

BLEEDING DISORDERS AND HEPATITIS C

My choice to tell – family, friends, new partners

For some people, disclosing or telling others that they have hepatitis C and a bleeding disorder is not easy. For others there are few, if any problems. Deciding who to tell and how and when to tell them are important choices. What you feel is right for your situation may change at different times of your life.

You do not have to tell friends, family or partners – the decision is entirely up to you.

“Certainly I don’t tell people I don’t know. So it’s people I have a relationship with. There’s got to be a reason for it, a need to know.”

Some people may also be co-infected with HIV. This raises several other issues for disclosure – talk to your Haemophilia Social Worker/Counsellor or HIV organisation for more information.

DISCLOSING TO FRIENDS AND FAMILY

Telling people about your bleeding disorder or hepatitis C can be daunting. You may be worried that you will be treated differently once people know.

Some questions to think about:

- What will the benefits be for me if I disclose?
- Will my friends and family continue to love and care for me?
- Will they be a valuable source of support?
- Will they tell other people?
- Will they be worried about how it could be transmitted to them, or to children?
- Will they be worried about my health?
- What are their pre-conceptions about bleeding disorders or hepatitis C?
- Will they wonder why I haven’t told them before?

“The group of people that I’ve associated with – well, they know you’ve got something wrong with you if you walk like me. But then you discuss the fact that you’ve got haemophilia, and along with that, that you’ve contracted hep C through blood product. And I think that people are more compassionate these days than anything. They don’t discriminate; they’re more interested to make sure that you’re well.”

“I realised my mother hadn’t told her brothers and sisters about hep C. Maybe she didn’t have confidence in the way they would deal with it.”

“She stuck by me. And that was the rock on which our relationship was built.”

It can be valuable if friends, partners and family members know about your health conditions. They can give support at times when you might be feeling uncertain about your future and concerned about your health. They can help you cope with the ups and downs of living with a bleeding disorder and hepatitis C. They can help you deal with the challenges of treatment. They can support you if others are negative or unhelpful.

Different people will have different reactions. Some may find your news perfectly normal and offer you support. Others may be concerned for you - worried about your health and your future. It may be that they wonder why you are telling them at this point – perhaps hurt that you haven't told them before. They may worry that there is something seriously wrong with your health that has prompted you to tell them now. You may need to ask about their concerns and reassure them.

Unfortunately, there can sometimes be negative reactions when you tell family members and friends – they can be upset, they might retreat for a while, they may have concerns about what it means for them and be overly afraid of transmission, or make discriminatory remarks. Sometimes they stop contact altogether.

This kind of reaction can happen because many people know little about bleeding disorders or blood borne viruses - what they are, how they are passed on and how they affect someone. They may also be a result of the preconceived ideas people have about hepatitis C transmission and their own ignorance and prejudice. If this happens, remember, it is not a reflection on you and you are not responsible for their reaction.

“With hep C, people are not sure whether it's an issue. I got some weird responses extended family - they shied away from a kiss on the cheek. ”

“I've found with certain friends, you tell them you have hep C and they automatically have an image of why you've got hep C - using drugs, sleeping around without using safe sex and that stuff.”

“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. If they then have some sort of a worry, I'm only too happy to help them with some knowledge.”

HOW TO PREPARE TO TELL OTHERS

- **Find out as much as you can about your bleeding disorder or hepatitis C before you tell others.**

This will help you to answer their questions about what it means for your health as well as what it means for them. Do you still have hepatitis C virus in your blood or have you cleared it? How is your liver health? If you are not sure what your hepatitis C status is, talk to your Haemophilia Centre or hepatitis clinic about checking it for you

- **Have some accurate information – eg, pamphlets, fact sheets, information from the internet – ready to give them and be prepared to answer their questions.** This often helps reassure people and corrects any misinformation

- **Practise disclosing first** – you may prefer to practise in your mind, with a friend who you trust, or with a social worker or counsellor

- **Think through all the possible responses the person might have and how you might react to that.**

Think about their possible worries or concerns and what information you might need to tell them or give them

- **Have a supportive person or people you can easily contact when you are disclosing to someone who is important to you.** It can be a big thing to share something you may have told very few, if any, people about

- **Think about what might happen if the person told other people, friends or family** – there is no legal obligation for family or friends to protect the privacy of your haemophilia or viral status. It might be helpful for the person you are telling to know who else knows

- **Choose a time and place when you can take some time, can talk openly and safely and the person can feel free to go and think about things on their own**

- **When you disclose - no matter how they react – offer them the opportunity to talk to your health care team or phone a hepatitis helpline for more information.** This might help them understand your feelings and symptoms and answer any questions or concerns

- **Give the person time to come to terms with this new information about you.** They may be very surprised, so give them as long as they need to absorb everything, including reading through and following up the information you gave them

- **If you are not sure about the person's attitudes, test the waters first.** Start some discussions that might give you an idea of their attitudes, such as blood rules in sport, first aid precautions, drugs in school, celebrities with hepatitis C and see how they respond

Remember, you are simply sharing information about yourself. You are not making a confession and you have nothing to be ashamed of, even if you feel embarrassed.

NEW PARTNERS

If you are beginning a new relationship, the decision if, when and how to tell your new partner about your hepatitis C status might require some thought, particularly if you are also telling them about your bleeding disorder.

What issues might there be with disclosing to a new partner?

Risk of passing it on

- Hepatitis C virus (HCV): very small risk of sexual transmission, increased if blood is present or with cuts, grazes, sexually transmissible infections or HIV
- Bleeding disorder: may be a risk passing on a bleeding disorder to future children. New partners may find it helpful to discuss the risks and options available with a haemophilia health professional.

In all cases, if you are starting a new relationship it is advisable to follow safe sex practices such as using a condom to protect both partners against sexually transmissible infections, eg herpes, as these are common in the community and sometimes people are unaware they have them.

When to disclose?

- You may prefer to tell a new partner early on. It may make no difference to the relationship or even bring you closer together. But if the person can't accept the news, it may feel easier to leave the relationship before you have both become attached
- You may prefer to wait until the relationship has developed and it looks like it might continue. You may feel you need to know them better to have an idea how they might react and see whether they will respect your privacy

A fully informed partner is in the best possible position to be able to make a decision as to how they feel about you having a bleeding disorder or a blood borne virus.

"I found myself having to disclose to my partner early because we went out, my partner stayed the night at my place and I walked in in the morning and there's my toothbrush in my partner's mouth. And I'm just like, we have to have this talk right now. Because my being a haemophiliac as well, my gums bleed a bit when I clean my teeth, so chances are there's a bit of blood on the toothbrush."

"My new partner went to her own family doctor and said, I'm partnering with a haemophiliac who's got hepatitis C. Give me the facts. So she was informed. She's a great lady."

CONVERSATION STARTERS

Make sure what you say feels comfortable and right for you. Here are some ideas on how to raise the subject.

"I've got something I'd like to chat with you about. Quite a while ago I found out I have hep C. Is it OK with you if we talk about it now?"

"I feel as though we are really starting to get to know each other and I would like to tell you something personal. I have a condition called haemophilia, do you know much about it?"

"I feel like we have a really good relationship. There's something I feel you should know so you can understand me better. You know that I use treatments for my haemophilia. Well years ago the treatments weren't as safe as they are now, and I ended up getting hepatitis C from my treatment product."

"You know you were telling me last week about something you have hardly told anyone about? Well, there's something like that for me too."

"I find you really attractive and would like a serious relationship. I think there's something you should know before we go any further."

DISCLOSING TO YOUR CHILDREN

Kids interpret things as kids, not as adults ...

Some parents tell children earlier rather than later. Others disclose gradually, and just explain what it means in practical terms, eg that you have a problem with your health that makes you very tired sometimes. Your child will be most concerned with what affects them, eg if you have treatment, go to hospital, have symptoms such as nausea or tiredness.

Things to consider

- **Why you are disclosing to them**
- **How much and what you should tell them** considering their age, their level of maturity and what they can understand
- **Children are good observers** and can pick up on what we express through our actions and emotions. When we avoid talking about certain topics, children get the message that it is not OK to talk about that subject. If they ask questions, it is important to answer honestly and at their level
- **Children do not think the way adults do.** They will have theories about any symptoms or treatments they have noticed. They often believe that what happens around them is because of something they have or haven't done. If they do not understand, they may think that changes in your mood relating to your health or being on treatment are their fault. It is important to reassure them that they have done nothing to cause it and that you and your health care team are looking after your health
- **Children can find it very hard to keep secrets.** Placing the burden of secrecy on a child—even a teenager—can lead to problems for both them and you if or when that child does end up telling others. If you want to keep it private, emphasise that it is only for family or someone trusted and not for school or friends. Think about who else your child can talk to safely
- **Talk to other parents who have already been through this process**

How much do you tell their school? What about the parents of children they play with?

- Try to find a school or child care centre that has a helpful attitude in this area. You can do this by making telephone calls to discuss the matter generally with the principal or school counsellor, or by contacting your local Haemophilia Centre or haemophilia or hepatitis organisation
- Find out about other parents' attitudes before you tell them and be prepared to give them accurate information if you decide to disclose.

Disclosing is rarely easy. Be proud of yourself for having had the courage to share something very personal with others.

WHERE TO GO FOR MORE INFORMATION AND ADVICE

If you would like to talk over these issues 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, hepatitis or HIV organisation. They can also help with a referral to a counsellor.

Links to further resources are on the Haemophilia Foundation Australia (HFA) web site: www.haemophilia.org.au
To contact a hepatitis helpline, phone 1300 437 222 or go to www.hepatitisaustralia.com.

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.

Hep C fact sheets: telling others. Hepatitis C Council of NSW, Sydney, 2007.

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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.

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