

Sharing experiences with haemophilia

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Acknowledgements

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“ Planning a family ”



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Sharing experiences *with haemophilia*

“ The choice is yours - having all the facts can help you make your decision. ”

WHAT IS HAEMOPHILIA?

Haemophilia is an inherited condition where there is a life long clotting defect of the blood. There are two types of haemophilia. The first type is haemophilia A where there is a deficiency of factor VIII in the blood. The second type is haemophilia B where there is a deficiency of factor IX. Factor VIII and IX are two of the proteins present in blood which enable blood to clot following bleeding. In both types of haemophilia factor VIII or IX are either partly or completely missing.

People with haemophilia bleed for longer than normal. The bleeding usually occurs in the joints and

muscles and can happen spontaneously or as a result of trauma. Haemophilia affects all races and socio-economic groups.

If you were born with haemophilia or, as a woman, carry the haemophilia gene you may be concerned about passing the condition to your children. This leaflet is intended to inform you and your partner about the range of options available to you if you are planning a family. It will help you make an informed decision about whether or not to have a child and how this can be accomplished safely.

A LITTLE BIT OF THE HISTORY OF HAEMOPHILIA TREATMENT

Treatment for haemophilia A and B can prevent and stop bleeds that may occur following major or minor injuries (and sometimes without obvious cause) in people with severe haemophilia. In the past, because such treatments were derived from human blood, unfortunately people with haemophilia were at risk of contracting Hepatitis C and/or HIV. Today, much of the treatment for haemophilia A and B is derived from recombinant blood products, which are made synthetically, or from plasma products in which any viruses have been inactivated. Therefore your risk of contracting HIV or Hepatitis C from your treatment has been virtually eliminated.

THE IMPORTANCE OF SAFER SEX

Taking steps to ensure sex is as safe as possible is essential for the long-term health of everyone - with or without haemophilia. Practising safer sex means ALWAYS using condoms with a new or different partner (the best way to avoid sexually transmitted diseases), or limiting the amount of penetrative sex. Without safer sex, not only are you in danger of contracting life-threatening diseases such as HIV, Hepatitis B, or cervical cancer, but also other infections such as cervical warts, herpes, gonorrhoea, syphilis and chlamydia.

If you received treatment for haemophilia before the advent of virally inactivated plasma products or recombinant products, it may be that you contracted HIV/HCV through your treatment. If this is the case, it is important that you practice safer sex to protect your partner.

If you are concerned that you have contracted or are at risk of HIV, it is important that you are tested as soon as possible. Contact your Haemophilia Centre, your local genitourinary centre or the Terrence Higgins Trust on their helpline **0845 1221 200** for a list of clinics or visit their web site **www.tht.org.uk**.



CHOOSING YOUR CONTRACEPTIVE

Using an effective contraceptive protects you from unwanted pregnancies, giving you time to decide whether or when you want to start a family. If you feel you are not ready to have a child, either because of the hereditary nature of haemophilia or for any other reason, careful contraception is particularly important.

There are many types of contraception available; the table below gives you an idea of the different methods and level of effectiveness. For advice and further information on contraception and pregnancy, visit www.mariestopes.org.uk or call **0845 300 8090** or the Family Planning Association (fpa) National Helpline **0845 122 8690**.



THE RANGE OF CONTRACEPTIVES AVAILABLE TODAY

Name	How it works	Suitable for	Effectiveness
The combined contraceptive pill	Contains oestrogen and progestogen, stopping the ovaries from releasing eggs.	Women under 35, non-smokers, of reasonable weight	If taken correctly, 99% effective Note: drugs including enzyme inducers (some anti-depressants) and antibiotics can affect the absorption of the combined pill.
The Progestogen - only pill	Contains progestogen, which thickens the cervical mucus to form a barrier, stopping sperm from entering the uterus. Also makes the uterus lining thinner, to prevent a fertilised egg from implanting.	Women who are breast-feeding, smokers or those unable to take the combined pill.	It must never be taken more than 3 hours late, as this reduces its effectiveness. If this happens alternative birth control methods should be used. Antibiotics do not affect the progestogen-only pill. If taken correctly, 98% effective
Contraceptive injection	Works in the same way as the progestogen-only pill, but in the form of an injection, which can last up to 12 weeks.	Women who are breast-feeding, smokers or those unable to take the combined pill.	98% effective
Implants	Works in the same way as the progestogen-only pill. Small rods (between 1 to 6 depending on the brand) are inserted beneath the skin on the inside of the upper arm under local anaesthetic. They can last up to 5 years.	Women who are breast-feeding, smokers or those unable to take the combined pill or who require long-term contraception.	98% effective

Male condoms	Made of a very thin latex or polyurethane and act as a barrier contraceptive, but also give protection against STDs. N.B. If HIV+ extra protection can be provided by using a brand which contains Nonoxynol 9 a spermicidal lubricant, active against HIV.	Men	Between 94-98% effective Note: Check for the European kite mark number, BS EN 600.
Female condoms	Made from polyurethane, they fit inside the vagina and overlap the outer area to form a barrier contraceptive. Also give protection against STDs.	Women	If used carefully, up to 95% effective.
Diaphragm/Cap with spermicide	Made of rubber and fit over the woman's cervix to form a barrier contraceptive. They must be used with spermicidal pessaries or cream, and have to be left in place for six hours after sex.	Women	If used correctly, between 92-96% effective.
Intra-uterine device	Fitted by a doctor or nurse into the uterus via the cervix. They prevent fertilisation and stop the fertilised egg from implanting on the uterus wall. There are two types, one which releases the hormone progestogen and one which doesn't. Methods last up to five years.	Women with one partner. (Having sex with someone other than a regular partner can cause pelvic inflammatory disease, so condoms are recommended for extra protection).	98-99% effective
Sterilisation	Permanent surgical methods of contraception, carried out under local anaesthetic.	Men and women	100% effective
Natural methods	Women must be aware of when they are fertile or approaching fertility and avoid unprotected sex at those times.	Women	Very low

Information is available from your GP, family planning clinic or www.mariestopes.org.uk

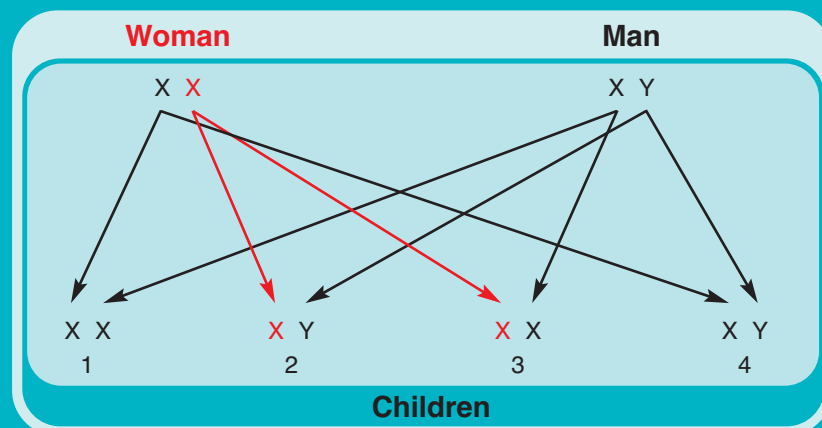
HOW IS HAEMOPHILIA IS INHERITED?

Genes contain the genetic instructions for life. They determine the physical characteristics which make us into unique individuals, for example the colour of our hair and eyes. Genes are carried on structures called chromosomes. Each individual has 46 chromosomes arranged in pairs.

Two of these chromosomes, the X and Y chromosomes, decide the sex of a baby. Women have two X chromosomes i.e. XX, and men have an X and a Y chromosome i.e. XY. Haemophilia is a 'sex linked' disorder. This means the genes for haemophilia A and B are

found on one of the sex chromosomes - the X chromosome.

Look at the following diagram. The woman is a carrier of haemophilia. She has two X chromosomes, one of which, shown in red, contains the haemophilia gene. Her partner has two normal chromosomes, one X and one Y.



Child 1 - is a girl (XX). She has inherited a normal X chromosome from both her mother and her father. She is not a carrier of haemophilia.

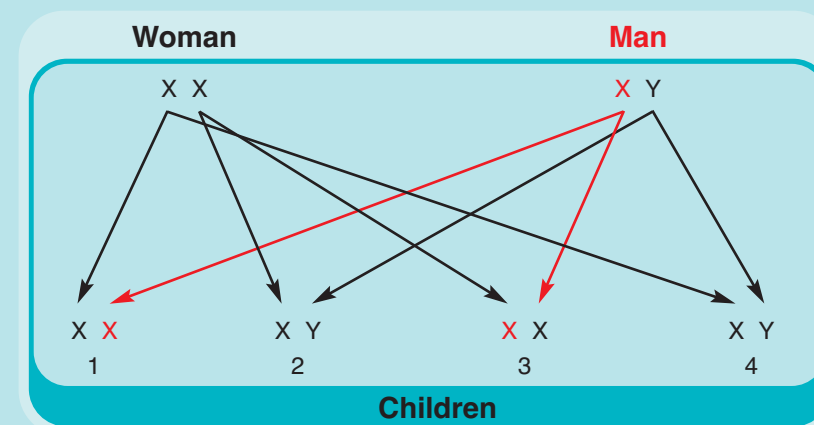
Child 2 - is a boy (XY). He has inherited a Y chromosome from his father and the haemophilia gene from his mother. He has haemophilia.

Child 3 - is a girl (XX). She has inherited the haemophilia gene from her mother. Because she has also inherited a normal X chromosome from her father this overshadows the haemophilia gene on the X chromosome she inherited from her mother, so she does not have haemophilia (although she may have some mild symptoms). She is, however, a carrier like her mother.

Child 4 - is a boy (XY). He has inherited normal chromosomes from both his mother and father. He does not have haemophilia.

So a woman carrying the haemophilia gene has a 50:50 chance of her son having haemophilia or her daughter being a carrier.

Now look what happens if the man has haemophilia:



As you can see, in this case both the daughters will be carriers (Children 1 and 3) but none of the sons will have haemophilia (Children 2 and 4).

Both the type and severity of haemophilia are inherited, so if a mother has the gene for haemophilia A, the son will develop haemophilia A as opposed to haemophilia B. Similarly, if there is a family history of moderate haemophilia, then a moderate level of severity will be passed on to future generations.

In a third of the cases haemophilia occurs where there is no family history. This is called a 'genetic mutation'. Once the haemophilia gene appears, however, there is always the possibility that the person with haemophilia or the carrier will pass it on to their children.



PLANNING A BABY

When you and your partner consider starting a family, and one of you carries the haemophilia gene or has haemophilia, there are some considerations that you may wish to take into account if you choose to conceive.

BEFORE CONCEPTION - YOUR PRENATAL CHOICES

If you are a man with haemophilia or a woman carrying the haemophilia gene, deciding whether or not to have a child can be a very emotionally challenging time. You may feel guilty, angry or anxious about the possibility of having a child with haemophilia and may wonder if you will be able to cope with the demands associated with this extra responsibility.

These feelings can be discussed confidentially at your Haemophilia Centre where the staff can also advise you on the different choices available to you, such as:

- To remain childless.
- Natural conception, with the possibility of having an affected child.
- Natural conception followed by prenatal diagnosis and the possibility of termination of an affected fetus.

- Assisted conception with 'washed sperm' or 'donor sperm' for HIV sero discordant couples - this means where the haemophilic man is affected with HIV whilst his partner is not.
- Pre-implantation genetic diagnosis (PGD) - enabling the detection of the haemophilia gene by biopsying pre-embryos following IVF techniques and, if available, selecting two unaffected embryos and implanting them into the uterus (womb), giving them a chance to develop into a pregnancy.
- Adoption.

It is important to think through the implications of the options outlined before making your decision. The sort of issues to consider include:

- If you have a pre-natal diagnostic test and the results are positive, you may choose to terminate the pregnancy. The legislation regarding termination of pregnancies varies between countries. Undoubtedly this will be a very difficult decision for you and your partner to make. Whatever you decide, the choice that you make is a very personal one for you and your partner. You may find seeking advice and information from the health care professionals at your Haemophilia Centre or another expert advisor useful. In the UK you can contact the British Pregnancy Advisory Service, Tel: **08457 304030**.
- It is important to remember that any assisted means of conception will be time-consuming, costly and possibly stressful. Many people who undertake sperm washing or PGD involving IVF will have had more than one attempt to conceive and, because stress can be a high cause of infertility, the process can be even harder. For these reasons, you will have to attend counselling sessions before starting any Assisted Conception Programme, to offer support enabling you to understand the psychological effects that the process could have on you and your relationship.
- Assisted conception programmes are not always available under the National Health Service and, although advanced methods such as PGD have been available for many years, many health authorities do not have the budget to provide for them. Therefore you also need to be aware of the financial commitment this type of treatment could take.



SCREENING TESTS

If you decide to conceive naturally, there are several tests available should you become pregnant. These tests fall into two groups:

- 1 A test which monitors the progress of the pregnancy and can identify some fetal anomalies - ultrasound.
- 2 Tests which determine whether the fetus has haemophilia, such as Chorionic Villus Sampling (CVS), Amniocentesis and Fetal Blood Sampling.

ULTRASOUND

You will routinely be offered an ultrasound scan during your second trimester, at approximately 18-20 weeks. The sex of your baby can often be determined at this stage but the accuracy is not 100%. This information can help your doctor manage the delivery of your baby. If it is important for couples not to have a child with haemophilia, further investigations involving amniocentesis or CVS are required.

AMNIOCENTESIS

This procedure assesses the amniotic fluid (the fluid which protects the baby in the womb) for haemophilia or any other 'sex linked' disorders. Although this is a safe and simple procedure carried out in the second trimester after 16 weeks of pregnancy, it is an invasive procedure where a needle is inserted into the uterus through the abdomen. A sample of the fluid is then drawn up through the needle. The discomfort felt is minimal. The sample is sent to the laboratory where it is cultured (left to grow into multiple cells). The results are usually available in 3 to 4 weeks.

If you opt for this approach, you may have felt your baby move by this stage and find it emotionally more difficult to have a termination.

CHORIONIC VILLUS SAMPLING (CVS)

This method of diagnosis looks for the haemophilia gene in a small amount of tissue (chorionic villi) taken from the placenta. There are two ways that this test can be carried out, Vaginal CVS or Abdominal CVS. Both require the procedure to be carried out under ultrasound scan. The results for either route are usually available in 2-3 weeks.



VAGINAL CVS

The Vaginal route involves a speculum being inserted into the vagina enabling the cervix to be seen. The ultrasound probe is then placed on the abdomen, locating the baby in the uterus. A fine tube is passed beside the cervix into the uterus. As this is being carried out under ultrasound guidance, the tube can be seen clearly on the screen and is guided to the placenta where a small sample of chorionic villus is removed.

ABDOMINAL CVS

This procedure is carried out in a similar way to that of amniocentesis. The sample of chorionic villus tissue is obtained by passing a fine needle through the abdominal wall into the uterus then into the placenta under ultrasound guidance. There is a small chance that the doctor may not get enough tissue or that the laboratory is unable to make an accurate diagnosis, in which case the procedure will need to be repeated.

Some parents express concern about the needle possibly harming the baby.

However ultrasound guidance enables the needle to be inserted away from the baby.

CVS can be carried out earlier than amniocentesis - between 10 to 12 weeks into your pregnancy. You probably will not have felt your baby move at this stage, so may find it a little easier if you decide to go ahead with a termination.

CVS is the more commonly used pre-natal diagnostic test for families with a history of haemophilia.

FETAL BLOOD SAMPLING

This diagnostic procedure is not carried out routinely and is only available in specialist centres. It is best carried out at 18-19 weeks of pregnancy. The technique is similar to amniocentesis, however in this instance the fetus' blood is sampled and analysed to detect the level of factor VIII or IX present.

If you decide to have pre-natal diagnosis you need to be aware that all these investigations are associated with small risks, including premature labour and bleeding or leaking of the amniotic fluid. In some cases, damage to the baby's limbs, respiratory system and even a miscarriage can occur. Amniocentesis and CVS are associated with about a 1% chance of miscarriage whereas Fetal Blood Sampling is higher, in the region of 5%.

ASSISTED CONCEPTION TECHNIQUES

Before you may begin any assisted conception programme you have to complete a number of rigorous medical investigations to check that you are generally in good health and are fertile.

Women have a full medical examination (which will include a discussion about weight, alcohol intake, smoking habits) and blood screening for hepatitis A, B and C, HIV, syphilis, rubella as well as a hormone profile. A transvaginal ultrasound of the pelvis and uterus will also be carried out to ensure the baby can be carried successfully. In order to increase the chances of conception extra hormones may be given so that as many eggs as possible are produced.

Men have similar medical questions and tests, plus a semen analysis to assess the volume, number and motility of their sperm and, if they are HIV positive, a viral load and T cell count will also be carried out. Positive viral screens do not necessarily exclude further treatment. However if both partners were found to be HIV positive it is unlikely that treatment would be offered.

PRE-IMPLANTATION GENETIC DIAGNOSIS (PGD)

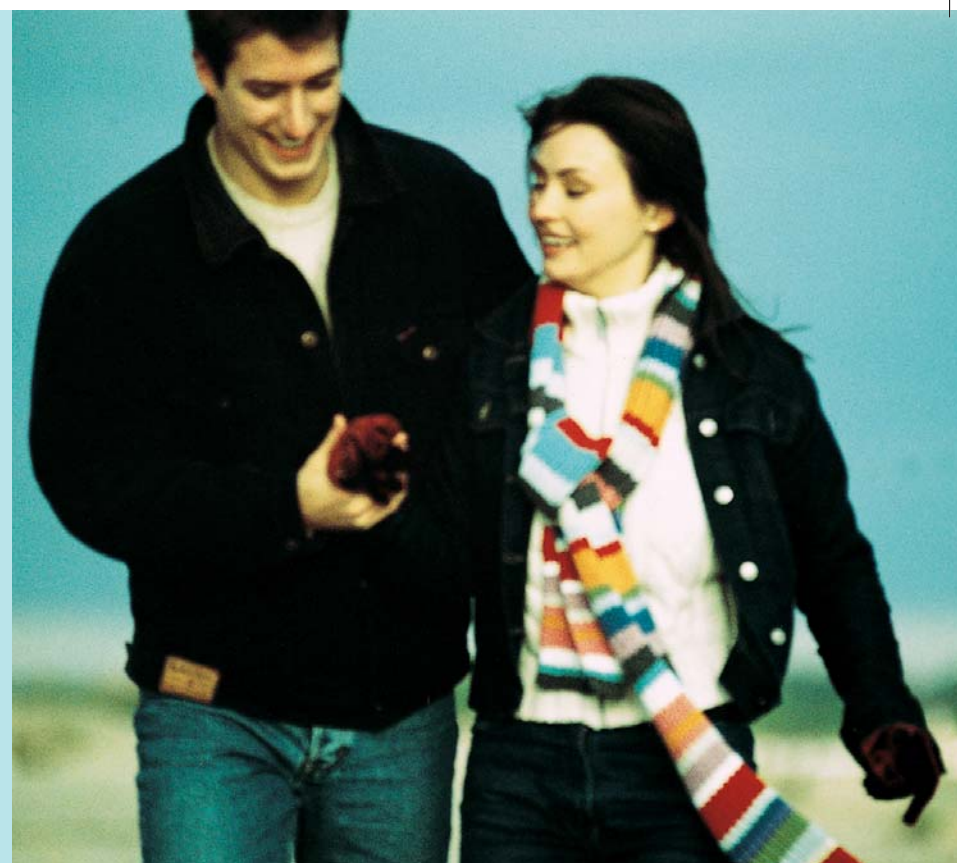
If for religious or personal reasons you would not consider termination of an affected pregnancy, pre-implantation genetic diagnosis may be a suitable option for you. Using PGD it is possible to screen embryos for some genetic disorders such as haemophilia or to diagnose the sex of the embryo. This method works in the following way:

The woman takes daily medication and injections to suppress her pituitary glands and to stimulate her ovaries to produce as many eggs as possible. Mature eggs are collected from the woman's ovaries and mixed with sperm from the male. This is known as in vitro fertilisation (IVF).

After three days one or two cells are analysed. This is called an embryo biopsy. The embryos which are either diagnosed free from disease or are of a certain sex can then be transferred to the uterus. Usually two embryos are transferred and hopefully at least one will develop into a pregnancy. (This is the recommendation of the Human Fertilisation and Embryology Authority.)

Before opting for PGD, it may be worth taking the following points into consideration:

- There are other options, for example egg donation from a donor who does not carry the haemophilia gene.
- PGD is still considered an experimental programme. Only a relatively small number of babies worldwide have been born after PGD.
- Embryo biopsy can slightly increase the risk of early miscarriage.
- You may give birth to twins as two pre-embryos are usually transferred.



- IVF has a success rate of approximately 20%. Women under the age of 30 have a pregnancy rate of 28% compared with women over 30 years of age, where the success rate drops to 21%. As a general rule the younger you are the better your chances are.
- Embryo biopsy is difficult and still is an experimental procedure, so misdiagnosis is a real possibility.
- You can't use all the embryos. All embryos except the two that are implanted are destroyed.
- It's a long-term decision. This technique will require your child to be monitored both after birth and throughout childhood.

WASHED SPERM

If both of you are fertile, and the man is HIV positive, using partner's washed sperm may be a viable option. In this technique sperm is separated from its seminal fluid, which is where HIV infected material is primarily carried, and tested for viral load. If negative, following manipulation it is then inseminated into the womb during the ovulation period. This does not totally remove the risk - it is a risk reduction method.

DONOR SPERM

An alternative risk free option is to use donated sperm. All donors are anonymous and are rigorously tested for all sexually transmitted diseases such as HIV and hepatitis B and C. They attend at least one counselling session prior to their first donation.

The method of insemination is exactly the same as for sperm washing but all semen is frozen for 180 days and then tested again before it can be passed as ready for use.

BEFORE CONCEPTION - KEEPING HEALTHY

So, you and your partner have decided to conceive, either via assisted means or naturally. Now it is essential that you look after yourselves. Here are some basic tips on how you can achieve good health:

- Cut down stress.
- Keep at a reasonable weight for your height.
- Eat healthily - a balance of calories, protein, carbohydrates (starchy as opposed to sugary foods) and vitamins are essential for your health.
- Drink 6-8 glasses of fluids per day.
- Increase your intake of folic acid to 400µg (this can be taken in supplement form and should also be taken during the first 12 weeks of the pregnancy). Folic acid reduces the chances of neural tube defects, such as spina bifida.
- Ensure immunity from rubella (or German measles) as this can harm fetal development in the first three months.

DURING PREGNANCY - LOOKING AFTER YOURSELF

Although, once pregnant, you will be closely monitored by your obstetrician, midwife and Haemophilia Centre, it is still imperative that you take good care of yourself throughout pregnancy. As well as following the advice above, you should also try and take the following steps to remain healthy during your pregnancy:

- Cut down on tea and coffee.
- Take gentle exercise such as swimming, water-aerobics and low-impact aerobics, making sure you don't dehydrate or overheat.
- Stop smoking - the serious consequences for your baby include complications at birth, premature birth, being born underweight or cot death.
- Avoid alcohol - at least for the first 3 months while your baby's organs are developing. Regular drinking, i.e. more than 4 units* of alcohol a week can lead to mental and physical problems for your baby.**
- Avoid medication - especially in early pregnancy. Tell your pharmacist about your pregnancy before buying over the counter medicines.

*1 unit is equivalent to one small glass of wine or one half pint of beer.

**Information from www.mothersbliss.co.uk

CHECKING YOUR CLOTTING FACTOR LEVELS

When you are a carrier of either haemophilia A or B there is a chance that you yourself could have low levels of clotting factor VIII or IX. Your level of clotting factor, therefore, will be checked early in your pregnancy and again during your third trimester (34 weeks). It is important for your obstetrician to establish the level of clotting factor as, if you have low levels, you could need treatment to prevent bleeding during any invasive procedures, such as prenatal diagnostic tests, epidural or caesarean section.



DURING DELIVERY - WHAT YOU CAN EXPECT

If you are a carrier of haemophilia A your levels of factor VIII will rise during pregnancy, especially in your third trimester. So epidurals during delivery should not result in bleeding. If you are a carrier of haemophilia B, your levels of factor IX will not rise during your pregnancy and you may need treatment to make your blood clot if you choose to have an epidural for pain relief during labour.

If there is a chance of your baby having haemophilia, the use of fetal scalp probes and other instruments such as Ventouse suction will not be used to assist delivery as this could cause the baby to bleed. Your obstetrician will make the decision whether or not to proceed to caesarean section should instruments be required.

AFTER THE BIRTH - EXTRA PRECAUTIONS FOR YOU AND YOUR BABY

If your baby is a boy, a blood sample will be taken from the umbilical cord to establish the factor VIII or IX level to find out if he has haemophilia.

There is a possibility that your baby may be given recombinant clotting factor at birth. The process of being born is traumatic and factor concentrate may be given as a precautionary measure. In some cases it may be necessary to scan your baby's head to make sure there is no internal bleeding. Do not be alarmed by this. Your obstetrician will simply want to make sure that your baby is in good health.

As with all pregnancies, there is a risk that you may bleed after giving birth. If you have low factor levels this risk will obviously be increased. Therefore your obstetrician may wish to check your factor levels even a few days after delivery so that if you have haemophilia A you can be given DDAVP, and if you have haemophilia B, a recombinant clotting factor. These treatments do not pass into breast milk, so you can still breast feed your baby safely.

For more general information on planning a baby or pregnancy visit www.mothersbliss.co.uk



ADOPTION

If you have decided not to have a child naturally, or feel that aided conception is not for you, adoption could be a rewarding and viable alternative. Social services and adoption agencies work very hard to ensure they match children and parents well so that they can go on to lead a happy family life. Before you begin the adoption procedure, however, you need to recognise the commitment you will need to make in terms of time, patience and money.

There are more adoptive parents than adoptees in the UK and the number of available children under 1 is very limited, making the criteria for adoption of babies even more stringent. Older children may bring with them emotional problems, possibly resulting from previous neglect, which may place further stresses on the adopting family.

Just as in having any family, adoption will be costly. Families considering adoption should make themselves aware of the financial commitments involved.

There are only two real restrictions on who can adopt. The first is a criminal record and your suitability will depend on the severity of the offence or how long ago it was committed. Obviously, people who

have committed violent or sexual crimes will not be considered. The second is a degenerative, debilitating or life-threatening disease, which would increase the likelihood of you not living into old age. Haemophilia is not considered a restriction on health grounds, as with today's successful virally inactivated plasma products and recombinant treatment, people with haemophilia are more than likely to have a normal life expectancy. In fact, having haemophilia may mean that you will be considered capable of dealing with all the problems associated with a life-long condition and find you are matched to a child with a similar condition where treatment needs to be taken on a regular basis, such as diabetes.

Before you can gain full responsibility for a child there are many stages to go through and the whole process can take between two and ten years. For further information, contact the British Agencies for Adoption & Fostering on 020 7421 2600 or visit www.baaf.org.uk.





MAKING DECISIONS FOR YOUR FUTURE

Whatever decision you make about starting a family, it is very important that you plan. Whether you decide: to stay childless; to adopt; to have a baby naturally and accept the possibility of having an affected child with haemophilia; to conceive naturally with the option of pre-natal diagnosis and the possible termination of an affected child; or to opt for assisted methods of conception, it is essential that you are well informed.

This leaflet has given you and your partner a starting point, to help you discuss your options with each other and the relevant medical professionals, such as your GP, obstetrician and Haemophilia Centre.

Planning ahead will give you
a greater chance of having the
family you want -

so Good Luck!

FURTHER READING.

(All available from the Haemophilia Society)

"Living with Haemophilia" by Peter Jones

"Inheritance of Haemophilia" by the National Haemophilia Foundation

"Haemophilia with HIV - You Can Think About Starting a Family"

by Lara Oyesiku, Rona Beresford-Webb and Jane Kennedy (Supported by an educational grant from Bayer plc)

"Raising a Child with Haemophilia" by Laureen Kelly

USEFUL ADDRESSES:

The British Pregnancy Advisory Service

www.bpas.org.uk

Actionline: 08457 30 40 30

BPAS Head Office, 20 Timothys Bridge Road, Stratford Enterprise Park, Stratford upon Avon, Warwickshire CV37 9BF.

Tel: 0845 365 5050

fpa (formerly The Family Planning Association)

www.fpa.org.uk

National helpline: 0845 122 8690 (Open Mon to Fri 9am - 6pm)

England:

50 Featherstone Street, London EC1Y 8QU.

Tel: 020 7608 5240

Wales:

Cardiff - Suite D1, Canton House, 435-451 Cowbridge Road East, Cardiff CF5 1JH.

Tel: 029 2064 4034

Northern Ireland:

Belfast - 3rd Floor, Ascot House, 24-31 Shaftesbury Square, Belfast BT2 7DB.

Tel: 0845 122 8687

Derry - 3rd Floor, Carlisle Road, Derry BT48 6JL.

Tel: 028 7126 0016.

Northern Ireland Helpline: 0845 122 8687 (Open Mon to Fri 9am - 5pm)

Scotland:

Unit 10, Firhill Business Centre, 76 Firhill Road, Glasgow G20 7BA.

Helpline: 0141 948 1179 (Open Mon to Thurs 9am - 5pm, Fri 9am - 4.30pm)

Genetic Alliance UK

www.geneticalliance.org.uk

Unit 4d, Leroy House, 436 Essex Road, London N1 3QP.

Tel 020 7704 3141

The Human Fertilisation and Embryology Authority

www.hfea.gov.uk

Finsbury Tower, 103-105 Bunhill Road, London, EC17 8HF.

Tel 020 7291 8200