

STARTING UNIVERSITY OR COLLEGE

It can be daunting starting at a new university or college. Make the process easier, try to ensure that everything is set up for you, says *Nikki Stowe*.

Before applying

- visit the place
- contact the disability advisor/ co-ordinator - details in the prospectus
- arrange a meeting with them to discuss the support you'll need.
- make sure the disability advisor/ co-ordinator fully understands your needs. Take the '*Ataxia. What's that?*' leaflet.
- take an independent tour to assess accessibility. Don't accept any help (unless you'll have a paid helper to help you move around campus).

Applying

- stress on your application that you have a disability. Unless you declare a disability, you won't receive the help you need.
- arrange another visit, especially if you're applying to multiple places. You must be confident that your needs will be met.
- ask to see where your lessons will be. Parts of the campus may be fully accessible - but not necessarily where you'll spend most of your time.

Congratulations! You've received a place

- contact the course tutor direct, stating what you have and the help you'll need. Send them the *Ataxia, what's that?* leaflet.
- supply the disability advisor/ co-ordinator with ataxia leaflets again, along with information on the course you're joining.
- arrange another meeting with the disability advisor/ co-ordinator to check your needs will be met. Make sure they know if you use a wheelchair, for example. If you'll need additional help, such as a writer on the first day to complete enrolment forms, tell the disability advisor/coordinator now so they can arrange this.
- follow up a week before starting to triple check everything's in place.

Top Tips

- ✓ If you're a wheelchair user, check 'wheelchair accessible' doesn't just mean 'on the ground floor' - you may have problems in narrow corridors or small doorways.
- ✓ Check if disabled toilets on campus use the RADAR key. You may have to buy one from your local council.
- ✓ Ask how many current students have disabilities. This gives you an idea of how well they cope with people with disabilities.
- ✓ Find out how to apply for DSA (disability student allowance), for funds towards equipment or personal helpers, for example.
- ✓ Ensure staff who will be working with you are fully aware of ataxia, your needs and any special arrangements for you. You must state that you **do** want staff to be informed, otherwise they will not be told.

MY EXPERIENCES OF UNIVERSITY

“Be completely upfront with your friends. They will be your major source of support, in more ways than one. If they’re not receptive, they’re not worth knowing.”

I started at Glasgow University in 1995 to read Medicine. I have an unidentified cerebellar ataxia. Although I was and am fully mobile, my balance is impaired and I have lost the hearing in my right ear. I wanted to become a doctor since I was 11, mostly triggered by my own experiences whilst in hospital. There were a number of people who thought my career choice was foolish. However I was determined.

My experience at University was generally good. I was in touch with the disability convenor of the University who was very helpful and supportive. The Medical Faculty were also very supportive, being extremely sympathetic to my particular needs. This mainly involved getting extra time in written exams and informing the examiners in Clinical exams. I was also lucky to meet some fantastic friends. They would always link arms with me when walking around the campus, lend me their lecture notes as my writing was not very fast and I often found it hard to keep up, and sit with me at the front of the lecture theatre so I could hear better.

Socialising was the fun part! I would reasonably frequently be refused entry to nightclubs as I was 'too drunk'. I would put my hand on my hip and say “Do you mind young man, I have a neurological problem called Friedreich's ataxia and I walk like this all the time!” The bouncers were always very embarrassed. They would let me in and sometimes said I didn't need to pay entrance!

On a more serious note, I owe a lot to my friends who were always very helpful and sympathetic to my needs; for example not being able to carry a drink in a pub, helping me dance in a nightclub and always finding me a seat.

I spent six years at Glasgow University and achieved my dream of becoming a doctor. I am currently training to be a psychiatrist and I love my job! If I had listened to those people who doubted my ability to go to university, I would be full of regrets. Further education was a very positive experience for me!

Harriet

“I joined numerous societies and felt accepted by the students.”

I was diagnosed with Friedreich's ataxia when I was six. At 20, I went to Lancaster University to study Combined Science. I used a support agency called Community Service Volunteers (CSV). I would definitely recommend CSV (www.csv.org.uk) for any venture involving carers. I employed eleven carers over my three years.

I lived on campus and had four rooms, three for my carers. Transport to and from lessons, and even into town by bus, was easily accessible.

In my second year I was voted Disabled Students Officer for my college. I was relieved that the speech I gave in front of 100 people wasn't for nothing!

I graduated in 2005 and am currently finishing a few Open University courses. As expected of a graduate, I'm still seeking employment

Antony

“Going to university was something special that has changed me forever. Not only because of the skills I learnt as a student, but also because of what I learned about myself.”

I was diagnosed with Friedreich's ataxia in 1992. I was fifteen and in my final year of my GCSEs. Although I was bright, my morale had already dropped to a low due to my poor handwriting and tiredness. The diagnosis was the final straw. I only passed the subjects that had no coursework element. The diagnosis also put an end to what I always felt was an eventual destination, university. At sixteen, I was working full-time at a fast food restaurant and my hopes for the future were gone.

By 1996 I was unemployed and demoralised. I met a girl. She was very bright, talented and motivated. She saw something in me, and encouraged me to develop. I started a foundation course with the Open University. I had the books, recorded the TV programmes and sent my assignments by post. My girlfriend and her mother took me to my monthly tutorials. I really enjoyed the OU way of learning. My assignments came back with good marks, and I eventually completed a Diploma in European Humanities.

I wondered if my new qualification could be used to show my abilities and commitment to finish my degree at university. After a few disappointments, I rang Oxford Brookes University, was encouraged to apply, and was accepted!

I met the university's disability advisors before I started, and agreed on the support I would need to get to and from my lectures. I enjoyed my new independence, my new friends, new experiences and I was still together with my girlfriend. I became a student rep on a university committee making decisions on disability issues. Determined to make a statement for people like me, and growing in confidence, I stood in the election for Students with Disabilities Officer at the end of the year. I won easily, as I was uncontested and had been nominated by the outgoing officer!

In the first term of my third year, I did an exchange in the University of Rhode Island which counted towards my degree. I arranged a direct payment to cover the costs of my girlfriend being my helper/notetaker. I came back and

worked hard. Towards the end of my final year, I stood for election as Deputy President of the Students' Union, responsible for welfare, accommodation and equal opportunities. I won the election, finished my dissertation and went on my honeymoon!

I graduated with an upper second with honours ten years after leaving secondary school with almost no qualifications. I am very proud to be the first member of my family ever to graduate from university. The following year as a student leader was fantastic, I gained more valuable confidence and experience and a very good basis for a career.

Richard

Inform your tutor and lecturers yourself

I was at boarding school until I was 16 at which point I was getting so overtired that I chose to come home for the sixth form. During my A-levels I did not require much help. All I needed was extra time in my exams which was easy to get with a letter from my Occupational Therapist explaining the slowness of my writing.

When I was applying to university I knew that I didn't want to live at home but also didn't want to be too far away. All the universities I applied to had a direct train to my home town. I looked at all the universities and met their disability co-ordinators. At this point I was told about Disabled Students Allowance. I was assessed for DSA which provided me with a computer (including speakers, printer, Microsoft Office and voice activated software), an office chair, a book allowance, a photocopying allowance and an allowance for paying fellow students to write my notes. An amazing service!

I thoroughly enjoyed my first year and a half at university. I started going out with a great guy who I was with for the next six and a half years, made loads of friends and got on well with my course. In January 2000 I began to use a wheelchair to get to lectures. I got very down and began to find it hard to cope. It was only then that I discovered my tutor had no idea of my condition and in fact the disability co-ordinator had not passed this information to anyone. With hindsight, I would advise informing your tutor and lecturers yourself. You may be allowed extra time in your coursework as well as exams although I would be careful about this as it's easy to get behind.

In my experience, most people – students and staff - are very helpful when you let them know. I am very glad to have had the opportunity to go to university and now live on my own with carers coming in. I coach maths to sixth formers at the local sixth form college and at my home on a part time basis. I am really enjoying my life.

Rachel

BACKGROUND INFORMATION

Disabled Student's Allowance (DSA)

The DSA is a grant provided by Central Government through Local Education Authorities (LEAs) to assist students with an ALN (Additional Learning Need) to meet the additional costs they might incur whilst studying at university. The DSA is available to full time and part time undergraduate and postgraduate students, and distance learning students.

Other sources of funding may be available depending on your circumstances. Ask your LEA, Registry or the Students' Advice Centre.

Disability Discrimination Act (2005)

The government recently amended existing disability legislation, through the Disability Discrimination Act (2005), to require all public authorities, such as universities, when carrying out their functions, to have due regard to the need to:

- Promote equality of opportunity between disabled people and other people;
- Eliminate discrimination that is unlawful under the Act;
- Eliminate harassment of disabled people that is related to their disabilities;
- Promote positive attitudes towards disabled people;
- Encourage participation by disabled people in public life; and
- Take steps to take account of disabled people's disabilities, even where that involves treating a disabled person more favourably than other people.

What does the general duty to provide disability equality mean?

The university must reflect on all its policies, procedures and practices related to disabled people (staff, students and the external community), and promote disability equality through all its activities.

What does the specific duty to provide disability equality mean?

The university must produce a Disability Equality Scheme (DES) every three years and report on it annually. The DES should be developed in partnership with relevant stakeholders such as disabled people (staff, students and the external community).

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For more support or information please contact:

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We have a number of other publications on the ataxias available free of charge. We publish a quarterly magazine called *The Ataxian* containing articles on research, living with ataxia and other relevant information. Our website also contains news of research projects.

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