



THE
HAEMOPHILIA
SOCIETY

Careers with a bleeding disorder and the world of work

Thanks to the treatment options now available in the UK, young people with a bleeding disorder now have a greater array of career choices than ever before.

In years gone by, the reality of life with regular, unpredictable bleeds and long periods in hospital limited the career choices of our older members and previous generations – and many people took steps to conceal their condition in order to follow their chosen path:

‘My dad never told anybody at his work about his condition as he would never have gotten the job he wanted. He travelled the world as a roadie for ELO and worked at the airport for over 30 years.’

Now that preventative treatment (prophylaxis) is the norm for those who need it, many working roles and environments that were off-limits a generation ago are wide open to today’s generation of young people.

Young people today are being inspired to take on all sorts of careers, despite their bleeding disorder. Our members have various roles, including some very physical ones: members with severe haemophilia A have told us they work in construction, quarrying and heavy plant machinery, and on printing presses, as well as office, retail and management roles.

‘I have a factor XI deficiency and have been denied a job twice in the past – once in the building industry and once in a factory (off the record, of course!). I’ve worked in ‘heavy’ construction and now work as a dental technician.’

Conversely, others have had to quit physically demanding roles that caused more bleeds – one member found that being a cameraman was causing him problems, and has since retrained as a driving instructor.

‘I worked with adults with special needs and had to leave my career because of von Willebrand disease.’

Lateral thinking

Having a medical condition brings risks, and access to some career paths is still limited by restrictive recruitment requirements for some institutions and professions, including the armed forces, police, fire service, frontline prison service, or airline pilot and lifeboat volunteer. (It has to be said that such restrictions are generally there for good reason.)



THE
HAEMOPHILIA
SOCIETY

‘One of my sons wanted to be a royal marine...but when he saw the medical form, he tore it up and he’s a junior paramedic now!’

‘My middle son wanted to join the army and was devastated when we told him he couldn’t. He’s decided to become a PE teacher instead, and wants to work with obese and learning disabled kids...not bad at the age of 14!’

‘My son, who’s 16, dreamed about being in the army for most of his life. Sadly we knew his dream would never come true, and he’s just started an apprenticeship as a welder. He has a severe factor 13 deficiency.’

So think laterally – we have members working within the prison service – as a facilities manager – and the fire service – in an office/risk management role. These employers decide on a case-by-case basis, rather than having a blanket exclusion policy, as is the case with the armed forces.

‘My son, who has moderate haemophilia A, is taking a public services course at college with the aim of becoming a firefighter or paramedic. The fire service didn’t say no to him joining, but they wouldn’t say a definite yes. Said they judged individual cases.’

‘I’m a sports officer working within a youth offending team, was previously a prison officer and I have moderate haemophilia.’

Anecdotally, there seems to be a very high proportion of our members working in medical and caring roles like nurses and paramedics – perhaps because growing up with so much exposure to health services can breed a desire to ‘give something back’ and become part of the teams that step in to help when needed.

How does the law help?

Supported by changes in employment law, workplace cultures are slowly changing to offer more flexibility for those affected by a medical condition, or those with caring responsibilities.

Since October 2004, every employer has to make ‘reasonable adjustments’ to enable employees classed as having a disability to do their job (Equality Act 2010, Disability Discrimination Act 1995). Importantly, the definition of disability is likely to include many people living with a bleeding disorder – as a long-term medical condition that affects daily



THE
HAEMOPHILIA
SOCIETY

life at least some of the time. Reasonable adjustments might include, for example, flexibility to allow for a treatment regime and hospital visits.

Whether or not to tell an employer about a bleeding disorder is a personal choice, though not doing so may not be in the employee's best interests. For example, if someone has trouble in their job or is treated unfavourably, it can be harder to solve the problem or make a formal complaint as the employer can claim they didn't know about the disability. On the other hand, if an employer knows about someone's disability, then under the Equality Act they must make reasonable adjustments.

As of 30 June 2014, all workers have the right to request a flexible working pattern once they've been with their employer for 26 weeks, regardless of their personal circumstances. This should make it easier to request part-time or variable hours to fit with a treatment regime or caring responsibilities. Employers don't have to say yes, but they must act reasonably in considering the request. They can say yes, try it for a trial period and then still say no, so it's important to be realistic about the possibilities. Employers must have a good business reason for saying no, but for smaller employers this might be that it's simply not affordable.

Employees can help by being flexible too – compromising on their ideal working pattern might enable the employer to agree to an arrangement that suits everyone. The same applies on an ongoing basis – employers don't actually have to give someone a day off to go to a medical appointment, but offering to do another shift or be on a back-up rota for someone else may help.

Opportunity knocks

If the risks are well managed by employees and employers, the majority of occupations should be open to people with bleeding disorders. With a flexible approach and some lateral thinking most people will be able to find a satisfying choice of career.

'Instead of looking at your career choice through the lens of your bleeding disorder, choose what gives you the most joy, then set about finding a way to make your bleeding disorder a non-issue. Don't let your condition run your life. I don't let my haemophilia determine who I am – it's only a small part. I'd urge others to think in the same way.'

If you feel your employer is treating you unfairly or you're being unreasonably excluded from a job you could safely do, please [talk to a member of our team](#).



THE
HAEMOPHILIA
SOCIETY

Useful links

Disability and employment rights

www.acas.org.uk

www.equalityhumanrights.com/your-rights/in-employment

Flexible working

www.gov.uk/flexible-working/overview

Working with a medical condition

[www.nhs.uk/Livewell/workplacehealth/Documents/ChronicConds Employees Factsheet A4.pdf](http://www.nhs.uk/Livewell/workplacehealth/Documents/ChronicConds_Employees_Factsheet_A4.pdf)