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HAEMOPHILIA FOUNDATION AUSTRALIA

## *Getting it right:*

**Hepatitis C needs assessment  
evaluation and implementation report**

**January 2009**

# *Foreward*

This evaluation highlights Haemophilia Foundation Australia (HFA)'s ongoing commitment to addressing the needs of the bleeding disorders community affected by hepatitis C.

In October 2007 Haemophilia Foundation Australia released its Hepatitis C Needs Assessment Report (*"A Double Whammy": living with a bleeding disorder and hepatitis C*). HFA then began the evaluation and implementation stage of the Needs Assessment. This report summarises the findings and outcomes from this stage of the needs assessment.

Why evaluate the HFA work on hepatitis C so far?

For HFA there were two important aspects to take into account:

Have we got it right? Is what we are doing having the impact we hoped? Do we need to adapt any of our activities or recommendations? Can we find answers to the questions raised in the needs assessment?

The process of consultation is important in itself. It gives a voice to our members - people with bleeding disorders and their partners and families - raises awareness of the issues and invites people to start working on solutions. Listening and taking note of feedback is crucial to an effective response. Both community and health professionals have an opportunity to comment on what has been recommended and feed back on issues and changes they feel are significant.

Many people have been involved in the evaluation and implementation stage: individual members of the bleeding disorders community, state and territory Haemophilia Foundations, health professionals, Hepatitis Councils and the National Association of People Living with HIV/AIDS (NAPWA), along with staff at HFA, along with others who gave support and advice..

As was the intention with this stage, consultation has worked hand in hand with development. When they have reviewed their current practices and activities and considered ways to comment on or implement the recommendations, the Foundations, Hepatitis C Councils and health professionals have directed considerable energy towards working on the hepatitis C needs identified in the Report and renewing relationships with each other.

Thanks to all those who have participated in creating this report.



Gavin Finkelstein  
President  
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## SUMMARY OF KEY FINDINGS

### Health and treatment issues

- Experiences of hepatitis C variable. Some are well. Some have more severe symptoms and an erratic pattern of health which impacts ability to carry out daily activities. Some feel haemophilia is more of a problem than hepatitis C.
- Haemophilia Centres continue to report seeing increasing numbers of older patients (30 yrs and older) with deteriorating liver health. People in their 20s more likely to feel well or have cleared the virus. People less likely to check their liver health or seek treatment if not aware of symptoms.
- As people age, health problems become more complex and impact on each other. Overload with health conditions an issue for some, with fatigue and mobility problems limiting their ability to manage all of their health care issues. Can be further complicated if they are HIV co-infected. They deal with the most pressing issues and let others slip, sometimes with serious health consequences.
- Treatment barriers: concerns about financial issues, length of time off work required, already vulnerable in the workplace due to haemophilia; side-effects; likelihood of treatment success; other health issues.
- Factors assisting with monitoring and treatment: hearing other people's experiences; prompts from the Haemophilia Centre to review liver health; support from professionals and family/friends; good relationship with specialist.

### Health services

- Greater focus on hepatitis C care and liver health review in Haemophilia Centres over last 12 months. More confident about process. Some undertaking systematic review, larger centres review when they see patients. Loss of contact with significant number of people and hepatitis C health due to delivery of factor to individual, mainly those with moderate or mild haemophilia or von Willebrand disorder – less need to visit hospital and less opportunity to begin review process.
- Haemophilia Social Workers/Counsellors vital in providing networking and communication between hepatitis clinics and Haemophilia Centres: little routine contact. Hepatitis care can be lost to follow-up.
- People with more complex issues would like a more holistic approach to their care: more co-ordination of care and appointments and support for managing multiple health problems and negotiating the health system and social services.

### Living with hepatitis C/support/education

- Lasting impact of diagnosis with hepatitis C. Also has impact on parents and siblings.
- Many experience fear of future and feel hepatitis C adds to their vulnerability.
- Dealing with unsuccessful or unavailable treatment a significant problem
- Difficulties for single men to start new relationship; support of partner very important
- Indirect costs associated with hepatitis C. Would be helpful to have a financial advisor to help ends meet. Flexible working arrangements needed to manage erratic health problems and appointments. Hepatitis C can impact on ability to work from 30s onwards.
- Disclosure: some have had painful experiences, others received compassion. Have become more skilled at knowing how to disclose and to whom over time.
- Support: men rarely seek support directly. Culture of stoicism and self-sufficiency. Wary of acknowledging need for help or mental health issues. Carers also need

support but sometimes do not know when and where to go. Would be helpful to have safe and facilitated environment to talk about clinical issues with other men.

- Young people need education on hepatitis C, relationships, disclosure, finances, diet and exercise

### **Feedback on information and HFA hepatitis C publications**

- **Hepatitis C information:** some had noticed more information on hepatitis C available in last 12 months; others had not. Plenty of in-depth information available from Hepatitis C Councils
- **HFA hepatitis C information booklet:** useful, concise, relevant. Some had not seen it before the focus groups. Add information on doctor-patient relationship.
- **'Double Whammy' Report:** nearly everyone had received a copy. Too big for some, others found depth useful. Understood need to provide evidence for government and health services. Personal stories powerful; felt connected, encouraged to take action on health; good to see HFA taking action on hepatitis C. Break report down into shorter "bites" on topics and republish. Rerelease summary as many missed it – was placed in front cover of report. Experiences resonated for most; some had more positive experiences. Recommendations appropriate.
- **Hepatitis C updates:** good format and information. Liked personal stories; need more positive stories about treatment. Need to promote.

### **Outcomes**

- *'Double Whammy'* Report distributed widely
- HFA Hepatitis C Working Party prioritised and began implementation of recommendations; planned strategic response
- Successful submission to government on extending access to subsidised retreatment for hepatitis C
- Continuing work with haemophilia health professionals on following up key findings of report
- Production of brief hepatitis C updates on priority issues (treatment and test results). Newsletter articles on topics from *'Double Whammy'* Report and personal stories
- Funding sought for other resources and wellbeing workshop
- Expert advice sought on insurance and superannuation issues. Guide circulated.
- Presentations and promotion of HFA publications to raise awareness among health professionals of hepatitis C issues for people with bleeding disorders
- Community interest in Report and issues

## HOW WAS THE EVALUATION CONDUCTED?

Consultation with community and health professionals for the evaluation and implementation stage of HFA's hepatitis C needs assessment took place between December 2007 and September 2009. Some further discussions were held with the Australian Haemophilia Nurses' Group and the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group in October 2009.

The evaluation and implementation stage aimed to

- Seek feedback on the *'Double Whammy'* Report and other recent HFA publications and activities relating to hepatitis C
- Check whether needs in all states and territories were consistent with the HFA hepatitis C needs assessment (*'Double Whammy'*) report and identify further or different needs, if relevant
- Seek feedback on the impact of Haemophilia Foundation and health service work on hepatitis C in the last 12 months
- Gather further information on some identified gaps
- Prioritise and fine tune the Report recommendations
- Commence implementation of the recommendations.

Consultation and feedback involved:

- Intensive consultation on hepatitis C issues in two states/territories where focus groups had not previously been held. This included community focus groups and in-depth discussions with local Haemophilia Foundations, haemophilia and hepatitis health professionals and Hepatitis C Councils.
- Consultation with all Australian haemophilia centres about any changes to patients' hepatitis C health and services in the last 12 months
- Community feedback on the *'Double Whammy'* report and HFA hepatitis C publications through the *'Your Say'* feedback form. Haemophilia health professionals were also asked for any community feedback on the Report or HFA publications
- Feedback discussions with the Australian Haemophilia Nurses' Group and the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group.

### Focus groups

Three focus groups were held in two states during March 2008. Separate focus groups were held for people with bleeding disorders and for partners/parents/family. They were led by the HFA Policy Officer and the Haemophilia Social Worker/Counsellor.

Participants included:

- 8 men with bleeding disorders affected by hepatitis C
- 3 parents. The parents were not related to people in the other focus groups.

The information concerning one participant was withdrawn on request for personal reasons.

People were invited to participate in the focus groups through a mail out by their local Haemophilia Foundation. Before the focus groups in each state the Haemophilia Social Worker/Counsellor discussed what the focus groups would involve with all people who volunteered to attend. There was no focus group of partners/family in one state due to lack of participants.

Each focus group used the same set of questions covering various aspects of people's lives and asking for feedback. They were adapted from the questions for the 'Double Whammy' Report by the HFA Policy Officer and the Haemophilia Social Worker/Counsellors.

For privacy reasons, the stories and information from these focus groups do not identify which state or territory individual participants came from. Other details that could identify an individual have also been deleted.

### **Feedback on HFA hepatitis C publications**

HFA has actively sought feedback on the needs assessment report from the community and from health professionals. Anonymous feedback forms ("Your Say") were distributed

- In the community mailout with the Report
- On the HFA web site
- In the December 2007 HFA email news
- In some state/territory Foundation newsletters, eg HFWA.

HFA Council delegates were also asked to promote the feedback forms to their local community.

The initial response deadline was 31 January 2008, but this was extended to April 18 2008 due to community requests.

Haemophilia health professionals were also asked for any feedback on HFA publications as part of the consultation process. This included feedback and comments from community members as well as their own responses.

## FOCUS GROUPS

### HEALTH IMPACTS

#### Health impact of hepatitis C

What is it like to live with hepatitis C and a bleeding disorder? Like the previous focus groups, the Stage 3 focus groups underlined how variable this experience can be.

- Some participants generally felt well.
- Others with more severe hepatitis C symptoms described a more erratic pattern of health, which impacted on their ability to carry out daily activities.
- Some felt that their haemophilia was more of a problem than their hepatitis C.

*I find myself extremely healthy at present and I am very determined to stay that way as far as doing my walking, doing my swimming, doing all the healthy things we do in life.*

*Basically, you're dealt with something on the day and you deal with it. If you've got energy you do things, if you don't, you don't. Some days you feel good, some days you feel bad, but you cope with it as you get it - pretty unpredictable.*

Most symptoms were consistent with those described in the first round of focus groups: lethargy and fatigue, depression, nausea. Other symptoms included skin disorders, night sweats and severe diarrhoea.

Sometimes participants found it difficult to separate the impact of hepatitis C from their bleeding disorder or the effects of ageing. When they had symptoms of hepatitis C and problems caused by haemophilia and/or HIV, participants said that their health problems "compound" and "play against each other". Their signs of "ageing" also seemed to occur at an earlier age than the general population.

Overload with health problems was an issue for some, with fatigue and disability limiting their ability to manage their health and well-being. One health problem could lead to another, with serious health results for some.

*You don't know whether being knackered at 1pm every day is because I'm [mid 50s] or because I've got hepatitis C... the hepatitis C is so intertwined with the haemophilia that it's not one or the other necessarily... I've got an infected prosthesis and they won't put me on the interferon and ribavirin program because apparently it reduces your immune system and if you have an infection, that's not a good idea...*

*But your arthritis is not necessarily hepatitis C. Your arthritis is your haemophilia. Trying to walk with an arthritic joint is debilitating too, it's harder to walk. You take more energy to walk.*

*I find when I'm weary, it has a flow on effect, then you get crooked... I've been working in a company... and I've had the worst luck with health since I've been under pressure. And I'm starting to make the connection that maybe I got that infection and prosthetic [joint] because I wasn't keeping a close enough eye on the signals because I was stressed.*

## Looking after your health

Most people in the focus groups had made changes to their lifestyle to improve or maintain their health. They had given up or cut down their alcohol intake, were careful with their diet, some had given up smoking, and others were trying different ways to manage stress. Some made sure they did activities or kept up hobbies they enjoyed: playing sport, swimming, music, golf, going to the beach, reading, keeping pets, spending time with their family or friends.

As one participant commented, maintaining a health lifestyle was “easier said than done at times”. Reflecting on his lifestyle in the past, another talked about the reasons for his lack of motivation.

*I was not doing anything to help myself. I used to drink until I couldn't stand up. But I paid for it the next day walking about with yellow eyes and yellow skin... But I thought it [hepatitis C] was going to kill me anyway.*

Parents commented that their sons in their 30s and 40s were keen to live a “normal” life and preferred not to think about health issues. If they experienced depression with hepatitis C, they countered it with sport or physical activity, but this could then cause problems with bleeds because of their haemophilia.

As with the first round of focus groups, there was a strong culture of stoicism and participants actively looked for ways to overcome physical problems.

*I've heard people say about hepatitis C, that you get the nausea – I get the nausea and I've got a way of getting over it. I think of something else and I get on and do something, and it might take half an hour and it passes. But it is terribly difficult for someone who is unable to move about, to be stuck with a pain in the guts and not able to do any other thing. I can tell you, that while I'm better than I was, tomorrow, I could still have a terrible day and whatever I've got planned to do, I'd still do it, but I'd have to make up my mind I was going to do it.*

People with mild haemophilia were sometimes able to reduce the likelihood of bleeds with less physically demanding jobs and leisure activities, which left them with more energy to deal with other health issues such as hepatitis C.

## Being younger

Some people with bleeding disorders acquired hepatitis C when they were children. Their ages now range from being young adults, in their late teens to being in their 30s. Focus group participants identified several issues about living with hepatitis C for this age group:

- Establishing relationships or a social life can be difficult
- Even though unlikely, sexual transmission can be a concern, especially if you want to have children
- You are generally in better health
- You may fear discrimination from other parents if you have young children
- If you can adjust to having hepatitis C when you are young, it puts you in a better position as you grow older

*When you're younger, it affects everything, like meeting a partner, your sexual relations, everything like that goes out the window. You're already not a great prospect. You're*

*getting around pretty fragile and then when you put the hepatitis C in as well and for some blokes, the HIV, it's hard to back yourself. Your confidence wouldn't be huge, would it?*

*I just think as a teenager it's difficult because you know you're different but you don't want to be different. And you're at a stage when you want to form relationships with the opposite sex or whatever and it's a difficult situation to be in. Do you say something, don't you say something? And that's been very hard for my son. [parent]*

## **Growing older**

As with the 2007 focus groups, participants noted the effects of growing older with hepatitis C from their mid-thirties onwards.

*As I get older, it gets increasingly complex. One issue plays off the other issue, that affects the third thing, so it's becoming more complicated to manage as I mature.*

## **TREATMENT**

### **Antiviral treatment experience**

Stage 3 focus groups took place in states with larger populations and more sophisticated hepatitis clinics. All of those who participated, even if they lived in rural/regional areas, had confidence they could access high quality hepatitis C treatment if they wished to.

As in the focus groups for the Double Whammy report, the Stage 3 focus group participants described a range of hepatitis C treatment experiences.

- Some had relatively good liver health and were not intending to undertake treatment at the moment
- Others had had unsuccessful treatment, sometimes on multiple occasions
- One was unable to start treatment due to health problems with his haemophilia
- One was investigating treatment
- Some were waiting for new treatments that would have more likelihood of success.

For many, dealing with the disappointment and frustration of unsuccessful treatment or waiting for potentially successful treatments was a significant issue.

*I had a biopsy which was much more positive than I had the right to expect. And at that point it became apparent that the best thing for me was to not have any treatment and wait and if it ever became necessary, then hopefully the treatments might have improved down the track.*

*I've had all of them [clinical trials] and two have failed. Every kind of interferon, every kind of drug, because I was one of the first, but it didn't work unfortunately.*

*Our son was put on the interferon program initially about the mid-90s. But he was taken off it when his white blood cells became too low. And he was extremely depressed at that stage too. So it was just advised that he come off the program and he picked up after that. But it was a frustration. To think you were almost there. [parent]*

## Treatment decision-making

How did participants make decisions about hepatitis C treatment? How would they decide in the future? What would they suggest to others?

*I decided that I didn't want to or need to do treatment because I was feeling well.*

*I think ask the questions about how successful it's going to be and then weigh up your options. If you're the right genotype, go and do it. If you're in the really remote end of the scale like me, in hindsight, with the strike rate that I know that they're getting now with the bad genotypes, just not do it. Wait for them to come along with something better.*

*[After unsuccessful treatment] I know where I stand now 100%. It's not always hanging over my head, should I have tried it, should I have done it then.*

Other factors involved in decision-making included

- Assessment by the hepatitis clinic of the person's liver health and psychiatric vulnerability
- Shopping around for the hepatitis specialist that they felt most comfortable with
- Length of treatment time before they know whether they are likely to respond to treatment
- Need for support during treatment
- Need to prepare for treatment, particularly with work
- Talking to someone else who has experienced treatment
- Consulting a hepatitis specialist for accurate information on treatment and likelihood of success
- Needing the expertise of both the haematologist for a broader view on health and lifestyle issues as well as the hepatitis specialist
- Need a trigger to consider treatment, particularly if feeling well

*Males don't want to know – like a female would go out and say, I need to have this checked this year. Males, unless you push them, don't necessarily want to do that. 'I'm fine'. They're in denial a lot of the time. Until something may come along which triggers a poor blood test and then they find out a lot more is happening than what they really realise. [parent]*

## Treatment support

Participants felt that support during treatment was crucial. Experiences varied widely, from very little support during early interferon monotherapy programs to recent treatment programs in a multidisciplinary clinic, with nursing and social work support. Informal support from workmates, family, friends and neighbours was also important.

## Preparing for treatment

In the focus groups for the 'Double Whammy' Report, some felt that if they had planned for treatment adequately, their treatment experience would have been better.

In the second round of focus groups, some talked about the importance of timing treatment so that it worked in with their life situation. For those with fewer supports, preparing for treatment was more difficult.

*I've had a family breakdown, and you don't want to be doing it in that situation, without the family support. So I'd be prepared to look at it now but a couple of years ago I was not prepared to look at it because I had a few problems.*

*I've got to prepare more than any of you guys because this is the crux for me, I don't have a distinct set of backup friends, support, family even. I'm in a bad position.*

## HEALTH SERVICES

### Interactions with doctors and nurses

All of those who participated in the focus groups attended a large metropolitan public hospital with a major hepatitis treatment centre, even if they were from rural areas. Most had been referred to the hepatitis clinic or the infectious diseases unit some years in the past and had a long relationship with the specialist who provided their hepatitis care.

Most were very satisfied by the care and competence of those who provided their care.

*I see the hepatitis C clinic and they're terrific. They answer all the questions that I need.*

Those who attended the Infectious Diseases Clinic felt there was a comprehensive approach and assistance with managing the complexity of their care, particularly if they were co-infected with HIV.

*I'm happy continuing with what I've got. The way [ID doctor] does my clinic, does the reviews, manages everything. She just tells me what I need to do, gives me the [diagnostic and referral] slips, understands my level of care and concern and she does all the work.*

### Keeping a check on liver health

Most participants with bleeding disorders had liver function tests two to four times a year.

- Some had liver function tests at the Haemophilia Centre or Infectious Diseases Clinic, which were sometimes interpreted at the unit where the blood was taken and sometimes referred to the hepatitis clinic for interpretation.
- A participant from a rural area had his liver function tests at the local pathology centre and had his results faxed to the metropolitan hepatitis clinic with an annual appointment at the clinic.
- Some also had an ultrasound or liver biopsies for a more detailed check of their liver health.

What did participants identify as barriers to monitoring liver health?

- No apparent impact of hepatitis C on their health
- Anger at the route of acquiring hepatitis C
- Haemophilia treatment is delivered to home or work so many who are busy with work see no reason to attend the hospital for haemophilia or hepatitis care unless they have severe bleeds or hepatitis symptoms.

*From the time I was diagnosed and did the initial testing, I never bothered about hep C for a long time. Everyone is telling you to do the right thing and get checked. It wasn't my problem. I didn't give it to myself, I didn't want to know about it... It wasn't affecting me, it wasn't making me sick... But now it is catching up and I've got to start doing the right thing.*

What would help people with bleeding disorders and hepatitis C to review their liver health? Many felt that there needed to be a trigger for the process.

- Moving to another city and obtaining a referral to a new haemophilia centre for factor treatment and the hepatitis clinic as well.
- Easy to lose track of haemophilia and hepatitis care needs when struggling to manage work and other life issues along with the complexities of their health care. Need assistance from the hospital with automated prompts.
- Parents thought that a personalised letter from the Haemophilia Centre would be more likely to be read and followed up.

*I'd like a prompt from the haemophilia treatment centre. Like, I haven't seen you for a while, it's time for you to come in and have blood tests for your ALT levels, maybe do half a dozen other things that I should be doing to keep an eye on it. That would be helpful. So that it pops up like a calendar reminder, or a letter.*

*I go to [doctor] at the ID clinic, and if I don't go to see [doctor], [doctor] starts ringing me at home.*

*Something from the haematologist or someone in authority in the hospital, in the [Haemophilia] Centre - a personal letter to these guys [people with bleeding disorders and hepatitis C]. I'm just wondering if something like that would work. It might interest them and make them think, well, someone does care, or is interested in us and maybe I should do something about it. [parent]*

Other participants felt they needed to be more proactive themselves.

*Taking that time. Keeping track of it. Taking a bigger interest in your own health in reference to hep C. But as we say, it's time and effort and sometimes we tend to forget. And if you are feeling fairly well, you put it aside, so you don't do it. But to help and make it better you should do it more often, have your bloods taken and see your liver specialist.*

## **Understanding hepatitis C and test results**

For most participants, coming to grips with medical information about hepatitis C was a struggle and accurate information from health professionals played an important role in making decisions about their health and lifestyle.

Many participants said they only had a minimal understanding of their hepatitis C test results and were very reliant on their specialist to explain their results to them.

*When you do see your liver specialist, they'll put [your test results] on the screen and tell you what it should be or where it's going and different levels. I don't really understand the medical side of it all, but take their word for it whether it's good, bad or indifferent. And then, looking for answers as to whether you should get to a point in doing something about it, like taking pegylated interferon, as the case may be.*

Some had previously gained their knowledge about hepatitis C from the media, which painted a bleak picture of their future:

*But I thought [hepatitis C] was going to kill me anyway. I got my knowledge out of the newspaper. And I thought that for a long time. It was actually [haemophilia social worker/counsellor] who said, no, that's not the case at all.*

### **Improving the health care experience**

What sort of hepatitis C services would work best for people with bleeding disorders affected by hepatitis C?

- A holistic and multidisciplinary approach to their care, particularly if they had arthritis and joint problems. Some found it difficult to travel to clinic, sometimes multiple times in a short period.
- Care to manage their hepatitis C and their bleeding disorder was complex and involved a range of services – eg, participants discussed appointments with physiotherapy, orthopaedics, podiatry, dentistry and occupational therapy as well as haemophilia, hepatitis and HIV services.
- Multiple appointments were problematic for people who were working.
- A program to review the person's health with haemophilia and hepatitis C comprehensively every 6 to 12 months would be useful.
- The ideal health care consultation was a multidisciplinary clinic with all their appointments in the one place on the one day.
- A home visit could be valuable for some to observe day-to-day problems, including mobility issues and mental health issues such as depression.

*I have to come here so often. I have to tell my work, sorry I've got another appointment, I'm going to put in a sick leave application. Two weeks later I'm in to see another person, and maybe twice in that week I've got an appointment. And it's so hard.*

*If you ask about the perfect consultation, I think these haemophiliacs, they're like sports cars. They need to come into the pitt lane... We get the arthritis, we get the hep C, we get the HIV, and those when they combine, create a mental health issue. And also there's counselling you need if you are in work. You are going to need some support to stay there. You need someone to help you get out of bed in the morning sometimes. You need rails in your bathroom. Other times you need other things...*

*I've been to the [clinic] in [other capital city] and they cover everything. You see orthopaedics, you see hep C, you see HIV, you see physiotherapists. It's not even a day, because it's all together in the one clinic. You go to one room, someone walks you through each of the rooms and explains to the next bloke or the next physiotherapist, and they arrange for if you want rails put in the [bathroom], the occupational therapist is there on the day, takes your details, you want non-slip tiles in your bath, see her then.*

Limits on public hospital services had become an issue for one group. This involved further travel to private specialists in other suburbs and was an added cost for the individual.

One health problem could lead to another. Some participants struggled to understand or keep up with their priority health needs. They were concerned that lack of communication between specialist services meant that some health problems were being missed.

*I lost my knee [through a joint infection] because I couldn't look after my feet. I'm sure that's when the infection started. And it's just not something that was ever considered [by the health professionals].*

### Health services feedback – last 12 months

As it was 12 months since HFA had commenced the needs assessment, participants were asked whether they had noticed any differences in hepatitis care in the last year. Responses included:

- New hepatitis C treatments on the horizon: *my doctor has mentioned that there are new [treatments] happening in other countries... and she will keep me informed as to whether they work or don't work or when they arrive.*
- Haemophilia social worker/counsellor positions vacant for some time at one Centre: *That's been a noticeable difference. It's good to have the Social Worker to talk with, even if it's not the Hep C Counsellor.*
- More activity in relation to hepatitis C in one Haemophilia Centre: *There's far far more being done about hepatitis C than I've ever really seen before. And I have seen quite a bit over the last few years.*
- Some had not noticed any differences.

## LIVING WITH HEPATITIS C

### Diagnosis

In the focus groups for the 'Double Whammy' Report in 2007, it was clear that that the experience of finding out they had hepatitis C had left a lasting impact on the participants. The Stage 3 focus groups in 2008 confirmed this and highlighted the importance of several factors.

- **Stage of life:** those who were older, already had girlfriends, a stable relationship or family and were more established at work and in their social circle did not experience as many difficulties as those who were adolescents and just beginning friendships and their education.
- **Understanding your hepatitis C status:** very little was known about hepatitis C when most were diagnosed and some assumed it would not be much of a problem. Some had misunderstood their status: this could be thinking they had hepatitis C when they were HCV PCR negative and no longer had the virus; or thinking they no longer had the virus and were just HCV antibody positive, but were still HCV PCR positive and did actually have hepatitis C.
- **Previous experience around HIV:** some were relieved to have hepatitis C rather than HIV. Where other family members had HIV, the diagnosis with hepatitis C had a more dramatic impact.
- **Knowledge about transmission:** concerns about transmitting hepatitis C to those around them added weight to the diagnosis. Some felt it was less of a problem when they understood and could explain to others how hepatitis C is transmitted. Others voiced concerns about sexual transmission and its impact on relationships. This was a particular concern for single men.

- **Impact on parents:** some participants spoke about the ongoing sense of responsibility and guilt that parents had felt that their dependent child had acquired hepatitis C while under their care. Sometimes parents felt their children had blamed them for their status at the time.

*My son was actually very ill when he was first [diagnosed with hepatitis C]. He was off school for quite a long while and that in itself was difficult, to go back to school, how do you explain why you've taken this period of time off school... He was very cranky with me, he couldn't understand how I could possibly have let this happen, why didn't I ask the right questions of the doctor before he was given the first infusion, and it just went on and on and on for many years. [parent]*

*Our boys were married when they found out [about their hepatitis C]. It followed AIDS, and they got through that, and then it was just one of those things. They happened to have a blood test and it showed up. And I don't think that it was any great big deal, because they really didn't know what the future was going to hold as far as what was happening. [parent]*

*I had an amazing reaction when I found out. I was [mid 30s] and that was before my brother had actually died [of HIV]. And they kept it all quiet in the family... So when I finally was told, it was just the offhand way that it was, in the early 90s by a nurse [at another health facility], oh, by the way, you know you are hep C positive. I was angry mostly because of the fear of spreading it to someone and of course I'm a single person, and I thought, well, I'm going to be buggered here.*

### **Psychological impact**

Participants raised a number of issues relating to the psychological impact of hepatitis C:

- Fear about their future with hepatitis C
- An added layer of vulnerability on top of managing the experience of growing up with haemophilia
- Some participants were relieved that they had acquired hepatitis C rather than HIV, unlike others with bleeding disorders.
- Some participants were co-infected with HIV and hepatitis C; one had a brother with haemophilia who acquired and died from HIV, which left a lasting impact on him
- Difficulties managing the silence about hepatitis C imposed after the HIV epidemic: fear of discrimination by families, instructions not to complain by health professionals.

*It's the constant worry of thinking, when this disease is going to kick in. We've heard that it was given a name in '88, but they say we may have had the virus for 30-40 years. You don't know whether you can make plans. You don't know how sick you are going to be a year from now, two years from now. You have to factor that in as well as...*

*I wonder which one's going to kill me first – HIV or hep C? I used to always think it was the HIV. Now you see more people get sick and die from hep C.*

*I might say, when I was a young kid, all the other boys were playing cricket and I couldn't play cricket. I had to make up my mind that I was going to do other things. Fortunately I got through it and I was right. But there was a period at that time when I was very, very confused about life and why I was even born. And I came to understand that it was up to me.*

*[How son with haemophilia managed diagnosis with hepatitis C]: I'd say initially denial, anger, frustration – that's from a teenage boy's point of view. But as he's matured, he's accepted a lot more and realised that he can bleed and lead an almost normal life, if he has a positive attitude. [parent]*

*I said to my doctor, I'm hep C positive. And he said, well, you haven't got HIV and you should be happy. I've been mentally ill... as a result of [brother] dying. Then to be told, well, you shouldn't worry about this so much, because you should thank God you haven't got HIV. Where are you? I've still got to wear this. But you can't argue that way. There's always someone worse off than you.*

## **Personal and family relationships**

How had hepatitis C affected the personal relationships of people with bleeding disorders?

All of the single men who participated in the focus groups were cautious about entering into relationships. They had been worried about the possibility of transmitting hepatitis C sexually and were relieved to find that hepatitis C was not classified as a sexually transmissible infection. However, they were also concerned about what they had to offer a partner in the future, with the combined impact of haemophilia, hepatitis C and, for some, HIV as well, as they grew older.

*Forgetting the infectious side of that, there's also the flip side of that, that you're opening yourself up to a relationship where they may have to become your primary caregiver further down the track.*

*I think our son always had a fear that maybe he had only so many years to work and try to get a good financial background happening. That meant not going into a relationship because why would you want to bring somebody else into your life who then you may not be able to support later on. So he started off to try and achieve the best he could to get a good financial basis going. And he's now given himself more confidence to then go into a relationship. [parent]*

Some with partners acknowledged the value of their partner's support.

*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.*

Was there any impact on family relationships? For sisters and brothers of those affected as children, knowing who to talk to at that time could be difficult.

*[Our daughter] took a bit of a back seat for a long while, just not sure how to deal with [her brother's hepatitis C diagnosis]. I don't think she discussed it with her friends necessarily for a while until she knew how to deal with it herself. At the time I think she felt a little bit left out because there was so much attention focussed on our son. I sometimes felt that she wanted to know more but didn't know quite who to ask for more information. Because she knew it was an emotional issue for everyone. [parent]*

## Working and finances

With the complexity of their health issues and the growing costs in managing from day-to-day, some participants felt they needed a financial advisor to “make ends meet”.

*Because if you have a chronic illness, you're forking out money all the time. It's not only hard to stay in work, the money that you get goes.*

How could the cost of living with hepatitis C be calculated? Participants thought this needed to factor in the costs related to the unreliability of their health:

- Health care appointments also included the costs of driving a car, parking, taxi fares. Travel costs from rural areas were higher and difficult to claim successfully through the present government reimbursement system
- Loss of income if they needed to take unpaid leave because they had used up all their sick leave at work
- Costs of vitamin supplements and non-prescription medications, particularly for pain management
- Pharmacy dispensing fees for hepatitis C treatment
- Expensive short-term stop-gaps, such as take-away food when fatigued or ill
- Working time lost due to symptoms, eg fatigue, diarrhoea
- Potential for hepatitis C treatment to cost a large amount if their treatment fell outside the approved circumstances for subsidisation by the Pharmaceutical Benefits Scheme
- Obtaining insurance was a problem.

*I had to use all my leave and then leave without pay. So, I'm at home, because I'm crook but there's a period of time where there's no money coming in. And that obviously affects paying off a mortgage or rent.*

As with the ‘Double Whammy’ Report focus groups, the issue of financial recompense was raised by participants. In one group some commented that they felt it was unjust that people who acquired HIV through the blood supply received financial compensation while those who were exposed to hepatitis C did not. Others thought the HIV compensation scheme had not been shared out fairly.

*There was no justice in it whatsoever... [Some] people that needed money and were sick got bugger all. Some didn't even live to see their [compensation payment].*

For some, hepatitis C symptoms interfered with their day-to-day functioning to a point where they were unable to sustain a full-time job.

- This could lead to a loss of status and earning capacity
- Need for a flexible workplace or flexible working hours to manage the complexity of health issues with hepatitis C and a bleeding disorder
- Partners' income sometimes essential for keeping the family unit afloat financially. This could also give flexibility to change career or cut back on working hours to manage symptoms.

*I couldn't have done what I did without my wife. My wife was the financial mainstay of our household for the last 20 years.*

*For me at the moment it would be being able to reduce my work commitments from five days to three, so I could take care of my health a bit.*

*From a haemophiliac point of view, I think I've been fortunate, I haven't had much. But from a hep C point of view, it's been a disaster. It's made me stop working at an early age. I would expect to be still working even now as an [artisan], which I was, but the lethargic feeling you can get when you get run down from hepatitis is pretty terrible. Now you imagine in a business situation and you get an urgent message [diarrhoea] and you're somewhere you can't find a toilet, it's terrible.*

*When you were [late thirties] and making a decent living, to get to the situation where you can't work at a fraction of the speed you were working at, like piecework, and you're just put on the minimum wage. You've just got to accept all that.*

With moderate or severe haemophilia, some had moved into careers which accommodated them and were less physically demanding. If they were established in their workplace when diagnosed and had few symptoms, some did not find problems once they had educated their workplace about the low risk of transmission.

### **Telling others**

Participants in the focus groups had spent some time considering how and when they would tell other people about their or their child's hepatitis C.

Their decisions were based on a lifetime of experiences, of living through the HIV epidemic and dealing with the reactions when they had told others about their haemophilia or hepatitis C. For some, these experiences caused them to be more open; others were more cautious. Some felt the decision to disclose had been taken out of their hands when hepatitis C was linked to haemophilia in the media.

*I tell nearly everyone I come in contact with, because I don't give a stuff what they think.*

*In the early days, my in-laws gave me my own mug with a chain on it and said, that's for you. They didn't want to get it mixed up with anyone else.*

*It's the education of the public to know what is a haemophiliac. What is hep C. It's usually just a headline. And half the time it's linked up with a paragraph on AIDS, and that's the damage doer, when you get it all linked up together.*

*I'm not shy of telling [co-workers] I have haemophilia, but in the press it was reported not that long ago that 99% of haemophiliacs have got hep C, so those who think about it long enough will work it out.*

In many cases there was a sense that telling others about their hepatitis C and their haemophilia made them vulnerable. This was particularly the case if they were not confident that some people, for example, those in their current workplace, would be supportive.

*People think hep B is hep C. They think a coffee cup is an issue, a kiss on the cheek is an issue. I got some weird responses at a wedding I was at on the weekend; they shied away from a kiss on the cheek - extended family. The point is they're not sure whether it's an issue. So I tell my friends. I don't tell people at work; I think it's suicide to tell people at work to be honest. I tell, obviously, lovers and family. My bookie I won't tell.*

Some feared losing their job:

*It wasn't so long ago that if someone said I'm a haemophiliac – oh, you've got 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. [parent]*

*The other thing is that [sons] don't want to take time off. They don't want to ask for time off, because they don't want to tell the boss that they've got haemophilia or hep C. [parent]*

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

With friendships, it was sometimes important to know that the friends could be trusted before disclosing to them. Some had painful experiences when friends had treated them badly after being told about their hepatitis C or haemophilia. This led to further isolation, and in some cases, depression.

*I think in our son's situation, he was more wary of who he would reveal anything to because he'd had incidences where it was used against him at university and even at school with people he thought he could trust. So that made him withdraw even more into himself at that stage... And that's when the depression started, in the late teenage years. He couldn't form relationships; people he thought he could trust with the information [about his hepatitis C] then threw it back at him or let the whole world know about it, then no one wanted to be around him. [parent]*

For single men, telling new partners was difficult. Some waited until the relationship was more definite before bringing it up.

*So at what point do you say, just before we go ahead and do this, by the way, I've got hepatitis C? It doesn't happen. I don't do it. If I'm still sleeping with someone a little way down the track, then you talk about the haemophilia. My thing has always been to play safe and knowing that it's a real outside chance that it's going to get transmitted, I don't say anything in those first one or two encounters.*

Over time some had become more skilled at knowing who to trust with the information about hepatitis C. Although this meant that they were unable to confide in some friends or relatives, there were other occasions where telling those they trusted gave them valuable support.

*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.*

*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, a bleeding disorder, 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.*

Some saw telling others about their hepatitis C and haemophilia as an opportunity to educate others in the community.

*I don't have any problems with [telling people about my hep C], obviously, because I'm older and I don't really mind. Also because 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.*

## **Discrimination**

Clearly, many of the participants had experienced discrimination related to hepatitis C and haemophilia in workplaces, and from friends and others in the community at various times in their life. At other times they had experienced support and compassion rather than discrimination. They had learned to be more judicious in choosing those to tell and some were more confident in their ability to educate those who were misinformed.

Many participants thought they were more likely to disclose if the person's safety was at risk, for example, if they injured themselves and had a large blood spill in a public place.

However, they had been surprised at the lack of knowledge about hepatitis C among doctors and in hospitals. In the past some had experienced health care workers refusing to care for them or to provide adequate or respectful care.

*And the nursing staff at the time knew nothing [about hepatitis C]. And the [catering staff] wouldn't even come into the room, they used to put my food trolley on the floor and kick it in with their foot. Because I had an open wound. My sister saw them do that, and she trotted off after the surgeon because he had just left the room and he had no idea what was happening and then he went and tore strips off the catering staff.*

## **Support**

What supports did the participants find helpful?

- Their partners, family, parents
- Haemophilia Centre staff
- Haemophilia social worker or counsellor
- Hepatitis C counsellor or social worker
- Haemophilia Foundation
- Haemophilia and hepatitis C newsletters and magazines
- Hepatitis C Council
- Men's groups
- Online discussion forums

*You do get really depressed when you get that awful feeling, how has this happened to me. But I was very lucky; I had a wife who was working in [health field]. She understood most of it, perhaps better than most people, and she was a huge help to me.*

*I also find these online things good too. I get a lot from chatting with other people in similar situations, so information in that way would be good too. Like an invite to hook me up with some of the other blokes for a [men's group] session.*

*I gather from just a few of us at this table that this sort of forum is beneficial. Because you bounce off each other, find out about each other. To sit down and talk about stuff that was important to us that we were scared to tell someone who wasn't someone who had a bleeding disorder or your cousin or your workmate that you'd love to have said*

*something about [your hepatitis C or haemophilia], but you couldn't. But you can with people of like situations.*

*I do find, as with that [Double Whammy] report and the [Hepatitis Council] magazine, just reminders, eat healthy, just to refocus when you are getting a bit reckless.*

Most of the single men said they lacked support and felt the burden of having to take care of themselves. Life was particularly isolated if they lived in rural areas or had mental health issues.

*If you are lucky enough to have a partner, even if it's a new thing, life is much better. And it's not easy for us blokes and a lot of us have to go without. It's a harsh reality if you don't have a partner.*

*I don't get any support. I'd like to get someone to help me build my house, finish off my shed, just three weeks' work. Simple basic things like that. I've always had to look after myself.*

Some found the focus groups to be helpful as the discussions were facilitated and focussed and there was an invitation to discuss their clinical issues which had been discouraged in their local men's group.

*And the mediator is someone who says, OK this is something that has come up over and over again, it's something that's not been dealt with, maybe we can actually progress with this. But it's people who have a common thread with hepatitis C, but it needs to be mediated because it can get off the track.*

## **CARERS**

All those who acquired hepatitis C from their plasma products are now adults. Parents in the focus groups described their role in caring for their adult children with hepatitis C as one of support, but thought that their influence was fairly limited.

*Just encourage regular checkups and positive attitudes. Support, always be there. [parent]*

Sometimes they approached their son's partner in the hope that their partner might persuade them to have a liver health check.

### **Carer support**

What were parents' needs for support? The participants felt that this could be variable.

Parents could be unsure who to confide in.

*And you don't know who to discuss things with because friends can become very wary. They're not sure – oh, should my child be playing with your child? And you don't want that to happen.*

They also had uncertainties about accessing professional or peer support.

*It's hard to know when to ask for help because you don't want to feel as though you're not coping. And it's then hard to know who then to go to for that help. Do you go to the Hep C Council, do you go to the Haemophilia Foundation, do you go to a clinic? Is it only you that's not coping? Is it you that can't get it?*

Some commented that the HIV experience had made peer support or gathering together to share experiences or ideas more unlikely.

*It's getting people together in the first instance to enable [peer support] to happen is very difficult. And the only time we had a resounding attendance at the meeting was when it was announced that HIV/AIDS was in the Australian blood stream. That was held here [public hospital] and [haematologist] delivered it and then after that everyone disappeared into the ether. And people would ring and say take my name off the list, they didn't want to see the word haemophilia associated with AIDS.*

They and their family had used some services and found them helpful: the state/territory Haemophilia Foundation, the Hepatitis C Council.

*I find the Foundation particularly – reading the newsletter and the information that comes from them – helpful. The Hep C Council has been particularly good for my son.*

## **INFORMATION FEEDBACK**

### **Information needs**

What other information or education about hepatitis C would be helpful?

- Holistic approaches to hepatitis C
- General good health and wellbeing
- What the future holds for someone with hepatitis C
- Hepatitis C genotypes
- The importance of having your liver health reviewed
- Available tests to review liver health, including types of liver biopsies, eg transjugular and through the abdomen
- Where to go for more information
- There is plenty of current information about hepatitis C from the Hepatitis C Council, HFA and the local Haemophilia Foundation

*Once you become aware that you have hepatitis C, you need to be additionally aware of what genotype you have so you can understand a little bit more about what the outlook is.*

Some participants remarked that they were uncertain about the types of tests available and some were unaware of advances in hepatitis C tests in the last few years.

*[Genotype] is actually something that's confused me. Because when the doctor explained to me, you've got a genotype that can be treated. It confused me a bit because he said, some genotypes can be treated and some can't, and the ones that can only have a certain success rate. But now I'm understanding that I have one that's treatable, but it's not 100% effective.*

*I just think for a lot of people with [bleeding disorders and hepatitis C], unless they can see it, [liver damage] has not happened to them. So maybe this new way of dealing with that [transjugular biopsy] should be advertised more readily so that they are aware that they can know a little bit more about where they're up to.*

How should people be kept up-to-date with information on hepatitis C?

- Send information by both mail and email to suit personal preferences
- Younger people don't read newsletters, even if they are on mailing lists
- Parents read newsletters: this keeps them informed about the latest on hepatitis C
- Few people go to information sessions as they are too busy
- Take care with confidentiality: information needs to arrive according to the individual's preference

*[Son] was so busy, he probably never opened [the Foundation newsletter]. It went straight in the bin. [parent]*

*[Updated information about hepatitis C] could go in the newsletter. Because we read the newsletter. Mums read the newsletter, mum and dads, maybe not dads, but mums do. [parent]*

*You could have patients who would be a bit annoyed if [hepatitis C information] popped up on their screen, whether they wanted their wife to know or their mum and dad or some kids running around the house. [parent]*

### **Feedback on hepatitis C information**

Some participants had noticed an increase in hepatitis C information in the last 12 months. They had noticed or accessed the information

- In the hepatitis clinic
- From the Haemophilia Centre
- From the Hepatitis C Council
- In Haemophilia Foundation newsletters
- In the media

*I'd say there's a lot more information about hepatitis C being printed all the time. I don't collect it, but I see it in the waiting room for the hep C clinic. And I think that's great.*

*The Canadian haemophilia magazine give quite a bit of currency to hep C. But theirs is more on compensation, bad blood and everything else.*

Others had noticed no difference in the amount of information available recently.

### **Feedback on HFA hepatitis C publications**

Participants were asked for comments on recent HFA publications about hepatitis C.

Hepatitis C information sheet no. 1

- Some had seen it and read it  
*A lot of it's just common sense.  
A couple of pictures of people would be good.*
- Some thought it was useful for people just starting to learn about hepatitis C, either people with bleeding disorders or others such as partners/family

- Some were unsure whether they had seen it or read it. Most from one state thought they had not seen it.

#### HFA Hepatitis C Needs Assessment 'Double Whammy' Report

- Nearly all had seen it
- Some thought that it was too big, too complicated
- Others enjoyed the personal stories and the evidence that HFA was taking action on hepatitis C
- Some thought a simplified version would be better and had read the summary
- Some had not noticed the summary
- Most felt the recommendations were good, although some declined to comment

*I would rather it came in 3 separate volumes so you had time to pick out what you wanted to read about it, just the sheer thing of having to pick it up and flick through it.*

*I loved it. I loved the testimonies, I found they helped me, because I could see other blokes were going through some difficulty, in a lot of cases a lot more difficulty than I was even and I found that really bolstering.*

*For someone starting out to learn about their hep C, that is too daunting. I read through [the Report] from cover to cover. Read through it on the toilet, that was fine. Picking this up and flicking through it. Just the mindset of this is my illness, how many of these things am I going to go through. You can't start with that.*

*[The Report] was an eye-opener for me. I appreciated actually seeing some of the harsh things that were in it. It made me aware that hey, I've had a similar experience.*

What additional comments did they have?

- They would like to see further action in response to the Senate Inquiry recommendations on financial assistance
- They would like to hear more positive stories about managing hepatitis C treatment

*It was nice to know that people were gathering information and were maybe preparing again to have another push and say in that Senate Committee that happened, you guys admitted that these guys were in a bad way because of some things that could have been prevented and you promised to help them. You said, no compensation, but we're going to help these people and so far, I've seen sweet FA... So this has been encouraging because I think this is the start of the process, but I think it has been a while now [since the Senate Inquiry recommendations] and I think a lot of our people are suffering. It would be great to see the fruit of that promise coming down - we're going to provide assistance for these people.*

*We should hear more of these positive things that people actually do to get over the side-effects.*

*When [hepatitis C specialist] gets up on the podium and says there is a cure for hepatitis C, after we've been living with hepatitis C for a long time - that really sparks up interest. And now of course with the effectiveness of some of the treatments, there are more and more success stories, so we should hear more of them.*

## PRIORITIES

What were their priorities in relation to hepatitis C?

Some felt that health and wellbeing issues were most important:

- Knowing more about their current hepatitis C status
- Improving their liver health, eg through a liver transplant, so that hepatitis C was no longer life-threatening
- Successful hepatitis C treatment
- Proactive hepatitis C care from the hospital
- Enjoying life with their new partner

*I don't fear death but I'd like to not have to die of a terrible liver disease that's going to be a bad quality of death. A lot has got to do with the way I feel about the living rather than the dying. But it would be a shame if I were to die of liver disease rather than something that is perhaps haemophilia-related.*

*I'd just like to think that I could manage hepatitis C with the help of the people at the [public hospital] and that when I'm in dire need, they'll look after me.*

*I should follow up and get more results on where I am situated with hep C. What my health status is with hep C. But I'm quite healthy at present, but that doesn't mean I shouldn't follow up and know where I'm at.*

For participants, health and finances were dependent on each other. Some felt that maintaining their current health as long as possible was a priority to give them the best options financially. Others thought that financial assistance or recompense was the most pressing need. This would help people who are currently struggling to manage financially and would make treatment affordable.

*For me, just to try and stop any decline into worse health, to try and maintain where I'm at would be great, I'd be very happy with that. And to hopefully stay productive. What would be great would be to stay in work long enough to pay off my flat so I've got somewhere to live when I do need to get out of the workforce.*

*I think the priority is to get financial – to make the interferon treatment affordable for members. I'm talking about recompense to enable a guy to take the time off work. The guy's got to pay a mortgage, how does he live on \$280 or \$300 a week. How is he going to educate his children? And his wife can't go to work, and if she's got to go to work, who looks after the children? It's endless. That's the biggest single problem that the guys face... There is an obvious alternative. Don't have the treatment. That's their choice. Can I afford it? Yes or no. Life threatening? Yes, I need to have it. How will I finance it? [parent]*

## CONSULTATION WITH HAEMOPHILIA FOUNDATIONS

Consultation to follow up the 2007 Needs Assessment was conducted with Haemophilia Foundations in two states/territories alongside the focus groups.

### Health issues and treatment

- **Long-term infection:** have had hepatitis C for a long time. Health issues relating to hepatitis C are changing as people age and disease progresses.
- **Complexity of health issues:** increase as people grow older. If hepatitis C was under control, would make it easier to deal with haemophilia
- **Treatment uptake:** not sure how many people are taking up treatment if appropriate. Some may be used to managing it and unsure about taking on treatment. Possibly some misunderstandings about the nature of hepatitis C. Sense that there is a lack of action among some people with bleeding disorders about their hepatitis C care.

### Health care services

- **Access to hepatitis C treatment:** Relatively easy access to high quality treatment in major cities. Variability in hepatitis clinic environment and resourcing between cities and states. Access to treatment in rural/regional areas more difficult – not enough hepatitis C specialists. Better to come to major city. Co-infection care more co-ordinated.

### Support

- **Professional support:** not available recently in one state as Haemophilia Social Worker/Counsellor positions vacant. In other state, always available if requested. Is very important during treatment but sometimes hard to access.
- **Barriers to seeking support:** culture of stoicism, being independent, self-sufficient as a way to manage haemophilia. Tend to try to work around hepatitis C rather than seek help. Needs with bleeding disorder always changing, have to adapt to many situations, can become overwhelming. Extra complications if HIV co-infected.
- **Other supports:** reliant on family, friends, partners
- **Rural/regional areas:** difficulties with confidentiality, access to support

### Financial issues

- Length of time on treatment is a barrier. Difficult financially. May have to take time off work and are vulnerable workwise. Earning capacity already low and cost of living is high. Employment opportunities not as wide as others. Since HIV experience, men are wary of disclosing haemophilia to employers; it is then doubly hard to raise hepatitis C, as would have to disclose haemophilia as well. Fear discrimination.

### Other issues

- **Being older:** difficulty of dealing with hepatitis C along with everything else. Hepatitis C can take a back seat to other conditions or be masked by other conditions. More likely to have liver damage, although some well. Become more fragile with haemophilia.
- **Being younger:** relationships, disclosure, finances. Need education on hepatitis C, also on diet and exercise.
- **Being female:** not much known. Perhaps may feel like the odd one out because information and services more geared to the man with haemophilia.

## CONSULTATION WITH HEALTH PROFESSIONALS

In-depth consultation was held with haemophilia and hepatitis health professionals in two states/territories to accompany the focus groups.

In other states/territories, haemophilia health professionals were consulted about changes in the last 12 months and feedback on HFA hepatitis C publications.

### Health issues and care

- **Health status:** Haemophilia Centres continue to report seeing increasing numbers of older patients (30 yrs and older) whose liver health is deteriorating. A few people in each state are progressing to end stage liver disease; some are on liver transplant lists. Of the younger patients (in their late teens or early 20s), some are more likely to no longer have hepatitis C as they cleared it naturally or had successful treatment when they were young. Those in their 20s seem less likely to have major hepatitis C symptoms as yet.
- **Monitoring:** In the focus groups states/territories hepatitis clinics perceive that Haemophilia Centres now have a better understanding of hepatitis C monitoring and are providing monitoring to more patients. This is confirmed by the Haemophilia Centres, although they are concerned about the patients they don't see and have been unable to review their hepatitis C status.

Nationally: Haemophilia Centres report that they have a greater awareness of reviewing the hepatitis C status of their patients where possible. In some states the Centres are undertaking a systematic review. Others review patients when they have the opportunity, eg during a hospital visit, particularly where the Centre deals with large patient numbers.

- **Treatment uptake:** In the focus groups states/territories hepatitis clinics have not reported a higher uptake of hepatitis C treatment by people with bleeding disorders in the last 12 months, although the Foundations, focus groups and Haemophilia Centres reported that more people are thinking and talking about treatment. The clinics continue to be concerned for the liver health of the patients who are not engaged with the Haemophilia Centre.

Nationally: Haemophilia Centres note that patients in their 20s are more focussed on managing their lifestyle concerns, establishing themselves in relationships and careers, and are generally not considering treatment at the moment as they are too busy. One Centre noted that people in this age group usually do not prioritise treatment unless they are experiencing major symptoms. They thought this was due to concerns about side-effects and managing the length of treatment, which could be from 6 -18 months, particularly as they are not well-established financially. However, treatment is more likely to be successful when the person is younger.

Several Centres commented on a renewed interest in hepatitis C treatment among their patients with the prominence of hepatitis C over the last 12 months, especially if they hear personal stories about the new treatment regimes, eg at the Haemophilia Conference, in Haemophilia Foundation publications or from others who have completed treatment. This includes people who have previously not been interested in treatment, eg those who have genotype 1, which usually is less responsive to

treatment than genotype 3, or have had unsuccessful treatment with interferon monotherapy.

- **Patient contact:** Some Centres report that they do not have contact or responses to review letters from many patients as home delivery of factor means they no longer need to attend the Centre. Some Centres no longer have clinics and maintain contact with patients via phone or email. The Centres commented on the impact of the loss of “waiting room discussions” to the informal support and information in the bleeding disorders community. Most Centres have lost contact with a significant number of people, particularly those with mild or moderate haemophilia, and do not have information about their current hepatitis C status. If the person’s haemophilia and hepatitis C is being managed by their GP, the GP may have referred them to a hepatitis clinic but the Centre would have no communication about this unless their GP has set up an Enhanced Primary Care multidisciplinary team arrangement with the haematologist. Centres are concerned that some people may not be having their liver health monitored.

In other forums, other Centres have reported having more contact with patients because they are in touch to order their home deliveries. Some Centres maintain a regular multidisciplinary haemophilia clinic for adults; one includes an informal drop-in support group in an adjoining room led by the local Haemophilia Foundation and the Haemophilia Social Worker/Counsellor, which provides a forum for informal discussion about people’s health and wellbeing and the latest on monitoring and treatments.

- **Communication between hospital departments/co-ordination of care:** Haemophilia Social Workers/Counsellors are vital in providing networking and communication between hepatitis clinics and Haemophilia Centres. In most states except one there is little routine communication. This was brought home in one state/territory where the positions were unfilled for some time. During this period there was very little information flow from the hepatitis clinic.

If the person’s haemophilia is well-controlled and they do not need to attend the Haemophilia Centre often, their hepatitis C care may be lost to follow-up. There is usually no follow up at the hepatitis clinic after hepatitis C treatment failure. Some Haemophilia Centres have a proactive program to follow up monitoring and treatment results and review patients with hepatitis C regularly, but this is resource intensive as a staff member needs to consult individual medical files and research and co-ordinate the relevant results.

One Centre suggested that with the current system the person could decide which clinic or doctor is responsible for monitoring their hepatitis C care and let the other members of their care team know who this is. This information could be part of their comprehensive care plan.

- **Complexity of care needs:** People with bleeding disorders and hepatitis C can be overwhelmed by the complexities of their health problems, especially if they are also co-infected with HIV. With mobility problems and hepatitis C symptoms, let alone HIV, they can find it too difficult to manage all of their health care issues. They deal with the most pressing and others they let slip, leading to further health problems for some. This highlights the importance of a comprehensive care model which includes support for managing multiple health problems and negotiating the health system and social services.

## Support and psychological/social issues

- **Providing support:** Men with bleeding disorders and hepatitis C rarely seek support directly and many are wary of acknowledging health problems or mental health issues. Health professionals need to build a relationship of trust over time to work effectively with them. Usually this involves informal catch-ups when people have come into the hospital for other reasons, eg during a hospital stay as an inpatient or when they are visiting the Haemophilia Centre for a review or health problem or to pick up product.

Some men would like to discuss their health with each other but feel they lack the proper environment as they no longer see each other at the Haemophilia Centre and their men's groups have focussed on social activities. Weekend workshops and support groups can work well if well-facilitated and safe environments for discussion are provided.

Informal discussion groups, such as the drop-in group for people waiting for their Haemophilia Clinic appointment (see **Patient contact** above), can be very effective in providing support and a sense of connection to the bleeding disorders community.

- **Managing unsuccessful or unavailable treatment:** Support and care for people who currently cannot have hepatitis C treatment due to other health problems or whose hepatitis C treatment was unsuccessful are becoming increasingly important. Existing mental health issues and issues resulting from treatment continue to be a problem and people require support that is provided sensitively. Some do not want to consider treatment if it involves a psychiatric assessment.
- **Impact of lifestyle issues:** concerns about potential financial hardship are preventing many people from considering treatment at a time when treatment is more likely to be successful. Difficult for people to take the time off work to attend hepatitis clinics when waiting to see specialist and have blood tests can take several hours. Evening clinics unavailable in some areas.
- **Disclosure:** people need step-by-step assistance with how to disclose. There also needs to be information targeted at partners.

## Co-infection

- **Hepatitis C treatment:** Some people are now stable with their HIV drugs and could consider hepatitis C treatment. Some are also looking at IVF to have children, which is not compatible with hepatitis C treatment due to treatment side-effects. Others struggling to gain control of HIV. Treatment is less likely to be successful than if mono-infected with hepatitis C, but some have had successful treatment.
- **Hepatitis C management:** usually people who are co-infected have their hepatitis C and HIV managed by the Infectious Diseases/Immunology Unit. Most have their liver health reviewed carefully if they attend the clinic. Most units hold regular multidisciplinary meetings with Haemophilia Centre about individual patients. Some people do not attend HIV/co-infection clinics, particularly those who do not believe HIV causes AIDS.

## Rural/regional/remote

- **Hepatitis clinic services:** one state has directed extra resources for hepatitis nurses in regional/remote areas. This has enabled haemophilia nurses and social worker to facilitate the introduction of the person to the hepatitis clinic and there is

now a contact at the clinic to reinforce and support the person. In other states there is limited access to hepatitis services. It is unknown how much people know about their liver health and hepatitis care. Some people come to the major city to access hepatitis care.

- **Attitude to care and treatment:** people tend to be more self-sufficient in remote areas and prefer to manage with less support. Will seek treatment when see that they need to. Often managed by GP; otherwise by haematologist.
- **Financial issues:** travel to major centres for treatment and care can be expensive. People have difficulty managing the cost. Reimbursement processes have been complicated in the past.
- **Support:** difficult to access in rural/regional areas.

#### **Paediatric centres**

- Do not currently have any children or young adults with hepatitis C. Children from countries where hepatitis C is common are screened before they come to Australia and none so far have hepatitis C. Can access relevant information on hepatitis C from the adult centres or from the Hepatitis Council, if needed.

## **FEEDBACK:**

### **'DOUBLE WHAMMY' REPORT AND HFA HEPATITIS C PUBLICATIONS**

HFA sought formal feedback on the needs assessment report from the community and from health professionals through

- An anonymous community feedback form ("*Your Say*")
- Meetings/teleconferences with haemophilia health professional groups (see **Outcomes**).

Community feedback form ("*Your Say*")

There was a low response from the community to the formal feedback process.

- 7 feedback forms returned by 18 April, 1 in May 2008
- 7 agreed or agreed strongly that their experiences were like those in the Report; 1 did not respond
- 7 agreed or agreed strongly that the current recommendations will meet the needs of people with bleeding disorders affected by hepatitis C; 1 didn't know
- 6 made additional comments. These included
  - Reading other people's stories helped to identify symptoms not previously associated with hepatitis C
  - Need more information for people who are HCV antibody positive but do not have symptoms
  - Need more information on preventing the spread of infection at home, around food
  - Helpful if HFA provided a secure chat room on web site to share feelings and experiences
  - Difficult to co-ordinate haemophilia needs in mainstream services when not at Haemophilia Centre. Haemophilia Centre access difficult for some, but not using Haemophilia Centre can result in poor care.
  - Disability and pain associated with haemophilia and hepatitis C is the major problem. Need for permanent full-time carer and supported accommodation with rehabilitation facilities at a relatively young age, especially if single.
  - Hepatitis C has had a great psychological impact. Anger about the route of acquisition, silence in the family and among others due to their experiences of the HIV epidemic, and being informed casually when it was a serious issue have all left their mark
  - Physical and emotional pain caused by hepatitis C is frustrating and difficult to make real through a report; leaves you feeling isolated
  - Have been living in difficult financial circumstances as a result of hepatitis C acquired through the blood supply. Would like to see acknowledgement and support from government, but have no confidence in anything changing to improve quality of life.

#### **Informal feedback on '*Double Whammy*' Report**

Haemophilia health professionals were also asked about any informal community comments on the report during the evaluation consultation.

There has been some feedback from Haemophilia Social Workers/Counsellors that members mostly agreed with the Report. Some members thought that the people in the focus groups had probably understated how angry they really were. Others have come forward to tell more positive stories about treatment. Reading about other people's experiences had helped some members to see that they were not alone. They had looked at their liver health again and reconsidered treatment to improve their quality of life.

HFA intentionally included personal stories in the Report in the hope it would assist people feeling isolated, and the feedback confirms how important personal stories are. In response, HFA has included some personal stories from the “*Double Whammy*” Report in *National Haemophilia*. Personal accounts have also become a major part of information fact sheets, both in print and on the web site.

#### **Summary of feedback on *Double Whammy* Report**

- Most people noticed the Report and the title caught their interest. Some read it, some dip into it at times. Some read the summary instead, although many did not notice it as it was placed inside cover of report. Some felt it was too large for them, although they understood its use as evidence for government and health professionals.
- People were pleased to see action on hepatitis C and a forward plan.
- Some people have had more positive experiences with hepatitis C and treatment than reported in the *Double Whammy* report. Hearing about these experiences as well would give hope to those considering treatment.
- Otherwise experiences were largely similar, although perhaps the level of anger understated. Recommendations appropriate. The personal stories were powerful and important: people don't feel so alone and some were encouraged by them to take action on their health. Others thought the personal stories might be too daunting at first for someone coming to terms with their hepatitis C.
- Would be good to recycle personal stories in bite size pieces, eg by topic or to illustrate fact sheets. Promote or re-release summary as some people overlooked it.

#### **Other HFA hepatitis C publications**

Haemophilia health professionals and Haemophilia Foundations were also asked for any feedback on other HFA hepatitis C publications as part of the evaluation.

- **Hepatitis C information booklet:** helpful and readable information; concise. Need more information on treatment options, being comfortable with your medical practitioner
- **Hepatitis C updates:** good format and information, especially *Understanding Your Test Results*. Liked personal stories; need more positive stories for treatment. Need to promote as many people missed them due to timing of release just prior to World Haemophilia Congress.

Further community feedback on HFA publications is included in the Focus Groups section of this report.

## OUTCOMES

### **'Double Whammy' Report distribution**

The HFA needs assessment 'Double whammy' report was completed and released at the Haemophilia Conference in October 2007.

The report has been distributed to:

- The bleeding disorders community through mailouts
- Haemophilia Foundation Council delegates and Committee members
- Participants at the Haemophilia Conference
- Haemophilia health professionals
- The HFA Hepatitis C Advisory Group
- Hepatitis C Councils who participated in the consultation
- PLWHA organizations who participated in the consultation
- Other key stakeholders

The community mailout also included an 8-page summary of the report.

The report and the summary are also available on the HFA web site.

### **HFA Hepatitis C Working Party**

Immediately after the release of the Needs Assessment Report, HFA Council established the HFA Hepatitis C Working Party. This Group reviewed and prioritised the recommendations in the Report and prepared a plan to implement the recommendations.

### **Access to hepatitis C retreatment**

HFA made a submission to the Pharmaceutical Benefits Advisory Committee (PBAC) on 11 April 2008 recommending that the criteria excluding people who have previously had interferon-based treatment from subsidised retreatment be reviewed and that hepatitis centres providing treatment should also be required to provide an education and support package for patients and their partners/carers. A copy was also sent to Professor Robert Batey from the Hepatitis Sub-Committee of the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis at his request.

This submission was considered at the PBAC meeting on 9-11 July 2008. HFA was advised in August 2008 that PBAC had recommended retreatment for hepatitis C should be covered by a government subsidy under the Pharmaceutical Benefits Scheme (PBS). PBS listing will take place as of 1 December 2008. PBAC has referred the HFA recommendations about a support and education package to specialists providing hepatitis C treatment.

### **Haemophilia health professionals**

To follow up the Report, the co-chairs of the Haemophilia Nurses' and Social Workers/Counsellors' Groups were consulted for feedback and further action. On their recommendation, there were further discussions with their Professional Groups. These discussions highlighted:

- People with bleeding disorders' experience of hepatitis C is variable and both Haemophilia Foundations and Haemophilia Centres need to deal with it in a multi-faceted way, trying a range of approaches
- Importance of a holistic approach

- Informal support alongside Haemophilia Clinics (tea/coffee and chat) with Haemophilia Social Worker/Counsellor and Haemophilia Foundation representative has been very effective in raising awareness of hepatitis C issues and promoting action on health without intimidating patients
- Resources: A4 fact sheets on specific disclosure/discrimination issues would be more useful than booklets; also a general information sheet on financial management; general resources to support counselling and specific advice
- Patient funding for transport/travel to appointments is inadequate, particularly for those in rural and remote areas, and is a serious barrier to hepatitis C monitoring and treatment.

### **Resources and education**

As part of Hepatitis Awareness Week, HFA released two brief information updates:

- Understanding your hepatitis C test results
- Hepatitis C Treatment Snapshot

These included personal stories, as advised by the community advisory group, and were targeted at people who use the internet for information. They were launched by the HFA e-news bulletin and are available on the HFA web site.

In response to Report feedback, a series of newsletter articles were developed on particular topics using personal stories from the Report. These have been printed in *National Haemophilia* and have been circulated to state/territory Foundations for reprinting in their newsletters.

HFA has made funding applications for:

- Discrimination and disclosure booklets
- Web site information on hepatitis C (less text, high quality graphics)
- Revision of Hepatitis C information booklet/series of updates on priority topics
- National wellbeing workshop – development and pilot

### **Insurance, superannuation and financial issues**

HFA Board is addressing the approach HFA will take in relation to members who require financial support.

Australian insurance law assumes that companies will use actuarial advice (ie, statistically, what are the risks involved in insuring this person?) to develop policies and premiums and allows discrimination where this is seen to be reasonable. Having a pre-existing medical condition such as haemophilia as well as a blood borne virus may severely impact on access to insurance.

- HFA has sought expert advice in this difficult area.
- John Berrill from Maurice Blackburn has developed a national guide on insurance and superannuation for people with bleeding disorders and has been working with haemophilia social workers and counsellors nationally. The guide is available on the HFA web site.

### **Community responses to Report/awareness**

There have been several radio segments on the Report:

- Radio interview - 3RPH (Vision Australia) 15/1/08 – Guest of the week (national)
- Radio interview - HepChat 3CR –21/2/08 – also available in podcast
- Segment on ABC Radio Morning Show (Brisbane) – 31/7/08

### **Health professional awareness**

In the follow-up to the needs assessment, hepatitis health professionals and medical education groups were consulted for feedback and noted that many hepatitis health professionals are not aware of the issues for people with bleeding disorders and hepatitis C. A number of opportunities have been taken to raise awareness of these issues:

- Poster and abstract at the National Symposium on Hepatitis B and C, held at St. Vincent's Hospital in Melbourne in November 2007 for hepatitis C specialists and GPs from around Australia
- HFA's hepatitis C publications have been included in the ASHM Viral Hepatitis Models of Care database, which is a resource used by health professionals and community workers specialising in hepatitis
- Poster presentation for the USA National Hemophilia Foundation conference in November 2008
- Presentation at the national Viral Hepatitis Conference in Brisbane in October 2008 for hepatitis health professionals and community workers