

# INVISIBLE CONDITION REP GUIDE

Thank you for signing up and joining our community of invisible condition reps.

This guide will help you understand what your role is, and what it is not. It contains lots of helpful resources for you to signpost your colleagues living with invisible conditions to, plus we've answered some common questions and provided some sections to support you and promote your role.



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# 1

## WHAT IS YOUR ROLE?

As an invisible condition rep, you will be a point of contact for anyone in your company who has an invisible disability or condition. This is a voluntary role. Your official job title won't change and you'll remain employed by your company in that role. Someone with an invisible condition could also speak to their line manager or HR – but some people might not yet have the confidence to have a formal conversation or perhaps just want a different perspective. This is where you come in.

Your role is to listen to anyone who comes to talk to you about their invisible condition and signpost them to the relevant

resources. These resources could be our campaign materials or your company resources such as internal policies. It could also be external support such as your company's employee assistance programme or external charities.

It's important to keep your conversation focused on their invisible condition. There might be lots of other things going on in your colleague's life such as bereavement, money troubles or relationship problems. These things may impact on their invisible condition, but they are separate issues – so remember just signpost where you can and keep focused on the invisible condition. At the end of this

## WHAT IS YOUR ROLE?

guide, we've provided a list of helpful resources for common queries outside of invisible conditions.

Remember, you will not know the answer to all the queries that come your way and that is fine. Sometimes finding out the answer will be down to the individual, their manager or HR. You do not need to know the ins and outs of employment law; if your colleague thinks they are experiencing discrimination or have legal questions, you should signpost them to your HR team, or your union rep if you have one.

If someone with a visible condition wants to talk to you, although your role is primarily to support people with invisible conditions, you can signpost them in the same way. It is worth being mindful that someone can have both an invisible and visible disability or condition. Also, a condition could have originally been invisible but over time it becomes visible perhaps due to surgery or the progressive nature of a condition.

Remember, as invisible condition rep, it's not your job to give out advice, but to listen to staff with invisible conditions, and signpost them to the relevant resources.

Having an invisible condition can be incredibly isolating. In addition to getting to grips with the day-to-day management of your illness, the prospect of trying to explain your circumstances to your employer can be extremely stressful and daunting, especially if they do not have experience with less common conditions such as IBD.

That is why the role of invisible condition rep is so important. Not only can you be the person who understands and supports individuals who may be struggling with their condition, you can also be a voice for those who do not have the confidence to speak up about their needs.

This guide from Crohn's & Colitis UK is an excellent tool to make a success of the invisible condition rep role, regardless of past experience. It can be difficult knowing what to say to someone who is in need of support, however this guide has you covered. By providing a structured approach to these conversations and tips on how to get the most out of support sessions, this guide will empower you to be the best advocate for your colleagues.

**MAX, INVISIBLE CONDITION REP, LIVING WITH CROHN'S DISEASE**

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## TALKING TO A COLLEAGUE

If someone wants to talk to you about their invisible condition, it's important to consider the following things:

### BEFORE YOUR CHAT

#### MAKE TIME FOR THE

**CONVERSATION:** pick a time and place that works for you both. There is no point in having a rushed conversation where all you are thinking about is getting to your next meeting, so agree a date and put it in the diary.

#### MANAGE EXPECTATIONS:

make sure at the start of the conversation that the focus is on their invisible condition and that your role is a signposting role. When it gets toward the end of the meeting say how long you have left, so the conversation starts to winddown.

**REMOTE WORKING:** if your conversation is online via Teams or Zoom we suggest you have your video on. This will allow you to build rapport. Internet quality can vary so if there are time delays or poor video quality then moving over to audio only or the telephone is fine.

## DURING YOUR CHAT

**LISTEN:** your main role is to listen. People with invisible conditions often feel misunderstood, so do not underestimate the power of listening.

**CONFIDENTIALITY:** reassure the person you're speaking to that your conversation will remain between the two of you. However, let them know that if any safeguarding issues are raised, you will have to talk about details of your conversation with HR. Check in with your HR team on your company's safeguarding policy to be sure, but generally these would include: if you believe them to be at risk of harming themselves or others, or if claims of bullying, harassment or unfair treatment in the workplace are made.

**ASK QUESTIONS:** someone might find it difficult taking about what is going on for them, asking some open questions could help. Open question avoid 'yes' / 'no' responses. You could ask:

- Tell me what's been going on
- What support do you feel like you need in the workplace?

**NORMALISE:** it's completely normal for someone with an invisible condition to need things that someone without a condition does not. This does not mean they are making a fuss; it just means they might need a little more support.

**EMOTIONS:** talking about your chronic condition can be emotional. Here are some phrases that could be useful if someone is getting upset

- That sounds really difficult
- It's ok, take your time, I'm listening
- When you're ready go on

**SIGNPOSTING:** it is really important that your colleague feels empowered to do things for themselves. By signposting you are giving them the tools and information to go forward and make things happen themselves. This is the most important part of your role – pointing people in the right direction. Not sure what to say? Remember, if you're not sure of the answer to something just say so. You could suggest they look into it further or speak to HR.

**FINISHING THE CONVERSATION:** it would be useful to point out when there is 5/10 minutes left. This helps you manage their expectations and gives you a chance to do all your signposting. Remember you can use page 21 of this guide to note down anything you might want to signpost to.

**END OF THE CALL:** it can be emotionally draining to talk about an invisible condition. Suggest your colleague takes 5/10 mins after the call to reset - perhaps a short walk or even just making a cup of tea before starting work again.

## AFTER YOUR CHAT

**LOOKING AFTER YOURSELF:** if you need it take 5/10 mins after the call to winddown before you get back into work. And remember if there are any safeguarding issues you need to raise please do so straightaway following your individual company process – if you are unsure please check in with your HR.

**SIGNPOSTING:** if you said you'd send them some information try and do it soon after the call whilst it is fresh in your mind.

**SAFEGUARDING:** if there are any safeguarding issues you need to raise please do so straightaway, following your individual company process(es) – if you are unsure please check in with your HR team before starting your conversations as an invisible conditions rep.

*Please note that some people might not want a face-to-face conversation. It's possible that someone might email you with questions. There is no reason why you can't support over email, particularly where it is a simple signposting question. It's up to you and your colleague to decide. Some people might not feel confident chatting and a simple signposting email might be all they need from you.*

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## COMMON QUESTIONS

### **“I’M STRUGGLING TO DO MY JOB BECAUSE OF SOME OF THE SYMPTOMS OF MY CONDITION AND I’M NOT SURE WHAT TO DO”**

That sounds really difficult. . Most people with an invisible condition have been in this position at some point.

Have you spoken to your manager or HR about how they can support you? If not, that might be helpful. Depending on your condition the Equality Act 2010 might mean that our employer has to make reasonable adjustments to help you manage your condition. Think about what you need to be able to do your job as well as possible and make a list of these. Adjustments might be more regular breaks, adjustment of office equipment, a parking space closer to the office etc. It will depend on your condition though, so it would be best if you talk to your manager.

### **“I’M WORRIED ABOUT TALKING TO MY BOSS ABOUT MY INVISIBLE CONDITION.”**

That is perfectly normal. It can feel difficult to talk about something so personal, but it can also be really helpful for someone at work to understand what support you might need.

You can talk to your manager or you could also talk to HR. I’ve got a guide that can help prepare you for having a conversation – I’ll send it to you.

There might be some online resources that outline your condition that you could send your line manager or HR ahead of the meeting. This will give them the chance to read the information beforehand and means they should start the conversation with you with a little bit of an understanding already. It could also be useful to write down the key points you want to cover in the meeting – this should help you feel in control of the conversation.



## COMMON QUESTIONS

### **“MY LINE MANAGER DOESN’T UNDERSTAND MY CONDITION OR WANT TO HELP ME. WHAT DO I DO?”**

I’m sorry to hear that. Your manager, as part of this campaign should now have access to a guide to help support them with conversations about invisible conditions. Would you feel comfortable trying to talk to your manager again? You could also ask for HR to attend the meeting too or speak to HR separately if you wanted. You have options. What do you think you’d feel comfortable doing? [If your colleague says they are being discriminated against by their manager than you should signpost them to HR or your union rep if you have one.]

### **“I’M WORRIED ABOUT ASKING FOR TIME OFF TO TAKE A MEDICAL APPOINTMENT WHAT SHOULD I DO?”**

Our company has a policy on taking time off for medical appointments, I’ll send it to you. Time off for medical appointments could be a reasonable adjustment our company could make if you are defined as having a disability. If you have any queries you can ask your manager or HR for more details.

### **“I’VE JUST COME BACK TO WORK AFTER A LONG TIME OFF ON SICK LEAVE AND I’M WORRIED ABOUT HOW I WILL COPE. WHAT SHOULD I DO?”**

It’s quite common for people to have concerns about coming back to work after a long time off. I suggest you have a conversation with your manager or HR – they should discuss with you how to manage your return to work. They should give you the opportunity to talk about

## COMMON QUESTIONS

any concerns you might have or request some adjustments. For example, you might not feel able to work a full day at first, so you might want to discuss a phased return where you start by working fewer hours and gradually building up to your usual hours. Or having a reduced workload to begin with might also be helpful, or some refresher training.

**“I FEEL LIKE MY TEAM LEAVE ME OUT OF THINGS BECAUSE OF MY CONDITION AND IT’S GETTING ME DOWN. ONE OF THEM ALSO MADE SOME HURTFUL COMMENTS ABOUT MY CONDITION.”**

I’m sorry to hear this is happening to you. It sounds like there are potentially three issues to talk about. One, that you feel left out by your colleagues, two, a colleague has made a hurtful

comment about your condition and three, you are feeling down about all of this. Does that sound right to you?

If you are being left out of work that is part of your role then you should speak to your manager or HR about it – talking through some specific examples of when it happened is helpful, so perhaps write down a few examples before your meeting.

If you are feeling left out socially of work, perhaps you could suggest to your team or your manager or social committee alternative social activities or timings.

You could ask your manager to talk to your colleague who made the hurtful comments about your condition – perhaps explaining how they made you feel. Or if you felt comfortable perhaps

you could talk to your colleague direct – you could always ask your manager to be present too.

If you have any information about your condition you might want to consider passing onto some of your colleagues or talking to them directly about it. Having an invisible condition is personal and it is up to you what you tell people about it – but if you think people might benefit from understanding more about your condition then this could help.

You also mentioned all this was making you feel down – living with an invisible condition can be difficult sometimes and it’s perfectly normal to feel down sometimes. I can suggest some wellbeing resources that might be helpful. You could also let your manager know how you are feeling now. It can be helpful for

other people to be aware you are not feeling your best at the moment. If you are feeling down frequently, you may find it helpful to book an appointment with your GP, and see what further support is available.

**“I’M HAVING FINANCIAL PROBLEMS BECAUSE OF MY INVISIBLE CONDITION. WHAT ADVICE WOULD YOU GIVE ME?”**

I’m sorry to hear that. My role doesn’t cover training about financial issues but I know our employee assistance programme / Citizen’s Advice can offer financial advice. I can send you the details if you don’t have them.

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## NOTES

Here is some space to make notes as your colleague is talking. This will help you remember any resources you might want to signpost them to. Just avoid writing identifying information about them.

A large white rounded rectangular box with a thin grey border, intended for taking notes. It occupies the right half of the page below the 'NOTES' header.

## COLLEAGUE CONCERNS

**RELATED TO INVISIBLE CONDITION**

**OTHER**

## SIGNPOSTING

**CAMPAIGN RESOURCES**

**COMPANY RESOURCES OR INDIVIDUALS**

**OTHER CHARITIES / ORGANISATIONS**

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## SUPPORT FOR YOU

It's important that you know where you can go if you have any questions. Remember, the following support is out there for you:

**THIS GUIDE:** get to know it well!

**HR:** we recommend you have a meeting with HR before you start in this role. They should make you aware of any relevant policies such as safeguarding, leave for medical appointments or details of your employee assistance programme

**OTHER REPS:** if your company has a lot of staff, they may have appointed several invisible condition reps. It's a good idea to work out a way of keeping in touch and supporting each other – whether that's

monthly catch-ups or regular communication via email or whichever chat platform you use, such as Teams. Do not discuss any details of your conversations with staff with invisible conditions with the other reps.

**SAFEGUARDING:** be familiar with your internal safeguarding procedures before you get started. If you're concerned about a colleague harming themselves or others then you should follow these procedures immediately, contacting the relevant people/department

**FEEDBACK:** please complete our annual rep survey and let us know if there are any additional assets that would help you in your role

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## PROMOTING YOUR ROLE

You can use the following ideas and resources to promote your role as the Invisible Condition rep:

**INTERNAL COMMS:** ask your internal comms team to promote your role by sending out our template news item / email to all staff – make sure your name and contact details are included. You might also want to add a section on why you have taken on the role. Which leads us onto our next point...

**TALK ABOUT THE CAMPAIGN:** if you feel comfortable, consider talking about the campaign and your role in it perhaps in an internal news piece or even at an all staff meeting.

**DIGITAL ASSETS:** use our digital assets. Update your Digital profile pictures with our Invisible condition rep profile picture frame and rep email

signature so people know who you are. There are also screensavers and posters which can be rolled out across your company.

**EMAIL ADDRESS:** to help keep it distinct from your day job you might want to set up an invisible condition rep email address. Check with your HR first.

**HR:** arrange to catch up with your HR, let them know how the role is going, any challenges or good news stories – this will give you the opportunity to get any support you need and also keep the conversation about invisible conditions on HR's radar. These catch-ups are also a good opportunity for you to ask HR where they are up to with implementing the campaign pledges, and to encourage them to promote each pledge to all staff, so everyone is aware.



## RESOURCES

Here are some of the resources that you might want to signpost people to:

**EMPLOYER CONVERSATION GUIDE:** supports HR and line-managers to have conversations with staff about their invisible condition.

**EMPLOYEE CONVERSATION GUIDE:** supports anyone with an invisible condition to start a conversation about their condition regarding their needs and reasonable adjustments they might need in the workplace.

**EMPLOYEE ASSISTANCE PROGRAMM:** some companies have an employee assistance

programme which offer supports, such as counselling. Many employee assistance programmes offer wider support such as financial advice or couples counselling.

**CONDITION SPECIFIC CHARITIES:** you are not expected to know every condition out there and your colleague may not tell you what condition they have, but you could suggest seeing if there is a charity for their condition. Many charities have resources offering advice for managing conditions in the workplace. Many also have helplines for people to call for information and / or emotional support.

## CROHN'S & COLITIS UK

If your colleague has Crohn's or Colitis please signpost them to:

### VISIT

[crohnsandcolitis.org.uk](http://crohnsandcolitis.org.uk)

### HELPLINE

0300 222 5700

### EMAIL

[helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)

### LIVE CHAT

[crohnsandcolitis.org.uk](http://crohnsandcolitis.org.uk)

## MENTAL HEALTH

The following resources might be useful

### MIND

a leading UK mental health charity

### SAMARITANS

a leading UK mental health charity

### CIRCA

for children with Crohn's or Colitis and their families

### EVERY MIND MATTERS

a wide range of NHS-approved information and resources

### MENTAL HEALTH UK

provide support across England, Scotland, Wales and Northern Ireland

## WELLBEING

If your colleague has Crohn's or Colitis and is struggling with their mental health then this wellbeing guide specific to these conditions could be useful.

### WELLBEING GUIDE

[www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/mental-wellbeing](http://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/mental-wellbeing)

## GENERAL SUPPORT

Your main aim is to focus on their invisible conditions, but if someone needs legal or financial advice you can signpost to:

### CITIZENS ADVICE

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### BENEFITS

[www.gov.uk/universal-credit/other-financial-support](http://www.gov.uk/universal-credit/other-financial-support)



[CROHNSANDCOLITIS.ORG.UK](https://CROHNSANDCOLITIS.ORG.UK)  
[NOTEVERYDISABILITYISVISIBLE.ORG.UK](https://NOTEVERYDISABILITYISVISIBLE.ORG.UK)

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