

UNIT 8: THE GOOD, THE BAD AND.....

TEACHERS' NOTES: UNIT 8

OBJECTIVES

To explore how genetic information about people has been used (and misused) in the past and might be used (and misused) in the future.

To ask students to examine their own attitudes towards developments in human genetics

SUGGESTED AGE RANGE

14-16 year olds.

CURRICULUM LINKS

For use in PSE, Religious and Moral Education, Science, English, History, Social/Contemporary Studies etc.

SUMMARY OF CONTENT

Students read and discuss any one of five illustrated scenarios covering different aspects of the use (and misuse) of genetic information in the past, present and future. They are then asked to indicate how they feel about recent developments in human genetics and to think about how we can ensure that such developments benefit rather than harm us.

TEACHERS PLEASE NOTE

You may like to read the Notes for Teachers on the Scenarios on pages 90—93 before the lesson.

It is important to be aware of the fact that some students in the class may themselves have a genetic condition, or be a carrier, or have relative who is affected. Sensitivity is required to avoid putting such students under stress.

PART 1

MATERIALS NEEDED

Each group of three students will need one copy of the illustrated scenario which you have selected for them together with the questions for discussion for that scenario. The five scenarios are as follows:

Scenario A: Testing and termination

Scenario B: 'Improving' the human race

Scenario C: Reducing the risks

Scenario D: Genetic information — who wants it?

Scenario E: Getting rid of genetic disorders.

If possible, have a glass exactly half full of water in the classroom.

If you want to 'ballot' students at the end of the lesson you will need some small slips of paper.

WHAT YOU DO

- Hold up the glass of water and ask students to finish the sentence, 'This glass is...' Encourage them to carry on describing the glass until you have had a range of responses, including 'half full' and 'half empty'. Point out that people can react to and interpret the same thing in different ways according to how they feel about a subject and the attitudes and beliefs they hold.
- Explain that the purpose of today's lesson is to explore different ways in which ordinary people's lives have been, are now, and may in the future be affected by our increasing knowledge and understanding of human genetics, and to explore how students feel about such developments

Hand out copies of the scenario(s) you have selected and ask students to work through them in groups of three. Set a time limit for the activity.

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WHAT YOU DO continued

Write USES OF GENETIC INFORMATION at the top of the board/flipchart. Then draw a line down the middle of the board/flipchart and write ACCEPTABLE at the top of the left-hand column and UNACCEPTABLE at the top of the right-hand column.

When the time limit is up, come back together as a whole class for feedback. Then ask students individually or in their groups to tell the rest of the class:

- what their scenario was about
- whether they felt that the use of genetic information in their scenario was acceptable or not, giving their reasons.

As they do so, either you or a student from each group should make notes in the appropriate column on the board/flipchart.

[N.B. You can use the Notes for Teachers on the Scenarios on pages 90-93 to alert you to some of the issues underlying the uses of genetic information which are explored in each scenario.]

When you have finished, ask students if they think the things listed in the two columns will always be acceptable or unacceptable? How can we ensure that developments in genetic technology benefit rather than harm us? And who should be responsible for making sure that the things in the 'unacceptable' column do not happen?

At the end of the lesson, you might like to take a quick vote to see how students feel about human genetics in the future. You could do this by a show of hands, or by handing out slips of paper and asking students to show how they feel using a ☺ or ☹ symbol, or a number between 1 and 10 (1= very negative, 10= very positive).

You could also ask students to complete the following sentences anonymously to give you informal feedback about the lesson:

One thing I liked about the lesson was.... but I didn't like...

One thing I learned was...

NOTES FOR TEACHERS ON THE SCENARIO

SCENARIO A:

TESTING AND TERMINATION

Commentary

It can be helpful for prospective parents who find out in early pregnancy that their fetus is affected by a genetic disorder to have access to accurate, up to date information about the disorder. There are more than 4500 known genetic disorders, many of them rare. GPs may be familiar with some, but speedy referral to a Regional Genetics Service and access to a genetic counsellor can help a pregnant woman (and her partner) to explore more fully the implications of the diagnosis. Other organisations such as the Genetic Interest Group and Contact a Family (see Useful Addresses) may be able to supply the contact address and telephone number of an appropriate support group. Many of these groups are made up of affected people and their families and can be very valuable sources of further information.

It can be devastating if/when routine prenatal tests reveal that a foetus is affected by a genetic disorder. Some people say that the testing of foetuses for a wide range of genetic conditions could lead to increased pressure on parents to have an abortion if the foetus is affected (and perhaps even pressure to pay for medical care if they choose not to terminate), and increased pressure on doctors to abort for non-medical reasons (e.g. if the foetus is not of the desired sex). They suggest that doctors will never be able to test for all causes of foetal abnormality, and that the more tests which are on offer, the more likely it is that prospective parents will develop a false sense of security and the expectation that each pregnancy will lead to the birth of a 'perfect' baby

Then there are those who say that testing is valuable because it facilitates choice and informed reproductive decision-making. They argue that whatever one's views on abortion, it is legal in this country, and that parents have a right to know if their fetus is affected by a serious inherited disorder so they can choose whether or not to carry on with the pregnancy. People who believe that termination is

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SCENARIO A continued

morally unacceptable are free not to test, or if they do and the tests reveal that the fetus is affected by a serious genetic disorder, to continue with the pregnancy.

Others focus on a different aspect of the debate. They argue that it is a legitimate and praiseworthy goal for doctors to try and reduce, and eventually eradicate, genetic disorders because such disorders do not in any way enhance the value or 'moral worth' of an individual, and given the choice, all people would choose to be free of them. They firmly believe that a desire to reduce the incidence of genetic disorders through testing and selective termination is not the same as a desire to eliminate people with a genetic condition, and that to prefer to avoid disability where possible is not to prefer non-disabled individuals as persons.

Some people are pressing for a list of conditions where termination is, and is not, justified. The Genetic Interest Group (GIG) believes that it is neither practical nor sensible to attempt to draw up such a list and that the decision whether or not to proceed with an affected pregnancy is ultimately the responsibility and right of the pregnant woman. GIG also believes that before this decision is made, the woman should have access to adequate information and counselling so that she can be confident that the decision she has reached is the right one for her.

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SCENARIO B: 'IMPROVING' THE HUMAN RACE

Commentary

China's recent law on Maternal And Infant Health Care, which took effect on 1st June 1995, caused widespread concern amongst geneticists. It was seen by many as sanctioning the practice of eugenics and as a serious abuse of human rights based on genetic information about individuals. One article in the law states that physicians must give medical advice to couples who have been diagnosed with certain genetic diseases considered to be 'inappropriate' for child-bearing, and that the two may be married only if they agree to take 'long-term contraceptive measures' or to be sterilised. A statement presented at the 9th International Congress of Human Genetics in 1996 which drew attention to the fact that '...some provisions of the law conflict with the counselling principles accepted by most human geneticists', and which acknowledged that '...genetic legislation has a tragic history', received almost unanimous agreement from participants.

HUMAN GENETIC ADVISORY COMMISSION

In the UK, regulatory and advisory bodies such as the Human Genetic Advisory Commission and the Advisory Committee on Genetic Testing have been set up in order to ensure that developments in human genetics stay within responsible and ethically acceptable limits. A draft statement from the European Alliance of Genetic Support Groups (EAGS) points out some of the safeguards which need to be built in to protect the rights of people affected by a genetic disorder. They include:

- that medical genetics should serve the interests of individuals who are affected or at risk from a genetic condition;
- that access to information and facilities should be based on need and safeguarded;
- that individuals should be free to decide for themselves whether or not to make use of available information and facilities;
- that genetic services should facilitate diagnosis, provide options leading to informed decisions about treatment and preventative measures, and promote the provision of appropriate services;
- that the continual improvement in the quality of life and care of those affected by a hereditary or congenital disorder should be promoted through, for example, changes in legislation;
- that people with a disability or disease should be entitled to unrestricted acceptance and solidarity from society.

If ethical codes based on these or similar recommendations were to be universally adopted, fears of a possible resurgence of the eugenic practices which took place earlier in the century would perhaps be allayed.

Human gene therapy has the potential to both prevent or treat disease and enhance physical and behavioural characteristics. Surveys of scientists, doctors and the general public tend to show support for gene therapy if it has a therapeutic value (i.e. if it helps to prevent or cure disease), and there appears to be small but growing public support for the idea of using gene therapy in the future to enhance physical and behavioural characteristics.

People argue that as we already enhance human characteristics through education, diet, and in some cases surgical intervention, gene therapy could be used to achieve the same effects. Others say that if/when it becomes technically possible to enhance characteristics such as height, appearance, and intelligence, the range of what is considered 'normal' and 'desirable' will become much narrower. They ask who would be able to make use of this service - everyone or just those who could afford it? - and point out that as ideas of physical perfection change over time, we could end up making entirely inappropriate choices for our unborn children. The idea of using gene therapy to change behaviour raises further questions. Would 'risk-taking', for example, be classified as a 'desirable' characteristic (leading to innovation and discovery) or an 'undesirable' (leading to law-breaking, anti-social behaviour)?

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SCENARIO C: REDUCING THE RISKS

Commentary

Many current and future developments in genetic science have tremendous potential with regard to common diseases. The idea is that genetic information will be used to predict and prevent the onset of a disease, and that this will be particularly beneficial where the disease has no known cure.

Up to now, one approach towards the prevention of certain common conditions has been to suggest a lifestyle change. For example, people who have already had a heart attack or are thought to be at risk through high blood pressure may be given medication and advised to give up smoking, modify their diet, avoid stress and take regular exercise. However not everyone finds it easy to follow such advice.

Increased knowledge of genes could lead to a more precise understanding of predisposition towards common diseases with a genetic component. DNA analysis could be used to predict future health and guide doctors towards appropriate methods of treatment and prevention, for example:

- encouraging lifestyle changes;
- giving people specific drug treatments which would lower their chances of getting certain common diseases;
- the development of new drugs and vaccines which could be precisely targeted (to the extent that a drug which was toxic to one person might be effective in a person with a different genetic make-up).

Developing drugs like these is technically demanding, time-consuming and expensive. Before making any new drug available to consumers, it would of course be essential for doctors and researchers to establish that it had no unforeseen or undesirable consequences for other genetic material within the body.

SCENARIO D: GENETIC INFORMATION — WHO WANTS IT?

Commentary

It could be beneficial for individuals to have access to personal genetic information. It could help them to avoid ill-health by alerting them to the need to make lifestyle changes or take other preventive measures to lower their risk of disease. It could also help them to make appropriate reproductive decisions and plan for the future.

But concerns exist about how such genetic information might be interpreted, stored and used. Should our 'genetic profile' be kept with other confidential medical records and used only by doctors wishing to prevent or treat genetic disorders, or should it be made available to anyone who asks?

Genetic information is unusual in that it has implications not just for individuals but for family members and close relatives as well.

Some of the questions currently being debated by geneticists and other interested parties include:

Should individuals be compelled to share genetic information with other members of their family? What if previous disclosures have had harmful consequences for that particular individual or family?

Should couples wishing to have children together have access to genetic information about each other in order to help them make appropriate reproductive decisions?

Is it fair for insurance companies, employers, mortgage lenders etc. to refuse insurance cover, a job or a loan on the basis of genetic information about an individual?

Should the police be allowed access to genetic records in order to help identify suspects following a crime?

Is it possible to guarantee the confidentiality of computerised records?

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SCENARIO E: GETTING RID OF GENETIC DISORDERS

Commentary

Scenario E illustrates two different medical procedures which require doctors to have a very clear understanding of specific genes and how they function. Many people view potential developments in genetic science such as these with great excitement. They say that as genetic disorders do not in any way enhance the value or 'moral worth' of an individual, doctors should do all they can to alleviate their effects and where possible, prevent them from happening. Others are more cautious. They claim that we do not know enough about how genes function and interact with each other to be sure that we are not going to cause damage. A few are deeply distrustful of genetic research. They say that gene manipulation is interfering with nature.

Picture A

Gene therapy is an experimental technique in which specially engineered viruses, or in some cases fatty particles called liposomes, are used to carry working copies of a gene into the relevant part of a person's body (e.g. the lungs of a person with cystic fibrosis, or the muscles of a boy with Duchenne muscular dystrophy). The idea is to compensate for a missing or faulty gene by introducing working copies of that gene which will then help the affected cells to produce the protein they need to function properly. So functional copies of the gene are made in a laboratory. These genes have to be inserted into the viruses or liposomes which carry them into the right cells. Those cells have to accept the new genes which then have to work properly. Although scientists have in some cases succeeded in getting working copies of a particular gene to the right cells, they have not yet found an effective way of getting them to function properly for any length of time. Germ-line gene therapy (manipulation of genes within the germ cells i.e. the sperm or the egg) is against the law.

As genetic disorders can affect not just individuals but whole families, many thousands of people in the UK are either directly or indirectly (as siblings, parents, or carers of an affected person) pinning their hopes on the development of gene therapy. But a breakthrough in this area has so far proved elusive, and there is a limit to how much time and money pharmaceutical companies can devote to developing forms of treatment for what are known as 'orphan diseases' (i.e. diseases which affect relatively few people). Although there are over 4500 known genetic disorders, many are rare, and it can be difficult to persuade people of the need for continuing research into orphan diseases when the NHS is already pressed to provide adequate funding for acute services. Resource allocation is always difficult when faced with a wide range of options, all of them deserving. Questions to ask might include:

- what other sources of funding (if any) are available?
- what would the money be used for?
- who would benefit, and how?

Picture B

Pre-implantation diagnosis (PID) is being developed to help families affected by certain single-gene disorders. It is currently available in only a few countries around the world and for a limited number of conditions. Many of the issues raised by PID also apply to IVF (in vitro fertilisation) procedures and are already safeguarded by legislation relating to embryo research. In pre-implantation diagnosis, eggs are taken from the woman and fertilised in vitro. At a very early stage in the development of each fertilised egg, a single cell is removed and its genetic material (DNA) analysed. Only embryos which do not contain copies of the faulty gene are re-implanted in the woman's womb where it is hoped that one embryo will go on to develop into a baby. Doctors are still working to confirm that the embryo is not damaged by the removal of a single cell and that pregnancy can be regularly established after the procedure. By mid 1997, PID had successfully led to the birth of about 70 babies worldwide, so the technique is still very new.

For some couples affected by a genetic disorder who wish to have children free of that disorder, it is preferable to be able to choose to re-implant an embryo known to be free of the faulty gene than it is to terminate each pregnancy until tests show that the woman is carrying an unaffected fetus.

Few couples opt for complex and expensive experimental procedures without thinking very carefully of all the possible consequences, and PID is no exception to this. But to anyone who believes that life begins at conception, PID is as unacceptable as termination of pregnancy.

ACTIVITY SHEETS FOR STUDENTS UNIT 8

SCENARIO A TESTING AND TERMINATION



The more doctors know about genes, the more likely they are to be able to predict the future health of a fetus

Some people say that choosing to abort a fetus because it would be born with serious physical or learning difficulties is a form of discrimination against disabled people – what do you think?

QUESTIONS FOR DISCUSSION

The woman pictured above and her partner know that their baby is at risk of being born with a wide range of physical and mental problems. How might they be feeling?

What sort of things will affect the decision they make about whether to have the baby or choose abortion?

Do you think that testing the fetus early on in pregnancy to see if it is affected by a wide range of disorders is a good idea?

Why/why not?

If your baby was going to be mentally or physically disabled in some way, would you prefer to know in advance, or to not know until it was born?

Suppose DNA analysis showed that a fetus:

- Had a life-threatening genetic disorder
- Had a 90% chance of developing cancer of the colon by the age of 40
- Was male and the parents were desperate for a baby girl
- Had a combination of genes that suggested low intelligence
- Had a combination of genes which suggested bi sexuality

DO YOU THINK THAT PARENTS SHOULD HAVE THE RIGHT TO CHOOSE ABORTION UNDER ANY OF THESE CIRCUMSTANCES?

ACTIVITY SHEETS FOR STUDENTS UNIT 8

SCENARIO B

IMPROVING' THE HUMAN RACE

A: 'Ever heard of the 'eugenics' movement? It was made up of people who thought that they could 'improve' the human race. I

B: 'Oh yeah? And just how did they expect to do that? By saying to someone, 'Okay you're tall, healthy, clever, good looking, here's a woman who's the same, have, children with her and bingo, you've bred a winner'? That's gross. It isn't even scientifically sound because not all of those things are passed on in the genes anyway.'

A: 'Yeah, well, we know that now, but they didn't in the late 19th century when eugenics began. The idea was that the right sort of people should be encouraged to marry and have children and 'undesirables' should be stopped from breeding altogether.'

B: 'And just who exactly were these 'undesirables'?'

A: 'That was the problem. Many were ordinary people who happened to have a disability or mental health problems. Some were alcoholics and drug addicts. In the 1930s in Germany and in some states in the USA, thousands of people were sterilised against their will.'

B: 'What, just so that they couldn't pass on their genes? That's outrageous. I reckon any government which wants to dictate whether or not I am genetically 'fit' to have children is into social control, not science.'



QUESTIONS FOR DISCUSSION

Fifty years later, some countries are still hoping to 'improve' the human race by passing laws which forbid people with certain genetic conditions from marrying and having children. Is this fair, or do you think that everyone should have the right to choose who they marry/live with/have children with even if it means that their child will be born with a genetic disorder or some form of disability?

Some people worry that the gross abuses of human rights which took place in the 1930s in the name of eugenics will happen again. How do you feel? Are you fearful of current developments in genetic science, or are you confident that as long as there are safeguards in place, increased knowledge about genes and how they work is a good thing?

How far do you think doctors and scientists should go in their attempts to 'improve' the human race? Should they limit themselves to trying to get rid of genetic disorders? Or if such things become possible in the future, should they try to enhance human characteristics such as intelligence, appearance, resistance to HIV infection etc.?

ACTIVITY SHEETS FOR STUDENTS UNIT 8

SCENARIO C

REDUCING THE RISKS

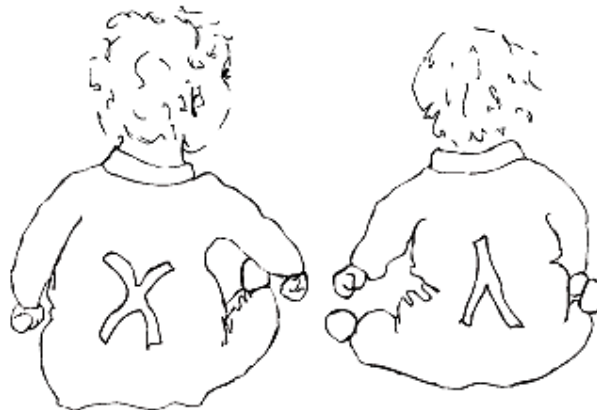
A: 'In the future, doctor's will be able to analyse a baby's genes and predict how likely it is to get heart disease, or cancer, or asthma, or diabetes or just about any other common condition you care to name.'

B: 'So as soon as the baby's born, someone rushes off to tell the proud parents what diseases it's going to get...! They're going to love you.'

A: Wait, I haven't finished. Imagine the baby's genetic profile says, 'Heart disease - higher than average risk'. No problem. You just tell the parents to make sure their child has a healthy, low-fat diet for the rest of its life, never becomes a smoker and exercises regularly and the risk goes right down.'

B: What?! No chips, no slobbering out in front of the TV...? Get real.

A: Okay, if you don't fancy that, try this instead. Imagine yourself even further into the future. The baby's DNA profile shows a high cancer risk. Eventually, all it will have to do is take a specially developed drug every day and its chances of getting cancer will go right down too. Brilliant, eh?



QUESTIONS FOR DISCUSSION

- Imagine that your genes have been analysed. They show that you have a high risk of developing heart disease in your early 20s. Your doctor tells you that because your genes suggest that you will develop heart disease at a young age, it is particularly important for you to look after yourself (e.g. eat a healthy diet, do not smoke, avoid alcohol and other drugs, take regular exercise and get lots of rest). Would you follow the doctor's advice, or would you take no notice and hope you'll be okay?
- Imagine that it is ten years on from now. Scientists have developed a range of drugs which can lower your chances of getting certain serious diseases. Your genes suggest that you might develop an eye disease and go blind in your 30s. Would you take one of these new drugs if you were told that it might stop you from going blind? What would you want to know before agreeing to take the drug?
- One young person commenting on developments in genetic science said: 'Look, in the end, it's all about giving people choices. I mean, suppose everybody could choose between having, or not having, asthma or cancer or Cystic Fibrosis or whatever. No-one's going to say, 'Oh yes please, I really want to be ill', are they? They're going to say, 'If knowing more about genes is going to help us get rid of certain disorders for ever, then we should go for it.'
- Do you agree with her? Why/why not?

ACTIVITY SHEETS FOR STUDENTS UNIT 8

SCENARIO D GENETIC INFORMATION - WHO WANTS IT?

'I would go for Marie Baker every time — I thought she was by far the strongest candidate.'

'I agree, but I really don't like \ the look of her genetic record sheet. It suggests mental health problems and a worryingly high cancer risk.'

'She might prove very expensive to us —time off work, high health insurance premiums etc. Okay, let's offer the job to Dianne Simpson then. She had a good interview and her genetic profile seems to be clear of any major problems.'



QUESTIONS FOR DISCUSSION

In the future, we might all have a Genetic Record Sheet showing what genes we have inherited and whether or not those genes put us at risk of developing a wide range of common health problems and diseases. Why do you think the A1 Insurance Company might want access to Genetic Record Sheets?

Would you want to have a Genetic Record Sheet which shows how likely you are to develop certain serious medical conditions (e.g. cancer, arthritis, high blood pressure etc.)? Why/why not?

Which of the following people do you think might be interested in the contents of your Genetic Record Sheet, and why?

- a) you
- b) members of your family (e.g. parents, brothers, sisters, any children you may have)
- c) your boyfriend/girlfriend
- d) your doctor
- e) your employer.

How many positive reasons for wanting this information can you think of?

Should the information on your Genetic Record Sheet be confidential, or should everyone have access to it?

Where, and how, would you like genetic information about you to be stored?



Confidential medical records?

'Look, we agreed a price some time ago. Okay, I need the genetic record sheets of the following people...'

'I've found what you're looking for. But it'll cost you because I'm running a big risk tapping into confidential medical records''

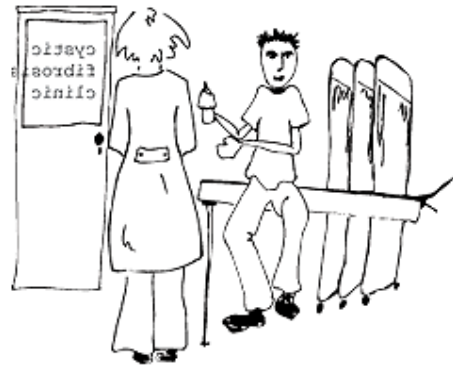
ACTIVITY SHEETS FOR STUDENTS UNIT 8

SCENARIO E GETTING RID OF GENETIC DISORDERS



A

Well, you'll be glad to hear that the news is good - We've checked all six embryos. Two of them have the faulty gene but the rest are clear, so we're going to put the two strongest-looking embryos back into your womb and hope that at least one goes on to develop into a baby!



B

You're telling me that after all these years of physiotherapy and breathing exercises and taking pills every day in order to stay well, all I have to do now is take regular puffs of this nasal spray and it'll make the faulty genes in my lungs work properly again? I can't believe it! I mean, this is just amazing!

QUESTIONS FOR DISCUSSION

Many doctors and scientists hope that increased knowledge of genes will lead to better treatments for people with genetic disorders, and eventually to the elimination of genetic disease altogether. But some people take the view that manipulating human genes is a bad thing because it is 'interfering with nature' or 'playing god' and could have unknown future consequences.

How do you feel about this?

Do you think you would view things differently if you, or a member of your family, had a genetic disorder?

In Picture A, the young man with cystic fibrosis is using a nasal spray to deliver working copies of a particular gene to his lungs. This is a form of gene therapy which is still experimental and is expensive to develop. If you had to choose between putting money into this kind of gene therapy, cancer research, or a charity which supported people in the community with mental health problems, which would you choose and why? What questions might you want to ask before you decided?

In Picture B, the woman is having two embryos re-implanted in her womb. Six of her eggs have been fertilised in vitro (as for 'test-tube' babies). But this woman has a 50% (1 in 2) risk of passing on a genetic disorder to each and every child she has. So before doctors put any embryos back in her womb, they examine the DNA in each embryo to see which (if any) carry the faulty gene (this is an experimental technique known as 'pre-implantation diagnosis' or PID). Then they put back a maximum of three embryos which they are fairly sure do not contain the faulty gene and hope that the woman will go on to have a normal pregnancy and a healthy baby nine months later. Some people say that PID is like abortion because doctors are 'destroying life' when they get rid of unwanted embryos.

What do you think? If you were on a medical committee, which had to approve a woman's application for PID, would you agree? What sort of things would you want to know to help you decide?