

BLEEDING DISORDERS AND HEPATITIS C

My choice to tell — at work

"They wanted me to go overseas and work under fairly high pressure and I guess I just wasn't able to. Just managing all of that [hep C and haemophilia] would have been more than I could handle, so there came a need to discreetly discuss that with my immediate management and further up."

Disclosing or telling other people you have a bleeding disorder and hepatitis C is an experience some people with bleeding disorders have to consider at times. Although you may feel confident generally about situations where you would or wouldn't tell people, the workplace can raise new questions, particularly if your circumstances change, you start a new job, begin a new treatment or have some health problems.

Some people may also be co-infected with HIV. Most of the information in this fact sheet is also relevant to people with HIV, but contact your Haemophilia Social Worker/Counsellor or local HIV organisation for more information.

WHEN DO I NEED TO TELL OTHERS?

In most situations, whether or not to tell others is entirely up to you. In a small number of instances you may be required by law to tell others that you have a bleeding disorder or hepatitis C. In these situations, the organisations are exempt from discrimination laws.

For hepatitis C, these include:

- **Working in the Australian Defence Force (the Navy, Army or Air Force).** You might be required to leave the force, although this is determined on a case-by-case basis. Entry guidelines state that you will be 'unsuitable' 'if your blood or body fluids carry an infectious disease'. The guidelines also state, 'It is important that you advise the medical officer of all existing medical conditions to allow a judgement to be made on the relevance of that condition. If you do not disclose an existing condition, which subsequently causes difficulties during training, it may result in your discharge from the [Australian Defence Force]'
- **Performing exposure prone procedures if you are a health care worker.** An infection-control practitioner will provide confidential advice about whether or not you need to notify your employer and how having hepatitis C could affect the work you do. A hepatitis organisation, your union or the health department in your state or territory will be able to give you more information about this. Requirements differ from state to state
- **Donating blood**

For bleeding disorders and hepatitis C:

- **Applying for health, life, income protection, mortgage or travel insurance or superannuation, if the question is asked.** If you do not provide this information, the company can refuse to pay any claim you make on the policy where your bleeding disorder or blood borne virus is a contributing factor. Be sure to read all insurance policies carefully and seek advice if you feel you need to.

WAYS OF TELLING PEOPLE

Telling people can raise a number of concerns. You might be worried that you will be treated differently once people know you have the virus or a bleeding disorder. Will you be discriminated against? Will you lose your job?

"It wasn't so long ago that if someone said I'm a haemophiliac – oh, you've got to have time off work, out the door. And it's only with the change of laws that it's discrimination. But just the same, we know guys that have worked for years and years and years with the boss not knowing. Others have been able to work with it and with the companies having full knowledge of their plight."

There may also be benefits in telling people. Would it help to manage being unwell, having to attend doctors' appointments, organising treatment or managing potential accidents if your manager or your work colleagues were aware of your health situation? Would it be better to tell some people you can trust and not others?

In different situations people may choose to use varying types of disclosure:

- Non-disclosure: not telling anyone
- Strategic disclosure: telling only certain people, eg their work manager but not their other colleagues
- Substitute disclosure: telling people they are unwell or have a liver or blood condition but not giving specific information about the condition
- Open disclosure: telling everyone openly

"I'm quite open; I tell people I've got it. I haven't detected anything although when you're the boss people don't exactly say certain things to your face. There are some clients and customers that I've told."

"It's easier for my son to say, I've sprained my ankle, then he goes in on a crutch."

IT MAY BE HELPFUL TO THINK THROUGH THESE QUESTIONS:

- Can you manage and explain your symptoms and/or side effects of treatment to your manager and work colleagues if you choose not to tell them?
- Can you keep your job without some form of disclosure? Would your boss assume you are not interested in your job and are taking time off for other reasons?
- Can you keep your medication private at work if it needs to be kept in the fridge?
- How will you make sure hepatitis C is not transmitted or that your bleeding disorder is taken into account with emergency services if you have an accident or a blood spill?

"I'm happy to disclose my haemophilia to people. I like people in my workplace to know in case there's an industrial accident and I get knocked out. I've got a MedicAlert ID now, but they need to know quick get me to the hospital because I don't want to die of a brain haemorrhage. Those sorts of things I'm happy to disclose, but hepatitis C I'm not because of the history of the past."

Explaining symptoms or side effects without full disclosure

Some people find that sounding vague and forgetful about what their condition is called works well for them. Having 'a blood problem' or 'crook liver' is an option. It's important to be consistent about what you are calling the condition – it will only lead to more questions if you tell one person it is a blood problem and another that it is a liver problem! Focus on what you want out of the situation. 'I can't remember what it's called, but the doctor said I would have these problems, so I need...'

Telling your boss or workmates

Consider what you want or need from the situation. A caring and understanding employer could make things easier for you by giving you time off for treatment or when you're not feeling up to work. They can support you if others you work with are not understanding about your condition. They can help arrange your workspace and/or hours to ensure that you are comfortable, or they can make changes to the job you do so that you can cope more easily with being at work.

You are in the best position to be able to predict how the people you work with will react to being told you have a bleeding disorder or blood borne virus.

- Are they likely to be supportive?
- Will they respect your confidentiality?
- What conclusion is your boss likely to make about your work commitment if you use lots of sick leave?
- Are they likely to be open to you reducing work hours or needing more flexible work arrangements?

"My husband would always keep his personal health to himself and now his work knows he has hep C but he hasn't ever told them he has haemophilia. My daughter and I had this conversation with him, why would you say that and not the other, and he just said I don't want them to panic and worry, and I think that's from past experiences."

Make sure you have your facts right and know what your rights and responsibilities are:

- Find out how much sick leave, annual leave or long service leave you have and when you will be due for more
- Some managers worry about Occupational Health and Safety issues. They may fear you will not be able to do your job properly or might put other people at risk. You might feel that something official in writing is the best answer. If you ask your specialist doctor for a letter, ask them to make it brief, with start and stop dates of treatment, if applicable, potential symptoms and side effects and best ways to manage these. Have the letter sent to you first so that you can decide whether it suits your needs and who you would give it to
- If your boss asks, stress the confidential nature of your illness – "I have some blood problems and need medication but I want to keep this confidential between us".

The purpose of strategic disclosure to your manager or work colleague is to have an ally. If in doubt about their attitudes, you might like to test the waters first with some general conversations about related topics, like people having time off work for cancer treatment or blood rules in sport.

WORK SAFETY

Occupational Health and Safety (OH&S) laws cover all places of work and state that employers must provide easy access to first aid materials and must treat all blood spills in the workplace as if there is an infection present. This means that all blood is assumed to carry a blood borne disease. For this reason there is no need to tell anyone at your work that you have hepatitis C if you do not wish to.

If you are unsure about the quality of first aid at your work, you could volunteer to be the first aid officer. Then you can be sure that the first aid kit is always complete (with latex gloves, bandaging, and so on) and that proper first aid procedures are followed.

For people with bleeding disorders, similar procedures apply with emergency services at work as in the community. Many people wear a tag to notify emergency services about their bleeding disorder, eg a MedicAlert bracelet. They may have their support person or Haemophilia Centre phone number coded into their mobile phone under ICE (In Case of Emergency) to advise about special needs. They may make sure their medical record at their local hospital has an alert about their bleeding disorder in case they are brought in unconscious or very unwell.

"I don't have any problems with telling people about my hep C, because I'm older and I don't really mind. I have a fair knowledge about it and I know that I'm not going to contaminate other persons with hepatitis C and if they then have some sort of a worry, I'm only too happy to help them with some knowledge."

If you do decide to disclose at work, you may need to educate your workplace about your condition. Make sure you have some up-to-date, relevant printed information with contact numbers and web sites to give out so that work colleagues can follow up their questions privately and in their own time. It may also be helpful to have some advice and support on how to tell your workplace. Haemophilia Centres and hepatitis organisations often undertake and assist with workplace education for individuals and can help with information, support and advice.

PRIVACY

Employment forms

When applying for a job, you might have to fill out a form that asks questions about your health. You do not have to answer questions about your bleeding disorder or hepatitis C, any treatments you have had, or time that you have had to take off from previous jobs because of your health unless it is necessary in order to determine whether you can meet the essential requirements of the job. This will only apply in a small number of cases, eg jobs involving exposure prone procedures.

What if you need to take unpaid time off?

- If you need to take time off and are applying to Centrelink for sickness benefits you need to give Centrelink a reason for being away from work. They will require a confirmed diagnosis, probably in the form of a letter from your doctor or Centrelink medical certificate
- Some people have income protection insurance or can draw on their superannuation to cover periods of unpaid absence from work. In these cases, the insurance or superannuation company will need to know why you need time off.

Your rights to privacy and fair treatment

- The information you give to insurance companies or Centrelink should not be passed on to your employer or people you work with. Your private health information is protected, and there is no reason for it to be given to anyone at your work
- Any health-related information you give to your employer or other people you work with is private and confidential: legally they can not pass it to another person or agency without your permission.

You have control over your health information. If you feel you have lost that control at work, you could have grounds for making a complaint.

Everyone has the right to be treated fairly and with respect. If you feel that you have been discriminated against or that your workplace has treated you unfairly, you can do something about it.

Complaint systems and anti-discrimination laws vary from state-to-state – see below for where to get advice on what you can do.

WHERE TO GO FOR MORE INFORMATION AND ADVICE

If you would like to talk over these issues, including making a complaint or dealing with discrimination, or get more information, it may be useful to speak to your Haemophilia Social Worker/Counsellor. You can also contact your local Haemophilia Centre, or haemophilia or hepatitis organisation. For contact details and links to a range of resources on disclosure and your rights, see www.haemophilia.org.au or phone HFA on **1800 807 173**.

Sources and acknowledgements

Adapted with permission from *My choice, my rights: disclosure, anti-discrimination and health complaints information for people with hepatitis C*. Hepatitis Australia, Canberra, 2008.

Murphy, G, Freestone, K. Disclosure and hep C treatment. *Hep C Review* Sep 2008; 62:24-27.

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Important Note: This fact sheet was developed by Haemophilia Foundation Australia for education and information purposes only and does not replace advice from a treating health professional. Always see your health care provider for assessment and advice about your individual health before taking action or relying on published information. HFA is not qualified to give legal advice and readers are advised they may need to seek advice from a lawyer about specific situations.