

Conversation guides

GENERAL GUIDE

How to talk about your colitis

Here are some things to consider when you are worried about talking about your colitis.

1. Your feelings are normal

It's completely understandable to feel embarrassed, anxious, or unsure how to explain your condition. Many people with colitis feel the same way. Acknowledging your feelings may help reduce your stress.

2. You get to choose what you share

You decide how much, or how little, to say. You can keep things very simple, give general information, or share more detail depending on the situation and the person. It's important that you get to talk about your colitis in ways that feel comfortable and that meet your needs.

3. Think about what matters most to you

Before you speak, you might ask yourself:

- Do I want privacy?
- Do I want understanding?
- Do I need support today?
- Do I just want to prevent misunderstandings?

4. Notice unhelpful thoughts... they don't have to guide you

It's common to think:

- "People will judge me."
- "I'll say it wrong."
- "I shouldn't talk about this."

These thoughts are normal, but you can still choose to communicate in a way that feels right for you.

5. Keep your explanation simple

You don't need to give medical detail. A short, clear sentence is often enough.

6. Start with small, easy conversations

If talking about your colitis feels hard, start with people you trust or with less personal topics, then build up to more challenging ones.

7. It's okay to set boundaries

You can protect your privacy and still communicate clearly. You might repeat your main point, say you don't want to share more, or redirect the conversation.

8. Misunderstandings are common - you can correct them gently

If someone assumes something, you haven't done anything wrong. Colitis is often invisible and can be complicated. You can correct someone briefly without giving extra detail.

9. Choose another way to communicate if speaking feels too hard

You can write a message, choose a calmer moment, or share a prepared sentence instead of talking face-to-face.

Just remember...

You're in control of how you talk about your condition.

Keeping things simple, choosing what matters to you, and taking small steps can help these conversations feel safer and easier

GENERAL GUIDE

How to talk about your colitis

Here are some things to consider when you're worried about talking about your colitis. Everyone's situation is different, and the "right" approach will depend on who you're speaking to, your relationship with them, and the setting (for example, work, social, or home). There is no single correct way to explain your condition—what matters most is finding an approach that feels appropriate and comfortable for you.

1. Your feelings are normal

It's completely understandable to feel embarrassed, anxious, or unsure how to explain your condition. Many people with colitis feel the same way. Acknowledging your feelings may help reduce your stress, and those feelings may shift depending on the person or environment.

2. You get to choose what you share

You decide how much, or how little, to say. The amount of information you share may differ between a colleague, a friend, a partner, or someone you've just met. You can keep things simple, give general information, or offer more detail—but only if *you* want to. You're allowed to change your approach depending on the moment.

3. Think about what matters most to you right now

Before you speak, you might ask yourself:

- Do I want privacy?
- Do I want understanding?
- Do I need support today?
- Do I want to prevent misunderstandings?

Your priorities can vary between situations—for example, you might aim for clarity at work but seek emotional support from a friend.

4. Notice unhelpful thoughts... they don't have to guide you

It's common to think:

- "People will judge me."
- "I'll say it wrong."
- "I shouldn't talk about this."

These thoughts are normal, but they don't decide how the conversation goes. You can still respond in a way that fits the context and feels right for you.

5. Keep your explanation simple

You don't need to give medical detail, especially in settings where it isn't necessary—like work or casual social events. A short, clear sentence is often enough. If you feel comfortable, you can give more context in closer relationships or more private settings.

6. Start with small, easy conversations

If talking about your colitis feels hard, begin with people you trust or with less personal topics. Over time, you can build toward conversations that feel more emotionally demanding or happen in more formal environments.

7. It's okay to set boundaries

You can protect your privacy while still being clear. Setting boundaries may look different at work versus with friends. You might repeat your main point, say you don't want to share more, or gently change the subject. All of these are valid.

8. Misunderstandings are common – you can correct them gently

If someone makes an assumption, it doesn't mean you've explained things poorly. Colitis is invisible and often misunderstood. You can correct misconceptions briefly and in the way that fits the situation—more detail with friends, less detail in professional settings.

9. Choose another way to communicate if speaking feels too hard

You can write a message, share a prepared sentence, or choose a calmer moment. This can be especially helpful in work environments or situations where you need time to think through what you want to say.

Just remember...

You're in control of how you talk about your condition.

There is no single right script—different situations call for different approaches. Keeping things simple, choosing what matters to you in that moment, and taking small steps can help these conversations feel safer and easier

USEFUL PHRASES

It can be difficult to know what to say, so here are some general phrases you may want to consider. Adapt them to what works for you.

A. Keeping things general

- “I have a long-term health condition that affects my digestive system.”
- “I manage a condition that can flare unpredictably.”
- “I’m having a difficult symptom day.”

B. Explaining colitis simply

- “Colitis causes inflammation in my gut.”
- “It can cause pain, fatigue and urgent bathroom needs.”
- “It varies a lot day-to-day.”

C. Explaining invisible symptoms

- “My symptoms aren’t always visible, but they can still be difficult.”
- “I might look okay, but internally I can be struggling.”

D. Talking about limitations or plans

- “I need to be near a bathroom today.”
- “I may need to take breaks or adapt plans.”
- “I’d love to join, but my symptoms mean I need flexibility.”

E. Setting boundaries

- “I prefer not to go into detail, but here’s what’s useful to know.”
- “I’m keeping some things private, but I can share the basics.”
- “That’s all I’m comfortable saying for now.”

F. Handling misunderstandings

- “It’s a bit more complex than it sounds.”
- “I can see why you’d think that, but the reality is...”
- “Actually, my colitis affects me like this...”

G. Advocating for support

- “It helps me if I can take short breaks.”
- “I need quick access to a bathroom at times.”
- “Flexibility makes a big difference on difficult days.”

H. Reducing embarrassment

- “This feels a bit awkward to say, but it’s just part of how my body works.”
- “Talking about this isn’t easy, but it helps things go more smoothly.”

Scenario-based conversation guides

Situation

Someone asks why you've been unwell, but you don't want to share that it's because of your colitis.

What's going on in this situation?

It's understandable that this situation feels hard. Questions can catch you off guard, and you might worry that not mentioning your colitis seems dishonest or feel as though the other person is pressing you for details you don't want to share.

What matters most to you here?

- ☐ Protecting your privacy
- ☐ Helping someone understand
- ☐ Getting practical support
- ☐ Avoiding misunderstandings

What you might feel or think

It's common to feel embarrassed or under pressure when someone asks direct questions. You may also feel resentful about being asked something so personal or about feeling responsible for educating others about colitis when it's still new to you.

What you could try

Give a brief, general answer that doesn't reveal more than you want

- "I've had a flare-up of a long-term condition"

Set a boundary kindly but firmly

- "I appreciate you asking, but I'd rather not go into the details."

Shift the focus if you don't want to continue the conversation

- "I'm on the mend now. How are things with you?"

Use a prepared phrase if you find these situations stressful. Having a rehearsed line can make the moment feel less pressured.

Remind yourself that **privacy is legitimate**. You're not being dishonest, you're protecting your comfort and wellbeing.

What to keep in mind

You don't owe anyone personal medical details. Choosing what to share (and with whom) is part of looking after yourself. A simple, polite boundary is enough.

What would you say in a situation like this?

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Situation

You want to explain what colitis is like to someone else.

What's going on in this situation?

You may want someone to understand colitis so they worry less and so you feel less anxious about being misunderstood. Sharing can help you feel supported, but it's normal to find it hard to explain when you're still working things out yourself.

What matters most to you here?

- ☐ Protecting your privacy
- ☐ Helping someone understand
- ☐ Getting practical support
- ☐ Avoiding misunderstandings

What you might feel or think

You might worry about saying the wrong thing or feel unsure how to describe colitis clearly. It's common to feel uncertain or to doubt whether you have the "right" words.

What you could try

Start with a simple explanation. You don't need to describe everything at once.

- "Colitis is a long-term condition that affects my gut and can cause flare-ups."
- "It's an inflammatory condition that affects my digestion and energy."

Explain in your own words. You don't need medical terminology.

- "Colitis can affect my day differently from one day to the next."
- "It's unpredictable at times."

Prepare a **"go-to" phrase** beforehand to take the pressure off.

- "I have a long-term inflammatory condition that affects my gut. It's manageable, but it can make life unpredictable."

Use a comparison if it helps. Analogies can make something unfamiliar easier to grasp.

- "The fatigue is constant. It's like I'm weighed down from the moment I wake up."
- "Everything has changed and I'm just trying to grab pieces of the old me."

What to keep in mind

You don't need the perfect words to explain colitis. Keeping it simple is fine. Share only what feels comfortable, and it's fine if your explanation changes as you learn more about your condition.

What would you say in a situation like this?

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Situation

You want to explain how your symptoms affect your day-to-day life.

What's going on in this situation?

You may want to help someone understand why you need more time, change plans, or need support day to day. Explaining the impact of your symptoms can make your needs clearer without sharing personal details, though it can still feel uncomfortable to talk about.

What matters most to you here?

- ☐ Protecting your privacy
- ☐ Helping someone understand
- ☐ Getting practical support
- ☐ Avoiding misunderstandings

What you might feel or think

You may feel unsure about how much detail to give or worry that you will overshare. It's normal to feel self-conscious or uncertain when talking about symptoms, especially those that feel private.

What you could try

Use everyday language to explain the impact.

- "Sometimes my symptoms make me tired or mean I need to stay close to a bathroom."
- "It's unpredictable at times, so I may have to change my plans at the last minute."

Explain the effect, not the full symptom list.

- "I may need more breaks."
- "Some days I won't feel my best even if I look fine."

Share only what feels relevant.

- "It means I can run out of energy quickly."
- "I may need to leave the room in a hurry to go to the toilet."

Invite questions only if you want to.

- "I'm happy to answer a couple of questions."
- "You can find out more about colitis on the Crohn's and Colitis UK website ([Crohn's & Colitis UK](#))"
- "That's all I want to say for now."

What to keep in mind

You can explain the impact of your symptoms without going into personal details. A simple description of what you need or how you're affected is often enough for others to understand and support you.

What would you say in a situation like this?

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Situation

You find it embarrassing to talk about colitis symptoms.

What's going on in this situation?

Symptoms involving digestion or urgency can feel too personal to talk about, so embarrassment is completely normal. Most people aren't used to discussing these topics, which can make it hard to find the words even when you want support.

What matters most to you here?

- ☐ Protecting your privacy
- ☐ Helping someone understand
- ☐ Getting practical support
- ☐ Avoiding misunderstandings

What you might feel or think

You might feel embarrassed, ashamed, or self-conscious talking about symptoms. You may worry that bringing them up will make the other person uncomfortable or change the way they see you. You may also feel unsure how much detail is "too much," or worry that you'll say something you regret. All of these reactions are common, many people find it difficult to discuss symptoms, even with people they trust.

What you could try

Use simple, neutral language. You can explain what you need without going into personal detail.

- "I sometimes need the toilet urgently."
- "My symptoms can be unpredictable."

Describe how symptoms affect you day to day, rather than giving specific details. This helps people understand your needs without discussing anything you find embarrassing.

- "I might need extra breaks."
- "I may need to stay close to a bathroom."

Make a list of words you're comfortable using. Having your own vocabulary (words that feel safe, matter-of-fact and you would normally use) can make conversations easier.

Practise with people you trust. Talking with someone you already feel safe being open with can help build confidence before you talk to others.

Write it down if that feels easier. A short message or note gives you space to choose your words and reduces the pressure of saying things aloud.

What to keep in mind

Feeling embarrassed is completely normal, talking about symptoms is hard for many people. You never have to share more than feels comfortable, and simple explanations are usually enough. As you gain confidence, you can decide if you want to share more, less, or nothing at all.

What would you say in a situation like this?

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Situation

Someone misunderstands you or makes unfair assumptions because of your colitis.

What's going on in this situation?

Because colitis is mostly invisible, people may make assumptions that aren't fair or accurate. They might question your reliability or your need for things like disabled toilets because they can't "see" your symptoms. These moments can feel embarrassing or frustrating, and even when you want to correct the misunderstanding, finding the right words can still be difficult.

What matters most to you here?

- ☐ Protecting your privacy
- ☐ Helping someone understand
- ☐ Getting practical support
- ☐ Avoiding misunderstandings

What you might feel or think

You might feel embarrassed, annoyed, or upset that someone has misjudged you. You may also worry that speaking up will make things awkward or require you to explain more than you want to. It's common to feel unsure about how to respond when assumptions take you by surprise.

What you could try

Correct the misunderstanding with one clear fact.

- "I have a medical condition that isn't visible but does affect what I can do."
- "I do need this toilet/adjustment, even if you can't see why."

Explain briefly how colitis affects your day-to-day needs.

- "Symptoms can come on suddenly, so I sometimes need quick access."
- "My condition can be unpredictable, so plans may change without warning."

Use words you're comfortable with. A short list of terms (like flare-up, urgency, fatigue, or bathroom access needs) can help you respond clearly in the moment.

Prepare in advance. Writing down or rehearsing a few simple lines can make it easier to respond calmly when misunderstandings happen. Tools like the [CCUK "Can't Wait" card](#) can give you more confidence.

Know that **you don't have to respond immediately**. If it feels uncomfortable or unsafe, it's okay to disengage and decide later whether you want to explain... or not at all.

What to keep in mind

Misunderstandings don't mean you've done anything wrong. Colitis is largely invisible, and people often don't know what it involves. A brief correction is enough. You don't have to explain more than feels comfortable. Your needs and experiences are valid, even if someone else didn't recognise them at first.

What would you say in a situation like this?

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Situation

You don't feel that you are getting enough support and want to speak up for what you need.

What's going on in this situation?

It can be hard when people around you don't understand what colitis is like or what support would help. They may not realise how unpredictable symptoms can be or how much they affect daily life. You might feel overlooked or unsure how to bring it up, especially if you're worried about being judged or not taken seriously.

What matters most to you here?

- ☐ Protecting your privacy
- ☐ Helping someone understand
- ☐ Getting practical support
- ☐ Avoiding misunderstandings

What you might feel or think

You might worry that asking for help will be seen as demanding or that your needs won't be taken seriously. You may also feel frustrated or discouraged if you've tried before and didn't feel supported. These reactions are common, advocating for yourself can feel challenging even when the need is completely reasonable.

What you could try

Say clearly what support would help you. Being specific helps others understand what you need.

- "I need quicker access to a toilet when symptoms start."
- "I need more flexibility when I'm unwell."

Explain briefly why the support is important. A short explanation can help people (professionals and non-professionals alike) see why it matters.

- "Without this, it's harder for me to stay well."
- "This will help me to still take part."

Give an example to show what's been difficult. A concrete example helps clarify what's not working.

- "Last week I struggled because I couldn't access support quickly enough."

Suggest practical options. Offering possible solutions can make it easier for the other person to act.

- "Could we look at different working hours?"
- "Who is the best person to contact when my symptoms are urgent?"

Ask who else can help if the person you're speaking with can't make changes.

- "Who would be the right person to talk to about this?"
- "Is there someone else who can help us find a solution?"

What to keep in mind

Advocating for yourself isn't being difficult. It's an important part of managing a long-term condition. You deserve support that helps you stay well and take part in daily life. A clear, simple conversation is often enough to move things forward.

What would you say in a situation like this?

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