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POSITIVELY WOMEN

Plain speaking about HIV and AIDS
and how it affects women written for
women by the experts – women.



HIV, PREGNANCY AND CHILDREN

Your child and your rights

If you or your child are antibody positive, you mustn't worry that the child will be taken into care by the council's social services department. Social workers have a clearly defined brief and that's to give support to parents and children AT HOME. Your child cannot be taken away and put into care simply because the parents or the child have HIV infection or AIDS. There is also no reason your children will be taken into care if you are claiming Attendance or Mobility Allowance.

If you have any problems over housing, benefits or legal rights, call Positively Women and we will put you in touch with experts who can give you professional and confidential advice.

HIV infection and AIDS are becoming a problem when children are abused sexually and when women are raped. If this has happened to you or your child, do not agree to an HIV test without getting fully informed about the test and before you're given proper counselling. If your test turns out to be positive, contact Positively Women.

Pregnancy

If you're antibody positive to HIV, should you get pregnant? Opinions differ, but the facts as we have them are:

- **All babies born to HIV antibody positive mothers are born with their mother's positive maternal antibodies.**
- **After 6 to 18 months the maternal antibodies clear and research suggests that approximately 70–87% of babies will be virus free (though these statistics are constantly changing). Obviously, that means that 13-30% of babies will have HIV infection and these children are at risk of developing AIDS.**
- **The most common way for a baby to become infected with HIV is in the womb or during birth. HIV positive women who have good access to milk formula (soya formula suits some babies better) and sterile feeding equipment and water are advised not to breast feed as it can increase the chances of transmitting the virus.**

A lot of doctors advise women who are antibody positive to HIV to have a termination. Armed with the facts given above, a woman must be left to make up her own mind. If she decides to go ahead with the pregnancy, she should be given all the support she needs. If you're in this situation, we advise you to call Positively Women straight away.

If you're already pregnant, make sure your antenatal clinic doesn't test your blood for HIV antibodies without your fully informed consent. You have the right to refuse. When they're taking your blood for the usual tests, ask what tests are going to be done. If you consent to an HIV antibody test, make sure you get full counselling before the test and after the result. If your test comes back positive, call Positively Women.

If you decide to go ahead with a termination, don't feel guilty about it. Remember, it's your choice.

If you or your partner are HIV antibody positive and you're thinking seriously about having a baby, there are several things you should think about:

- **There's the risk of your getting infected if you're negative and your partner's positive.**
- **If you're positive and your partner is negative, you run the risk of infecting him.**
- **If you are both positive you may run the risk of re-exposure to the virus. People have asked if, when both partners are positive, there is a higher chance of the child being infected. This is not the case – the risk does not change.**

Artificial insemination

When one partner is HIV positive, some couples decide to opt for Artificial Insemination by donor – thus not putting the negative partner at risk through unsafe sex. Many women who are not in a relationship with a man also choose Artificial Insemination. Remember, donated sperm may also contain HIV – so it's advisable to contact a reputable agency like the British Pregnancy Advisory Service, which screens all donors for HIV, if you are considering this method of getting pregnant.

Birth

In the past there has been conflicting information, but the general consensus now is that whether you choose vaginal or caesarian delivery, the risk of infection is the same. Everyone should be treated the same in hospital regardless of their status but unfortunately this is not always the case. Extra precautions are sometimes taken when a woman has been honest enough to reveal her HIV status. Until attitudes change, those of us who are positive will always encounter a certain amount of ignorance.

There is now some evidence that the longer the period between the membrane rupturing and birth the greater the chances of transmission. If a woman already has a child who is HIV+ the chances of subsequent children being infected at birth are increased.

Groups and services

Black HIV and AIDS Network:

Write: 111 Devonport Road,
London W12 8PB.
Phone: 081 749 2828;
Helpline: 081 742 9223.

Blackliners: Write: Unit 46,
Eurolink Business Centre,
49 Effra Road, London SW2 1BZ.
Phone: 071 738 7468;
Helpline: 071 738 5274.

Body Positive/Women's Core Group:

For addresses and phone numbers of
BP groups phone or contact
Body Positive office: 071 835 1045;
Helpline: 071 373 9124 daily, 7-10pm.

British Pregnancy Advisory Service:

Write: 7 Belgrave Road, London SW1.
Phone: 071 222 0985.

Childline:

Confidential counselling for children and
young adults in trouble or danger.
Write: Freepost 1111, London N1 0BR.
Phone 0800 1111 - calls free 24 hours.

Great Ormond Street Hospital:

Write: Infectious Diseases Unit,
Great Ormond Street Hospital,
Great Ormond Street, London WC1.

Haemophilia Society:

Phone: 071 928 2020.

Immunity's Legal Centre:

Free full-time specialist legal centre for
people with HIV living in Greater London.
Phone: 081 968 8909.

The Landmark: Day centre for people
who have HIV infection and people who
have AIDS. Offers meals, recreational
facilities - Mo and Th 10am-9pm, Tu and
Fr 10am-5pm, We 10am-7pm. Women-
only evening We 7-9pm. Advice sessions
including legal advice from Immunity's
Legal Centre We 5-7pm. Plus info for
other people. Write or drop in:
47 Tulse Hill, London SW2.
Phone: 081 671 7611.

London Lesbian Line: Information,
support and advice for women.
Phone: 071 251 6911 Tu-Th 7-10pm.

London Lighthouse: Residential care
and drop-in centre. Offers counselling,
health advice, support at home, breaks
for carers, terminal care and advice
sessions - including legal advice from
Immunity's Legal Centre and North
Kensington Law Centre, Th 5-7pm.
Write: 111 Lancaster Road,
London W11 1QT.
Phone: 071 792 1200.

Mainliners: An organisation in the
drugs and HIV field that promotes self
help and provides services. Write:
205 Stockwell Road, London SW9 9SL.
Phone: 071 738 4656 (client services)
or 071 737 3141 (advice).

Mildmay Mission Hospital:

Convalescence, respite and terminal
care. Plus day care and 24-hour call-out
home care service, covering City and
East London. Has family care centre for
parents and children to remain together.
Write: Hackney Road, London E2 7NA.

National AIDS Helpline: Phone: - free
of charge - for confidential advice:
0800 567 123 (24 hours).

Positive Partners/Positively

Children: Self-help support for anyone
affected by HIV.

Write: The Annexe, Jan Rebane Centre,
12-14 Thornton Street,
London SW9 0BL.
Phone: 071 738 7333.

Positive Women Scotland:

c/o Scottish AIDS Monitor,
26 Anderson Place, Edinburgh EH6 5NP.
Scottish AIDS monitor also provides a
full range of advice information and
support services.

Rape Crisis Centre:

Physical protection and emotional
support.
Write: PO Box 69, London WC1.
Phone: 071 837 1600 (24 hours).

Terrence Higgins Trust:

Information about and counselling over
HIV infection and AIDS. Plus support
groups and trained volunteers to help
people who have HIV infection and AIDS.
Write: 52-54 Grays Inn Road,
London WC1N 8JU.
Phone: 071 831 0330 (admin only).
Helpline: 071 242 1010
(12 noon-10pm).

The Women's Group, Manchester:

c/o George House Trust,
PO Box M60 1PU.
Telephone: 061 839 4340.
Support group for HIV positive women in
the North West of England.

Women's Health and Reproductive Rights Information Centre:

Not an
AIDS specialist - but helpful. Advice on
all health issues affecting women,
including HIV infection and AIDS.
Write: 52 Featherstone Street,
London EC1Y 8RT.
Mo, We, Th, Fr 11am-5pm.
Phone: 071 251 6580/6332.

Children who are antibody positive

Like adults, children can be infected and remain completely well.

In the early stages, children who are positive may suffer from ordinary childhood conditions – such as diarrhoea, running nose, sore throat or ears, skin rashes, kidney problems and lung disorders. Other possible difficulties include slow development, lack of coordination and seizures. All of these can be early symptoms of HIV infection.

More severe symptoms of HIV infection can be serious lung problems – which may need long-term treatment with oxygen, and cancers, such as lymphoma of the central nervous system.

If your child is antibody positive to HIV and shows any of the symptoms we have listed here, see your doctor. The condition could be a minor childhood ailment; it's often very difficult to tell the difference. But if it is HIV-related, prompt treatment could avoid problems in the future.

The Department of Health recommends that all positive children, whether symptomatic or not, should be immunised against measles, mumps and rubella. They should also be immunised against polio and whooping cough using an inactivated vaccine. It is important to remember that if your child has been given a live polio vaccination, any member of your family who has AIDS may be at risk as the polio virus may be excreted in urine; so be careful for example when changing nappies. BCG vaccinations should NOT be given. For further information consult your doctor.

If your child comes into contact with chickenpox or measles, even if they have been immunised, you should contact your GP as soon as possible as they may need a shot of immunoglobulin in case they have not developed sufficient antibodies to cope with these infections.

Children who are antibody negative

Many HIV antibody positive women may find it difficult to have a loving relationship with their children who are antibody negative. They don't need to worry. It's impossible to infect a child through loving and affectionate behaviour.

You may find yourself becoming a bit neurotic over this. If you do, call Positively Women – more often than not we can help as many of us are positive mothers ourselves.

Make sure you carry out standard hygienic practices: covering any open sores, cuts or grazes with a plaster.

Living in the community

If, for some reason, you decide to tell your neighbours that you, or your child, have HIV infection, think about it carefully before you go ahead.

A lot of people are still ill-informed. If you feel you have to tell the neighbours, gauge their reaction by talking about HIV infection in a general sense.

If they are obviously ignorant about the subject, slowly try to educate them yourself. Once you have done all this you may decide to go ahead and tell them about your, or your child's, antibody status.

You'll want to keep your life as stress free as possible. If telling them is going to cause you any aggravation, don't say a word. If you have to tell them, get someone who knows about HIV to be present to support you.

If it's you who has got HIV infection, think about what happens to your child if you fall ill. The obvious thing to do is to arrange support through your immediate family or close friends. For your own peace of mind make sure you've made a will, saying exactly who's going to care for your child. If you don't have any family or friends you can fully rely on, see the bit about foster parents further down this page.

If it's your child who's got HIV infection, it's important to allow them to play freely with other children in the community. There are no known cases of children infecting each other through everyday activities.

Most local authorities have very clear policies on what help and support that parents or children who have HIV infection need.

If coping at home is difficult, ask your local authority for a home help.

Day nurseries and day care facilities should always accept a child with HIV infection – so should registered child minders. Everyone involved should have had full training from the local authority, not just in looking after children with HIV infection but also in counteracting discrimination.

If you can't take full care of your own child, the local authority should ensure that any foster parents are fully briefed on the care and support a child who has HIV infection needs.

Schools

Children who have HIV infection should attend school freely. Parents whose children are antibody positive to HIV need not tell the school authorities, although you may find it preferable to inform the head teacher, to make sure your child gets full support. Ask the head to give you an assurance the school's staff won't write or talk about it as confidentiality is imperative.

There is no record of HIV being transmitted at school – if this were the case, thousands of children would be infected.

Children who have HIV infection are entitled to receive as normal an education as possible and to be allowed access to the full range of school activities – and it's not just us who say so, that is a quote from the Local Authority Associations' Officer Working Group on AIDS.

Your child shouldn't be stigmatised at school – and shouldn't be hassled by the other children or their parents. Bear that in mind when you're deciding what you tell the school – and who you inform.

Positively Women

An organisation run by women for women with HIV and AIDS. We offer the following services: support groups, open only to women who have HIV and AIDS, telephone and one-to-one counselling and consultancy services. Write to us at 5 Sebastian Street, London EC1V 0HE or phone us on 071 490 5515 (client services) 071 490 5501 (administration).

Positively Women produces other leaflets in the series 'Women and AIDS', the titles of which are:

- 1. Prevention**
- 2. Positive Result? – Look after yourself**
- 3. HIV, Pregnancy and Children**
- 4. Women, Drugs and HIV**
- 5. African Women's Health Issues**

Copies of these leaflets can be obtained from Positively Women.