



Join and have your questions answered!

“Employment issues”

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LIVING WITH A CHRONIC CONDITION AND WORK

When we have a chronic health condition, there are certain barriers added that make access to the world of work more difficult. When we speak about haemophilia with an added burden of inhibitors things can be very unpredictable. You can be fine for a long time and then suddenly not. One day you may look perfectly fine, and the next day you may be on crutches or a wheelchair. Or you need to spend a very long time recovering from a bleed and in a hospital. This all creates a very precarious and ever-changing situation in terms of work.

So how to deal with those barriers?

Managing the change

Many changes can occur over the lifetime of employment within employment and/or personal environments, such as illness, bereavement and many others. The changes can be various, but most likely all of us will experience them over our lifetimes.

The changes that impact your ability to work, can result in loss of earnings and subsequently low self-esteem. There is also a risk that it may lead to isolation and exclusion.

In terms of employment change, we can look at a variety of things – perhaps moving to a new position, getting promoted or demoted, it could be having a new manager, staff member or a colleague, it could be a new computer system or it can be changing employer or becoming unemployed. All of those changes can have a big impact on our work-life.

When we live with a condition like inhibitors, where extra support may be needed, there are also quite a few things that can impact and change our situation in terms of work. It is things like health, education, accessibility and mobility, travel, accommodation, as well as the financial aspects. **When one's health is impacted, then it affects all the other areas as well.** Luckily, today the technologies allow us

to do things remotely. To have a good education you do not have to sit in a university all day, or you do not have to be in the office physically from nine to five. This facilitates many things.

Nevertheless, there may be lack of understanding and information about working with people living with a disability, which then may lead to employers having concerns when hiring someone with mobility challenges or a chronic illness.

These concerns are often based on the employer's belief and misconceptions, for example, that the person will not be able to do the job or do a full day's work, that they will be absent from work due to illness, or will not get along with other staff. These examples I have received from the students I work with on a daily basis.



How can this be overcome?

It is important to be aware and acknowledge the facts and debunk the myths! Focus on your positive attributes – how you manage your disability: **determination, positive attitude and reliability.**

Focus on your abilities and alleviate possible concerns employers have about disabilities.

You do not necessarily need to disclose your condition; it is up to you! In terms of European law, you do not need to do this, unless it affects your ability to do the job. For example, if I want to be a bus driver, but I have epilepsy, where the seizures would not make it possible for me to drive, then I do need to disclose. Then again, if you have haemophilia and want to do an IT job, it will not really affect it. So, I would never disclose, until I need to – never during the first interview, or when it is negotiation time.

If your mobility is restricted, you would need to disclose to have the accommodations made at the work place. Most of the employers would be fine doing that, if need be, for the interview as well. But the most important is to focus on the positive. Because most of the time, people living with a chronic condition have so many skills and qualities that other people do not have. **They have a positive attitude, they have determination, they have resilience which has become a big thing in employment now, they are able to cope with change, to manage change and get on with things.** These are things that you can use to describe your condition! Flip everything and use the positive!

What do the employers want? This will help us to prepare as well! The list can be long, but these are the most common:

- Good communication skills
- An ability to work as a team member
- Good interpersonal skills
- Problem-solving skills
- Self-motivated
- Flexible
- Hardworking
- Enthusiastic
- Positive attitude

And this list applies to everybody – with or without a condition.

Employers just want somebody who can get the job done for them.

How to develop coping strategies when you have been unemployed or on a sick leave for a long time? How do you keep up your skills and training?

- Employment that offers flexible hours and locations
- Get involved in education / training (there are a lot of free schemes available)
- Do voluntary work or work experience (internship)
- Accessing supports available - social welfare benefits and incentives available for employers to employ someone with disability
- Hobbies and free time involvements (e.g. giving a presentation for EHC)

Doing all this will help you build:

- Practical Skills – computers, phones
- Personal Skills – organisational, budgetary management, time management, problem solving, communication and creative skills
- Interpersonal Skills – working with people as part of a team
- Transferrable skills, experience and self-esteem
- Allows you to set your own pace, within your own timeframes
- Supports building effective citizens and communities

All of this can be added to your jobs tool kit!

In addition to this, it can be very helpful to familiarise yourself and be able to discuss grants/ supports available to employers such as:

- Workplace / Equipment Adaptation Grant (WEAG)
- Employee Retention Grant
- Wage Subsidy & Youth Schemes
- Disability Awareness Training Support Scheme (DATS)

These things could be found on the government or municipality websites, as well as googling “*Education and training opportunities in Europe*”.



If I am employed and I need to go to a doctor for a regular check-up, do I need to take a vacation?

It will depend on the company, as well as the country legislation regarding sick-leave. For most countries you are allowed a certain amount of days off. It is always advisable to check with the department of the person responsible for the Human Resources (HR).

If you are not willing to disclose your health situation and your check-up appointments are only once every six months, you can always use your annual leave. In Europe everyone, either working full time or part time is entitled to 20 days of annual leave.

I am highly skilled software engineer, but due to my inhibitor, I have had only odd jobs for the past couple of years. I am trying to get back into the job market. How should I deal with this situation?

At the moment we can see two tendencies. One is that a lot of big companies are looking into being socially responsible and giving something back to society. Which means that they may be more interested in employing someone with a chronic condition.



And second is that IT is one of the most demanded sectors right now and there are still gaps to be filled. But the problem is that lot of those applicants do not have experience. They have a lot of qualifications, but no experience. **In this situation it can be helpful to look for internships.** That would be my advice to you as well. Lots of companies are offering internships (good or not so good, paid or unpaid) and this will give you the 3 or 6 months of experience for your CV to get back in. I would just look up those companies and start emailing them.

Another option is to get involved in voluntary work, for example, for your NMO or other organisations. This will be a good addition to your CV too!

As for the gaps in your CV, you are not obliged to disclose anything. You might just say that you took time off to support a family member, for example.

The good news about working in IT is that you can work remotely!

But you also need to think, if you want to remain in the IT sector? **Or are some of the skills that you have transferable to other fields?**



How about the possibility of self-employment? Can that be an alternative?

If you are a consultant and self-employed, you do have more flexibility. But again – you need to do your research. There are a lot of agencies or government schemes available.

The only thing I would be mindful about is if you receive any government support, e.g. disability pension. It may have an impact on that if you are self-employed. It really depends it on the country and how the system is set up. Sometimes it can be more