

INFORMING THE DONOR

The Letter

The initial contact will usually be by a standard letter, which should be reassuring in tone and specifically mentioning that the reactive test result has nothing to do with AIDS. The donor will be invited to come back for further testing in order to clarify the significance of the findings. An early appointment should be offered.

The Interview - First Counselling Session

Requirements: donor record, including list of previous donations, screening and confirmatory test results with interpretation further test results on original serum if available - ALT, anti-HBc, anti-HBs.

Blood samples:

It is recommended that further specimens be taken in order to confirm the results on the donation, and to check liver function tests.

Breaking the news

The initial news-breaking should be direct and simple, with the minimum of preliminary. The essential information is that one of the tests done on every donation has shown a positive reaction. Explain that this is a new test for a mild form of hepatitis, or jaundice, called hepatitis C. This can be passed on by blood transfusion, but we have not been able to test until now.

Q: What does a positive test mean?

Since only donors with positive confirmatory tests will be counselled, it is reasonable to explain that we do extended testing with very specific tests, so that we are already fairly sure that the donor truly has antibodies to the virus known as hepatitis C.

This virus is very common in the population - about 1 in every 200 donors has a positive test. This may mean that they have been in contact with the virus at some time in the past. Emphasize that the tests detect antibodies, not the virus itself, and that the virus is not necessarily still present.

Q: Does it mean I've got hepatitis?

At the moment we have very little in the way of data from blood donors with anti-HCV, but from studies of patients who develop post-transfusion hepatitis C, we know that the vast majority have no symptoms whatever, the infection just showing up as a rise in transaminases (sometimes referred to as "transaminitis"). In about half of those infected the liver function abnormality lasts 6 months or more. In a third of these a liver biopsy will reveal some evidence of inflammatory activity, and in approximately 10-15% this may ultimately result in chronic active hepatitis or

WTD/ 2302

cirrhosis. It is worth expphasizing that the natural history of the infection in transfused patients may be quite different. Thus it is likely that the long-term consequences are much less serious for carriers in the general population than for patients infected by blood transfusion.

If the ALT has already been done, the result will be very useful in finding the reply to this question. When it is not available, it is important to emphasize that a few simple tests will help to determine the significance of the test result for the donor.

Q: Will I die of this?

If the donor asks for a prognosis, it will be necessary to be slightly guarded without causing alarm. If the ALT is raised explain that there are many possible reasons for this, and that it will be possible to sort it out after one or two further blood tests have been done, but that sometimes a period of monitoring will be needed to be absolutely sure of the significance. We can say with confidence that very few cases of serious liver disease due to hepatitis C occur in the community, so for most people this is an incidental finding unlikely to cause serious disease or symptoms of any kind.

Q: How did I get it?

Though hepatitis C is very common in the community, we have little idea as yet of the routes of spread. We don't know if it can be spread by food or water, nor is much known about mother-to-baby spread, but sexual transmission can occur (albeit not as efficiently as other viruses, eg hepatitis B). There seems to be a high incidence in intravenous drug misusers, suggesting that parenteral spread is the most efficient. Thus tattoos, ear-piercing, acupuncture, dental treatment, electrolysis and so on could be relevant.

Q: Am I likely to infect other people?

It is not yet known with certainty what proportion of antibody-positive donors will be true carriers, able to transmit to other people. Initial studies suggested that the majority of donors would not be infectious, but this was before a confirmatory test was developed. We should regard all donors with confirmed positive tests as potentially infectious.

Situations in which others are at risk are those in which blood or body fluids may be exchanged, eg blood transfusion, needle sharing, and probably sexual contact, though it may not be logical to take any additional precautions with a longstanding partner. A condom should be advised with new sexual partners, while the necessary precautions for longstanding partners should be talked through.

There is no evidence of risk associated with ordinary daily contacts within the same household, and some evidence that there is no risk of transmission. Ordinary rules of hygiene should be observed, and donors should be advised not to share toothbrushes or razors. Donors must be advised to tell doctors and dentists that they are carriers of hepatitis C.

Q: Can I ever give blood again?

At the moment there is no prospect of readmitting seropositive donors, even if on follow-up they go seronegative. Further refinements in testing may lead to this being reconsidered.

Q: What about my previous donations?

The recipients of previous donations will be traced and their Consultants or GP's informed. We hope to obtain results of any tests carried out.

Q: Could I be sued if anyone was infected?

We guarantee the confidentiality of the donor. We strongly advise that the donor's GP be informed, but we shall not divulge the information to any other party without the donor's consent.

Q: Could I have got it from giving blood?

No.

Q: Should I tell anyone apart from my spouse?
My employers, for instance?

At present there are no official guidelines, and therefore no requirement exists to inform any other person. In the case of health care workers, consultation with the appropriate occupational health service is recommended.

Q: Do I need to change my diet or take any other health precautions?

Regardless of the results of ALT etc, donors should be advised that a period of medical supervision and repetition of the blood tests is advisable, either through their GP or at a suitable hospital clinic. The only specific advice justifiable is that those with liver dysfunction should avoid alcohol, and even those with normal liver function should take no more than modest amounts.

JG
7th September 1990

~~WTD/~~ 2304

MAIN/ 1329

NHBT0000190_009_0003