

One in Ten

TRANSCRIPT

GUIDE

Hello and welcome to *One in Ten*.

We're so pleased you're here.

I hope you can hear me alright.

Feel free to turn up the volume if you need to.

I'll be your guide for this audio experience.

It will last about 30 minutes.

During the audio experience there'll be times when I will give you simple instructions.

It's always your choice how to respond.

Everyone is different and there are no rights or wrongs here – this experience is for you, and you must do what's right for you.

While you're listening, you might find that you stop paying so much attention to your surroundings, so I just want to remind you to stay safe.

Take care of yourself.

Now, I'd like you to find a place to sit. Make yourself comfortable.

I'll give you a moment to do that.

Close your eyes or soften your focus and look down at your lap.

You're in a library.

Full of books.

Imagine all of the stories and experiences, captured in words and put into these books.

I'd like you to take a nice deep breath, and relax.

You probably haven't been thinking about the floor under your feet, or the seat under your legs – the surfaces supporting the weight of your body.

Can you feel them now?

We don't usually sit consciously thinking about what these surfaces feel like – they're just there and our brains have decided they're not that important.

Now I'd like you to shift your attention to your breath.

Where do you feel this breath in your body?

In your nose or chest or stomach?

Is your breathing fast or slow?

Your body usually breathes without you even being aware of it – you don't need to pay attention because this is just what happens.

Your brain is incredible – it's receiving lots of signals from different bits of your body all the time, so that it knows what's going on, but most of the time, you're completely unaware of those signals.

They are below a threshold – which just means they're dealt with unconsciously. Your brain is doing its job.

By *not* making you aware of these things it's making sure you can get on with all the other things you need to do.

There's so much going on right now in your body that you're not conscious of – your heart and your lungs; your guts and skin, your eyes – so much that if you were consciously aware of everything then you'd be bombarded - you would be completely overwhelmed.

So, most of these things stay below the threshold of what you need to know, for now - that is, unless something changes or goes wrong.

How you are feeling now?

Does anything feel uncomfortable?

Do you have a headache, or an irritating itch, or toothache?

I hope not, but if you do, you'll probably notice these things – because they've moved above the threshold.

I'd like you to just focus on your throat for a moment.

In fact, let's go there. Inside the throat. It's warm, humid, dark, packed full of nerves.

You probably wouldn't usually notice these nerves - they're just there, receiving all the time, under the threshold - unless they detect something different.

Say, for example, you breathe in dust, right now, or a bit of water goes down the wrong way. What do you feel like?

Your throat is suddenly irritated and the nerves flash into action, firing up electrical signals to your brain at lightning speed, making you feel like you want to cough.

Your nerves send messages back from the brain, activating the cough muscles – you take a breath in, your voice box closes, and then the muscles in your chest contract and force air out very suddenly. Up to 50 miles an hour.

The cough reflex. It's there to protect you.

Come back to your surroundings now. Do you have the pen or pencil and paper in front of you?

Take a sheet of paper or turn to a blank page in your notebook.

Write the word 'cough' in the middle.

C O U G H.

You don't have to write in English. Write 'cough' in a different language if you prefer.

Look at this word, 'cough', sitting there in the middle of your page. Draw a circle round it if you like.

What are the next three words that come to mind when you look at this word 'cough'?

Write or draw them on the same page. I'll give you a moment to do this.

Can you think of the last time you coughed? You might not even be able to remember it.

Have you ever had a cough that you couldn't control? When your throat doesn't stop tickling. Where the nerves in your throat are signaling so much that the sensations go over the threshold in ways they wouldn't normally do. When you're always aware of an irritation, when your throat is always there.

If you're sitting, I'd like to invite you to stand up now if you can.. You're going to be moving around for the next few minutes. Feel free to take a seat again when you need a rest.

VOICES Shhhh

GUIDE You're in a library, surrounded by books. Big books, small books; funny, serious, sad books. Imagine all of the stories and experiences, captured in words and put into these books.

VOICES Shhhh
Who is making that cough?

GUIDE Can you walk over to a book shelf? Now walk along it, maybe run your fingers along the spines. Do you notice any books that stand out? Perhaps because of their size or colour or shape.

VOICES [coughing]

GUIDE 1, 2

VOICES [tutting]

GUIDE 3, 4, 5, 6, 7, 8,

VOICES [coughing]

There it is again.

Who is making that cough?

GUIDE 9, 10

VOICES Do you want to get away?

GUIDE [guide counting from 1 to 10 in the background]

VOICES [coughing sounds increase in the background]

GUIDE What if these books were people and the stories inside were their lives? Just imagine. One in ten of those stories would include chronic cough. One in ten people live with chronic cough.

VOICES I was reading a story to my grandson and when I started coughing he immediately put his hands over his ears. That made me feel immensely sad that the timbre of my cough actually affected his wee ears.
At work they put me in the filing room so my cough wouldn't disturb anyone.
So, I've been researching cough for over 20 years now.
Cough is what I'm known for.
Cough is with me all the time, even when I'm not coughing.
A scuttling centipede in my throat
Pickaxes chipping away in my throat
My husband jokes that I can clear a train carriage in three seconds.
I'm exhausted.

GUIDE

Cough. It's not completely uncontrollable is it? Not like hiccups, or sweating, or shivering or sneezing. You can't make yourself shiver or sweat. But you can make yourself cough.

Could you cough now? I'll count down from 3. Ready?

3, 2, 1

Is anyone looking? Is anyone else coughing?

What if you kept coughing? How would that be? [pause] Imagine not being able to stop coughing in a quiet place.

What if someone said something to you?

Or raised their hand.

VOICES

Don't come any closer.

You shouldn't be here.

You're infectious.

Cover your mouth.

You're going to give me something.

It sounds like you're dying.

Why aren't you at home?

Have you had your test?

Have you got Covid?

There was an incident, about 20 years ago, when I went to a concert in Manchester. My husband likes Debussy – so there we were, in the concert hall. My cough was quite prevalent then and I had no way of controlling it. So we got in, and it was Clair de Lune they were playing – very soft. And I hacked my way through it. The ushers kept coming up and passing things to the person on the end of the row saying, “give that woman a sweet.”

So, I'm given lots of sweets and mints and things, and at half time I say “I'm not going back in.” My husband says “come on, it'll be fine.” Ok, we go back in, the conductor comes up, turns to the audience and says:

“Right now then. If we can possibly settle down all the *coughing* we'll carry on.”

And I can safely say I *still* can't really listen to Debussy - my husband still loves it, but I actually have to leave the room when it's on.

One of the things that sticks in my mind is the incident I had after lockdown, during Covid, when I went to my local supermarket and started having a bit of a bad coughing session in there.

And the elderly lady on the mobility scooter was giving me a right evil look as she was driving by me, and she just constantly stared at me as she was driving away and I'm sure she was muttering something under her breath, and the next thing you know, because she was staring at me, she actually ran into one of the assistants who was pushing one of the cages in the shop, which was, you know, really funny and not very nice at the same time because I was coughing.

But I thought, well, maybe there's a bit of karma there somewhere along the line because she ended up demolishing this cage and the shop assistant wasn't very happy!

I suddenly noticed I had a persistent cough.

I woke up and started coughing and have never stopped.

I had a cough on and off for years.

I had a cold.

It started from a hiatus hernia.

I was coughing for no reason.

It started when I was really young.

It started when I was older.

I had a virus.

It started gradually.

I got a dry cough.

A hacking cough.

A disgusting cough, full of phlegm.

A tight cough.

A cough that wouldn't go away.

My cough has become known as 'Granny's cough.' The children ask me 'why do you cough'. 'When will you stop coughing?'

I've had so many tests.

Scans,

x-rays,
tubes down my throat,
camera up my nose,
sputum tests,
blowing into things,
endoscopy
bronchoscopy
MRI scan
Biopsy
back to the doctors,
hoping for results
hoping they will find something.
Hoping they will say, you've got this,
you've got that,
we've got a pill for that.
We tried everything and nothing helped.

I started researching cough back in 2000. At that stage, things were very different. So when I first set up the clinic, which was about three or four years later, we just didn't have any treatments for patients whose cough wouldn't go away when we just treated the underlying condition.

So there's lots of different conditions that underlie chronic cough. But the commonest ones are probably asthma, nasal disease, sinusitis, rhinitis and acid reflux. So we could treat those conditions. But if the cough didn't go away, then you really didn't have anything else to offer people.

And all the literature and all the clinical guidelines at that time basically said, you know, if you treat these conditions, the cough will get better and if it doesn't get better, you're probably just not doing it right.

So one of the things that's changed enormously since then is the recognition that chronic cough won't always go away when you treat these underlying conditions – and it's is a *chronic problem* for people by itself - there's *more to it* than just those conditions.

It's only really in the last 10 to 15 years that people have started to accept that idea that *cough can be a problem in itself and that it's a sensitivity of the nerves that control the cough reflex that's driving the coughing.*

So I guess the other thing that has come out of this is that people have really recognised the role of the nervous system for people with chronic cough and the whole idea that the nerves in the airways and their connections in the brain control the cough reflex.

GUIDE

Hello again. How are you doing? Maybe you're sitting or perhaps you're still standing. Either is fine, as long as you're comfortable.

Did you hear what she just said? That the nerves in your airways and brain control your cough.

Have you thought about that before? That your brain controls your cough? Your brain. The most mysterious, complex, biological structure in the known universe.

And a cough. Just a cough. A little, simple, boring, trivial cough. Just a cough.

I'd like you to find another piece of paper or page of your notebook. At the top of the page write 'BRAIN' or draw a picture of a brain, a simple oval shape will do. At the bottom of the page write 'LUNGS' or draw a picture, like an upside down tree, with a trunk splitting into two main branches and lots of smaller branches. Now draw a line between the brain and the lungs, joining them up.

There it is. The pathway between your airways and your brain. Can you draw in more lines of the nerves? Brain to throat. Brain to lungs. Brain to airways. Those electrical signals running up and down, up and down. Under the threshold, without you having any conscious awareness of them.

On another piece of paper or in your notebook, draw a horizontal line halfway up the page. Find the centre of your line with your pen or pencil, draw a small circle over the line and colour it in.

This is an ion channel. It's one of thousands and thousands of ion channels found in the cells lining your airways. It's how your cells sense the world around them.

Now make 6 or 7 tiny dots in the space above your line.

These are molecules – chemical messages that trigger the channels to open – the tiny particle of diesel pollution you breathed in earlier , the chilli from a spicy meal, the spray cleaner for your kitchen worktop, the change in temperature when you opened your front door, the steam of a shower. But there’s a tipping point. Not everything stays under the threshold of your conscious awareness.

This is an avalanche.

VOICES

A million tons of snow.

A million ion channels sensing.

A slight shift.

A tremor.

A tickle.

A shudder.

A scratch.

A trigger.

A vibration.

The pressure of one flake too many.

The channels respond, the channels open

The signal is sent, over and over. [pause] The response.

A cloud of icy particles rises into the air,

The snowpack shatters, tumbles and falls, racing, hurtling.

Explosive power; unstoppable force.

Will I be sick, will I black out, will I wet myself or crack a rib, have a panic attack, put my back out

Will I be stared at, will I be shamed, will I frighten my grandson, embarrass my husband

What will they say, will they be kind

I’m eating my lunch. Enjoying freshly baked bread with melting butter. Then it happens. The quick intake of breath and I know what’s coming.

The choking, spluttering, tears running down my cheeks as I try to suppress the cough. I fight back the sensation that my bread is going to projectile across the room.

I gratefully grab the glass of water passed to me by my son (one more lunch spoiled by my cough).

My son hands me a tissue and I wipe my face and calm myself. I return to eating, no longer enjoying the bread but eating carefully.

We've had an issue for a long time - that people don't take cough research seriously.

I do feel like it's getting better, slowly - but when I first started there was very much a sense of "Why would you want to spend your time working on that?"

Lots of people do try to help.

People mean well.

Would you like a sweet? Murray mint, polo mint, fresh mint, chewing gum?

Glass of water? A tissue?

Cough syrup, honey and lemon, kind words.

Antibiotics, inhalers, bay leaves steeped in tea.

Nasal sprays, tablets, lotions, potions.

We try everything and nothing helps.

Cough is triggered by:

cleaning products,

sprays,

changes in atmosphere,

changes in temperature,

warm to cold,

cold to warm,

singing,

humid to dry,

dry to humid,

spicy food,

perfume,

deodorant,

laughing.

Don't make me laugh.

Sometimes sensitive nerves will fire off a cough without any trigger at all.

Sometimes you can't find a reason - sometimes it's *nothing* that makes you cough!

It is an alien invader.

This alien within.

This slimy, ugly creature that bullies me day after day after day.

This bully, it forces me to think about it all the time. To plan every day meticulously, knowing it will appear. The silence, when it's not there is sometimes the worst, waiting, waiting for the trigger, the bullet, the bomb in my lungs.

It is: headaches

exhaustion

broken ribs,

sleepless nights

leaks

separate beds

irritation

back pain

aching muscles

panic attacks.

It is coughing until you are sick,

choke

nearly black out.

If I met this alien, this thing, this cough, I would torture it to death. Slowly.

Sometimes you've got to laugh.

I was on a skiing holiday a few years ago with my niece. We were skiing in the shaded part of the mountain so decided to get the bus to the sunnier side. We started off, and then the bus driver started shouting something back in German.

I speak some German and I said to my niece - "I think the driver is looking at us."

We wondered if he was telling us we were in the old folk's seats!

And then I caught something about "Krankenhaus". I said to my niece "he's talking about the hospital."

Well, he got louder and louder and eventually pulled up at a place that wasn't a bus stop. And he sort of turned around and spoke to me. And what I translated was, "you are dreadfully ill. You need to go to hospital. I will take you."

And then he said to the rest of the bus "Would anybody have any major objections if I take the bus to the hospital?"

Well my niece was nearly on the floor in embarrassment but to my absolute amazement everybody in the bus agreed to go to the hospital - "Let's go, let's go" - thinking, this poor woman is dying, come on! And I'm trying to say in German, "no no, it's a frog in my throat" - not even realising I'm coughing! And when we finally got to our stop, everyone was looking at us and people were trying to give me sweets and schnapps and anything that might help. And it was so embarrassing but so nice really - so many people willing to change their plans for me on that day.

It's like the flipside of people being really horrible.

And now as soon as I say Krankenhaus to anyone I know, they fall about laughing.

Sometimes you've got to laugh.

I have tried to find a way to adapt to it, accept it and live with it.

I am aware of things I need to avoid or limit.

I do not want it to rule my life.

I still go to concerts quite often - but now I choose really loud, clanging, cymbal type music so that if I happen to cough, most of the time, people don't even hear it

GUIDE

Hi again.

I wonder how you're feeling now?

What's changed for you since you wrote that word 'cough' at the start of this experience?

Can you find the page that you wrote on?

Do you have anything that you'd like to add to that page now? Any thoughts or feelings?

I'll give you a moment to write or draw.

Can you find another piece of paper? Or a blank page?

Is there anything you'd like to say to the people whose voices you've been listening to? Anything you'd like to tell them? Anything you'd like to share?

I'll give you a moment, in case you'd like to write or draw something. Only if you want to.

VOICES

There's a lot of serendipity – we took a punt to see whether this treatment would work - not realising that this was the one that would have the big effect.

We started a small trial - it was about 26 patients from our clinic.

It was like nothing we'd ever experienced before where, within days of starting this treatment, people were ringing up saying I'm loads better. You know, in studies you might get small effects or a little bit of a placebo effect, but this was completely different and it really was just profound.

It was completely obvious to us that we'd found something.

There are lots of similarities with pain - people are far more familiar with the idea of 'chronic pain'. We realised that in chronic cough this hyperexcitability of the nerves - the chemical ATP is making the nerves in the airways more active.

We don't want to block this completely - just to tone down the reaction of the nerves.

It's very exciting. We really have found something.

GUIDE

If you're sitting down, stand up now and stretch your legs if you can.

Take a deep breath. How are you doing? Look around you. What can you see? Who can you see? Are there any familiar faces?

We really have found something.

VOICES

I'm Dean, and I've had a chronic cough for 15 years and I want to tell you that meeting other people who suffer with this and finding out I'm not alone has changed my life.

I'm Jacky, and I've been researching chronic cough for 20 years and I want to tell you there has never been a more exciting time for chronic cough research, we really have found a drug that works.

I'm Linda, and I've had a chronic cough for more than 25 years and I want to tell you that knowing there's excellent research going on to understand the biology of cough gives me hope for the future.

I'm Eric, and I've been researching chronic cough for 12 years and I want to tell you that it is a long and arduous journey but hope is finally on the horizon.

I'm Siobhan, and I've been treating people with chronic cough for 12 years and I want to tell you we need to find more ways of talking about cough and sharing experiences between professionals and patients so that it's taken seriously.

I'm Sudhir, and I've had a chronic cough for 6 years and I want to tell you that meeting others with chronic coughs and understanding the biology behind the cough has been very assuring to me and made it easier to live with.

I'm Jono and I've been researching chronic cough for eight years and I want to tell you that this area of unmet clinical need is finally getting the recognition it deserves. This research is ongoing but it's now regarded as vital and worthy of pursuit.

I'm Bethan and I've had a chronic cough for 12 years and I want to tell you that I want to live more comfortably with my cough and hope that the research can help me with that.

I'm Joan and I've had a chronic cough for 30 years and I want to tell you I will not let my cough stop me from living my life on my terms.

GUIDE

Thank you for listening to *One in Ten*.

We'd love to keep in touch. You can find more information about our project, Let's Talk About Cough, at www.letstalkaboutcough.net