

**Understanding your rights
and advocating for yourself
in the workplace
- a guide for people with MCAS**



WELCOME

Welcome to our guide designed to help you to understand your rights and advocate for yourself as someone affected by MCAS.

We hope the information in this pack will help you to be able to communicate your needs to your employer, enabling you to better manage your MCAS at work.

MCAS is complex and each person experiences unique triggers and symptoms and will have differing management techniques.

The information in this pack will help you to understand your rights under the law and how 'reasonable adjustments' could be put into place to support you in working with MCAS.

There are further resources to support people living with MCAS available to download for free on the Mast Cell Action website.



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1

Understanding your rights under UK law



Understanding your rights under UK law

In the UK, people with disabilities are protected under the Equality Act 2010.

Under the Act, someone is considered to have a disability if both of these apply:

- they have a physical or mental impairment
- the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities

This definition means that many people with MCAS would be considered disabled under the Equality Act. It's important to recognise that you don't need a formal diagnosis in order to be considered disabled either, as the impact of your 'impairment' is what matters.

The Equality Act requires employers to make "reasonable adjustments" to accommodate employees with disabilities, such as providing flexible working hours, making physical changes to the workplace, or providing additional support.



2

What are reasonable adjustments?



What are reasonable adjustments?

Reasonable adjustments are accommodations made by employers to remove or reduce a disadvantage related to someone's disability. Reasonable adjustments can include:

- making changes to the work environment
- making changes to working arrangements
- finding a different way to do something
- providing equipment, services or support

Under the Equality Act, employers have a duty to provide reasonable adjustments for employees, workers, contractors, self-employed people hired to do the work, and job applicants.

What is 'reasonable' will vary depending on the circumstances surrounding the request, including the size of the employer and the nature of the job. However, if they couldn't accommodate an adjustment, they would need to work with you to find other ways to support you.

For example, if an employee requested a room for themselves within an office in order to avoid exposure to scented products worn by colleagues, a small organisation may not have the means to provide this. Instead, they may agree to implement a policy that prohibits scented products being worn in the office.



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3 Requesting reasonable adjustments



Requesting reasonable adjustments

1. Identify your needs

The first step in advocating for yourself is to identify your needs. You'll need to identify how your symptoms impact you and what adjustments could help reduce or remove the disadvantage you face. This will help when requesting adjustments as a candidate during a job application, as well as as an employee in the workplace.

You can use our Reasonable Adjustments Reflection Template to identify your symptoms and triggers, and what adjustments could potentially help you. This may help you communicate your needs to your employer, or potential employer.

Adjustments that could be helpful for MCAS

Changes to the work environment

- Reducing exposure to triggers like strong scents or chemicals
 - asking cleaning staff to use a scent free cleaning range
 - asking colleagues to kindly avoid spraying fragrance
 - removing any scented candles, reed diffusers or air fresheners in the space
 - removing scented hand wash and air fresheners from the work toilet
- a pet-free workspace
- the option to work in a safer space within the office
- an air purifier with an Ultra Hepa filter in the communal working space
- asking colleagues to refrain from bringing in foods that you are allergic to
- lower lighting environments without fluorescent lights and warmer uplighters instead if light sensitivity is an issue

The first step in advocating for yourself is to identify your needs. You'll need to identify how your symptoms impact you and what adjustments could help reduce or remove the disadvantage you face.



Requesting reasonable adjustments

Changes to working arrangements

- flexible working to accommodate medical appointments or times when you may be experiencing symptoms. This might include:
 - leaving early or starting late, and making up the hours elsewhere in the week/month
 - time off for appointments that doesn't need to be made up elsewhere
 - compressed hours eg. 10 working days completed over 9 working days, allowing one day off a fortnight for medical admin
 - working from home during the summer months to avoid going outside
- hybrid or remote working
- phased return to work after an absence
- reduction in contractual hours
- regular breaks to allow for movement and fresh air
- finding a different way to do something
- a slower working pace
- flexibility around targets and deadlines
- adapting the role to reduce mental or physical task demand
- distributing the workload differently across a team
- providing virtual training rather than in-person
- avoidance of heavy lifting or strenuous activity like high-intensity exercise that can increase histamine
- work instructions being given in writing rather than verbally
- providing more time to complete a test during a job interview
- providing a written copy of questions during a job interview



Requesting reasonable adjustments

Providing equipment, services or support

- assistive technology
 - voice-to-text software to reduce the use of a keyboard for those with joint pain in hands and wrists
 - screen reading software for those with visual impairments such as blurred vision
 - reminder systems to reduce the impact of memory issues
 - note-taking systems to support processing large amounts of information provided in meetings
- blue, amber and red light-blocking glasses
- noise-cancelling headphones to help with noise sensitivity
- emergency buzzer for further support from colleagues
- access to medical facilities, such as a private space to administer medication or rest if needed
 - a shelf or cupboard with all emergency medications that others are briefed on and trained how to use in case they're required
 - suggesting that your employer allocates a room free from all triggers with an UltraHepa Air Purifier for you to use as needed
- support from colleagues or management, such as providing assistance during a reaction, sharing the workloads and being flexible at the last minute if a reaction occurs
- staff to be trained in using an epi-pen and have first aid training
- taking taxi's to work if you can't take public transport (funded through Access To Work)
- adjustments to trigger points within the absence management policy



Requesting reasonable adjustments

2. Communicate Your Needs

Once you have identified your needs and reflected on what adjustments could support you, it is important to communicate them as early as possible. Ideally, it might be best to have at least some of your reasonable adjustments in place before you join an organisation, although this may not always be possible.

Communicating your needs can be done in several ways, including:

Requesting adjustments during the recruitment process

When applying for a job, you may be asked if you require any adjustments at the start of the application process. This is your opportunity to outline what your needs are and how the employer can accommodate you. Alternatively, if you are not prompted to share this information, you can do so by contacting the hiring manager or any other contact within the job advert.

Don't be afraid to give the organisation a call to understand more about the adjustments they are able to provide; they may be able to let you know about an adjustment you'd not previously considered.

MCAS Support groups can be a good place to learn what has worked for others.



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Requesting reasonable adjustments

Requesting adjustments when starting a new job

When starting a new job, aim to get the offer in writing before discussing adjustments. Once you've formally accepted the offer, you could request a meeting with your HR department or new line manager to discuss your needs. You may want to use our Reasonable Adjustments Request template to let them know in advance that you'd like to discuss reasonable adjustments.

After introductions and finding out a bit more about the company and the role, you may want to broach the topic of reasonable adjustments if they don't bring it up.

- You could begin by disclosing your condition or the symptoms you experience, along with triggers, outlining how these impact you at work.
- You could then outline some of the reasonable adjustments you think could support you, explaining how they reduce the impact of your condition and will allow you to better carry out your role.

Your employer may not be able to agree to reasonable adjustments immediately as they may need to consult with other teams such as HR, Health and Safety, Estates and IT. However, they should aim to consider your request and put adjustments in place as soon as possible.

You should send a follow-up email outlining what was discussed and consider providing a letter from your healthcare provider outlining your diagnosis, symptoms, and recommended accommodations, as these can help support your request.



Requesting reasonable adjustments

It's also worth asking for a copy of your organisation's HR policies and procedures to get familiar with. These may cover things such as sick absence management and reasonable adjustments. Not all employers have HR policies but they are still required to follow the law.

Requesting adjustments with your current employer

You may be in a position where you already work for an employer and need to request reasonable adjustments due to a change in your health or a change in the job role. You can communicate in a similar way as outlined above.

If you or your employer needs support

If you or your employer are not quite sure of what challenges you may face in the workplace, or what adjustments could help remove or reduce these, your employer may want to look into one of the following:

Access to Work

This is a free service provided by the UK government that helps people with health conditions and disabilities get or stay in work. They can provide workplace assessments to let your employer know what support an employee may benefit from.

Occupational Health Service

Some employers may use an Occupational Health service, either in-house or through an agency. Occupational Health services can carry out assessments of employees health conditions, allowing them to provide recommendations to your employer on what reasonable adjustments may help you.

Lauren asked her line manager to support her at work. Lauren has MCAS and was struggling with fatigue. Her line manager approved hybrid working to reduce Lauren's commuting time, allowing her to avoid triggers while travelling to work and also get a little more rest. Lauren feels much less tired and is able to focus more on completing her work!

Requesting reasonable adjustments

Advocacy

You may feel more comfortable with support in attending these meetings and discussing your needs, in which case you can ask your employer if someone can join you. For example, this could be someone from your network of friends and family, a union representative or a member of the HR team.

You could also find an advocate. Advocacy involves getting support from another individual who can help empower you to express your views and get them heard in order to make a positive change in your life. You can find a number of advocacy organisations below:

POhWER - Offers independent advocacy services throughout England. pohwer.net

WinVisible - A multi-racial grassroots group, offering collective self-help information, support and advocacy. winvisibleblog.wordpress.com

The Advocacy People - An independent charity that offers a free and confidential advocacy service in locations across the South of England.
theadvocacypeople.org.uk

There may also be a number of advocacy services in your local area which you could consider getting in touch with. There is further information about advocacy on our website here: mastcellaction.org/advocacy

In all discussions around reasonable adjustments, be sure to keep a note of what was discussed and when.

Follow up each conversation with an email and ask those involved to confirm they agree with the points covered.

Requesting reasonable adjustments

3. Follow Up and Document Your Progress

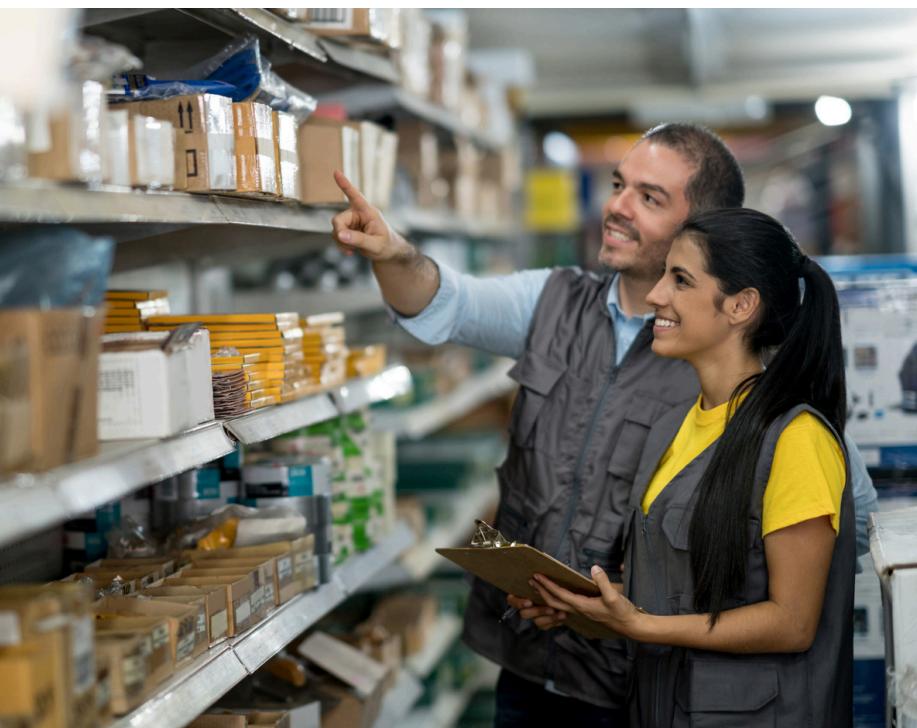
After you have agreed reasonable adjustments with your employer, it is important to create a record of these. You could use our Workplace Adjustments Passport template to outline key details of your condition/s, what adjustments are in place and when these will be reviewed.

Initially you may want to review fairly often, such as once a month, to understand if the adjustments are working as intended. Once you are sure they are effective, you could choose to review less often.

You may also need to share some of your adjustments with your colleagues as the adjustments may require support and flexibility from them. You could choose to raise this in a team meeting, in 1:1 catch ups, via email or through your manager.

Whichever way you choose, don't worry about what they may think; hopefully, your colleagues will want to support you and will be more than happy to adjust their behaviour so that they can reduce the symptoms you experience at work.

If there are any changes to your health before the next review, you can still raise these with your line manager and consider if any adaptations are needed. Remember to keep a record of all conversations.



Whichever way you choose, don't worry about what they may think; the majority of people will want to support you and will be more than happy to adjust their behaviour so that they can reduce the symptoms you experience at work

Requesting reasonable adjustments

Employers duty

Employers have a duty to provide reasonable adjustments promptly so as not to leave you at a disadvantage due to your disability. If you feel that things are moving slowly, raise this with your line manager and outline the importance of getting them in place as soon as possible.

If an employer refuses your request

An employer may refuse your request if they feel it is not reasonable. Reasons for this may include because they cannot afford it, it's not practical, or it impacts the health and safety of other employees. In this situation, your employer must explain why they feel it's unreasonable and work with you to understand what other adjustments could support you. They may suggest alternative adjustments that you've not considered before. It's worth trialling these for a set period and reviewing them. Keep notes of the trial so that you can clearly demonstrate to your employer if they're not suitable for you.

If you feel that your request has been unfairly refused, and you cannot come to an agreement after discussing with your line manager, you may want to raise this formally through the channels that exist within your organisation. This may involve writing to your HR department or to a senior leader outlining the situation. You can use our template to help you with this. You should aim to get a response in writing that outlines the reasons that the adjustment has been refused, as this will be helpful if you need the records for future action.

If your employer continues to refuse your adjustments, and you're unable to get the adjustments you need to work, this may amount to disability discrimination. In this case, you may wish to obtain advice from a third party to understand what your rights are.

Alex's decision to request reasonable adjustments at work was a turning point in his life. His employer, understanding the importance of inclusivity, responded by implementing a 'Time in Lieu' policy so that Alex could work more hours when he felt well and rest more when he needed to. Alex's confidence and job satisfaction soared, which also help to increase his productivity.

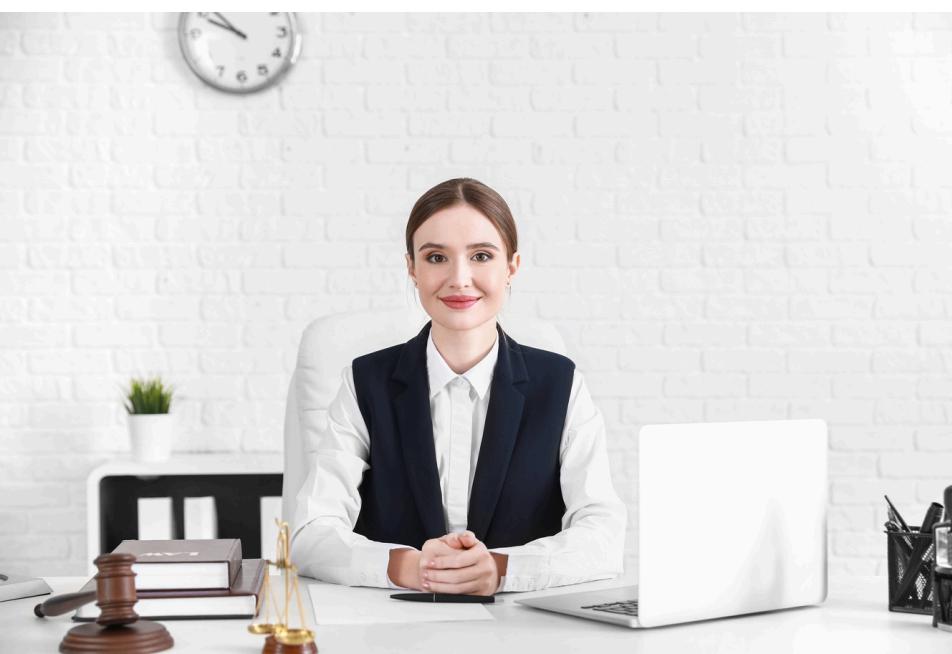
Requesting reasonable adjustments

Organisations that can offer support

A number of organisations can provide you with advice and support on obtaining reasonable adjustments, or taking an employer to a tribunal if your employer is not fulfilling its duties under the Equality Act. These include:

- ACAS - Can give free, impartial advice on workplace rights and employment law, including in relation to reasonable adjustments and discrimination. acas.org.uk
- Citizens Advice - Can provide free, independent and confidential legal advice on a number of issues including employment, housing and debt. citizensadvice.org.uk
- Equality Advisory Support Service - Can advise and assist individuals on issues relating to equality and human rights, including disability discrimination. equalityadvisoryservice.com
- Civil Legal Advice - Can provide free and confidential legal advice to those eligible for legal aid. gov.uk/civil-legal-advice
- Disability Law Service - Can provide free advice on employment matters, including reasonable adjustments and discrimination. dls.org.uk

In summary, advocating for yourself at work as someone affected by MCAS can involve identifying your needs, communicating them to your employer, and following up to ensure that reasonable adjustments are being made. It is important to understand your rights under UK law and seek legal advice if necessary.



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4 Tools and templates



Templates

There are various templates which may be helpful in seeking reasonable adjustments in your workplace. You can use the following resources to support, monitor and discuss your original request.

Visit mastcellaction.org/resources for:

- **Reasonable adjustments reflection template**
- **Template for requesting reasonable adjustments discussion**
- **Letter challenging a refusal for a reasonable adjustment template**
- **Workplace Adjustments Passport**

For additional resources, and information about services and support, please visit mastcellaction.org

Sarah's journey to better work-life balance took a positive turn when she approached her employer for reasonable adjustments. With open communication and understanding, her workplace implemented small changes like allowing flexible work hours to accommodate her unpredictable symptoms. Sarah's productivity soared, and her commitment to her job became even more evident. The accommodating work environment not only improved her overall well-being but also inspired her colleagues to be more considerate and compassionate.

Further support



If you have found the information in this pack to be useful and would like to access further information, support and resources, please visit:

mastcellaction.org

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Make your legacy a lifeline for people with MCAS, leave a gift in your will to Mast Cell Action.

