

# iNForm your University

A comprehensive guide to navigating  
higher education while living with NF.

**(Neurofibromatosis Type 1 (NF1), NF2-related-  
Schwannomatosis (NF2) and Schwannomatosis (SWN).**



# Contents

<b>Introduction.....</b>	<b>3</b>
<b>Applying to university.....</b>	<b>4</b>
<b>Applying through UCAS.....</b>	<b>6</b>
<b>Student Finance.....</b>	<b>8</b>
<b>Disabled Students Allowance (DSA).....</b>	<b>9</b>
<b>Choosing the right course.....</b>	<b>11</b>
<b>Alternative routes to university.....</b>	<b>13</b>
<b>Accommodation.....</b>	<b>15</b>
<b>Offsite placements.....</b>	<b>17</b>
<b>Transport &amp; accessibility.....</b>	<b>19</b>
<b>Contacts before enrolment.....</b>	<b>20</b>
<b>Enrolment.....</b>	<b>21</b>
<b>Important contact details.....</b>	<b>26</b>
<b>Making a formal complaint.....</b>	<b>28</b>
<b>Support from CAR (Centre for Appearance Research).....</b>	<b>30</b>
<b>Support from Nerve Tumours UK.....</b>	<b>31</b>
<b>Acknowledgements.....</b>	<b>32</b>

# Introduction

Starting university is a big step for anyone, full of new experiences, opportunities, and change. Suppose you're living with Neurofibromatosis Type 1 (NF1), NF2-related Schwannomatosis (NF2), or Schwannomatosis (SWN), in that case, there may be a few extra things to think about along the way. However, that doesn't mean it's any less possible, exciting, or worthwhile.

This guide has been written to help you feel more confident and prepared as you take that next step. From applying to Uni and finding the right course, to managing health needs and navigating campus life — it's all here. Think of it as your friendly, go-to resource, made by someone who's been through it too.

There's no 'one way' to do university with NF. Still, with the right support, planning, and mindset, you can shape a brilliant and fulfilling experience. This guide won't tell you what to do — it'll help you explore what works best for you.

**Let's get started!**



# Applying to University

Thinking about going to university is a huge decision for anyone to make, and more so if you have added factors that need to be taken into consideration.

Applying to university with NF may lead you to have hundreds of thoughts and scenarios running through your mind. However, while the university application process can be challenging and stressful, it's also a unique opportunity to shape your future; there is nothing to be afraid of.

With the right mindset and preparation, you can make the journey smoother and more rewarding. Here are some effective strategies to help you navigate this important step:

## Start planning

Begin your research and planning as soon as possible; early preparation allows you to manage deadlines and reduce last-minute stress. Key things to consider early include:

### Research available university courses

Look into universities and programs that align with your interests and goals. Make sure you explore and research a variety of different institutions. Your current educational institution should be able to advise you on what steps to take in your best interests.

- What are the course requirements?
- What results do you need?

### Go to Open Days

Attending open days gives you a chance to explore the campus, speak to students who attend the university, speak to tutors who work in the establishment, and partake in the many fun activities the university has set out for potential students.

- **Campus accessibility** - Visit the campuses you are considering (in person or virtually) to identify accessible routes, parking, and buildings.
- **Transportation** - Explore accessible transport options to and from campus and the surrounding amenities.
- **Accommodation** - If you need on-campus housing, ensure it meets your needs (e.g. wheelchair-accessible rooms or nearby facilities).

Always call ahead to discuss your requirements before you make the trip to campus!

## **Prepare your documents early**

To access university support, permit applications, or Disabled Students Allowance (DSA), you may need:

- A letter of diagnosis from your consultant or GP
- A summary of how your condition affects your daily life
- Any previous exam arrangements or support evidence

Try to organise these early, so everything is in place before you enrol.

## **Manage your stress**

Balance hard work with self-care. Break the application process into smaller, manageable tasks, and set realistic goals. Remember, it's OK to take breaks and lean on your support system when needed.



# Applying through UCAS

In the United Kingdom, all students applying for full-time undergraduate courses must apply to the Universities & Colleges Admissions Service (UCAS) to gain entry to their universities of choice. Their website has a mammoth of university information - they even have a tailored quiz to see what option is best for you!

## UCAS support for Disabled Students

When applying through UCAS, there's a section where you can voluntarily disclose a disability, long-term health condition, mental health condition, or specific learning difficulty (like dyslexia or ADHD).

- This information is only shared with the university's disability or support services after you accept a place. It does not affect your application outcome.
- Disclosing early can help ensure reasonable adjustments (e.g. exam arrangements, accommodation) are ready for you when you start.

## UCAS guides and advice pages

**UCAS has dedicated online resources:** The "Disabled Students" advice page offers a clear explanation of what support is available, how to disclose your disability, and what to expect. It also includes checklists and advice on:

- Planning your application
- Preparing evidence (e.g. medical letters)
- Accessing support services
- Applying for Disabled Students' Allowance (DSA)

 <https://www.ucas.com/disabled-students>

## The UCAS Personal Statement

Every UCAS application requires a Personal Statement, which has a dedicated section on the application portal. A lot of universities receive thousands of applications each year, and the personal statement is often the part of your application that separates you from the crowd.

This means it can be quite a daunting aspect of the application process, even for students without NF! Your experience with NF is unique; use your statement as an opportunity to showcase who you are, beyond grades and test scores.

- Highlight your passions, experiences, and goals. Authenticity and a clear narrative can make your application stand out.
- Share your unique story and aspirations. Universities are looking for more than just grades; they want to know who you are.

### **Personal Statement support**

Writing a statement can be very hard, especially when you don't know what to say or how to say it. Every student applying for university needs help with it.

- Have a teacher, mentor, or friend review your statement drafts for clarity and impact. Don't hesitate to reach out to teachers, school counsellors, or mentors for advice and recommendations. They are there to help and can provide valuable insights and support throughout the process!
- Take advantage of your school's personal statement writing sessions, and if you need more help, there are plenty of resources on the UCAS website and elsewhere on the internet.

Remember, this is the start of an exciting journey. Approach it with confidence and curiosity, and trust that your hard work will pay off. The application process is a stepping stone to an exciting new chapter in your life. Celebrate each milestone, and keep your focus on your goals. Good luck!



# Student Finance

Sorting out your student finances is one of the most important parts of preparing for university. For many of us, getting the right financial support can make the difference between enrolling or not, so it's worth getting ahead of this early.

## What is Student Finance?

Student Finance England (or Student Finance Wales, Scotland or Northern Ireland, depending on where you live) provides loans and grants to help pay for:

- Tuition fees (usually paid directly to your university)
- Maintenance support – to help cover rent, food, travel and everyday costs
- Extra support if you're on a low income, have children, or have a disability

You apply online through the Student Finance website for your part of the UK.

<https://www.gov.uk/student-finance>

## When should you apply?

As early as possible! You don't need to wait until your final grades are in. Applications open around February–March each year for the following autumn, and the earlier you apply, the more likely your funding will arrive on time.

## What will you need?

- Your National Insurance number
- Your passport details or other ID
- Your course and university choice
- Your household income (your parent/guardian may need to submit info)
- Any evidence of a disability, if you're applying for extra help



# Disabled Students' Allowance (DSA)

Disabled Students' Allowance (DSA) is financial support from the UK government to help cover extra costs a student may face, due to a disability, long-term health condition, mental health condition, or specific learning difficulty like dyslexia or ADHD. It's not a loan, so you don't have to pay it back.

The allowance can help with things like specialist equipment, non-medical helpers (e.g. note-takers or mentors), extra travel costs, and other study-related expenses. DSA is tailored to each student's individual needs, and is not based on income.

## How To Apply

If you have NF1, NF2, or SWN, you may be eligible for Disabled Students' Allowance (DSA). Start by checking your eligibility. You can apply online through your student finance account, or by using the DSA1 form if you're not applying for other student finance.

### To apply, you'll need:

- A letter of diagnosis or medical report confirming your condition
- To tick the disability box when applying for student finance

Once your application is reviewed, you'll be invited to a needs assessment to determine the support you're entitled to.

### Full details and application steps:

 [gov.uk/disabled-students-allowance-dsa](https://www.gov.uk/disabled-students-allowance-dsa).

## Can you apply for DSA before enrolling?

Yes, you can apply for Disabled Students' Allowance (DSA) before you've officially enrolled in your course. As long as you've applied for student finance and have a confirmed place (even if it's a conditional offer), you can start your DSA application. This allows time for your application to be processed and any support to be put in place before your course begins.

## Let your university support you

Universities can act on your behalf when speaking to Student Finance — this is especially useful if your condition makes it hard to manage paperwork or calls. You can give consent for your university's Disability Advisor to:

- Speak directly to Student Finance
- Help with DSA forms
- Chase up payments or problems

Just ask your Disability Officer or support team how to give permission.

## Helpful Tips

- Always ask for help if the process feels overwhelming. There's no shame in needing support — it's what the system is there for.
- If your circumstances change (e.g. health flare-ups), update Student Finance so they can reassess your support.
- Keep copies of emails, letters, and forms just in case you need to follow up.



# Choosing the right course

Your academic, personal, and professional destiny can be influenced by the course you decide to study. You may have an exact course in mind, but it is also in your best interests to explore other potential and similar options. Sometimes limiting your options can hinder the experiences you can have! Here are a few crucial things to think about while you are pondering what course to apply for...

## Field of study

What are you passionate about? Consider your strengths, weaknesses, career aspirations, and subjects you enjoy.

## Career goals

- Does the program align with your long-term goals? Do you think this specific course will help you achieve your dreams?
- Research how graduates of the program succeed in the field.

## Program ranking

Research the university's ranking in your chosen field, not just overall (UCAS and the university websites are a good place to start), and try to attend any open days that the university offers; see what other students on the course say!

## Course requirements

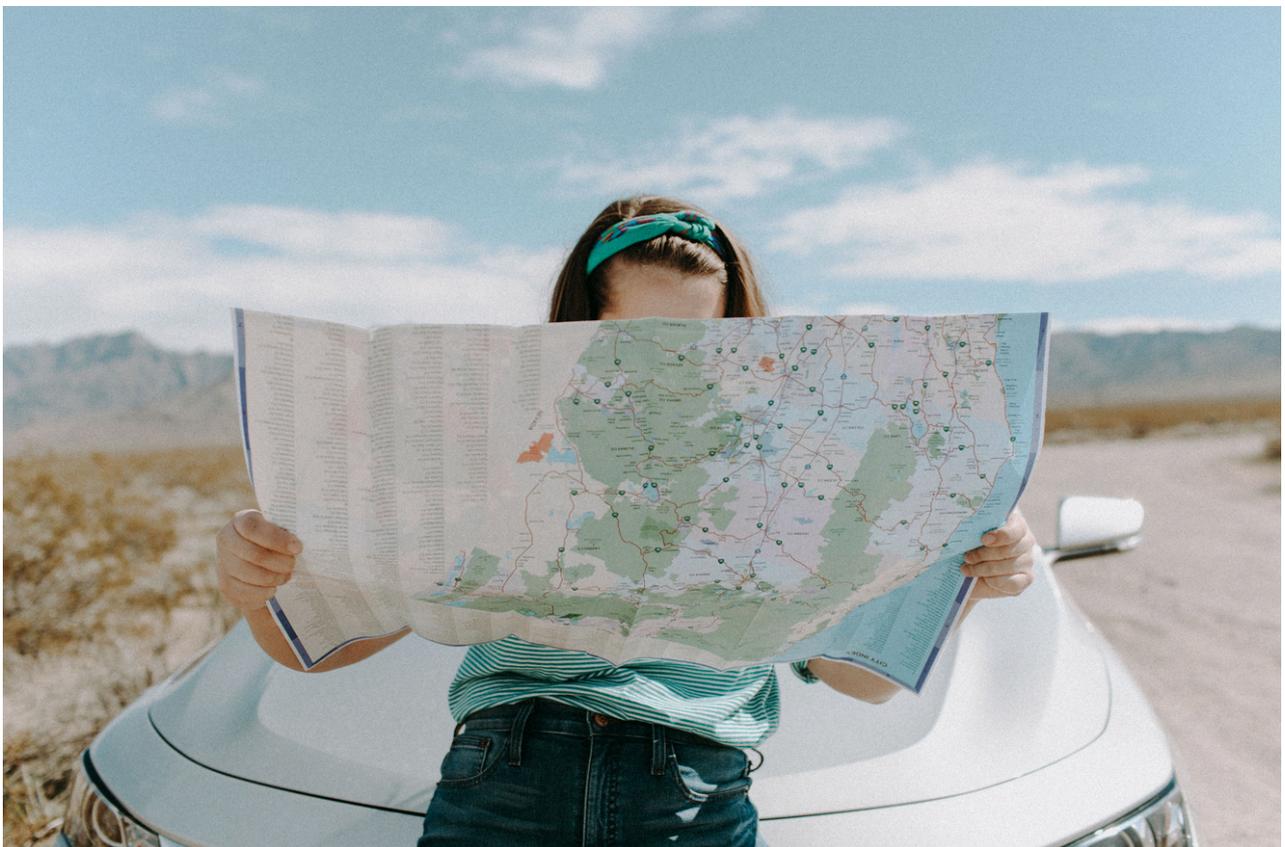
- What grades and levels of experience are required for a place on your chosen course?
- Consider your current grades and what you've achieved up to this point.
- What qualification pathways have you taken? GCSEs? A-Levels? BTEC?

## Research the curriculum

What does the course involve? Will you be required to take part in any activities, field trips etc., which may prove more difficult? Speak to the university to see what help can be given.

## Offers

When you have applied for your course, depending on your grades, or where you are currently in your journey, you may receive a conditional offer (an offer that is subject to certain conditions being met before the offer can be accepted), or an unconditional offer (a guaranteed place on a course at a university).



# Alternative routes to university

If you don't have the grades, don't worry, there are other options:

## Access to Higher Education (HE) Diplomas

Often referred to as CAVA (from the awarding body), these courses are ideal for students aged 19+ who don't have A-levels or equivalent qualifications.

- Tailored to specific subject areas (e.g. healthcare, social sciences, science, business)
- Usually takes one year (full-time) or two years (part-time)
- Delivered by colleges and some adult education centres
- Accepted by most UK universities
- Offers support for students with disabilities or learning needs

**Funding note:** You can apply for an Advanced Learner Loan, and if you later complete a university course, the loan is written off.

## BTECs & NVQs

Vocational qualifications like:

- BTEC Nationals (Level 3)
- NVQ Level 3
- T Levels

These are accepted by many universities for practical or career-based courses (e.g. animal care, IT, health & social care). They often include coursework over exams, which can suit those with health or sensory needs.

## Online learning platforms & Open University

Some universities accept Open University credits, and you can build these up at your own pace.

- Suitable if full-time college attendance is difficult due to health
- You can start studying from home while preparing for full university entry
- Offers disability support and often flexible deadlines

## **Foundation Years at university**

Many universities offer foundation year programmes (sometimes called "Year 0") for students:

- Without traditional qualifications
- Who are returning to education
- Who need extra preparation before a degree

These are built into a four-year degree and give you a supported start.

## **Functional Skills & GCSE equivalents**

If GCSEs weren't accessible to you, consider:

- Functional Skills Level 2 in English and Maths
- Adult GCSE re-take programmes at local colleges with exam accommodations
- Online providers with adapted assessment formats

These are accepted by many universities in place of standard GCSEs, especially for entry into foundation courses.

## **Accredited Experience (APEL or RPL)**

If you've done relevant work experience, volunteering, or informal study (e.g. caring roles, community work), some universities offer:

- Accreditation of Prior Experiential Learning (APEL)
- Recognition of Prior Learning (RPL)
- This route is more flexible but may depend on the institution.

## **Support for disabled students on these pathways**

- Colleges and training centres must provide reasonable adjustments under the Equality Act 2010.
- You can apply for DSA when entering university, and some colleges offer early needs assessments too.
- Speak to the Course Advisor or Disability Officer at your chosen college or provider before enrolling.

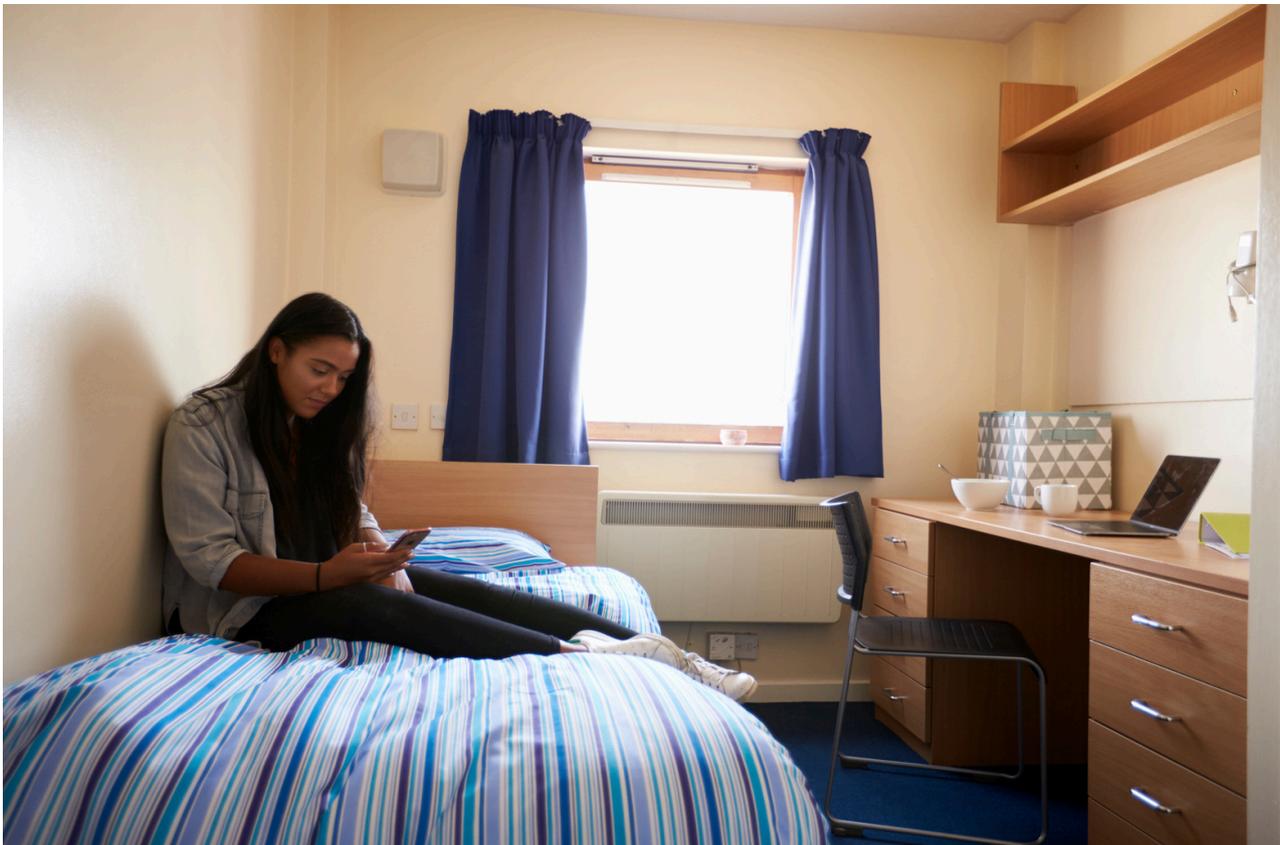
# Accommodation

All universities ought to provide student disability services and accommodation for students with disabilities/conditions. Since it is their responsibility to assist you in locating the ideal space, it is a good idea to contact them to learn more about your lodging possibilities.

Plan and list your preferences, and discuss your needs with them, and they will assist you in determining the best option or will help in setting up any necessary modifications. To determine which options are ideal for you, the university's website should provide an email address or phone number.

## **This team can:**

- Assist in identifying suitable housing.
- Provide information on funding or grants, e.g. Disabled Students' Allowance (DSA), to further assist with any needs.
- Liaise with accommodation providers to ensure modifications are made where needed.



## Key Considerations

- **Proximity to campus** - Shorter travel distances reduce stress and effort.
- **Customisable rooms** - Adaptations like grab rails, height-adjustable furniture, and specialised lighting if needed.
- **Emergency systems** - Accessible safety measures (e.g. close to a fire exit).
- **Physical accessibility** - For students with mobility challenges, look for accommodations with features like ramps, elevators, wide doorways, and adapted bathrooms if needed.
- **Sensory needs** - Consider accommodations with soundproofing, quiet areas, or visual fire alarms for those with sensory sensitivities.
- **Medical needs** - Ensure facilities for storing medications, ease of access to healthcare, or proximity to the university campus and your designated medical centre.
- **Assisted technology** - Check if rooms support devices like communication aids or motorised wheelchairs, if needed.
- **Emotional support** - Consider options for a quieter environment and nearer to support services.



# Offsite placements

As a student, you may need to attend a placement (similar to work experience) as part of your course. Off-campus placements are crucial in ensuring fair access to instruction and hands-on learning opportunities. Usually, these positions are made to meet the unique requirements of individual students with specific conditions, while collaborating with the appropriate personnel.

## Key considerations

### Accessibility planning

- Universities should collaborate with placement organisations to ensure the environment is physically and socially accessible.
- Adjustments may include wheelchair ramps, accessible bathrooms, assistive technology, or alternative communication methods if you need them.

### Tailored support

- You may need tailored support such as a one-to-one, additional training, or flexible working hours.
- Disability services at universities often provide resources and help coordinate these adjustments.



## **Inclusive communication**

Open communication among yourself, your university, and your placement provider is crucial. You should be involved in discussions to express your personal needs and preferences.

## **Reasonable adjustments**

Current UK legislation, for example, the Equality Act 2010, specifies that institutions must provide reasonable adjustments to accommodate disabled students.

## **Health & safety**

A risk assessment may be necessary to identify potential barriers and ensure safety without compromising your learning experience.



# Transport & accessibility

## University-provided transport

### Shuttle services

Many universities offer free, accessible shuttle buses equipped with ramps or lifts to accommodate wheelchairs and other mobility aids.

- Check that your chosen university & campus have these facilities if needed.

## Public transport accessibility

### Accessible buses and trains

The Equality Act 2010 and other similar laws require public transport to provide reasonable adjustments for people with disabilities, and carriers often provide wheelchair-accessible vehicles, ramps and priority seating.

### Discounted fares

Depending on where you live and what mode of transport you prefer, disabled students may qualify for reduced fares or free travel with appropriate documentation or passes. Check the university's local council website to see what you are entitled to.

### Local authority scheme

In the UK, several local authorities have programs to assist those with special needs with their taxi expenses. The kind of assistance that is offered, will vary depending on where you reside, so you should enquire with the university's local authority to see whether they have a program in place.

- This could be ideal if you decide to live at home to avoid the stress of public transport and its costs.

### Parking and personal vehicles

#### Accessible parking

Campuses typically designate parking spaces for disabled students close to key facilities. Some students may have their vehicles adapted for specific needs.

#### Permits

Students may need to apply for disability parking permits through the university or local authorities. These include a current 'Blue Badge' or a statement from a GP or consultant, confirming your diagnosis and its impact on mobility, to allow you to apply for disability parking permits through the university.

# Contacts before enrolment

If you have a disability and need support with preparing for university before enrolling, the best people to contact are:

## Disability Support/ Disability & Neurodiversity Team

Every UK university has a dedicated Disability Service. They can:

- Offer guidance on available support (like Disabled Students' Allowance, access arrangements, or mentoring)
- Help you understand what adjustments are available (e.g. accommodation, study support, exam arrangements)
- Assist with any paperwork or assessments that need to be completed in advance

You can usually find their contact details on the university's website under 'Student Support', 'Disability Services', or 'Wellbeing'.

## UCAS

If you're still applying, or have questions about how your disability might impact the admissions process, UCAS advisors can help:

### UCAS contact for disabled students:

<https://www.ucas.com/applying/applying-to-university/students-with-individual-needs/disabled-students>

## Your funding body (e.g., Student Finance England)

If you're applying for Disabled Students' Allowance (DSA) early, you can:

- Apply as soon as you've accepted a university offer (even if not yet enrolled)
- Contact Student Finance England for help with the DSA application

## The university's Admissions or Wellbeing Office

If you can't find a direct disability contact, email or call the admissions or student wellbeing teams, and they'll refer you.



# Enrolment

Now that you've secured your place at university — congratulations! The next step is making sure you're set up for success, both academically and personally. This includes registering with the right support services, planning your needs, and making the most of what your university offers. Here's how to get started:

## Understand your rights

Under the Equality Act 2010, all universities in the UK are legally required to provide reasonable adjustments for students with disabilities, long-term health conditions, or neurodiverse needs. This means you have the right to:

- Request adjustments (e.g. extra time in exams, accessible housing, or recording lectures)
- Receive learning support
- Access counselling or mental health services
- Be treated fairly and with respect

You don't need to disclose your condition to everyone, but telling the right people early can open doors to the support you deserve.

## Who should you speak to?

Once your place is confirmed, try to connect with the following people or departments, before the term begins:

### Disability Services / Student Support

Your first stop! These teams can help organise accommodations, apply for DSA, liaise with your lecturers, and support you through any changes. You can usually contact them before the term even begins.

### Head of Course / Academic Tutors

Once you're assigned a tutor, it's worth setting up a quick chat or sending an email explaining your NF (NF1, NF2 or SWN) and how it might impact your studies. You don't need to share everything — just enough so they understand what support you may need.

### Residential / Accommodation Services

If you require specific housing needs (e.g. ground floor, quiet space, proximity to medical care), make sure you've informed this team early — ideally before you move in, but after you've accepted your place!

## Student Health & Wellbeing Team

This includes mental health services, counselling, and on-campus medical support. They may also help with stress, fatigue management, or signposting services during term time.

### What Should You Share?

**Your diagnosis** - Explain your condition in your own words, and highlight any related needs (e.g. fatigue, sensory issues, chronic pain, ADHD, or anxiety).

**Reasonable adjustments** - This could include:

- Extra time or rest breaks in exams
- Lecture materials in accessible formats
- The ability to record lectures
- Timetable flexibility
- Priority housing or parking

**Emergency plans** - If you may need help evacuating a building or require medical access during flare-ups, this should be shared in advance.

**Note:** These details are kept confidential. Staff can't share your information without your permission.

### Managing personal needs

University life can be a big adjustment, but your well-being matters just as much as your academic success. Some helpful strategies include:

- **Create a daily routine** - Use a planner or app like Google Calendar to balance classes, meals, rest, study time, and breaks.
- **Use quiet spaces** - Whether it's your room, the library, or a calm café, find somewhere to decompress when needed.
- **Set boundaries** - Don't feel pressured to say yes to every event. It's okay to prioritise your energy and self-care.
- **Explore support services** - Most universities offer free or low-cost gym sessions, mindfulness workshops, and counselling.



## Tips for when lectures begin

Once your timetable kicks in, here's how to stay supported:

- **Let tutors know early** - A quick email or chat explaining your NF and any reasonable adjustments you've been approved for can make all the difference.
- **Use a formal support letter** - Your disability team can provide a summary of your agreed support (sometimes called a "Learning Support Plan") to give to lecturers if you're unsure how to start the conversation.
- **Ask questions** - Don't be afraid to ask about lecture materials, extensions, or classroom adjustments. Most tutors want to help.
- **Follow up if needed** - If something isn't working, say so. You have every right to ask for a review of your arrangements.

## Communication tips

- Be polite and confident — your needs are valid.
- Keep emails short and clear.
- Use real-life examples when explaining what helps you succeed (e.g. "I may need an extension if I have a seizure or hospital visit").
- Stay positive — most staff will appreciate your honesty and clarity.

## Freshers' Week

Freshers' Week — often called Welcome Week — takes place during the first week of your university journey. It's a mix of social, academic, and admin-focused events designed to help you settle in, meet new people, and get to know your surroundings.

Starting university can feel overwhelming, especially if you're adjusting to new routines or managing a condition like NF. But Freshers' Week is a brilliant opportunity to explore your new environment, communicate your needs early on, and begin building your support network — even if you're living at home.

## Social events

- **Welcome parties** - Icebreakers, themed nights, and student socials are designed to help you relax and meet other first-years — everyone's in the same boat!
- **Society fairs** - A great way to explore student clubs and interest groups. Joining a society is a fantastic way to meet like-minded people.
- **City tours** - If you're moving to a new place, guided tours can help you feel more confident navigating your new town or city.

## Academic introductions

- **Induction sessions** – Meet your module tutors, academic advisors, and disability support staff. This is a great time to share any specific needs and learn what help is available before classes begin.
- **Introduction lectures** – These cover course structure, grading systems, and the resources you'll have access to throughout your studies.
- **Campus tours** – Get familiar with the buildings, lecture halls, and accessible routes around campus.
- **Library tours** – Learn how to borrow books, use digital resources, and get help with coursework or exam prep.

## Administrative essentials

- **Enrolment & registration** – Complete your paperwork and collect your student ID. It's best to do this early in case there are any delays or corrections needed.
- **Accommodation support** – Get settled in student housing, and contact your university's disability services or welfare officer, if you need help with adjustments.
- **Health services information** – Find out how to register with the university's GP and what health support is available on campus.

## Practical tips

- **Talk to key departments** – Don't be shy about speaking to your disability support team, course tutors, or the students' union. They're here to make your experience as smooth and inclusive as possible.
- **Attend workshops** – Look out for sessions on budgeting, mental health, time management, and more. These are great for building confidence and independence.
- **Be yourself** – Many students feel nervous about meeting new people. You don't have to share everything about your condition straight away — but being yourself will help you find the people who make you feel most at home.



## Final advice

Enrolment is about setting yourself up to thrive — not just academically, but emotionally and socially too. By being prepared, speaking up, and accessing the right services, you give yourself the best chance to enjoy everything the university has to offer.

You deserve to feel supported and empowered. And if something doesn't feel right, speak up — there are people ready to listen and help.



# Important contact details

Every university should have a dedicated section on its website — usually titled something like "Support for students with a disability" — where you'll find a wealth of information about the services available to you.

If you're ever unsure where to start, your Head of Course or Personal Tutor should be able to direct you to the right people and help make introductions or referrals where needed.

## Key contacts to look out for

- Disability Coordinators
- Wellbeing Advisors / Welfare Officers
- Mental Health Advisors
- Students' Union Welfare Team
- University Student Support Groups
- Buddy or Peer Mentoring Schemes
- Chaplaincy and Multi-Faith Centres
- Library Services (for accessibility, study help, and quiet spaces)
- Academic Staff (Head of Course, Personal Tutor, Lecturers)

These teams exist to support your journey — whether it's arranging accommodations, finding quiet spaces, or offering emotional support during tough weeks.

## Build your confidence & community

Taking ownership of your condition and getting involved in university life can be a huge confidence booster. It's also a great way to meet new people, find support, and build experiences that enhance your CV, for life after uni. Here are a few ways to make your mark:

- **Join the Disability Council** – A chance to represent your peers and help shape accessibility across campus.
- **Get active in student groups & initiatives** – Many student councils welcome input from disabled students to help improve inclusivity.
- **Explore student societies** – There's a society for almost everything — from baking to politics to film. If one doesn't exist for your passion, you can even start your own!
- **Find on-campus jobs** – Whether in the SU café, the library or helping out at events, student jobs are flexible and can fit around your health needs.
- **Volunteer** – It's a brilliant way to meet people, learn new skills, and give back to the community — all while gaining experience.

**Pro tip:** Save important phone numbers and email addresses in your phone or planner early on — it's much easier than hunting them down when you're stressed or need urgent support.



# How to make a complaint or raise an issue about disability

If you are ever unsupported, you have the right to speak up. Raising a concern can feel daunting, especially if the situation is emotionally difficult, but it's important. You deserve to feel safe, supported, and treated fairly. Every university is required to have clear procedures for resolving complaints, and they are there to protect you.

## Know your university's process

Each university has its own process for addressing disability-related complaints or accessibility issues. These are usually outlined on the university's website, or you can ask Disability Services or the Student Complaints Office for help.

You are encouraged to raise your concern as early as possible — the sooner something is addressed, the sooner it can be resolved.

## Making a complaint

Here's a general outline of how complaints are usually handled:

### Contact Disability Services first

This is your first point of contact. They may be able to:

- Help resolve the issue informally. This route is often faster and less stressful, and many issues can be resolved this way.
- Act as a mediator between you and other departments
- Support you with paperwork or advocacy if your condition makes it difficult to handle alone

### Document everything

Write down what happened, when, and who was involved. Keep:

- Emails or messages
- Notes from meetings or conversations
- Medical letters or needs assessments (if relevant)
- Having a clear timeline and evidence will help if the issue needs to be escalated.

### Make a formal complaint (if needed)

If informal attempts don't work, you can submit a formal complaint. This usually involves:

- Writing a clear summary of what happened
- Explaining how it affected you and your studies
- Stating what resolution you are seeking

Your university's Student Complaints Office or Equal Opportunities Team will guide you through this process.

## Following up

After submitting a formal complaint:

- Keep a record of your communications
- Don't hesitate to follow up if there are delays
- You have the right to ask for updates and outcomes in writing
- If you feel the complaint wasn't handled fairly, you have the option to escalate it.

## External support options

If your issue remains unresolved or is particularly serious, there are national bodies that can help:

- **Office of the Independent Adjudicator (OIA)** – for current or former students in England and Wales [www.oiahe.org.uk](http://www.oiahe.org.uk)
- **Equality and Human Rights Commission (EHRC)** – enforces disability discrimination laws in the UK [www.equalityhumanrights.com](http://www.equalityhumanrights.com)
- **Parliamentary and Health Service Ombudsman (PHSO)** – for unresolved public service complaints [www.ombudsman.org.uk](http://www.ombudsman.org.uk)
- **Disability Justice Project** – provides legal aid and support for disabled people in education [www.disabilityjustice.org.uk](http://www.disabilityjustice.org.uk)

## Not sure where to start?

If you're unsure what to do, you can always speak to:

- Your Disability Advisor
- Your Head of Course or Personal Tutor
- The Students' Union Welfare Team

They can talk you through your rights, university policies, and next steps — and support you every step of the way.



# Support from The Centre for Appearance Research

Starting somewhere new and meeting lots of people can be stressful for anyone. For people with NF, it can be even harder—especially if café au lait patches or neurofibromas are visible and draw attention.

If you're feeling self-conscious or worried about how others might react to your appearance, you're not alone—and support is available. The Centre for Appearance Research offers free, evidence-based resources for anyone with a visible difference, including those with NF.

You can find these resources on their website, including a free mobile app called ACT It Out, designed to help you build confidence and cope with challenges

## **CAR Support Link**

[www.VisibleDifferenceSupportHub.com](http://www.VisibleDifferenceSupportHub.com)



# Support from Nerve Tumours UK

Nerve Tumours UK is the UK's national charity supporting everyone affected by Neurofibromatosis (NF) — including Neurofibromatosis Type 1, NF2-related Schwannomatosis (NF2), and Schwannomatosis (SWN).

NTUK is a safe and empowering space, offering practical information, emotional support, and community connection for individuals, families, and caregivers navigating these conditions.

## How NTUK can support you at university?

NTUK offers a wide range of support to help you feel confident, informed, and empowered to thrive in your studies and beyond.

### What NTUK provides

- **Educational materials** - Downloadable factsheets, diagnosis guides, and best practice letters — ideal for sharing with tutors, GPs, or Disability Services.
- **Social Media support groups** - Welcoming community of students and young adults living with NF — a great place to ask questions and share experiences.
- **Specialist advice** - NTUK has a dedicated network of Specialist NF Nurses and a helpline team ready to support you with personalised advice about education, daily life, and healthcare.
- **Support your mental health** - Access to university counselling, peer support, and well-being resources can help you manage stress and feel more in control.

"Talking about your condition can be scary, but reaching out for support can change everything. You deserve to feel understood and respected at university."

## NTUK Specialist Nurses & Helpline

In some areas of the UK, you can access a community-based NF Specialist Nurse for one-on-one advice. If that's not available in your region, the NTUK National Helpline is here for you. No question is too small — if you're unsure, anxious, or need clarification, they're ready to help.

**Helpline Availability:** Monday, Wednesday & Friday – 9 am to 5 pm

Contact Details:

- **Phone:** 07939 046030
- **Freephone:** 0300 102 17 22 (check with your provider for any call charges)
- **Email:** [helpline@nervetumours.org.uk](mailto:helpline@nervetumours.org.uk)
- **Website:** [www.nervetumours.org.uk](http://www.nervetumours.org.uk)

Emails can be sent anytime and will be answered on the next working day.

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