



Chronic illness and fighting against low expectations – Ursula’s story¹

Ursula is a university student in her early 30s who has drug-resistant epilepsy. Her seizures do not respond to medication, and Ursula sees a neurologist regularly to explore ways in which her condition can be managed. Despite related challenges, Ursula wants to complete her degree and secure employment.

When describing her school self, Ursula indicated that she preferred the more creative or art-related subjects and that her love of drama underpinned a desire to work in theatre. However, the onset of a chronic health problem in Year 8 stymied her ambitions and instead led to different academic outcomes to what she expected.

The stress of Ursula’s final year of secondary school triggered more seizures. Upon leaving, she took up some part-time work close to home. Ursula moved between jobs, and while she started some further training, her health issues impacted on her ability to sustain her studies to completion. Eventually, Ursula enrolled in an arts degree.

Youth with disability are more likely to experience mixed pathways. View this [fascinating visualisation](#) of school-to-work pathways for more information.

Key Learning: Ursula’s educational and vocational journey has not been a linear progression but has been typified by starts and stops, movements between work and study, and disengagement from the labour market.

Ursula’s health condition affects her educational journey in several ways. A part-time study load suits Ursula’s need for low-stress and slower-paced study. She also takes semesters off if her neurologist recommends trialling a new medication that might have side effects that

¹ This story is the experience of one university student interviewed as part of the research project: O’Shea et al. *National Career Development Learning Hub for students with disability*. National Careers Institute Partnership grant (2021–2023). The research involved interviews and surveys with students, parents/carers and stakeholders and analysis of existing data sets.

impede her capacity to study. Ursula has been working on her degree for more than eight years and still has three to go. She has received special consideration to be able to take longer than stipulated to complete her qualification.

Key Learning: Individualised course progression supports students like Ursula with chronic health conditions.

Persisting at university has not always been easy for Ursula. Indeed, during her academic career, Ursula has experienced a lack of understanding and awareness of disabilities like her own and inadequate funding of disability support. Another barrier she encountered is the lack of coordination between support units across the university, which further impacts on Ursula's valuable time and energy.

None of them discuss things with each other ... and that's where all the flaws are. Ursula

Ursula describes playing "phone ping pong" and being passed from service to service, often dealing with people who are unable to provide her with the answers she needs.

Key Learning: A lack of disability awareness and the absence of a coordinated approach have had an impact on Ursula's higher-education success.

Speaking about her career development, Ursula explained how the university she attended did not have enough support dedicated to exploring future employment options and, in particular, how she might "put the pieces together". Unfortunately, Ursula has not had a job for 12 years, and acquiring work experiences and employability skills is challenging for her. She highlights the difficulty of travelling to a work placement and getting the accommodations she needs to maintain her health once she is there. Full-time placements are too much of a load for Ursula, and if she gets paid, there are implications for her disability support payment.

Key Learning: Finding suitable work experiences that meet the unique needs of students with chronic health conditions is challenging.

Another barrier Ursula experiences comes from government service staff in the form of "low expectations", and sometimes there is explicit encouragement to be satisfied with accepting financial support rather than seek employment. Ursula finds this attitude unhelpful and disheartening as she has clear aspirations for her future.

I want to contribute to society. My dream is to work. I feel like my brain works, I feel like I have something to say, and something to contribute. Ursula

During her enrolment, Ursula took an elective in community development and has added this focus as a second major to her degree. Ursula described how the content in that subject resonated with her, given her own lived experience of disability within educational and bureaucratic systems, and how society views people with disability or chronic illnesses.

Key Learning: The lived experience of people with disability can inspire professional and educational choices – such insights need to be included and built upon in program design and delivery.

Implications for career development learning (CDL) in further education

- Many students do not have linear journeys into education and work, particularly students from rural, regional and remote areas and from low socioeconomic status backgrounds. Young people with disability are more likely to experience complex pathways with multiple shifts and time disengaged from the labour market. Alternative pathway courses, microcredentials, volunteering, part-time work and other options can be supportive choices for students with chronic health conditions.
- Each learner will have specific and unique aspirations that may or may not accord with socially acceptable or expected goals. Tapping into the lived experience and interests of the student supports CDL tailored to the student.
- Working in partnership with student support services not only within the institution but also external to the institution can greatly assist students in navigating the support available and help in achieving their goals.
- CDL staff that are disability aware and confident provide an environment for CDL activity that is inclusive of students with chronic health conditions.

Implications for employers

- Flexible working conditions such as variable hours; remote, part-time and casual work; and volunteering can provide opportunities to employ a greater diversity of employees who can make unique contributions to the organisation.
- Open dialogue with employees and work experience students with disability about needs and supports is important for successful outcomes.
- A coordinated approach to supporting employees with mental health conditions is critical. Line managers, the human resource unit and support services in your organisation should work in partnership with the individual worker to understand and support their needs and requirements.
- People with disability can provide benefits to employers such as increased performance and creativity, improved morale, greater diversity, staff retention, enhanced reputation and a more positive customer view of your brand. Read more in a [An Employer's Guide to Employing Someone with Disability](#).
- A guide to good practice in supporting students with disability in the workplace is available in the [CDL Hub](#) for students with disability.