

SUMMARY OF “A DOUBLE WHAMMY” REPORT (revised)

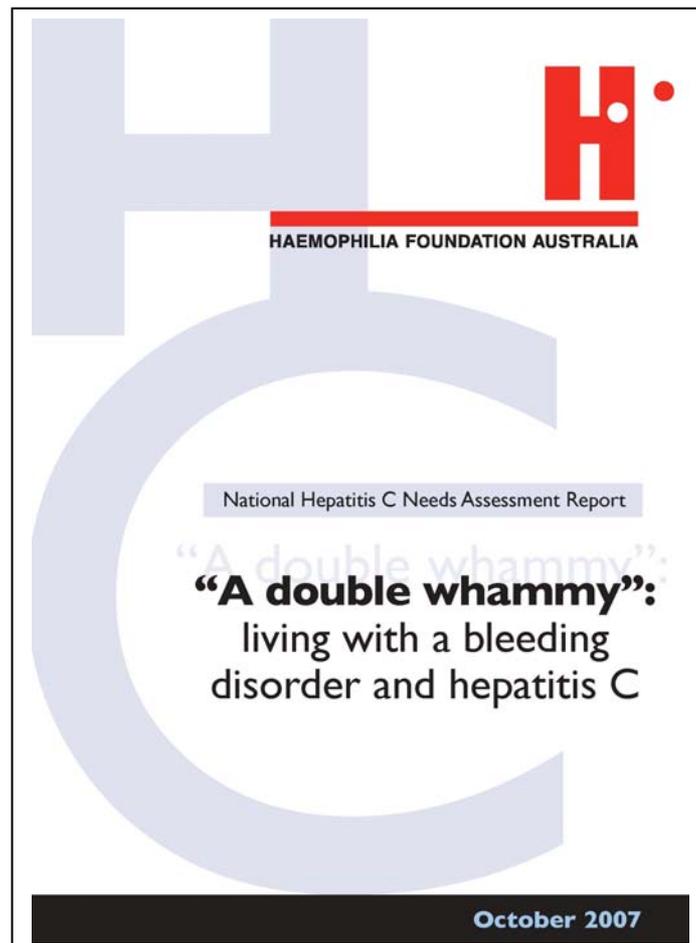
To understand the needs of the bleeding disorders community affected by hepatitis C, Haemophilia Foundation Australia (HFA) has undertaken a national needs assessment which included:

- Establishing the HFA Hepatitis C Advisory Group (2006)
- A national hepatitis C survey of HFA members (2003)
- Focus groups with 26 people with bleeding disorders affected by hepatitis C and their partners, families and carers in three states/territories to discuss their experiences relating to hepatitis C (2007)
- National consultation with state/territory Haemophilia Foundations and haemophilia and hepatitis health professionals (2006-7)

The Report was launched on 5 October 2007. It includes personal stories and recommendations.

What next?

HFA Council has formed the HFA Hepatitis C Working Party to develop strategies to carry out the recommendations in the Report. Progress will be reported in the *National Haemophilia* magazine.



It's a double whammy, because at the time I was doing everything I could to improve my situation [with my bleeding disorder].

Life had been pretty tough. Haemophilia, arthritis, HIV and hep C, and dealing with normal day-to-day pressures were getting pretty hard to deal with. I was constantly fatigued, in pain, suffering nausea and my mood was pretty flat.

“You have hepatitis C”

What’s good, what’s bad? I feel I’m doing alright, and just carry on regardless... I’m not here for a long time, I’m here for a good time. That’s pretty much the attitude that I’ve got.

Most people with bleeding disorders who were treated with clotting factor concentrates made from human plasma were exposed to hepatitis C virus before these products were inactivated for hepatitis C. Some were children or teenagers at the time. Some were co-infected with hepatitis C and HIV, others also with hepatitis B. Some people cleared the virus naturally, others through antiviral treatment. However, most have now been living with hepatitis C for 20 to 30 years or more.

I’ve had hep C for so long, I don’t know what it’s like to be healthy... Sometimes I have good days, some not so good.

For people with bleeding disorders, being diagnosed with hepatitis C had a profound psychological impact. In the mid-1980s people with bleeding disorders in Australia had been deeply shocked to find that around 30% had acquired HIV from contaminated blood products. They were still coming to grips with this in the early 1990s when many found out they had acquired hepatitis C from their blood products. In some cases, this had happened to more than one member of the same family.

When I found out in 1993 it was a nurse who just happened to mention it to me in passing, about how did I manage having hepatitis C. I didn’t even know I had it.

[I hope] that there’s no surprises. I hope we know what we’re doing... It’s like, great, we’ve got this wonderful stuff called cryo[precipitate], and then heck, here we go, HIV and those sorts of things.

Many had a negative experience of being told they had hepatitis C and in some cases accidentally found out their diagnosis some years later. Some were angry at the way they became infected. They were dependent on blood products to survive and no longer thought they could trust that their blood products were safe. They felt at the mercy of economic decisions by health bureaucrats. Some believed that if authorities acknowledged that it was a health system error, it would help people with bleeding disorders deal with their anger.

There will be a next time... because there’s always people out there balancing economics versus people’s health...It’s happened with HIV, it’s happened with hep C, what’s next?

Recommendation

- *That Australian governments should deliver an apology to those who acquired hepatitis C through the blood supply*
- *That people with bleeding disorders are/continue to be represented in health advisory groups on issues that may impact on them.*

What was the impact of hepatitis C on their health?

- Some people did not have symptoms and felt that hepatitis C was not affecting them. This included some people who were HCV antibody positive but no longer had hepatitis C on their RNA PCR test and some who had completed treatment successfully.
- Most felt chronically unwell and described feeling “down”, tired, lacking stamina, having liver pain, nausea and “brain fog”. Many were experiencing depression.

- If they had moderate or severe haemophilia, hepatitis C was an added burden on top of joint pain and disability caused by haemophilia and sometimes HIV as well. Without successful treatment, this often made their level of disability unmanageable by the age of 35-40 years.

My son is the spitting image of good health at the moment. When you see him you wouldn't have a clue that he had any medical problem whatsoever.

Hep C has had much more effect. The long term effects of bleeds into joints are now beginning to hit me pretty hard. I've had haemophilia for [more than 60] years. I've had hep C for [more than 20] years and the last 20 years the limiting, debilitating influence on my life has been fatigue not haemophilia.

Keeping track of hepatitis C

Recently Haemophilia Foundations and haemophilia health professionals had seen more cases of people with bleeding disorders and hepatitis C developing serious liver disease and some people had died. They were concerned that many people with bleeding disorders might not have checked their hepatitis C or liver health recently. The HFA hepatitis C member survey in 2003 confirmed that some people did not know or understand about their hepatitis C. When they were first diagnosed in the early 1990s some people were told not to worry about their hepatitis C. Some did not contact the Foundations or Haemophilia Centres regularly. They might not realise if their liver health was becoming worse and could miss an opportunity to have hepatitis C treatment.

I only know what two of my tests are and that's my [haemophilia levels], so that's like two out of eight tests I get every six months. So other than that I have no idea what they're testing for. Just eight vials of blood

I think I understand [test results] reasonably well but that's because I've known to ask.

I'd say go for treatment if you are given that option. I think we have regrets in that department... and we now since find out that he's got the good genotype and it's too late.

Often if I get a funny result – I take mine home, I analyse it and I'll get on the Internet and have a look on the Internet, and then if I can't pinpoint something down..., I'll go back to the nurse or the doctor and say, well what's this?

In consultation many Haemophilia Centres reported they were working actively on hepatitis C. Some Centres were doing a systematic hepatitis C review with all their patients. Some health services reported that they were under-funded and under-staffed. This led some hepatitis clinics to have problems tracking patients and scheduling timely appointments.

People with bleeding disorders and their families in the focus groups felt they needed to be proactive to get information about their test results from hospital staff. Health professionals reported that there were sometimes communication difficulties, particularly with very young men. Where people did not understand the meaning of their test results, they sometimes made decisions such as not having their liver health checked regularly or not seeking treatment. This could have serious consequences if they had liver damage.

Recommendations

- That HFA collaborates with Haemophilia Centres and state/territory Haemophilia Foundations on a campaign to raise awareness about liver health and treatment for people with bleeding disorders and hepatitis C
- That health care professionals make sure people with bleeding disorders are routinely involved in keeping track of their own health

Treatment

I had the interferon when I was [a teenager]. Everyone said it was going to give me side effects and all this. And I felt nothing. I had it and felt healthy the whole time.

I'd read all the side effects and said, oh well, I might be lucky and get two or three of them and then I felt like I had all of them. It slowly got better, but it lasted the whole treatment.

Hepatitis C treatment generally takes between 6 to 12 months.

What were people with bleeding disorders' hepatitis C treatment experiences?

- Some had already had successful treatment
- For many others, treatment had failed or they had relapsed after treatment, particularly if they had interferon monotherapy in the early 1990s
- Most had not had treatment
- Some were considering treatment
- Others would not have treatment again until the success rates improved
- Some had no or few side-effects
- Others had moderate to severe side-effects, including major depression and fatigue. This affected their relationships, family life and ability to work. Some stopped work during treatment
- If they were not living with family, support during treatment might not be available to them
- Some were delaying treatment until they could afford it or have adequate support
- Others did not have treatment options, as available treatments had not been successful or their liver disease was too advanced.

My doctor said I should have treatment, but I am worried about whether I would cope. They say it's pretty bad and I live on my own. Besides I am not sure that I could cope with work as well – and I couldn't afford not to work. I already use most of my sick leave and recreation leave on time off because of bleeds.

I've been on two courses of treatment now and both times I've relapsed as well. So I'm at a loss now where to go.

I think I'll go again because it doesn't get rid of the virus but it gives it a hell of a hiding. I think that makes a difference.

Antiviral combination therapy is what we went through... It was hell to live through but it had a positive outcome. [partner]

Access to treatment could be limited for people with bleeding disorders, especially for those who had unsuccessful treatment with earlier less effective regimes. Under current guidelines, people who have already had interferon-based treatment are excluded from government-subsidised treatment. In rural and regional areas, treatment was sometimes unavailable or there were long waiting lists. Liver disease sometimes became life-threatening while the person was waiting for treatment.

Recommendations

- *That the Pharmaceutical Benefits Scheme Section 100 criteria excluding patients who have had previous interferon-based treatment from receiving subsidised hepatitis C treatment should be removed.*
- *That governments increase resourcing to hepatitis services so that they can provide adequate medical, nursing and social work/counselling support to people during and after hepatitis C treatment.*
- *That hepatitis and haemophilia services work together to help people with bleeding disorders prepare for treatment, including education, support, help with services, and linking to others who have had treatment.*

Health care services

I have a pretty good relationship with the staff [at the hospital]. I find if you get to know the system, you can usually get through relatively quickly.

I've always tried to keep fairly active. And I've relied on anti-inflammatories to keep the joints a bit mobile. And when you have cirrhosis, they advise you against taking all those.

Overall people with bleeding disorders and hepatitis C were looking for comprehensive health care that took into account their bleeding disorder, hepatitis C and other aspects of their lives and involved their partners and carers. Haemophilia and hepatitis appointments and services were often not co-ordinated and health reviews could take days. This created extra difficulties and expense for people who were working, were not very mobile or in pain, or were from rural or regional areas, eg taking time off work, travel, parking, waiting long periods. Some actively worked around system problems. Among older people, the combination of their bleeding disorder and hepatitis C created greater disability and meant that many required supported care and accommodation.

Recommendations

- *That Australian governments provide greater resourcing for haemophilia and hepatitis services to increase and improve services for people with bleeding disorders and hepatitis C.*
- *That haemophilia and hepatitis health services follow a comprehensive care model for people with bleeding disorders and hepatitis C.*
- *That Australian governments give urgent priority to developing hepatitis C services and care in rural and regional areas*

Living with hepatitis C

Hepatitis C symptoms and treatment side-effects had a major effect on some people's home and social life. They were unable to do their share of household and family duties and no longer socialised outside the home. Some withdrew socially, especially if they lived alone. Partners or family were usually actively involved in caring for the person. They cut down their own working hours to provide this support. This could put stress on the family and carers often felt very isolated.

I am self employed with a wife and two kids – I had two lots of unsuccessful interferon treatment for hepatitis C... We had to sell the house because of financial problems because I couldn't work a couple of years ago...My family has had to endure our decline from a normal lifestyle with security to not knowing what tomorrow will bring and living from day to day.

If people did not have symptoms, hepatitis C did not make much difference to their work or their finances unless they decided to have treatment. With symptoms, many people had to reduce or stop work from their late 30s. Treatment caused big disruptions in their working life. Many people were unable to get personal, health, travel, income and mortgage protection insurance. This often led to great financial hardship for them and their families. Partners often had to go back to work to maintain the family income.

It is a real strain on our marriage. Often I am not well enough to go out and I feel unwell. I can't do my share with the kids. My wife has to do it all and she is working part time as well.

I took 12 months off work to have treatment, so did my Mum.

Most people with bleeding disorders had not experienced much hepatitis C-related discrimination, but most did not tell many people about their hepatitis C. Many were concerned about the stigma in the community where hepatitis C was associated with injecting drug use and casual unsafe sex and were very careful about their privacy. This meant they sometimes did not use some social services. There had been cases of discrimination in health care settings, the workplace and residential aged care facilities.

You learn from telling people about your haemophilia and the reaction you've got there that you don't want to tell too many people about the hepatitis... That person might be your boss in the next two years and in that case you don't want him to think..., he might be a burden to us, he might get sick...

It's really hard, I don't let myself get close to people, and I haven't had a girlfriend either. How could I tell her my story – I feel like I have no future, no health, no money, and lots of anger. It's not a good look.

Certainly 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.

Recommendations

- *That Australian governments provide financial assistance to people who have acquired hepatitis C through blood and blood products, including*
 - *Consideration of the impact of hepatitis C on the person now and in the future.*
 - *Income support for those who experience loss of income due to hepatitis C, including carers and partners/families of those who have died.*
 - *Ensuring that life, health, travel, income and mortgage protection insurance is available to people with bleeding disorders and at a premium equivalent to healthy people in the general community.*
- *That Australian governments support a national media campaign to raise awareness about hepatitis C in the general community and prevent stigma and discrimination*
- *That Australian governments support the development of workforce education on hepatitis C, particularly in relation to discrimination in the health care setting and in residential aged care facilities.*

Support

As a result of all these issues, people with bleeding disorders and hepatitis C and their partners and families had a great need for confidential counselling and support. Some found that talking with others with bleeding disorders and hepatitis C was important so that they did not feel so isolated. Support was also important for partners and carers.

At that time, we did go to the Hep C group because it was suggested that we go. But that made us – or even me – feel better to handle it, I'm not the only one, all these guys are crazy! It got to the point where this is normal. [partner]

[Husband] spoke to [another patient] so I think that made him realise that his tiredness came from his hep C and his liver rather than him just getting old... Someone else's experience was the only thing that hit home to him, no matter what the doctors were saying. [partner]

Recommendations

- *That haemophilia social workers/counsellors and Haemophilia Foundations work together to develop networks and activities for people with bleeding disorders and hepatitis C to support each other, eg one-to-one over the telephone or email, men's groups, women's groups, other people's stories in the newsletter or on the web site.*
- *That they also investigate options for carer/partner/family support*

Information

What sort of information did people need?

- Bleeding disorder specific information on hepatitis C, liver health, treatment, transmission in the home, support and services available, mental health, relationships, disclosure, and financial management
- Other high quality information was available from Hepatitis C Councils
- People with bleeding disorders preferred to receive this information in bleeding disorder environments, such as Haemophilia Foundation newsletters, web sites, emails, Haemophilia Centres.

Recommendations

- *That HFA develop or source information aimed at people with bleeding disorders and hepatitis C on the topics required*
- *That Haemophilia Foundations and haemophilia health professionals continue to work with Hepatitis Councils to make sure the Council resources were available to people with bleeding disorders in newsletters, on haemophilia web sites or through Haemophilia Centres.*

Priorities

For some people with bleeding disorders, hepatitis C was not a high priority in their life, particularly if they had cleared the virus or did not have symptoms, or had more immediate problems such as severe pain from haemophilia or being very unwell with HIV. For others, priorities around hepatitis C were

- Improving their health
- Being better informed about hepatitis C and their current and future health and wellbeing
- A better treatment experience
- Educating the broader community to reduce stigma
- Helping people with bleeding disorders and hepatitis C financially
- Safeguarding the blood supply for future generations.

Maybe some information from other people who have been through the treatment.

My priorities... that the blood system is safe so that no one else is put in the same situation.

Other recommendations

- *That men's health education should involve activities that interest them and a focus on wellbeing*
- *That HFA should investigate further the needs of people with bleeding disorders and hepatitis C*
 - *In rural and remote areas*
 - *In indigenous communities*
 - *In an ageing population*
 - *In particular, hepatitis C education and information needs of women in the bleeding disorders community*

For a full list of the recommendations made as a result of the HFA Hepatitis C Needs Assessment, see the full report: **"A double whammy": living with a bleeding disorder and hepatitis C.**

Copies of the full report are available from

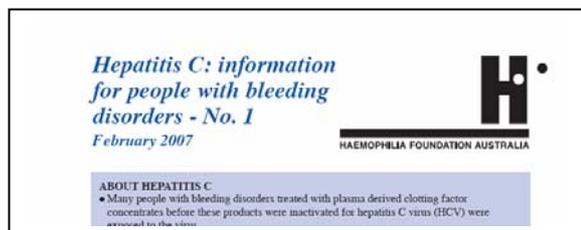
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A PDF version of the report is on the HFA web site: www.haemophilia.org.au

HEPATITIS C – WHERE TO GET INFORMATION, SERVICES AND SUPPORT

HFA has produced a basic information booklet on hepatitis C for people with bleeding disorders. This is available from your local Haemophilia Centre or Haemophilia Foundation. It is also on the HFA web site:

www.haemophilia.org.au



There is a lot of high quality information on hepatitis C available from Hepatitis Councils. HFA has developed a hepatitis C section of the HFA web site with links to selected information from the Councils and other sources. Haemophilia Centres and Haemophilia Foundations usually have a range of relevant resources as well.

Many people have questions about superannuation or insurance. Maurice Blackburn Cashman has developed a national information booklet on this for people with bleeding disorders and hepatitis C. The booklet is available from Haemophilia Social Workers/Counsellors and on the HFA web site.

Services and support

Your Haemophilia Centre can provide you with information about services for people with hepatitis C. If you have not asked very much about hepatitis C at the Centre before but would like more information, you could ask one of the health professionals you feel comfortable with or the Haemophilia Social Worker/Counsellor. If appropriate, you would be referred to a specialist health professional for more information.

If you have hepatitis C and would like to be put in touch with another person with a bleeding disorder and hepatitis C, contact your Haemophilia Social Worker/Counsellor. Hepatitis Councils also offer peer support services.

For other information about services for people with bleeding disorders and hepatitis C near you, contact your Haemophilia Social Worker/Counsellor, your state/territory Haemophilia Foundation or HFA. You will also be able to obtain valuable information from Hepatitis Councils.

If you have any other questions, contact **Haemophilia Foundation Australia**
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