

Hep C - my story



Contents

Terry's story P.1

Ben's story P.2

About bleeding disorders P.3

Les's story P.4

This is hepatitis...

This is hepatitis...

For people with a bleeding disorder and hepatitis C, it's another life challenge

Three Australians with haemophilia and hepatitis C tell their story

Terry's story

How did you find out you had hepatitis C?

In the early 1990s, after the hepatitis C virus had been identified, we enquired at the hospital about being tested for it. To our surprise we were told that I had hep C, based on blood tests that had been taken years earlier.

Whilst it was a shock to hear this, it also explained much about how I had been feeling "out of sorts" since the early eighties.

Having a diagnosis meant that I could bone up on what hepatitis C was all about and what is required to deal with it.

How has hep C affected you over the years?

From the early eighties I had been feeling increasingly tired and unable to concentrate as well. I frequently needed to go to bed early each night so that I felt sufficiently rested to face work the next day. Despite this, by early afternoon it felt like I hit a brick wall - I felt extremely tired and experienced "brain fog".

Our social/family life suffered over many years because of the physical and mental fatigue - it was not uncommon for us to be last minute apologies for family/friends gatherings.

By the mid eighties I stopped working full time because of the effects of hep C coupled with ever increasing problems with arthritis.

Why is hepatitis C an issue for people with bleeding disorders?

People with inherited bleeding disorders, such as haemophilia or von Willebrand disorder, often need to use clotting factor treatments to stop or prevent bleeding episodes or "bleeds".

In the past most people with bleeding disorders used clotting factor treatments made from donated human blood plasma. In 1990 Australia began testing blood donations for hepatitis C. Manufacturers also developed and introduced steps to remove or inactivate hepatitis C in clotting factor products.

But by 1990, many Australians with bleeding disorders had already been exposed to hepatitis C through their clotting factor treatment products. Some of these people have now cleared the hepatitis C virus from their blood naturally or through treatment, but others still live with hepatitis C.

Now most people with haemophilia are treated with 'recombinant' synthetic products manufactured in laboratories that contain little or no human or animal material and are very unlikely to transmit blood borne viruses.

Continued on page 2...

This is Hepatitis... GET THE FACTS!

Hepatitis C is a virus carried in the blood that can affect the liver

More than 210,000 people in Australia have hepatitis C

New infections are highest in 20-29 year olds

Liver disease can happen slowly and without symptoms if left untreated - people with hep C need to have their liver health checked regularly

Symptoms can include tiredness, abdominal pain, nausea, irritability, depression, forgetfulness

There is no vaccine for hepatitis C

Treatment can cure 50-80% of people, but side-effects can be hard to manage

Looking after your health and wellbeing can sometimes help with symptoms

The earlier and younger you have treatment, the more likely it is to be successful



Terry's story continued

Have you had hep C treatment?

In 1995 I was part of an interferon monotherapy trial. Unfortunately I suffered numerous debilitating side effects to the extent that I was advised to withdraw from the trial early. In view of this I decided to put hep C in the too hard basket and concentrate on my haemophilia and other chronic illnesses.

However, several years ago we began to hear of "combination therapy" and that it had been used on people with haemophilia. We decided to monitor the progress of this new treatment. After hearing of a few successful outcomes, we decided it was time to seriously revisit the possibility of treatment once again.

Last year I completed the combination therapy treatment and earlier this year was given the great news that I had cleared the virus. That moment was surreal, given that for the first time in my life I had been cured of a chronic illness, which in this case had affected me and my wife, family and friends for over thirty years.

If you have learned one positive thing from living with hep C, what would it be?

I guess I learned that like any chronic illness it helps to gain as much knowledge of the condition as possible so that you feel empowered to accept and therefore deal with it. I have never subscribed to the "why me" attitude as it only serves to drag you down.

Another life challenge...

We asked 3 men with haemophilia about managing hep C in their lives

Who or what has helped you live with hep C over this time?

I would never have survived the thirty years of living with Hep C had it not been for the love, encouragement and support of my wife who also endured so much of the side effects of my hep C.

I also received much appreciated support from family, friends, the haemophilia community and many health care workers. My faith was of great comfort, particularly in times of self doubt.

What do you think is different about having haemophilia and hep C?

Having haemophilia teaches you to deal with many challenges such as the highs and lows that accompany the condition. With this background, you are more equipped to take on the difficulties that hep C presents. However, at times the combined effects of haemophilia and hep C can be overwhelming.

When you look to the future, what do you think is the most important thing for you in relation to hep C?

Over many years I have learnt that life is very precious. It is so much richer when you are surrounded by those you love and respect. Hep C has made me enjoy even more the basic pleasures of life.

To give is to receive and I feel I have received in spades.



Ben's story

How did you find out you had hepatitis C?

A nurse happened to mention it whilst I was attending an appointment on an unrelated matter. I think she assumed that I was aware of my hep C status, but I had received no notification to that point.

It was frightening and I was a little angry that I hadn't been properly informed. This was in the early 90s.

How has hep C affected you over the years?

I have been unreasonably lucky, in that the only symptoms I've had to manage are fatigue and occasional issues around mental health and staying positive.

"Over many years I have learnt that life is very precious."

Keeping a positive outlook about the future was made a lot easier once I got a liver biopsy. The biopsy provided me with a clear picture of where I was at, and what was likely

and unlikely to occur in the future. It helped me to choose the attitude I was adopting to my diagnosis. It took quite a few years to get there though.

At work, fatigue's the big bogey man for me. I find I really have to work hard and spend time exercising to stay energised. Otherwise things start to fall apart.

Also I have the occasional paranoia - "Who knows? What's their level of understanding? Have they bothered to inform themselves? Is this thing holding me back in my career?" That sort of thing. Every time you get a knock back, for a new position or

Hepatitis: Get Treated

In many cases hepatitis C can be cured

Dealing with complex problems



something, you have to face down those demons.

My diagnosis was revealed to me after I had left home, and was living independently, so my family's understanding largely comes from the things I tell them.

They're OK, but don't seem particularly interested in talking about it. Maybe they assume I don't want to talk about it, that it's a private matter. Maybe there's a communication break down there actually.

Sometimes in the past, I have simply chosen to ignore it, put my head in the sand and made no concessions to moderation or better diet. At times I believe that may have adversely affected my relationships with people who care about me.

Have you had hep C treatment?

The advice I've received is not to have treatment. The virus has been in my body for between 20 and 30 years and hasn't caused significant damage to my liver. I've been fortunate in that respect. It's

best for people like me to wait for treatment options to improve.

If you have learned one positive thing from living with hep C, what would it be?

It's powerful to inform yourself, and it's powerful to have a positive attitude. Try not to bury your head in the sand. I had a gloomier picture of the future than I needed to. Once I'd informed myself, I was able to take control. Ask for the help you need. Ask for the information you need. Don't give up until you get it.

Who or what has helped you to live with hep C over this time?

Talking things out with someone – regularly – has been a big help. At one point I took a significant amount of time out of the workforce. I accessed disability support to concentrate on my health, I committed to regular exercise. I made and attended as many appointments as I could and became informed about where I stood. I found out what support structures were available to me.

Where I could see that there was room for improvement, I joined my state Haemophilia Foundation so that I could lobby for change and work collectively with others who have similar concerns.

Being proactive, informing myself and talking about things have helped me get back on track.

What do you think is different about having haemophilia and hep C?

Having haemophilia means managing a whole range of things: joint pain, bleeds, mobility challenges, co-infections, social isolation, mental health challenges, relationship complexities, medications, expenses associated with chronic illness, work issues.

When you add hep C complications to the mix, it can be the straw that breaks the camel's back. It's also in this context that treatment side effects can overwhelm a bloke. Support is absolutely crucial. Going through this stuff alone just isn't an option.

Continued on page 4...



This is Hepatitis... GET THE FACTS!

Hepatitis C is carried in blood

To be passed on, infected blood from one person needs to get into the bloodstream of another person

Sharing drug injecting equipment is the most common way hepatitis C is transmitted in Australia

Other risks include: unsterile body art and piercing, accidental exposure in healthcare settings, and blood products or transfusions before 1990

It is very uncommon to get hep C from sex, except if the person also has HIV

You can't get hep C from kissing or hugging sharing food or drinks sneezing or coughing toilets or swimming pools washing machines or showers

About bleeding disorders

Haemophilia and von Willebrand disorder are the most common inherited bleeding disorders in Australia

Haemophilia is a rare inherited genetic bleeding disorder. It occurs when an essential blood clotting factor - factor VIII (8) or IX (9) - is missing in a person's blood or doesn't work properly. Bleeding is mostly internal and can cause muscle and joint damage. To stop or prevent bleeding episodes (or "bleeds"), people with haemophilia can be treated with replacement clotting factor products, which are injected into a vein. Without treatment, bleeding episodes can be life-threatening. Although both men and women can carry the haemophilia gene and pass it on to their children, usually only males with the gene have haemophilia.



Von Willebrand disorder (VWD) is more common than haemophilia but not as well known. VWD is a bleeding disorder where people do not have enough of a protein called von Willebrand factor in their blood or it does not work properly. As a result, it can take longer for bleeding episodes to stop.

Most people with VWD only have mild symptoms, but some can have more severe symptoms and can have bleeding into joints and muscles. Common symptoms include frequent nose and gum bleeds, prolonged bleeding after an injury or surgical and dental procedures, easy bruising, and very heavy or long menstrual periods.

Many people are not aware they have the disorder and are currently undiagnosed. Like haemophilia, VWD is inherited, but occurs in males and females equally.



HAEMOPHILIA FOUNDATION AUSTRALIA

+8 YbY5 j Ybi Y
Malvern East Vic Australia 3145
P: 03 9885 7800
F: 03 9885 1800
Freecall: 1800 807 173
E: hfaust@haemophilia.org.au
www.haemophilia.org.au

Important Note: This booklet 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.



This is Hepatitis... GET THE FACTS!

For more information on issues and services for people with bleeding disorders and hepatitis C, contact Haemophilia Foundation Australia, your state or territory Haemophilia Foundation or your local Haemophilia Centre.

www.haemophilia.org.au

For more information about transmission, testing, self-management, treatment and the effects of hepatitis C, call

**1300 HEP ABC
(1300 437 222)**

www.hepatitisaustralia.com

If you require an interpreter call **131 450**

Ben's story continued

When you look to the future, what do you think is the most important thing for you in relation to hep C?

I need to ensure that my health challenges do not become the dominant theme in my life. I need to focus on having a good quality of life, within the confines of what possible.

I can achieve this when I eat well and exercise regularly, when I have employment and am productive, when I have stable accommodation and a place within a community that values my contribution.

The most important thing in relation to hep C is that I am able to access help, so I can create these things.

Want more information on telling people about having a bleeding disorder and hepatitis C?
Check the **Telling Others** page in the Hep C section of the HFA web site - www.haemophilia.org.au

Les's Story

How did you find out you had hepatitis C?

I was told by my treating haematologist that I had non-A non-B hepatitis. At the time it didn't seem a really big deal for me, and possibly the medicos, as I had already been told I was HIV positive. During my adolescence and as a teenager living with severe haemophilia my life had already been thrown up in the air, and then I was trying to - and having to - cope and come to terms with the diagnosis and bleak future that I had been dealt.

At the time the stigma/hysteria and fear/lack of knowledge associated with HIV was a huge fear for me and my family. As a result we have been very private and select in who knows about my situation.

The years passed and then a test was developed. It was then recognized as hepatitis C and was more serious than first thought. More was learnt about the virus and now we know that hep C can have severe implications for the liver long term, especially if you are co-infected with HIV.

How has hep C affected you over the years?

Hep C and HIV are constantly in my life and it can be challenging but I try to go about my daily duties in a positive way as best I can. My life is already altered

due to haemophilia and the mobility issues caused by the repetitive bleeding into joints over the years, and as a result I suffer from chronic arthritis and joint pain. The many joint bleeds have also led to joint deformity and I suffer limited joint function.

I am no longer working; physically my body could no longer handle it. My home life is great and I do have a good social life. All relationships have their ups and downs and I have to say there have been a few troubled times over the years - not surprising with the extra baggage.

But our relationship with all the hurdles is still strong. We as a couple and a family have a way to deal with it on a daily basis.

Have you had hep C treatment?

I have been on the treatment for Hep C but I only got to week 12 as I did not show a negative HCV PCR result. This test showed the level of hepatitis C virus (HCV) in my blood after 12 weeks was not low enough to continue, and was an indication that the full treatment program was not likely to be successful.

In a way it was a good thing as the side effects of the drugs caused me and my family a few issues - the irritability was the most troublesome problem. But it

was disappointing not getting to week 48 and having a chance to clear the virus and have one less chronic condition to worry about!

If you have learned one positive thing from having with hep C, what would it be?

I guess it's not only being hep C positive but having HIV and haemophilia too. If you have it all dumped on you, you have to find a way of coping as best you can, and not dwell on it, but accept it all and try and live with it.

Who or what has helped you to live with hep C over this time?

My family and my contacts within the haemophilia and bleeding disorders community have helped me. Peer support groups are really important too as they are the only ones that know what it is like to live with multiple chronic conditions.

When you look to the future, what do you think is the most important thing for you in relation to hep C?

I'd like to remain as well as I can and be around as long as possible for my family.

I will consider re-treatment with the current or up and coming treatments to have another crack at clearing the virus.

Thanks to Terry, Ben and Les for sharing their experiences.
"Terry", "Ben" and "Les" are not the authors' real names.
All photos in this publication are of models.

Artwork from the 2010 World Hepatitis Day campaign provided by Hepatitis Australia.