

INVISIBLE CONDITION EMPLOYEE CONVERSATION GUIDE

This guide will support and guide employees in having a conversation with their manager and/or HR about their potential needs at work.



CONTENTS

- 1** ABOUT THIS GUIDE **PAGE 4**
- 2** WHY TALK ABOUT YOUR DISABILITY /CONDITION? **PAGE 6**
- 3** WHO CAN I TALK TO? **PAGE 10**
- 4** PLANNING YOUR CONVERSATION **PAGE 14**
- 5** YOUR NOTES **PAGE 20**
- 6** COMMON CONCERNS **PAGE 28**
- 7** SUPPORT FOR YOU **PAGE 32**



ABOUT THIS GUIDE

This conversation guide is for anyone living with an invisible disability or condition, to help you feel confident discussing your condition and needs in the workplace. It can be challenging to manage a condition alongside a job, so it is perfectly normal to need support at work.

You might not have told work about your condition, or perhaps you have, but your needs have changed – whatever your situation, this guide is full of hints, tips and examples of how to approach conversations about invisible disability in the workplace.

The guide explores the benefits and challenges of talking and the different people you can talk to, and provides practical tips for having conversations. There's also a helpful notes page and further support for you.

We know everyone's invisible condition affects them differently.

This guide will help you consider your situation right now and help you figure out what you can do to feel better supported in the workplace.

This guide is part of the Not Every Disability is Visible campaign, this means your company has pledged its commitment to supporting people with invisible disabilities and conditions in the workplace. This guide is one of many resources to help your company and colleagues better understand and approach conversations around invisible disability. We want both sides of the conversation to have the confidence and resources to talk about invisible conditions, so we have also created a conversation guide for the people you will be talking to about your condition: managers, HR staff and your Invisible Condition Rep.

2

WHY TALK ABOUT YOUR CONDITION AT WORK?

It is your decision whether you tell your workplace about your invisible disability or condition. Below, we consider some of the reasons for telling work and explore the benefits and challenges of doing so.

ACCESSING SUPPORT AND REASONABLE

ADJUSTMENTS: If you tell your workplace that you have a disability or condition, they should ask you to tell them a bit about the condition, particularly how it can affect you at work and what, if any, support you need. The benefit is that if work know about your condition, they can better support you. If you have a disability, as defined by the Equality Act 2010, this means your employer has a duty to make 'reasonable adjustments' for you at work. If your condition does not fall under the legal definition of a 'disability', a good workplace should try to offer support where they can, though they are not legally obliged to. Adjustments are individual to each employee, but some common reasonable adjustments include:

- Flexible working hours
- Time off for medical appointments (not counted as annual leave)
- Working from home
- Making adjustment to your office equipment
- Frequent breaks
- Moving your office desk closer to different facilities, e.g. the toilets or the kitchen
- Having a parking space closer to the office entrance

Reasonable adjustments can be permanent or temporary, as some of your needs might be permanent, and others might change over time.


Depending on your workplace and your specific job, your employer may or may not be able to make the adjustments you request. They might suggest alternative adjustments. Some jobs, such as being a bus driver, do not allow for home working. It's important you take your time to consider if the adjustments or the alternative suggestions work for you. When talking to your employer about adjustments that would help you, do highlight the benefit to the employer – e.g. frequent breaks could help you feel more focused and productive.

FEELING UNDERSTOOD: You might not want or need any reasonable adjustments; some people simply find it helpful for work to be aware of their disability or condition. For some people, it can feel like a weight off their mind or helpful if they suddenly become unwell.

CONCERNS ABOUT

TELLING WORK: People often have concerns that they will be seen as 'making a fuss' or won't be believed because their condition is invisible. Asking for support isn't 'making a fuss': it is about making sure you have the right support in place to be happy and productive at work. A good workplace should be supportive of you opening up the conversation – we have provided resources to help employers think about invisible disability, to help challenge the outdated perceptions of disability as being visual only. In pledging their support to this campaign, your employer has shown they are committed to changing these attitudes where they still exist.

DISCRIMINATION: If you do not feel you are getting the support you need, remember there are lots of different people you can talk to at work or, if that fails, outside work (see next page). If you feel like you are being discriminated against, it is important that you seek support from your HR team or organisations like ACAS (see page 33 for more details of external support).



My employee is a huge asset to the team and works very hard. Outwardly, she can appear fine, and I think that's a huge difficulty with invisible conditions. I check in with her regularly about how she's doing and feeling, and am flexible with working hours and annual leave. I encourage her to work shorter weeks and move her hours around so that she is in control and feels as well as she can.

CAIREEN, EMPLOYER OF SOMEONE LIVING WITH AN INVISIBLE CONDITION

3

WHO CAN I TALK TO?

There are lots of different people you could talk to at work. It is important to consider your options and speak to who you feel most comfortable with:

YOUR INVISIBLE-CONDITION

REP: This is a colleague who has been appointed as part of the Not Every Disability is Visible campaign to be a point of contact for staff with invisible disabilities and conditions. They have been chosen for the role because they have experience of invisible conditions – either because they have a condition themselves or because they are close to someone who does. The rep can help signpost you to your workplace's policies and other helpful resources. They can also help give you hints and tips on talking to other people at work about your condition. They would not be able to put reasonable adjustments in place for you.

YOUR MANAGER: Managers have a duty of care to people they manage and are able to put reasonable adjustments in place for you because they understand your day-to-day work and workload. Managers should have regular catch-ups with the people they manage, so this could be a good opportunity to talk to them about how your condition is impacting your work and any support you might need.

HUMAN RESOURCES (HR):

In addition to your manager, you can talk to HR; most companies have a least one HR employee. Perhaps you've spoken to your manager, but you may not feel you are getting the support you need from them, or you might want to speak to your manager with HR present. HR should be experienced in supporting people with numerous types of conditions or disabilities. HR staff could attend a meeting with you and your manager to help facilitate a productive conversation. If you are in the unfortunate situation where you feel your relationship with your manager has completely broken down, then you can speak to HR alone. If you're in this situation, and your workplace doesn't have an HR team, you could try speaking to your manager with a trusted colleague present.

A TRUSTED COLLEAGUE:

Some people find it helpful to let a colleague or friend at work know about their condition. Do remember that they might have questions about your condition – remember that you can tell them as much or as little as you feel comfortable with.

OCCUPATIONAL HEALTH:

Sometimes to understand your condition better, HR or your manager might ask you to talk to Occupational Health. Occupational Health experts are often external, and they specialise in the physical and mental wellbeing of employees in the workplace. After talking with you about your condition, they would make recommendations to your workplace about how they can support you and your manager. The recommendations of occupational health are just that, recommendations – they are not legally binding. If you are asked to talk to Occupational Health, you are not legally required to. To find out more, please visit: www.acas.org.uk/using-occupational-health-at-work

If you choose to tell work about your condition, there are lots of different people you can talk to. Remember you can disclose as little or as much as you want about your condition – the most relevant information being how it affects you at work. If you do feel like you are being discriminated against, please speak to your HR team or see page 33 for details of independent organisations you can also contact for more advice.

4

HAVING YOUR CONVERSATION

BEFORE THE CONVERSATION

MAKE TIME FOR YOUR CONVERSATION: Make sure you've arranged a time and place that suit both you and the person you are talking to. 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.

WHAT DO YOU WANT TO TELL THEM?: Talking about your invisible disability or condition can feel challenging, and it's easy to forget things in the moment. You can use the notes page on page 21 to help you prepare for the conversation and take your notes to the meeting. Remember, you're not

expected to teach your employer everything about your condition – how much you disclose is entirely up to you. It is best to focus on the parts of your condition that affect you the most at work.

REMOTE WORKING: If your conversation is online via Teams or Zoom, we suggest you have your video on. If you can see someone's face, it is easier to tell if they have not understood what you've said. However, it's important to do whatever you are most comfortable with. Also, internet quality can vary, so if there are time delays or poor video quality, moving over to audio only is fine too.

DURING THE CONVERSATION

A LITTLE ABOUT THE CONDITION ITSELF:

It can be helpful to start with some general information about your condition such as: how common it is in the UK, what treatment generally looks like and what the main symptoms are (including any side effects from treatment). It can be helpful to leave them some information to digest after the meeting, as they may not remember everything you've said. The NHS have an A-Z of many health conditions, or many charities have employer specific information about conditions (see page 33 for Crohn's and Colitis employer specific information).

HOW YOUR INVISIBLE CONDITION AFFECTS YOU AT WORK:

Because your symptoms are invisible, sometimes it can be difficult for people to understand how severely your condition affects you. It may come as a surprise to people that you have a long-term health condition at all.

So be prepared to talk them through the invisible symptoms that affect you at work – focus on some practical examples. The Notes page (page 21) will help you with this. Also consider what support would help you manage these symptoms (see page 33 for some examples) and be ready to explain not only the benefits of the adjustments to you but also the benefits to work.

QUESTION TIME: Allow some time for them to ask you any questions they may have about what you've talked about. Whilst it's important they have the chance to clarify things and check their understanding, remember you only have to disclose what you feel comfortable with. You do not need to tell them your whole medical history, and you do not have to answer questions you feel are too personal or distressing to talk about. The main focus of the questions should be around how your condition affects you at work.

IT MIGHT FEEL AWKWARD AT FIRST, BUT PEOPLE ARE MORE UNDERSTANDING OF THINGS WHEN THEY ARE MORE INFORMED.

BECKY, LIVING WITH AN INVISIBLE CONDITION

MY MANAGER'S APPROACH IS VERY MUCH THAT MY HEALTH IS THE MOST IMPORTANT THING.

SHE SAYS, "WE WANT TO SUPPORT YOU, ANY WAY WE CAN". AND THAT ENCOURAGES ME AND OTHER STAFF TO BE OPEN ABOUT THESE THINGS EARLY ON, SO THAT THEY DON'T ESCALATE.

ROSALEEN, LIVING WITH AN INVISIBLE CONDITION

After talking to my employer about my invisible condition, they immediately put in place a programme of practical and emotional support. This enabled me to manage my condition in the workplace and feel a valued member of the team

RACHAEL, LIVING WITH AN INVISIBLE CONDITION

I was incredibly nervous to mention my Crohn's when I joined my current job. My confidence had been knocked from a previous bad experience, so I didn't tell them about it during the hiring process. I had nothing to worry about – my manager was so sympathetic and understanding. They assured me they would help however they could.

MAX, LIVING WITH AN INVISIBLE CONDITION

CHECKING IN, GOING

FORWARD: Before you end the conversation, it is worth discussing how you want to update your manager or HR about your condition, going forward. You might want to have regular check-ins as part of your 1-2-1s, or you might just want to talk again if you're struggling. Having this conversation will help manage expectations and avoid your workplace checking in with you too often or not enough.

AFTER THE MEETING

LOOKING AFTER YOURSELF:

If you need it, take a 5/10 minute break after the call before you get back to work. It is perfectly natural to feel drained talking about your condition – so give yourself a little time to reset. If the conversation is with your manager, or they are aware that it is taking place, let them know that you may need a short break afterwards.

MAKING NOTES: It might be useful to make a brief summary of the discussion and any action points that were agreed whilst the conversation is fresh in your mind. You can use our Notes page (page 21).

NOT READY TO TALK YET?

If you are not ready to talk yet, remember you can email your Invisible Condition Rep/manager/HR about your condition, particularly if you just want signposting to some specific policies or information. Do bear in mind if it is more than just signposting, some things are difficult to explain in full over email, so they may have some follow-up questions that might be best discussed over the phone to avoid any confusion.

5

YOUR NOTES

Here is some space to make notes

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

MY CONDITION

FACTS ABOUT MY CONDITION

MY OCCASIONAL SYMPTOMS

MY MAIN SYMPTOMS

**THINGS THAT ARE SOMETIMES
DIFFICULT FOR ME TO DO**



MY CONDITION

A BAD DAY FOR ME LOOKS LIKE

A GOOD DAY FOR ME LOOKS LIKE

MY NEEDS AT WORK

I'M WORRIED ABOUT...

MY NEEDS AT WORK

**THESE ADJUSTMENTS COULD
HELP ME AT WORK**

I'M STRUGGLING WITH/TO...

NEXT STEPS

6

COMMON CONCERNS

We've compiled a list of common concerns – we've included a response to each question to help empower you in starting your own conversation.

1. I'M WORRIED ABOUT TALKING TO MY MANAGER 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.

As a first step, you could email or talk to your Invisible Condition Rep about your concerns. They should be able to discuss any specific concerns you have and perhaps share their personal experience of talking about invisible conditions in the workplace.

To help you start off your conversation with your manager or HR, there might be some online resources that outline your condition that you could send them ahead of your 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 (see Notes page, page 21) – this should help you feel in control of the conversation.

2. I NEED SOME SUPPORT AT WORK, BUT I DON'T KNOW WHAT SUPPORT I'M ENTITLED TO:

Your manager or HR will be best placed to put in place measures to support you at work. If you have an invisible disability, as defined by the Equality Act 2010 your workplace has a legal obligation to make reasonable adjustments for you, if your condition is not defined as a disability, a good workplace should regardless offer you support. For examples of reasonable adjustments, please see page 35 alongside more details of your rights.

3. I'M WORRIED ABOUT ASKING FOR TIME OFF TO TAKE A MEDICAL APPOINTMENT. WHAT SHOULD I DO?

Some companies have medical appointment policies that allow staff to take time off for medical appointments outside of their annual leave. Not all companies have a policy, but it is worth asking your Invisible Condition Rep/manager/HR if your company does. If there is a policy, check the maximum amount of time the appointment

can be for and who you have to notify before taking it. If there is no policy, it is worth asking HR and your Invisible Condition Rep why this is the case – if the company knows there is demand for it, they might be able to look into making a policy around it.

4. 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. You could have a conversation with your manager or HR to discuss how to manage your return to work. They should give you the opportunity to talk about 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.

5. 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:

There are three separate issues here: (1) that you feel left out by your colleagues, (2) a colleague has made a hurtful comment about your condition and (3) you are feeling down about all of this.

If you are being left out of work that is part of your role, 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 of work socially, perhaps you could suggest to your team, your manager or social committee some alternative social activities or timings that suit you and others who are not currently catered for.

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, you could talk to your colleague directly, with or without your manager present.

You might want to consider passing on information about your condition to 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, 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. There are some wellbeing resources on page 34 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



SUPPORT FOR YOU

Here are some of the resources that you might find useful.

EMPLOYEE-ASSISTANCE PROGRAMME

Some companies have an employee-assistance programme that offers support, such as counselling. Many employee-assistance programmes offer wider support such as financial advice or couples counselling.

CONDITION-SPECIFIC CHARITIES

If there is a charity out there to support people with your invisible disability or condition you might want to visit their website/contact them for support. They might also have specific information you could give to your workplace. If you have Crohn's or colitis, our Employer Guide can be given to your manager or HR to help them better understand the condition.

CROHN'S & COLITIS UK

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

VISIT

crohnsandcolitis.org.uk

HELPLINE

0300 222 5700

EMAIL

helpline@crohnsandcolitis.org.uk

LIVE CHAT

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

CICRA

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

Provides support across England, Scotland, Wales and Northern Ireland

WELLBEING

If your colleague has Crohn's or colitis and is struggling with their mental health, this wellbeing guide is tailored to these conditions.

WELLBEING GUIDE

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
Helpline (England):
03444 111 444
Helpline (Wales):
03444 77 20 20
Webchat: via website

ACCESS TO WORK

Support at work if you have a disability or health condition

www.gov.uk/access-to-work

ACAS

Provide information and guidance around occupational health
www.acas.org.uk/using-occupational-health-at-work

REASONABLE ADJUSTMENTS

Information and advice on what reasonable adjustments are available to you

www.gov.uk/reasonable-adjustments-for-disabled-workers

BENEFITS

www.gov.uk/universal-credit/other-financial-support

CORONAVIRUS AND EMPLOYMENT SUPPORT

www.gov.uk/coronavirus/worker-support



[CROHNSANDCOLITIS.ORG.UK](https://www.crohnsandcolitis.org.uk)

[NOTEVERYDISABILITYISVISIBLE.ORG.UK](https://www.noteverydisabilityisvisible.org.uk)

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