

DEAR MANDY,

THIS QUESTIONNAIRE HAS  
BEEN COMPLETED GIVING THE  
MONITORING OF MY HUSBANDS  
ILLNESS BEFORE HIS DEATH IN SEPT  
1994

Yours sincerely  
MAUREEN MURPHY.

94, HILARY AVE  
BOWRING PARK  
LIVERPOOL  
L14 6US  
25 9. 95

The following questions are about Hepatitis C as it affects you.  
You do not have to answer all the questions if you do not want to.  
All answers that you do give will be treated in the strictest confidence.  
If you prefer, you do not have to give your name.  
However, it'd be useful for the Research Worker at the Haemophilia Society to be able to contact you in the future if you were happy with this.

Age 59

Centre Attending LIVERPOOL

Sex MALE

1) When were you told you were HCV Antibody positive?

JANUARY 14<sup>TH</sup> 1992 (CIRRHOSIS DIAGNOSED)

2) What date were you tested, if known?

4 WEEKS AFTER KNEE REPLACEMENT OP.

NO KNOWN TEST GIVEN

3) Do you know how long ago you were exposed to the virus?

HEPATITIS B (1979) AFTER ULCER HAEMORRHAGE

HEPATITIS NANB (1981) AFTER ULCER OPERATION

4) What information were you given about HepC?

prognosis WILL RESULT IN DEATH

everyday risks of transmission, NONE

sexual risks of transmission NONE

treatment options NONE

other, please specify POSSIBLE PROBLEM WITH VARICES THE SERIOUSNESS OF THIS PROBLEM WAS NEVER STRESSED. WITHIN 3MTHS OF CIRRHOSIS BEING DIAGNOSED, THREE LIFE THREATENING ATTACKS OF VARICES OCCURED. 1<sup>ST</sup> - 17/4/92, 2<sup>ND</sup> - 30/4/92 3<sup>RD</sup> 14/5/92

5) What information would have been useful?

ANY INFORMATION ~~AT~~ WOULD HAVE BEEN USEFUL!  
E.G. 'LIVER FAILURE' (7<sup>TH</sup> AUGUST 1994) EARLY STAGES OF COMA WERE MISSED DUE TO THINKING THAT MY HUSBAND WAS EXTRA TIRED THAT DAY. INFORMATION ABOUT THIS MIGHT HAVE HELPED!

6) Were you offered the opportunity to talk through any questions or concerns with a Social worker or Haemophilia Nurse? COMMUNICATIONS WITH HAEMOPHILIA STAFF WERE AS NORMAL.

If yes did you want to?

If no, would you have welcomed counselling/support?

WOULD HAVE WELCOMED IF WE HAD KNOWN WHAT LAY AHEAD.

7) Who do you think'd be the most appropriate person to provide counselling/support?

MEMBERS OF HEPATOLOGY TEAM.

8) What advice were you given about what drugs you should or should not be using?

NONE

9) What advice about alcohol were you given?

BEFORE JAN 14<sup>TH</sup> 1992 - NONE

10) What advice about sexual transmission were you given?

NONE

11) Does the Centre offer the opportunity for sexual partners to have an anti-HCV Antibody test?

NONE BEFORE SEPT 1994

What was their view?

12) What follow-up arrangements did the Centre make with you?

JUST NORMAL CLINIC APPOINTMENTS.

13) Is there a special Hep C clinic at your Centre?

NONE BEFORE SEPT 1994

14) Do you have your liver monitored? (eg LFT's/ALT levels or ultrasound scan)

POSSIBLY? TWO KNOWN ULTRASOUND SCANS WERE PERFORMED

How regularly?

JAN 1992 , JULY 1994

15) Have you seen a liver specialist/hepatologist?

NINE WEEKS BEFORE DEATH

16) Have you been offered access to a liver specialist?

Did you accept / refuse?

Why?

SEE Q. 15

17) What discussions have you had about Liver Biopsy?

A BIOPSY REQUESTED BY THE SURGEON DEALING WITH MY HUSBAND'S VARICES. THIS WAS A THOUGHT OF AS BEING OUT OF AS BEING OUT OF THE QUESTION BY CENTRAL DIRECTOR.

18) Please say if you have had one.

19) What discussions have you had about Interferon?

NONE

20) Have you been offered Interferon?

NO

Did you accept or refuse?

Why?

21) Have you had any discussions about alternative therapies?

NO

22) The following question is of a sensitive nature and answering it is optional.

Have you had discussions about the implications of co-infection with HIV & HCV?

NO

23) Please describe your current state of health in relation to Hepatitis C, both in clinical terms and in your own terms. How has it changed, if at all, since you were infected?

DEATH OCCURRED 3<sup>RD</sup> SEPTEMBER 1994



The following section asks you to say what impact HCV has had on your life.

24) What would you say are the social implications for you/your family of living with Hepatitis C?  
Checklist may include

Employment UNABLE TO CONTINUE AFTER DIAGNOSIS OF  
CIRRHOSIS

Education —

Lifestyle NO QUALITY OF LIFE AFTER JAN 1992

Family UNABLE TO TAKE MUCH INTEREST IN NORMAL FAMILY LIFE  
ALWAYS TIRED OR IN DISCOMFORT

Obtaining insurance or mortgage MORTGAGE PROTECTION WAS REFUSED IN  
1971 BECAUSE OF DECLARING STOMACH ULCER, NEVER MIND  
HAEMOPHILIA.

Diet

SALT FREE DIET ADVISED AFTER 1ST ATTACK OF VARICES  
THROUGHOUT ILLNESS DIGESTION OF FOOD BECAME QUITE A PROBLEM  
Stress levels NOT BEING ABLE TO TALK FREELY ABOUT CONDITION

Emotional KNOWING TIME WAS LIMITED

Relationships DUE TO HAVING A GOOD MARRIAGE (35 YRS) WE  
COPED WITH THE ILLNESS BUT FOUND IT DIFFICULT TO  
ACCEPT.

25) What extra financial costs have you incurred as a result of your HCV status? (APPROX  
LOSS OF SALARY FROM JAN '92 - SEPT '94 (£50,000 IN TOTAL  
SURRENDER OF POLICIES NOT BEING SURE WHETHER REASON  
FOR DEATH MAKING POLICY INVALID

26) What do you think are the most important things for Haemophilia Centres to be providing in  
relation to HCV? CAREFUL MONITORING.

SYMPTOMS TO WATCH FOR AND REPORT FOR FOLLOW-UP

27) What do you think the Haemophilia Society should be doing in relation to HCV?

FOLLOWING UP ALL THE POINTS MENTIONED IN THEIR  
HEPATITIS C CAMPAIGN LITERATURE

28) Are there any other comments you would like to make? PRIOR TO 1992 MY HUSBAND  
WAS UNAWARE OF HAVING A LIVER PROBLEM. HAD MY HUSBAND  
NOT HAD KNEE OPERATION, I WONDER WHEN WE WOULD HAVE  
FOUND OUT THAT HE WAS SUFFERING FROM CIRRHOSIS.

Name and Address (optional)

SEE LETTER ATTACHED  
WILLIAM MURPHY 94, HILARY AVENUE, LIVERPOOL 14

Thankyou for taking the time to complete this questionnaire. If you have any concerns or queries which you  
would like to discuss at a later date, please do not hesitate to contact me at the London office.

Please return to Mandy Cheetham at the Haemophilia Society, 123 Westminster Bridge Rd, London SE1 7HR

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