd be very cautious about having any type of flavour in an ice cream in case it triggered my cough.

6

The best thing people can do in a social situation is just ignore my cough really. I remember being out one time with a friend in a little tea room or somewhere. I had a big coughing fit and she said, everybody here must think I'm really terrible sitting here, just completely ignoring the fact that you're coughing, but that was the best thing she could do. I told her, no-one can do anything – and it will pass.

7

It can help to think, actually, if I do cough, does it matter? There are obviously some situations where you really don't want to cough, like at a wedding or something, but in most situations, maybe it doesn't really matter that much?

8

For the last seven or eight years I've been Santa Claus at work. From the first year I did it, I loved every minute of it – and then it was just expected that I'd do it every year. But this year, with the cough being so bad, I had to make the decision that it would be best if I just stood down, because it wouldn't be fair on the children. And I was so upset and annoyed because this cough is changing my life completely – you know, it is turning everything upside down and stopping me doing the things that I absolutely love doing.

9

I used to work in an open-plan office. And they'd ask me to leave the office when there were any VIPs coming in – they'd ask me to leave my desk and go out of the office while they were there.

10

If I'm on a Zoom work call, I make sure I always have my inhaler and my tissues and my water to hand.

11

On the nice side of things, I've had people coming up to me in the street and giving me sweets and offering sips of water and things like that. But then you've got people wanting you to get out of their sight, and there's nothing you can do. And if you find yourself trying to stifle a cough, you end up coughing even more and then it's like a machine gun cough.

12

Sometimes, if I know my cough is bad and I'm going to a busy place then I wear a mask, because that just makes me feel more comfortable.

13

In an exercise class, I don't want to start panicking everyone in the middle of it when I start coughing. So I speak to the teacher beforehand, and say if I start coughing, I'll just do this or just do that and then carry on. And then the teacher knows beforehand so I'm not just waiting for it to happen and feeling worried.

14

If I go for a facial I'll tell the therapist that I need to be in a slightly raised position. I know I'm more likely to cough if I'm lying flat.

15

When I go to the dentist I ask them to turn the air conditioning off.

16

My hairdresser is brilliant, because we've had this chat and I've told her that coming in to the sprays and the heat just sets me off. And she knows to get me a glass of water if I haven't got any with me, and she just passes it to me with a wink.

17

It's the people we are close to who it is hardest for sometimes – they get so fed up listening to us.

18

Sometimes I have an early night or go out for some fresh air because I can see my husband getting weary of it, little signs and I think he is so fed up with hearing me cough. He gets to the point where he says "can you just stop now?".

19

My grandchildren ask me a lot of questions. "Why do you cough?" "When will you stop coughing?". So I tell them about the research and say, maybe you can become doctors or researchers and find the answers to that question.

20

I'm recognised by my cough. My husband can even find me in a supermarket by my cough!

21

If my children notice me starting to cough they know to quietly pass me a glass of water and some tissues.

22

I take my bottle of water everywhere – pals laugh at me sometimes – I always have it with me.

23

You know, when I was reading a book to my grandson it was really sad for me, because he said I was hurting his ears when I was coughing. So the impact goes far beyond me.

24

I can have a 20-minute coughing fit, and it can go on for even longer. I mean, once my husband called the doctor out because I'd been coughing for about two hours. I once popped a rib out, I was coughing so hard – so when we're talking a big cough, we're talking really big.

25

If I haven't seen them for a while, friends will say "oh you've still got that cough." And I try to laugh and say "yeah, that's my affliction!" And others say, "oh if you didn't cough, it wouldn't be you." And, you know, everybody's been very kind over the years.

26

When we went to stay with my daughter a few years ago, my husband said "you're going to wake up the whole house with that cough".

27

We have to have separate bedrooms now as my cough keeps us both awake otherwise.

28

My cough keeps me awake at night so I'm exhausted all the time.

29

If I'm coming in from the cold into a warm room I'll tell people, "don't worry, it's a thermal trigger." That helps them understand, so they don't panic, and often they're interested then, so we can have a chat after about the kinds of things that trigger cough.

30

It can be really hard to say things like, "can you take the artificial flowers out of this room because it will set my cough off" and it's hard to predict things like air fresheners in bathrooms.

*cough triggers*

31

If I'm going somewhere in public where I know my cough will be triggered, like the cold aisle in a supermarket, or somewhere with strong perfumes or cooking spices, then I'll wear a scarf over my mouth and nose or a mask as that can help.

32

I have people staying in my house who cook food with quite strong spices, and if I'm in the dining room on a work call, I just sort of say "oh, can you just close the door whilst you're cooking or have the window open because I've got really sensitive airways".

33

One thing I used to love is a glass of good wine or a good bottle of beer with my curry. Only a little bit – but I can't have any of that now as the alcohol is a trigger connected to my cough.

34

I used to leave the room if I started to cough – but the family have kind of got used to it now. You know – “don't make mum laugh” – is a famous one now, because if I really started laughing I could actually lose myself and be heaving and be in paroxysms.

35

My cough is triggered by stress or anxiety. If I know I'm going to be in a situation where I might be anxious then using meditation techniques can help me stay as relaxed as possible, otherwise I end up coughing more.

36

Sometimes I make something up about why I cough. So I'll say, “I'm terribly sorry but I'm allergic to chilli” or whatever I think is appropriate.

37

It's indoor air pollution. And even small things that people can do to take away those triggers – like not using sprays in public places can make such a massive difference.

38

There are things that are hard to talk about. There are implications for new relationships and having sex or doing exercise and things that make you breathe heavily. And it can be really helpful to be upfront about this – it can really take some of the shame out of it and be more empowering. And to realise that it's okay to talk about these things so that you can navigate ways of making it better.

39

I always loved singing when I was younger. I was a really good singer. But after I had children one of the things I found really difficult was trying to sing to my children – nursery rhymes and songs – not being able to sing without having spasms of coughing. You know, not being able to share that with them. And it's a little thing, singing to children, but it's really important to me.

40

I only have to go outside into the cold and I start coughing.

41

The best thing is when people stay calm. Because what you don't want is someone thumping you on the back and coming over with loads of drinks and panicking around you.

42

For me, the most helpful thing is if people give me space and time. I know that's kind of counter intuitive because everyone wants to help and pat you on the back to make you feel better, but sometimes you just need a bit of space to manage it. It's okay to just take a bit of time, or to withdraw from a room for a while, and then to come back. It's best when people are calm about it.

43

You just have to keep going. Work out your own copng mechanisms. And don't give up!

44

If people understand in advance what might happen that can really help to reduce the anxiety and that reduces the cough.

45

I take advantage of the good days – I like to be out in the countryside or go down to the sea. I think you've got to reinvent your life in all sorts of ways.

46

You need to really listen to your body in order to live well with it and manage it.

47

You can feel empowered if you learn about what's behind chronic cough – being able to use words like 'chronic' or 'hypersensitive' or 'trigger' can really help.

48

A lot of the time, when I've told people in advance that it might happen then it never does. And I think partly that's because I know it's covered. I'm calm and in control. And of course it does still happen sometimes, but when it does happen, it's just a little bit easier to manage in front of people when they know what's happening.

49

I wear a pair of period pants, for reassurance, so that I know that I'm covered for any eventuality. It means I feel in control in front of other people and that's really important – to have dignity.

50

I'm determined not to let my cough turn me into a grumpy person!



Part 2

# Social Tips & Tricks

**On the following pages you will find a list of ideas and suggestions about managing cough and coughing in social situations. On the left hand pages are tips and tricks for people who cough. On the right hand pages are tips and tricks for people who respond to cough.**

You can read these tips together or separately. Some of the ideas might work for you. Others probably won't. That's okay - feel free to doodle, make notes, fold corners, cross out anything you don't agree with. There are also some spaces and prompts for you to add your own thoughts. Adapt this book and make it your own.

## If you have a cough

You will find suggestions about how you might manage social situations in proactive and positive ways – from getting to know your cough and its triggers, to talking about your cough and feeling more in control.

## If you know someone who coughs

You will find suggestions about how you might respond to people who cough in supportive ways – from being kind and staying calm, to taking time to learn more about cough and the impact it has on people's lives.

## Know Your Cough

Listen to your body. Get to know your cough and what triggers it. You can use this knowledge to manage your cough in public spaces and in social situations. Talking about your triggers could help you to avoid them or allow people to understand why you are coughing. Ask for what you need to live more comfortably with your cough.

Related Anecdotes 5 14 15 32 46

telling people what I need

What triggers your cough?

## Be Kind

Try to avoid responding to someone with chronic cough with unkind words or looks. A simple smile of reassurance can make a huge difference to someone who is coughing. Feel free to offer water, sweets or tissues, but know that different things help different people. Make people feel welcome and included, even if they are coughing.

Related Anecdotes 2 3 9 11 21 25

Some people know what to do

Ways to be kind to people who cough...

# Feel Prepared

Plan ahead so that you have what you need if you do start coughing. You could create your own personal 'Cough Survival Kit.' Being prepared can make you feel calmer and more in control. Let other people know in advance if you think you might start coughing, to avoid unwanted reactions. Let people know how you'd like them to respond if you cough.

Related Anecdotes 10 12 13 22 31

water!

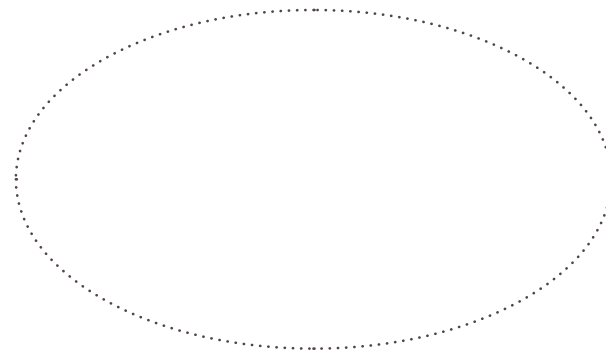


# Give Time and Space

One of the things that people with chronic cough say is that they find it embarrassing when people panic and make a big fuss or when people stare at them. Usually the coughing will pass in a short time and the person just needs a moment. Be patient, keep calm and don't overreact.

Related Anecdotes 6 41 42

just ignore it!



# Give Information

Learn about the biology of cough and share your knowledge with other people. This can defuse a situation if you do start coughing and help people to understand more about chronic cough. Have some key facts or phrases ready that you feel comfortable with.

Related Anecdotes 29 32 47

# Ask Questions

If you know someone who coughs, ask how you can support them. Show an interest in their condition and how it affects them. Take their cough seriously – don't trivialise it. Talk in advance about what they would like you to do if they start coughing. Show them you understand that different things work for different people.

Related Anecdotes 16 44

*have a chat*

Rather than saying 'it's not infectious'  
say what your cough 'is'

MY CHRONIC COUGH IS TRIGGERED BY...  
I HAVE SENSITIVE AIRWAYS  
THE NERVES IN MY THROAT OVERREACT  
MY ALLERGIES MAKE ME COUGH

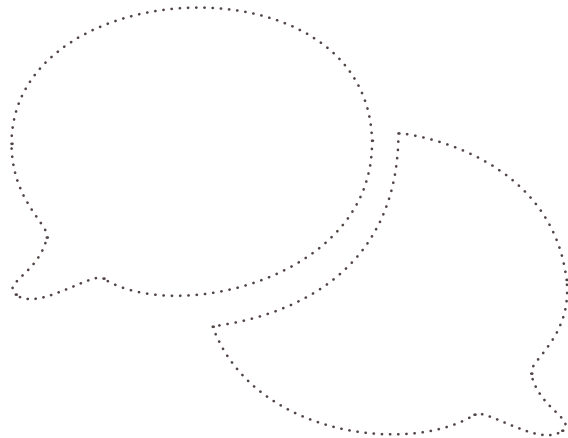
HOW CAN I HELP?  
WHAT TRIGGERS YOUR COUGH?  
HOW DOES YOUR COUGH AFFECT YOU?  
WHAT HELPS YOUR COUGH?

# Talk About It

Having conversations about your cough can help people to understand and empathise and this might make you feel more positive too. Sometimes it will feel difficult to talk about your cough but finding your own way to open up can be empowering.

Related Anecdotes **19** **38** **48**

*take the shame away*



# Find Out More

Take time to learn about cough and the impact it has on people's lives. Find out about the common triggers of cough and when they cause the biggest problems for people. Understand the effects of a long-term cough on someone's body, on their mental health and on their relationships with friends and family.

Related Anecdotes **1** **8** **17** **24** **27** **33** **39**

*always waiting*



Cough is...

# Feel in Control

You are the expert on you and your cough. Trust yourself and work out what makes you feel prepared, positive and in control. Living with cough is not easy, so do whatever works for you to live well with your cough.

Related Anecdotes 7 35 36 43 45 49

*the good days*

What makes you feel in control?

# Take Responsibility

We all have a responsibility for the impact we have on the air around us. If you spend time with someone who coughs, think about how you can make your environment more 'cough friendly'. Consider changes that you can make so that life is more comfortable for them.

Related Anecdotes 30 32 37

*take away the triggers!*

- AIR FRESHENERS
- DEODORANT
- CLEANING SPRAYS
- SMOKE
- STRONG SMELLS
- 
- 
- 
-

# Let's talk about **COUGH**

This pocket book was created by the participants and collaborators of Let's Talk About Cough. Let's Talk About Cough aims to create empathy and understanding about chronic cough and its impact on people's lives by sharing stories in creative ways.

If you would like to find out more about chronic cough, please visit our website.

[www.letstalkaboutcough.net](http://www.letstalkaboutcough.net)

You can find us on X and Instagram at

[@LetsTalkCough](https://twitter.com/LetsTalkCough)

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