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**The unpredictable body, identity, and disclosure: Identifying the strategies of chronically ill students at university**

Louise Toller, University of Exeter\*

Dr Hannah Farrimond, University of Exeter

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\*Corresponding author: [lt328@exeter.ac.uk](mailto:lt328@exeter.ac.uk)

## **Abstract**

The experiences of university students with chronic illnesses have been neglected in previous research, despite the fact that they make up the third largest disability category in the UK. The propensity of chronic illnesses to fluctuate unpredictably sets them apart from other forms of disability, yet little is known about how this inherent uncertainty impacts experiences in higher education, or the strategies students develop in order to simultaneously manage their illness and studies. This article presents a thematic analysis of episodic interviews with 13 current or recent UK university students with chronic illness. One student (Sophia)'s narrative is used as a case study through which the main themes are illustrated, with the stories of other students woven around this, building up a picture of uncertainty and unpredictability.

The ill body was consistently experienced as a frustrating barrier around which life had to be reshaped. Utilising university disability support required disclosure and the acceptance of a disabled identity, yet also minimised the intrusion of illness by enabling students to work within their limitations, reducing the risk of symptom exacerbation or relapse.

While participants did not struggle to be accepted as disabled or to access support, the fluctuating nature of their chronic illnesses failed to fit the narrower conceptualisations of disability that institutional systems were often created for. Participants felt that the support systems provided were not designed for liminal conditions, that standard support and adjustments were not always relevant to their needs, and that provision was inconsistent.

In conclusion, this mismatch between the needs of chronically ill students and support provision demonstrates that gaps between equality policy and practice exist in UK higher education institutions.

Prepare as much in advance and prepare for the worst case scenario, because I didn't think about it, because I didn't think I needed to, and then it would've been easier at the time I think if I'd already thought, oh this *could* happen, and this is what I'd do in that situation (Sophia, age 19, undergraduate, chronic pain condition).

Ignoring your illness and trying to be a 'normal' student will eventually backfire tremendously. There is no such thing as a 'normal' student so be yourself, chronic illness included' (Lauren, age 19, undergraduate, ME/CFS)

## Introduction

There is a growing body of research on the university experiences of disabled students in general (e.g. Fuller, Bradley, & Healey, 2004; Fuller, Healey, Bradley, & Hall, 2004; Goode, 2007; Hopkins, 2011; Tinklin & Hall, 1999), and on some specific groups of disabled students in particular (e.g. physical disabilities, Borland & James, 1999; mood disorders, Demery, Thirlaway, & Mercer, 2012; Asperger Syndrome, Madriaga, 2010; dyslexia, Mortimore & Crozier, 2006). However, despite the fact that students with long-term health conditions make up the third largest disability category in UK universities, accounting for around 10% of all students who disclose a disability (Higher Education Statistics Agency, 2019), previous UK research and the majority of international research has not differentiated between the experiences of these students and those with other forms of disability. This leaves us with very little understanding of the impact chronic illness has on university experiences, and how issues key in the chronic illness literature play out in the context of higher education.

## ***Background: chronic illness at university***

### *Accessing support*

Support provided by university disability services is of vital importance in enabling disabled and chronically ill<sup>1</sup> students to participate in higher education. Without it academic performance, quality of life and health can all suffer (Jung, 2003; Moríña, 2015; Mullins & Preyde, 2013). In order to access this support students must disclose their condition to their university; however, for a variety of reasons not all choose to do so. Like students with other forms of disability, those with chronic illnesses may worry about encountering stigma in using support services (Hammer, Werth, & Dunn, 2009).

Alternatively, students with chronic illnesses may not identify as disabled (Boyd, 2012; Jung, 2002), or may not be aware that they are eligible for support via disability services or ‘count’ as having a disability (Eccles, Hutchings, Hunt, & Heaslip, 2018; Tinklin & Hall, 1999). Finally, students may worry that they will encounter stigma or delegitimation within disability services due to a lack of awareness or understanding of chronic illnesses, or suspicion surrounding fluctuating or invisible conditions (Åsbring & Närvänen, 2002; Jung, 2002; Magnus & Tøssebro, 2014; Valeras, 2010).

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<sup>1</sup> Central to the definition of chronic illness used in this research is the unpredictable, waxing and waning nature many chronic conditions share, a characteristic that does not fit many people’s stereotype of disability as permanent and static (Lightman et al., 2009; Wendell, 2001). While fluctuating symptoms are not unique to chronic illnesses, and there is no clear line between chronic illnesses and other forms of disability, the impact of fluctuations on experiences is a major theme across the chronic illness literature (Charmaz, 1997; Grytten & Måseide, 2005; Moss & Dyck, 2002; Vick, 2013; Wendell, 2001), and has been largely neglected by past research on disability at university.

### *Disclosure decisions*

Some students, however, do choose to disclose. Grytten and Måseide (2005) describe disclosure of chronic illness as a strategic choice, depending on how the individual perceives the balance of risks and benefits in their specific situation. In a higher education context, students must weigh up the possible risks discussed above with the benefits of accessing support. Additionally, they must consider the potential costs of nondisclosure; if students choose not to access the support they need, function may be sacrificed and symptoms exacerbated as they try to study in the same way as their healthy peers (Sabik, 2010). Lacking in the literature, however, is an understanding of how they make these decisions.

### *Accessing suitable support*

In the UK, disability, including chronic illness, is one of a number of ‘protected characteristics’ covered by the Equality Act 2010. This means universities must take positive steps to both ensure students who disclose a disability can fully participate, and to avoid substantial disadvantage caused by disability. This includes taking advance action in anticipation of students’ needs, rather than reacting to individual students’ needs as they arise. If students are at a substantial disadvantage, universities have a legal duty to make reasonable adjustments to alleviate this; what counts as ‘reasonable’ or ‘substantial’, however, is ambiguous. Despite this, when students do choose to disclose a chronic illness they are not guaranteed to receive support suitable for their illness and needs. With regard to the situation in US universities, Royster and Marshall state that ‘the needs and wants of students with chronic illnesses tend to differ from the institutional resources and privileges that can routinely be offered’ (2008, p. 121). This mismatch between students’ needs and

support provision is partly due to the tendency of many chronic illnesses to fluctuate unpredictably; impairments vary in intensity and impact over time, meaning students' levels of functionality, limitations and needs also change (Boyd, 2014; Lightman, Vick, Herd, & Mitchell, 2009). Boyd (2012) notes that the support offered by universities is often based on constructions of disability as permanent, predictable and stable. Support systems designed with static disabilities and needs in mind can struggle to cope with the volatility of chronic illnesses, and institutions can be rigid and unwilling or unable to adjust. Canadian students interviewed by Jung (2003), for example, found they were only able to choose from set types of support which were put in place for the entirety of their university career, when what they needed was an ongoing process of negotiation depending on the severity of their symptoms, and deviation from the standard support on offer (see also Korbel, Lucia, Wenzel, & Anderson, 2011 on the situation in the US).

Constructions of disability as static and stable, and a resulting failure to accommodate the subjective experiences and needs of individuals with unpredictable chronic illnesses, are not limited to higher education. Lightman and colleagues, for example, found the same issue in the Canadian welfare system. Individuals were required to position themselves as either wholly able (and employable) or wholly disabled (and unemployable); those with chronic illnesses, however, shift from one category to the other as they move between periods of relative health and illness (Lightman et al., 2009; Vick, 2013; Vick & Lightman, 2010). They possess a 'betwixt-and-between' or liminal status (Turner, 1974, p. 232), with the instability of their subjective symptom experience echoed by a conceptual instability as they move around in classificatory space (Jackson, 2005; Moss, 2000). Designed with the dominant construction of disability in mind the system does not contain

a space for such unpredictable bodies to occupy, which can leave individuals feeling that their experiences of disability are not legitimate.

### *Barriers to studying*

In addition, students may find that their illnesses form barriers that may not be acknowledged and that support cannot always negate. The dominance of the social model of disability means the emphasis is on removing social and organisational barriers to participation (Oliver, 1990). Research on disability in higher education has also focused largely on these same barriers. While this has been of huge importance in understanding the issues faced by students with disabilities, and in widening opportunities and participation, it means the experience of impairment can be neglected (Crow, 1996; de Wolfe, 2002; Shakespeare, 2006). Impairments such as pain and fatigue create what Wendell refers to as ‘suffering that justice cannot eliminate’ (2001, p. 31): struggles that will remain even if all social barriers are removed (Crow, 1996; de Wolfe, 2002). If someone suffers from fatigue, for example, ‘there is a limited amount that can be done to help’ (Shakespeare, 2006, p. 50).

Previous research shows that impairments from chronic illnesses can form a barrier to studying (Moriña, 2015; Mullins & Preyde, 2013). Symptoms, such as fatigue, pain and cognitive dysfunction, and the fluctuations in their severity over the course of a semester or year, may lead to problems completing assignments or sitting exams (Hammer et al., 2009; Jung, 2002; Lawson, Werth, Dunn, & D’Abadie, 2008; Mullins & Preyde, 2013). Attempts to counter this impact by using disability support services or developing personal study strategies are not always successful, leading to missed deadlines, absences, disruptions, and even failure to complete. This can result in students having to manage

their expectations of what they are able to achieve and setting the bar lower to accommodate their illness and associated limitations (Royster & Marshall, 2008; Werth, Hammer, & D'Abadie, 2014).

It is clear that the impact of symptoms and their unpredictability is a key issue and major source of anxiety for students with chronic illnesses, who lack control over relapses and the subsequent consequences on their studies (Hammer et al., 2009; Lawson et al., 2008; Werth et al., 2014). However, previous research has only touched on this issue. This study therefore aims to explore the impact of having an unpredictable chronic illness on university experiences in the UK, and the strategies students use to try and manage both their illness and their studies.

#### *Reflexive note*

*[First author]* These gaps in the literature were particularly evident to me. I became ill with what would later be diagnosed as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) when I was an undergraduate, and it has had a significant impact on my university experiences ever since. I constantly have to negotiate the barriers thrown up by my symptoms: fatigue and easy fatigability affect how much work I can do, cognitive issues make reading, thinking and writing hard – sometimes impossible, and fluctuations mean every day is different. Like Nielsen (2007), a PhD student with chronic pain, I felt that some of my experiences were not represented in the literature on disabled students, and it seemed unlikely that I was the only chronically ill student having these experiences. A desire to give others an opportunity to share experiences that, from my perspective, had been neglected by much previous research was, therefore, a key motivating force behind this research.

## Methods

### *Episodic Interviews*

In order to explore the ‘cultural, social and uniquely personal aspects of living with illness’ as a student (Holloway & Wheeler, 2011, p. 12), from the students’ own perspectives and in their own words, qualitative methods were utilised. Interviews were conducted using the episodic interview format developed by Flick (1997). This format encourages participants to recount a series of narratives about their own lives, specific to the topic under investigation, by explicitly asking for stories to illustrate each question, thereby keeping the data grounded in specific, concrete experiences. The episodic interview is designed to overcome some of the limitations of both semi-structured and narrative interviews. As Holloway and Jefferson (2000) suggest, the question and answer structure of semi-structured interviews can suppress stories, while they also tend to elicit abstract statements rather than narratives. In contrast narrative interviews encourage participants to tell their stories and are grounded in concrete events, but can be very long and the emphasis on the unique story of the individual makes comparison across cases difficult (Flick, 1997). It can also be hard for individuals to sustain a lengthy narrative with only minimal prompting, especially if they have cognitive impairments (Ross, 2011).

By using an interview guide the episodic approach enables the research topic to be covered comprehensively and makes thematic comparison across cases easier, while also allowing participants to tell a number of shorter narratives rather than one long biography.

The interview guide for this study was developed with reference to Flick’s (1997) guidelines, covering areas of relevance from the first author’s personal experiences and from literature on chronic illness and disabled students (Åsbring & Närvänen, 2002; Dickson, Knussen, & Flowers, 2007; Grytten & Måseide, 2005; Hammer et al., 2009;

Lightman et al., 2009; Moriña, 2015; Mullins & Preyde, 2013; Werth et al., 2014), with the aim of covering all relevant areas while still leaving space for new aspects to be introduced by participants. Following explanation of the episodic principle, the guide<sup>2</sup> covered: details about illness, onset and diagnosis; impact of illness on daily life; impact of illness on academic and social aspects of university; and more abstract opinions on chronic illness. While all areas were covered in each interview the guide was not followed strictly; the order of topics and questions was in part determined by each participant's responses, allowing the interview to develop organically.

*[First author]* An additional reason for choosing to use episodic interviews was the hope that it would help to ameliorate the risk of taken for granted assumptions and shared knowledge arising from my position as an 'insider' researcher (Hodkinson, 2005). Willig (2013) suggests that expressing ignorance can be an effective way to obtain detailed accounts in any interview, but there is clearly a balance to be struck between naivety and the familiarity that helps build rapport over shared experiences. By constantly eliciting specific personal examples, however, episodic interviews have an inbuilt structure that automatically creates space for an insider researcher to ask for more detail. This should help to ground the data in participants' experiences, reducing the risk of falling back on pre-existing knowledge from my own experiences to fill in any gaps.

### ***Participants***

Ethical approval was obtained from the Social Science and International Studies Ethics Committee at the University of Exeter, UK. Adverts were placed on two social media groups for young people with chronic illnesses, a multiple sclerosis charity blog, an

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<sup>2</sup> See appendix for full interview guide.

internet board for young people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and spread through personal contacts. The insider status of the first author was helpful here, as her membership of several online groups for young people with chronic illnesses made advertising on them possible. This led to the recruitment of thirteen participants, aged between 19 and 29, eleven female and two male. All levels of higher education were represented: one participant was completing a foundation degree, seven were current undergraduates, one a Masters student, and one a PhD student; the remaining three had completed their degrees, two at undergraduate and one at PhD level. One was studying via a further education college, two were with the Open University (OU; an inclusive, open-to-all university offering flexible, part-time, distance learning), and the remaining ten at universities in England. All self-identified as having a fluctuating chronic illness: six identified as having a physical condition; one a mental health condition; two as having multiple physical conditions; and four as having comorbid physical and mental health conditions. In accordance with ethical requirements, participants were given an information sheet and consent form, and the opportunity to ask any questions, prior to the start of the interview.

***Reflexive note: accommodating illness-related limitations in research***

*[First author]* I was aware my methods would have to account for participants' illness-related limitations – as a fellow chronic illness sufferer, I was perhaps more aware of this, and of the need to be flexible and defer to participants' own knowledge about what they were able to do and how (Morris, 2003). However, I also had to take my own illness and limitations into account and accommodate myself in my design – something that is often not addressed, but that is essential for disabled researchers (Kerschbaum & Price, 2017). There is a 'misfit' (Garland-Thomson, 2011) between my capabilities and research based

on face-to-face interviews. I am not realistically able to travel long distances to meet participants – at least, not reliably, and not without significantly impacting my health and, therefore, my ability to work in subsequent days and weeks. But I *can* use Skype: interviews are still draining, but without spending time and energy travelling they are manageable, and their impact is milder and of shorter duration.

Skype video calls helped my ‘square peg’ fit into the ‘round hole’ of interviewing (Garland-Thomson, 2011, p. 593) and, by being easy to rearrange and not requiring either party to travel (Deakin & Wakefield, 2014; Hanna, 2012; Holt, 2010), would potentially be suitable for many participants. However, I was aware they might not be suitable for all, depending on their specific condition and symptoms. I therefore decided to offer the choice of interviews via Skype video calls, audio calls, or email, in the hope that this would make taking part accessible to as many people as possible. Price laments that ‘it is not yet a viable option to attend interviews in pajamas’ (Kerschbaum & Price, 2017, p. 37), but ultimately this was my goal: that my participants could all be in a situation that was least likely to exacerbate their symptoms, even if this meant they were in their pajamas, in their bed – and that I would be able to do the same.

Given these options, two participants chose to take part via email, one due to hearing problems, the other due to extreme fatigue; four participated via Skype but audio only, three due to problems looking at a screen for prolonged periods and one to problems with the internet connection; the remaining seven were interviewed via Skype video calls. For email interviews, questions and answers were exchanged in five sets; duration varied depending on the speed of participants’ responses, with one taking two weeks and the

other six weeks to answer all questions. The duration of Skype interviews ranged from 1 to 2 hours, with an average of 80 minutes.

### *Analysis*

All interviews were conducted, audio recorded and manually transcribed by the first author, while email responses were copied into a Word document. Thematic analysis was carried out by the first author following Braun and Clarke's (2006) guidelines, which set out a six-phase method of analysis that aims to allow researchers to systematically identify and interpret patterns within qualitative data. Transcripts were read repeatedly and initial ideas noted; the entire data set was then systematically manually coded to generate initial codes, and all relevant data extracts collated. Codes were then sorted into potential themes, which were reviewed and refined by checking against both collated data extracts and the full transcripts. These themes were then further refined, and sub-themes within them were identified. This included broad themes generated in response to pre-existing theorisation (e.g. the mismatch between chronically ill bodies and the demands and expectations of institutions) as well as new themes generated inductively, and sometimes unexpectedly, during the coding process (e.g. decisions surrounding disclosure). The analysis was read and the original data examined by the second author; changes were suggested, and incorporated into a final analysis agreed by both authors.

### **Findings**

We identified three significant factors impacting participants' higher education experiences: the chronically ill body as a barrier around which life had to be reshaped, institutional support for unpredictable bodies, and the lack of awareness of chronic illness. Considering these factors together, we offer an analysis of the strategies students

developed to try and enable academic success, and some of the barriers they faced in doing so.

### *Case study: introducing Sophia*

Thematic analysis can sometimes fragment data and result in the context of quotes being lost, something that the use of case studies can help to ameliorate as they allow consideration of the whole (Bryman, 2012; Riessman, 2008). Smith and Sparkes (2008), for example, use the narrative of Jamie as an exemplar to illustrate shifting embodiment and narratives in spinal cord injury, while Williams (1984) uses three case studies to illustrate different narrative reconstructions in people with rheumatoid arthritis.

Importantly, Williams does not claim that these three people are ‘representative’, but they do portray three different but ‘typical processes’ found throughout his participants’ experiences (1984, p. 176). In order to provide a more coherent, intact narrative, we therefore use the story of one student, Sophia, as a case study through which to illustrate the main themes. As with Williams’ case studies, Sophia was not representative of all participants’ experiences. She did, however, have typical experiences of the impact of symptoms, support, and scepticism that are reflected throughout the data. The stories of other students are woven around her narrative, building up a picture of uncertainty and unpredictability – in the chronically ill body, and in institutional responses to their needs.

Sophia (not her real name) was a nineteen-year-old undergraduate student at a post-1992 university in the south of England. During her final year at secondary school (aged 15-16), she suffered an injury, followed by a virus, and then the gradual onset and worsening of a chronic pain condition that also causes fatigue. At the time of the interview, her pain was ‘always there, and it’s noticeable’, but was at a level she could cope with. However, this

constantly fluctuated: each week would contain several good days, several days she was unable to do much, and perhaps one really bad day. As she described it, she could go from ‘what I think as normal functioning to almost no functioning – and it could be anywhere in between’.

### ***The chronically ill body: a barrier to studying***

What Sophia called ‘normal functioning’ is clearly far from the normal functioning of most students. The pain and fatigue of her illness impacted her ability to attend lectures – during the second term of her first year, in the depths of her worst crash, she only managed to go to a handful of lectures – and also her ability to study, whether this was reading, writing an essay, or preparing for and sitting exams:

Normally a typical day might involve either like a two hour lecture or me doing some work, and then I normally sleep in the afternoon for a bit and see my housemates in the evening... if I spread out all the activities I can do everything that I want to do, and need to do, but it takes a lot more effort.

Other participants noted cognitive dysfunction that made them feel they were falling behind their peers, or that meant they could prepare for a class and then have no memory of what they had read or the notes they had made. While for Sophia limited energy meant spreading activities out over the course of a day, for Emily (age 23, undergraduate at a campus-based university in the Midlands of England) it manifested more as a lack of stamina:

I can’t sustain effort for more than two weeks... I can revise for my exam for two weeks and I can do pretty well, but then that’s comparing with everyone else who’s been revising for two months.

As well as her illness impacting how she could study, Sophia also experienced a delayed reaction to exertion:

If I've worked really hard revising or doing an essay or something, it's very delayed so then the next day I'll like, really struggle, but I don't necessarily notice it at the time.

This worsening of symptoms sometimes only had a short-term effect. At times, though, it could be much more significant and lasting, and 'overdoing it one day can sometimes affect most of the whole term'.

Although symptom exacerbation and flares can be the predictable result of doing too much, thinking too hard, or staying up too late, sometimes things just get worse, for no discernible reason. Chronic illnesses can flare 'out of nowhere', and chronically ill bodies can crash 'for no reason', preventing students from doing the work they had planned. As Beth (age 22, foundation degree at a further education college in the Midlands) explains:

It's always a surprise when it happens... I had planned to do a massive essay writing session but now I've got a massive migraine and I'm gonna have to spend the day in bed.

No matter how much students plan, and build their days and studies around the limitations and needs of their ill bodies, these bodies can still betray them – something that can be highly frustrating, as Sophia explains here:

Even if I plan and break everything down and stuff, I can just have a random week out of nowhere I can't do any work and I can't control that... it can be quite difficult emotionally, like not having that control and not being able to do anything about it.

Sophia's worst crash came shortly after she began at university, and was prolonged by her attempts to study on days she felt a little better, leading to a rollercoaster, 'boom and bust' pattern of activity:

I survived fresher's week and I survived my first week of lectures, and then I crashed, and didn't really recover... and then came home over Christmas and recovered, went back and crashed even further, and that's probably the illest I've ever been... I went to about five lectures in that whole term... that was really difficult because it meant that I'd have like, four terrible days, one good day, and then the next day would be a decent day and I'd go to a lecture, and then that would push me straight back into terrible days.

Unsurprisingly, this was hard to cope with emotionally, perhaps particularly because Sophia's illness began due to an injury doing something she loved – dancing – and went on to prevent her from being able to return to this activity, and was then exacerbated by another valued activity – studying:

That was really difficult because I'd gone from my illness when I lived at home did affect me but not, I wasn't anywhere near that ill, and it was studying that pushed me over the edge, and that was really difficult to kind of be like, I really want to be here, I don't want to have to take time off, and that was when I decided to go part-time. But yeah, it was studying that made me ill, and that was really, really hard to come to terms with because studying was something that I thought I could still do.

***The chronically ill body: reshaping life around limitations***

Charmaz notes that ‘ill people become innovators in handling their illnesses, inventors of their lives, and creators of ways of coping’ (1997, p. 135). There is no doubt that this was true of the students interviewed here; they were ‘not really able to work in the same way as everybody else’ (Martha, age 23, undergraduate at a London university), so had to find their own, unique ways of studying. Most of the strategies they developed to simultaneously manage their illnesses and studies fell into two categories: personal study strategies, and utilising university disability support services.

As mentioned in the quote above, following her major crash, Sophia dropped down from full- to part-time study, although she was still technically enrolled as a full-time student. This was not an option she was initially aware was possible; it was not offered to her when she explained her situation to the university – of being too ill to study full-time, but unable to financially afford studying part-time – leaving her thinking she had no option but to drop out altogether. It only became visible to her when she spoke to her mentor, who ‘kind of on a, as kind of aside said, ‘oh yeah, you don’t have to do eight modules a year,’ and I was like, ‘what? I don’t?’” Sophia regarded this as a failure of communication on the part of her university, who ‘didn’t tell me that, you know, vital piece of information, but once I knew that it was very easy to change but it was just communication, they weren’t really thinking about it’. Once in place, this reduction to 75% of full-time made things more manageable as she had less lectures to attend (and recover from), less work, less deadlines, and less exams to prepare for. Looking ahead, it meant that in her final year Sophia would only be taking two modules alongside her dissertation. She particularly noted the potential benefit this could have as, even allowing for bad days and flares, it would give her more time and energy to focus on producing a good dissertation.

But even a reduced workload required careful management. For Sophia, this began with balancing her activities across each week, using a diary that enabled her to see how activities were distributed:

Visually I can look across and see like, oh I've got too much on one day I'll move that, or like, that's a really busy day but I can't do anything about it, I'll just make sure the next day is clear.

She also found ways to save energy, such as working from home rather than going to the library. This strategy was also used by Sarah (age 27, Masters with the Open University), who referred to how her chronic conditions had made her 'really academically lazy', as she always sought shortcuts or ways to preserve her limited energy.

When it came to essays and coursework, a common strategy among participants was to start early, using the maximum amount of time possible for a piece of work. Beth referred to 'catastrophe planning', as this allowed for times when flares meant she was unable to work. A second common strategy was breaking work or working time into smaller sections. Megan (age 25, undergraduate at a campus-based university in the Midlands), for example, found that while she was unable to spend a whole day reading, she could instead 'sit and read for like half an hour a few times a day'. Similarly, Emily used timers to structure her working time and ensure she took regular breaks, finding that she could 'literally work half the time, and everything takes twice as long as it should'. Sophia used a combination of these two strategies:

I would always start as soon as I can, so even if it hasn't fully been set yet I'll start doing research and things if I know we're gonna have an essay soon. I start normally by just planning it really well, and breaking it down into little sections and then it means that when I'm ill, when it's quite hard to kind of think about

different things at once I can just focus on one little section and work on that...

often if I'm trying to think of something as a whole it gets quite overwhelming.

She openly acknowledged that this section by section approach 'might not be the most efficient way of doing it', but for her it was essential, and the only way she was able to produce academic work.

Sophia used a similar approach when it came to revising for exams, starting well in advance of most of her peers and breaking everything down into small, manageable topics. Her capabilities when it came to how much she could do in a session before becoming fatigued changed over time, however:

A year ago I could do twenty minutes before I'd just collapse, now I can do a lot more.

Chronically ill students, therefore, need to be able to adapt not only to their 'ordinary', baseline symptoms and limitations, but also to changes in these limitations, both positive and negative. The unpredictable shifting nature of many chronic illnesses means strategies that work one day – that have worked for many days – may not work the next. An illness this changeable cannot be adapted to just once, but requires ongoing adjustment: it is impossible to be static in the face of such dynamism.

### ***Institutional support for unpredictable bodies***

In addition to the study strategies students developed themselves, they also accessed support and adjustments from university disability services – services that all UK universities are legally obliged to offer in order to provide disabled students with support and adjustments. For many participants, this support was essential, although not all chose to use it. The support utilised included deadline extensions, exam adjustments such as

extra time or the use of a computer, mentoring, and the provision of resources in a suitable format. Sophia's extensions added to her strategy of starting coursework early, meaning she was able to work at her own, slow pace, with no need to push herself beyond her capabilities and increase the risk of a flare. Extensions could also be helpful when she had multiple deadlines, such as happened in the previous term:

I had lots of deadlines at the same time, so it was working out when I could use my extensions to spread them out because I can't really work on multiple things at once.

In UK universities, it is normal for disability support plans (under a variety of names) to be sent to the student's department, tutor and/or lecturers to make them aware of the adjustments students are entitled to. Participants perceived this as helpful, as it meant they either did not need to discuss their needs with their lecturers or made approaching them easier, as they did not have to explain themselves or provide evidence to legitimate their illness or needs, as Martha explains:

I just feel like I've got something official behind me... it just helps 'cause it's really nerve-wracking to have to ask for special measures or extensions.

As discussed below, however, not all individual lecturers responded positively when it comes to students actually using the adjustments to which they were entitled.

While Sophia used the support and adjustments available to and arranged for her, not all participants did. Just knowing that they were in place, however, was helpful. Megan described her deadline extensions as a 'safety net', while for Martha having exam adjustments arranged in advance meant she did not have to worry about flare-ups or symptom exacerbations. For both, and for other participants, the stress associated with the

unpredictability of illness was reduced, as they knew that if something were to happen, then contingencies were already in place.

***Developing strategies and accessing support: acceptance and disclosure of illness***

Of course, you can only develop strategies and access support from university disability services if you recognise that you need them, and that you need to reshape your life around an illness. For Sophia, this process began after she had applied to university but before selecting her final choice of institution, when she realised her illness was going to impact her A Level grades and her university experience. She therefore chose to go to a university requiring lower entrance grades, and that was smaller and less pressured than some of her other potential choices. This resulted in less pressure on her A Levels, and also less anticipated future pressure during her degree. Sophia was not the only participant whose illness affected their choice of university. Isabel (age 23, undergraduate at a London university), for example, decided not to apply to Scottish universities as she felt the longer, darker winters would have too much of a negative impact on her Seasonal Affective Disorder (SAD), while Claire (age 22, undergraduate at a post-1992 university in south-west England) decided to apply to only campus-based universities, as walking around an open day at a city-based university exhausted her so much that she collapsed.

But while Sophia recognised that she might need to make some concessions to her illness, it is clear that she failed to fully appreciate the potential ramifications it might have, largely due to the gradual onset and mild severity she had experienced up to that point:

I just thought it would be totally fine, and it would all be really easy, and I know how to deal with it.

The crash she suffered during her first year shattered this illusion. When asked what advice she would give to other young people with chronic illnesses thinking about going to university, Sophia's answer betrayed a sense of regret:

Prepare as much in advance and prepare for the worst case scenario, because I didn't think about it, because I didn't think I needed to, and then it would've been easier at the time I think if I'd already thought, oh this *could* happen, and this is what I'd do in that situation.

Despite beginning to accept her illness-based limitations prior to starting at university, and getting in touch with her university's disability support office to arrange adjustments, Sophia did not consider herself to be disabled at this point. She applied for Disabled Students' Allowance (DSA; a government grant for disabled students, to cover additional costs due to disability), but only because someone mentioned that she should, and even this did not alter her perception of herself. It was only when things got much worse that this changed:

I was confused and a bit like, ok well I count for DSA but I'm not *actually* disabled. And it wasn't until I was in my first year and got very ill that I was like, no actually I am disabled, like I can't, most days I can't walk or cook or things... it was quite a hard acceptance process, but now I'm, yeah, I'm a disabled person... but at first it was just very confusing, and I didn't really, didn't really think that was me.

Sophia may not have seen herself as disabled when she started at university, but she did at least recognise that her illness would have some impact on her studies, and that she would require some degree of support. James (age 24, undergraduate at a university in north-east

England), however, had not yet reached this point. James became ill as a teenager with what would later be diagnosed as ME/CFS, but healthcare professionals failed to give him the information and support he needed:

The paediatrician was... quite naïve really and they were just saying generally people tend to get better and they just instilled the idea that it wasn't really very serious or worth considering and just to carry on as usual.

At university he struggled to do this, becoming increasingly disabled as his illness became more intrusive, impacting more and more on his ability to study, until he could no longer ignore it:

I had to transition through the phase of actually realising, this is 'cause I've become disabled and it's actually 'cause I've got this illness, which before I scarcely realised could have such a profound effect.

This realisation that he was struggling because he had ME/CFS enabled James to label himself as 'disabled' and therefore in need of, and eligible for, support from his university.

By accepting a disabled identity like this, James, Sophia and other participants were able to access support and develop strategies to manage both their illnesses and their studies. This minimised the intrusiveness of illness, as students were able to work within their limitations rather than constantly having to push beyond them. Without support and strategies, they often encountered a 'misfit' (Garland-Thomson, 2011) between their ill bodies and academic demands, which could exacerbate their symptoms or cause relapses, making it impossible for them to successfully maintain an academic identity. This is perhaps clearest in the case of Lauren (age 26, undergraduate first at a university in the north-east, then with the Open University), who struggled with the tension between who she wanted to be and the reality of her illness. When Lauren first started at university, she

rejected her ill identity, as she wanted to be a normal student: 'I chose to ignore my ME instead of working with it'. She therefore neglected her pacing and the other strategies she had previously used, which led to her illness becoming worse and having a greater impact on her ability to study. Eventually, she suffered a major relapse and was forced to withdraw, losing the academic identity she had so desperately wanted to maintain. When she later returned to university, Lauren took steps to accommodate her illness – studying a subject with a lighter workload, part-time, and from home via the Open University; this meant she had to identify as ill, but also allowed her to identify as a student. Reflecting on her experiences, Lauren recognised the importance of accepting an identity as chronically ill, a theme also evident across other participants' experiences:

Ignoring your illness and trying to be a 'normal' student will eventually backfire.

There is no such thing as a 'normal' student so be yourself, chronic illness included.

***Lack of awareness of chronic illness: institutional responses to unpredictable bodies***

Despite students' best efforts, their strategies were not always successful. There appeared to be two main reasons for this: the university offering support that was unsuitable for their needs, and their unpredictable ill bodies.

While some participants were very happy with the support their university provided via disability services, a feeling that the system was not designed for people like them was common. Many perceived it as being set up for students whose disabilities and needs were stable, whereas the support they needed 'could change every day' (Sarah), something the system struggled to deal with. Also common was the feeling that support was not well tailored to the needs of individual students, or was 'a little bit tick boxy' (Martha), with

some services unwilling to consider providing support that was not on a standard list of adjustments they had offered previous students:

It's very much sort of, these are the things that we've got, these are the things that we're willing to do – which of these do you want? When actually in some cases it's none of these things are things that I want, what I want is something else and something that you're refusing to even think about giving me (Isabel).

This issue is evident in Sophia's experience, in terms of her adjustments for both lectures and exams. The disability memo sent from disability support to her lecturers contained details on how her condition affected her and the adjustments she was entitled to, but not all of these adjustments actually helped her:

In there is says stuff like, if I can't sit still for a long time then I can get up and move around. But in there is a lot of information that isn't correct, so actually for me getting up and moving around is *not* helpful because I'm too tired, if it's affecting me that much I can't move.

Similarly, she described her exam adjustments as 'half helpful', comparing them unfavourably to the adjustments in place for her A Level exams:

Again it's almost like they're close but not quite what I need, so in A Levels I was able to take breaks for whenever I wanted for as long as I wanted, I could just sit at my desk and be quiet and not write for ten minutes, they just had to take my paper away and write down the times. At university, I can have ten minutes every hour, but I have to move away from my desk, out of the room, which for me is very unhelpful because I just need to sit there and not do anything for ten minutes and moving is difficult.

Unlike her lecture and exam adjustments, deadline extensions *were* helpful and suitable for Sophia. The responses of individual lecturers to her using them, however, varied. When she fell behind on a large piece of work and emailed to say she would be using her extension on it, 'they were like that's totally fine, take as long as you want, like get in touch if you need anything.' This willingness to offer further help if she needed it, even though she did not, was something Sophia clearly appreciated, as she felt it demonstrated that 'they don't just think I'm lazy'. In contrast, she described several negative reactions from the previous year:

I had someone just be like, you need to work harder when I emailed, and someone else say you can't use your extension, which I wasn't asking I was telling them, like it's not an ask for, like I'm entitled to it I'm using it, and another person who was just like, if you can't do the work by the due date you shouldn't be at university, even though I'd kinda said this is kind of a legal thing, it's called reasonable adjustments... it was sorted out in the end because obviously legally they can't refuse, but it just wasn't very nice to kind of, it did make me doubt myself and whether I should be at university.

Both Sarah and Isabel also had similar experiences with their tutors, at times when they were struggling to keep up with their work. An occasion when Isabel fell behind with group work was one of several when her tutor was unsympathetic:

I emailed my tutor... he said, 'I've talked to your group mates and they said you're not pulling your weight so there's not really a lot I can do to help you'.

Isabel later changed tutor due to this lack of understanding, and found that having a supportive tutor made a real difference:

She seems to understand it a lot better. Listens to sort of what I say about it and what I can do and what I can't do, and I think appreciates that I want to pass the course, and am doing my best to do that.

Sophia may have encountered resistance from some lecturers, but in terms of procedure it was easy for her to use deadline extensions. However, procedures surrounding extensions vary from institution to institution, and can sometimes be difficult for students with chronic illnesses to access. Megan benefitted from a system similar to that at Sophia's university, which made it easy to apply for extensions once an illness had been disclosed to disability services:

I can just point to the Disability Referral Form and say... I've kind of handed in evidence for this already, and it's just a particular flare up issue or whatever that I'm having at the moment.

However, this was not the case for other participants. At some universities, the system seemed better suited to acute illnesses, and each application for an extension required new proof of illness in the form of medical evidence such as doctor's notes. This is something that students with chronic illnesses could find difficult to provide, either because they no longer saw their GP as they had been diagnosed and were not receiving treatment, or because they were unable to provide evidence of illness on specific days:

You had to have a lot of medical letters and evidence. I could prove (just, with a few letters) that I have migraines but not that I have been ill on this many days and unable to work (Beth).

As Martha said, a system more like those at Megan and Sophia's universities would be far better suited to her situation:

If there was some way I could just use the inclusion plan as proof of a chronic condition, that'd be really helpful

Common among participants was the feeling that both people and systems struggled with the instability and fluctuations inherent to their conditions. Sophia identified this as an issue when it came to her lecturers, but also with her disability advisor:

She didn't understand that I was sat in her office looking totally fine, but on some days I couldn't walk or study.

Similarly, Martha felt that 'it would be easier or more understandable if it was something that affected me in the same way everyday, and if I had to have the same adjustments all the time'. Several participants discussed how they felt that binary classifications of illness failed to fit their experiences, but that this was how others attempted to categorise them. Sophia acknowledged that 'our understanding of illness is often acute versus chronic, but it's often also kind of fluctuating versus stable'. Claire, meanwhile, felt that others tried to categorise her as either 'well' or 'ill' but, as her illness fluctuated, this was impossible:

I do think that a lot of people are looking to box you, and, especially with a chronic illness you can't do that, one day I might be in the right box, one day I'm in the wrong box, and I think that's what a lot of people find difficult.

### ***The chronically ill body: unpredictability as a barrier***

Even good, suitable support and adjustments, in conjunction with personal study strategies, may not always be enough when the chronically ill body can behave so unpredictably. At times a heavy workload and overstretching was unavoidable and would always have consequences or a 'kickback', but even day-to-day studying could exacerbate symptoms such as pain or fatigue, or could make a previously manageable condition

deteriorate, as happened to Sophia when she started at university. While Sophia was currently managing, not all participants could. Some clearly recognised that any support they received could only go so far, and could not either prevent or alleviate symptom exacerbation. If they were unable to attend a class or meet a deadline due to illness, then nothing the university did could change this. As Sarah stated:

There's only so much that they can do, like if you're literally not well enough... I still have to be able to do something in order for everything that they do to make any difference.

Lauren, for example, received support that went 'beyond my expectations', but when she suffered a relapse it was not enough to counter the physical limitations of her illness and she had to withdraw.

## **Discussion**

Sophia is not a 'typical' chronically ill student, because there is no such thing. Every chronic illness is different, and even people with the same illness experience it differently. But her experiences do illustrate many of the issues the participants in this study faced: from managing day-to-day studying with an energy-limiting illness, to negotiating adjustments within a system that struggles to accommodate shifting needs, to the frustration of living in a volatile, unpredictable body.

Across all illnesses and levels of study, participants found that their lives were significantly impacted by chronic illness, leaving them unable to have a 'normal' university experience. The ill body was consistently perceived as a barrier between students and what they wanted to achieve (Winger, Ekstedt, Wyller, & Helseth, 2014); in order to reduce this barrier and work around their limitations, participants had to reshape

student life to better suit them. Study strategies and university disability support helped them to simultaneously manage their illnesses and studies. This reshaping, however, required students to see themselves as disabled: without defining themselves as chronically ill, they could not recognise the need to accommodate their ill body and therefore could not develop effective ways to live and study with it (Charmaz, 1997). Participants who had been ill for a number of years were often able to begin this process earlier, finding innovative, creative ways to compensate for the limitations imposed on them by their bodies right from the start of their university career (Carel, 2008; Charmaz, 1997).

For most students, one part of their strategy was disclosing their illness to the university in order to access support via disability services. This willingness to disclose conflicts with some previous literature. Jacklin (2011), for example, discusses the case of a postgraduate student in the UK who chose not to disclose her condition to her university as she felt that being identified as disabled would prevent her from maintaining an academic identity. For her, these two identities were mutually exclusive and could not co-exist, but the participants in this study seem to have perceived this differently. By identifying themselves to university disability services and utilising the subsequent support, students were able to minimise the intrusion of illness into their academic lives. This, in turn, enabled them to reach at least a degree of academic success. Charmaz (1997) suggests that the process of creating new strategies for living that are shaped around chronic illness and its limitations can act as a form of control: it helps to preserve the body, by aiming to minimise symptom exacerbation, and can also help to preserve the self. It seems this may have been true for some of the students here, with strategies not only reducing the impact

of symptoms but also enabling them to maintain aspects of the self that were not defined by illness.

The support received from university disability support services, however, while crucial was not always suitable for students' needs. In theory, the Equality Act 2010 should lead to all students with chronic illnesses being provided with the support and adjustments necessary to prevent them from being at a significant disadvantage compared to their healthy peers. However, it appears that this does not always happen in practice, and that there are sometimes resource issues and gaps in provision. The fluctuating nature of chronic illnesses meant participants often needed different forms of support to students with other disabilities, forms that some universities were unable to consistently provide; Sophia, for example, wanted to be able to take exam breaks at her desk instead of having to leave the room, while Beth and several others wanted to be able to use documentation from disability support services, rather than medical letters, as evidence supporting extension requests. Just as the students' ill bodies were unpredictable, so were the responses of institutional bodies, with students unaware of whether they were going to be well supported or fall through the gaps in provision until it happened. In contrast to Lightman et al.'s (2009) welfare applicants, the students in this study were accepted into the system as disabled. However the existing frameworks in terms of available support and processes for accessing it did not always have space for the limitations and needs of such a diverse range of shifting conditions. Participants found that they were able to get into the system, but once inside, it could be experienced as rigid and unwilling to adapt in the face of their changing support needs. While previous authors (Jackson, 2005; Lightman et al., 2009) discuss how individuals with chronic illnesses challenge classificatory systems from the outside, these students challenge institutional systems

from within. They are accepted as having a disability and needing support, but fail to fit the narrower conceptualisations of disability as stable and predictable for which systems and supports were created. Despite legal requirements and the apparent existence of reliable systems for supporting all students, findings suggest that universities still lack a consistent and standard way of responding to the varied – and varying – support needs of chronically ill students.

Jung (2003) describes this lack of fit between students' needs and support provision as the requirements of the student being 'subordinated' to the support the university is habituated to providing; this is reminiscent of Garland-Thomson's (2011) concept of 'misfitting'. Boyd (2012), meanwhile, touches on it as a form of delegitimation: the institutional and individual constructions of disability fail to match, thereby disconfirming the students' subjective experiences and their perceptions of their own limitations and needs (Ware, 1992). When their experiences and needs were acknowledged and appropriate support was offered, this was highly valued, even as participants recognised that it may not be enough to alleviate all their illness-related limitations.

The unpredictable nature of chronically ill bodies can render even the best, most suitable support unsuccessful, as was the case for participants such as Lauren, with illness and university sometimes becoming incompatible. Impairment effects clearly played a large, and frustrating, role in participants' experiences, and the downplaying of such effects by the social model of disability results in support systems based on it sometimes struggling. As Wendell (2001) discusses, the removal of social barriers cannot completely negate all the limitations of chronic illness. Yet universities have a legal obligation to support these students, and so need to find ways to fully incorporate them into the conceptualisations of

disability used in support systems. Particularly relevant here is the instability of many chronic illnesses, in terms of both subjective symptom experiences and the corresponding conceptual shifting. The failure of chronic illnesses to fit dominant stereotypes of illness or disability results in sufferers having additional challenges to deal with, and impacts both the reactions of others towards them and the suitability, or otherwise, of the support they are offered. The continual unpredictable shifting threatens the success of students' strategies, both those they develop themselves and those provided by university disability support services.

### ***Study Limitations***

This study has several limitations. Firstly there were a number of technological issues in using Skype for interviews, notably freezing, time lags and inaudible segments, although none of this resulted in the loss of the essence of what participants said. However the benefits far outweighed the limitations, particularly in enabling a wider range of individuals to participate. Secondly the sample is not representative of all university students with chronic illnesses: it was small, lacked ethnic diversity, was predominantly female and middle-class, and while it included a range of conditions, six of the participants had the same illness. Additionally, six participants were recruited from a social media group with an emphasis on positivity, so it may be that members have a different illness experience to others. However, the study was intended to be exploratory and to give voice to a group of students who have been under-represented in previous research. While participants' experiences may not be typical and may not generalise to the wider population of students with chronic illnesses, findings do suggest that the experiences of these students differ from those of students with other forms of disability.

### *Implications for Research, Policy, and Practice*

Further qualitative research with a larger, more diverse sample has the potential to reveal far more about the experiences of chronically ill students. No gender differences were evident in this study, but this may be due to there only being two male participants; future research with more participants may, therefore, reveal differences. Additionally, no differences were evident between participants with one or multiple diagnoses, but again this may be due to the small sample size. Future research should also focus on recruiting students with diverse ethnicities and cultural backgrounds, as this may impact how they perceive their diagnoses and support needs; it should also recruit students from more diverse socio-economic demographics, as the majority of participants here were middle-class. It could also extend this research beyond the UK setting of this study, exploring how the experiences of chronically ill students differ within different higher educational systems.

The findings from this study highlight a number of questions that such research could explore, relating both to students' experiences and to university policy and practice.

Firstly, why were students willing to disclose their illnesses to their universities when previous UK literature suggested they might not be? It appeared that at least some participants felt there was no reason for them not to make use of available support for which they were eligible, but the reasons for this remain unclear. It is possible that students may now be more aware of their rights and universities' legal obligations to provide support; additionally, they may be less concerned about the stigma of using disability support services. It is important to note that in the UK, it is normal practice for students to disclose their disabilities to university support services, who then forward

information on adjustments to the relevant tutors and lecturers. It is possible that in other contexts, such as the US, where students themselves disclose to their lecturers, that students' perceptions of the potential risks and benefits of disclosure, and therefore their decisions surrounding it, may be different as the system is less standardised and they risk encountering stigma from individual faculty whose responses cannot be predicted in advance.

Secondly, how could disability services improve provision for students with chronic illnesses? Under the Equality Act 2010, UK universities must provide support to prevent all disabled students from being substantially disadvantaged, but findings suggest that in the experiences of individual students there can sometimes be a gap between policy and practice. Finally, and related to this, what do students with chronic illnesses want from disability support services? The current anticipatory approach has led to a move away from individualised support, with its undesirable echoes of disability as a personal tragedy rather than a social problem. However, it seems this can, in some cases, result in less adequate support, and in the voices of students not being heard. Findings suggest that students experience 'tick box' systems, where support options are selected from a predetermined list, as rigid and not accommodating of their limitations and needs. Such lists often seem not to have been generated with chronic illnesses in mind, and deviations are not always sanctioned, resulting in support perceived at best as partially helpful, and at worst as inadequate. Students, it seems, want individually tailored support, specific to their own situation and needs, something rigid systems mean some universities are unable to consistently provide. Further research is required to explore how this 'misfit' (Garland-Thomson, 2011) between needs and provision – between the 'square peg' of fluid, ill

bodies and the ‘round hole’ of rigid institutional systems – could be addressed in practice, to make the fit more harmonious and to better support students with chronic illnesses.

There are clear examples of good practice in this data, demonstrating that it is possible to find a system that works with the limitations and needs of chronically ill students. Greater awareness of chronic illnesses, especially of their propensity to fluctuate, among both disability support services and university staff more widely, would go some way to helping more students access the adjustments they require; additionally, greater awareness of the legal status of these adjustments among lecturers would make using them easier and less anxiety-inducing. Having specific members of disability support teams who specialise in supporting students with chronic illnesses could also make a difference. Greater knowledge of chronic conditions, and experience in finding suitable adjustments, is likely to make the process easier, as such specialists would be more familiar with the types of support that may be helpful and with finding alternative options to those offered as standard. Knowing that their disability advisor had prior experience supporting chronically ill students would also reduce students’ anxiety over how they and their condition would be perceived, perhaps making them feel more able to ask for support and adjustments they feel would help them, but that are not regularly offered.

Perhaps most importantly, students need to be listened to and believed when discussing what adjustments would help them; after all, they are the only people who truly know their unpredictable bodies. Just as individual students find they have to be creative in developing effective ways to work within and around their limitations, so universities may need to be willing to step outside the box of what they usually provide and offer a wider

range of personalised options in order to better support students who do not neatly map onto conventional images of disability.

## **Concluding Thoughts**

The insights gained from this study contribute to the scant literature on the experiences of university students with chronic illnesses, identifying the strategies they develop and some of the barriers they face in implementing them, whether these are thrown up by the ill body or by external factors. Findings highlight the centrality of unpredictability to students' experiences: unpredictability of the body, of institutional responses, and of whether or not support and other strategies will be successful. While some students receive exemplary support, a decade on from the Equality Act 2010 others still struggle to access the help and resources they need. Improving the consistency of institutional responses to students with shifting limitations and needs cannot erase all the barriers they face to participation, but does have the potential to remove one source of uncertainty and worry from their university experiences. It is perhaps unsurprising, if not inevitable, that the difficulties in understanding the nature and impact of chronic illness prevalent in society as a whole can also be found within university policies and procedures.

Considering the prevalence of long-term health conditions among those disclosing a disability to UK universities, gaining greater insight from their perspectives is crucial, uncovering the issues particular to students with unpredictable bodies and finding ways to support them to reduce barriers and improve the success of their strategies – finding ways to help them to 'prepare for the worst case scenario', and to support them when it happens.

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