



HAEMOPHILIA FOUNDATION AUSTRALIA

National Hepatitis C Needs Assessment Report

“A double whammy”:
“A double whammy”:
living with a bleeding
disorder and hepatitis C

October 2007

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EXECUTIVE SUMMARY

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 people cleared the virus naturally, others through antiviral treatment. Some were co-infected with hepatitis C and HIV, others also with hepatitis B. Most have now been living with hepatitis C for 20 to 30 years or more.

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 affected more than one member of the same family. Many had a negative experience of being told they had hepatitis C and in some cases found out their diagnosis accidentally some years later. Some were angry at the way they became infected. They were dependent on blood products to survive and no longer felt able to trust the safety of their blood products. They felt at the mercy of economic decisions by health bureaucrats. Some believed that an acknowledgement by authorities that it was a health system error would help people with bleeding disorders deal with their anger.

The health impact of hepatitis C varied:

- Some people did not have symptoms and felt that hepatitis C was not affecting them
- 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. This often made their level of disability unmanageable by the age of 35-40 years.

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 know their current hepatitis C or liver health status. The HFA hepatitis C member survey in 2003 confirmed that some people did not know or understand their health in relation to 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 make regular contact with the Foundations or Haemophilia Centres, might not realise their liver health was deteriorating and miss an opportunity to have hepatitis C treatment.

Many Haemophilia Centres were working actively on hepatitis C and modifying their review procedures. Some Centres had developed systematic processes to follow up a hepatitis C review with all their patients. Some health services reported being under-resourced. There were problems tracking patients and scheduling timely appointments in some hepatitis clinics. In general people with bleeding disorders 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 or not seeking treatment. This could have serious consequences if they had liver damage.

While some people with bleeding disorders had undertaken hepatitis C treatment successfully, 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 but others would not have treatment again until the success rates improved. Hepatitis C treatment takes between 6 to 12 months. 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 could have adequate support. Others did not have treatment options at present, as current treatments had not been successful or their liver disease was too advanced.

Access to subsidised treatment could be limited for people with bleeding disorders, especially for those who had unsuccessful treatment with earlier less effective regimes. Under current Pharmaceutical Benefits Scheme Section 100 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.

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 partners and carers. The lack of co-ordination between haemophilia and hepatitis appointments and services created extra expense and difficulties for people who were working or had mobility and pain issues or were from rural or regional areas. Among older people, the combined disability issues of their bleeding disorder and hepatitis C meant that many required supported care and accommodation.

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 limited their own working hours to provide this support. This could put stress on the family and carers often felt very isolated.

For those who did not have symptoms, hepatitis C made little difference to their work or their finances unless they decided to have treatment. With symptoms many had to reduce or stop work from their late 30s. Treatment caused big disruptions in their working life. Many were unable to obtain personal, health, travel, income and mortgage protection insurance. This often led to great financial hardship for them and their families. Partners often had to return to the workforce to maintain the family income.

Most people with bleeding disorders had not experienced much hepatitis C-related discrimination, but most did not tell many people about their hepatitis C status. 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.

The complexity of issues and concerns about privacy meant that there was a great need for confidential counselling and support among people with bleeding disorders and hepatitis and their partners and families. Peer support with others with bleeding disorders and hepatitis C was important to manage their feelings of isolation. Support was also important for partners and carers.

There was an identified need for 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.

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

RECOMMENDATIONS

Consumer participation

1. That people with bleeding disorders are/continue to be represented in advisory groups relating to health policy, services, including aged care services, and public health strategies for hepatitis C, HIV/HCV co-infection and blood supply issues that may impact on them.

Information and education

2. That Haemophilia Foundation Australia collaborates with Haemophilia Centres and state/territory Haemophilia Foundations in a campaign to raise awareness among people with bleeding disorders and hepatitis C about the need to keep a regular check on their liver health and improvements in treatments. This should be targeted at those who are not in regular contact with the Haemophilia Centre or Haemophilia Foundations.
3. That Haemophilia Foundations and haemophilia health professionals continue to work with Hepatitis C Councils to promote and distribute relevant Hepatitis C Council resources through the bleeding disorder community networks and in Haemophilia Centres
4. That Haemophilia Foundation Australia develop or source bleeding disorder specific information on hepatitis C, liver health, treatment, transmission in the home, support and services available, ageing, mental health, relationships, disclosure, and financial management.
5. That this information should be made available to people with bleeding disorders in a variety of accessible formats, such as printed leaflets, newsletters, web-based information, interactive web sites and emails.
6. That education for men with bleeding disorders and hepatitis C is developed using a “men’s health” approach, involving activities that interest them and with a focus on wellbeing.
7. That Haemophilia Foundation Australia should investigate further the education and information needs of women with haemophilia or von Willebrand disorder, carrying the haemophilia gene or as carers.
8. That Australian governments support a national media campaign to raise awareness about hepatitis C in the general community and prevent stigma and discrimination
9. 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.

Treatment

10. That the Pharmaceutical Benefits Scheme Section 100 requirement that a patient has had no previous interferon-based treatment to enable them to receive subsidised hepatitis C treatment should be removed. Subsidised treatment should be available to all patients recommended by doctors who are S100 hepatitis C treatment prescribers. The recommendation should be a clinical decision based on benefit to the patient.
11. That Australian national and state and territory governments increase resourcing to hepatitis services to ensure each service is able to provide adequate medical, nursing and psychosocial support to people who are undergoing hepatitis C monitoring and treatment.
12. That hepatitis and haemophilia services collaborate to ensure that preparation for people with bleeding disorders undergoing treatment includes
 - Education and support for the person and their partner/carer/family
 - Guidance on how to use support services, including counselling
 - Linking to one-on-one peer support with another person with a bleeding disorder who has undertaken treatment, if desired.
13. That hepatitis services ensure that medical, nursing and psychosocial support continues after treatment to manage treatment outcomes and ongoing side-effects.

Services and support

14. That Australian governments provide greater resourcing for haemophilia and hepatitis services to enable for people with bleeding disorders and hepatitis C
 - Patient follow-up, particularly for those who do not communicate regularly with the Haemophilia Centre or hepatitis clinic
 - Regular monitoring
 - Timely access to treatment
 - Routine patient education and information on hepatitis C
 - Communication with other health care providers providing the patient's regular care on the patient's hepatitis C status and health
 - Collaboration with other specialist health services nationally to develop best practice models of care
15. That Australian governments increase resourcing for haemophilia services to provide psychosocial services for people with bleeding disorders and hepatitis C. Services include
 - Helping the individual to manage the complexity of their medical, social and psychological issues
 - Directing and linking the individual into social and financial services and assistance
16. That Australian national and state and territory governments prioritise initiatives to develop hepatitis C services and care in rural and regional areas as a matter of urgency
17. That haemophilia and hepatitis health services follow a comprehensive care model for people with bleeding disorders and hepatitis C. This should involve
 - Integrating health review and treatment information relating to the individual's bleeding disorder and hepatitis

- Co-ordinating the individual's care, eg holding a hepatitis clinic at the Haemophilia Centre; scheduling all reviews for the same day
18. That health providers ensure that people with bleeding disorders with hepatitis C are routinely involved in monitoring their own health. This would include developing patient education strategies to support this process, for example, regular discussions about their progress and providing printed test results with an explanation from the nurse or doctor so that they could keep a record of their own liver health.
 19. That haemophilia social worker/counsellors and Haemophilia Foundations work together to develop peer support networks and activities for people with bleeding disorders and hepatitis C. This could include
 - One-to-one support via telephone or email, especially for treatment, eg formal or informal "buddying" systems
 - Peer support groups that meet informally
 - Other people's stories in newsletter articles or on the Internet
 20. That haemophilia social worker/counsellors and Haemophilia Foundations investigate options for carer support.

Financial assistance

21. That recommendation 6 of the Senate Inquiry into hepatitis C and the blood supply in Australia be implemented. This was to establish a national post-transfusion hepatitis C committee to
 - Deliver an apology to those who have acquired hepatitis C through the blood supply
 - Establish an effective Lookback program
 - Improve service delivery sensitive to the needs of people who have acquired hepatitis C through blood and blood products
 - Establish and manage a fund to provide financial assistance for costs not covered through existing services to people who have acquired hepatitis C through blood and blood products¹
22. In addition to the Senate Committee's recommendations, that this financial assistance should include
 - Consideration of the impact of hepatitis C on the individual in the future
 - Income support for those who experience loss of income due to hepatitis C, or for their partners/families for the financial loss if that person has died
 - Income support for carers who experience loss of income to care for the person with hepatitis C
 - Health care card access and prioritised public housing
 - Other psychosocial support including grief and loss counselling
 - Ensuring that life, health, travel, income and mortgage protection insurance is available to people with bleeding disorders and providing financial assistance to make the premiums equivalent to healthy people in the general community

Further areas for investigation

23. 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
-

1. “Recommendation 6

6.134 That a national post-transfusion hepatitis C committee be established as a priority with the purpose of:

- Formulating, co-ordinating and delivering an apology to those who have acquired hepatitis C through the blood supply;
- Establishing an effective Lookback program; and
- Improving service delivery through a case management approach that ensures that appropriate medical, counseling and welfare services are provided, sensitive to the needs of people who have acquired hepatitis C through blood and blood products.

That membership of the committee include representatives of the Commonwealth, State and Territory Governments, the Australian Red Cross Blood Service, representatives of organizations which support people with hepatitis C acquired through the blood supply and individuals who have acquired hepatitis C through the blood supply.

That the committee establish and manage a fund to provide financial assistance for costs not covered through existing services, which could include the costs of visits and transport to general practitioners, prescribed medication and surgical aids, dental, aural, optical, physiotherapy and chiropody treatments, home care and/or home help, and alternative medical treatments, to the people who have acquired hepatitis C through blood and blood products.

That the committee, and the fund it establishes, be jointly funded by the Commonwealth and State and Territory Governments.”

In: Australia. Senate Community Affairs References Committee. Hepatitis C and the blood supply in Australia. Canberra: Senate Community Affairs References Committee Secretariat, 2004:x-xi.

INTRODUCTION

... 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.
Neil, aged 43

Why a needs assessment?

In 2003 Haemophilia Foundation Australia (HFA) agreed that its work on the national HFA hepatitis C strategy was a priority. A key element in developing the strategy was to understand the current and future needs of the bleeding disorder community affected by hepatitis C.

Many people with bleeding disorders have now been living with hepatitis C for 20 to 30 years or more. Ages range from young adults to people 80 years and older, some of whom now require nursing home care. Studies investigating the impact of hepatitis C on the general community suggest that some people with hepatitis C may develop more serious liver health problems if they have hepatitis C for more than 20 years without treatment.¹

What are the current needs of people with bleeding disorders affected by hepatitis C and their partners, families and carers? Building up an understanding of these needs has led to more specific questions:

- What has been the impact of ageing with haemophilia and hepatitis C?
- What do people with bleeding disorders affected by hepatitis C know about their hepatitis C?
- What is their current contact with the health system?
- What is their experience of hepatitis C care and treatment?
- What sort of health services do they need now and in the future?
- What has been the social, psychological and financial effect of living with hepatitis C?
- How can this be improved for the future?

In 2003 HFA conducted a survey of its members on hepatitis C issues. In 2007 HFA followed up this work by consulting with focus groups of people with bleeding disorders affected by hepatitis C and their families. HFA also consulted with state and territory Haemophilia Foundations and haemophilia health professionals. The HFA Hepatitis C Advisory Group, which includes people with bleeding disorders and specialists in hepatitis C and bleeding disorders, also gave valuable advice on key hepatitis C issues. The results of this work are summarised in this report.

Hepatitis C

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

Hepatitis C is not a new virus. Hepatitis following transfusion with blood or blood products has been reported by doctors since the 1940s. By 1973 the hepatitis A and hepatitis B viruses had been identified and in 1972 Australia introduced screening for hepatitis B in blood donations. Doctors noticed that some of their patients who received blood products or blood transfusions were still developing hepatitis. By excluding hepatitis A and hepatitis B as possible causes of this hepatitis, it became clear that there were other forms of viral hepatitis, which were named 'non-A non-B hepatitis'. When the hepatitis C antibody test became available in Australia in 1990, the vast majority of non-A non-B hepatitis cases were identified as hepatitis C.^{2,3}

Inherited bleeding disorders

People with inherited bleeding disorders have varying needs for blood products. Some use blood products regularly, while others only use blood products occasionally.

Many have haemophilia, which is a genetic blood clotting disorder which usually occurs in families, although in a third of cases it occurs in families with no previous history of the disorder. Haemophilia affects mainly males, but occasionally women as well. Men with haemophilia can pass the haemophilia gene onto their daughters but not their sons. Women with the haemophilia gene are carriers and may pass haemophilia on to their sons and the gene on to their daughters. Some women carrying the gene may have symptoms (symptomatic carriers) and have bleeding problems.

Haemophilia A is the most common form of haemophilia and is due to the deficiency of clotting factor VIII. Haemophilia B is due to the deficiency of clotting factor IX. The severity of haemophilia is determined by the level of clotting activity of factor VIII or IX in the blood.

The deficiency in clotting factor produces bleeding episodes, usually into the joints or muscles. These bleeding episodes, or 'bleeds', may have no obvious cause or may occur as a result of trauma or injury, cuts, knocks or falls. The bleeding is controlled by an injection of the clotting factor into a vein. If internal bleeding is not treated quickly with factor treatment, it will result in pain and swelling. Over time, repeated bleeding into joints and muscles will cause joint and tissue destruction which leads to permanent damage such as arthritis, chronic pain and joint damage requiring surgery.

People with severe haemophilia bleed frequently into their muscles and joints, sometimes once or twice a week and often from no apparent cause. They use large amounts of clotting factor concentrate as treatment throughout their life. People with moderate haemophilia bleed less frequently. People with mild haemophilia usually only bleed as a result of surgery or injury.

Another inherited bleeding disorder is von Willebrand disorder. This is the most common bleeding disorder and affects both women and men. It is caused by a deficiency or defect of a blood clotting protein called von Willebrand factor. Unlike haemophilia, bleeding

may occur in the linings of the mouth and nose rather than in the muscles and joints. Easy bruising, heavy periods and bleeding after childbirth can occur in some people. It can often be undiagnosed. Although more recently people with von Willebrand disorder have been encouraged to go to a Haemophilia Centre or haemophilia service for treatment, it has usually been managed by other health professionals in the community. Most people with von Willebrand disorder have a mild form and do not need treatment unless they have surgery or an injury. People with severe von Willebrand disorder may have frequent bleeding episodes, and sometimes joint and muscle bleeds. Some people with von Willebrand disorder can only be treated with clotting factor VIII concentrates made from human plasma which contains von Willebrand factor, while others can also be treated with synthetic hormones.⁴

Blood products

Before clotting factor concentrates became available to treat haemophilia in the 1960s, it was not uncommon for people to die from uncontrolled bleeding. With the arrival of concentrates, bleeds could be controlled with an infusion (injection) of the missing clotting factor. Initially treatment was only available to treat bleeds as they occurred. This was known as “on demand” treatment. However, this treatment does not prevent bleeding. Since 1995 prophylaxis treatment to prevent bleeding has been available for children and younger people in Australia. Clotting factor is given usually two to three times weekly, to keep factor levels high enough to prevent bleeding. The availability of concentrates which can be injected at home has allowed people to manage their haemophilia themselves and has reduced the need for such frequent hospital visits. Many people growing up with haemophilia today have a normal life expectancy, unless there are complications. This means the younger generations in Australia are less likely to experience arthritis and joint damage as they grow older.

Since the 1970s, people in Australia have used several different products for their treatment.

Cryoprecipitate was a clotting factor concentrate made from the plasma of a single human donor or pooled from a number of human donors. It is no longer used in Australia.

Other clotting factor concentrates were manufactured from the pooled plasma of many human donors and included factor VIII, factor IX and Prothrombinex™ (which was mainly factor IX, but also included factor II and factor X). Pure factor IX was not available until the early 1990s. Over the years, improvements to the quality and safety of these products have been made regularly.

Recombinant factor is a clotting factor made by genetic engineering, containing little or no human product.

Clotting factor concentrates can cause complications for some people.^{4,5,6}

During the 1970s and 1980s there was an awareness that blood products could cause viral hepatitis in people who used them. An Australian Red Cross Service study published in 1982 found that 2% of people who received blood transfusions developed post-transfusion hepatitis.⁷ However, people with bleeding disorders had a higher risk of coming into contact with viral hepatitis through blood products: many used blood products regularly, and pooled donor concentrates could contain hepatitis virus if only one of the thousands

of donors had viral hepatitis. In 1982 Sydney haematologists and gastroenterologists published a study of 243 people with haemophilia. Although treatment had been mainly with single donor cryoprecipitate with only some pooled donor concentrates, 27% of the people had developed non-A non-B (NANB) hepatitis. They were more likely to have NANB hepatitis if they had severe haemophilia, meaning they had to use more blood product more often than if they had mild or moderate haemophilia.⁸

When hepatitis C antibody testing was developed and introduced in 1990, it was found that the majority of people with haemophilia had hepatitis C. The number of people with bleeding disorders who now have hepatitis C in Australia is currently being collected for the Australian Bleeding Disorder Registry but is not yet known. It is thought that up to 85-90% of people with haemophilia who were treated with plasma derived blood clotting factor products may have been exposed to hepatitis C virus (HCV) before the late 1980s. Exposure may have occurred multiple times if they were using concentrates regularly. Some of them were children at the time. Some may have cleared the virus naturally from their blood, especially young children who are more likely to clear it than adults. Others may have cleared it with hepatitis C antiviral treatment.

Discovering that so many people with bleeding disorders had been exposed to HCV was an added blow to the bleeding disorders community. In 1985 when the HIV antibody test was introduced, about 30% of people with bleeding disorders using blood products at the time were found to test positive to HIV. Those with severe haemophilia were more likely to be affected. Some people with bleeding disorders now discovered they were co-infected with HIV and hepatitis C. Some were co-infected with hepatitis B as well. Some were children or teenagers.^{9,10} Co-infection with hepatitis C and HIV, or with hepatitis B, may cause liver damage to occur more quickly. If they have liver damage, people who are co-infected may find it more difficult to tolerate their HIV drugs.¹¹

Blood product safety

Various steps have been taken over the years by regulatory authorities, blood banks and manufacturers to reduce the safety risks of clotting factor products made from human plasma.

The hepatitis C virus was not identified until 1988, but Australian blood banks introduced hepatitis C antibody testing of donor blood in February 1990, as soon as the test became available. By May 1985 the impact of the HIV epidemic had caused the Australian Red Cross to add legally binding questions to their donor questionnaire and interview which excluded people who had ever injected drugs, also one of the key risk factors for hepatitis C.

Although HIV could be eliminated from blood products with heat treatment at 60°C, it was necessary for manufacturers to increase heat treatment to 80°C to inactivate hepatitis C. In Australia, factor VIII that was heat treated to 80°C became available in 1990 and factor IX (Prothrombinex™) in 1993. Other improvements to safety have continued to be made. In Australia, a major development to minimise the risk of known and unknown blood borne pathogens, including hepatitis C and variant Creutzfeldt Jakob Disease (vCJD), in treatment products was to supply imported recombinant clotting factor to people with haemophilia A and haemophilia B. Recombinant products are genetically engineered and contain little or no human material. Recombinant factor VIII was first made available in Australia in the mid 1990s, when there was a shortage of factor VIII derived from human

plasma, and was rationed to children and younger people with bleeding disorders who did not have HIV or hepatitis C. Recombinant factor IX became available later under similar arrangements. In 2004 Australian governments agreed to fund access to recombinant products to all people with bleeding disorders, regardless of their age or viral status.^{12,13,14,15}

There is currently no recombinant clotting factor treatment suitable for people with von Willebrand disorder and those who must use a factor VIII product, must use one made from human plasma which contains von Willebrand factor.

Managing hepatitis C and haemophilia

People with bleeding disorders in Australia are encouraged to get treatment and care for their bleeding disorder from a specialist haemophilia centre and to have their bleeding disorder reviewed regularly, at least once a year. These centres are generally located at a major public hospital and/or children's hospital in the capital city of each state and territory. There are also other hospitals which provide some haemophilia services. Most provide a multidisciplinary team of a haematology specialist doctor, and a haemophilia nurse, social worker or counsellor and physiotherapist or access to these services. Some people with bleeding disorders also see their general practitioner (GP) for other health care.

With improvements to haemophilia treatment, many people can treat themselves at home and can have their blood clotting products delivered to their home or at a location convenient for them. Some, especially those with mild haemophilia or von Willebrand disorder, do not often need blood clotting products. Unless they have a major bleeding episode or an accident, give birth or need surgery, they do not need to come into the hospital for treatment and may have little or no contact with the Haemophilia Centre. This can limit opportunities to check the liver health of those with hepatitis C and inform them about new developments.

People with bleeding disorders usually have their condition managed at their local Haemophilia Centre or haemophilia service. When the hepatitis C antibody test became available in 1990, testing for HCV was mainly carried out through the unit where people with bleeding disorders normally received their care. Liver function tests to check the liver health of those with hepatitis C are now carried out in the Haemophilia Centre/haemophilia service in some states and territories or referred to the hepatitis/liver or infectious diseases/immunology clinic in others. People with bleeding disorders have usually been referred to hepatitis specialists for treatment for hepatitis C.

Hepatitis C symptoms and treatment

One aspect of the Needs Assessment was to investigate the current effect of hepatitis C on the health of people with bleeding disorders. If they did not clear the virus, they have now been living with hepatitis C for 20 to 30 years or more. Is their experience of having hepatitis C different to that of the general community? A recent Australian study found that common symptoms of hepatitis C are:

- Irritability, physical and mental tiredness
- Depression
- Abdominal pain and nausea
- Forgetfulness, poor concentration, sleep problems
- Joint pain, general body pain.¹⁶

In Australia in the early 1990s hepatitis C was treated with the antiviral drug interferon alone, also known as monotherapy. People on treatment found the side effects hard to tolerate and the treatment was often not successful. By the late 1990s, a combination treatment of interferon and ribavirin had been introduced. This treatment was more successful but side effects were still difficult to manage. More recently a combination of pegylated interferon and ribavirin has become the treatment of choice for hepatitis C. This has had success rates of around 50% for people with HCV genotype (strain) 1 and 80% for people with HCV genotypes (strains) 2 or 3. Information on the HCV genotypes among Australians with bleeding disorders is still being collected. Side effects with the recent treatment have improved but still are known to include:

- Flu-like symptoms
- Tiredness, sleep problems
- Loss of appetite, nausea
- Hair thinning
- Anaemia
- Depression, mood swings, problems with concentration and memory.

Side effects vary from person to person.^{17,18}

Some people with bleeding disorders have had treatment for hepatitis C with interferon monotherapy and some with combination interferon and ribavirin therapy, including pegylated interferon treatment. Some have had multiple courses of treatment. Data on the numbers who have had treatment and success rates is currently being collected for the Australian Bleeding Disorder Registry.

Access to treatment is often limited by the person's eligibility for subsidised treatment or clinical trials of new versions of the treatment. If people meet certain criteria under the Pharmaceutical Benefits Scheme Section 100 (S100) guidelines, the Australian government pays most of the hepatitis C treatment costs.

In 2006 the S100 requirement to have a liver biopsy before treatment was removed, but people with bleeding disorders were usually exempt from this requirement as liver biopsy can cause complications in people with bleeding disorders.^{19,20} In the past having a liver biopsy has also been a requirement of many clinical trials of new hepatitis C treatments. There has also been the question mark over how to give people with bleeding disorders accurate information about their liver health, when liver biopsy has been considered to be the "only definitive" test.²¹ Haematology specialists worldwide have been researching options for safer liver biopsy for their patients and transjugular biopsy (taking a sample of the liver through the jugular vein) has been one option. Other ways of assessing liver health have included ultrasounds and magnetic resonance imaging (MRI).^{22,23}

S100 guidelines also require that the person has not had interferon-based treatment before. This has excluded some people with bleeding disorders, who had unsuccessful results from earlier versions of interferon-based treatment. Pharmaceutical company retreatment compassionate schemes can assist some people to have subsidised treatment again but there are only limited numbers in these schemes and they require substantial documentation and support from the person's hepatitis specialist.

Financial support

If their bleeding disorder, hepatitis C or HIV affected their ability to work, some people with bleeding disorders may have been eligible for financial payments from Centrelink, including Disability Support Pension, Sickness Allowance or Carer Payment. Some people may have been able to claim some or all of their superannuation and others may have been eligible for monthly benefits or lump sums for disability under their superannuation or personal or employment insurance policies, if they had them. However, insurance companies may have tried to exclude people with inherited bleeding disorders and hepatitis C from life, health, mortgage protection, income, disability and travel insurance, or may have required an extra premium in order to cover them.

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2003 HFA HEPATITIS C MEMBER SURVEY

In 2003 HFA surveyed its membership about hepatitis C related issues. For privacy reasons HFA does not keep health information about any individuals on the HFA database, and therefore had no way of knowing who had a bleeding disorder and/or a blood borne virus. The questionnaire was sent to everyone registered on the HFA newsletter database. The survey was intended to gather information about the hepatitis C related experiences and needs of HFA members and was largely based on a survey conducted earlier by the UK Haemophilia Society.¹

More than 250 questionnaires were completed by members who described the impact of hepatitis C on themselves and their families. Responses were received long after the “cut off” date, which suggested the relevance of the survey to those who were not able to respond immediately for health and/or other reasons, but who persevered nevertheless because the issues were so important to them. Of these surveys, 228 were suitable for analysis.

Bleeding disorder	Total surveys	HCV antibody positive (only)	HCV/HIV co-infected
Haemophilia A	160	121	26
Haemophilia B	33	28	2
von Willebrand disorder	33	16	2
Carrier	1	1	-
Other	1	1	-
Total	228	167	30

Table 1. Number of survey respondents by bleeding disorder and hepatitis C status

Many of those who completed the survey had great difficulty, and often felt there was no point, in separating out the impact of hepatitis C from the already difficult social, economic and emotional impacts associated with having haemophilia. For many people, in particular those with severe haemophilia and those who also had HIV, hepatitis C was of lesser consequence. For this group, the seriousness of hepatitis C was far outweighed by their HIV status and the social and financial consequences could not be separated from those already encountered as a consequence of their haemophilia and HIV status.

Clearly, a factor for many was the ongoing fear of other viruses entering the blood supply on which most people were still dependent for their treatment and for many there was an unresolved anger about the past.

The surveys also demonstrated that several members of the same family could have hepatitis C infection, with brothers, for example, both completing surveys relating to their hepatitis C experiences.

Overall, however, the responses to the questionnaire identified experiences of people which fell into three main groups:

1. Those who had serious concerns about their future health and mortality due to hepatitis C.
2. Those who were already experiencing major effects of hepatitis C on their health and capacity to live active and fulfilling lives, some of whom had undergone treatment unsuccessfully.
3. Those who were HCV PCR RNA or antibody positive to hepatitis C but had not experienced any serious symptoms or illness from hepatitis C and were not bothered at the present time. This also included a group of people who were more worried about the impact of their bleeding disorder than hepatitis C.

Main difficulties raised

- side effects of interferon treatment
- uncertainty of treatment outcomes
- uncertainty about disease progression
- inability to access hepatitis C combination treatment
- fatigue
- concern about discrimination, prejudice, and the association with drug use
- fear of the consequences of disclosure/privacy issues
- social/relationship difficulties
- avoidance of intimacy
- depression and anxiety
- school students with haemophilia and hepatitis C experienced discrimination and other difficulties with school-based activities and in social interactions
- inability to obtain insurance

Most people had only disclosed their hepatitis C status to the people closest to them and health professionals.

Financial impact of hepatitis C

A significant proportion of people who replied to the survey indicated they were unable to work without the threat of disruption due to the need for treatment for hepatitis C or treatment of bleeds. There was a high incidence of casual, part time and intermittent work. Many people were concerned about their future financial status in the event of disease progression. Many people were in receipt of government income support: 49% (82 out of 167) people with hepatitis C only and 50% (15 out of 30) of those co-infected with hepatitis C and HIV were receiving pensions or other forms of government financial assistance. People with severe bleeding disorders and hepatitis C were more likely to be unable to work. Carers and family members had given up work to provide care, and many reported that partners/spouses needed to work part-time and/or seek other forms of financial assistance.

Safeguarding their future financially was also a major difficulty. Of the 197 people with hepatitis C or co-infected with hepatitis C and HIV, 66 (34%) reported problems with obtaining insurance or superannuation. Many others reported that they had not declared

their hepatitis C or sought insurance, often because they knew there would be problems or they would be refused.

Understanding about hepatitis C

It was difficult to assess the level of understanding about hepatitis C from the survey, however there was a suggestion that many were unsure/unaware of the extent of disease and several relied on outdated information. It was apparent that many people did not understand the natural history of hepatitis C and the future health implications for them. There was a concerning number of people who were unable to indicate the extent of their liver disease, how far their disease had progressed and had little clinical monitoring. For example, 11 of the 28 people with haemophilia B who were HCV positive were unable to assess the current stage of their hepatitis C. Most had been tested for antibodies and had an HCV RNA PCR test some time in the past.

Treatment

37% of people only infected with hepatitis C, and 30% of people who were co-infected with hepatitis C and HIV had undertaken treatment at some time. Some noted on the survey that their treatment had been unsuccessful.

Bleeding disorder	Total HCV antibody positive (only)	Number treated	Total HCV/HIV co-infected	Number treated
Haemophilia A	121	40	26	6
Haemophilia B	28	17	2	1
von Willebrand disorder	16	3	2	0
Carrier	1	1	-	-
Other	1	1	-	-
Total	167	62	30	7

Table 2. Number of survey respondents by bleeding disorder and treatment status

There was a general indication that education and information about treatment options was necessary or would be helpful.

Experiences

People completing the surveys made a number of personal statements about the effect of hepatitis C upon their lives. The following is a sample of their comments

Health/treatment issues

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

My doctor said I should have treatment, but I am worried about whether I would cope – they say its 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 have had treatment twice, but it hasn't worked for me, so I really don't know what to expect in terms of my health in the future, I do worry about getting cancer because I have had hepatitis for so long.

My husband has died. Hepatitis C and HIV was listed as a contributing factor on the death certificate.

I didn't know until a year ago that I have hepatitis C. It was a shock the way I found out after all these years. I haven't needed treatment for vWD for many years. If I had been tested before, no one has told me, and I would remember that. It is really hard to deal with it, I think of all the times I cleaned up blood spills with my grandchildren, and of my husband and children. When you find something like this at my age it is really hard. I didn't know where to turn. I only used blood products a few times, it is just not fair.

I have chosen not to have treatment because it will impact so much on my earning potential and lifestyle. Besides, I would not have enough to live on if I could not work during treatment. I have elected to go this way because my genotype is not the best one for treatment success, but this might be a bad decision in the long run.

I have haemophilia A with inhibitors to factor VIII. I also have hepatitis C and feel very unwell at times. My life is pretty shithouse actually. I live with pain because I have gone without treatment for so long and the hepatitis is flaring up all the time now. I am not a candidate for treatment so the future doesn't look too bright for me.

Social consequences

We are about to retire, and we won't have a lot to live on. I am beginning to spend more time at the doctor's. I had a biopsy recently and found out I have cirrhosis and will need much more monitoring which means lots of travel. In some ways I feel better knowing, but I am resentful that I have to bear all the costs. I shouldn't have to pay. There should be some compensation for this. I haven't been able to look after my aged parents because of the hep C.

I never tell anyone that I have hepatitis C. I am only 15 now and I am not sure if it will affect me in the future. I am well now though.

Our son lives overseas and we would like to visit him. I can't get travel insurance.

Even my own children have been "over the top" about infection control issues and it was years before my husband would kiss me after we found out I had hepatitis C. I found that my personal relationships deteriorated as my hepatitis C progressed to cirrhosis. I think this is because I couldn't keep up with people, and they didn't understand the illness. I didn't have the energy for others and they didn't seem to care about me and I was fairly depressed about it.

I haven't told anyone I have hepatitis C. I won't tell anyone. I don't have to and I don't think it is their business.

Psychological issues

It's all about quality of life. Ours is really poor now. I am self employed with a wife and 2 kids – I had two lots of unsuccessful interferon treatment for hepatitis C. Not sure if I can face combination therapy. We had to sell the house because of financial problems because I couldn't work a couple of years ago. I worry that I may not be able to look after my family. Hepatitis C has destroyed my quality of life and now endangers my family. 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. I have the disease, but the others are the ones suffering.

Career and employment issues are now secondary thoughts for me. Now I have a two year old son, I am more concerned about how long I will be here for him.

I have no family. Hepatitis C broke up marriage.

Discrimination

I still feel like an outcast – some of my teachers and friends discriminated against me when I was at school because of my haemophilia and then when my parents were told I had hepatitis some teachers were pretty bad about it - so now I don't tell very many people at work about the hepatitis if I can get away with it, and luckily I am not sick, but they can see my haemophilia.

I encounter people who think I am lazy. They don't understand the fatigue of hepatitis C.

Health professionals treat me most differently and even the people who do my blood tests often ask me how I got hepatitis C.

My parish priest doesn't want me taking communion.

I am an allied health professional and I don't tell people/colleagues of my hepatitis C status because so many are so judgmental about others with hepatitis C that I don't want them to know I have it.

I live in a small country town. It is really difficult to have any privacy here. Everyone knows your business. I live in fear of the doctor's receptionist telling my neighbour I have hepatitis C.

I can't get work because of both my haemophilia and hepatitis C. The bleeds and hepatitis C fatigue stop me from working. I lost the last job because I had to take hours off for treatment. It affects relationships also. But I reckon hepatitis is worse than haemophilia because the discrimination is worse. The dentist steers clear of me, leaves me to the last patient and it always looks like he has cleared the surgery before I arrive.

Relationship issues

Our sexual relationship has been quite restricted because of the fatigue.

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 stopped having sex with my partner because I was scared I would give her hepatitis

even though doctors told me this would be unlikely – she already had to cope with my haemophilia.

I am 17 and I haven't had a girlfriend yet. Most of the girls I know now know about my haemophilia and they understand I won't die from a cut, but they don't know I have hepatitis C.

Hepatitis puts a lot of stress on my family. I only have mild haemophilia and I am pretty much OK most of the time from that point of view because I don't have many bleeds, but I am often too tired to be a dad and do my share.

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.

Career limitations/restrictions

I am only a student, but I am worried that when I have to do shift work in hospitals I won't be able to keep up with my peers because of fatigue. It is already a problem and I am only just a student.

I have mild haemophilia, but that is not a problem, as I rarely have bleeds any more. Recently I had the choice of 2 jobs – one with a salary of \$60,000 pa and another at \$130,000 pa. The higher paid one fits well with my competence, tertiary education, career goals and interest, however I accepted the lower paid position with less responsibility as I knew I would struggle to manage the additional hours and sophisticated input required as my health is too unreliable these days. My wife and I have decided not to have any children because of the health problems I have because of my hepatitis C, but we have a mortgage and I remain concerned that I will leave her with financial commitments that she cannot meet.

Income/economic issues/career choices

I have just been told I have cirrhosis and my health has been deteriorating. I work for myself, and expect my income will reduce by 50% this year.

I only have mild haemophilia, but I have a lot of hepatitis C! I am on and off work all the time and will be starting treatment soon. My parents encouraged me to be independent, capable, and ambitious. I manage my haemophilia really well, but I get really angry when I think that it is not my haemophilia that restricts me, but the hepatitis C. Hepatitis C has limited my choices and stopped me going into the career I wanted. I won't have the money for further education after that, so I am not sure what I will do, even if the treatment is successful.

My son is still at school. I am worried for his future, and his income potential, whether he will be able to work full time. His haemophilia is fine, he is on prophylaxis and he doesn't have very much joint damage, but I worry most that hepatitis C will interfere with his life. His genotype is the least likely to respond to treatment.

My income decreased by 40% in 10 years. I had a good career ahead of me, but I decided to leave that and work from home. My wife works so we can keep up our mortgage payments and the kids' school expenses but it's pretty hard on her.

I have used all my sick leave with hepatitis C and now when I have to take time off, it has to be unpaid leave.

I would like to see government financial support. What if my hepatitis C takes a turn for the worse? I am self employed with three children and a wife to support. I am self employed and I can't get loss of income or disability insurance because of my haemophilia and hepatitis C.

Shift work became impossible for me when I was having treatment because I was tired all the time and could not operate the equipment safely.

Uncertainty about my health is the reason I didn't pursue career advancement and seek higher paid positions. I have had treatment for hepatitis C but it was not successful so I am not sure what my future will be. I didn't finish my university studies, and now that I look back on it and don't like to admit failure, I know it was because I just wasn't well enough to do all the work. I couldn't concentrate and I was sick fairly often and I became depressed at one time.

1. A sample of survey questions is available from Haemophilia Foundation Australia on request

FOCUS GROUPS

During February and March 2007, Haemophilia Foundation Australia (HFA) held focus groups in three states and territories with people with bleeding disorders affected by hepatitis C and their families. The aim of the focus groups was to discuss their experiences and needs relating to hepatitis C.

Each focus group discussion was led by the HFA Policy Officer and the local Haemophilia Social Worker/Counsellor. People were invited to attend through mail outs by the local Haemophilia Foundation and the Haemophilia Social Worker/Counsellor. The social worker/counsellor talked to each person before the focus group and checked that they understood what would happen in the focus groups and felt able to answer the questions about hepatitis C.

Each focus group used the same series of questions covering different parts of people's lives. The questions were developed in advance by the HFA Policy Officer and the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group.¹

Across the three states and territories, 26 people participated in the focus groups. This consisted of 20 men and women with bleeding disorders and 6 partners and parents. Partners and parents were not always related to the people with bleeding disorders who participated. The focus groups for people with bleeding disorders were held separately to the focus groups with parents and partners and had slightly different questions.

To maintain the confidentiality of people who participated in the groups, the stories from the focus groups do not mention which state or territory the person comes from. Any other detail which could identify an individual has been deleted or sometimes changed slightly.

“You Have Hepatitis C”

Being diagnosed with hepatitis C had a profound impact on many of the people with bleeding disorders who participated in the focus groups.

They described feeling angry at the way they had become infected with hepatitis C and struggled with their inability to have prevented it at the time. Some talked of more than one member of their family who had acquired hepatitis C from blood products. Their dependence on blood products and medical care to survive meant they had accepted the products without question, a situation that had now changed.

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

in terms of hep C, there's a lot of issues. The biggest one is due to the knowledge that I became infected through no fault of my own... Unfortunately we've become more educated as a result of all these things because nowadays I don't think we're anywhere near as willing to let a doctor stick stuff in your veins without knowing what it is that he's going to do. Whereas there was a time when the doctor was saying, hey, we've got this new product. You can take it home and put it in the fridge and you can do it yourself. And we thought, great! Nobody ever said, hey have you thought there might be a problem with that?... And we've had our fingers burned... by blindly accepting what the medical profession are telling us is good for us. And we know now it's not always the case. Actually they don't know. Often.

People with bleeding disorders talked of “TNV – The Next Virus”.

what's lurking in my blood that I don't know about?

The experience of finding they had acquired hepatitis C from their blood products shortly after so many people with bleeding disorders discovered they had acquired HIV had shaken their assumption that any of their blood products were safe.

[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.

As a community, people with bleeding disorders were deeply shocked by HIV.

I'll tell you what it did to me, what it was like, is back in the 80s, when HIV was the big issue of the time and the daily newspaper came out... And I was at work and it was pretty busy and so on. And my paper was delivered to me and I opened it up like that and I looked at it and emblazoned across the top it had “Haemophiliacs doomed” and then it said, it has just been announced that haemophiliacs in Australia are doomed to be infected by HIV virus which will lead to AIDS. And that was shattering... and I just said to the boss, I said, look I'm going home. You can't bloody go home, you know. I'm going home, walked out the door. And I got in the car to drive home and I was just physically shaking, like I couldn't drive home. I had to sit there for about 15 minutes before I could actually stop shaking just to drive home and tell my wife.

It is possible that some of the people with bleeding disorders may also have been co-infected with HIV, although none disclosed having HIV in the groups. Some family members in the focus groups mentioned HIV, but family members were not necessarily related to the people with bleeding disorders who participated. HIV left a lasting impact on the community. Hepatitis C they saw as another burden, one that was potentially life-threatening. With the day-to-day difficulties of living with haemophilia, it could make their life unmanageable.

I went to three specialists, and the prognosis was not very encouraging, especially when they started trotting out figures... leading to cirrhosis, in a certain percentage of cases leading to liver cancer in 20 years. And that's been in the back of my mind for the last 25 years that I've had hep C.

An important point to note is that it's [haemophilia] going to get worse. So, I can maintain a full-time job now even with the difficulties. I've got to push myself every morning. I've got to get up and psych myself into getting over the pain barrier, loosening up the joints, the pain involved in getting to places. So it's a constant battle with your mind to beat it. Now how long I can sustain that, I don't know. It depends. If I get some other – if another weight is added on to me through some other illness.

Using human blood products had become “playing Russian Roulette” for them and they felt they were at the mercy of health bureaucrats.

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?

This led to great anxiety about choosing to change blood products, particularly with the new synthetic recombinant products which had been marketed as safer for viruses but may create complications for bleeding disorders.

So I have to weigh up the risk of additional blood borne viruses against a risk of changing product... Should I change or shouldn't I to recombinant. So each factor in the environment which changes, I have to reassess all my risks. And I don't think people understand those things. I don't think HFA or the doctors understand what you have to do and that's on top of dealing with all the illnesses, like just at a day-to-day level.

Participants had also experienced discrimination in accessing new safer blood products because of their hepatitis C infection. Some noted the frustration of being forced to continue to use plasma derived products which could not exclude unknown viruses.

because earlier, recombinant has been around for quite a while, but they'd only allow the young fellows to have it that were “clean”. The word was that they were “clean” and us dirty old soiled blokes weren't allowed to have it, because the government said.

Oh yeah, you've got hep C so you can have any old product now, it doesn't matter what. It's not going to kill you so why not [have] something else [ie, less safe plasma derived product].

It was difficult to balance their feelings of anger with their appreciation of having blood products made available to them and the costs of the product covered.

that's all fantastic. I'm eternally grateful that that has been made available to me. But at the same time, I ended up with hepatitis C.

Those who had acquired hepatitis C when they rarely used blood products found it even harder to manage and spoke of being “robbed” of their life.

Some felt that an acknowledgement by authorities that it was a health system error would help the community to deal with its anger.

It's nice to be recognised, so that you get the recognition that somebody or some system has let us down and there's an acceptance of responsibility of some kind even in a small way that the medical problems we've got arose through the adversities of the medical system... rather than the benefits.

Health Impacts

General health and wellbeing

People with bleeding disorders who participated in the focus groups had various words to describe their general health, from “good” to “dodgy” or “fragile”.

How they felt about their health was usually related to the effect of their hepatitis C or their bleeding disorder and, for some, included other associated conditions such as arthritis, HIV or diabetes. People had a range of experiences. Some did not think hepatitis C was affecting them. Most described feeling “down”, tired, lethargic, lacking stamina and always “catching colds or flus”. A few had cleared hepatitis C naturally or through treatment. Others had never had treatment or had treatment unsuccessfully, or were no longer able to have treatment as their liver disease was too advanced.

The level of their haemophilia also played a role in how well they felt. While people with severe haemophilia often talked of arthritis and painful joints, those with mild haemophilia said they were only aware of the impact of their bleeding disorder when they needed surgery or dental work or when they had a major bleeding problem.

All of the people with bleeding disorders had acquired hepatitis C many years ago, some when they were children. Many could not remember the experience of feeling well.

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.

Although their daily life might include ongoing pain and fatigue, some adopted a stoic attitude.

What's good, what's bad? I feel I'm doing all right, 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.

Being the people who observed the everyday experience of the participants with bleeding disorders, their partners and families were more blunt in their comments:

My husband is showing a lot of tiredness. He comes home exhausted and he virtually comes home, eats and goes to bed.

His health is very erratic, up and down. And I would put that there's a lot of fatigue, there's a lot of mood swings.

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.

[My husband] is quite lethargic... he always presents that he's fine but you know things aren't quite right.

Health impact of hepatitis C

When asked about the impact of hepatitis C, some participants were uncertain. They knew little about the symptoms of hepatitis C, expected that their haemophilia would cause them substantial health problems and were unsure what was responsible for their pain and fatigue.

I don't have the information to ... know which ways it can affect you, so I can't say well this is affecting me because of hep C,... the reason why I'm having particular pains...

If you were going to ask me how has hep C affected me, I can't tell you.... because if I go to work during the day I might get up at 10 o'clock because I'm too tired then, and I don't know whether that's hep C or because of my lifestyle.

I don't know whether it's because I'm just getting older, you have to use a little bit more energy walking around because of the problems that we have, or it's just the hep C.

Because I didn't know anything about the hepatitis C, I could be blaming the haemophilia and it could have been the hepatitis C all along...

Partly this lack of knowledge was due to the haemophilia culture of the time when they were growing up, where they were discouraged from acknowledging their health problems.

You try to carry on just like anybody normal, but you can't say much because back in those days it was taboo to mention hepatitis C or haemophilia. You'd get a big frown from everybody if you said a word about it.

Having been brought up to be stoic about their health, many of the mostly male participants with bleeding disorders dealt with health issues in the focus groups by understating them or making jokes about them. One participant commented:

I tend to, I suppose like most guys, ... downplay some of these things

This makes it difficult for other people to understand the actual severity of symptoms, as partners noted:

He plays himself down. He would never mention that he's having a bad day... or he wouldn't mention how tired he really is.

For the participants with moderate to severe bleeding disorders, the pain and disability due to haemophilia was something they had learned to manage.

You learn to live with haemophilia. You're born with it, you grow up with it. It's only in later life that you start this other arthritis and the other pains start... The pain now is coming from all the joints, from the arthritis.

Most participants experienced hepatitis C as another weighty burden on top of their haemophilia. Older participants noticed that hepatitis C had more of an impact on them from around 35-40 years of age.

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.

Up to 35, [the main issue] was haemophilia. But I'm [late 40s] now and I'd say from [late 30s] to [late 40s] it's been all about hepatitis.

And looking back I would say I probably contracted hepatitis C when I was about 16... My first experiences with alcohol were disastrous. Not so much drunk as ill. But apart from that no obvious symptoms until 10, 15, 20 years later when I got increasing fatigue and that was the biggest thing... the fatigue and just feeling drained of energy and going to sleep.

One partner described the relative impact of haemophilia and hepatitis C:

Well, I don't know which one you put on top? They're all life-threatening really, all at different degrees, and I suppose if you really think about it, the haemophilia is probably the easiest one because it's more treatable than the others.

The participants and their partners and families described a range of symptoms: extreme tiredness, lack of energy, liver and spleen pain, inability to tolerate alcohol, nausea, sleeping problems, mood swings, depression, "foggy brain", skin problems, nose bleeds.

I'm not working full-time but the days when I work, come 2 o'clock I hit a wall. Want to just put my head forward and doze off. I guess that's my biggest problem.

...the daily nose bleeds and things like that, the tiredness, I guess the stress of his hep C which has progressed on to a [liver] cancer. [partner]

Over the years, because he's had it since [early 1980s], and as he gets older, it's impacting more... there's a constant foggy brain, there's a constant fatigue. But he can wake up one morning and be fine and charge around like a maniac... then you've got fatigue and mood swings and foggy brain the day after. [partner]

... you can actually notice his lack of concentration. Definitely. It's not necessarily what he would say. Having lived with him for so long, I think you can really see the daily patterns. So there's a definite lack of concentration and the fatigue comes down like sleep, for no reason. [partner]

But now I increasingly get the tiredness and get soreness under the ribs there at some times, particularly at night some discomfort... Certainly my biggest issue is the tiredness factor which I find a daily battle.

Some could not identify any symptoms that related to hepatitis C and were more aware of their arthritis and joint pain. They described themselves as feeling "good", "fine" or "OK" in relation to their hepatitis C. This included some participants who had cleared hepatitis C: younger participants who had been told they were HCV antibody positive and PCR negative and may have cleared HCV naturally, as well as some participants who had had successful treatment.

For others, hepatitis C had advanced to more serious liver disease and they were very mindful of the potential for hepatitis C to limit their life.

I personally from my own point of view felt that my haemophilia has been fairly well managed....But the hep C is still very unknown. And in fact in 2001 I was told that in 5 years it would probably all be over.

But I know one of these days it's going to probably have the ultimate effect on me, to the point that now, when I go in, instead of just having scans and things, I now have MRIs on the liver just to see how things are going.

I suppose to summarise our situation, we've been married thirty years and I guess hepatitis C is threatening that ... it's threatening my husband's life. That's where we're at. [partner]

Liver disease also had an impact on their ability to tolerate medications such as anti-inflammatory drugs, which increased their pain and limited their mobility.

[my husband] mentioned to me last night that he possibly won't be able to take anti-inflammatories... That's a big worry because he has an anti-inflammatory every day. He can't really get around without it; he's in a lot of pain without the inflammatories. [partner]

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. So then you might take painkillers... But I find I get really bad headaches... because the liver is not metabolising a lot of drugs. They go straight to your brain. So, you spend the next day or two with a headache so that you can't do much anyway.

Some found that with treatment for their hepatitis C, their energy levels and feeling of wellbeing improved. Others described after-effects of treatment where they still felt tired and lacking in energy. A number of participants had had unsuccessful treatment. In some of these cases treatment led to more health problems.

I got [hepatitis C] at the peak of my life, I feel robbed ... – I never got over having the flu effects...And the worst thing I did is I actually went onto the interferon program, because I had a relapse...from that point on my life was cut in half health wise. Definitely.

Interferon treatment caused another participant to develop an infection in the joint. As a result he had a prosthetic joint removed and was left with a permanently stiff limb.

Having antiviral treatment

Living with a bleeding disorder usually means that a person is familiar with the health care system and having to take medications. Many of the participants mentioned that they visited the local Haemophilia Centre, based at a major public hospital, regularly to have the bleeding disorder managed. Some treated themselves at home with blood product injections. Others with more mild haemophilia had been more likely to visit their GP about their haemophilia in the past and only had haemophilia treatment in hospital in emergencies or when having surgery or dental work.

To have medical antiviral treatment for their hepatitis C, most participants were referred to specialist clinics at a public hospital, usually the liver or hepatitis clinic or infectious diseases clinic. If they had treatment when they were children, they were treated at the Children's Hospital. Many described treatment experiences that had occurred up to 15 years previously with various versions of the treatment, from interferon monotherapy in the early 1990s to combination interferon and ribavirin treatment or the more recent pegylated interferon and ribavirin combination treatment. Some had received multiple courses of treatment. Some had not had treatment while others were considering it. A few were unable to have treatment because of advanced liver disease.

What was hepatitis C treatment like for them? Some participants described themselves as "lucky":

I've had the hepatitis C treatment for it for 6 months and it didn't affect me whatsoever. I just went straight through it...

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.

Side-effects were a point of discussion for many others.

It's just like severe flu, I feel shaky and cold and aches and pains

The side effects... the actual flu-like symptoms and so on, that probably lasted about two or three weeks when you first go on it. And I was watching my diet and total abstinence from alcohol in the first couple of times. Didn't have any at all and that probably killed me more than anything. I just carried on and it was fine. The first couple of times, because they were low doses, there wasn't any problems and I just breezed through it

I've had the side effects which was 10 times worse than the disease. I was suicidal, breaking furniture, got very violent.

I had flu-like symptoms, particularly during the first 4 weeks, a lot of nausea, a lot of fatigue, needed to rest a lot to deal with those things. Certainly there were personality changes. Not just in the first 4 weeks but for the whole duration of the treatment and probably for several years afterwards. You become less tolerant, certainly harder to live with, moody. As I mentioned before there were certain fluctuations in sugar levels which affected the way I behaved and how much energy I had.

I was olive green the first night, just shaking and sweating. I can remember it as clear as day, the very first treatment I had. I'd read all the side effects and said, oh well, I might be lucky and get 2 or 3 of them and then I felt like I had all of them. It slowly got better, but it lasted the whole treatment.

Although they found the side effects hard to manage, some participants were determined to persist with the treatment. They talked about some of the factors that made a difference to them completing the treatment.

[The treatment] got stronger and stronger with the pegylated and the ribavirin... There were signs that the liver was actually improving... But it was the fact that it might have been OK if I was in the situation where I was able to just do nothing, but at the time I was trying to earn a living and dealing with all life's little issues and stuff like that... It was just too overwhelming... I only got 8 weeks into it, so that was it. It was all over.

I was cared for 24/7 when I was on treatment years ago. I was living at home with mum and dad and mum was my carer. She did everything for me. Fed me, got me out of bed, sent me off – I continued to work, but it was a struggle.

my wife actually had to come to work and give me the injections 4 hours before I knocked off so when I went home the reaction would start and I would sleep it off... after 15 injections I didn't want to go on, after 50 I didn't want to go on. 70 my wife stood and insisted on giving me the last 2.

If treatment was successful, participants felt “fantastic” and “fabulous”. Relapsing after treatment or having treatment fail while they were undertaking it was a difficult experience.

And then you come off treatment then 8 weeks later you think, OK I've got to go and have the blood test... and then you get a negative result. It just hits you straight in the face and you just go straight downhill into depression.

Several of the people who had undertaken treatment commented that they still felt some side effects for months to years after treatment. This added to the length of time they felt they had devoted to treatment, particularly if they had experienced severe side effects.

And basically that treatment took 5 years out of my life. And I said there and then when I was so crook, I just said that's it, don't want to know it any more and I've had 4 goes.

Multiple experiences of treatment failure also left some participants with an uncertain future.

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.

As a group, people with bleeding disorders who have hepatitis C are unusual in Australia. Many of them were encouraged to have interferon monotherapy when they were first diagnosed in the early 1990s. One participant had been “cured” of his hepatitis C through this treatment. In general this treatment was not as successful as

later combination therapy and several of the participants had experienced treatment failure with monotherapy.

Under Pharmaceutical Benefits Scheme guidelines, people who had already had interferon-based treatment were excluded from government subsidised treatment. They were also required to have a liver biopsy before going on treatment in some clinical trials, which could be life-threatening for a person with a bleeding disorder. Participants described the efforts their doctors made to gain them access to the latest treatment through special access schemes and clinical trials.

I have considered treatment, but it took my doctor a long time to persuade me, with good justification, until he managed to put it before the ethics committee, so that it wasn't necessary for me to have a biopsy, because I wasn't prepared to do that.

It was sometimes hard for the participants to understand or appreciate these efforts, especially if they were struggling with the treatment or the research demands of a clinical trial and felt their own needs were being ignored.

I think they get upset because basically for you to go to your third treatment, they tell us that they're putting their heads on the line by putting our name forward. You're supposed to have one treatment, and the second treatment you're lucky to have... I said, well I didn't ask for it. And if I say I don't want any more that should be it ...

When I did my third treatment, it was more that the information was more important for the supplier and the doctor rather than poor old me... I don't mind being a guinea pig, that's not the issue. The issue was, I wasn't getting the information I should have been getting.

Participants were mainly satisfied with their experiences of hepatitis services. One talked of the frustration of visiting the hospital from a regional area.

I'd come down to [capital city] from [regional town] and they'd write out the script and I'd go to pharmacy and the pharmacist would look at it and say, yes, come back in 6 hours, we'll have it ready for you... when you are going through treatment, you don't need that.

After treatment finished, the level of medical and nursing care from the hospital appeared to change.

Once I was finished and I was still suffering from side effects, they said go and speak to your GP. Now when I went outside to see about it... I went to three or four [GPs] till one got his computer up and started looking into the effects of interferon and the drugs before I got anywhere.

The hospitals didn't seem to want to transfer the information they had back to the GP ... There were a couple of GPs that I had earlier when I contracted hep C, if I pulled out any articles, I would take them down and show them to them and they would read up on what I'd gathered for them. That was good.

Treatment decision-making

Decisions about whether to undertake treatment or not covered many aspects of the participants' lives.

Some were most concerned with the likelihood of success and whether they had a genotype that was more likely to respond to treatment.

if it's less effective, then depending on the side-effects it had, I might not do it because it would be too much of a burden to carry. Already on my [haemophilia] prophylaxis I have to do that every 2 days, plus whatever else.

Among many of the participants there was a concern that liver health might be deteriorating and that their life may be limited in the future if they did not have treatment.

But then you have to weigh up the options of what's going to happen in the future. Am I going to be for a year and a half or two years Depressed In the Corner Dad then maybe clear the virus, or am I going to be Thirty Years Dead Dad?

Living longer. That's the reason why I did it, at least for the second and third time. You wouldn't go back for something like that just for the sake of it.

One commented that even when it was unsuccessful, treatment was still worthwhile for his liver health.

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.

Some had not had their hepatitis C monitored regularly. Others had liver function tests at the Haemophilia Centre but had not discussed their treatment options with hepatitis specialists for several years and were not aware of current treatment recommendations. When they were assessed, some had been surprised by the deterioration of their liver health and found that liver disease had advanced beyond the point where treatment would be effective. One partner spoke about the need for regular monitoring and good information about individual options.

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.

Some were thinking about treatment but very concerned about their ability to manage the side effects and the effect of this on their family, especially if they had young children:

...the idea of undertaking some course of treatment that could potentially make me depressed, tired, unable to work – it's not feasible. Aside from the emotional things, financially I can't afford to do it. Because if I can't work, then we're stuffed.

If the person with hepatitis C had treatment, participants felt that support would be crucial. Some were delaying treatment as they did not have family or friends who could give them support at the moment. One parent of a young man with hepatitis C thought he would probably live with his parents during treatment and thought the parents may

need to limit their own work to support their son through treatment and manage the side effects. In this case decisions about treatment were a family decision.

Starting treatment at a younger age when they had fewer commitments or were still living with or near their parents would have worked better for some. However, the option of treatment was only made clear to them more recently.

I know I've had hepatitis C for at least [more than 10] years. The option of treatment was only ever presented to me 3 years ago... as far as I was concerned I had something that was incurable and that was it. End of story, no treatment, nothing... And I don't know whether I should have been more curious or whether I should have done more research or at the end of the day you have to be responsible for your own outcomes.

For those who had undertaken treatment, was it worthwhile? If treatment had been successful, most participants and their families felt it was worth doing.

Well, it's one thing less to live with, isn't it? If you can get rid of it, it's one less thing you've got to worry about.

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

If they had not had symptoms before treatment and experienced severe side-effects, some participants questioned the value of treatment.

When I had that treatment I was sick as a dog... I've only just started to come back last month. Before – you wonder – it wasn't affecting me that much before. Did I have to have that treatment to get rid of it or didn't I? There are a whole lot of ways where I could maybe kick the bucket 12 months down the track. Why did I go through all that pain and suffering for nothing?

For some people and their families the experience was “horrendous” and where treatment was unsuccessful, they would not consider having interferon again. Others who had relapsed were prepared to take on treatment again if they had any chance of success with it.

Treatment support

Many of those who had undertaken hepatitis C treatment in the past struggled with the lack of psychological and emotional support.

If they had treatment in the early 1990s before hepatitis C services had developed, they were usually given only basic medical services at the hepatitis clinic. Some who had treatment more recently felt that they got good support from the doctors and nurses at the hepatitis or infectious diseases clinic on the drug therapy but little advice on how to manage the psychological and social impact of the side effects.

Support for [husband] in terms of medical questions, if you've got any questions... come back and see us. All of that was there, but nothing for me, nothing for the family, and it wasn't until after the process had ended and I could look back, that I realised how bad it was and how much of an impact it did have on the whole family. [partner]

Relapsing after treatment was distressing. The lack of support or guidance on how to use support services meant that some participants felt very isolated at this time.

I found that there was no real supports at that time of getting those negative [post-treatment] results back...I felt that I was left on my own to deal with it which at the time was really, really hard. Because most of the time you get the answer over the phone as well, and more often you might be at work when you are getting the answer, and it just hits you in the face. And that's it, your whole world comes tumbling down, no support at all.

when bad news comes [that you have relapsed]... And then they say, oh well, this consultation is over, open the door, see you later. Out you go. I know the support is there at the Haemophilia Centre but it's just one of those things that you just go out and get in your car and get on with it.

Some who had treatment in the early 1990s were referred to the support group at the Hepatitis C Council and found this experience to be helpful.

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]

Looking after their health

Many of the participants with bleeding disorders were conscious of the need to look after their health. Most had made adjustments to their lifestyle.

Tried to do a lot of things with losing weight, trying to eat properly, eat better, trying to keep up my exercise. So I'm trying to do things that are in my control, and they're hard, I won't lie about it, it's difficult to do

Although some felt they drank more alcohol than they should, most had limited the amount of alcohol they drank and some did not drink any alcohol. Some made changes to their diet to manage their constant feeling of nausea as well as to improve their

health. This could be difficult to maintain, particularly if they were away from home. While they tried to keep active with sports such as bike riding and swimming, both the joint difficulties with haemophilia and the fatigue and nausea with hepatitis C limited the amount of exercise they could do, which in turn impacted again on their mobility if they had moderate to severe haemophilia.

Some had invested in complementary therapies, including dietary supplements, massage, reiki, biofeedback and homeopathy. Some felt this was beneficial to their health while others felt that it did not make much difference.

Carer role

Although some people did not think of themselves as carers, partners and parents were usually involved in caring for the person with a bleeding disorder in some way. Carers played an active role in supporting the person with hepatitis C. This was a role they felt they needed to play carefully and sensitively: their partner or child sometimes preferred to guard their independence or did not always agree with the carer's point of view.

At a basic level, they felt the carer's role was "being there", especially when day-to-day life became difficult. Attending the hepatitis clinic with the person depended on individuals and their relationships. Some went to the clinic with their partner only when they were needed, others usually went. Some people preferred to go to clinic alone without their carer. Carers felt that there were advantages to attending the clinic sometimes with their partner or child:

I occasionally go in to see the doctor... If I go in it's usually because something is impacting the whole family and the message is not getting through to the doctor. That what he's suggesting is having an adverse effect on everybody and that he needs to be considerate, perhaps. [partner]

it's good to be in the consultation with the person who's having the treatment. To be with them so that you can be an extra pair of ears and eyes that picks up other things than what the patient has to deal with... there are just so many issues and questions you just can't keep stock of them all... It just helps if someone else is in the room and listens to the answer the doctor gave so they can repeat it for you later on. [parent]

I've always been there with [husband] because he's a quiet person and doesn't always say everything to the doctor... But there was a time when I wasn't there because of my job, when he was going to the liver clinic here, and he wouldn't always say things or tell me – ... you are better off being there, because he just stopped going. I saw [haematologist] and he'd say, he hasn't had a blood test for a while or hasn't done this, and that's when we found out he was really badly ill and had to go back to clinic again. [partner]

Often carers were involved in gathering relevant information about hepatitis C and maintaining health, researching with or on behalf of their partner or child, and reading and understanding the information so that they could help them more effectively. They sometimes filtered the information so that the person was not upset by the more brutal medical literature.

They also took a supportive role with lifestyle changes, preparing food and vitamin supplements, when the person was happy to take them, and monitoring the amount of alcohol the person drank. This could be a challenging role and some carers found their efforts to help the person with their health were not seen positively: "mum's nagging again".

In the early 1990s when test results first showed that some people with bleeding disorders had acquired hepatitis C, parents were required to make decisions on behalf of their children. With little information available, they were reliant on the advice of their

children's doctors and the experience of others having treatment to decide whether to enrol their children in treatment.

In the early days even the thought of going to an interferon thing, you'd hear what other people's experiences were, you'd say, I don't really want to subject my kid to that now ... I'll wait until there's a more clear sign that's either going to solve the problem or that his symptoms are sufficient to want to do something about it... We certainly discussed it, talked about it with the doctors, and the general thinking was no, it's too early or they're too young to do anything serious or significant about it. [parent]

These children were now adults and getting health care independently. Their parents acknowledged that they no longer had a right to information about their child's health and had to rely on whether their child wished to discuss their health with them. Parents were concerned about their child's hepatitis C status and were aware that other people were now becoming ill with hepatitis C. In spite of their concerns, their approach to their child's health had to be more restrained.

But of course now he's looking after his own health we might catch a little mention of it, but we don't want to worry him. You don't want to say, well what are you doing about your hep C? It's like, listen Mum, I've got plenty of other things to worry about – that would be his reaction. Or mind your own business. So we're a bit discreet... We query about the results and when the opportunity arises I ask a polite question, what have the doctors been saying about that, are you considering doing... just sort of dropping a hint. [parent]

Carer support

Because they felt very isolated, carers were very aware of their need for support. Their first avenues for hepatitis C support were the Haemophilia Social Worker/Counsellor, the doctor and nurse at the hepatitis clinic and, for some, their extended family.

Other useful supports they had found in the past included organised weekends, for example a women's weekend on hepatitis C. This included women with hepatitis C and female partners of people with hepatitis C.

it actually created...an instant network of people, a support network... That was just a weekend thing. But we probably spent 50% of our time on hepatitis C and the rest of it on other issues. It was looking at the clinical, the treatment, the social and all of those sorts of things. [partner]

These peer support activities gave carers opportunities to find out more information than they had gained from their partners or the medical specialists.

The interesting thing was that most of the partners of the men with haemophilia who were infected had no knowledge. They knew their partners had hep C but they didn't know what that meant at that time... you find out as much as possible from your own sources, you don't rely on the medical profession... for getting the full picture...

Interactions With Health Services

Diagnosis experience

The process of being diagnosed with hepatitis C was a negative experience for many participants, leaving them feeling angry and bewildered.

Some thought that most people with bleeding disorders in their state or territory had acquired hepatitis C in the early 1980s but many individuals were not actually informed about their non-A non-B hepatitis or hepatitis C status until many years later. Most found out they had hepatitis C in the early 1990s. Only one mentioned that he had counselling at the time.

Health authorities and hospitals appear to have handled hepatitis C diagnoses of people with bleeding disorders very cautiously. In many cases this resulted in a sense that they were not being told the full story.

It's made me very suspicious of the way things were done... you come into a place like this hospital... you think you're going to be looked after, yet you don't get that feeling when you go in here...you feel as though you're a burden, that the fact about the whole hep C thing is... I feel like they don't want to say as much as they can, because they're afraid, so where does that leave someone like me? Who wants to understand his illness and how he got it?

Some were informed through letters or phone calls from hospitals that they needed to come in for further tests. While some were advised at that point that they may have come in contact with contaminated blood, others were not told how they may have acquired hepatitis C until they received a positive result, if at all.

Others found out that they or their partners may have hepatitis C through the local media.

We were down in [other capital city] in the 80s and the news came out one day in the [local newspaper], headlines on the front page saying hepatitis C in the blood bank down there... Then they started testing some of the haemophiliacs and they said that they were finding that most of them had it. And... that was the first thing you think, that my husband might have hep C. [partner]

Not all were informed officially that they had hepatitis C.

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.

Participants understood that they had acquired hepatitis C through blood products. For many there were still unanswered questions about how they came to acquire hepatitis C or a sense of being particularly unlucky, especially if they did not have severe haemophilia and only used cryoprecipitate or only had a single episode of using factor VIII in a crisis.

I don't know where it came from either... I'm not a particularly severe haemophiliac and I was always on cryoprecipitate for years. Can you get it through that? Did it happen when they shifted me to [factor VIII concentrate]? I don't know.

Interactions with doctors and nurses

Processes varied from state to state, but generally participants visited the Haemophilia Centre to have their hepatitis C monitored, attended the hepatitis/liver or infectious diseases clinic for information, monitoring or treatment for hepatitis C, and went to a different public hospital if they needed to attend the transplant clinic.

Before the early 1990s they felt they had been in “no man’s land” with information on hepatitis C. When hepatitis C virus was identified and the interferon treatment trials began in the early 1990s, they felt they needed to be proactive to get enough information about hepatitis C. Their GP knew very little about hepatitis C. Some people and their partners contacted the local hepatitis C council and followed up with their own research.

Relationships with doctors depended on the approach of individual doctors.

Since [early 1990s] I've been under constant care under Dr X at the hospital... And I've always had a very good relationship with him, we've discussed – he'd make it very clear and invites questions and explains things lucidly... anything I wanted to ask and any information, all the information was divulged by Dr X, very reassuring.

[Haematologist] has been my doctor for as long as I can remember and all the people associated with him have been fantastic... The haemophilia side of it, I couldn't say a bad word about anyone. Unfortunately on the hep C side, we've been lacking information, lacking care. It just doesn't seem like they've done it before either... They're learning and that's why they can't tell us anything.

one doctor in particular... wouldn't tell me anything. I kept all my results from everything... and [the doctor] basically wouldn't give it to me. I'd ask [the doctor] each time... and [the doctor] basically stopped me from having that proper diary of what was happening.

I can think of another one... who I was referred to for a second opinion and I found him aloof and most unreassuring and he actually put me into a sort of short-term state of depression. The message that came out of a couple of consultations with him was I was just going to get liver cancer; that was just his attitude.

my husband stopped going for quite a while... because of the personality of [the doctor]... Why would he want to go and see the bearer of bad news, especially if he wasn't given a lot of hope or good outcomes, he just said, well, what's the point of going

Participants appreciated being given time with the doctor and nurse in the hepatitis clinic to discuss the range of issues. If they lived in regional towns, it was less likely that they would find a GP or a specialist who knew much about hepatitis C.

there was only one specialist there who would know anything about it. And it was fortunate that he was keeping contact with some of the other guys around the country

and they used to go to conferences together and they would keep up-to-date. And I have been rather fortunate that those have been the guys who looked after me.

They had concerns about the quality of their care when there seemed to be little communication between the hepatitis clinic and the Haemophilia Centre or where they did not see the same doctor consistently.

at the moment I only see the people at the Haemophilia Treatment Centre... It really depends on who's running the clinic, so it's a different doctor each time... it's hard for me to feel that there's any consistency with treatment... I feel like I've got to explain myself to them, I feel like they won't know the history... I was in hospital for 2 weeks, it was fairly major stuff... and [the major consultant] didn't know even I was in hospital... It's definitely a question about their communication... as a patient I would hope that my specialist were across [would know] when I would be in hospital or not.

If you get the same doctor they can see your progress and they can let you know. I find that's better. [partner]

Monitoring

Most people in the focus groups were currently keeping a check on their hepatitis C status at the local public hospital.

Hospitals had a different approach to monitoring in each state and territory. Liver function tests were sometimes done at the hepatitis clinic and sometimes at the haemophilia centre. If the participants lived in regional areas, some needed to attend the sexual health clinic.

The other thing that I didn't like... was having to go to a sex clinic at the hospital to have a treatment for a blood disorder. That didn't make sense in my mind, queuing up there and having to go through that...

Liver function tests took place from two to four times a year. Some states and territories were more active in their monitoring than others. In one region blood tests were provided with little comment or intervention.

Every six months and that's it. Don't talk about them [tests] or anything. I get a blood test and they say how are your legs.

In another region participants received regular blood tests and six-monthly liver ultrasounds. In a third region participants had regular blood tests, an annual liver ultrasound and also reported having MRI scans if their doctor had any concerns about their liver health.

Having the liver function tests to check on liver health took time. Some participants reported spending two hours to half a day attending clinic - looking for a car park as well as waiting to have the tests done and getting the results. For those who were working this could be a barrier to keeping check on their health. Some had developed strategies to make the process quicker.

I've been into [major public hospital] that much over the years, I feel like I should be on the payroll...I have a pretty good relationship with the staff up there. So I find... that if you get to know the system, you can usually get through relatively quickly.

Many participants preferred to get a printed copy of their test results to take home so that they could monitor their own health.

the haemophilia nurse just generally gives me a printout on what the tests are and the computer program they have there is excellent and it tells you what the levels should be so you can read it up and down. Just grab your piece of paper and go home and read it when you want. And I find that that's tremendously helpful. Because you can sit down at your own leisure later on and you can have a look at it and you can compare it as well. It will tell you what it was last time you had a blood test and you can do a fair bit of self-monitoring, if you can get that piece of paper.

Although participants who attended the focus groups said they were currently checking their liver health regularly, this was not always the case. Some had stopped having liver function tests in the past and had been shocked to discover their liver disease had become much worse while they were not being monitored. As one parent remarked, it was hard to keep hepatitis C on the agenda if the person was not feeling particularly ill.

If there's no immediate symptomatic thing, then I reckon it will probably slip from memory, it's like I've got this, why am I going to worry about it... I think sometimes the only times [son] mentions hep C is when he is at the clinic, and has got the result that says, you've still got a viral thing here, or there's still a marker that says there's something there... The thing that I find insidious about hep C is that it's sort of there, and it's like a time bomb and maybe one day it will go boom and blow up in your face. And I worry about that because it would be nice to think that we could deal with it before it got to that stage. [parent]

Understanding test results

In general focus group participants felt they needed to be proactive to get information about their test results from the hospital staff.

Interviewer: Did you all feel that you understood the tests and the results you were getting?

Participant 1 – Not at the start. Until you started enquiring and asking and prise it all out of them.

Participant 2 – And you would notice something on the form and would ask, why is that, and then you'd ask them what does that mean?

Participant 3 – Why is that item highlighted in red?

My local GP. She keeps me informed all the time. It's just the specialists that don't want to tell you anything.

the [clinic doctor] I saw there was quite good, but certainly – ...if my wife went, she was quite good, she had a list of questions and wanted answers... But certainly nothing is volunteered...

It was noticeable that older participants often felt more confident and skilled to find out information from the hospital specialists and nurses. They had developed several techniques to find the answers they wanted.

I think I understand [test results] reasonably well but that's because I've known to ask. If I don't understand then there are a number of different things I can do. One is to ask the doctor straight away, and depending on who the doctor is I will get an answer that is quite detailed or less than satisfactory. So then in that situation, I can start seeking other sources of information, whether it be through the local [hepatitis] council, through publications, through Internet, and there are some very good web-based sources on the Internet.

I always have lots of questions, which you can just keep asking questions and questions forever probably. So every time I go in, I ask a different question.

I know what a lot of them [test results] are, what the abbreviations are and all that sort of stuff. Only because it's been explained to me a few times. And I know the key ones to look for. And it's just a matter of taking the time to understand that because the staff are more than happy to help you with that kind of thing. And you've got to enquire, you've got to ask these sorts of things, I feel. Then once you do that then you can pretty much keep control on what's happening with yourself.

I 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 on the Internet, then I'll go back to the nurse or the doctor and say, well what's this?

The younger men were more likely to be confused about what the tests were and what the results meant.

I only know what two of my tests are and that's my [haemophilia levels], so that's like two out of 8 tests I get every 6 months. So other than that I have no idea what they're testing for. Just 8 vials of blood.

Some had been told they were HCV RNA PCR negative and only had HCV antibodies but did not understand what this meant and were concerned about their future with hepatitis C. When asked whether the results were explained to them, they said that they had been told but had forgotten.

They were uncertain about how to ask questions.

unless there's something that I don't understand... sometimes it is a hassle to ask them, what does that mean to me... Sometimes you feel a bit silly... or knowing that for him [doctor] it might be a minor issue, and he's thinking, OK, why is this person asking me so much about it... you have to ask right.

Not having the implications of hepatitis C explained to them could have an impact on their decision-making. One participant, who did not seek treatment until his liver disease was too advanced for it to be effective, commented:

There's a bit of a culture with the liver people, they really don't want to tell you any more than you need to know. So there's almost not secrecy but I'm not sure if they

don't want to scare you or certainly when I reflect back to the early days when I used to go to the liver clinic and they used to look at hepatitis C and I used to go every three months and in some respects I didn't feel unwell at the time and I felt the benefits of the treatment, the interferon and so on, were undersold. It was never explained to me the problems that I might encounter. Yet at the same time I felt the ambulance officers and police officers who would get needlestick problems, they would for the 7 days they had to worry about hepatitis C contact, and I'd wonder, what are they so worried about, there hasn't been a problem for me. So there was certainly an issue that even though it was recognised I had hepatitis C, it was never fully explained statistically, or in any other way, these are the very real possibilities you may be dealing with at a later time.

Improving The Health Care Experience

Participants in the focus groups were asked about what sort of hepatitis C services would work best for them and others in their situation. They reflected on their own experiences of treatment and care and thought of ways to improve the experience for themselves and others in the future.

Improving the hepatitis C consultation and check-up

Several participants from different states and territories commented that they would prefer to discuss their hepatitis C with a hepatitis specialist rather than a haematologist or a GP. Some thought the consultations should take place in the Haemophilia Centre. While they were in the consultation referrals could be made to other relevant services.

...a regular blood test, but also giving you information that you can see a specialist, a hep C counsellor and here's the telephone number and address, or they can arrange it while you're there with the doctor and get it done while you're there before them.

Overall participants were looking for health care that was holistic, that covered all aspects of the person's life with the bleeding disorder and hepatitis C and where the health professionals who cared for the person met with each other and the person and discussed the person's care.

in terms of discussions and treatment options... yes, the information was delivered... So it's the specialist problem. Specialists only look at their slice, they don't broaden the view to look at the individual person that they're dealing with, let alone broaden it a little bit wider to look at what else is in their life and who else is in their life. With conditions like hep C, that becomes very important.

if it turns out you've got haemophilia, hep C and maybe some other complications, that you'd rather be seen as a whole so that somebody can look at it and say this is having an impact on that, and that's having an impact on something else, and you've got all these things to deal with... [the haematologist and hepatologist] don't always talk to each other or meet... And it would be useful and has been helpful with some of our clinics to have the range of physicians that deal with the patient there at the same time... This is probably an indictment on our hospital system that the clinics tend to be like a service station, like the next vehicle comes in and we'll look at all the bits and pieces, and then we'll push them on until the next one. So the patient tends to be like an object... one of the reasons why we have [Haemophilia Social Worker/Counsellor] is to put a bit of sanity into this.

It was important to the participants that their experience of hepatitis C, symptoms and treatment side-effects was acknowledged by the doctor to be valid even if it was unusual, eg with symptoms that were uncommon. If they had an interest in complementary therapies, participants would prefer a specialist who “works with alternative therapies; who's not against it, who works in conjunction”.

Getting comprehensive liver function tests regularly with clear explanation of the results was a common thread in the discussions.

once you're in the consultation, those results are explained to you... in a way that you understand them... Honest feedback about the state of the liver. And... I feel... when I come in to get results for hep C, it's very dismissive... sometimes I have to even ask for them, so it's not as though they are volunteered or given to you as part of your consultation... They're – like, can I please see what are my hep C levels like, and these are just LFTs which in itself don't tell you much. So things to address those, make sure it's routine in consultation.

Many participants monitored their liver health actively and several kept files of their liver function test results. One person suggested having the results presented visually, for example, in graphs, to help them to understand and compare their results.

One debate concerned how often to get liver function test results. For some, getting results more often would help them to assess the impact of their diet, lifestyle or stress. Several thought that a home testing kit would be useful.

I guess, in a perfect world... it would be like the diabetic test. A prick on the finger and do your own self-analysis and touch your little touch pad and the computer throws it up for you and tells you how you are travelling and you can do it on a daily basis.

For research purposes it would be excellent because you'd be able to say, right, I had fish and chips last night. My levels are really high today... Or I drank 10 beers the night before, or the rest of the week I've continued to eat healthily and then your levels start to drop down again. So it would be a good indication of what affects your life... Ok, if I'm stressed, let's do a test and see how it's affected your levels.

And you wouldn't need to have an actual needle put into your arm every day for blood tests. And in my case, I don't have any veins left. This was my last one, which I had recently a Pick line put in, and I break out in a sweat every time a needle comes near me now because I'm worried about my veins.

Some thought that daily results may not be helpful.

it's a big thing when you see things dropping down, you tend to relax a bit more. But then all of a sudden it just goes up 2 or 3 on the scale, and you go, ooh, the stress levels come up. So I don't know whether it's a good thing that you know or not. Stress is a factor in hep C.

Another concern was being seen in a timely way at the hepatitis clinic, with an underlying anxiety about what was happening to the person's health while they were waiting for an appointment.

I think we need more clinics... whenever you try to rebook an appointment, they often say, well if you're not a regular of the clinic, there's a so many month waiting list... Even going to [other major public hospital] to make an appointment – oh, well look, there's so many months' waiting list. And I said, but he's got cancer. Well, we've got to go through the liver clinic first and there's months, and you're a new person, so you're getting in pretty quickly. And I'm thinking, oh, here's the big C to make things jump, but no they don't. [partner]

Partners generally felt that they could attend the clinic with the person if they asked to, but thought that they should definitely be encouraged to be involved in the consultation at specific times:

at ... those critical decision points, critical information points. Or if you feel the person is not presenting the whole story to the doctor... Just generally, not just under treatment, but this is the yeah, everything is going OK, or the forgetting to mention something that may be of relevance or not. [partner]

Improving treatment

A consistent theme was the need for both people with bleeding disorders and their families to prepare for treatment. This included getting the latest advice on the specific treatment, likely side-effects and how to manage them. One participant suggested group information sessions on this for the person and their partner/family. Involving partners and family in consultations with the doctor and nurse was also important to provide perspective from a third party and for understanding the potential impact of treatment.

my wife for quite a period of time thought I was just malingering. She did not understand hep C and the tiring effects of it, and that was even before I went on the ribavirin that really knocked the stuffing out of you and just sapped you of energy...She insisted on talking to the doctor... he went through it and justified, hopefully dispelled misunderstanding.

If there had been more preparation and some more support, somebody outside who could see what was happening... And that is what could have been needed. That outside view to say, hang on, you think things are hanging together but they're not. I think that would have made a difference to the whole thing. [partner]

If my son is contemplating treatment, it's going to have an impact on his life and my life and the family, then we would want to be some party to the discussions about all those impacts... if they are living at home... then they're going to have an impact on the rest of the family... And if the treatment's got adverse effects, then we'll want to know what the complications are so we can help, we can prepare ourselves, or respond... [parent]

To maintain their motivation during treatment some people had kept the copies of their pathology results and monitored their progress. Information on their liver test results was vital to them. Others who were about to start treatment felt that indicators of treatment progress would be a help to them.

I think it would give you a more positive outlook if you could see something – that it's reducing.

A good flow of information between the clinic and their GP was also considered important, especially for out-of-hours support or follow-up after treatment.

Another recommended lowering expectations.

I would advise people to be prepared before treatment starts to make very big changes in their lifestyle during the treatment period...Don't expect for example to be able to cope with your current daily routine, such as work and family commitments and social

commitments...Be prepared if necessary to stop work....my advice would be to plan for it. OK if you then feel you can continue on, that's a bonus, rather than planning to continue on and finding you can't.

Improving support

Carers took their role in hepatitis C seriously, one describing herself as a “watchdog, making sure he gets enough sleep and food”. Some felt that they needed the support of doctors and nurses to reinforce health messages.

I don't need to help him, other than to have someone else tell him to get off the alcohol ... a little bit more discussion where people are encouraged to make lifestyle changes... if the doctors encouraged the partner to be there as well so that when they are told you shouldn't drink beer then you've got something to come back on - well, the doctor said, you really should be off that... [partner]

Support for both the person and their carers prior to and during treatment was discussed frequently. Some thought that an informal ‘buddying’ system would be a very effective means of support: one-to-one telephone contact between people with bleeding disorders with hepatitis C about to start treatment with someone with a bleeding disorder who has had treatment.

finding other people who are experiencing the same thing and hopefully exchanging a little bit of information anyway about, well, how did it go for you? Was it really that bad? ... And I find that gives me more with that one-to-one than in a group.

[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]

People in the focus groups commented that meeting each other and discussing their experiences had made them feel less isolated. They thought that stories of other people's experiences in Haemophilia Foundation newsletters would also be helpful.

maybe some information from other people who have been through the treatment... So when you're going through it yourself, if you read something, you'd think, well maybe I am supposed to feel like that, this does happen or that does.

Partners thought it was important for those with bleeding disorders and hepatitis C to meet informally and share their experiences, for example the local men's support group that met regularly.

*Partner 1 – Yes, because we can talk about it all we like. We don't have it and don't really experience it, so I think it's good to unload sometimes, isn't it.
Partner 2 – With somebody that understands it.*

Some suggestions for support were focussed on the practicalities of managing day-to-day life when one partner was unable to help with household tasks or looking after children or was ill and needed to be cared for.

It would depend on how you are feeling, how sick they become, and perhaps some help could be around the house. If you've got young children, that could be quite difficult, even if someone came and washed the floors, or did something for you just to give you a break. Even coming to the house for morning tea and things like that. [partner]

I guess my concern at the moment is with starting the treatment, if [husband] gets really sick, because I go away for [periods of time] with my work... That's a concern. What services would be available or can I get out of going away, can I rearrange my schedule. They're things I need to look at because if he's not well, I won't be going away. I would make sure I was around but you still need other support around as well. [partner]

Another concern was how to manage financially if the person was ill, especially if the partner was unable to work, either because they had small children or were caring for the person full-time.

finding out what else is available and are you entitled to have it, that's the big thing. Because if you're working, you're not really entitled to too much assistance, as in, I'm looking at government support or home help or things like that. When you're working there's not a lot of support out there that you can access. [partner]

if you're at that time when it's difficult for you to go away or to get leave, perhaps a temporary pension, will they do such things? Just at least to have some money coming in. [partner]

Living With Hepatitis C

Living with others

People with bleeding disorders were conscious of their responsibility to protect their family or partner from infection with hepatitis C. They took care with their blood in the home, making sure they cleaned up if they cut themselves. Some wondered about the need for safe sex, particularly younger single participants who were unsure about sexual transmission and what this might mean for their future.

I thought a lot about when I do get married, what impact it will have on that. Just at the clinic we never talk about it and I've never been told anything really about how it operates, and I don't really know how it's going to work with them so I've been very conscious about that when getting into relationships.

Partners and parents in the focus groups had informed themselves about ways hepatitis C is transmitted and were confident about their ability to manage it at home with “normal hygiene”. When people with bleeding disorders were first diagnosed with hepatitis C and counselling services had not yet been set up, their experiences with their family were sometimes very different.

But it certainly made a difference to my family life by having it, because they didn't understand and there was no offer, in those days... of any counselling for them to explain it to them... And my wife at the time, I had a lick of the grandkid's ice cream, and she snatched it out of my hand and threw it away because the kids might catch hep C from me. I mean, that hurts

If they had symptoms of hepatitis C, these often had a major effect on participants' home and social life.

It's had quite a big impact on my social life and my relationships with my wife and kids because various treatments that I've been on over the years, particularly the dual treatment with ribavirin and interferon, I was falling asleep... in the lounge chair, in company which was not going to go down too well.

the tiredness affects – we don't go out for dinner any more. That's something we used to do a lot. If he's not in bed by 8.15pm, he's pushing it. And sometimes he's just too tired to eat with you at the dinner table, working through the dinner. You can see it. So we don't go out socially. [partner]

Social activities with friends and work colleagues for most men involved drinking together, usually at the pub. Their inability to tolerate alcohol was a problem for several. If they enjoyed drinking beer or wine, it was hard to give it up completely. Some men found that a decision not to drink alcohol caused comment and pressure to keep drinking from the people they worked with or their friends.

Fatigue from both hepatitis C and the treatment meant that partners had to take over the household tasks and care of the family even if they were working themselves, commenting:

But basically the day-to-day workload increased for me on a consistent level. [partner]

Depression and mood swings related to hepatitis C and treatment also put a strain on the rest of the family. Partners and children sometimes found the person's behaviour to be incomprehensible, with violently angry reactions to small setbacks. Fatigue and mental health issues also meant that people with bleeding disorders and their partners did not always have the personal resources to support their children through any difficulties they may be having, such as managing their teenage years or final years of schooling. In retrospect some parents felt this affected ongoing family relationships and made a difference to whether their children completed education and their subsequent career choices.

For mothers who were carriers of the haemophilia gene, responsibility for the loss of their child's quality of life with hepatitis C was something they felt keenly.

there's this guilt factor that my mother has, that because she gave birth to me and her child has haemophilia and now has hep C... why can't her child be normal...

Working

Experiences of working varied. For many, working was important to their identity and lifestyle, necessary to support their family and giving them opportunities to socialise. Some who were retired or on a pension felt their health or quality of life was more important.

Growing up with more severe haemophilia had meant missing part of their schooling and some made career choices based on what they thought they could manage physically without causing a bleed. Working was a battle with bleeds, joint pain and, as they grew older, arthritis. Those with mild or moderate haemophilia only occasionally had interruptions to their work relating to their haemophilia.

For those who did not have symptoms, having hepatitis C currently made little difference to their work, unless they decided to have treatment. For others, having hepatitis C and a bleeding disorder was a double burden. Younger people with bleeding disorders were waiting to feel the impact of hepatitis C symptoms and had some anxiety about planning to reduce or stop work to manage treatment and future disability. From the mid-30s onwards, symptoms such as extreme fatigue, depression, brain fog, sleep deprivation, liver pain and the associated stress and worry caused many people increasing difficulties with work.

It certainly... impacted on working ... sitting down next to a [person], I fell asleep because of treatment I was on... You've just got to get around it, you've just got to make sure you stand up and don't fall asleep on your feet. It sure knocks you around by the end of the day.

I find that the haemophilia is fairly well managed with treatment, but come lunchtime the fatigue that sets in does make it very difficult to go on.

The decision to have treatment meant that the person and possibly their family needed to be ready to limit or give up work for at least 6 to 12 months. It also had lasting effects on the person's capacity to work effectively.

have you got a gap of 6 months somewhere in your life where you can do that [treatment]. You need the space in your own life and... probably your relatives, your family, your immediate family, because they need to help you through. [parent]

once you go on treatment, you end up with a hole in your head and... if you're at work and someone asks you a question, you go blank quite often after treatment

Those who had been self-employed, or in physically demanding jobs such as trades or in high profile stressful roles were more at risk of losing their career at around 40 years of age when their hepatitis C symptoms prevented them from being able to work a full day or required them to go on treatment.

I had to give up work because I was in a fairly stressful position... But tiredness mainly... I just couldn't run the day.

I've worked for myself all my life. There's no way in the world I could continue to work with those 3 treatments and that's in the last 10 years.

Giving up work meant going on the disability support pension or starting a new career from the beginning. If they had been managing their own business, some considered retraining and starting again in "a job I can do" but this was not an affordable option for some with dependent partners and children. It was also a loss of status.

Centrelink... said, we can help you here but you're going to start at the bottom of the rung... I've tried to get study access, but basically you have to pay a lot of money for it. Centrelink will only give you not even half... So that's stopped me studying now... my biggest problem to date is I need a job, I need someone to help me get a job, and I can't be put back in down here [low]... .. It's too far down and it isn't worth it because I'm better off staying at home and looking after the family and staying on the pension.

Quality of life was more important than working for some who had been told their lifespan may be limited. For others, the decision to stop working was less straightforward.

Hep C played a significant role in [husband] giving up work in [early 1980s] because of the lethargy, the tiredness. The whole pile of symptoms at the time were at the point where the advice was, if you can give up work, now is the time to start living your life because there may not be a lot of good years left. [partner]

[husband's] business is very important to him. He started it up from nothing. And I keep saying, just stop work, stop everything. It's only money, and stuff; we've got our health and our lives that we've got to worry about.... disability pension isn't enough monetary income; he sees what effort he has put into this business, now is a really bad time to sell... I wish that he would stop work because I think by him working he's actually becoming sicker. [partner]

Supporting the person with a bleeding disorder and hepatitis C also involved adjustments to the working lives of partners and parents.

I've worked part-time since [early 1980s]... basically to have [time] up my sleeve which is available for that carer role, that support role... Has it impacted my career in terms of progression and achievement? No. I'm quite happy with where I'm heading and where I'm at from that point of view. I think it would have been a bit faster if I'd been prepared to work 5 days a week, but not an option. [partner]

And I know for sure that [wife] would reduce her hours of work or even stop work if that required it in order to care for him. Because he's not married yet, therefore they're going to call on mum and dad, aren't they? [parent]

Finances

Some people thought that hepatitis C had not had much impact on their financial situation, particularly if they were not experiencing symptoms or had more disability relating to their haemophilia than hepatitis C.

Most, however, felt strongly that hepatitis C had reduced their income and increased their costs over the many years they had lived with the virus. Working part-time or giving up work and living on a disability support pension led to a substantial loss of income.

I've been part-time for [more than 10] years which meant a drop in salary of about \$15,000 a year for [more than 10] years, so that's a lot of money.

If they had been able to establish themselves in a career and had a partner who was working, participants were more likely to be able to manage financially. Sometimes their partner took over as the primary breadwinner.

As... [husband] has of late not been able to work, I've had to take over and I'm the person who brings in the income. [partner]

Some felt strongly their responsibility for maintaining the family income.

I still manage to work full-time, although these days it tends to be clerical so I can sit down... There's times I wish I wasn't there and didn't have the stress and just the effort of doing it, but I do it. I've still got children at school. But ...you just do the best you can.

Those who had been self-employed had big financial losses from being forced to give up work.

I had a really successful business and when I eventually got too ill, I had to sell all that, so financial-wise I actually suffered really badly when I then changed into what I'm doing now ... I had to start again, which was a lot less struggle on my body physically.

Having to give up work with a dependent partner and children could have disastrous results.

Because I stopped work, I ended up with a tax bill... which I couldn't pay. They [government] sent a letter saying if you don't pay they'd sell my house... I only owed \$X on my house when they made me sell it and it would be worth maybe [several hundred thousand dollars] today. And that's a hell of a lot of stress that wouldn't be in my life now.

Those who were in their 30s or early 40s were trying to prepare for the financial losses they were likely to have in the future.

in terms of financial situation is how long can I sustain the current level of work that I have...I'm trying to plan for it. Three years down the track I'll have to cut back, or 5 years down the track I'll have to cut back a certain amount. What will that cost me?

A major issue for all people with haemophilia was their inability to get health, travel or income protection insurance with both haemophilia and hepatitis C, which left them with a worrying future financial situation.

because of this medically acquired condition that I've got through no fault of my own,... that precludes me from getting income protection insurance and puts my family at risk... but if something happened to me, it would be good to know that there was some sort of recourse so that we don't end up destitute and on the street... I wake up at night about that.

I went through all of those years with just paying off mortgages and so on, with absolutely no protection at all. And it was probably one of the contributing factors for why I never had a family, because I knew that there was always that possibility that something could happen tomorrow and – we're out, we've lost the lot.

Having hepatitis C resulted in many additional costs, even if treatments were subsidised. Several participants had multiple courses of treatment.

There's always that hidden cost of fuel, transport costs to and from the hospital while you're on treatment. Some people have a lot of panadol and that adds up while you're on treatment and other pharmaceutical costs, the costs of small fees you've got to pay at [major public hospital] or this or if you decide on the off chance, I'd just better go to the GP, you've got your hidden costs with the GP

Participants had known they had hepatitis C for many years. Some made changes to their diet, ate organic food and took vitamin tablets to maintain their liver health. Some used complementary therapies, which could cost thousands of dollars. If they were on pensions, these lifestyle changes might not be an option.

we'd say our biggest budgetary cost is health-related stuff, definitely.

It's all that sort of stuff can be really expensive when you add it up after a while. Especially because you're on it for such a long time.

It's a huge cost just eating three vegetables and two fruit a day. So trying to live and eat the right way, it's huge, financially. To put in the other [complementary] therapies.

Telling others

Through the bleeding disorder community's experience of HIV, people with bleeding disorders and their families had learned to be wary of disclosing their hepatitis C status unnecessarily.

when I first found out that I had hepatitis C somewhere in the 90s..., there was all this media frenzy about hepatitis C being the new HIV... And I was petrified to tell anybody because I thought, well there goes my social life. Tell someone I've got hepatitis C and no one is going to talk to me again.

To be honest it is much easier to tell people about hep C than HIV. I've not had any adverse reactions at all. With HIV you develop a habit of not disclosing to many people anyway, so it's not been a major issue. [partner]

Most were very careful about whom they told.

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.

A couple of participants were more open with telling people.

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

I would rather tell people what the problem is and leave it to them, rather than hide it, because if I hide it, I'm going to stew on it...

Most had told family, some close friends, doctors and dentists and sometimes employers, especially if they were sick, going on treatment or the work that they were being asked to do was too difficult for them to manage.

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

With the lack of community understanding about haemophilia, disclosing haemophilia was already a problem for some. Some disclosed their hepatitis C and not their haemophilia, while others disclosed their haemophilia and not their hepatitis C. Sometimes they felt it was necessary to deny the person's hepatitis C status. This was related to their concerns about the "distorted attitude" in an uneducated community and the community's reaction to risk, either from a bleeding episode or hepatitis C, or both.

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 2 years and in that case you don't want him to think you're not capable of that ... they might think,... he might be a burden to us, he might get sick...

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

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

In the early days, when it was advertised a bit more, you did hear a little on the news and you'd read something, people would say, oh did that affect your husband? And you'd say, oh no. So it's easier to say no than to have to explain - or the fear of what their reaction might be, the risk. [partner]

Deciding whether to tell friends was complex. Participants wondered if their friends would understand; whether they could trust them to be supportive. Some felt the nature of friendships between males made disclosure more difficult. Others were aware that not disclosing also had an effect on friendship.

You make new friends and you drift apart from friends all the time, that's life, but there have been a couple of times that I've felt that having disclosed, the friendship has crumbled fairly quickly without anything being said.

this is maybe a male thing too, telling another male that you have an illness, you get a sense of feeling you're giving them the upper hand... a work colleague or someone like that... So you have to be very careful how you tell people and who you tell. But with females it's probably not as bad. I find that they tend to be more understanding than males...

You don't know how much to tell about yourself... You're not giving much of yourself to that other person, which makes them feel like, when you're trying to be friends, how come you're giving less

With a double burden of haemophilia and hepatitis C, participants were aware that new relationships could be difficult to establish and that rejection could be very painful.

I don't tell them... until you've established a close enough relationship. Because it's hard otherwise. You're scared... Worried that they're going to take it the wrong way.

If you're single it would just be devastating. That would just be a whole other thing to get over. Then you tell every partner you meet that I'm a haemophiliac with hepatitis, do you want to have a relationship?

I've been separated for a number of years and I get to a situation where I think I'd like to get into some relationship, there's all these doubts about whether you really want to because do you want to go through all this stuff again and then you might get to a situation where something's really happening in your life and all of a sudden, just gone, just like that.

Some talked about situations where they had felt obliged to tell their new partner about their hepatitis C.

within the first 8 weeks of being in the relationship with [partner], the doctor rang me and said the treatment is available, do you want to go on the treatment... I found that very, very difficult telling [partner] in a new relationship that I had hep C and this is what's going to happen, do you want to continue.

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

Both relationships continued in spite of the health problems that followed with treatment and major bleeding episodes. Some people felt that if the new partner could overcome the initial difficulties of disclosure and the realities of the health problems, the relationship would be strong.

she stuck by me. And that was the rock on which our relationship was built... I always think of that if we're having hard times, hang on, I was in a bad position and she was around.

Participant 1 - Definitely for me disclosing stuff to my then girlfriend, now wife, it's a powerful thing... But if you can get through the initial – you think, oh no, you're sweating and it's horrible.

Participant 2 – It may be, but I've been married for X years and I'll tell you, it's a good thing, the best thing.

Other situations also occurred where people felt the pressure to disclose. What responsibility did they have to inform a professional if they had not taken proper infection control precautions and the person's blood had come in contact with equipment?

I mean we tell our family and we tell our close friends but do we tell the barber?

The beer and wine drinking culture that dominates in Australia was also an issue.

Other people's perception of you if you're not drinking. It's really quite odd... It's just the – why aren't you drinking? And then you're in a situation where you just think, ok, well do I trust you enough to tell you? Can I be bothered telling you? Do I even like you? And all of a sudden, you're out having a meal and having a social engagement and suddenly you're having to think about serious things. And...I don't really want to go there.

Another issue that was raised during the focus groups was participants' concern at having their details listed on the government register for notifiable diseases. They were unsure whether this meant they had legal responsibilities and were not permitted certain activities, or whether their names would be removed if they cleared the virus.

Stigma and discrimination

Most people felt they had not experienced a great deal of discrimination relating to hepatitis C but this may also have been connected to the fact that they did not disclose to many people.

I've been worried sometimes telling people, but it really hasn't been that much of a problem when you come down to it. ... I don't want to just go bandying it around to everyone because it's more that we are good friends and... I know that they're not going to think certain things when I tell them.

Some felt that there was less stigma attached to having acquired hepatitis C through blood products.

when I have told certain people, they've been very understanding because they already know that I've got haemophilia. And when I just say I got it through a dodgy blood transfusion, I've never had any stigma attached to it.

The association of hepatitis C with injecting drug use or alcohol dependency had caused difficulties for some people.

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

I find when you go to a new GP... and you tell them you have hep C, the first thing they automatically assume is that you're an intravenous drug user. And I've had one really bad experience where basically I was pushed out the door. Didn't want an explanation at all, and just automatically assumed that I had got it through drugs.

The lack of education about preventing the spread of hepatitis C in the general community and in the workplace had painful consequences for some people.

When my first son was born, I joined a mothers' group... somehow I disclosed to them that I had hep C and it wasn't until the children were about 9 months old that one of the ladies rang me and said, we're pulling out of the mothers' group because there's a chance that your child would have hep C and the children have been biting each other. And I was taken aback a bit by this because I knew that it's not easy to contract hepatitis C through a simple bite and basically this group of girls that I'd formed a friendship over a 9 month period just didn't want to know me or my child any more.

I remember one incident at work, after I was cleared, there was a guy that stood up in the lunch room and said [participant] shouldn't be working here, he's got hep C... But there was one guy who was a close friend of mine and he happened to be reading his book there, and he stood up and said, if you don't know the facts, just shut up, because he's cleared... but had I not been cleared, I don't know what I would have felt like.

Hospitals, GP, dental and acupuncture clinics could also be a scene for discrimination around transmission issues. Where staff were well-educated about infection control procedures and used them confidently, participants had not experienced any problems. However, several had seen a different approach from other health care professionals.

there have been times when I have had odd reactions from members of hospital staff, usually people I'm having one-off contact with, not my regular team... A kind of hands-off... keep your distance approach, without actually having said anything to me and a couple of times I noticed for practical reasons during that particular procedure, being regularly scheduled as the last patient of the day, even though we all had to turn up at 7 o'clock in the morning. And so they had extra time to deal with infection control which was probably totally unnecessary, when you consider they should be treating every patient the same way

But when hep C came around, the most intimidated that I've ever felt was the day when I went in there for a [dental] checkup, and instead of going into the normal surgery, they ushered me into the other surgery. And then all the staff came in and they had these gowns on and they had shatterproof helmets on and all of the equipment, all the tubes and things were all shrouded in plastic bags... And I felt so intimidated and humiliated, it was just unbelievable

Information needs

Participants felt that in general there was a lot of information on hepatitis C available on the Internet, in Haemophilia Foundation newsletters and from the Hepatitis C Councils. To them it was more important to pick out information that was relevant to their individual needs. Although they did not expect all their information to be produced for people with bleeding disorders, they thought there was a lack of information around specific issues for people with bleeding disorders and hepatitis C.

to the extent that some of the other complicating factors might be haemophilia-related, that's when we might want to know more. Like liver biopsy. Is it good for a person with haemophilia to have a liver biopsy? It depends who you're talking to half the time. And that was a barrier for a long time... what does it involve? [parent]

They also thought it was important for the information to be written in plain English.

[In future] when they publish things, they publish them in layman's terms, particularly if they come through a layman's organisation. You know, some of the stuff that comes through here is so technical, you say, I'm not going to read that, I don't understand it. I've got to get an interpreter.

Information on how best to maintain your liver health was one key area of need. Participants were interested in liver test alternatives for the person with a bleeding disorder. Did they need to have a liver biopsy? Would an ultrasound be as helpful to let them know how their liver was faring? What other factors were involved in looking after your liver health?

Another key area was hepatitis C treatment.

whatever treatments are coming up, improvements they've got, whether treatments are working, how they affect people, the effects they have on your life... what the drugs do ... the actual treatment – does it really work? And to what degrees does it work, because everybody is a bit different.

I keep up with it, if something does break, I'd really like to know about it really quickly.

what I would like to know is the experiences of other people, who like myself have been through treatment; what they are now experiencing in terms of possible long-term effects. Because you're told you've cleared the virus, you're fine, but then, why am I still fatigued, why am I still getting symptoms when the tests all say it's gone... it would be interesting to see or not whether other people who have cleared the virus have the same issues or not.

Participants also felt it was important to have more information relating to blood supply safety and hepatitis C and the impact of contamination with hepatitis C virus, both in Australia and compared to the rest of the world. They wanted more open information on how they came to have hepatitis C and information on financial assistance schemes overseas and in Australia.

Participant 1 - I would like to know why other countries have had big payouts and this particular country has been really forgotten about. [A relative] paid off his mortgage, only 2 years ago... in the UK.

Participant 2 – Because the class action over here got knocked on the head, didn't it?

Participant 1 – But Canada got huge amounts of money.

While the people in the focus groups wanted some information for themselves, they felt there was a greater need to inform the general community.

The public needs to know more about it. That's how discrimination starts in the first place. We know about it. Well, most of the public don't know about it.

really the general public should be getting that information as well. Why just tell us, like for instance don't put your toothbrush in the bowl in with your family's toothbrushes in case you have a bleeding gum and the toothbrush rests on their toothbrush and then we end up, we've passed hepatitis C onto them. Well, that's not the sort of thing you should just be telling us - it's the general public.

Getting information

People in the focus groups were asked how they would prefer to receive information about hepatitis C.

Where it was information about their own individual health, people preferred to have the information given to them by a hepatitis or liver specialist. They also wanted to be able to keep copies of their medical information, including test results, to understand their own medical history.

*Regular visits with liver specialists that understand issues associated with the illness...
Keep my own medical records.*

Knowing what questions to ask the doctor was often a problem. They felt a set of common questions about hepatitis C, treatment and liver health would help them to put their thoughts into words.

One of the biggest things when you go to the doctor, you've got a little 10 minute span, you've got to get in there and ask your questions and get your answers and get out, and if you haven't asked the ones that get to the point

when you are asking, you are going there about something that really you don't know very much about. And you don't really know what questions to ask to find the right information ... where there is something written that might explain what you've got in the back of your mind and you just can't get out.

They thought it would be useful to have the information in print, in emails and on the Internet, including chat sites. Information should be made available in places that people with bleeding disorders and their families visit regularly so that they are likely to come in contact with it.

you need to have a range available because different people take in information in different ways and it needs to be there when people need it... Haemophilia Centre, Haemophilia web sites, with links to the hep C places or even links back from the hep C places would be useful. That's where people go first off.

Or if you got something on the Haemophilia web site, you can put a level of trust in that. As long as it's maintained and kept up-to-date. Because stuff that's 5 years out of date is useless. And it needs to be dated when it's put up, so you know what the currency is.

Us old fellows are not up with this computerised this and this. The newsletter would be the best way.

I would probably need it delivered to me because I'm a bit too lazy to go looking for it... Email is probably the thing that I would look at the most.

Dealing with the stigma associated with hepatitis C was an everyday issue for some people with bleeding disorders. They were concerned that the information should come to them in a way that respected their privacy and that they should be asked about their individual preferences on this, for example, which email or postal address to send it to.

obviously it would have to be a private email address, because I wouldn't feel very comfortable about that sort of stuff.

one thing that I do get a little bit edgy about is some of the material that you get delivered to you from the Haemophilia Foundation, that's fine, it's got the logos and so on on it, but I dread the day that something will come through that has got hep C written all over it... to make sure it is private, confidential, and not necessarily stamped all over it, but just in a plain envelope without any headings and so on.

Priorities

What was most important to people in the focus groups relating to hepatitis C?

Priorities varied. For some, maintaining or improving their health was highest on the agenda.

A quick cure

Maintain the status quo in relation to hep C

Ensure that processes which lead to further complications, like other bloodborne viruses and other effects which would impact on the hep C, if I became sick with something else, that those issues are fixed.

Minimising the effects of it. If you can't get rid of it.

Looking after yourself.

Many spoke about a need to be better informed about hepatitis C and their liver health, and being given a clear understanding of their current and likely future health. They wanted to know not only how hepatitis C affects you physically, but also how it affects you emotionally and the implications for partners and family.

Knowing what happens when we get to the stage of liver transplant and things like that. Knowing what the future holds. When none of these treatments have worked. How many years before they expect something else to happen, cancer to start...

none of us actually talk about hep C - when I'm getting my prophylaxis for haemophilia, actually discussing it with me, that would be nice

Treatment was another common priority. They were hoping for a better treatment experience.

As little discomfort as possible with treatment. And support while we're going through the treatments.

Maybe some information as you go along, just so that you know what is happening. If things are getting better or things are getting worse, what are the complications. And I suppose if you know all those things, then you can perhaps work with them, not the complications so much, but how you are going to feel and to realise that the way you feel is OK, because that's part of the process that you go through.

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

Others felt it was more important to educate the broader community to reduce stigma.

For some hepatitis C was not a high priority in their life. They or their partner or child had already cleared the virus or had other major health problems that they currently had to deal with.

Some felt it was too late to make a difference in their lives. Discussions about priorities focussed on ways to inform or help younger people with hepatitis C or safeguarding the future for the next generations.

for younger people the compensation in relation to the loss of income or the debilitating effects, changing lifestyle, is almost insignificant and I think that should be addressed. Especially if you are a much younger person than I am and trying to establish yourself, especially with the cost of houses and getting yourself set up in a partnership or married life.

Participant 1 - Obviously at our stage of life and we've been through when hepatitis C has been discovered and the doctors are seemingly a little bit tardy at passing information, perhaps the information that has been gathered is available for our children and grandchildren so that they are better informed.

Participant 2 - And that's what it's mainly about..., it's the next generation that us oldies are...

Participant 3 - I think we had TV shows just about everything there is that can go wrong with the human body today, but I've never seen a show, a documentary, anything that goes on haemophilia or on hepatitis.

Participant 4 - When hep C was first discussed and all that... it didn't really impact. I thought, well, just lie down, it will pass in a while. Just another splinter in the backside.

Participant 5 – The further you go down the banister

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

1. A sample of focus group questions is available from Haemophilia Foundation Australia on request.

HEPATITIS C/HIV CO-INFECTION

While it is possible that some people with bleeding disorders in the focus groups were co-infected with hepatitis C and HIV, none disclosed being co-infected to the groups. This section is drawn from discussion with Haemophilia Foundation members who are co-infected and their families, and consultation with Haemophilia Foundation Committee members and haemophilia health professionals.

Hepatitis C and HIV co-infection has had a big impact on people with bleeding disorders. As one member commented, with haemophilia, HIV and then hepatitis C:

How can you look at a community that has had up to three prognoses of... life expectancy thrown up in [our] face, especially in early stages of people's development? ... guys of our age [35-50 years old], our mortality has been in our face since the day we were born. So it certainly gives us a different perspective in regards to values of life ... guys were not expected to live long and productive lives

Nearly all of those who acquired HIV from their blood products also acquired hepatitis C. They were still rebuilding their lives after discovering they had HIV when they were informed that they also had hepatitis C. In some regions, many surviving people with co-infection had been children when they acquired HIV and hepatitis C. Not all of them were told at the time: some parents waited until the children became adults to tell them about their HIV and hepatitis C status, which had a profound psychological effect.

The Haemophilia Foundations and health professionals were aware that some people had ongoing difficulties with managing co-infection. Some preferred not to think about their hepatitis C. Some were alcohol or drug dependent. Some were not working and had financial problems.

On the other hand, some had controlled their HIV well. Others had found their HIV had not progressed, were young and had not yet had problems with haemophilia and were in good health overall. Some were experiencing health problems but had a stable home and financial situation.

In the early days of HIV, people with bleeding disorders who were co-infected were not expected to survive. Some states or territories reported that most did not. AIDS and liver disease took the lives of many. Being co-infected with hepatitis B as well added further health problems. When the new HIV treatments became available in 1996 and HIV became more manageable, the focus shifted to hepatitis C and liver health.

Foundations and haemophilia health professionals reported that most people with bleeding disorders who were co-infected were under the close care of an HIV specialist. They were usually monitored regularly for their HIV so were used to the concept of keeping check on their liver health as well. Some were receiving antiviral treatment for their HIV, while others were not, particularly if they were well or had a different

belief system about health, eg that HIV does not cause AIDS. There was a perception in some states and territories that those who were HIV co-infected were not prioritised and not encouraged to have hepatitis C treatment, particularly in clinical trials where they were often excluded. However, individual members felt their doctors had supported treatment. One said that his doctor needed to persuade him strongly to take up treatment as he was very concerned about side effects, which others described as worse than side effects from their HIV drugs. Some members had taken up hepatitis C treatment so that they could tolerate their HIV drugs better and had been surprised by their increase in energy after treatment. Other people were trying to get control of their HIV so that they could undertake hepatitis C treatment.

Many of those who were co-infected also had severe haemophilia as they were more likely to be using large amounts of blood products regularly and were more at risk of both HIV and hepatitis C infection. As they had grown older, their levels of disability related to their haemophilia had increased. Some young people also had significant disability. It was a universal comment that people with co-infection found it hard to distinguish between the effect of their haemophilia, HIV and hepatitis C, but that the sum of all was to create a greater burden of overall ill-health. Some felt that people currently had other priorities than hepatitis C. This could be dealing with serious health problems caused by HIV, or managing arthritis or joint problems, or dealing with depression and other mental health issues.

As with the focus groups, there were some suggestions about improving the experience of keeping check on hepatitis C and having treatment. Most suggestions related to co-ordinating their care. Some felt it would be good to have a single referral point in their care, eg a haemophilia nurse or social worker/counsellor, who could refer to other specialist services when more information was needed. Under HIV they were also managed holistically by a multidisciplinary team, which meant, for example, they could deal with their nausea with the dietitian. They felt this was a valuable approach, but thought there could be more consultation between their HIV and hepatitis specialists and that hepatitis C could be higher on the agenda of the non-medical part of the team.

The HIV experience had left its scars. Many had experienced discrimination and did not disclose to others lightly. This impacted on their ability to seek support. In some regions people disclosed their co-infection status openly in bleeding disorder support groups; in others they did not disclose. For those who did not want to disclose their hepatitis C or HIV status to their community, they felt a one-to-one “buddying” support system for treatment would work better if the “buddy” lived in a different region or state and they communicated by telephone.

Although the new HIV treatments had given many a future, they were now confused. They had not expected to live more than five years. Some had been diagnosed in their early teenage years. As one member remarked,

How many times have I admitted that I've gone down the wrong path? If I'd known that I was going to be here now... I had a 5 year plan, because 5 years was virtually the limit.

They had not developed long-term goals. Co-infection had impacted on their career choices, their ability to work, their family relationships and their decisions whether to have children. Now they realised they could have a future and had longer-term responsibilities. Some were working full-time, while others were on a disability

pension. Financial issues were complex. The Australian campaign for HIV financial assistance had been very stressful: many had felt angry, some had felt obliged to make their HIV public, discrimination in the community had been rife and the government response inadequate. Some had not registered for financial assistance because of the stigma with HIV. All commented that it is almost impossible to get insurance. Ongoing health issues with hepatitis C, HIV and haemophilia, as well as the length of time they had not been working, meant that getting back into the workforce was problematic for those on a pension. Some were not interested in pursuing legal action around hepatitis C; others thought that financial assistance was a priority.

HAEMOPHILIA FOUNDATION CONSULTATION

Haemophilia Foundations are state/territory-wide self-help, not for profit organisations which are member organisations of Haemophilia Foundation Australia. They provide support, information and services for people affected by bleeding disorders, their families and carers. Foundation Committee members are largely drawn from their local community.

Committees of all state and territory Foundations were consulted for this report. Some had more contact with members who were affected by hepatitis C than others.

National Hepatitis C Strategy

In general there was a perception that people with bleeding disorders and hepatitis C did not fit with the targets in the Australian National Hepatitis C Strategy 2005-2008.

Health and wellbeing

The health of members with hepatitis C was a concern for all Haemophilia Foundations. The Foundations felt the message did not seem to be reaching people with bleeding disorders with hepatitis C that they need to be monitored for their liver health as liver disease can be occurring even when people are feeling well. Anecdotally the Foundations were starting to see members suddenly reporting serious liver disease in their late 30s, 40s and older after many years of not being particularly aware of their hepatitis C.

The Foundations estimated that there was a large proportion of people with bleeding disorders who preferred not to think about their hepatitis C and might have missed the changes in health messages. The earlier message people received from their doctors was not to worry about their hepatitis C if they felt well. People with bleeding disorders had now had hepatitis C for 20 years or more. How many of them were now developing serious liver disease? How could this be prevented for others whose liver disease was still low level or moderate? Many of these did not make contact with the Haemophilia Foundations – were they visiting Haemophilia Centres? If not, how could the current message be made clear to them?

One Foundation commented that it was probable that most people were unclear about their liver health status with hepatitis C. If they were being monitored, most were relying on ultrasounds and blood tests, which might only provide limited information. Most had not had a liver biopsy.

Foundations reported that community members had variable approaches to lifestyle and wellbeing. Some had taken care with how much alcohol they drank while others had not. Some were very involved in sport while their joints allowed it. In some states and territories, the Foundation had worked with the local Hepatitis C Council or

Haemophilia Centre to provide information sessions which included complementary therapies and wellbeing. One Foundation could identify a small group of people who were over 35 and were focussed on making positive lifestyle changes, including diet, vitamin and mineral supplements and liver tonics.

Age-related differences

It was common for Foundations to distinguish between older and younger people with bleeding disorders. They felt that there were age differences in behaviour and priorities around hepatitis C related to the introduction of prophylaxis and the impact this had on preventing haemophilia-related disability.

In the experience of the Foundations, if the symptoms of hepatitis C were not severe, hepatitis C often became less of a priority. Symptoms were less in more of the younger members they saw, who had acquired hepatitis C about 20 years ago, in comparison to the older members who might have been infected for 30 years or more. Some younger men (under 35) tended to ignore hepatitis C and concentrate on developing their social life, career and relationships. In some older men (35-40 yrs and older), joint issues could take priority if these caused them their major problems in daily life, with chronic pain and difficulty in moving.

Multiple Foundations thought that ageing with hepatitis C was an issue for this older generation. They felt there might need to be work done with some services, eg to ensure staff at nursing homes could take care of people with bleeding disorders and blood borne viruses and had access to accurate information about hepatitis C.

A member of the HFA Youth Committee commented that while some young people had been encouraged to be proactive by their parents, others lacked the skills or confidence to ask questions and learn about health problems and their causes. This could affect their ability to find out about their hepatitis C and liver health status.

One Foundation remarked that to get a more distinct picture of the specific impact of hepatitis C, it would be useful to consult with those with more moderate haemophilia and the younger people as they were experiencing fewer problems with haemophilia. They felt that it was difficult for community members to distinguish between the effects of hepatitis C, HIV and haemophilia. There was a synergistic impact of all three, and each added to a burden of illness and disability. Having haemophilia caused pain issues and fatigue, as did hepatitis C. Fatigue was very debilitating and people were too tired to do anything. For members, the impact of hepatitis C became clearer after treatment when the symptoms were reduced.

Treatment

A low uptake of hepatitis C antiviral treatment was common across all states and territories. Haemophilia Foundations saw a number of barriers to treatment:

- **The complacency of feeling healthy.** Some younger men were more focussed on developing a “normal” life, socialising with their friends and becoming independent. Treatment would mean accepting help, a backward step. For those who were older and working, quality of life might be deteriorating but they felt they could not afford to stop and consider their current health. Some did not adjust their alcohol intake or lifestyle.

- **Negative stories in the community about hepatitis C treatment in the past.** Some people with bleeding disorders had interferon treatment when it first became available for hepatitis C. The experience was difficult and results were poor. Some did not know about the new success rates; for others with genotype 1, success rates were still not high enough to explore hepatitis C treatment again.
- **Side-effects could be severe for some** and more unmanageable than HIV treatments. Treatment amplified normal fatigue, and caused mood changes, anger, itching and sleeplessness, sometimes suicidal feelings. Reportedly, treatment could be for long periods (up to 18 months) and with bigger doses as many had genotypes 1a or 1b. This impacted on their ability to work, could lead to putting off or losing career or sacrificing school or university studies. There was stress on the family and members felt isolated. It was difficult for younger people to manage side-effects when they were out of their normal networks: they might have moved out of the parental home or moved cities to advance their career.
- **The “black cloud” of depression with hepatitis C doubled if treatment failed.**
- **Stigma could be a problem.** Members needed to disclose in the workplace because it was likely they would need time off work.
- **Uncertainty about when to start treatment**, especially if young and developing a career path, or juggling a job and family.
- **Access to treatment.** Those who had earlier interferon treatment that failed had difficulties getting into treatment trials and were excluded with the current S100 guidelines. In some regions there were long waiting periods for treatment, especially retreatment. Considering the length of time they had hepatitis C, timely treatment access was an issue. They were interested in new treatments and felt it was a government responsibility to fund free treatment.

In spite of these barriers, Foundations noted that some people were actively pursuing treatment. These people tended to be more self-motivated and informed. The Youth Committee noted that some younger people were planning to fit treatment into their lives in the next couple of years.

Foundations had several suggestions for improving uptake of treatment and the treatment experience:

- **Positive treatment stories published in bleeding disorder newsletters** to counterbalance the negative stories.
- **Change the message about treatment to “don’t wait until your liver deteriorates to go to the liver clinic”.** People with bleeding disorders were used to the culture of “not a lot can be done”, a result of the chronic health problems associated with haemophilia.
- **Good, up-to-date information on treatment** to assist with decision-making. Uptake of treatment would ultimately rely on medical opinion/advice; the doctors could best inform people if the treatment was appropriate for them, but people still needed access to the range of information to help make up their minds.

- **A more proactive approach to treatment from health services:** preparation and planning for treatment, diet, counselling, stress management, coping strategies.
- **Treatment support is vital.** A variety of support would be valuable: peer support network to advise on how to manage side effects apart from the usual medical advice; the haemophilia social worker/counsellor to help manage social and psychological effects.
- **Post-treatment follow-up from hepatitis clinics.** People with bleeding disorders reported that some treatment side-effects, especially “brain fog”, continued after they had completed interferon-based hepatitis C treatment. Hepatitis clinics did not offer follow-up after treatment for ongoing side-effects, yet this was having a significant impact on people’s day-to-day functioning even when treatment was successful.

Services

There was a perception in several states and territories that people with bleeding disorders needed to take the initiative at the Haemophilia Centre to have their liver health checked and to get information about hepatitis C treatment and a referral to the hepatitis/liver clinic. They felt the tendency was to wait for liver health changes before referring. Increasingly people with bleeding disorders had become aware of the need for monitoring by hearing stories of others who have been surprised by advanced cirrhosis or liver cancer or reports of successful treatment.

In comparison, other states and territories reported that the local Haemophilia Centre was more likely to give comprehensive, well-explained information than the hepatitis clinic.

Haemophilia Foundations noted a number of barriers to services for people with bleeding disorders and hepatitis C.

- **Some services were not orientated to the needs of the patient.** There was no co-ordination between haemophilia and hepatitis clinics, so patients had to wait long periods to attend the various appointments and undertaking regular health reviews could take several days. This was difficult for people with joint problems as they experienced mobility and pain problems. There were no services available outside of business hours. Parking at many hospitals was difficult and very expensive, particularly when you had to wait or return for further appointments and had to walk long distances slowly with mobility problems. Administration of some services was cumbersome and added difficulties for patients.
- **Taking time off work for medical care could be problematic,** particularly for younger people who had just started in the workforce. They feared losing their job for taking long periods of time off to attend clinic and some would not attend the hepatitis C clinic because of this.
- **Some hepatitis clinic environments were in a poor state of repair.** Patients felt they were dilapidated, lacking privacy and room for people who could not bend their legs, which could make them reluctant to return.

Suggestions for improving services included

- **Exploring the feasibility of locating the hepatitis clinic at the Haemophilia Centre,** as with other clinics, eg orthopaedics. The Haemophilia Centres were usually well co-ordinated and people would feel at home. Liver function blood tests could be undertaken at the Haemophilia Centre, where the vein care was more suitable for people with bleeding disorders.
- **Offering an option of providing haemophilia and hepatitis reviews on the same day.**
- **Integrating liver health information with the bleeding disorder review in a holistic approach.**

Rural/regional services

Rural and regional issues varied between the states and territories. Contact with remote areas tended to be minimal and little was known about hepatitis C issues and access to hepatitis C treatment and management.

Where the person with a bleeding disorder lived within a few hours' drive of the Haemophilia Centre, they tended to receive their hepatitis C care from the same hospital as it was easier than going on the waiting list for a country GP.

One Foundation reported that they had begun investigating the issues for indigenous people with haemophilia and hepatitis C in regional and rural areas. They were aware that health care may not be optimal and were working with indigenous workers to visit several areas and gain a better understanding of the issues.

Employment and finances

A key issue for people with bleeding disorders and hepatitis C was the ability to work and the impact this had on their financial situation.

Haemophilia Foundations commented that the disability and pain burden for many people with haemophilia was just manageable by the time they reached their 40s. The symptoms of hepatitis C on top of this, especially fatigue, nausea, pain, sleep disorders, depression/mood disorders and memory loss, meant that many had to reduce working hours or give up work. If they had not yet secured their assets, eg paid off their house, or did not have superannuation, they could lose their career, assets and future in a couple of years.

This affected their family as well, especially if the person was the breadwinner. Moreover, treatment generally meant loss of income for about 12 months at least due to side-effects, and might not be successful.

The Foundations noted that treatment for hepatitis C created another set of financial problems:

- People needed to work: they already had financial problems, housing was expensive and they needed two incomes to pay the mortgage
- People were hesitant to stop work when going on treatment. Some wanted to renegotiate working conditions.

- Those who had been on treatment felt it was better not to be working to sustain your credibility in the workplace. Some of these had had a supportive workplace and resumed work afterwards when their health was better.

For younger people there were additional concerns:

- Although they were usually working, they were on tight budgets.
- Stopping or cutting back work to undertake treatment might not be an option financially for many as they could not afford to go part-time.
- They needed to be working long enough to establish a good relationship with the employer before they could cut back their workload and retain their job. It could also create animosity in the workplace if they appeared to be getting special treatment.
- If they undertook treatment while working, they did not have health care cards and were then paying pharmacy dispensing fees for treatment.

One Foundation remarked that it was important not to add to young people's financial burden if encouraging them to seek monitoring and investigate treatment.

Some Haemophilia Foundations identified the need for a financial assistance scheme for people with bleeding disorders and hepatitis C. While compensation was paid to some people who acquired hepatitis C from blood products, most people with bleeding disorders could not obtain compensation because they could not identify the year or batch that caused their hepatitis C infection. Foundations believed the scheme should provide for loss of education and career opportunities, income and assets, protect income and assets, and provide opportunities for further vocational education/training to change careers without loss of income. It should support other costs associated with treatment and care, including travel and parking. It would also need to be able to be invested to secure future income for those who had not yet developed liver problems but might in the future.

One Foundation commented that they were concerned for the future financial burden on the Foundation. They anticipated that as more people undertook treatment and had to cease work or reduce hours, in the absence of government financial assistance more would come to the Foundation for financial assistance. The Foundation would not have the ability to service these needs.

Disclosure and discrimination

Little discrimination relating to hepatitis C was reported with family, friends or the workplace.

However, Foundations noted that people's experience with haemophilia and, for some, HIV, meant that they were much more selective in telling people about their hepatitis C and a better judge of when and where to disclose. Even younger people disclosed carefully in the workplace, with accurate information, and began with their manager, the Occupational Health and Safety Representative and then only the work colleagues they felt were appropriate. They often only told close friends. Their social life could be affected significantly. For example, they usually did not disclose hepatitis C when asked why they were not drinking alcohol with acquaintances.

Younger men were now coming to an age where they were starting relationships and

thinking about how to disclose to their partner. They were concerned about the label of being a drug user that goes automatically with hepatitis C. They found it hard to tell new partners and sometimes did not tell them about haemophilia or hepatitis C until the relationship was more serious or they had a bleeding episode.

Privacy was a major concern and Foundations reported that some had a strong fear of stigma.

- Some did not wish to disclose their hepatitis C even to other people with bleeding disorders.
- Many had not previously disclosed their haemophilia at work let alone their hepatitis C.
- Some people limited the social services they used for fear of loss of privacy around their hepatitis C status. For example, one individual no longer used social services after their medical information, including their hepatitis C status, came up on Centrelink screens when applying for unemployment benefits, possibly related to their disability status.
- A person needed skills and confidence to be able to disclose in the community then educate those they had told about their hepatitis C.

Some Foundations reported that in the past there had been issues with parents disclosing to children: where the father had hepatitis C, but had not told his children; and where parents had not told a child that the child had hepatitis C. In some children's haemophilia services, parents had previously been actively discouraged from telling children about their hepatitis C.

In the past there had been examples of perceived discrimination in health care settings, for example, where people who had accidents or required surgery were left to the end of the surgery list because of their hepatitis C, although this happened more with HIV. Foundations were unsure whether this was still an issue. They also commented that problems with health care systems could be perceived as discrimination by people with bleeding disorders and their tolerance for administrative barriers could be less if they were in pain or fatigued.

Recently there had been examples of discrimination relating to hepatitis C in nursing homes. For example, one residential aged care facility rejected a person with haemophilia and hepatitis C, saying, "we don't want people like that here". In another nursing home, a staff member wore a mask to serve dinner to the person with haemophilia and hepatitis C.

Foundations made the following suggestions:

- It would be helpful to hear **other people's stories** of how they disclosed at work and in relationships
- **Some residential aged care facilities need education** around hepatitis C

Family and relationships

Foundations had noticed that many people felt they needed to reconsider their values when the combination of haemophilia and hepatitis C made working impossible, at around 40 years of age. The reality was that partners and children made huge allowances as the person often needed to sleep for a lot of the day. Time was limited for

helping with household tasks, caring for the children, schooling or homework. This had a negative impact on relationships, especially with teenagers, who had high needs and were not yet developed enough to manage the situation.

Peer support

Foundations felt that peer support, where people with bleeding disorders affected by hepatitis C talk with each other, was important as many people felt very isolated. Examples could be

- The Haemophilia Foundation **men's groups** where men met each other for meals or social activities. These were open, non-discriminatory events where men could discuss their health issues with others who knew what it was like.
- A **'buddy' system, or small support group**, between a person undertaking treatment with someone who has had treatment. This would only work if all were people with bleeding disorders or their partners/family. Options for communication included meeting together, email, telephoning (interstate if there were privacy issues) or using voice communication programs on the Internet.
- **Holding the hepatitis clinic at the Haemophilia Centre** would enable peer support because people would have informal discussions in the waiting room.

Information and education

Generally the Foundations felt there was a lack of knowledge about hepatitis C among people with bleeding disorders. This included a lack of understanding about the range of services available to them.

Some other areas of information and education need included.

- Importance of monitoring hepatitis C.
- Transmission of hepatitis C in the environment. People with bleeding disorders were acutely aware about blood and concerned about passing on hepatitis C in the home and putting those close to them at risk.
- Issues specific to people with bleeding disorders on: hepatitis C, liver health and treatment, support, mental health, relationships, disclosure, financial management.

They made a number of comments about current information on hepatitis C and how people with bleeding disorders accessed information:

- Hepatitis C Council resources were useful and up-to-date. Sometimes the focus on drug use made them appear less relevant
- The bleeding disorder community preferred to have information on hepatitis C delivered in a bleeding disorder environment, eg displayed in the Haemophilia Centre, given to them by the haemophilia social worker/counsellor or nurse, reprinted in haemophilia newsletters, linked to HFA web site. Few were members of Hepatitis C Councils
- Hepatitis clinics usually provided information on hepatitis C well
- People would often look for hepatitis C information on the haemophilia web sites first, especially younger people. Older people did not necessarily have access to web-based information
- Print-based information via haemophilia newsletters was very important, and also information that they could collect at their monthly appointment at the Haemophilia Centre

- Some people had lower literacy and related better to practical approaches around information
- Younger people tended not to read print newsletters but their parents did and attempted to pass on the information and promote it
- Younger people preferred information in a brief email newsletter with links to more detailed information on the HFA web site. Most younger people had access to email, and were unlikely to use SMS technology for links to web-based information
- Web blogs would provide an opportunity for young people to discuss issues relating to hepatitis C, but the most effective way was to meet face-to-face, eg in a popular venue

Several Foundations thought that a “men’s health” approach would work best to provide education to men with bleeding disorders. Education and information would be centred around the things the men were interested in. For young men this included jobs, relationships, study, cars, stories of people with bleeding disorders involved in adventure activities. Workshops including hepatitis C should have a focus on wellbeing and also cover physiotherapy, exercise, managing joint issues, telling others, mental health and depression. It would be important to have an age mix and to include enjoyable activities and unstructured time for the men to talk and mix casually. Mentors, eg from the Youth Committee, could be available to work informally with the group.

Priorities

From the perspective of Haemophilia Foundations, priorities in hepatitis C and bleeding disorders included

- Encouraging people with bleeding disorders affected by hepatitis C to seek up-to-date information and be monitored for their hepatitis C through
 - Education. It should also cover liver health, treatment and lifestyle
 - More accessible services, eg holding the hepatitis clinic at the Haemophilia Centre
- Treatment
 - Access to treatment
 - Hearing about treatment from others who have experienced it
 - Peer support during treatment
 - A cure
 - Apology: it was important to the community to receive an apology from the government about the transmission of hepatitis C through the blood supply

HEALTH PROFESSIONAL CONSULTATION

Haemophilia Centres and haemophilia services are staffed by a team of health professionals with expertise in haemophilia: haematology specialist doctors, nurses, social workers or counsellors and physiotherapists. Staffing levels depend on the size and funding of the Centre or service.

Eighteen haemophilia health professionals from various states and territories participated in the consultation for this report, including nine nurses, seven social workers or counsellors and two doctors. Two hepatitis clinic nurses also contributed.

Many issues they raised were similar to those discussed by the Haemophilia Foundations. Only the issues where they provided different perspectives will be reported below.

Hepatitis C knowledge

Like the Haemophilia Foundations, the haemophilia health professionals were concerned about the current health of people with bleeding disorders and hepatitis C. They had seen cases of their patients with hepatitis C developing serious liver disease, and some of their patients had died. They were concerned for the liver health of those who had not had their hepatitis C checked recently.

Many Haemophilia Centres were working actively on hepatitis C in liaison with the hepatitis clinics and reworking their review procedures. Where proactive hepatitis C reviews had been in place for longer, the health professionals reported that more patients were aware of their hepatitis C status. They felt there were still large numbers of patients for whom hepatitis C was not a high priority. These patients preferred not to think about their hepatitis C, especially if they did not have symptoms. In the 1980s and early 1990s there was some uncertainty about the long-term effects of hepatitis C. Many patients were told not to worry about it and had not heard more recent health messages clarifying the need to have liver health checked as liver disease could be occurring even when they felt well. Some of them had been children when they were first diagnosed. They had all now moved on to the adult Haemophilia Centres and these Centres were sometimes unsure of the patients' understanding of their hepatitis C.

Checking whether the person understood their health status and test results could be difficult. Very young men sometimes relied on their parents to follow up their results and talked little during consultations. People would sometimes ask the same question again later, indicating that they had not understood or remembered when results were first explained to them.

Processes for referring patients for hepatitis care varied:

- Some referred patients to the hepatitis clinic for monitoring but may still do the blood tests at the Haemophilia Centre for the hepatitis clinic

- Some referred patients to the hepatitis clinic if they showed changes to liver function, but conducted basic liver function tests at the Haemophilia Centre
- All referred patients to the hepatitis clinic for treatment
- Some patients reported that their GP monitored their liver health

The Centres that provided monitoring commented that some liver function tests were expensive, for example, ultrasounds or magnetic resonance imaging. If the tests were not government funded, this could provide the Centre with added issues for financial management.

Haemophilia nurses sometimes provided informal support, answering questions about hepatitis C and talking about symptom management. Some were developing more structured approaches, eg one Centre was aiming to develop a patient management plan for chronic illness with their patients, which they thought would provide a holistic, patient-centred approach to hepatitis C management.

As the hepatitis clinic and Haemophilia Centres were separate units, communication between the two units about individual patients was variable. Patients were not always flagged as having a bleeding disorder on hospital patient databases. If a patient with haemophilia did not go to their appointments at the hepatitis clinic, this might not be reported to the Haemophilia Centre. Some patients did not want their information shared between units. In other cases, hepatitis clinic nurses rang regularly to discuss the progress of individual patients. Some units were working together at ways to improve communication.

Contact with people with hepatitis C

Haemophilia Centres were reviewing the hepatitis C status of their patients, some systematically, others as the opportunity presented.

Opportunities for raising the question of hepatitis C monitoring were limited. With the improvements in treatment and home delivery, patterns of contact with the Haemophilia Centre had changed. Some patients, particularly younger men, no longer attended. If patients had mild or moderate haemophilia or von Willebrand disorder, they usually would not need to come in to the hospital. There could be difficulty in contacting them as their details could be out-of-date. Health professionals suspected that people who were no longer on mailing lists might not know about changes in hepatitis C.

Methods to initiate a hepatitis C review for patients included:

- Mailing out letters regularly reminding them to make an appointment for review
- Mailing out new information about hepatitis C
- Providing a hepatitis C review if the patient reported symptoms or came into hospital for bleeding disorder care or another procedure

Patients sometimes did not respond to the letters. With low staffing levels and lack of resourcing, staff might not have time to undertake a mail out, or follow up patients who did not make appointments for review.

Health professionals noted that some patients were stimulated into action on hepatitis C through the need to know their status, for example, completing employment forms, or starting a new relationship.

Treatment

As with monitoring, patients often needed specific motivation for treatment. This could be thinking of the future with a new relationship or having a young family or seeing the benefits of someone else's treatment success. Health professionals commented that patients who had not had hepatitis C treatment before were more interested in treatment. Those who had previously had unsuccessful treatment often needed higher success rates to take on treatment again. For young men, treatment might not be an attractive option if they felt they had already spent a lot of their life in hospital.

Some patients had undertaken treatment successfully with few side-effects. Side-effects were hard to manage for others. One hepatitis clinic nurse remarked that patients with bleeding disorders were likely to be more socially isolated than other patients in the clinic and tended to raise their side-effects and other problems less in clinic visits.

Health professionals made several recommendations about treatment:

- Link patients to a particular hepatitis specialist whom they see regularly. Patients who had this experience tended to do better on treatment.
- Prioritise preparation and support during treatment
- Involve partners and families. Side-effects could have big impacts on relationships. Patients sometimes reported that "everything was fine" when their families had witnessed severe mood swings, suicidal thoughts, violent outbursts, and abuse in the home.
- Provide support after treatment. Some people continued to experience side-effects for some months after treatment.
- Greater access to hepatitis C monitoring and treatment in rural and regional areas. There were often long waiting lists – one regional area reported two-and-a-half years – and treatment was not available at all in some areas. There had been cases of rural patients developing serious liver disease such as liver cancer while waiting for treatment.

Social issues

Haemophilia health professionals described the diversity of social issues affecting the range of patients they saw.

Some people with bleeding disorders were largely unaffected by their hepatitis C. For some, the worries it caused sometimes kept them awake at night. Because of the demanding nature of the discussions, the focus groups necessarily represented people who were functioning well. Many others were experiencing greater social difficulties. They were withdrawn, not taking care of their health and using drugs and alcohol heavily, often unemployed, occasionally in prison, and usually experiencing depression and fatigue. They often did not seek counselling or support.

- As people grew older, pain with their joints and arthritis could become a big problem. They were used to being stoic and usually understated their hepatitis C symptoms or the side-effects of treatment. If asked, they would often say they were in good health, but would identify symptoms if shown a list of common symptoms for hepatitis C.
- Some regions did not have a bleeding disorder community as such. In some areas people may have known each other and discussed their hepatitis C, but in most they did not know each other and hepatitis C was seldom mentioned.

- To have an effective therapeutic relationship, it was important to build trust. This took a long time with this group due to their experiences with bleeding disorders and hepatitis C.
- Some were angry about having hepatitis C: they felt they had been betrayed twice with HIV then hepatitis C and had ongoing concerns with blood product safety.
- How they were told they had hepatitis C had a big impact. Some were not told as children and only found out as adults. Some found out when a doctor or nurse mentioned it in passing or they saw it in their medical file.
- Young men were struggling to become independent. Some had difficulty establishing relationships.
- There had been cases of discrimination in the workplace, particularly for young people just starting work who were unsure of their rights and whether they had to disclose.

Working and finances

The majority of people with hepatitis C seen by the health professionals were working.

Many were determined to work as long as they could, but could not maintain full-time work as they grew older. This created a big financial burden for many. If they were in administrative jobs or had good superannuation, they were more likely to be able to adjust their working hours to part-time and manage financially. Those who were self-employed had difficulties getting income protection insurance. They could not access sickness benefits through Centrelink. Their assets were tied up in their business and many would not contemplate treatment as their financial situation was too tight.

For those who were unwell and on social service benefits, Centrelink payments were not adequate and often their wives had to return to the workforce full-time. If they had a genetic history of haemophilia, there were often lower incomes over generations and little inherited family money. Some men were frustrated when they wanted to provide for their families. They may have missed some of their schooling due to bleeding episodes and their absences from their families when in hospital could be difficult. Many were depressed. The situation could be stressful for the family as a whole.

Raising awareness

Health professionals felt that there was good information available from Hepatitis C Councils. Any new information for people with bleeding disorders should be targeted to specific concerns, eg for young people wanting to have families.

They had several suggestions for raising awareness about hepatitis C among people with bleeding disorders who were not in contact with Haemophilia Centres or Haemophilia Foundations:

- Articles in local media, health magazines and women's magazines. These might be read by mothers and wives who were likely to draw them to the men's attention
- Information on men's health web sites
- Audio segments with downloadable podcasts, eg on popular radio shows or web sites
- Making GPs aware that this was an issue

OTHER CONSULTATION

Hepatitis C Council consultation

Hepatitis C Councils reported little contact with people with bleeding disorders. They were aware that people with bleeding disorders preferred to receive information about hepatitis C through bleeding disorder networks. They were happy to make their resources available for distribution through Haemophilia Centres or for reprint in Haemophilia Foundation newsletters or web sites.

Some also had dedicated rural workers. In rural and regional areas access to good hepatitis care and treatment was a universal problem. The rural workers kept up-to-date with the latest information on availability of hepatitis services in rural and regional areas and shared this information with any workers or individuals who were seeking it.

Consultation with PLWHA organisations

Like the Hepatitis C Councils, the organisations for people living with HIV/AIDS (PLWHA) that were consulted reported that they had little contact with people with bleeding disorders who were co-infected with hepatitis C and HIV. They understood that people with bleeding disorders preferred their own support networks, and were supportive of their needs. The organisations were open to providing support or capacity building, for example, with public speaking, and made their resources available through bleeding disorder environments, eg the haemophilia social worker/counsellor.

KEY FINDINGS

Results from the focus groups and consultation carried out in 2007 were consistent with the results from the HFA hepatitis C member survey in 2003.

People with bleeding disorders who were HCV antibody positive in 2007 acquired hepatitis C through contaminated blood products more than 20 years ago. Some were co-infected with hepatitis C and HIV, others also with hepatitis B. Some were children or teenagers at the time they acquired hepatitis C.

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

Diagnosis

- Many people with bleeding disorders and hepatitis C were angry at the way they acquired hepatitis C. They felt there was not enough care taken of their needs when they were dependent on blood products for their survival and that blood supply decisions by health authorities were weighted towards economic considerations.
- Finding out they had hepatitis C after living through the HIV epidemic increased the psychological impact of hepatitis C on people with bleeding disorders. Some were co-infected with hepatitis C and HIV. Many no longer trusted the safety of their blood products.
- They experienced discrimination in accessing new safer blood products because of their hepatitis C infection: before 2004 new recombinant products were not available to people who already had hepatitis C or HIV.

- Many people with bleeding disorders had a negative experience of being told they had hepatitis C, leaving them angry and bewildered.
 - Some were not informed until many years after they acquired it, including some who acquired hepatitis C as children
 - Some were alerted to it through the local media
 - Some were told in passing by a doctor or nurse who read it in their medical file
 - Some were informed very cautiously and became suspicious that they were not being told the whole story
 - Some were called in to the hospital for further testing and informed at that point but few received counselling
- Some felt that an acknowledgement by authorities that it was a health system error would help the community deal with its anger.

Health

- Some people did not have symptoms and felt that hepatitis C was not affecting them. This included people who had cleared HCV naturally or through treatment.
- Most felt chronically unwell and described feeling “down”, tired, lacking stamina, having liver pain, nausea and “brain fog”.
- Health professionals and Haemophilia Foundations reported that many people were experiencing major depression.
- There was a culture of being stoic and many played down their symptoms or made jokes about it.
- Those with moderate or severe haemophilia were used to the joint pain and disability caused by their haemophilia. The added burden of symptoms from hepatitis C often made their level of disability unmanageable from the age of 35-40 years, particularly with fatigue and mental health issues. Liver disease from the hepatitis C also affected their ability to tolerate anti-inflammatory drugs which meant they were no longer as mobile and experienced more pain.
- Some had made efforts to improve their health with diet, complementary therapies and exercise and adjusting their alcohol intake. This could be difficult if they were depressed or had joint pain and arthritis. Not drinking alcohol also limited their social activities, eg having a beer with their friends at the pub. Some people had complex physical, social and mental health problems and were using drugs and alcohol heavily. They were less likely to seek support and to check the impact on their liver health.

Keeping a check on liver health

- Knowledge about the long-term effects of hepatitis C was limited in the early 1990s when many people were diagnosed. At that stage some were told not to worry about it and had not heard more recent health messages recommending that they have their liver health checked. It is now known that after about 20 years some people with hepatitis C begin to develop more serious liver disease.

- Haemophilia Foundations and haemophilia health professionals were concerned that a large proportion of people with bleeding disorders might not know their current hepatitis C or liver health status. They might not realise their liver health was deteriorating and miss an opportunity to have hepatitis C treatment. In the last few years there have been a number of cases of people with bleeding disorders and hepatitis C suddenly becoming sick or dying from serious liver disease.
- Some state or territory health services were more active in monitoring than others. In some services, patients were sent reminder letters, followed up by phone calls and received regular blood tests and ultrasounds. Others reported being under-resourced and had to rely on patients to make regular appointments and keep them. Monitoring might be limited to blood tests.
- Some people with bleeding disorders reported that they did not see hepatitis C as a high priority and did not monitor their liver health regularly.

Understanding test results

- In general people with bleeding disorders felt they needed to be proactive to get information about their test results from hospital staff. Older people felt more confident and skilled to obtain the information they wanted. Younger men were more likely to be confused about what the tests were and what the results meant. They were uncertain how to ask questions.
- Hospital staff reported that some people appeared to have difficulty understanding their test results and would ask the same questions several times. Very young men might not communicate a great deal and it could be hard to find out how much they had understood.
- Where people did not understand the implications of their test results, they sometimes made decisions that led to serious liver damage, such as not being monitored or not seeking treatment.

Treatment

- Negative stories about treatment were more likely to be published and talked about in the community than positive stories. Many people might not be aware of the improvements in new hepatitis C treatments.
- While some people had undertaken hepatitis C treatment successfully, for many others treatment had failed or they had relapsed after treatment, particularly if they had interferon monotherapy in the early 1990s. Some had not had treatment, some were considering treatment and some would not have treatment again until the likelihood of it being successful increased.
- Some people had experienced few or no side-effects when they had treatment. Others had moderate to severe side-effects. This had an impact on their relationships, family life and ability to work. Some stopped working 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 could have adequate support.

- Access to subsidised treatment could be limited for people with bleeding disorders. Under Pharmaceutical Benefits Schemes (PBS) Section 100 guidelines, people who had already had interferon-based treatment were excluded from government-subsidised treatment, which included many people with bleeding disorders. In rural and regional areas, treatment was sometimes unavailable or waiting lists were long. This sometimes meant that liver disease became life-threatening while the person was waiting for treatment.

Health services

- Overall people with bleeding disorders and hepatitis C were looking for holistic health care that took into account both their bleeding disorder, their hepatitis C and the other aspects of their lives. Partners or carers should be encouraged to be involved.
- Relationships with doctors depended on their individual approach. Some people were very satisfied with their relationship with their doctor, while others preferred a more positive and collaborative style.
- In some services communication between staff in the Haemophilia Centres and hepatitis clinics was more frequent than others. There was a preference for seeing the same doctor consistently to understand and monitor progress.
- Haemophilia and hepatitis appointments and services were usually not co-ordinated with each other. People often had to make a few visits to undertake their regular review and had to wait long periods to complete the testing process. This could be expensive and painful for those with mobility problems. It could be very inconvenient for those from rural or regional areas. For those who were working, it limited their ability to undertake regular monitoring or treatment.
- There needed to be more access to hepatitis clinics to ensure that the person was monitored and received treatment in a timely way.

Carers

- Partners and parents were usually actively involved in caring for the person with hepatitis C, a role they needed to play sensitively and carefully. They sometimes attended clinic with the person, helped them to keep check on their hepatitis C and supported them if they became sick, during treatment and with lifestyle changes.
- Carers limited their own working hours to provide this support. This often added to the family's financial and relationship difficulties: partners also needed to work to maintain household income if the person became too ill to work full-time. Fatigue and depression from hepatitis C and mood changes during treatment could put stress on the family. Carers often felt very isolated.

Living with others

- People with bleeding disorders and hepatitis C were often concerned about risks of transmission to others in their home or in relationships.

- Symptoms of hepatitis C, including fatigue and mood disorders, had a major effect on people's home and social life. They were unable to do their share of household tasks or care for the children and many no longer socialised outside the home. If they were depressed and lived alone, some withdrew socially.

Working and finances

- For those who did not have symptoms, hepatitis C had made little difference to their work or their finances unless they decided to have treatment.
- Even with government subsidised treatment, there were considerable additional health costs with hepatitis C, including pharmacy, travel, general practitioners, complementary therapy and dietary costs. People who were working did not have a health care card and had to pay full costs for any non-subsidised services or products.
- Growing up with severe haemophilia had meant missing part of their schooling and making career choices based on what they could manage without causing bleeds. Having hepatitis C created a double burden. With symptoms many had to reduce or stop work from their late 30s. Treatment caused big disruptions to working life. Those who were self-employed or in physically demanding or high profile stressful jobs were most likely to lose their career and suffer great financial loss as a result. Some struggled to stay at work which put a strain on their health.
- Many had experienced being unable to get health, travel, life, mortgage or income protection insurance. This left them and their family unprotected if their health deteriorated.
- Some of those who were unable to work were reliant on disability pensions and other government support. This was inadequate to maintain their lifestyle and could result in financial hardship and the loss of family assets, such as the family home.
- Partners often had to return to the workforce, sometimes full-time, to maintain the family income. Husbands often felt frustrated and depressed at being unable to provide for their family.
- The need to stop work or reduce their workload was an added difficulty for those considering treatment as many were not in a financially secure position and they and their families would suffer great hardship if they did not continue working. This included younger people on tight budgets and new to the workforce. In some cases adult children returned to their parental home to be cared for while they were undergoing treatment.

Telling others

- People with bleeding disorders' experience with haemophilia and, for some, HIV, meant they were more selective in telling people about their hepatitis C and a better judge of when and how to disclose.
- Disclosure in new relationships could be difficult. People feared rejection.

- People felt under pressure to inform professionals about their hepatitis C status if the professional was not taking proper infection control precautions and blood was involved.

Stigma and discrimination

- Most people had not experienced a great deal of discrimination, but they usually did not tell many people about their hepatitis C status.
- Some had experienced stigma in the community where hepatitis C was associated with injecting drug use and casual unsafe sex. Many were concerned about the stigma and were very careful about their privacy. They disclosed to few people and sometimes isolated themselves socially and from social services.
- There had been cases of discrimination in hospitals and other health care settings, in the workplace and in residential aged care facilities. This was often due to an unreasonable fear of transmission.

Support and care services

- The complexity of issues and concerns about privacy meant that there was a great need for confidential counselling and support in this group.
- Peer support with other people with bleeding disorders and hepatitis C was very important to manage the feelings of isolation.
- Support was also important for partners and carers.
- The combined disability issues of their bleeding disorder and hepatitis C meant that increasing numbers of older people would require supported care and accommodation.

Information and education

- High quality information about hepatitis C was available from Hepatitis C Councils. Sometimes the focus on drug use made the resources appear less relevant to people with bleeding disorders.
- People with bleeding disorders preferred hepatitis C information to be given to them in bleeding disorder environments, eg, Haemophilia Foundation newsletters, web sites, Haemophilia Centres. Few were members of Hepatitis C Councils or used the Councils directly.
- There was a need for 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.
- People with bleeding disorders and hepatitis C were of varying ages and accessed information in different ways. Some used email and the Internet first, others preferred printed leaflets and newsletters. It was important for them to get individual information about their health face-to-face with specialist doctors and nurses.

- Men with bleeding disorders and hepatitis C were interested in their wellbeing and might be more open to learning about hepatitis C in an environment with focus on other activities that interested them and opportunities to chat informally.



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