

Going to University?

- A Guide for Students with CFS/ME



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Going to university is an exciting prospect, but it may also feel quite daunting. It's a new environment with new people and new challenges. Making the most of university and all the opportunities that come with it is important to students. Will having CFS/ME affect this experience?

As with all parts of life there are going to be challenges, but don't let that stop you.

This guide aims to reinforce management principles of CFS/ME, identify potential challenges you may face at university, and to help you identify support mechanisms.

1. First things first.....

Whether you are going to university or not it's important to manage your symptoms as effectively as possible.

Refresh yourself with your Personal Management Plan and your Relapse Plan. These include all the techniques you can implement to manage your condition.

It's quite common for people to stop using management techniques when they feel stressed or have too much to do. This is the time when you need your coping strategies the most, so try not to let them slip.

Activity
Management

Gentle
Exercise

Diet /
Hydration

Sleep

Psychological
Well-being /
Stress
Management

Pain
Management

Relapse Management Plan

This plan is intended to support you and your family/friends in recognising signs and symptoms that may alert to deterioration in your condition. The plan also contains strategies to support you in responding to these signs with the aim of preventing or reducing the impact of a relapse or set-back.

Warning Signs / Symptoms

Strategies for addressing these symptoms:

Strategies to get back on track:

2. Disabled Students Allowance (DSA)

The Disabled Students Allowance aims to meet the cost of additional support a student may need when attending university. This support may be in the form of equipment or a support worker.

Examples Include:

- A laptop to take notes during lectures, or for home study to avoid busy IT suites on campus
- A dictaphone to record lectures or make notes
- Voice recognition transcription software to reduce need for lengthy writing or typing
- A support worker to take notes in lectures
- A support worker to help with accessing university campus / rooms etc

You will need to complete the DSA application form to access this support. It is a non-means tested allowance, so it will not be affected by your income or your family's income. Detailed information, eligibility criteria, and application forms are available at: <https://www.gov.uk/disabled-students-allowances-dsas>

3. University Support

Within each university there will be a department dedicated to supporting individuals with disabilities, long term health conditions, or other learning needs. This department often falls under the wider support mechanisms of "Student Services". Once you have chosen the university you would like to go to, I would recommend you contact them immediately. They will support you with your DSA application and help you to identify what support / adjustments you may need.

Universities often have existing support mechanisms for students to take advantage of, and I would recommend you find out what is available before you begin your course.

Examples Include:

- Ensuring your course leader is aware of your needs ahead of your arrival
- Arranging for you to have a personal tutor within your faculty to offer support
- Arranging a mentor
- Extended library loans
- Extra time during examinations
- Negotiating distance learning where appropriate
- Access to psychological support, e.g. counselling and pastoral care
- Advice and guidance around accommodation, finances and general welfare

4. Staying at home or moving out?

Deciding whether to live at home or move into student accommodation can be a difficult decision to make for students with CFS/ME. Some students may be attending university that is far away from their home and therefore this decision is made for them. However, for those attending a university close to home it is worth considering the advantages / disadvantages of each option. There is no right or wrong decision, it's what you feel is best for you.

Below are some points you may wish to consider:

	Advantages	Disadvantages
Staying at Home	Remain close to family and friends Support from family (emotional) Support from family (practical, e.g. cooking, laundry, cleaning etc) Familiar environment and routine No need to move Home comforts May not feel ready to move away from home yet	Miss opportunity to live independently and learn life skills Miss the opportunity to live in another part of the country May feel reliant on family May feel constrained by family routines and boundaries (not as much freedom)
Moving Away	Sense of achievement in living independently Sense of freedom and personal space Experience a different part of the country (environment, culture, opportunities etc) Develop life skills (budgeting, cooking, problem solving etc)	Away from family and may feel alone May be difficult to commute home regularly Moving can be stressful Need to balance studies with doing other tasks (cooking, cleaning, laundry etc) Student accommodation may lack home comforts and may be noisy Unfamiliar people and surroundings

University's offer accommodation suitable for disabled students and this may be an option for you to consider. Normally student accommodation is only available to students in their first year; however, some universities are able to accommodate disabled students for the duration of their course. This may be a worthwhile consideration for students who don't feel ready to move into rented accommodation after their first year.

5. Challenges – The 3 S's

Whether you are living at home or independently, attending university can be a balancing act between looking after yourself, completing your course, and enjoying a social life.

The 3 S's

SELF CARE	STUDYING	SOCIALISING
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The following tables show typical activities you may complete and also some advice / coping strategies for you to consider. Take some time to think about these activities and what you feel may be difficult for you. Consider what other strategies you could use to make them easier to do.

Self Care

ACTIVITIES	COPING STRATEGIES
Personal Hygiene	Make personal hygiene an integral part of your daily routine. Baths and showers can be relaxing and help with pain relief, so try not to skip them too often in favour of dry shampoo!
Taking Medication	Many people with CFS/ME may take regular medication, and this can be easy to forget when you are busy. Set an alarm on your mobile phone to prompt you to take your medication. Remember, if you are moving out of area, you will need to register with a new GP.
Preparing Meals	Maintaining a good nutritious diet and drinking plenty of water is crucial to energy levels, concentration, and general health and well-being. If you are planning to live at home you may have the support of family to prepare meals. If you will be living in student accommodation you will need to consider what the best options are for you. Some people may take advantage of student discounts and eat their meals on campus. For others you may wish to batch cook some meals and freeze them to make life easier after a long day studying. Consider meals and snacks that are healthy but also convenient. Plan your meals ahead and make sure you eat regularly. Don't be tempted to skip breakfast for an extra 10 minutes sleep; it will only make your morning harder as you will be running on empty!
Shopping	Online shopping is a great way to get what you need without having to go to a busy supermarket and carry all those heavy bags. Some supermarkets have a certain amount of money you need to spend before they will deliver, so you may want to combine your order with a fellow house mate. Also, buying items in bulk between 2 or 3 people can work out cheaper for everyone.
Cleaning	Stay organised and clear up as you go along, this will avoid you needing to do a big clean which may take up a lot more energy. Having set places for things will enable you to find them quickly. For those who will be living in student accommodation, remember that not everyone shares the same standards of hygiene. The key is to look after yourself, your room, and your possessions. Don't be tempted to clear up other people's mess, they may not thank you, and may grow to expect it.
Laundry	For those living at home or close by, your family may be able to help you with laundry, especially bigger items such as towels and bed linen. Student accommodation varies, with some having washing machines in shared living areas, whereas some universities may have a campus launderette instead. Be organised, do your washing regularly and avoid running out of clean clothes. If you have to go to the launderette, you may want to pack your clothes in a wheeled case to avoid having to carry your washing there and back. Having multiple sets of linen and towels may help, but remember you may only have so much storage space.
Budgeting	Firstly, make sure you are in receipt of all the financial support available to you; e.g. student loan, bursary, DSA, PIP etc. Citizens Advice Bureau and/or your university's welfare team can advise you on this. Work out what your weekly and monthly budgets are and stick to them. Being short of money can be stressful, so don't put yourself in a position where you have over-spent. Make use of your student discount card. If you do find yourself in difficulty, don't panic and access support from your university straight away.

Rest, Relaxation and Sleep	Make rest an integral part of your routine. It is very easy to skip rest periods when you are busy, but this will only cause problems further down the line. Remember the principles of quality rest, and try to practice some relaxation techniques to help with this. Relaxation is not only important for your energy levels, but its great for combating stress and general psychological well-being. Maintaining good sleep hygiene may be difficult if you are living in student accommodation. You may need to negotiate quiet times with your house mates.
Exercise	Regular gentle exercise has many positive benefits; physically, cognitively and psychologically. Try and incorporate gentle exercise into your daily routine. Walking to university from your accommodation may be an achievable daily form of exercise. You may however already be completing a graded exercise therapy programme which you should carry on with whilst at university. Your university may have exercise/sports clubs you can join, which may make it a more sociable and fun experience. Remember gentle exercise is best, e.g. walking, yoga, pilates etc.

Studying

ACTIVITIES	COPING STRATEGIES
Attending Lectures	Once you have begun university you will receive your course timetable. This will inform you as to how often you will need to be at university and what independent study time you have. Where possible aim to attend every lecture or seminar you have, as often it is the discussions you have with your lecturer and fellow students that enhance your learning. If however you are struggling to attend your lectures there are a few things to consider. You may be able to complete some of your course as “distance learning”. This is where you use online resources through your university to complete your studies, but reduces the amount of time you need to physically attend. This will require you to be disciplined and proactive though. Your university may be able to amend your timetable to make attending easier, and this may involve deferring some modules to complete at a later date. Make sure you discuss all your options with your personal tutor and/or course leader. Remember; make use of technology to assist you in lectures. Sometimes keeping notes on a laptop or Dictaphone is easier than handwriting. Some of you may also be eligible for a support worker to take notes for you. Take regular breaks during your day and remember to eat regularly and drink plenty of water.
Reading	As well as attending lectures and seminars, studying at degree level and above expects additional self-directed study. This is often in the form of reading. When you begin your course you will be given a reading list and advised on how many hours of additional study you will be expected to complete on top of your timetabled hours. You will need to develop really good time management skills. Draw up your own timetable for self-directed learning; this will make it more likely to happen. Consider energy saving techniques, e.g. audio books, use of an e-reader tablet etc. Complete reading in small chunks followed by rest or gentle exercise. Make notes when you are reading to help reinforce important points. Make use of quiet study areas or the university library if your accommodation is noisy or distracting.
Assignments	The majority of university courses will involve the submission of assignments. This may be in the form of essays, reports, literature reviews etc. Again, you will need to be organised and use your time efficiently. Avoid leaving assignments to the last minute as this will only cause you to feel stressed, and assignments always take longer than you expect. If you are struggling seek support from your personal tutor or module leader. You may be able to negotiate extensions on your assignments, but remember this may result in you trying to complete multiple assignments at once, rather than just concentrating on one or two.

Examinations	Examinations can be stressful, so consider the impact of this on your symptoms. Being prepared will help reduce this stress. Draw up a revision timetable to help you plan for exams. Use checklists and priority lists to keep you focussed. You may be entitled to extra time in your examinations, so discuss this with your module leader as early as possible. Additionally, you may be able to use a computer for your exams, especially if they involve long answers. This will avoid lengthy amounts of hand writing. Some individuals may also be able to negotiate the help of a support worker to type or write on your behalf.
Work Placements	Some courses involve work placements and/or gap years to work in industry. Discuss the nature of these placements with the course lead and consider what reasonable adjustments can be made. Do this as early as possible to give people time to prepare and accommodate your needs.

Socialising

ACTIVITIES	COPING STRATEGIES
Making Friends	Part of going to university is having the opportunity to meet new people and make new friends. Some of you will find this easy, where others may feel anxious about it. Universities are attended by students from all walks of life, and diversity is often more celebrated than you may have previously experienced at school or college. Take some time to consider if you wish to share with people that you have CFS/ME. There is no right or wrong decision, it is what you feel is right for you. Think about what you might say, and what may help people understand the condition better. You are always going to come across people who don't understand or believe in CFS/ME. Remember you can't always change people's beliefs or behaviour, but you can take control of how you react to them. Don't over-justify your symptoms, there's no need to. The more confident and comfortable you are in your own skin, the less stressful these situations will become. And, you will always come across like-minded people, who will see you and not CFS/ME. These are the people you should invest your energy in. Positive friendships and relationships can be beneficial to your psychological well-being and resilience. They can be a source of fun, inspiration, motivation, and compassion.
Nights Out	Nights out are often seen as part of the student experience. It is important that you feel able to have this experience if you want to. Though there are a few things to consider. Often nights out can involve staying out to the early hours of the morning. Think about the impact this may have on your sleep-wake cycle if repeated frequently. If you already struggle with disturbed sleep, then perhaps consider going home earlier. Night clubs and bars can be noisy and crowded. If you struggle with sensitivities to noise then perhaps these aren't the best locations for you. Consider a quieter bar or restaurant. Whilst dancing is a good form of exercise, try not to overdo it. Over-exertion may exacerbate your symptoms and make it more challenging for you to manage everyday life. Be aware that alcohol is often poorly tolerated by people with CFS/ME. Know your limits and stick to them. Alcohol is a depressant, so be mindful of its effect on your psychological well-being, especially if you are already struggling emotionally. Remember, a good night doesn't have to involve clubs and pubs. Consider; going to the cinema, bowling, trips to the theatre, eating out, film nights at home with friends etc.
Joining Societies / Clubs	Universities have an array of societies and clubs to join. These were traditionally sports based, but now there is a club for almost everything. Whether its yoga, photography or being a member of the student council, there is something for everyone. Consider joining a society or club. It's a great way to make new friends, have fun, and may incorporate a bit of gentle exercise.

6. Problem Solving – (Activity Analysis)

As for everyone, you are always going to come across challenges. The important thing is not to panic; this will only cause you to feel stressed, making the challenge feel more difficult than it actually is. Developing problem solving skills over time will help you to meet challenges more effectively. To problem solve, you need to stay calm and break the challenge down.

A simple activity analysis will help you to identify what the challenge or activity involves.

Activity Analysis

PHYSICAL	COGNITIVE	EMOTIONAL
What physical elements are involved in completing the activity?	What cognitive processes are involved in completing the activity?	What emotions are involved in completing the activity?
Movement Strength Endurance Speed Balance Coordination	Concentration Memory Learning Problem Solving Processing Information Prioritising	Motivation Confidence Enjoyment Determination Will the activity cause Stress or Anxiety?

The next step is to find solutions. Again, break this down into categories; me, environment and activity. Consider what will make the challenge or activity more manageable.

ME	ENVIRONMENT	ACTIVITY
What can I do differently to make the activity achievable?	How can the environment be changed to make the activity more achievable?	How can the activity be changed to make it more achievable?
Can I do the activity in small chunks a bit at a time? Can I do the activity with support from others? Can I do the activity over a longer period of time?	Can the activity be done in a different location? Can assistive equipment help? Can I do the activity from home?	Do I have to complete this activity, is there an alternative? Can I complete part of the activity? Can I suggest a different activity?

You will find that you can come up with solutions yourself, but from time to time you may need some help. Seek help from your personal tutor, course lead, disability advisor, GP, family, or friends. There may not always be a solution, but at least you will have their support.

Ask yourself.....

Is everyone facing this challenge or is it just me?

Often if you are finding something a challenge, others are too. Speak to people who are also affected, they may have some advice that can help you, or at least offer moral support.

What is the worst case scenario?

Often when you think about a challenge rationally and break it down, it's not as bad as you feared. The key here is "rational". When you are worried about something it is easy to get carried away. Take a piece of paper and write down your worries. Then write down what evidence you have for these worries, and how likely they are to happen. More often than not you will find there is little evidence to support your worst case scenario, and it is unlikely to happen. If this doesn't ease your worries, talk to someone and ask for some help and reassurance. Try completing a relaxation exercise, e.g. some slow breathing. This will help to calm your worries and allow you to look at the challenge more rationally.

7. Before you go.....

Whether you are moving away to university or not, your routine and daily activities will change significantly. It's important to prepare for this change.

Before you start university begin to practice some of the activities you will be expected to do when you are there. For example; reading, using the computer, cooking, doing laundry etc. The more you practice these before going to university, the more efficient you will be, and the less the change will impact your symptoms. Try and maintain a routine even over your holiday period. This will help your transition back into study mode, and make getting up on a morning again easier.

You will find it difficult to go from limited holiday-mode activity to beginning university if you don't prepare beforehand. This may increase the likelihood of a setback/relapse. Remember, you are going to use an increased amount of energy when starting university, learning new routines, meeting new people, finding your way around etc. Therefore, the more you can prepare and be proactive the better.

8. Where can I get more support?

It is important that you know where to find help and support at university.

Each student will have access to a personal tutor on their course, but you may also be able to negotiate the support of a mentor. This may be a member of staff, but it may also be a fellow student that is a little further along in their studies. Talk to your personal tutor and agree what support you may benefit from.

If you have made an application for Disabled Students Allowance, then you will already be known to the student services team. Most universities identify a specific disability worker (or similar) to support you. The disability workers are a good source of support and information for the duration of your time at university. They can help to negotiate any further support with your course leader, but also signpost you to other services you may find useful. For example; counselling, study skills support, mentorship programmes, welfare advice etc.

Your GP should be your first point of contact for health concerns. If you are moving out of area make sure you register with a local GP, and ensure you have any regular medications placed on repeat prescription. Remember, symptoms of CFS/ME do fluctuate and change over time, but if you become unduly worried it is important to visit your GP.

Across the country there are a number of CFS/ME charities offering support, advice and guidance. Find out what charities operate in your area, and what support they may be able to offer you when at university. Some run support groups and they may be able to put you in touch with other students with CFS/ME in your area.

Make a note of the people you can call upon for help and support.

Course Leader

Name: Tel:

E-mail:

Personal Tutor

Name: Tel:

E-mail:

Mentor

Name: Tel:

E-mail Address:

University Disability Worker

Name: Tel:

E-mail:

GP

Name: Tel:

E-mail:

Local CFS/ME Charity

Name: Tel:

E-mail:

It is important that you ask for help when you need it. Be assertive and communicate your needs. People can't help if they don't know you're struggling. There are lots of support mechanisms available at university so make use of them.

I hope this guide has been useful and informative. Please consider the advice included and think about what you may need to do before beginning university. Be prepared and plan ahead.

Above all, enjoy your time at university and make the most of the experience. Good Luck!