



Living with more than Hepatitis C

**A study of Hepatitis C and
Discrimination**

Written by Maud Blair *and* Joanna Blair

Acknowledgements

We would like to thank the following individuals and organisations for their help and support of this project.

National Hepatitis C Resource Centre Advisory Committee members:

Dr Fortune Ncube, PHLS

Dr Graham Foster, Consultant Hepatologist, Queen Mary's Hospital

Yvonne Dawes, Clinical Nurse Specialist Royal Surrey County Hospital

John Morris, Hepatitis Worker Haemophilia Society

Neil Hudson, Patient representative

Nigel Hughes, Chief Executive British Liver Trust

Grant McNally, Chair of UK Assembly and Tania Machell, Head of the National Hepatitis C Resource Centre who conducted the hearings.

Particular thanks must go to all the individuals who had the courage to come forward and share their often harrowing experiences with us. Without their candidness, frankness and honesty this project would have been impossible.

Thanks also to: Birmingham Drugline, The Eddystone Trust (Plymouth), STASH The Waterloo Project (Manchester), Swansea Drug Project and Capital C (Edinburgh) for hosting the hearings and helping identify individuals who took part.

Julia Cabbassi, Author of the Australian Hepatitis C Discrimination Report for her invaluable advice and help.

FOREWORD

By Basil Williams
Chief Executive, Mainliners

This important document is a unique study into the level of discrimination faced by people living with hepatitis C and represents a culmination of a key priority of the work of the National Hepatic C Resource Centre.

It is well documented that a hepatitis C diagnosis can be devastating and this is often further compounded by experiences of social exclusion. Our report shows that many individuals who have disclosed their hepatitis C diagnosis found their employment, health, residential, family or social status completely disrupted often resulting in feelings of isolation, social exclusion, depression and anxiety. Sadly none of what you will read in this report will come as a surprise, and much of the evidence may strike familiar cords with those who are involved with hepatitis C, either from a professional, personal or carer perspective.

The DOH (Department of Health) consultation document for a national strategy on hepatitis C for England highlighted the need to raise both public and professional awareness of hepatitis C. In light of the evidence of discriminatory practices being adopted in many sectors, which our report uncovers, this is an onerous task and one, which cannot be easily tackled or underestimated. The government must take a lead in ensuring that the strategy provides not just the framework but also effective implementation tools to ensure the development of appropriate and informed policies, which protects and safeguard rights of individuals.

Therefore in this report we have tried to identify and highlight many of the areas where legislative changes could reduce the experiences of stigma and discrimination experienced. I believe some of the stereotypes which lead to prejudice and discrimination is often prompted by an un-rational fear of transmission and comes from a lack of knowledge and ignorance and can be dealt with by providing training and information, both targeted and generally.

In carrying out the hearings we also aimed to raise the profile of hepatitis C . This is in line with our overall strategy to try and identify solutions for tackling the issues faced by those who are marginalised, isolated and excluded because of blood borne viruses. And now by reporting these facts I hope it will help to influence policy development and ensure that people living with hepatitis C have equity of access to a range of services.

Every person involved in the process of evidence gathering must be sincerely thanked, as without their contributions this report would miss the wealth of insight, depth, truth and poignancy their stories have given us and which makes this report possible.

29.04 03

CONTENTS

	Page
Foreword	i
Executive Summary	1
Introduction	4
Facts about hepatitis C	5
Methodology	7
Principle Findings - Interviews	8
Public and Family Responses	8
Accessing Services	9
Association with Drugs	11
Professional Services	13
Issues of Concern	15
Impact of Discrimination	15
Effects on Family	16
Principle Findings – Questionnaires	16
Public and Family Responses	16
Accessing Services	17
Issues of concern	18
Association with drugs	19
Impact of Discrimination	19
Hepatitis C and Gender	23
Conclusion	24
Policy Implications	26
Bibliography	27
Appendix 1 Hearings Flyer Notice	28
Appendix 2 Study Questionnaire	30

Living with more than hepatitis C

A study of Hepatitis C and Discrimination

EXECUTIVE SUMMARY

I keep it under my hat due to my fear of responses. This itself causes me to live a great deal of my life “under cover”. I am unable to express my fears, unable to justify my fatigue, unable to seek understanding and support. I feel I will be placed in a situation of the “deserving or undeserving” victims of a virus. I am a silent sufferer.

1. Background

This report presents the findings of a survey on discrimination experienced by people living with hepatitis C. There were three main components to the survey:

- group and individual interviews
- questionnaires
- telephone responses.

The study was carried out between July and November 2001 by the National Hepatitis C Resource Centre. Flyers were sent out to all drug services, to hospital clinics, to The Haemophilia Society, via the Hepatitis Nurse Specialist Forum, via the Mainliners newsletter and via the website.¹ In addition, the main contact at each venue took an active role in inviting clients to attend and helping to arrange the logistics for the meetings.

These interviews were conducted in Edinburgh, Manchester, Birmingham, Swansea, London and Plymouth. There were an average of 4 people at each interview, which was tape-recorded and later transcribed. A Total of 24 participants took part, 17 men and 7 women.

112 people returned survey questionnaires, 86 men and 26 women.

Notes from 4 of the telephone responses were analysed. The actual number of calls made is unknown.

The main aim of the study was to establish the extent and nature of discrimination experienced by those living with hepatitis C.

2. Main Findings

2.1. Interviews

- Mode of transmission - 9 people were certain that the mode of transmission was through past injecting drug use, 1 was certain they had caught it through infected blood products, and 14 were uncertain or failed to comment about their mode of transmission.
- Family and friends - Every person interviewed felt that their friends and/or family relations had been affected in negative ways, some experiencing total rejection from their loved ones and others finding relationships increasingly strained.
- Issues of concern - these included: the fear of disclosure of their condition; the physical

¹ See Appendix 1

and mental illness and pain experienced as a result of their condition; negative treatment received from professional staff when seeking help; the lack of awareness /training/knowledge of those in professional services and of the general public; the effects of discrimination on their health and their social lives; their employment prospects; the difficulties of accessing services such as insurance, mortgages and professional health care, and very importantly, the implications for their dependents.

- Accessing services - Most people in the survey had experienced difficulty in accessing services and appointments, with some having never been referred for treatment whilst others having to wait up to three months to have simple tests done. Particular difficulty and discrimination was experienced in accessing dental services.
- Association with drugs - Most discrimination was experienced as a result of the association of the hepatitis C virus with injecting drug use.

2.2 Questionnaires ²

- Mode of transmission - 51 respondents had caught hepatitis C via infected blood products; 36 via injecting drug use; 7 suspected sexual transmission and 13 did not know.
- Diagnosis - The majority (66) had had their diagnosis carried out at a hospital; 21 by their General Practitioner, 4 in prison, one was following a blood donor session and the rest were at alcohol or drug detox centres. 3 respondents claimed to have been diagnosed in the 1970s; 10 in the 1980s; 76 in the 1990s; 11 in the year 2000 and 8 did not know. (N.B. As hepatitis C was first identified in 1989 (NHS Briefing Paper, 2002), respondents who claim to have been diagnosed before that are probably referring to possible time of infection rather than diagnosis, or possibly to Non-A Non-B).
- Family and friends - Most respondents did not disclose their hepatitis C status to the general public, and others did not disclose to friends. Experiences with family and friends were variable. Most reported supportive families and friends but a significant minority had had negative responses ranging from 'they were upset' to 'I was treated like I had leprosy'.
- Issues of concern - The greatest concern expressed was around fear of passing the virus to family and friends. Most expressed fear and anxiety about the future and the likely or possible deterioration in the quality of their lives. Related to deterioration of health were the financial implications of giving up work. The majority expressed concerns about the lack of public awareness of hepatitis C and continuing ignorance amongst health care professionals.
- Accessing services - Over half the respondents had no difficulty accessing services. Of those who had had difficulty, most related to dental and insurance services.
- Hepatitis and drugs - The majority of respondents (63) expressed concern that they would face discrimination because of the association of hepatitis C with injecting drug use. 28 were not concerned, 9 were not sure and 3 gave no response.
- Professional services - Most (61) had had negative experiences with professional services. 29 had had no problems, 9 were not sure and the rest did not respond.
- Impact of discrimination - The greatest impact of experiences of discrimination had been depression, suicidal feelings, loss of self worth and confidence, isolation leading at times to reclusive living, loss of family and friends, loss of employment and increased insurance premiums.

² See Appendix 2

3. Recommendations

It seems clear from the above, that a number of steps need to be taken in order to improve the lives of those living with hepatitis C and also to promote a healthy awareness of the condition for the benefit of the public at large.

- i. There is need for a UK wide study to ascertain the extent of spread of hepatitis C and to develop better methods of prevention, control and eradication of hepatitis C.
- ii. There is a need for the Department of Health, working with partners, to conduct a national education programme to promote the facts about hepatitis C in order to reduce the stigma associated with the condition and which is potentially threatening to public health.
- iii. Factual knowledge and guidance about all aspects of hepatitis C need to be rigorously promoted to the healthcare sector as a whole, drawing on best practice from local and international examples.
- iv. The Department of Health must provide leadership to the medical profession and the healthcare sector on professional attitudes to patients which are non-judgemental and based on humane and compassionate consideration of needs.
- v. Guidance should be provided to local health authorities to conduct assessments of individual needs which allow for tailored provision adequately resourced by the Department of Health.
- vi. Help is needed to set up local advice centres where individuals can obtain medical, legal and other appropriate information that is free and unbiased
- vii. Such centres should be adequately equipped to provide pre and post-test counselling to patients
- viii. An investigation of the extent of spread of hepatitis C in prisons and the quality of treatment afforded to hepatitis C positive prisoners, is pressing.
- ix. Given the over-representation of minority ethnic groups within the prison service, these groups could be particularly vulnerable to hepatitis C and could experience double discrimination based on their hepatitis C status and their ethnicity. Monitoring the prevalence of hepatitis C by ethnicity is necessary.
- x. The Disability Rights Act must be made clear in relation to those experiencing discrimination on the basis of their HCV condition.
- xi. We recommend an assessment of gender differences in the experiences of those who live with hepatitis C in order to provide appropriate services to men and women

1. INTRODUCTION

Mainliners have for many years advocated for individuals at risk of blood borne virus infection. As such, they have become one of the leading specialists in the collection and dissemination of information about the hepatitis C virus and advocates for hepatitis C positive individuals.

In 2000 Mainliners set up a National Hepatitis C Resource Centre. The aims of the Centre are:

- To provide practical support and advice on all aspects of management and treatment, to people living with hepatitis C
- To develop a resource information bank which disseminates specialist information on the virus
- To provide specific advice to professionals and carers through training and seminars
- To liaise with local and central government on the need to effectively resource and maintain a national priority on hepatitis C
- To promote an increased awareness, understanding and knowledge on matters relating to hepatitis C
- To advocate for the establishment of hepatitis C support groups on a regional basis to ensure effective peer support and national focus
- To disseminate up-to-date information and models of good practice via research, conferences, seminars and consultancy

Over the years, there has been a growing awareness of the disadvantage experienced by those infected by the virus as a result of the stigma attached to hepatitis C. Telephone calls to Mainliners, to the Centre and letters to the Mainliners monthly magazine indicated that individuals were experiencing different forms of social exclusion which were directly, or believed to be directly, linked to their hepatitis C status. In order to raise official and public awareness and to better inform the work of the Centre, information was collected from a wider range of informants. A research project was begun in 2001 whose main objectives were:

- To assess the extent of discrimination
- To identify areas of worst discrimination
- To assess the impact of discrimination on individuals and their families
- To assess the availability of support and the level of responsiveness of local services to the needs of those living with hepatitis C.

The overall aim of the exercise was to ensure that the research findings informed policy and practice in a National Hepatitis C Strategy.

2. SOME FACTS ABOUT HEPATITIS C

This section draws on extracts from the *NHS Briefing Paper Hepatitis C: Essential information for professionals (2002)*.

As the Report attempts to reproduce the views of participants as far as possible, any factual errors in their statements, especially as they relate to medical treatment or medicines prescribed, need to be seen in the context of inadequate public information about the virus and against the facts as set out in the NHS document. It is important to note here that even where the medical practitioner may have been correct in their advice or recommended treatment, the loss of confidence and experience of distress on the part of the patient may be due to the manner in which the issues are discussed.

The section provides information on the following selected topics as given in the NHS document: What is hepatitis C? How is hepatitis C transmitted? How is it diagnosed? and Prevalence in the UK.

2.1. What is hepatitis C?

HCV is a blood-borne virus that causes liver disease. The effects of HCV infection vary from one individual to the next. Many people will remain symptom free, some will develop cirrhosis and a few will develop liver cancer. It is thought that significant numbers of people in England may be chronically infected with HCV. These carriers may be passing the virus on to others. Unlike hepatitis A and B there is no vaccine against HCV, but infection is preventable through strategies that minimise transmission.

Studies in the UK suggest that around 0.4% of people in England are chronically infected with HCV. As the average list size for GPs in England is 1800 patients, this equates to about seven patients per GP.

2.2. How is hepatitis C transmitted?

HCV is carried in the blood and has been detected in other body fluids. However, blood has been identified as the main vehicle of transmission.

The major route of transmission in the UK is by sharing equipment for injecting drug use, mainly via blood contaminated needles and syringes. Spoons, water and filters may also be vehicles of infection.

- *There is a risk to recipients of blood transfusions (before September 1991), or blood products (before 1986) in the UK. For example, there is a high prevalence of HCV in people with haemophilia who received untreated blood clotting factors before 1986. All blood and blood products in the UK are now screened.*
- *Mother to baby transmission does occur, but appears to be uncommon, with upper estimates of 6%. However this is increased to around 15-20% when there is co-infection with HIV. There is no association proven, as yet, between breastfeeding and HCV transmission, and HCV-positive mothers should not be advised against breastfeeding.*
- *Sexual transmission of HCV is possible but uncommon. Estimates for sexual transmission of HCV are less than 5% in regular sexual partners.*
- *Transmission can occur in medical and dental procedures abroad, where infection control may be inadequate.*
- *Health workers (and to a lesser extent other workers such as police, prison staff and social workers) may be at risk of HCV infection from occupational injuries, for example needlestick injuries.*

- *There is a risk from tattooing, ear piercing and body piercing and acupuncture with unsterile equipment.*
- *There is some evidence that transmission may occur through sharing of toothbrushes, razors and other personal toiletry items that could be contaminated with blood.*

There is no risk of HCV transmission from everyday social contact such as holding hands, hugging, or kissing, or through sharing toilets, crockery and kitchen utensils.

2.3. Prevalence in the UK

In the UK, injecting drug users (IDUs) are known to be at greatest risk of acquiring HCV. Over 30% of IDUs attending specialist services have evidence of hepatitis C infection, and some smaller studies have recorded levels nearer to 50-80%. Ninety-two per cent of positive diagnostic or screening tests for HCV reported to Public Health Laboratory Service (PHLS) between 1997 and 2000 were among those with a history of injecting drug use at some time.

Of all cases of HCV investigation in England and Wales reported to PHLS between 1992 and 2000 (including IDU and all other risk factors), the following characteristics were noted:

- *64% were aged between 25 and 44.*
- *the ratio of male to female was about 2:1*

2.4. How is hepatitis C diagnosed?

An initial antibody blood test will indicate whether a person has ever been infected with HCV. About 20% of people who become infected with HCV will clear the virus at the acute stage; however, these people will still have positive antibody results.

In order to establish if the virus is still present, and to diagnose the extent of the disease, further specialist tests are required. A polymerase chain reaction (PCR) test will identify current circulating virus. More sophisticated PCR tests can then identify the amount (viral load) and the genotype of the virus. Liver biopsy will show the degree of any liver injury (inflammation, fibrosis, cirrhosis, etc). Additional investigation may be appropriate.

2.5. What is the treatment for hepatitis C?

Increasingly effective treatments are available. The National Institute for Clinical Excellence (NICE) recommends a combination therapy of Interferon and Ribavirin in the treatment of chronic HCV. This treatment is successful in clearing the virus (with no detectable virus six months after treatment has ceased) in 38 – 43% of those treated.

The treatment generally lasts for six to twelve months and involves self-subcutaneous injection of Interferon Alpha three times a week, plus a daily dosage of oral Ribavirin.

Treatment is not recommended for drug users who continue to inject, where drug interactions, compliance and the possibility of re-infection are issues.³ This will need to be assessed on a case-by-case basis. The treatment is contraindicated for many patients, including those with pre-existing medical conditions and pregnant women. Side effects (fatigue, nausea, headaches, depression) can be intolerable for some.

More recently available is a newer Pegylated Interferon, which maintains therapeutic drug levels over a longer period, is administered only once weekly and, in combination with Ribavirin, appears to be more successful in clearing the virus than conventional Interferon and Ribavirin, with efficacy rates of around 55 - 60%. (Pegylated Interferon is currently being considered by NICE).

³ It is worth mentioning here that this is a contentious issue and is considered to be discriminatory practice. It has been included as it reflects the views presented in the NHS Briefing Paper.

3. METHODOLOGY

There were three aspects to the research. The first was the questionnaire. Questionnaires were posted on the website and there were 112 responses -one from the USA. 86 were male and 26 female. The majority of respondents (79) categorised themselves as 'white', 13 called themselves British, 1 Asian, 1 Iranian and the rest (12) did not give a category.

The questionnaires were collected between January and August 2001. As with all questionnaires, the quality of the responses depended on the clarity of the questions. One question (10) was ambiguous and elicited a mixture of responses depending on the interpretation of the respondent. Most respondents thought the question was the same as for question 4 and answered it in relation to their own Hepatitis C status rather than that of their families and friends.

The second part of the study was a series of regional meetings where group interviews were conducted. These took place in Edinburgh, Manchester, Birmingham, Swansea, London and Plymouth. In London the interviews were carried out at the Mainliners Boardroom; in Birmingham at the Drugs Service in Carrs Lane Church Centre; in Manchester at the Drugline Drug Service; in Plymouth with arrangements by the Eddystone Trust; in Swansea at the Drugs Service; and in Edinburgh at the Capital C Hepatitis C Support Group Service. There was an average of 4 people at each interview, which was tape-recorded and later transcribed. A total of 24 interviews were analysed. Anonymity was promised and so participant identities were not revealed. The number of regional meetings was constrained by both time and resources. The meetings were conducted by two members of staff from the Mainliners Hepatitis C Resource Centre. Participants were selected through a wide advertising process. Flyers were sent out to all drug services, to hospital clinics, to The Haemophilia Society, via the Hepatitis Nurse Specialist Forum, via the Mainliners newsletter and via the website. In addition, the main contact at each venue took an active role in inviting clients to attend and helping to arrange the logistics for the meetings. Travelling expenses were also offered to participants to encourage attendance. Interviews were usually held over a period of 2-3 hours, with flexibility built in for those who preferred to give individual interviews rather than in the group setting.

Interviewers recognised the stressful and sensitive nature of giving out personal emotional information and were careful to ensure a supportive environment. This was achieved by having small group interviews and also by having a counsellor available for respondents in case of need.

A third aspect to the research was provided by the few (actual numbers unknown) individuals who took the opportunity to contribute to the study by giving telephone interviews. Notes from 4 of these were transcribed and analysis of them has been included in the analysis of interviews.

Analysis of study

We have, in our analysis, attempted, as far as possible, to use the voices of those who participated in the study. We feel that this captures in a more vivid way than our interpretation could, the reality of their lived experiences.

The intention here is to capture as faithfully as possible the views and feelings of participants. Where individuals appear, in their comments, to lack medical knowledge of their condition, this is perhaps an indication of poor or lack of communication between medical practitioner and patient, but crucially may point to the urgent need for accurate and more widely available information about hepatitis C.

4. PRINCIPAL FINDINGS

4.1. The Regional Interviews

4.1.1. Public and Family Responses

Most interviewees felt that having the disease had affected their relationships with others in a significant way. They found themselves unable to talk with others about having the disease for fear of being judged, blamed or unfairly treated.

For the majority of people this fear resonated within the family environment. Some experienced lack of support from their partners and families and many felt their families blamed them for contracting the disease through leading an irresponsible lifestyle. One person illustrated the mixed responses received by friends and family:

My son is a teenager, perfectly healthy, goes to college and all his friends know and no problem whatsoever; my wife and a lot of our friends know, no problem; but my family no longer send me any birthday cards, Christmas cards or anything like that. They totally ignore me.

Some, on revealing their condition, were asked to leave their homes and denied contact with family members. Others were subjected to insensitive and insulting behaviour when they initially revealed their hepatitis C status to their families, as one man said:

My partner took it very badly and blamed me in front of my children for being a dirty junkie who was his own fault for sticking needles into himself. I found that to be one of the most devastating bits of discrimination that I have experienced.

This lack of support affected a person's general attitude to themselves and the way they consequently managed their condition. Another person spoke about the lack of understanding of hepatitis C by his family and their inability to empathise with what he was experiencing. As the disease was 'invisible' to them, they assumed that it was a product of his own mind.

My family...don't understand that there's something wrong with me because they can't see that I haven't got a broken arm or a broken leg and they can't actually see what's wrong with me - and there's something very wrong with me. The doctor doesn't listen, he just gives me stupid drugs or they tell me I can't have anything, or tell me to go and do this, do that, and I can't. There's nothing really there saying, "hepatitis C? Come here if you've got it. Hello, you know, I'll talk to you about it".

He goes on to say:

You know, it's just completely destroyed everything, the whole way of my life from being loved and cherished and having a family to having absolutely nothing but a dirty blood borne virus that no-one knows nothing about.

One woman spoke of the difficulties experienced in her marriage due to her hepatitis C status. She and her husband had previously engaged in social activities in which she now found herself unable and unwilling to be involved. Her husband was unsupportive to her in her new choice of a healthy lifestyle and had told her that he was unwilling to take care of her:

In terms of family, there is no way to do this but on my own. People I know don't know about it. It's broken my marriage up. It's been like a third person coming into the relationship. My husband, he was also a drug user and was injecting drugs long before me and we both went for the test together and he was clear of B & C virus and I wasn't and he cannot support me and doesn't want to know. He believes that he can't forgive me for taking that away from the relationship [she gave up taking drugs and drinking] to a point where even, you know even throughout the year he is offering me drugs, "let's drink together, lets get pissed together, lets do some pills, lets get a gram of coke" and I can't have that, I can't. And it almost feels like that is dangerous to me, and it denotes a lack of respect for my status and for what I'm going through and it makes me very alone because he's not in it and he's not prepared to adapt his behaviour, change our behaviour, look to a different future and he has actually told me that he will not look after me in fifteen years time or whenever I should become, if I become ill. He's not prepared to do that. He doesn't want to know. He can't do it, he can't cope with it.

These issues of blame, guilt and lack of understanding and support in the family environment were but one aspect of the individual's experience and denoted broader official and societal attitudes.

4.1.2. Accessing Services

Nearly all those interviewed spoke of difficulties experienced in accessing services and appointments. One person had been waiting for three months for an appointment, and was still waiting at the time of the interview. Many had not been referred for treatment by their doctors at all and some had even been refused referrals.

Another way in which people experienced difficulties in accessing services and appointments was through the treatment they received. Many spoke of the distant and insensitive behaviour of either their doctors or health centre workers, which left them unwilling to return for appointments or treatment. One woman in the north of England talked about being scared to ask her doctors what the symptoms of hepatitis C were for fear of what was going to happen to her both physically and socially. To this day, she says she still does not really know what the symptoms are, and her experience with her doctors leave her feeling demoralized.

I feel like apologising for wasting their time as I leave and I come away probably more divvy then I was when I went in just not knowing anything at all.

When asked how she felt about being apologetic when it was not normal to feel that way towards one's doctor, she replied,

*I get that initially and then when I'm outside I think," bloody idiot, what do you let people talk to you like that for?" But when somebody speaks to you like you're a piece of shit, it's hard for you to get your head around it and I can't say anything about it until after the event because you just can't believe it.
You're in a state of shock.*

One person spoke of his experience in the south east of England where he had applied three times to be put on the interferon treatment and was turned down every time. The reason given was that only one in a hundred people get onto the treatment, and they have got to "fit the right criteria". This person was a previous drug-taker, now on a prescribed

methadone treatment, and so according to him, he "wasn't worth it."

Another man spoke of his experience when he went into hospital to have an endoscopy to see whether or not he had an ulcer:

I was told by the receptionist in the waiting room that I would be the last in because obviously they don't trust the fact that they sterilize the operating equipment, so it really makes you feel contemptible going in. And I had to wait on a trolley with people sort of going in before me and then an old bloke came on to the ward last thing but they let him go in after me and I thought that's because he was elderly and I suppose they thought by the time he got it, it wouldn't matter he would be dead anyway you know, and I'm awake and I'm thinking God all these people are going in and it just makes you feel horrible to think that you're treated like some contagious thing you know, and I thought they should really be sterilizing the operating theatre between patients.

A large proportion of the problems arose in accessing dental care. Many interviewees had been refused access to their dentist when they had revealed their hepatitis C status. This meant they had to seek help elsewhere which could mean a long wait and a lot of inconvenience. One person stated that when he eventually found a dentist who agreed to see him at a time that was convenient for his working hours, he had to travel twenty miles to get there.

People had difficulty arranging convenient appointment times, finding they were only offered appointments at the very end of the day when everybody else had been seen. Not only did this create inconvenience for the patient, but, as the last quote illustrates, it also raises serious questions about the practice of sterilising equipment between patients whether or not they have hepatitis C. Here one man speaks about the effects of being turned away by his dentist, an account which raises serious concerns, not only for people with hepatitis C, but for the health of society in general.

That feeling is so devastating, to feel that you've been a dutiful citizen to then find out that you've been discriminated against and their service has been barred to you. It also highlights the fact that because of that it may put a lot of people at risk by then subsequently not disclosing to the dentist because I think if I had been a different person I might have just gone to the next dentist and thought "sod that I'm not going to tell them now". And when I hear of all these appointments at the end of the day, why? Don't you clean your equipment properly during the day? And I feel there's a possibility that that could put a lot of people at risk of hepatitis C.

This view is confirmed by the British Dental Association (BDA) who say that, *It is unethical to refuse dental care to those patients with a potentially infectious disease on the grounds that it could expose the dental clinician to personal risk. It is also illogical as many undiagnosed carriers of infectious diseases pass undetected through practices and clinics every day. If patients are routinely refused treatment because they are known carriers of infectious disease, they may either not report their conditions honestly or abandon seeking treatment; both results are unacceptable (p.4).*

The BDA document, 'The Infection Control in Dentistry' states in section 1.3, page 4, that: *Whilst a health professional has the right to accept or refuse to treat a patient, it is important that the dental profession accepts the responsibility of providing dental treatment to all members of the community. Dental clinicians have a general obligation to provide care to those in need and this should extend to infected patients who should be offered the same high standard of care available to any other patient. A practitioner who lacks the knowledge,*

skill or facilities to provide appropriate treatment should refer the patient to a professional colleague.

In general people interviewed had experienced severe problems in accessing dentists. They found dentists and their assistants to be disrespectful and dismissive of their pain, to be ignorant of their condition and insensitive of their needs. One person spoke of having “HEP C POSITIVE” written in a red marker on the front of their file, which meant that each new dentist they saw would judge them on this basis. Most people found their dentists would wear a mask and several pairs of surgical gloves when having contact with them, which they found unnecessary and offensive. Although dentists routinely wear masks and gloves, and are likely to wear multiple pairs of gloves as part of the infection control criteria, this was not always explained to HCV positive patients who assumed this to be a personal slight.

There was, however, one person who had had a positive experience with his dentist. Although the dentist had worn a mask and surgical gloves, he had informed his patient frankly and honestly that he did this as a way of protecting himself from all kinds of viruses and infections that he could potentially catch from his patients. The hepatitis C patient had subsequently felt a lot more comfortable with this as there had been less emphasis on the fear of hepatitis C and more on the doctor's concerns about all forms of transmittable diseases.

In one telephone interview, an informant told a member of the Mainliners Hepatitis C Resource Centre that she had been ‘told off’ by a consultant because she was carrying a bag with soiled clothes belonging to her Hepatitis C positive mother. He told her that she was spreading hepatitis C ‘spores’ all over his office and that furthermore he should know as he had had 20 years of experience.

In another telephone interview an informant reported that an undertaker had denied the right of a family to view the body of their late son. They were informed that the coffin had to remain closed because hepatitis C was an infectious disease. As one commentator declared, *‘Even in death my family and I could be discriminated against’*.

4.1.3. The Association of HCV with drugs

I think it's also ideologies, you know the stereotypes of drug use, which can relate to this seeming to be self-inflicted. Therefore it is your own fault that you've got it.

The interviews point strongly to prevailing notions of hepatitis C as a “horrible drug taking disease”. Hepatitis C seems to be associated with a drug-taking lifestyle in the same way that HIV was associated with a homosexual lifestyle 10 years ago. Whilst it is clear that most transmissions are via injecting drug use, this limited association has implications not only for the way hepatitis C patients are viewed and treated, but, as mentioned above, for the general health of the public. The idea that hepatitis C is a drug-user’s disease not only resonates in the general public but also resounds with uninformed healthcare professionals:

I found with hepatitis, this stigma's stuck on it, “Oh if he's got hepatitis then he must have been using drugs sometime in his life, they must have been intravenously using it”, you know. Some people think you can only catch it through using drugs, you know, and some doctors think this and you know, a lot of doctors put this stigma on your illness. If you are suffering from it then you must be a user, you must have been a user, why should we help you if you are a user, you know, why should we waste our time and money on you.

Those people who did have a drug history found their doctors unwilling to prescribe therapeutic drugs to them when they experienced pain. Some specialists refused to treat sufferers unless they were no longer involved with drug use, claiming their condition did not warrant it. A leading doctor in a Drug Clinic in the north of England was noted as saying that a person who had caught hepatitis C through blood transfusions was more worthy of treatment/medication than someone who had caught it through intravenous drug use. Another interviewee in this area talked about a distressing situation that he had witnessed when he had been advocating on behalf of a fellow individual with hepatitis C. They were in an appointment with a consultant in a hospital:

So we sat down and basically to start off with, he read through the notes that I had there. "Oh so you're a drug user such and such" and it was like "Oh well it's your own fault, yes, blah de blah this. Oh you tried to kill yourself when you were fourteen so what went wrong there then." And I was like, hold on. And I thought he meant what went wrong, why did you try and kill yourself, but "No seriously what went wrong, why aren't you dead?" and I thought I never experienced anything like it. And I kept waiting thinking he's got to turn around, there has got to be some reasoning in this mentality. And he didn't. It was like "Oh well, you seem to like using drugs, you're not prepared to stop using drugs, why are you here, you're not going to get treatment, it states that you know you've got hepatitis C, you know you're going to die, let's stop wasting each other's time". And the guy was dead a week later.

Another person mentioned that when they disclosed their hepatitis C status to their GP they subsequently had a red sticker put on the front of their file, which, as they had been told, marks them as a potential drug abuser. The result of this was that it *"seems to affect every interaction I have, about drugs which could help me alleviate pain"*. This person was suffering from arthritis, which had become so bad they were now prescribed morphine, but their doctor would not prescribe muscle relaxant drugs *"which I found help but about which caution is urged for people with a drug history"*. As already mentioned, the doctor's behaviour could be an indication of poor or lack of communication rather than poor practice. Another person commented:

There is still discrimination about drug use status that is invidious everywhere you go. The little note on the GP file that goes everywhere, follows you, does it not, for the rest of your life, everything that happens to you is seen through that filter of "we have to be really careful of what we do here, this is a drug user" and so treatments are just absolutely dismissed because you know "we can't talk about pain control here, we can't talk about that" it's just "this person's an addict".

Many people, especially those who did not take drugs, spoke about their fears of this association of hepatitis C with drug taking. A man who gave telephone evidence told Mainliner's staff that he had never been referred to a liver specialist despite having a complicated liver problem. His G.P., he felt, did not take him seriously, even refusing to test his partner. He was sure that a lot of the discrimination that he faced was based on the belief that HCV is caused by injecting drugs even though he had never been a user. The prevalent assumption that the root of all transmission for the hepatitis C virus is injecting drug use, left people feeling stereotyped and stigmatised.

This association with drug use was felt to set up a hierarchy of 'deserving and less deserving'. Judgements are made according to the type of drug taken, whether 'hard' or 'soft', and the individual's level of engagement with drugs. Conclusions are drawn from this about the moral worth of a person.

I know that from the day that I disclosed how I got hep C to my GP, my relationship (with him) completely changed. He just didn't see me as the same person that I was the week before. I could have rational discussions with him about medical possibilities, he knew I was a professional in the field and that I had a lot of expertise but as soon as it came out that I had used drugs in the past he didn't see me in the same light anymore. Our relationship had been fractured.

Assumptions are made about your morality now, if you were immoral enough to do what you did in the past are you still that immoral kind of person. And I think that is discriminating because it judges me, it makes a judgement about what kind of person I am, what kinds of things I could do.

A moral hierarchy existed in relation to different forms of addiction. One man in the south of England claimed that although he had managed to control his drug problems he still had a very large alcohol consumption, and as he said, *"but I'm okay, I'm socially acceptable now, I'm just a heavy drinker"*.

One woman talked about feeling ashamed about the fact that she was an ex- drug user and she felt distrusted by her doctors when she went for an appointment because they would think that she was just going in for drugs when she was going in because she actually did "feel lousy".

Two people raised the issue of social class and drug use. One woman in Scotland felt that inner city dentists were more tolerant to hepatitis C sufferers and to drug users than those in a middle class environment. Another man in the same group interview stated what he saw as the difference between the treatment of HIV as a sexually transmittable disease and hepatitis C. He thought that the former was perceived to relate to an economically stable class of people whilst the hepatitis C virus was associated with drug use and a traditionally poor, urban environment.

One man in London reported an experience he had had with the police. He had been attending a Mainliners support group one evening when he had been stopped:

I live in Stratford so it's quite a distance, I think I must have, I don't know, I got a tube and then a bus and I was walking down this quiet road and a police car pulled up and pulled me over and said, "What are you doing out at this time of night" sort of thing. "Can we look in your bag" or whatever. So I agreed to this and in the bag I'd actually just purchased a book called 'The Hepatitis C Handbook' by Matthew Dolan. They removed the book, looked at it and said " Oh right sonny, so, hepatitis, have you got that then?" I said I did have and they said, " Well you must be a drug user then. Have you got any drugs on you now?" And I said, "No" and they said, "Well can we just have a look in your pockets, you haven't got any syringes or sharp objects in your pocket that might injure us" and I said "No". So they looked through my pockets and searched me for drugs. This was very humiliating and sort of quite embarrassing. The fact that they just seemed to immediately presume I was a current IV user because I had some information about this virus on me.

4.1.4. Problems with Professional Services

The types of problems faced by respondents were similar across all the regions represented in the interviews. This points to the possibility of an even more widespread and largely

unheard voice among people living with hepatitis C. People experienced problems in many sectors of their lives including healthcare, income support, housing, mortgages, pensions, life and travel insurance, visas, police and prison services.

One person was still, after two years, waiting to receive income support benefits. Others discussed their problems with getting life insurance saying there was nothing set up for people with hepatitis C and so they were charged more money to be insured. There was no information available to them.

People from different parts of the UK mentioned that most of the problems they experienced related to the health services (dentists, hospitals, GPs). In a telephone call to Mainliners, one man described his horrendous experience when he was admitted into hospital following severe savaging by a dog. He was denied some basic things like earphones, the ability to sit and watch television in the common room, the use of a telephone and a newspaper. More seriously he heard staff complain about having to attend to him or give him necessary injections. He was left for days with blood caked on his head as no one would clean him. Eventually his wife had to do it. His wounds were so severe that the dressings should have been changed in theatre. Twice he was listed for this to be done, and both times were cancelled as medical staff feared transmission. Even more seriously, his consultant never once entered his room to examine him, explaining that he was at risk of infection if he did. Shortly after his diagnosis, this man had been advised by someone not to disclose his HCV status as it would change his life. He had not, at the time, understood what this meant.

Other issues included life and health insurance as well as problems accessing hairdressers and banks. One man who is living with haemophilia and who had become hepatitis C positive from blood products, spoke about his experiences with his hairdresser and the Bank that he had been using for many years. He was involved in a campaign on hepatitis C so his name had become public in association with the illness. Subsequently his hairdresser had refused to cut both his and his wife's hair for fear of catching the disease. Also his Bank with whom he had banked for many years, had refused to see him or talk to him.

Someone in the Midlands, on visiting a hospital, had been asked persistently about the route of transmission, a question which placed her under pressure and made her feel uncomfortable. This person had had tests done in a corridor outside a ward, with no privacy or confidentiality, in an environment that she felt was unsafe and not very clean.

One person, also from the Midlands, spoke about his fear of having judgements made of his professionalism because he was an ex-drug user. He said that drug users were scared to reveal their hepatitis C status to their professional drug workers because they feared being refused methadone and also because of workers' lack of knowledge about the illness. This, he felt, results in further problems because if people choose not to reveal their status, drug workers remain ignorant of the disease. In addition, people affected by the disease jeopardise their own (and other's, including workers') health if, as a result, they are not receiving appropriate treatment.

In Scotland, a man who had spent some time in prison had been denied privacy or confidentiality in accessing medicine and treatment. He spoke of the prison officers who would wear gloves during their daily search and who would punish him in a number of different ways. He had been left in the prison healthcare centre overnight with no care leading him to complain to the Board of Visitors. Prison officers would talk openly about his condition and subsequently other prisoners made assumptions about him and he frequently had his life threatened.

There were also problems with the police service as a previous example showed. In Wales, a woman had been questioned by the police about her use of a disability badge at work. On the street outside of her work they had loudly forced her to inform them what her illness was, as there were no physical signs of it. This was not only an infringement of this woman's rights as the police have no right to ask disability badge holders what illness they have, but it also put her job at risk. When she complained to the Chief of Police, questions were directed at her boss rather than directly at her, and then she was told to sign an empty sheet of paper, which she refused to do. The Officer subsequently wrote down two lines on the paper despite the fact that she had been talking to the police for over half an hour.

4.1.5. Issues of Concern.

Issues of concern which arose in the interviews included:

The fear of infecting others.

The fear of having to reveal one's HCV status and the implications of this.

Illness/ pain experienced in relation to hepatitis C. This ranged from lethargy, vomiting in the morning, problems with concentration, short term memory and brain fog, to rashes, swollen legs, ulcers, vitamin deficiency, liver, bladder and kidney problems.

The lack of knowledge/training/awareness of hepatitis C of the general public and of HCV positive individuals themselves was a grave cause for concern.

There were particular concerns about the attitude of people in healthcare services as well as the general public. People were worried about discriminatory treatment, negligence, isolating and excluding treatment in hospitals, and about a general lack of support and of pre- and post-test counselling.

The level and extent of ignorance and misinformation about the virus was particularly distressing and gave rise to anxiety and fear. For example, one man in Wales was told that he should not have children because of the risk of the virus being carried in his semen. Also in Wales, a woman complained about being given confusing information about breastfeeding. She had also had a traumatic experience during a caesarean section whereby she was told she had to be awake for it in case of haemorrhage. The issue here is not whether or not the procedure was correct, but the level of emotional support given which could have removed her anxiety and helped her understand why certain procedures and not others were adopted.

Unclear information about the roots of transmission of hepatitis C resulted in general paranoia, leaving people with the impression that unnecessary precautions were being taken in the treatment of hepatitis C positive individuals.

4.1.6. Impact of Discrimination

Discrimination impacted on the lives of people living with hepatitis C on many levels. Feelings of anger, resentment, disillusionment, loneliness, fear, stress and vulnerability prevailed. The psychological impact was to withdraw as much as possible from society because of the fear of entering into relationships.

Several people had had their work affected, many losing their jobs, many having their self-worth knocked because of their inability to perform to expected levels due to illness or work pressure. Some spoke of not applying for jobs because they did not feel comfortable filling in the health section on the application form. Others who did fill this section in found they

would not receive replies to attend an interview. One person who had lost his job had been looking continuously for another one, which had led to a lot of stress. He had been called for an interview and had received top points but was still not offered the job when his hepatitis C status had been revealed. The reason given was that the work was with a vulnerable client group so no risks could be taken. This person spoke of feeling dirty and ashamed because of people's reactions. Someone else spoke of having their hygiene certificate taken away meaning they could no longer work as a chef. This placed the person in a dilemma as to whether or not to reveal their status in the future.

One person working in a drug centre found they could not discuss their illness with their work colleagues for fear of prejudiced perceptions (that they would no longer be seen as intelligent, articulate or talented). This person's self-worth had been affected and they found themselves having to be more tactful in their dealings with colleagues.

Another interview participant told of a comment made by a doctor that she would probably be back on drugs in six months anyway. That, she felt, could have tipped her back into using drugs.

In some cases the discrimination experienced has led to legal action by people with hepatitis C, against hospitals or employers. This in its turn has led to further discrimination with people being told for example that a judge 'would not listen to a junky'.

4.1.7. Effects on Family and Friends

People were generally concerned about the effects on the children of someone with HCV. One person spoke of her fear that the doctor would judge her children because of the mother's status. Another person spoke about her fear of not living long enough to bring up her children. She was living in a small village and she was concerned about the effects on her children having to explain to their friends, and having to educate her children rather than leaving them to jump to their own frightening conclusions.

4.2. The Questionnaires

Most of the issues raised in the interviews were also touched upon in the questionnaires. By their very nature, questionnaire responses were more limited as they do not present the same opportunities as interviews, to follow up and expand on an issue with a respondent. Nevertheless, they were a rich source of information and together with the interviews paint a vivid picture of the hidden experiences of people living with hepatitis C.

4.2.1. Public and Family Responses

Many respondents preferred not to reveal their status to anyone. *'I don't share my HCV status with anyone'*. Some had only told their close family.

By and large friends and family were sympathetic but showed little understanding of hepatitis C. As one respondent said, *'They equated HCV with HIV'*.

Responses were variable. Some reported sadness or sympathy from their families and friends, others talked about family members being upset, or showing fear and panic. One respondent talked about his family experiencing *'total shock and disbelief'*. Another said of his family, *'They treated me, not like a person but a haemophiliac with a virus'*. Words used to describe family and friends' reactions were, 'concerned, upset, shocked, disgusted, outraged'.

Not surprisingly, some respondents were greeted with suspicion and distrust by family and friends. One person talked about being treated *'like I had leprosy'*. Another reported that he had been asked to stay away from his family, and others had lost their friends or their partners. Negative reactions were often based on the belief that it had been 'my own stupid fault'. The effect was increased withdrawal and isolation from society. A 31 year-old male had this to say,

My social life is inhibited because my pals always meet in the pub. I have no intimate relationships with the opposite sex because I fear (a) transmission, and (b) rejection.

It is unclear whether this respondent restricts his social life with his friends because he is afraid of transmission in a highly gregarious environment of a pub or whether he fears disclosure. Either way, the mental strain on a young man in his thirties of no social life for an indefinite period of his life must be heavy and signals the urgency of public education in order to remove the mystery and stigma surrounding hepatitis C, and guide those affected to appropriate styles of life. One 25 year old had even considered suicide *'as a practical alternative'*.

4.2.2. Accessing Services.

Unlike the interview participants, most respondents to the questionnaire had had no difficulty accessing medical services. This however, did not mean equal treatment. Two accounts will serve to illustrate the type of experience described.

'I have never had a problem accessing services. My dentist always gives me the last appointment of the day but always covers the lights and surfaces with cling film, which always makes me feel "unclean".'

'At my dentist I always have to have the last appointment in the session which makes for long waits'.

This provides a graphic example of the lack of knowledge and experience that is prevalent in the society and in the medical professions. The first experience begs the question of the level of hygiene generally available in surgeries if precautions are only taken with the last appointment where a disease is known to exist.

A significant minority had had difficulty accessing services of various kinds. The most difficult service to access had been insurance. A few had had difficulty finding a dentist to treat them and one talked about his wife losing her hairdresser because of his hepatitis C status. One respondent had had *'to pressurise my G.P. to get a consultant appointment'*, and another had been *'refused a leg operation because of HCV'*. A 30 year old prisoner said,

Being in prison has made this (access to services) difficult and although there is said to be no discrimination, I feel, through people who I have spoke to, there is less chance of getting treatment'.

Another respondent alluded to the effect that long waiting lists had on hepatitis C patients.

I find it frustrating that services at my liver clinic are so (original emphasis) overloaded that if I miss an appointment because of poor health etc, it takes up to 2 months to get another one.

4.2.3. Issues of Concern

There were, understandably, many issues of concern for respondents. One of the most frequently mentioned was the fear of inadvertently passing the virus on to others. This was closely connected to the lack of knowledge and information about the hepatitis C virus. There was concern about lack of information within the medical profession itself and the implications of this ignorance on public health. Public ignorance and lack of information was felt to be largely responsible for the discrimination experienced by those living with hepatitis C. The nature of the discrimination on the part of health professionals was associated more with this lack of informed knowledge than with ill will or bad intentions.

Another major area of concern related to the future. There was concern about, *'living with the knowledge of failing health and not knowing how to maintain a healthy lifestyle'*. One respondent stated his fear of *'constantly feeling ill'* and another worried about *'the lack of funding for interferon treatment'*. Individuals talked about lack of support, paucity of services, absence of treatment choice. These immediate and long term medical concerns were tied to fears about losing or having to leave one's secure job and face an uncertain future of diminishing health and diminishing quality of life. One respondent wondered, *'Will I die with dignity?'*

Other concerns of a practical nature were to do with the difficulty one might face when looking for work or keeping one's job if one's hepatitis C status were known. There was also widespread concern about the ability to access insurance services or the escalating cost of insurance for those living with hepatitis C. A 43 year-old male stated that he was concerned about

'...how my family will fare if I die early. Insurance is very hard to find and expensive'.

Access to insurance was said to also affect partners who were not hepatitis C positive.

'When my husband applies for Life Assurance, he is now asked the question, "Have you ever had a partner who has suffered from haemophilia?" which then leaves him subject to the same problems as I find trying to get Life Assurance'.

Another issue was the anxiety around confidentiality. As with those who gave interview evidence, there were examples in the questionnaires, of public humiliations in hospitals or dental surgeries, of having their status discussed openly in waiting rooms or obvious labels stuck on their medical records and left to public gaze. Respondents from prison talked about the lack of confidentiality within the prison service as prison officers were usually present at medical appointments.

Finally, but not least of all was the fear of discrimination. The stigma associated with hepatitis C, which is both informed by and informs public ignorance was felt to be a major source of discriminatory practice. One respondent illustrated this with his experience of discrimination at work.

'At work, unbelievable prejudice when I mentioned interferon. I was told in no uncertain terms to leave the job and when I was on the treatment I was called to a disciplinary hearing to explain why I was off sick despite sick notes explaining "side effects of chemotherapy", the letter from my G.P. and the drugs trial contract I signed accepting the risks. Unfortunately you had to have worked 2 years before you had rights to contest unfair dismissal'.

4.2.4. Association with Drugs

Respondents were asked whether they were concerned about the association of hepatitis C with drugs. The majority were concerned about this and some had experienced the effect at first hand.

I feel professionals look at me as a self-abuser and I don't get the support I need if I'm ill.

Many questionnaire respondents felt very strongly about the association of hepatitis C with drugs. Most were people living with haemophilia who had contracted hepatitis C via infected blood products. In response to the question about whether individuals were worried about this association, one man wrote,

Definitely! Programmes on HCV always, always include openings with drug abusers and alcoholics, prostitutes and lastly haemophiliacs who contracted HCV through blood products. Unfair!

Others wrote,

I feel strongly about this because the public just generalise and form their opinions which usually are unfounded.

When I had my daughter the doctors made me feel paranoia about how I could have passed the virus on to an "innocent young child". I was made to feel like a bad mother and given no support.

4.2.5. The Impact of Discrimination

The experience of discrimination had a profound impact on individuals. They were affected in most areas of their lives as is evident in this respondent's account.

Hep C has forced me to give up work. I now try to survive on benefits. I also had to find another hairdresser, and I am extremely careful in associating with anyone. Also I now never see any of my close relatives...Apart from my sister, no other member of the family associates with me. I rarely go out apart from visiting the hospital at least twice a week.

Although the ability to work has, for this respondent, been affected by his hepatitis C status, it is clear that it is the fear of, as well as actual discrimination, that have changed his life to a near recluse. Several respondents were affected in relationships. Some were alienated from or rejected by family and others by their partners.

'My mum threw me out and other family members were quite abusive'.

'My wife divorced me after two courses of treatment failed'.

'Family not sure of visiting because fear of infection. It is very upsetting'.

'A new partner walked out never to be seen again when I told him'.

'Family breakdown'

'Some friends went away and my wife has divorced me'

The emotion expressed by respondents was movingly captured by the account of one 40 year-old woman.

I keep it under my hat due to my fear of responses. This itself causes me to live a great deal of my life “under cover”. I am unable to express my fears, unable to justify my fatigue, unable to seek understanding and support. I feel I will be placed in a situation of the “deserving or undeserving” victims of a virus. I am a silent sufferer.

Fear of disclosure had not only driven individuals “under cover”, but forced them to actively withhold information about their medical situation. One respondent stated that as he cannot provide references from his landlord when he moves, and cannot provide references from his employers who had dismissed him as a risk to colleagues and clients, he would have to, *“continue lying about my condition to any landlord or employer”*.

A more disturbing aspect to this was when an individual was asked by her employer to ‘sign a promise of secrecy’ about her HCV status. Another respondent mentioned living in fear of violence if people knew about his medical condition. One woman had actually been physically attacked and verbally abused in her local pub.

Respondents talked about feeling embarrassed, frustrated, humiliated and angry. One said he felt

Anger at not being given same treatment as HIV sufferers although causes almost identical.

The difference between responses to HIV and hepatitis C were well illustrated by respondents who were in prison as one 40 year-old prisoner said,

In 1997 I shared a cell with ‘John’. We were both addicts, both robbers. Our backgrounds were similar -he was HIV+ and I was HCV+. His addiction has been maintained whereas I have to buy drugs. John is over-prescribed...Our prognosis is probably equally dire but he’d have spent his latter years in relative comfort and I’ll probably get stabbed to death over a gramme or even worse, liver failure.

The effects of different perceptions of hepatitis C and HIV were not confined to sufferers alone but also to those associated with them. One woman talked about the different treatment experienced by her sisters-in-law and by her. Her deceased brothers-in-law had been infected with HIV via contaminated blood and her husband (their brother) had similarly been infected, but with hepatitis C. Her sisters-in-law had received compensation whereas she had received none.

Some people had lost their self-confidence and feelings of self-worth especially in relation to their treatment by medical professionals .

For example: *‘Doctors make you feel like you’ve got the plague’*.

This, according to this respondent made him *‘feel even more alone than I do already’*.

Lack of knowledge on the part of medical staff created a vicious cycle for hepatitis C positive individuals when symptoms were misdiagnosed or treated as a product of the mind. Some respondents wrote that their GPs insisted that their symptoms were caused by depression or alcohol and one was referred for psychiatric treatment because her insistence on being tested led to the assumption that she was mentally ill. One respondent was treated for M.E. and her insistence that she be tested for hepatitis C was ignored for several years. Her husband expressed concern that in all those years she could unwittingly have infected others by not being given advice about an appropriate lifestyle.

One woman's harrowing account of her deceased husband's experience deserves detailed reproduction.

My husband's experience of discrimination comes from the medical profession (original emphasis). He asked no favours and expected none. He continued to work until the day of his collapse. Weekends were spent resting or sleeping in preparation for the week ahead. For three years he had oesophageal varices banded at (a London) hospital - the day after discharge he would be back at his desk... There were two doctors who admired his stoicism and determination but (a senior clinician) would insist that he had 'a good quality of life' and did nothing! After my husband's death I discovered from hospital notes that, subsequent to (a doctor's) reference to blood products (in 1983), the doctors for the following 14 years accused my husband of alcoholism. He did not drink! I did not, and do not drink. I am convinced that (another doctor's) notes of 1994 must refer to a different patient. My husband never drank beer - the expression, 'likes a few beers at weekends' would have been totally alien to my husband. Nobody cares - I am glad my husband died his terrible death without the terrible burden of knowing about these lies.

This account highlights a number of the issues facing people living with hepatitis C and indeed those who are close to them or left behind after their deaths. The first is the 'catch-22' situation in which someone attempting to live as normal a life as possible despite immense obstacles, will be considered to be 'not really ill' and therefore not needing urgent attention. 'A good quality of life' seems here to be as good a reason to discriminate as discrimination on the basis of a person's drug addiction or poor quality of life.

The second issue, and one of relevance to people living with haemophilia in particular, is the misreporting of a patient's condition, what the respondent refers to as 'lies' and which, had her husband lived to see these notes, would have been experienced as a smear of his good name and an added source of pain and distress. It clearly remains a source of pain to the respondent and the family. A number of respondents living with haemophilia talked about being part of a campaign to highlight the fact that their hepatitis C status was as a result of contaminated blood products and not the result of what is deemed to be 'an irresponsible lifestyle'. The insistence on associating the disease with alcohol or drugs may be viewed as either irresponsible in that it diverts attention from understanding the full range of sources of transmission, or arouses the suspicion (expressed by respondents) of a cover up for the Department of Health's alleged refusal to take responsibility for its mistakes.

A related element highlighted by this account and referred to a number of times in this report is that denial of hepatitis C, the source of contamination and the prevalence in the society perpetuates the ignorance which surrounds the disease, an ignorance which could have grave implications for the health of the whole of society.

Discrimination or fear of discrimination had had other effects of a more practical nature on respondents. Many referred to the discriminatory attitudes of insurance companies against those who were hepatitis C positive. One reported a 160% increase in his insurance premiums. This naturally caused concern for those who foresaw their incomes diminishing and had young families. Others had been dismissed or lost potential jobs.

I worked in the catering industry for 20 years, and battled against haemophilia, when hep C came along. It robbed me of my livelihood. No-one will employ someone with hep C to serve or prepare food.

The final word goes to a 61 year old man living with haemophilia who had contracted hepatitis C via infected blood products.

I have endured discrimination for nearly all my life -initially with haemophilia, and later with hep C. I have experienced discrimination from employers, dentists, hospitals etc -all my life- largely due to ignorance! I generally believe that discrimination is derived from ignorance.

5. HEPATITIS C AND GENDER

Hepatitis C knows no gender. However, there are aspects of living with hepatitis C that may be different for men and women and which need to be noted if provision is to be focused and appropriate.

The sample is necessarily taken from the questionnaires where sex was specified on the form. The sample is small (26 women, 86 men) and as no specific gender question was asked in either the interviews or the questionnaires, it is assumed that more gender related issues could be uncovered in a study that took this as its focus.

There was only one issue raised by a man that was not, and could not have been raised by women. This was the issue of the hepatitis C virus being passed to children via semen. All other aspects of men's concerns were also raised by women.

Both men and women were concerned about their continued ability to support their families. However, only women specifically raised the issue of caring for children, reflecting the traditional and continued dominance of women in this area. Closely related to this traditional view of the woman being the prime carer of children was that women were typically also made to feel guilty that they were 'bad mothers'. This was illustrated by one woman who was given confusing information about breastfeeding and left feeling uncertain about whether or not the virus could be passed to a child through breast milk. The same woman had also been told that she had to be awake during a caesarian section in case of haemorrhage. The rationale for this procedure, it seems, was not explained to her.

When I had my daughter the doctors made me feel paranoia about how I could have passed the virus on to an "innocent young child". I was made to feel like a bad mother and given no support.

Concerns that were unique to women thus revolved around birth and childcare highlighting the need to investigate the influences of gender in the experiences of those who live with hepatitis C.

6. CONCLUSION

In this report we have attempted, largely through the voices of research participants themselves, to highlight some of the key issues affecting people living with hepatitis C. Although at a national level, the sample of participants was small, one of the most important messages to come through is that the lack of information and the general ignorance about the disease hides what could be a social disaster waiting to happen - what Waller and Holmes (1995) have aptly referred to as 'the sleeping giant'. The mystery surrounding hepatitis C increases the stigma attached to the disease and this in turn feeds fears which themselves perpetuate the stigma in a circular or symbiotic relationship. That hepatitis C is a stigmatised condition is clear throughout and widely felt to underlie the various forms of discrimination experienced by those living with the disease.

What are some of the perceptions of hepatitis C that perpetuate the stigma and help to plant fear and insecurity in both medical and healthcare professional and the general public? The evidence is clear (NHS 2002) that the main source of hepatitis C is injecting drug use. However, it is also clear that many people who live with hepatitis C were infected by contaminated blood products in different situations. Most of those who gave questionnaire evidence were people living with haemophilia whose HCV status was stimulated by Factors VIII and IX and von Willebrands – blood-clotting agents given widely to people living with haemophilia during the 1970s and early 1980s.

The link between hepatitis C and drugs was perceived by informants as not only a form of misinformation but was seen to lead to gross injustices against those living with the condition and indeed against the dependents of those who died from the disease. It was felt that, on the one hand, it presupposes the existence of guilt or innocence and assumes a legitimate positioning of those affected in a hierarchy of 'deserving and undeserving'. The notion that drug addiction and therefore drug users, particularly heroin users are 'the lowest scum on earth' as one interviewee phrased it, denies the fact of drug addiction as an illness and the rights of all patients to receive equal treatment. The broader issues relating to drug addiction are beyond the scope of this report. What is important, however, is not only that medical and healthcare professionals re-assess their attitudes, but that there is acknowledgment of generalised discrimination against hepatitis C positive individuals whatever the source of transmission. This seems to contrast with the treatment of those living with HIV whose right to treatment and to a quality lifestyle is now rightly assumed.

6.1. Forms of Discrimination

Evidence suggests widespread experience of differential or discriminatory treatment of people living with hepatitis C. Those most supportive were family and friends although there were some exceptions where the rejection by family and/or friends was felt most acutely. In general, most discrimination was felt in healthcare situations. Such discrimination could range from direct rejection and refusal to treat a patient, being placed last on the list for treatment, public discussion of an individual's condition and public humiliation, and excessive precautions being taken (cf placing cling film on the lights). Invariably individuals felt powerless in such situations where their very lives were in the hands of those who discriminated against them.

There were various other ways in which individuals felt discriminated against. Employment was one area where many of those who gave evidence had been affected. The question was often one of disclosure or non-disclosure. The catch-22 situation for those who felt they had a social responsibility to disclose their condition, was that they might be dismissed or might

not be offered a post for which they were highly qualified. Non-disclosure, however, left open the possibility of discovery and could mean a humiliating dismissal with little chance of another job; or continuing under cover without the opportunity of discussing ways in which one could carry out one's job with a focus on safety for oneself and one's colleagues or clients.

Another area where people felt differentially treated was in accessing services such as insurance and mortgages and in some instances, visas for travel abroad. Concerns largely surrounded the future and welfare of dependents. High increases in insurance premiums, for example, raised the prospect of a diminished standard of living, especially when coupled with the prospect of failing health and threats to one's livelihood.

7. POLICY IMPLICATIONS

The findings of this report have serious policy and practice implications for the Health Service. There are implications for the human rights of individuals as well as implications for society in general. Leadership in this field needs to be provided by Health Service providers throughout the UK. Clear policies are necessary to guide health workers on both the principles and the practices of working with and providing humane services for HCV patients. Those who live with hepatitis C need to be an integral part of this process of policy formation and practical guidelines.

The current trend to view hepatitis C as an aberrant disease that is self-inflicted has potentially hazardous consequences for the whole of society. Yet this view itself highlights the contradictions of prejudice where on the one hand hepatitis C is viewed as self-inflicted, and on the other it generates fear of catching the disease, sometimes in the most irrational of situations. To illustrate: when Mainliners were arranging a courier to take conference packs to the 6th International conference in Lisbon, the courier was very late arriving. It subsequently transpired that the delay had been caused because the word 'Hepatitis' appeared in the title of the address and none of the couriers had wanted to take the job! This study has shown the dangers posed by such attitudes and may perhaps be only the tip of an iceberg.

8. BIBLIOGRAPHY

Conference Report, International Hepatitis C Conference (2000), National Hepatitis C Resource Centre

Annual Report 2000 - 2001, Mainliners, National Hepatitis C Resource Centre

Hepatitis C Information Pack – Mainliners, National Hepatitis C Resource Centre

Infection Control in Dentistry (2000), British Dental Association

NHS Briefing Paper Hepatitis C: Essential information for professionals (2002), National Health Service, England

'Change', Report of the Inquiry into hepatitis C related discrimination (2001), Anti-Discrimination Board of New South Wales, Australia



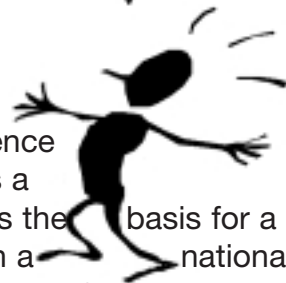
a Mainliners Project

Hepatitis C Discrimination Hearings

Have you been
discriminated against
because you are HCV+?

If you have, we would
like to hear from you!

I was refused
dental treatment
coz of my Hep C



The National Hepatitis C Resource Centre is taking evidence of discrimination and prejudice suffered by individuals as a result of their HCV status. We aim to use this evidence as the basis for a report which we hope will lead to this issue being addressed on a national basis. If you would like your experience heard there are three ways of doing this:

- 1) Attend and give evidence in a group or one-to-one
- 2) Send in a written submission
- 3) Fill in a questionnaire (Contact the Centre for copies)

1) Hearings will be held in 7 regional areas, Scotland, Wales, Midlands, North of England, London, Northern Ireland and South West.

2) If you would like to give a written submission write to:

Discrimination Report, National Hepatitis C Centre, P.O. Box 31844,
London SE11 4DT or call and tell your story by phone on **0207 735 7705** or
email: **advice.info@hep-ccentre.com**

The Hepatitis C Discrimination Hearings

All hearings will take place between 1pm – 3pm and a space for one-to-one sessions will be available between 3 - 4pm. Places are limited so please call and book a place in the city of your choice. Travel will be refunded (keep tickets/receipts).

Manchester

Wednesday 26th September
STASH – The Waterloo Project
Brentfield Avenue
Cheetham Hill
Manchester

Birmingham

Thursday 27th September
Birmingham Drugline
Dale House
New Meeting Street
Birmingham B4 7SX

Plymouth

Wednesday 10th October
Plymouth Eddystone Trust
Looe Street, Bretonside
Plymouth.

Swansea

Thursday 11th October
Swansea Drug Project
8 Calvert Place
Swansea
West Glamorgan, Wales

London

Wednesday 24th October
Mainliners 38-40 Kennington Park Rd
London SE11 4RS

The Centre wants to hear your experience of discrimination. You don't need to have lost your job or suffered similar serious discrimination.

Anything that you feel is discriminatory is important.

Your confidentiality is guaranteed.

If you are interested for more information or to book a place call the centre on 0207 735 7705 or e-mail info.advice@hep-ccentre.com.

Places are limited. Advice on written submissions can also be given. Phone submissions need to be booked –we will call you back.

These hearings are carried out on the basis that Mainliners will not seek to represent the views, needs and aspirations of those giving evidence, but the information gained can only be used in line with the stated objectives.

Belfast To be confirmed

Scotland To be confirmed

APPENDIX 2

Hepatitis C (HCV) Discrimination Questionnaire

The National Hepatitis C Resource Centre is taking evidence of discrimination and prejudice suffered by individuals as a result of their hepatitis C status. We aim to use this as the basis for a report which we hope will lead to this issue being addressed on a national basis. If you would like your story heard please complete this questionnaire and send to the FREEPOST address overleaf.

There is space overleaf for you to enlarge on your answers to any of the following questions.

(All personal details will remain confidential)

Age _____ Sex: M ___ F ___ Race _____

Where do you live _____

1. There are a number of modes of transmission of HCV. Please tell us how you were infected?
2. When were you diagnosed? _____
3. Where & by whom did you have the test performed? _____
4. What was your experience with members of the general public, friends and family on learning of your HCV status?
5. Could you describe the issues which are of most concern to you due to your HCV? This may include matters such as confidentiality.
6. What has your experience been in accessing services or appointments because of your HCV status?
7. Approximately 70% of people with HCV have become infected as a result of at least one episode of injecting drug use.
Are you worried that you will be discriminated against because of this fact, whether or not it applies to you?

Yes No Not sure

8. Have you ever had any problems with professional services (e.g. Doctors, Dentists, Social services, Employers or Schools) as a result of HCV?

Yes No Not sure

9. Describe the impact of any discrimination that you may have suffered from.
10. What has been your experience of discrimination because of the HCV status of your family or friends.

If you would like to provide more information on how you have experienced stigma or discrimination as a result of your hepatitis C please tell us details of what happened. Please continue on additional sheets and attach if necessary.

**Thank-you for taking the time to complete this questionnaire.
Please return to The National Hepatitis C Resource Centre, Freepost,
PO Box 31844, London SE11 4DT**

THE NATIONAL HEPATITIS C RESOURCE CENTRE

PO Box 31844 • London • SE11 4DT

Tel: 020 7735 7705 • Fax: 020 7735 6645

E-Mail: admin@hep-ccentre.com • Website: www.hep-ccentre.com

A Mainliners Service

Registered Charity No. 801862

Company limited by guarantee 2404043.