



UNIVERSITY & M.E.

the ME association



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Leaving home and heading off to university can be a daunting time for any person, particularly for those with a fluctuating condition such as M.E.

Arranging ways of working, studying and taking exams and assessments in high school give some preparation for moving on to a further education course, but there are often many new considerations to be assessed and coped with.

So – prior to taking a course – it is important to investigate more fully what is involved in (i) getting through the teaching, tutorials, producing the work, and assessments, and (ii) managing to live on your own.

Planning how to manage time, energy and money in some detail can help to get through all the new situations that are likely to be faced.

The more needs that have to be met, to allow concentration of activity on course requirements, the more additional costs are liable to be involved, and the level of student debt that could result should be investigated.

Fortunately, there are now multiple adaptations that can be made that may help to improve the student experience for those with the condition. Here are some areas you might like to consider:

CHOOSING A UNIVERSITY

☆ When applying to university, it may be a good idea to choose a location not too far away from home. This will make it easier for parents or guardians to help you out if you encounter difficulties, and also allow you to travel home more easily if you're feeling unwell or need a break from university life.

☆ Ensure you attend Open Days to get a feel for the university that you're intending to apply to. If you are a wheelchair-user, check that buildings and facilities, as well as walkways, are accessible. If you intend to walk to lectures, try this walking route in advance and look for benches, cafés or quiet places where you can sit and rest if you're struggling. If you're able to drive, enquire about university parking spaces: you are likely to be entitled to parking in disabled bays if you drive to your contact hours, but make sure you obtain permission before doing so as to avoid any unnecessary fines.

☆ Assess the surrounding location of the university carefully. Are there grocery shops and amenities within manageable travelling distances for you? Does the location have good public transport links or is walking necessary to get from place to place? Are the accommodation blocks close to a main road or busy area that are likely to be noisy when you're trying to study or rest?

LIVING ARRANGEMENTS

☆ If you indicate that you have a disability on your university application, you may be entitled to priority for selecting accommodation. This means that you can choose and apply for the room you like ahead of other students, and select the option most suitable for you. For those with M.E, this could be a room as close as possible to where your lectures will be, to cut down on walking distances.



*This leaflet has been written by **PIPPA STACEY**, who recently graduated from the University of York with an honours degree in BSc Psychology in Education.*

Pippa also runs her own social enterprise called Spoonie Survival Kits, and writes about life with M.E for various publications, including her own blog.

www.spooniesurvivalkits.com

lifeofpippablog.blogspot.co.uk

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☆ Most universities offer multiple accommodation options, with many now providing 'Quiet Blocks': flats for those who would prefer a calmer living environment. These blocks often have an enforced 'no noise' after 11pm rule and can sometimes be less sociable than other choices, but offer a good alternative for those who require regular rest and may be particularly sensitive to noise.

☆ You may be offered the choice between catered or self-catered accommodation. Catered options provide between 1-3 meals a day, which can be useful in removing the exertion required for regular food shopping, cooking, and washing up. However, accessing these meals may require students to leave their accommodation and walk to the canteen area, and only be able to dine between particular times, which may not always be appropriate for those who rely on pacing and activity management. There also may not be options suitable for those with particular dietary requirements. Self-catered options allow for much more choice and flexibility. However this relies on students being physically able to prepare food for themselves, and have the options to buy and store their food.

☆ Accommodation may vary in terms of cleaning arrangements. Students typically share a kitchen with between 4-12 others, meaning that cleanliness cannot always be ensured. It can be useful to choose accommodation options that offer a weekly kitchen cleaner, to help keep any potential mess under control. Some options may also offer a bathroom cleaner on a monthly basis. These features are often included in the overall price of the room, but it's a good idea to double-check this first to avoid any hidden charges once you've moved in. Whether or not such services are available, it may still be necessary to arrange more cleaning, laundry and other care services.

STUDY ADAPTATIONS

☆ Upon accepting an offer from a university, you should speak directly with their Disability Services team. You will be assigned your own Disability Advisor who should remain your first point of contact throughout your studies, and an initial meeting will be arranged to discuss your needs. It is recommended that this meeting be held before your course begins, to ensure there is plenty of time for your arrangements to be put in place.

☆ Following your initial meeting, a Disability Support Plan will be created for you. In the case of M.E, It is possible to ask for adaptations such as extended deadlines for assessments, lenience with attendance to lectures and contact hours, library assistants find books and resources for you so you don't need to walk around looking for them yourself, and sometimes even for study locations to be moved so that you don't need to climb stairs to reach them. Your Support Plan will be discussed with you to check you're happy with any proposed arrangements, and then you will be asked to sign it.

☆ Once this Support Plan has been agreed upon and signed by both you and your advisor, it will be emailed to all of your lecturers and academic contacts for the coming year. It's a good idea to also send a follow-up email individually to each of your academic contacts following this, just to introduce yourself and re-iterate your needs.

FINANCIAL SUPPORT

☆ When applying for Student Finance, you can also apply for Disabled Students Allowance (DSA). These are non-repayable grants made to those with long-term



conditions to address some of the additional costs that living with a long-term illness can present. The application form requires a letter of medical evidence from a professional and can take some time to process, so it's a good idea to submit this in plenty of time. Successful applicants may receive support in the form of technological equipment such as dictaphones for recording lectures, non-medical helpers such as note-takers who can attend lectures with you, additional resources such as paper and ink cartridges to print out work, and transport reimbursement such as covering the cost of taxis to and from contact hours for those who struggle with the bus.

- ✧ Becoming a student does not affect your right to apply for or continue claiming disability-related benefits, such as Personal Independent Payments. These allowances could be put to multiple uses at university, for example by employing care workers from agencies to help with daily living tasks. More information on claiming benefits whilst studying can be found on the National Union of Students (NUS) website. Problems with qualifying for and receiving payments of benefits can lead to cashflow difficulties, and planning to avoid debt crisis may be necessary.
- ✧ Students who earn under a specified annual income can also be exempt from NHS prescription charges. Completing an NHS HC1 form will determine your eligibility and you may be issued a HC2 certificate. This allows you to access any of your prescribed medications for free, as well as receive free dental treatment, sight tests, travel to and from NHS appointments and more. HC2 certificates last for one year, and a new form has to be completed on an annual basis.

SOCIAL LIFE

- ✧ Freshers' Week is a great time to socialise and meet new people, but participating in traditional



events, such as club nights, can be difficult when you have M.E. Many universities now offer 'Alternative Events' during Freshers' Week: evening activities that are often more gentle, and don't involve drinking or noisy nights out. These include scheduled events such as movie showings or comedy nights, which may be more easily enjoyed by those with chronic illnesses. They're also a great opportunity to meet friends who are likely to participate in similar things to you in the future.

- ✧ University is a wonderful opportunity for making life-long friends. However, suffering from chronic illness whilst those around you are enjoying an active social life can sometimes feel isolating and upsetting. One way to get around this is proposing your own ideas for how to spend your free time, suitable for your health needs: you could suggest a cosy night in with hot chocolate rather than a pub crawl, or a chilled pyjama party instead of a club night. Often, people will be more likely than you think to choose these kind of social events over partying!
- ✧ Managing your health whilst studying, living independently and managing a social life can be a difficult situation, and it's completely normal to feel overwhelmed at times. If you're experiencing any kind of

difficulty with any part of your university experience, don't be afraid to reach out; telling a friend how you're feeling can relieve some of the emotional burden, and admitting that you're struggling does not by any means imply that you are failing. Your university will also have a qualified welfare team who can support your emotional wellbeing, as well as a Disability Services team, who will be on hand to address any practical concerns you may have.

Studying whilst living with M.E is a remarkable achievement, and going to university can be incredibly rewarding.

Whilst you may be concerned that some of these suggestions may initially identify you as 'different' to your peers, it's important to remember that they're there to place you on a more even playing field with everybody else.

By obtaining the support you're entitled to, you'll be better equipped to embark on an enjoyable and memorable university experience.

FURTHER INFORMATION

■ The ME Association has published a *To Whom It May Concern* letter that sums up the special arrangements that may be needed when students with M.E. sit exams. It can be downloaded from our website and costs £1. To download it, please visit: <https://tinyurl.com/y6ae47wg>