### Would you want to know?

Susan's maternal grandmother died of Huntington's Disease (HD). Susan has been finding out about HD on the internet and has requested a genetic appointment to arrange pre-symptomatic testing. If Susan tests positive her mother also must carry the mutation and will develop HD. Susan's mother is very upset and states that she has no wish to know her own genetic status.



### Embryo testing

A couple who both have achondroplasia (genetic dwarfism) are expecting a baby and decide to have genetic testing on their embryo. The couple have decided that if the test shows that the embryo does not have achondroplasia they will terminate the pregnancy.



### Who gets treatment?

The Wilson twins (Jane and David) both have the inherited condition, familial hypercholesterolaemia (FH). David is receiving treatment to lower his LDL cholesterol, but the doctor is not giving Jane this treatment. Jane and David's parents want both their children to receive the treatment.



## Saviour sibling

John has the condition severe combined immunodeficiency syndrome. His only hope of survival is a bone marrow transplant from a matching donor. John's parents wish to have another child (a so-called 'saviour sibling') by IVF and use pre-implantation genetic diagnosis (PGD) to select an embryo which could be a donor for John.



## Designer baby

A couple are both carriers of the most common cystic fibrosis (CF) gene. After undergoing IVF treatment, four of their embryos are found to be free of CF.

The couple request that the embryo to be implanted is male as they already have a girl.



#### Who should know?

Alison applied for life insurance to cover the mortgage on the house she was buying. Because she suffers from colitis the insurance company asked for a medical report. She was refused insurance because it said in the report that her grandmother had died of Huntington's disease.



### Post-natal screening

Debbie has a newborn baby girl and, like all new mothers, she is offered genetic testing to see if her baby suffers from a rare genetic condition Phenylketonuria (PKU). Debbie decides to turn down the offer of the test. Initially her baby does well, but at age 5 it is clear that she has learning disabilities and she suffers from epilepsy.



### Match-making

Members of some Jewish communities in New York often carry a life-threatening genetic disorder called Tay-Sachs disease.

These 'Chassidic' people also normally have arranged marriages. As part of this process the young people are routinely screened to see if they carry the gene for Tay-Sachs. Carriers of the condition are only matched with a partner who is free of the gene.



#### Life style choices

A family has a very high incidence of diabetes. A genetic test indicating susceptibility to diabetes is now available. Those individuals who test positive are given advice about diet and life style.

It has been suggested that individuals who do not follow this advice and go on to develop diabetes should be asked to pay for their treatment.



### Genetic profiles for sale

A British company offers health advice based on genetic testing. Individuals are able to provide samples which are then used to test for 100 common genetic variations. The company charges about £125 for its services. The results of the tests are analysed and detailed information about their genetic profile is sent in a report to the individual.



most challenging dilemma



least challenging dilemma

