

Gastro or endometriosis? How your GP discusses uncertainty can harm your health

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Credit: Sora Shimazaki/Pexels

You wake with stomach pain that worsens during the day and decide to see your doctor. You describe your symptoms and your doctor examines you. Then the doctor says, "From what I hear, I think you could just have a stomach bug. Rest and come back in three days."

This might be a less definitive answer than you're after. But doctors can't always be sure of a diagnosis straight away. As my review shows, doctors



use various ways of communicating such uncertainty.

Sometimes there is a mismatch between what doctors say when they're uncertain and how patients interpret what they say, which can have harmful consequences.

Why does uncertainty matter?

Doctors <u>cannot always explain</u> what your health problem is or what caused it. Such diagnostic uncertainty is a normal and <u>ever-present part</u> of the processes leading to a diagnosis. For instance, doctors often have to rule out other possible diagnoses before settling on one that's most likely.

While doctors ultimately get the diagnosis right in 85%–90% of cases, diagnostic uncertainty can lead to diagnostic delays and is a huge contributor to harmful or even deadly misdiagnoses.

Every year, an estimated 21,000 people are seriously harmed and 2,000–4,000 people die in Australia because their diagnosis was delayed, missed or wrong. That could be because the wrong treatment was provided and caused harm, or the right treatment was not started or given after the condition had already considerably progressed. More than 80% of diagnostic errors could have been prevented.

Three <u>medical conditions</u>—infections, cancer and major vascular events (such as strokes or heart attacks)—are the so-called "<u>Big Three</u>" and cause devastating harm if misdiagnosed.

In my review, the top three <u>symptoms</u>—fever, <u>chest pain</u> and <u>abdominal pain</u>—were most often linked to diagnostic uncertainty. In other words, most of us will have had at least one of these very common symptoms and thus been at risk of uncertainty and misdiagnosis.



Some groups are less likely to be diagnosed correctly or without inappropriate delay than others, leading to <u>diagnostic inequities</u>. This may be the case for <u>women</u>, and other groups marginalized because of their <u>race or ethnicity</u>, <u>sexual orientation or gender identity</u>, or <u>language proficiency</u>.

How often do you hear 'I don't know'?

My research showed doctors often make diagnostic uncertainty clear to patients by using explicit phrases such as: "I don't know."

But doctors can also keep quiet about any uncertainty or signal they're uncertain in more subtle ways.

When doctors believe patients prefer clear answers, they may only share the most likely diagnosis. They say, "It's a stomach bug" but leave out, "it could also be constipation, appendicitis or endometriosis."

Patients leave thinking the doctor is confident about the (potentially correct or incorrect) diagnosis, and remain uninformed about possible other causes.

This can be especially frustrating for patients with chronic symptoms, where such knowledge gaps can lead to lengthy diagnostic delays, as reported for <u>endometriosis</u>.

Subtle ways of communicating uncertainty include hedging with certain words (could, maybe) or using introductory phrases (my guess, I think). Other implicit ways are consulting a colleague or the Internet, or making follow-up appointments.

If patients hear "I think this could be a <u>stomach bug</u>" they may think there's some uncertainty. But when they hear "come back in three days"



the uncertainty may not be so obvious.

Sharing uncertainty implicitly (rather than more directly), can leave <u>patients</u> unaware of new symptoms signaling a dangerous change in their condition.

What can you do about it?

1. Ask about uncertainty

Ask your doctor to share any <u>uncertainty and other diagnostic reasoning</u>. Ask about alternative diagnoses they're considering. If you're armed with such knowledge, you can better engage in your care, for example asking for a <u>review</u> when your symptoms worsen.

2. Manage expectations together

Making a diagnosis can be an evolving process rather than a single event. So ask your doctor to outline the diagnostic process to help manage any mismatched expectations about how long it might take, or what might be involved, to reach a diagnosis. Some conditions need time for symptoms to evolve, or further tests to exclude or confirm.

3. Book a long appointment

When we feel sick, we might get anxious or find we experience heightened levels of fear and other emotions. When we hear our doctor isn't certain about what's causing our symptoms, we may get even more anxious or fearful.

In these cases, it can take time to discuss uncertainty and to learn about our options. So book a long appointment to give your doctor enough



time to explain and for you to ask questions. If you feel you'd like some support, you can ask a close friend or family member to attend the appointment with you and to take notes for you.

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