CHAPTER FIVE

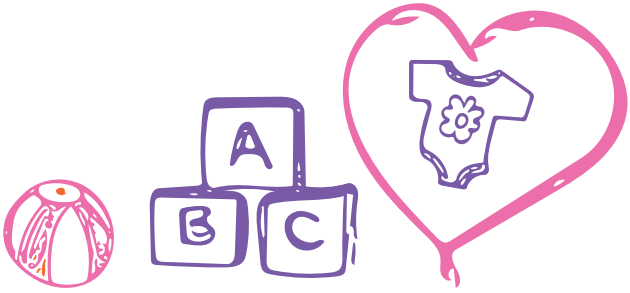

HAVING
CHILDREN

CONTENTS

INTRODUCTION

For many people the decision to start a family is one of the biggest that they will ever make. However if you live in a family impacted by Huntington's disease (HD) your decision might require further consideration due to recent advancements in science and medicine which can enable you to have a baby which doesn't carry the HD gene; an option which wasn't available to previous generations.

Family planning and having children is incredibly personal, and people can feel strongly about the issues involved. This chapter will give you the opportunity to consider having children naturally or choosing one of the various options available.



Let's have some fun and see what you know about babies?

BABIES QUIZ

TRUE/FALSE

1. Around 250 babies are born in the world every minute
2. It takes a year for a baby to double their birth weight
3. Babies have more bones than adults
4. A baby gets 23 chromosomes for their father and 21 from their mother
5. Babies are carried in the womb for 40 weeks
6. Identical twins have identical fingerprints
7. If one parent has brown eyes then their child will too
8. The gene for being able to roll your tongue is inherited from your father

1. True
2. False – it only takes 5 months
3. True – Babies have around 300, whereas adults only have 206
4. False – they get 23 chromosomes from both parents
5. True
6. False - they have different fingerprints
7. False- eye colour is determined by many genes
8. False- it can be inherited from either parent

THINGS TO THINK ABOUT

Starting a family can change a lot in your life. Here are a few things you might wish to consider before having a baby.

EMOTIONAL: Being pregnant and having a baby can be an emotional time. Having good support networks, such as family, friends and baby groups can help you manage this new chapter of your life.

FINANCIAL: In 2016 it was estimated that the cost of raising a child from birth to the age of 21 is £230,000. This might include things such as food, childcare, clothing, leisure and recreation activities.

MORAL AND ETHICAL: Decisions around having children, like many other areas of your life, can be shaped by your moral and ethical point of view. This can be influenced by your culture, religion or beliefs.

PHYSICAL: Having and raising children can be physically challenging. As well as this, children require a lot of nurturing, attention and interaction.

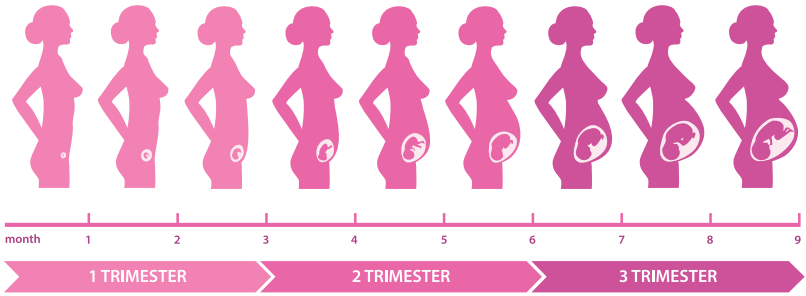
THE FUTURE: Looking after a child is a long-term responsibility and you may wish to think about how this could be impacted by HD within your family.

PREGNANCY

THE BASICS

Getting pregnant naturally, is when a man and woman have sexual intercourse which results in a sperm fertilising an egg and developing into a foetus in a female's womb. However, as we'll learn in this chapter this isn't the only way someone can become pregnant. Once you are pregnant it takes 9 months for the foetus to grow and develop before it is ready to be born and this time is split into three distinct trimesters. More information can be found on NHS Scotland's website.

STAGES OF PREGNANCY



1ST TRIMESTER

During the 1st trimester a mother may suspect that she is pregnant due to missing a period and feeling tired or sick. At this point it is best to contact your GP to speak to them.

During the 1st trimester the mother will go for an ultrasound scan. This scan shows how well the baby is developing.

By the end of the 1st trimester the foetus will be about 6cm long and will weigh about 14g (about the size of a small battery). Even though it is very small it still has eyes, ears, arms, hands, fingers, feet and toes.

2ND TRIMESTER

During the 2nd trimester the mother will feel the baby move for the first time.

Usually a 2nd scan will be carried out around the 20 weeks stage to check on the health of the baby and mother.

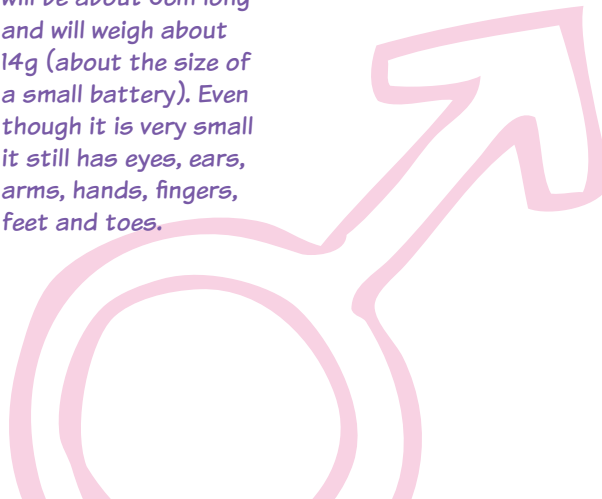
At the end of the 2nd trimester the baby will have grown to about 30cm in length and can weigh anything between 600g to 900g (about the same as two cans of juice).

3RD TRIMESTER

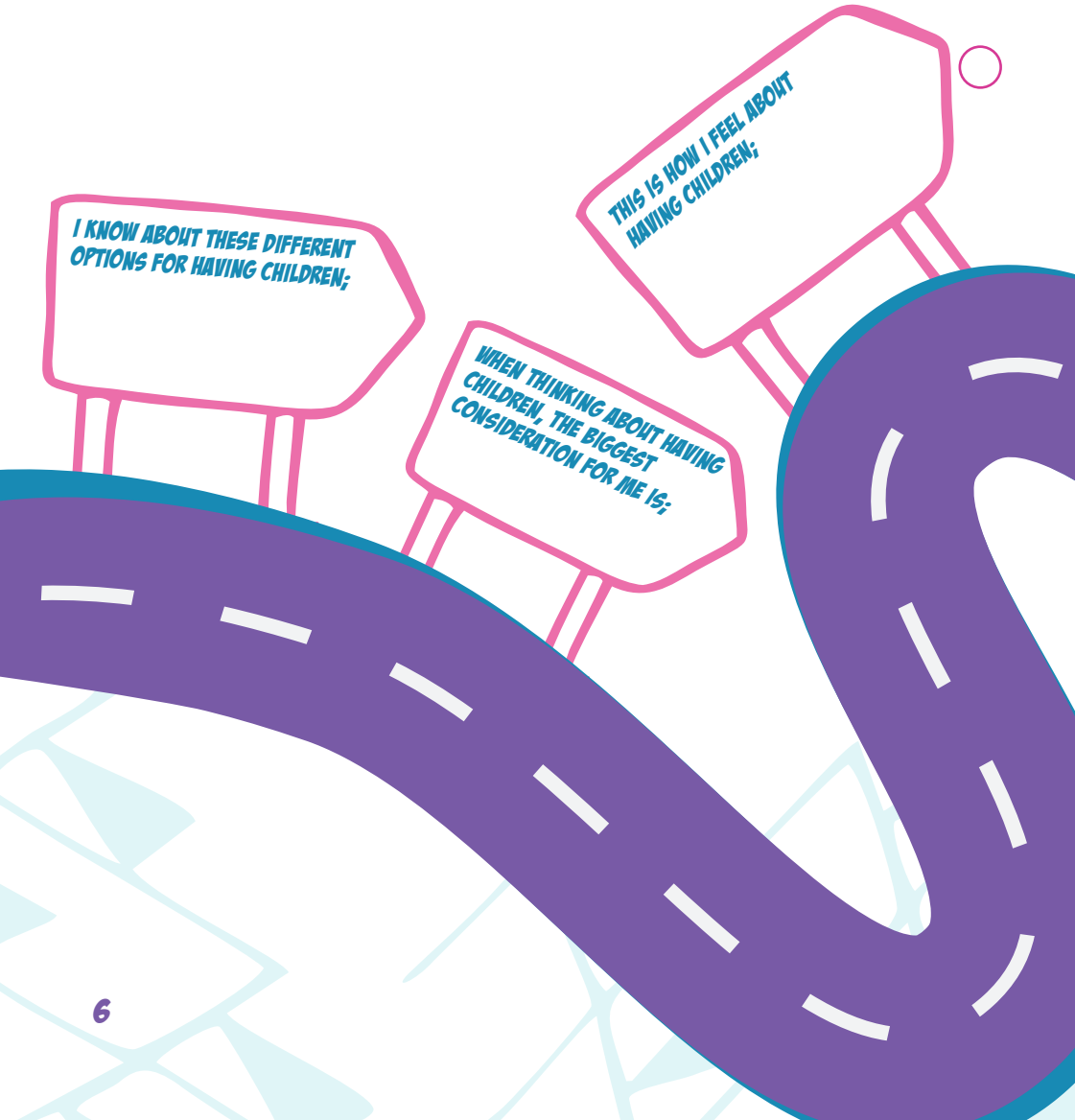
Near the end of the pregnancy the baby will usually change position in the mother's tummy to get ready for being born.

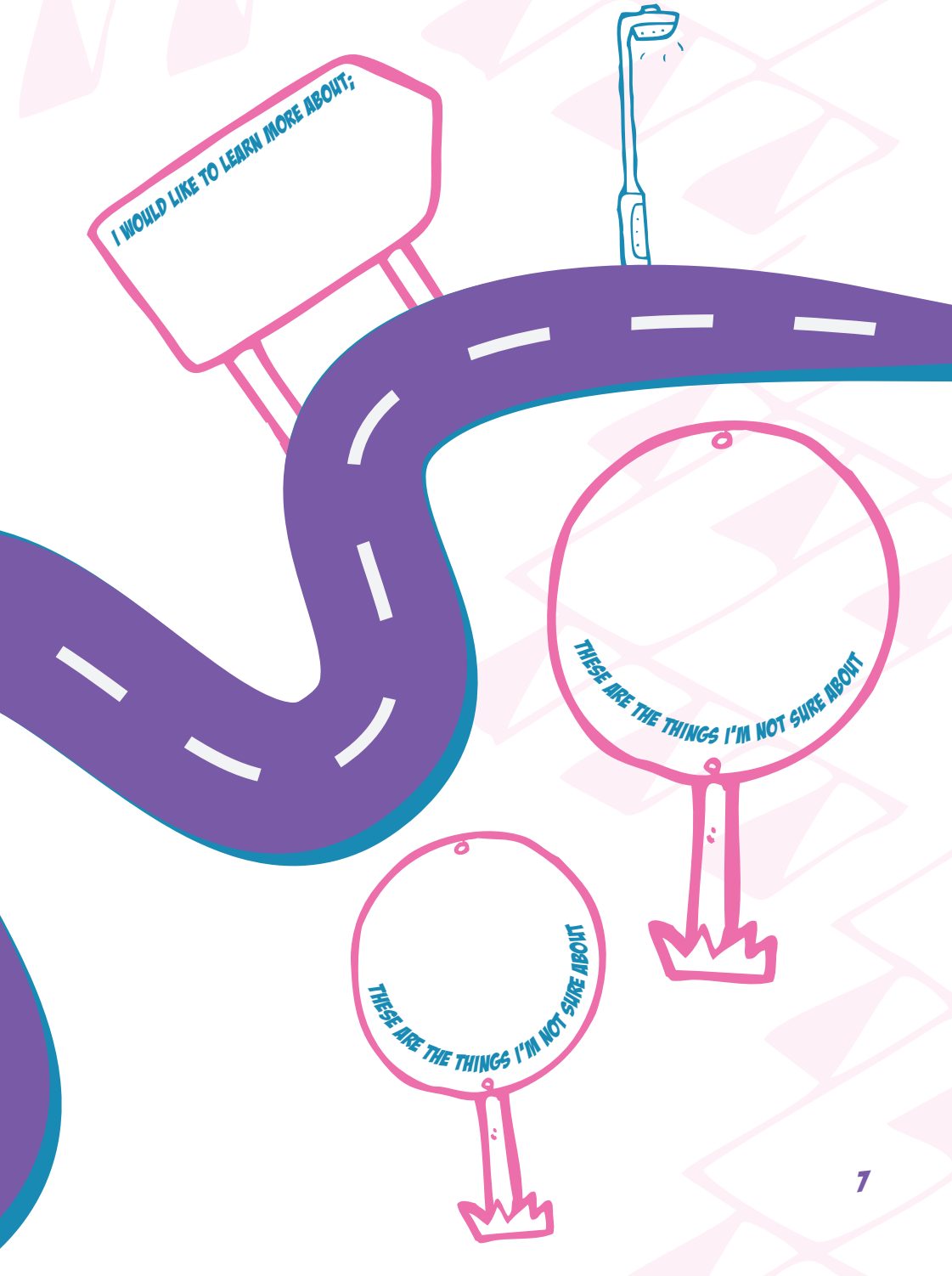
Due to the significant weight in her tummy the mother can be very tired and find moving about difficult.

Just before birth the average baby will weigh between 2.7-4.1kg (6-8lbs) and measure about 50-53cm long.



MY HD ROUTE


I KNOW ABOUT THESE DIFFERENT OPTIONS FOR HAVING CHILDREN;
WHEN THINKING ABOUT HAVING CHILDREN, THE BIGGEST CONSIDERATION FOR ME IS;
THIS IS HOW I FEEL ABOUT HAVING CHILDREN;


I WOULD LIKE TO LEARN MORE ABOUT;
THESE ARE THE THINGS I'M NOT SURE ABOUT
THESE ARE THE THINGS I'M NOT SURE ABOUT

Having a baby if you have a genetic risk for Huntington's disease

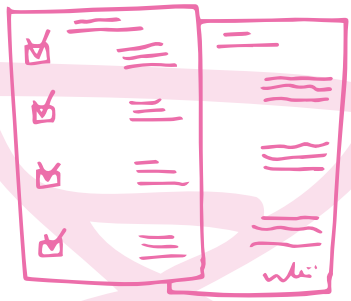
There are a number of options for an individual or a couple who want to start a family: Sexual intercourse is one, but some people may opt for sperm donation, egg donation or choose a surrogate to start a pregnancy.

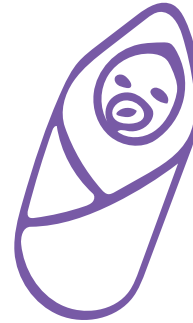
There are two things you may wish to consider about these options:

1. A child conceived to a parent who has (or is at risk of HD) may also inherit the gene that causes HD.

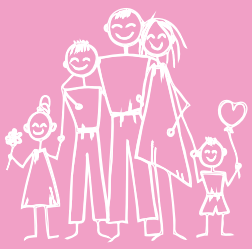
2. You have the same right to a family life as anyone else, but you might experience negative attitudes from other family members or from people out with your family. What matters is that you do what you and your partner, if one is involved, feel is right for you and your family.

More information on Genetic Risk can be found in HD Routes: Genetic Risk and Testing.





MEET THE SMITH FAMILY



Susan and Jim Smith have 4 children - Isabelle (12), Simon (10), John (7) and Sofia (4). Here they share their experience of having children in a family impacted by HD.

How did you first find out about HD in your family?

In 2007, out of the blue, my mother (Susan's) was sent a letter by her brother who lived overseas to say that he had been diagnosed with HD. This obviously came as a big shock to the family. Before long my mother also tested positive and this led to myself going forward for testing where I too received a positive result that summer. At this point we already had two children (Isabelle and Simon) and we quickly realised that this meant they also carried a 50% risk of inheriting the HD gene.

After testing positive you went on to have two more children, can you tell us a little about your experiences?

After the test result we had accepted that we had two children but wouldn't have any more due to the chance any new children could inherit HD. Our view was that having children naturally was not an option and I remember thinking to myself "Why would anyone knowingly bring people into the world who could get this disease?".

A little time later our genetic counsellor told us about a new technology called Preimplantation Genetic Diagnosis (PGD - for more info on PGD see page 16). This technology seemed to give us the chance of having children who were free from the risk of HD so we explored it as an option and decided it was for us. The ball started rolling on and we attended appointments, however, during the process we discovered we were not eligible due to my (Susan's) age. This was a blow as we had spent a lot of emotional and mental energy arriving at the decision to have more children.

At this point we thought and prayed a lot about what to do. We decided that we would still like to have more children and so considered our options. Although we could understand why people would want to check the status of a pregnancy, due to our Christian faith we didn't feel that prenatal screening (for more info on prenatal testing see page 12) was an option for us as we would not have wanted to have an abortion.

After much thinking and praying we decided we would try to have more children naturally who, by default, would also carry a 50% risk of inheriting HD. Over the next few years, we had two more successful pregnancies and welcomed John and Sofia into our family.

What made you change your mind regarding having children naturally?
There were several things that helped us make the decision to choose to have children naturally.

Firstly, our own understanding of what we felt was right and wrong developed over time. Increasingly our faith played a bigger part in our decision-making process which allowed us to discount various options and settle on having children naturally. Even with PGD as a possibility we would now probably still choose natural birth as our preferred option.

Secondly, we are very hopeful that during the life of our children medical science and research will have moved on significantly, to the point where our children's experience of living with HD will be vastly different to ours and previous generations. There may well be a cure or effective treatment by the time our children are adults.

Finally, the thought of our children having the incredible support network that comes from having brothers and sisters is something that we feel is extremely valuable. The thought that our children will not be alone in the world as they encounter the challenges associated with HD gives us comfort.

What were other people's reactions to you having more children naturally who were at risk?
No one has said anything negative to us after having our two youngest children naturally. We feel that people have been very understanding of our wish to have a larger family. If anything, the thing that raised more eyebrows was our age at the time of having the two youngest children, not the fact that we were having children at risk of inheriting HD.

What advice would you give to people impacted by HD who are considering starting a family?
We would encourage the person to take time to consider all the different options that are available in the light of their own values and beliefs. When you are impacted by HD starting a family can often be a very personal, complex and emotional decision, so it is good to take time to weigh each option up.

We would also say that it is ok to change your mind, to reconsider and reevaluate. For various reasons, how you feel in the future about a particular option may be very different to how you feel now.

MY THOUGHTS

PRE-NATAL TESTING

Pre-natal testing allows you to find out whether your unborn baby has inherited the HD gene. There are two main methods of Pre-natal testing:

1. CVS (CHORIONIC VILLUS SAMPLING)

CVS is carried out between the 11th and 14th week of pregnancy and involves inserting a needle through the mother's tummy to take a small piece of placenta. The cells are then tested to determine whether the foetus has inherited the HD gene. CVS carries an increased risk of miscarriage with estimates of between 1-2% of pregnancy's miscarrying after the procedure.

2. AMNIOCENTESIS

Amniocentesis is carried out between the 15th and 18th week of pregnancy and works in a similar way to CVS by using a needle to extract amniotic fluid. This fluid surrounds the baby in the womb and contains cells which can be tested to determine whether the unborn baby has inherited the HD gene. Amniocentesis also carries an increased risk of miscarriage at 1%.

RESULTS

Once the results of the CVS or Amniocentesis come back the parents need to decide how to proceed with the pregnancy. If the test comes back negative, meaning the unborn baby does not have the HD gene then the pregnancy can continue knowing that the child is not at risk. If the test comes back positive, meaning the unborn baby has inherited the HD gene then the parents need to make the decision whether to continue on with the pregnancy.

FURTHER INFORMATION Your GP or midwife will be able to give you more information about these procedures.

MY THOUGHTS

EXCLUSION TESTING

If one parent is at risk of HD, but does not wish to be tested you can undertake a procedure called exclusion testing which compares the DNA of the unborn baby, the at-risk parent and the HD affected grandparent. This test will indicate whether the unborn baby carries a high or low risk of inheriting the HD gene.

LOW RISK

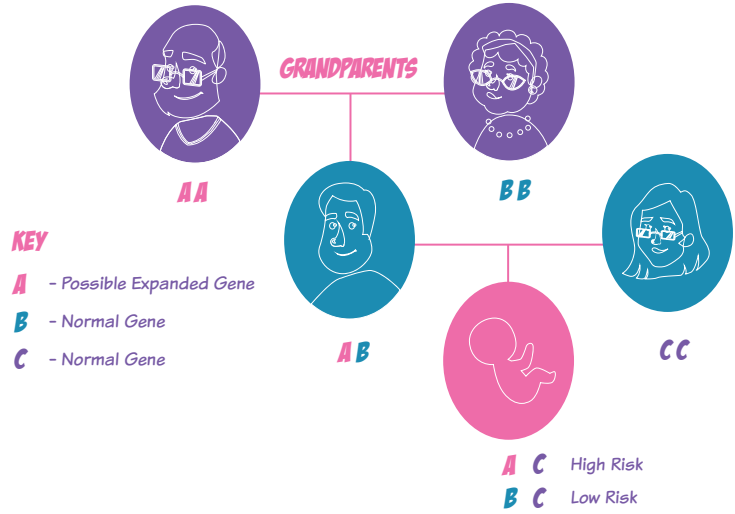
If the unborn baby has inherited a copy of chromosome 4 from the grandparent without HD, then it is at low risk. This does not tell the parent anything about their own genetic status and their level of risk remains at 50%.

HIGH RISK

If the unborn baby has inherited a copy of chromosome 4 from the grandparent with HD then it now classed as high risk. However, it is unknown whether this is the HD gene or the normal gene.

At this point the parents need to make the decision whether to continue or terminate the pregnancy. This decision is made more complex because there is a 50% chance the high risk unborn baby does not carry the HD gene.

If the decision is made to continue the pregnancy and the parent develops symptoms of HD, this means that both the parent and child have inherited the HD gene from the affected grandparent.



FURTHER INFORMATION Your GP or midwife will be able to give you more information about these procedures.

MY THOUGHTS

PRE-IMPLANTATION GENETIC DIAGNOSIS

Pre-implantation Genetic Diagnosis (PGD) is a type of IVF (in vitro fertilisation) which can ensure that couples with HD in their family can have children without the HD gene. PGD can be carried out if you are at risk, or if you have tested positive for the HD gene. The chance of having a successful pregnancy using PGD is around 30%.

PGD can be a lengthy and emotional process as it involves a lot of medication, medical appointments and procedures.

STEP 1: The female partner is placed on medication to suppress then stimulate her ovaries.

STEP 2: Eggs are then removed from her ovaries.

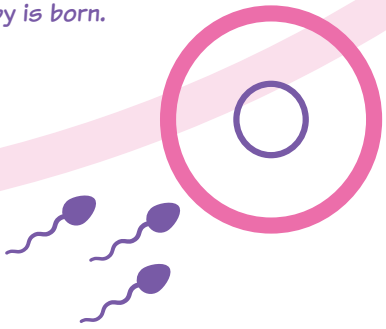
STEP 3: Eggs are fertilized with sperm in a laboratory and become an embryo.

STEP 4: The embryo is grown for the next 2-3 days in a laboratory until it contains approximately eight cells.

STEP 5: An Embryologist then removes and tests one of the cells from the embryo. The result will tell whether the embryo it was taken from has the gene that causes HD or not.

STEP 6: If there are any HD free embryos, one is then implanted into the woman's womb. Any other embryos that do not carry the HD gene can be frozen for later use. Embryo's which are found to have the HD gene are destroyed, or with the person's consent, used for research purposes.

STEP 7: If successful then 9 months later a baby is born.



PGD ELIGIBILITY CRITERIA (SCOTLAND ONLY)

Before the PGD process starts, couples who are interested need to satisfy the eligibility criteria. To be eligible for PGD you would need to answer yes to the following questions:

- Are you and your partner both Scottish residents and eligible for NHS treatment?
- Do you or your partner have a predisposed risk of a genetic condition (such as HD)?
- Will the referral be made before the female partners 39th birthday?
- Does the female partner have a BMI between 18.5 and 30?
- Are both you and your partner clear of HIV, Hepatitis B and C?
- Have you and your partner been in a stable relationship for a minimum of two years?
- If successful, will this be your first child who is not at risk of inheriting HD?

As well as this only couples who do not drink alcohol, smoke tobacco or use illegal/abusive substances will be eligible for PGD.

How to make a referral?

Couples who are interested in PGD can make a referral either by speaking with their GP or local Genetics Department. Couples are eligible for up to 2 cycles of PGD but any previous IVF treatment delivered by the NHS will be subtracted from this.

PGD CASE STUDY

Mike and Marie are a married couple living in Scotland who both come from HD families. Here they share their experiences of having a child using Pre-implantation Genetic Diagnosis.

As young people impacted by HD, how big an issue was family planning and having children?

Mike: Having children was always a big issue for us. I come from a large family with brothers and sisters so having children was always something that we wanted as a couple.

Marie, you tested positive for HD before starting your family. How did testing positive impact your thoughts on having children?

Marie: The main reason I went for testing was because we wanted to start having children. Someone once asked us if neither Mike nor I got tested and our children developed HD, how would we know who had passed it on? This idea started us on our family planning journey and made us look at the options open to us. I had never wanted to get tested before, but after thinking more about it I decided to go forward for testing.

Before you went ahead with PGD, did you consider any other methods of starting a family?

Yes, we did. I (Marie) had always wanted a family the 'natural' way. I couldn't imagine not carrying and giving birth to my own baby! We had looked into the other methods but nothing felt right until we were told about PGD.

Did you discount any family planning option (such as having children naturally) due to other people saying it is 'irresponsible' or 'too risky'?

No. Nobody ever told us that having children naturally was too risky or irresponsible. In fact, a lot of our family and friends reminded us that our parents/aunts/uncles didn't have other options for having children, but still did anyway.

So what were the main reasons you discounted other options and finally settled on using PGD?

By using PGD it meant we could carry and give birth to our child/ren, but it also meant we wouldn't pass HD onto them. As we are in a fairly unique situation whereby I (Marie) have inherited HD and Mike is at risk (but not tested) the chances of passing it on were increased and it wasn't a risk we were willing to take. However, when we found this out during one of my testing counselling sessions, PGD was suggested to us and it ticked all our boxes.

The actual PGD process can be quite demanding physically. Can you explain what was involved?

Marie: The first step in the process was to meet with a Consultant Geneticist who referred us to the PGD service in Edinburgh. We met the team of doctors who explained the process to us and were very helpful and supportive. I then started to take daily injections and go for monthly scans to check how my ovaries and eggs were responding to treatment. There was a lot of waiting to see if my body was doing what the doctors wanted it to do. This treatment had an emotional impact and I had a lot of mood swings during this time.

There were a few bumps in the road, but always a silver lining. For example, I produced a lot of eggs but this resulted in me staying in hospital and being off work with what is called Ovarian Hyper Stimulation. This pushed back the transfer date for the embryo as I had to recover first.

The PGD process was successful and you gave birth to a little girl called Sally. What has other people's reaction been to you using PGD?

There has been no negativity towards Sally being a PGD baby. The fact she is a PGD baby doesn't factor into things really. During the process, there was no negativity either. Just lots of support and lots of questions. I used to read up as much as I could so when someone asked a question I could try and answer it. I never shied away when people asked about PGD.

What advice do you have for other young people at risk/gene positive who are considering starting a family?

Our advice would be to look at all your options and do what feels right for you both. Speak to other people as well. We found out about PGD through SHAYP and the Genetics department, and we did a lot of research and asked a lot of questions. Even if you think you are dead set against an option, look into it as you might find it suits your situation, like we did with PGD.

Lastly, how would you describe the entire PGD process in 3 words?

Emotional, rewarding and (lots of) waiting.

MY THOUGHTS

OTHER OPTIONS

ADOPTION AND FOSTERING

There are many reasons why someone who is at risk, or tested positive for HD, would be keen to pursue fostering or adoption as a way of starting a family.

Adoption is a legal process and provides children who cannot be brought up by their biological parents with a new 'forever family'. Normally an adopted child loses all legal ties with their birth parents.

Fostering can be short-term or long-term and provides children with a safe home environment if they cannot live with their own parents. Fostering often aims to return children home to their biological families, however other children may stay in long-term foster care, some may be adopted, and others will move on to live independently. Foster carers often receive payment for their role.

Fostering and Adoption agencies thoroughly assess potential candidates in all aspects of their life, including looking at medical conditions. Therefore, just because you may have the HD gene or be at risk of HD does not mean you will be unable to foster or adopt a child.

EGG AND SPERM DONATION

Although less common than the other methods outlined in this chapter, egg or sperm donation is an option that can ensure that a child does not carry the HD gene. A consideration to this option is that the child would not be related genetically to the HD affected parent.

NOT HAVING CHILDREN

For some people they do not wish, or are not able to have children. Again, it is important to remember this is a personal choice which you have to weigh up for yourself and if you are actively trying to avoid pregnancy there are a range of contraceptive options available. Speak to your GP or family planning centre for more information.

TIPS FROM THE EXPERTS

We asked the Genetic Counselling team from the Genetics Department in Aberdeen to give us some top tips for young people who are considering their family planning options. Here they are:

1) As Genetic Counsellors, we can help and support you to think through family planning issues. These options can be complicated so we can help you understand them better and arrive at a decision.

2) Think through your options before becoming pregnant. It is harder to make decisions and for us to help make arrangements when the situation is urgent.

3) Some of the options (such as PGD) are complex. Give yourself plenty of time and space to discuss and consider the different options available.

4) Try and involve your partner as much as possible.

5) You don't have to be tested yourself. Exclusion testing is an option.

6) Remember it is ok to go ahead without testing a pregnancy.