

MCAS and higher education



WELCOME

This guide has been developed for students with MCAS in higher education and their families. The information shared in this resource has been designed to provide general guidance and help students to access support.

This information is intended to provide general guidance and issues to think about – we recommend speaking to the disability service in your university about your specific circumstances.

You don't have to wait until you start university to do this – you should be able to speak to the disability service at open day events and usually universities welcome a discussion about students' support needs prior to their course commencing.

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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Going to university?

Before you read the rest of the guidance in this pack, about support for MCAS at university, you may want to think about a couple of key issues:

1. Do you want to study online or in-person?
2. Do you want to commute to your university or live away from home?

There is support available for MCAS at university but you may feel that you will be safer or you will be able to control your environment to a greater degree if you live at home or study online.

It's entirely your choice, and there are lots of factors to take into account – but we wanted you to know that there are many options for studying a degree available. It's worth doing your research and visiting some university campuses, if you can, to check out all of the options available.

You might also want to look at financial advice <https://www.gov.uk/student-finance/who-qualifies> before making your decision.



How support in Higher Education works

Support for students with medical conditions (including MCAS) in Higher Education is organised very differently from the support in schools and colleges. This guide provides a quick explanation of some key differences: <https://nadp-uk.org/wp-content/uploads/2021/11/School-vs-university-a-glossary-and-explainer-1.pdf>

Some aspects of Higher Education support are funded and organised at a national level (Disabled Students' Allowance) and some at a local level (exams arrangements, adjustments and arrangements on campus).

The way each university organises its support, its exam rules and what's available in terms of adjustments, varies from institution to institution. There are also variations depending on the course and its requirements.

This means that you might be offered different support depending on the course and institution you attend.



How support in Higher Education works

This information is intended to provide general guidance and issues to think about – we recommend speaking to the disability service in your university about your specific circumstances. You don't have to wait until you start university to do this – you should be able to speak to the disability service at open day events and usually universities welcome a discussion about students' support needs prior to their course commencing.

This information also relates to the HE system in the UK – other countries will have different systems for support.

Who is responsible for what?

The student	It's your responsibility to share any information that you'd like your university to know about your MCAS. If you don't share any information, they won't know what they need to do to accommodate you. It's also your responsibility to apply for Disabled Students' Allowance if you're eligible; to access the support you have available; and to update the university if your situation changes.
Disability Officer at university	The Disability Officer puts in place any local arrangements and reasonable adjustments e.g. for exams. They can help with your DSA application if you need it. They may be able to liaise with the university accommodation team on disability related matters.
Funding body e.g. Student Finance England	They provide Disabled Students' Allowance.
Your school or college	Nothing. They are not allowed to share any information with your university due to data protection rules. However, you can ask them for copies of documents they hold about you e.g. the adjustments that have been made for you at school and then you can share them with the university.
Your accommodation provider	This may not be your university – many halls of residence are provided by student accommodation companies. They are responsible for health & safety of residents, so you may need to discuss access arrangements regarding your accommodation with them.

How support in Higher Education works

Parents and access to data

HE students are aged 18+ and so are legally adults. This is important because it means that parents do not have the right to access information about their child's support or to discuss their child's support with their university.

If, as a student, you would like to allow your parents to liaise with the university about your support on your behalf you will need to complete a formal process to give permission for that to happen. The rules about and processes to put this in place will be different at each university.



Medical evidence

One key issue to consider is that of medical evidence. Universities are required to make "reasonable adjustments" for students with a disability, and MCAS can count as a disability. Some universities will make reasonable adjustments based on a discussion with the student about their needs, but some universities (and some adjustments) will require medical evidence. You will definitely need medical evidence to apply for DSA, and often need it for exams access arrangements.

Given the difficulties in obtaining an MCAS diagnosis in the UK, this presents a challenge. However, if you don't have a formal diagnosis of MCAS yet, you may be able to use medical evidence relating to other conditions to obtain support. For example, if you have previously been diagnosed with IBS, POTS, anxiety or other medical conditions, you can use that medical evidence to obtain the support you need.

If you don't have any medical evidence relating to MCAS or any other conditions then you need to speak to your university disability service – it is often possible to put some adjustments in place on campus based on a student's reported difficulties, and for health and safety critical issues e.g., if you experience anaphylaxis, nobody should wait for medical evidence to put appropriate support in place.



Exams and assessments

You may have had access arrangements for exams at school or college. It's important to know that these don't "carry over" to university. Your university is its own awarding body so it sets its own rules for putting arrangements in place for disabled students. Often, you'll be asked to provide medical evidence to get exams arrangements.

Arrangements to consider & discuss with your university disability service are:

- Taking your exam in a separate room (so that fragrances etc worn by other candidates don't impact you)
- Rest breaks (if fatigue is an issue for you or if you need frequent toilet visits)
- Environmental conditions (windows open/closed; limiting cleaning in the room prior to the exam)
- Invigilation arrangements (such as requesting that invigilators don't wear fragrances)
- Additional time (if you experience brain fog or delayed processing)



Disabled Students' Allowance

DSA is a package of government funded support that disabled students can access to support them to study. There are slightly different, but broadly similar systems, operating in England, Wales, Scotland and Northern Ireland.

You can use these links to find out more about DSA:

England: <https://www.gov.uk/disabled-students-allowance-dsa>

Wales: <https://www.studentfinancewales.co.uk/undergraduate-finance/full-time/welsh-student/what-s-available/disabled-students-allowance/>

Scotland: <https://www.saas.gov.uk/guides/dsa>

Northern Ireland: <https://www.studentfinanceni.co.uk/types-of-finance/postgraduate/northern-ireland-student/extra-help/disabled-students-allowance/what-is-it/>

The kinds of support that you can access through DSA depend on how your MCAS impacts you, and on the other conditions that you have, but can include assistive technology packages. Part of the DSA application process includes a "Study Needs Assessment" and this assessment should look at your situation holistically to make recommendations about DSA funded support and about adjustments that your university needs to make.



Support on campus

Lectures

Many universities provide "lecture capture" – they make recordings of live lectures and these are made available to students online after the lecture has taken place. This can be really useful if you're unable to attend a lecture e.g. due to a flare or a reaction. It's worth checking whether this will be available on your course when you're visiting a university.

Labs/Studios/Practicals

Practical classes that take place outside of lecture theatres can pose additional challenges when you have MCAS. For example, there are likely to be many different chemicals and cleaning agents used in laboratories, art studios and IT labs. If chemical sensitivity is a concern for you, do consider this in your choice of course or institution. Eliminating completely the use of chemicals in this kind of environment is difficult because they are likely to be essential to the skills and processes that you are learning.

Diet

Low histamine or other specialist diets are unlikely to be catered for in catered halls of residence or in on-campus catering facilities. You will probably need to choose self-catering accommodation and be prepared to take food onto campus with you.



Support on campus

Fluctuations in your condition

Universities usually monitor students' attendance – they are required to do this by the Office for Students. Often, they will get in touch with students who aren't attending classes regularly. So, if your attendance is likely to fluctuate because of the impact of your MCAS, do discuss this with the university disability service in advance and follow your university's procedures to inform them of disability related absences. That way you shouldn't face any penalties because your absences are disability related.

Lifts & lockers

These may be useful if you experience fatigue and/or pain or if you need to carry lots of equipment e.g., in practical subjects.

First aid

Each university will organise itself differently, but ensuring that the First Aid and/Security team are aware of your needs if you experience anaphylaxis is important. Your university disability team will be able to advise you how things work on their campus.

Reactions when you're alone

It's worth thinking about how to manage any reactions that you experience when you're alone e.g., at home in your accommodation. Think about who you will call and who could help in that situation. Some students who experience anaphylaxis or seizures at university use an alerter which allows them to contact a named person with one button press.

Assistive technology

This kind of technology can really help you to manage your studies more effectively. Often, universities have assistive technology available to all students on campus. However, if you would find it helpful to be able to study from your accommodation at times, e.g. due to fatigue, then having the technology available on your laptop would be helpful. DSA may provide this for you. It's also worth checking what technology your university will allow you to access remotely before spending any money!

Accommodation & travel to campus

If you're not planning to live at home whilst you study, there are several things to consider relating to accommodation.

Location

Halls of residence close to campus or on campus can minimise walking distances to lectures. Discuss this with your university disability service as they may be able to refer you for accessible accommodation, which tends to be campus based.

Catering

Choose self-catering options so that you can control your diet. Catered halls are unlikely to provide a low histamine or other specialist diets.

Sharing

Consider carefully whether you'd prefer a studio flat or a shared flat. It's great to get to know other students when you share, but you're likely to have to live with their food choices and their cleaning products/beauty products etc in shared areas. Particularly if you experience severe reactions, this could have a significant impact on your MCAS. Whilst you can request that your flatmates avoid using food/beauty products etc that cause you a reaction, in reality it's likely that people will forget, particularly after a few drinks.



Support on placements/field trips/visits

Some courses include work placements or field trips. Some are compulsory parts of the course and others are optional. It's worth finding out more about these in advance – your university should make reasonable adjustments whether or not a particular aspect of the course takes place on campus or not and they (and the organisation providing your placement) will be responsible for assessing health & safety.

However, some workplaces, e.g. a hospital if you're a medical student, can pose multiple challenges for people with MCAS and it's unlikely that every potential trigger could be removed in reality.

Thinking ahead can help to remove risks which can be avoided and to have a plan to manage those you are likely to encounter.

Remember to have any medication you will need during the trip, including rescue and emergency medications if you have them.



Self-care

The Boom and Bust Theory is a concept that can help adults living with Mast Cell Activation Syndrome (MCAS) to understand and manage their energy levels. It is based on the idea that when people with chronic illness have periods of high activity or stress, or 'over-do it', they experience a "boom" of activities. However, this boom is often followed by a "bust," where the body becomes exhausted and symptoms may worsen.

To manage the boom and bust cycle, adults with MCAS should aim to balance their activities and energy levels and avoid overexerting themselves during periods of high stress or activity. This can involve planning ahead, prioritising tasks, and pacing themselves throughout the day to avoid becoming overwhelmed.

This is particularly relevant at university where, particularly in the first weeks, the pace of social activities, attending lectures and classes, getting used to living alone and finding out about a new area can be incredibly exciting, but also tiring! It's also important in the run-up to exams or assessments – staying up all night to meet a deadline or revise for tomorrow's exam may have significant impacts on your health. Pacing your workload over a longer period of time and taking time to rest as you go are good tips to follow.

In addition, adults with MCAS can also focus on building their resilience and improving their overall health and well-being. This can involve practising self-care activities such as getting enough sleep, eating a healthy diet, and engaging in stress-reducing activities such as meditation or yoga. Check out what your university offers in these areas – as well as sports societies and the gym many universities have wellbeing programmes where you can learn mindfulness meditation and other relaxation approaches.

Overall, by understanding and managing the boom and bust cycle, adults with MCAS can improve their quality of life and reduce the impact of symptoms on their daily activities.

Preparing to discuss MCAS at university

The Disability Officer at your university may or may not be familiar with MCAS and its impact. You could give them a copy of our MCAS for Disability Officers resource to help them understand more. However, what they will definitely not know about is you and your MCAS and the support you need. So, it's a good idea to think through what information you'd like to share with them. Advocating for yourself is important – if you don't explain what you need, the university won't know that they need to provide it:

Symptom	Impact	What adjustments do you need?
<i>e.g. fatigue</i>	<i>Variable performance on different days</i>	<i>I need people to understand this and for the university to be understanding if I need to take time out.</i>

You also need to think about emergency situations and what you need other people to do for you:

Type of emergency	What I need
<i>e.g. allergic reaction</i>	<i>I carry an epi pen.</i>

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:

www.mastcellaction.org

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