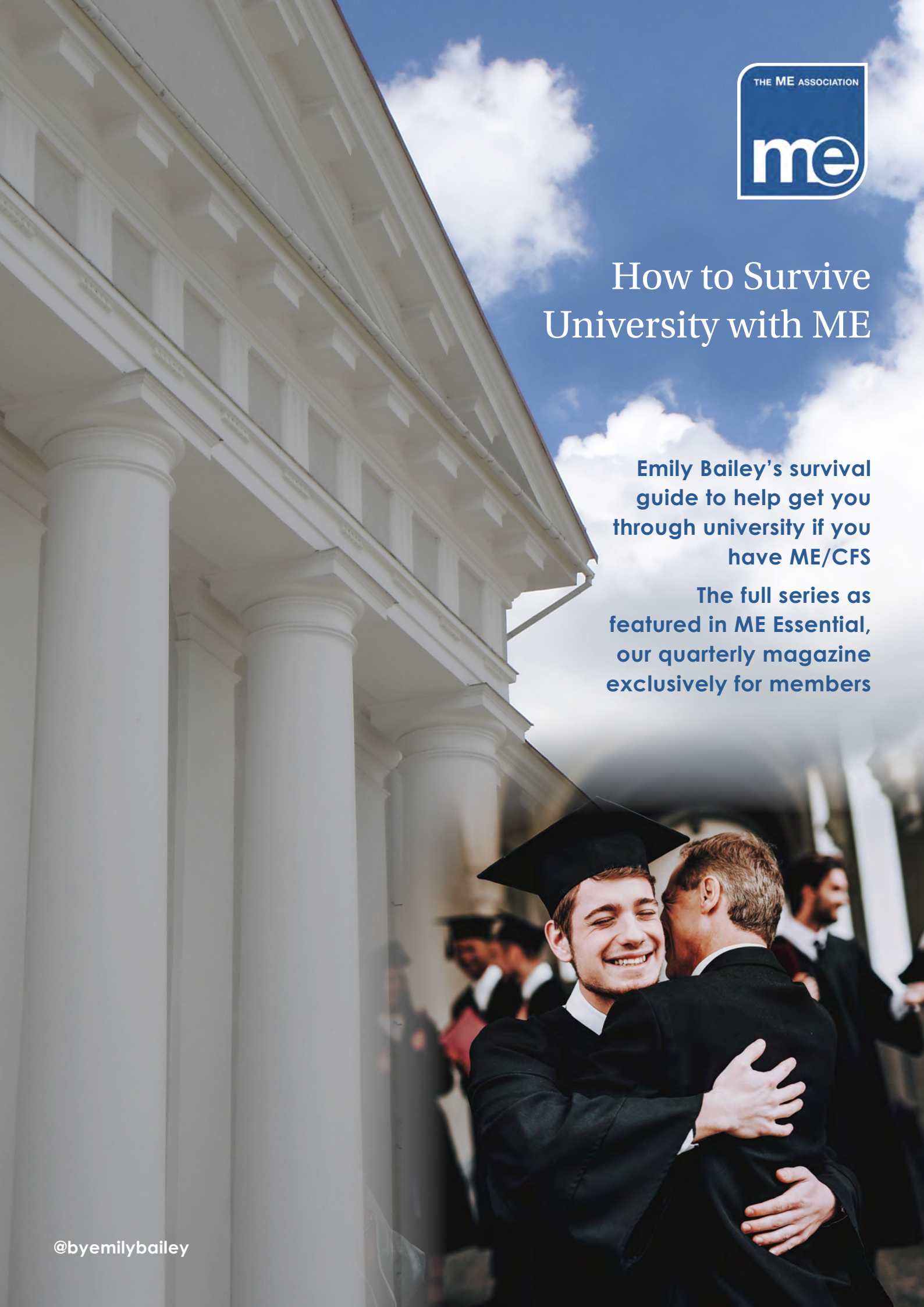

How to Survive University with ME

Emily Bailey's survival guide to help get you through university if you have ME/CFS

The full series as featured in ME Essential, our quarterly magazine exclusively for members

@byemilybailey

How to Survive University with ME

Emily Bailey recently started university and ME impacts every aspect of her study: She has had to have lecture rooms moved as they were inaccessible, has campaigned for a **Quiet Hour** at the on-campus shop and is in frequent dialogue with **Student Support** over how her study can be made to work with her ME. In this, our new series for young people with ME, Emily will take you through her survival techniques and offer help and advice on how to survive at university with ME.

I have now completed my first term of undergraduate study and that is something I cannot quite believe I get to say. But, I did it. I have attended the seminars (some of) and submitted the assignments (well, I still have a couple to go) and am, as I write this, heading home for Christmas to give my dogs some cuddles.

The decision to attend university wasn't an easy one – it was filled with weeks of panicking and questioning in what world I thought it was possible that I could manage it. The idea of going to university with ME and actually coping seemed pretty inconceivable. I just couldn't picture it working and I very nearly didn't try, which is why I am writing this. I didn't know what making friends was going to be like; how I was going to keep tutors onside when I had to keep missing classes; how to cope with group presentations; who to talk to about inaccessible buildings and broken lifts; how to balance my workload; how to feed myself… the list goes on. I shall be endeavouring to answer some of these questions over the next three years (perhaps longer), as I complete my degree, and give those of you considering university an idea of what undergraduate study and ME is really like.

The first term, for any student, is a lot. There's so much to get used to and many successes and failures along the way (yes, I did have to Facetime home to find out how to change my printer ink and my family are never going to let me live that down). So, to start with I have compiled a list of the good and the bad from my first term.

Things that are going really well:

- Lecture recordings – these are one of the main things which make study manageable for me. As long as everything goes to plan, all of my lectures are recorded. This means that I can watch them sat at my desk or laid in bed and avoid the heat and noise of a lecture hall filled with 200 people. It also nearly halves the number of contact hours that I have per week.

- My flat – I am growing increasingly fond of my flat (ironic, when it was one I didn't initially want to be in). It's the nearest on campus to my classes, yet still stays relatively quiet. It's a disabled flat, so all of the rooms and corridors are relatively big (a rarity in university accommodation). My flatmates and I all get on pretty well, and one of the huge benefits of us all being disabled in some way is that we generally get the "actually I can't do that" situations or the "can we get rid of those air fresheners, they're wreaking havoc with my chemical sensitivities" moments.

- My course – I mostly love my course. It's interesting and challenging and really fun (for a nerd like me who enjoys study). I think this is the most important thing for someone with ME who is attending university: the course has to feel worth it.

- My mobility scooter (Babs) – I like my mobility scooter, she is very helpful. Because of her, I can get from one end of campus to another. She also doesn't make me feel motion sick like electric wheelchairs do. I must admit that learning to drive her was an experience, which is to say that the first few weeks involved a few crashes!

- The microwave – I grew up in a house without a microwave, and now I don't ever want to live without one again. After I got over the initial fear of blowing the microwave up, I have not stopped using it. Every two weeks I have carers cook some meals for me, so all I need to do for my food each day is pop them in the microwave for a couple of minutes – something I've even managed to do on my absolute worst days.

Things I'm not so fond of:

- My flat's kitchen – where the flat falls short is in kitchen design. It's like a sunroom, with two walls consisting of windows, making it very bright (ugh, light sensitivity) and very hot for some parts of the day (ugh, temperature regulation). We also have a problem with slugs getting in.

- Group presentations – firstly, I will say that I was very lucky with the people I did my group presentation with. They were great fun and we clicked really well. However, having to be up to meeting them to discuss the presentation, the guilt of having to say you can't work on the project for a bit because seminars wipe you out, as well as the general stress of being well enough to attend the seminar to give the

presentation - all of this I found quite difficult.

- Old buildings and my mobility scooter – unless the entire campus was constructed in the past 20 years, the likelihood is that there are going to be some pretty inaccessible buildings. I'm talking narrow corridors with no turning circle, tiny lifts, doors that aren't automated, and steps everywhere! Needless to say, getting around can be quite difficult (particularly in the first few weeks). For some of these cases the solution is to have someone meet me on the way to a class in order to hold the doors open (which was slightly awkward to arrange the first week when I only knew one person from my course on Facebook and all we'd said to each other was "hello"). In other instances, my scooter is just too big to get around the building so I have to park it outside and walk part of the way. I may have to resign myself to the solution of an electric wheelchair at some point.

- Broken lifts – my legs do not like stairs very much and when the lift is out of order, I have to choose between putting my body through two flights of stairs or missing multiple seminars.

So far I have found that I am able to cope with far more than I expected (I'm pretty sure most of my family thought I'd have dropped out within the first month – me included!). However, I've also been reminded that I cannot do as much as a "healthy" person can. For this reason, I am looking into reducing the number of modules I take per term from three to two. If the university agrees, I can then make up the remaining credits by adding in another term at the end of my course, or through summer schools.

I have also developed an immense fondness for podcasts. Watching lecture recordings, reading through pdf documents, and making notes electronically are all a recipe for headaches. There have, therefore, been many periods of self-imposed screen bans and podcasts have been a great way to keep me entertained. I like listening to non-fiction ones throughout the day (occasionally I'll find ones that relate to my course and so count as studying as well) and fiction ones in the evening. Some current favourites are Wolverine: The Long Night (this one felt pretty reminiscent of The X-Files for me, so if that's something you like then I'd give it a go) and The Orbiting Human Circus which is delightfully whimsical.

Surviving a group presentation

Group presentations are hard. They have their benefits: the workload is shared, you have other people to bounce ideas off and they are a great way to get to know people in your first few weeks at university. However, they also put a lot of physical pressure on you: you need the energy to meet with your group to discuss the project; complications can arise if they don't 'get' your illness; you may be put in a group with someone who likes to leave everything to the last minute and write the entire presentation the night before, which doesn't work very well for pacing yourself so as to be well enough to actually give the presentation.

Communication is incredibly important (a common occurrence for managing ME at university). If it looks like any of these things are going to be an issue then try to let people know as soon as possible. After all, if they're unaware of your condition then they are unaware of how to help work with it. Let your group know early on that you have certain needs approaching the presentation. Talk to your tutor: drop them an email or visit their office hours to say that you're having difficulty managing your disability with your group. They'll probably have some good advice.

Be proactive. Get started on studying the material for the project as early on as you can, so that you have time to pace your planning and have a bit of a cushion if a flare-up of symptoms leaves you unable to work for a little while. It can be helpful to do a little more than your fair share of work at the start, if possible, so that it evens out if you have to rest for a few days before the presentation. This can then give the opportunity for anyone in your group who may prefer the last-minute approach to make up their share of the work.

Timing is really important for your presentation. If you have control over when to give your presentation then try to allow at least a month, so that you have plenty of time to work on it. If your tutor assigns your presentation weeks and they give you a week that doesn't work for you then try to have a word with them to explain the situation – just do this as soon as possible!

When meeting your group think carefully about your preferred location. The library or cafes may have too much sensory stimuli and not be ideal for you. Because my room had space for three people, I suggested holding our meetings there. This meant I didn't need to travel across campus – I was even able to just sit in bed! Be clear when you are out of energy and need them to leave.

Most importantly: pace! Leave the days prior to the presentation as free as possible so that you can rest. This may mean deciding not to go to a few seminars,

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PART 2

How to Survive University with M.E.

Emily Bailey continues with the second in her series on university life with M.E: Disabled Students' Allowance, Social Care and University Applications.

which is okay: an assessment is more important. That being said, your health is always priority number one. If you are not well enough on the day, then don't push yourself. Keep your group updated, and make sure you send an email to your tutor to explain the situation. Because of the likelihood of absence, it is possibly a good idea to try and be in a trio or larger group, rather than a pair. This means that you aren't leaving just one person to do the entire presentation if you are unwell.

These are some of the main things that I have learned (sometimes through error). Other things to bear in mind are choosing a topic you feel confident in and making the most out of the internet. Social media and shared internet folders, such as google docs, can be really useful for a group all working together without having to constantly meet up. ■

When I began the process of applying to university it felt like a Herculean task. How was I going to ensure I picked a university with a supportive environment? What if the course I was interested in had too many contact hours for me to cope with? How would I manage the personal care aspects of living alone, when at home I depended so much on the help of my mum? What universities would even accept me with only three GCSEs and two A-Levels? These questions seemed an insurmountable barrier between me and a degree. However, the further along the application process that I went, the more support I found was available for disabled students attending university.

DSA

The first of these supports is **Disabled Students' Allowance (DSA)**. DSA operates as a branch of Student Finance, which you apply for alongside the application for your student loans. M.E. falls under the eligibility category of a long-term health condition. Once DSA receives evidence of your diagnosis, such as a Doctor's letter, you are invited to an assessment.

I have been through the benefits system multiple times and without fail the word 'assessment' triggers nightmare flashbacks to PIP applications that leave me wanting to run for miles (which would be a bit of a miracle in itself). Luckily, where DSA is concerned, my apprehensions were unfounded. My assessor wasn't there to test the extent of my disability, rather we talked through my symptoms and how they impact my academic experience, followed by a demonstration of some of the supports which she could supply me with to help ease my university experience and the necessary recommendations to the DSA.

This can include things from notetaking software to printers, ergonomic seating to lightweight laptops (the student has to pay a contribution towards some items). If you can make a strong enough case for why something would help you academically, then DSA will likely consider it. They also provide Assistive Technology Trainers to show you how to use all the software. I made the mistake of not completing my training in the summer, so I had to fit my final few sessions in around lectures and seminars, which wasn't ideal.

Next you will receive a letter called a DSA2, which confirms the items DSA will fund and the approved suppliers of these items. You send a photo of this letter to the chosen suppliers who will, in turn, deliver your equipment.

SOCIAL CARE

Unlike DSA, whose application process is refreshingly easy, sorting **Social Care**, i.e. personal care for university, is a complex process. Firstly, there is the question of where you apply for funding: you apply to Social Services in the area of your permanent address, not your university address. If you put your postcode into www.gov.uk/apply-needs-assessment-social-services, it will tell you exactly which Social Services this is.

For me, the application consisted of the following stages (it may be slightly different in your area): an

online application for a needs assessment; the needs assessment and then the allocation of a social worker. My social worker and I discussed what help I needed and created an 'Adult Social Care Support Plan'. This consisted of help in the mornings to prepare breakfast; do the washing up; sort laundry and to get dressed, as well as twice weekly help bathing and washing my hair, and help every other week to batch-cook meals for freezing. We also requested that I have help in the evenings getting ready for bed. My social worker then applied for funding, which is where we started encountering some difficulties.

Firstly, social workers are busy, and your case will rarely be at the top of the pile. My case only moved along when I was proactively chasing it up. Unfortunately, it took me a while to realise this, which leads on to my second difficulty.

Funding wasn't approved for all the Social Care I had requested, so my social worker needed me to submit further evidence to present to the funding board a week before I was meant to be starting university. Whilst we did manage to get funding approved the next day, it wasn't enough for me to have help in the evenings.

PERSONAL ASSISTANTS

I then encountered the final hurdle in the process: my social worker didn't know where to find care agencies or Personal Assistants (PAs) near my university. With only a week to go, my mum spent the best part of three days calling different care providers trying to find one which could help. Retrospectively, we should have been looking into care providers before my funding was approved.

Originally, I'd planned to hire PAs, rather than use an agency. This was mainly due to the continuity: I didn't like the idea of an agency sending different people every day. Getting used to a stranger bathing me was difficult enough, I didn't want it to be someone new each week! With PAs I would personally interview and hire two or three people to rotate throughout the week, meaning I'd at least get to know the people helping me. However, the hiring process takes time: you have to advertise the role; hold interviews; send them for training and work out the paperwork, all before they can start. Whilst there are intermediaries who can help, I simply didn't have enough time to sort this and I had to use an agency for the first few weeks. After many phone calls, we had a meeting that went well and a few days later the agency began my personal care.

Luckily, they were on the same page as me over continuity of care and found me two regular carers, both of whom are students, so that I am comfortable knowing who will be helping me each day.

If you're wondering what having carers is like (I did), it's not as weird as you'd imagine. I was nervous those first few weeks as I got used to having strangers helping me bath and get dressed, but after the first month had passed it became normal. One of my carers is even in the final year of my course, which means that we get to trade stories about the tutors (don't tell anyone!).

If you have any questions, then you're welcome to send me a private message on Twitter or Instagram (@byemilybailey).

UNIVERSITY CHOICES

And what about the university itself? Which university you attend can make as much difference as DSA and Social Care. For someone with M.E, choosing where to apply can be more complicated than simply considering which course and campus you like best (not to undermine the importance of these two factors). For me it was important that the university was campus-based, so that I wouldn't need to travel far to get to my classes; that I was within an hour's drive of my home, in case I needed help from my family; and that I was in an environment where I felt supported by the university staff.

Like many young people with M.E, I have far fewer GCSEs and A-Levels than the typical university entrance requirements and many universities automatically discard applications which don't meet

these. I decided that my first step would be to contact the head of admissions for the courses I was interested in, to explain my circumstances and ask whether allowances could be made. The first to reply said that it was against university inclusion policies to hold disabled students to any other standard than their able-bodied applicants. Personally, even were I to persuade this university that their policy was by very nature discriminatory, I wouldn't want to apply: their response demonstrated a distinct lack of understanding of someone with complex medical circumstances, i.e. yours truly.

Luckily, their answer was the exception, not the rule. The other two universities I was looking at were

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willing to make adapted offers and to flag the application so that it wasn't automatically dismissed. In both cases I submitted my A-Level coursework as further evidence of my academic capability.

I am sure that everyone reading this will, at some point, have seen a university open day depicted in a film: crowded, busy, noisy. This didn't feel like the most M.E-friendly option. Instead, I went on campus tours, which take place separately to open days and are much quieter. I generally use either a wheelchair or mobility scooter to get around, so visiting the campuses and getting an idea of how accessible they were was important for me. I also met with each university's Student Support and a member of the course faculty. The Student Support Officers talked me through the assistance the university could provide, such as extended deadlines, notetakers, exam allowances and lecture recordings. These conversations gave me a sense of how accommodating each university would be of my M.E.

One of the most common difficulties is coping with the contact hours of a course. I made a point, at this initial meeting with a faculty member, to ask how many contact hours would be required of me. Typically, humanities will have fewer contact hours than sciences: my flatmate does Mechanical Engineering and can have eight hours of teaching in one day; my English course only has eleven hours in the whole week. Whilst I did manage this during my first term, I found it difficult. Thankfully my university was willing to create an alternative study plan with me which spreads the course modules over four years rather than three. I now have eight contact hours per week – three of which are lectures that I can watch the recordings of, rather than attend.

APPLICATIONS

Finally, after visiting the campuses it was time for me to sit down and complete my **UCAS** application. Although I was tempted to gloss over my M.E. in my personal statement – it's not one of my favoured talking points, after all - I decided to try to view my M.E. as a strength. Whilst the illness makes my education hard to pursue, the fact that I still wanted to go to university was a testament to my dedication to the subject. I received offers from both universities and an invitation to attend their Applicant Days. As someone who doesn't have particularly strong decision-making skills, these days were invaluable in helping me decide which university to make my first choice. I requested the days' timetables in advance, so that I could prioritise attending the sample lectures and seminars over the less vital activities.

I will admit that for most of the time that I was applying to university I didn't think that I would actually go. It seemed too far out of reach and I didn't want to be faced with another disappointment due to my M.E. – I'd had more than enough of those. If I hadn't gone through this process and ensured that all of these supports were in place, then it might well have been too much for me.

I enjoy being a university student. Maybe it's not quite the same as most people's experience, but it works for me. ■

PART 3

How to survive university with ME

Emily Bailey continues with the third in her series on university life with M.E: The ME-friendly university packing list!

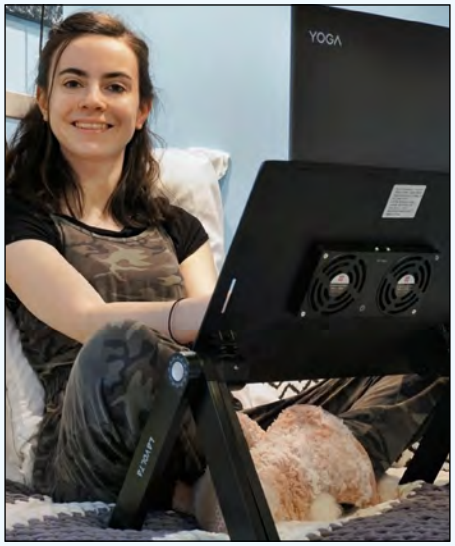
As I write this, I have just submitted my final piece of coursework for my first year at university. That's it, I'm done. I now have four months of rest and recuperation time ahead of me.

The past twelve months have been a rollercoaster; physically, emotionally and mentally. So much has happened that it's hard to put into words. Some of the time I feel like absolutely nothing has changed, yet at other times I hardly recognise the person I was a year ago.

I feel stronger now, more confident. I've coped with one of the scariest, hardest things I've ever had to do and come out the other side. What's more, I've enjoyed it. I've made friends with my coursemates and flatmates; spent evenings talking about anything and everything; founded a society; disastrously decorated a birthday cake... the list goes on. University has simultaneously been exactly how I expected it to be and nothing like I imagined.

There's a lot of things I'd like to tell the person that I was a year ago, the girl frantically trying to foresee any and all potential bumps in the road. Mostly, though, I'd just like to tell her that she's going to be okay. Yes, she may crash her mobility scooter an embarrassing number of times and have to get rid of some uncomfortably large spiders, but she's going to be okay.

That being said, I'm not sure she'd hear me, surrounded as she is by lists upon lists of packing guides. Pots and pans. Bedsheets and towels. Cups, plates and cutlery. Hole punch, stapler...



From stocking up the kitchen cupboards to decorating dorm rooms, there was many a thing to cover and plenty of online lists proffering advice. But what about the things most people don't need, the things which make life with ME a little easier?

THE ME-FRIENDLY UNIVERSITY PACKING LIST

A compact water heater

Not only can kettles be heavy to lift multiple times throughout the day, fatiguing you unnecessarily, but they are also generally supplied only in the kitchen. If this is a long (or even short) walk down the corridor, it's going to build up your general level of fatigue every time you want a cup of tea. A freestanding water heater which expels boiled water into your cup at the push of a button can be a good solution to this. Whether you want to store it in the kitchen or your room is, of course, up to you. I have the Breville HotCup 1.5 Litre, which does a good job but is quite noisy.

A filter water bottle

Tap water isn't necessarily the nicest water and, if part of your ME management includes avoiding exposure to the nasty chemicals/ bacteria that may be found in tap water, a filter water bottle (such as those made by Brita) may help. Whilst they may not filter out everything, a little filtration is probably better than none. I find a bottle works better than a full filter jug as... well, it's light enough for me to actually lift.

An electric can opener/ multi-tool

I don't know about you, but opening cans of tuna is one of my biggest challenges in the kitchen department. Manual can openers make my hands feel like they're being ripped to shreds, and by the time I've got the can open my arms are too tired to do anything with the food inside. This is a big problem for me as I am a massive fan of tuna sandwiches (apologies, vegetarians). There are a variety of different electric can openers you can try; from something small like the Culinare One Touch (I've tried one like this and, while it gets the job done, it can be a little flighty) to a larger, freestanding one like Morphy Richards. This one incorporates other handy kitchen tools (e.g. jar opener, water bottle opener).

A mini fridge

If you have medication which needs to be kept cold and you don't want stored in a communal kitchen, or if you want to have some chilled foods easily accessible on days when leaving your room is too much to ask, you may want to consider getting a mini-fridge.

A SAD lamp

A Seasonal Affective Disorder (SAD) lamp, is one which changes its colour throughout the day to mimic the pattern of sunlight. They can be used as gentle alarm clocks, slowly brightening your room in the morning, and to wind you down before bed by producing a more orange-tinged hue. As someone who struggles to keep on a normal sleep schedule and whose university dorm room is dark about 90% of the time, this has been really helpful for keeping me functioning on the university's timetable. There's quite a range of these at different price points with various bonus features. Lumie is a brand with an extensive collection.

Adjustable seating

Whilst most universities supply some form of seating for your desk, they're generally not the most comfortable, let alone ergonomic, option. In an effort to reduce the number of extraneous factors which can cause you pain and/or fatigue, get yourself a good chair. What this will be depends on you. Spend some time finding an option that best fits your needs. I was supplied with an office chair as part of my Disabled Students Allowance (DSA) package (information on how to apply for this was published in the previous issue). I believe that it was sourced from www.ergochair.co.uk. My favourite thing about my chair is its pivot mechanism.

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PART 4

How to survive university with ME

Emily Bailey completes her university series by describing what univserity can look like on good and bad days.

So far in this series we have covered the highs and lows of adjusting to university life, the different disability support services you can apply to for help during your time at university, and the equipment which I have personally found helpful in managing my experience of being at university with ME.

But what does life at university with ME actually look like? This is a difficult question to answer; just as your condition with ME fluctuates, so will your time at university. Some weeks I am able to attend all of my seminars and stay on top of the workload, pacing in a lunch with a friend as well.

Other weeks I spend most of my time in my room resting, as I cope with a symptom-flare. Most weeks probably land somewhere in the middle, with a couple of "good" days mixed in with a few "bad".

Your experience will also be affected by what course you take; my friends on science/tech courses have more contact hours than me but fewer independent study tasks, meaning they are likely to be in labs or workshops whilst I am tackling my reading load. This doesn't mean that undertaking a science course with a chronic illness is impossible: one of my friends at university is a fellow spoonie who is studying Mechanical Engineering. Her week just looks a little different to mine.

To give you an idea of what being at university with ME can look like, I'm going to walk you through one of my good days and one of my symptom-flare days at university.

Sitting in one position for an extended amount of time tends to exacerbate my joint pain, but this mechanism allows me to frequently adjust my position without having to manually realign the chair.

A lap tray/ bed desk

That being said, it is a touch optimistic to assume that all of your university work is going to be completed at your desk. Some days ME bodies just need to lie down (and, to be honest, sometimes you just want to lie in bed watching Netflix). However, you can still do this ergonomically with a good lap tray. I have the Lavolta Folding Laptop Desk (again supplied by DSA). Its adjustable legs are useful for adapting its position according to my own. However, it does take a little bit of time to work out what degrees to place the legs at to stop the desk from falling over.

Transport aids

You've got to get to lectures, and you may need some help. For the most support, you can get a mobility scooter or electric wheelchair (make sure your mobility scooter is small enough to get inside particularly compact lifts, if they're common on your campus – mine cannot). However, if you need less support a walking stick could be all you need. I have a foldable one which I can keep in my backpack or handbag to pull out when needed (although my dream is to one day have a black one with a silver dragon as the handle). Mine is by the brand Classic Canes England (do you think we can make #stickpic a thing? I think it most definitely should be).

Moulded earplugs

Earplugs come in very handy at university, whether that's to dampen sounds in seminars and social situations or to block the noise of drunken students when you're trying to sleep. However, the cheap yellow foam earplugs amassed at gigs and on aeroplanes are neither comfortable nor particularly inconspicuous (I always think they make me look like Shrek). Moulded earplugs, however, are comfortable and inconspicuous, not to mention more effective. There are a variety of suppliers, such as Emtec (where I got mine) and Mercury Hearing. Some offer increasingly customised options with specific decibel filters and even Bluetooth speakers. An alternative could be noise-cancelling headphones or earphones, depending on what suits you.

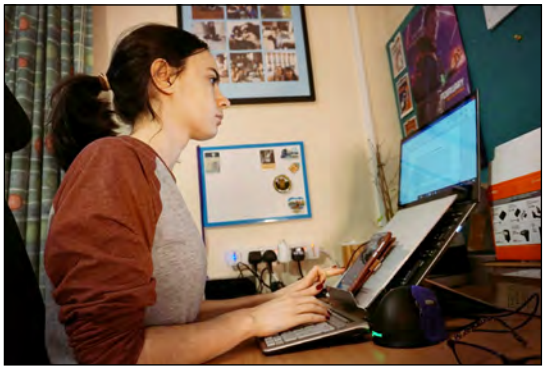
A sturdy backpack

Whilst they may not be the most fashionable, a sturdy backpack that fits you well is important for transporting things to classes. Again, it's all about minimising the things which may cause you unnecessary difficulty, like messenger bags applying uneven weight to your shoulders.

Flare-up supplies

Make sure that you're kitted out for flare-up days. For me this includes a well-stocked snack pile by my bed and lots of two-minute microwave meals. I also make sure to have symptom-management supplies handy (painkillers; travel sickness tablets; my favourite mints and ginger biscuits for when I'm nauseous...)

The summer before leaving for university is both exciting and scary. Thinking about what to pack to best support your experience helps ensure you have as much support in place as possible, come September. ■



A GOOD DAY (TUESDAY)

TIMETABLED WORKSHOP AT 12:00 AND LECTURE AT 15:00

Tuesday is generally quite a productive day for me. My timetabled workshop is only an hour long, meaning it's the class I am most often able to attend. The lecture is recorded so I will watch that tomorrow, as I have no timetabled classes to go to on Wednesdays.

The day starts as all of my days start: my carer arrives at eight in the morning, bringing breakfast to my room. She then makes the bed and does the previous day's washing up and laundry whilst I eat and rest. Her last task is to help me to get dressed before she leaves at nine. I then spend the rest of my morning charging up my internal battery so as to cope with my workshop.

As this is a good day and my symptoms are at the level I find manageable, I decide to put on a podcast for some of this time. I have become quite an avid podcast listener since starting uni. I enjoy putting them on in the background when I'm recharging as they stop me from getting too stir-crazy but don't fatigue me too much (unlike reading or watching TV).

At around 11.15am I start to pack my bag for the workshop, before heading to the kitchen to make myself something to eat. The worst thing for me to have to deal with in a seminar or workshop is the sudden onset of nausea and shaking that happens if I get too hungry; this means always having something to eat before I leave (this is generally toast and Marmite; I am all about that healthy university diet!). I give myself half an hour to get this all done so that I'm not rushing at any point in the process: that's a recipe for an adrenaline spike that will leave me exhausted in a few hours.

I then hop on my mobility scooter and drive across campus to my workshop. Workshops are my most informal class: they are led by a PhD student and we spend our time discussing assessment writing techniques (specifically referencing, aka the bane of all university students' existence). As it's only an hour long, I let myself use a little more energy than I would in a two-hour seminar. This can mean anything from being more responsive to the rest of the class, engaging in more conversations with friends or just letting myself relax and enjoy the moment (as I'm sure you have gathered by now, I am the sort of academic nerd that enjoys any and all teaching environments).

At the end of the class I drive back to my flat. I find that after a workshop, where we've spent so much time discussing essay-writing, I'm in assessment mode. I'll generally try to capitalise on this by spending a little bit of time working on my next assignment. At the moment this happens to be my group presentation.

I've written a script for my part (I do not trust myself to speak from my notes, brain fog does not make that easy) but it needs some editing. This means printing it out and scribbling all over it. At the end of 45 minutes it's probably illegible to anyone but myself. I'm now starting to hit my capacity for the day and decide to lie down for a bit.

At around 4.30pm I get a message from my flatmate saying that she's watching Netflix in her room, if I want to join her. She's the aforementioned fellow spoonie, and we'll quite often spend half an hour or so switching off together by watching some cooking shows as we both recharge.

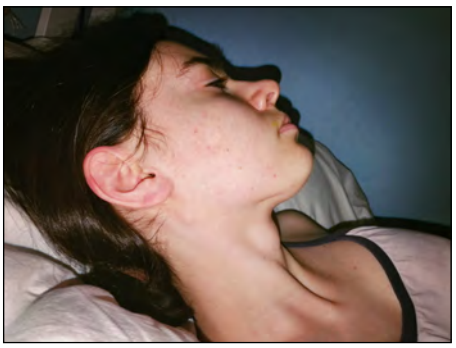
I make my way down the hall to join her. Once she leaves for the evening, my next task is to make my dinner (i.e. stick a pre-cooked meal in the microwave). I then relax with some Netflix before getting an early night (when at university, I need as much sleep as I can get).

SYMPTOM-FLARE DAY (THURSDAY)

TIMETABLED SEMINAR 14:00-16:00

Thursday is the day which I find most difficult to manage at university. I have a two-hour seminar timetabled in the afternoon, which I always find difficult to pace for. All of the unavoidable tasks of the morning and the necessary job of making lunch drain away at my metaphorical battery pack so that, by the time the seminar starts, I am far from my best. There are Thursdays where I will sit on my mobility scooter for five minutes trying to talk myself into driving to class, as my body asks me to go and lie back down. Some days I go, and adrenaline gets me through, other days I get back up and return to my room, knowing that it's just too much to ask of my body.

As soon as I wake up I know that this



is going to be a difficult day. I find myself flinching at the majority of my carer's movements as I struggle to cope with the sensory input. Getting dressed is an ordeal, as my limbs don't want to move freely.

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As soon as my carer leaves, I get back into bed to give my body as much recharge time as I can. Today, no podcasts or music are allowed, as I know that they will just fatigue me more.

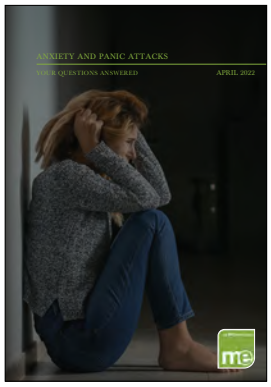
On days like this, all of my effort goes into trying to make it to my seminar; other work can be done at a later date but a missed class can't be caught up on. Unfortunately, when I get up to heat myself some lunch, my symptoms haven't dialled down.

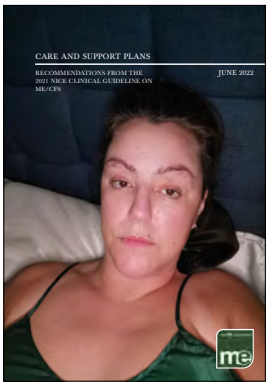
I pack my bag for my seminar anyway; I sometimes find that behaving like I am going to go to the class will kick off my adrenaline and get me through, however that's not working today. I am finding it difficult to function through the symptoms. Fifteen minutes before the seminar starts, I know that I'm not going to make it. I send an email to my tutor to let them know (I find these courtesies keep tutors on your side) and spend five minutes feeling sorry for myself (like I said, academic nerd who always wants to be in class).

Whilst I know that I wouldn't make it through a two-hour seminar, I feel like I could make it through the half an hour of a lecture recording that I have left over to watch. I set my laptop up on my laptop tray, so that I can watch it in bed. I then don't do anything else for the day except for eating dinner and watching a little bit of Netflix before going to bed. I call this type of day a Survival Day; I know that the best thing for me to do is just get through the day without exhausting my body, letting it recover so that I'll hopefully be back in action in a day or two.

On bad days I find it incredibly helpful to have a strong support unit to turn to. This can involve my family, my flatmates or internet friends experiencing similar situations. The Facebook group 'University and Chronic Illness' has become an invaluable resource for me in seeking advice and/or support (if you want to join the group, make sure that you answer the membership request questions). The group also uses the highly entertaining hashtag #spoonieuni; if that doesn't make you want to join, I don't know what will.

Before I left for university, I was convinced that it was going to be too much for me to cope with. Whilst I'd be lying if I said this is never the case, more often than not, with careful pacing around my seminars, it is manageable. More often than not it is better than manageable; more often than not university is everything I could have hoped for. ■





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