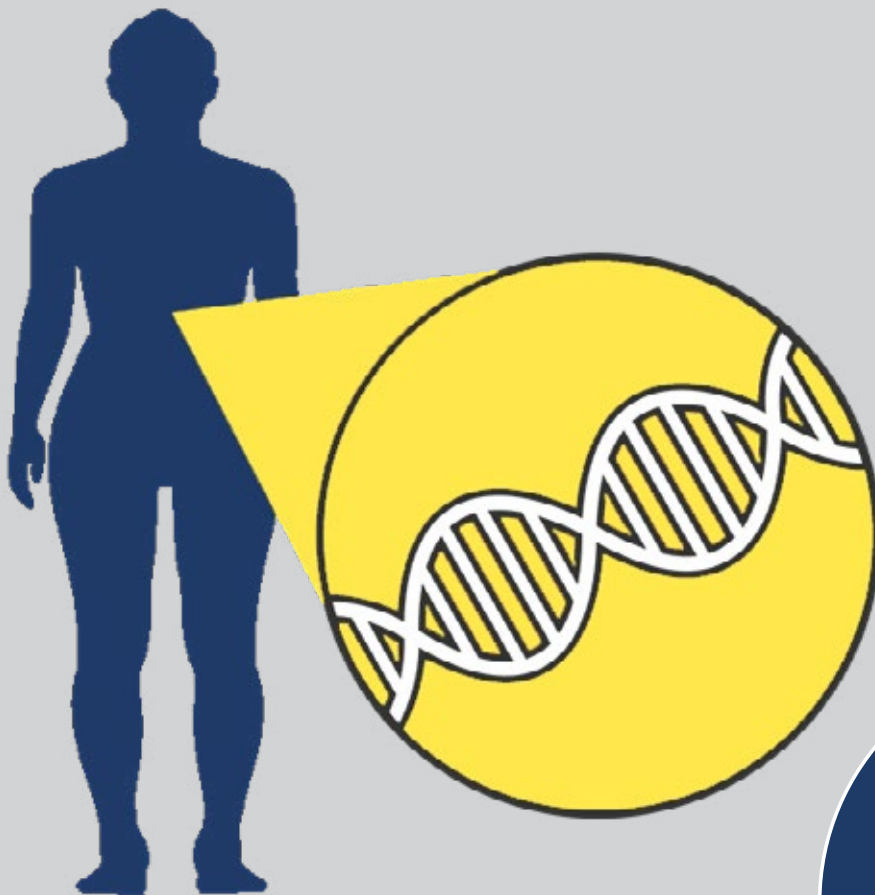




**UNSW**  
SYDNEY

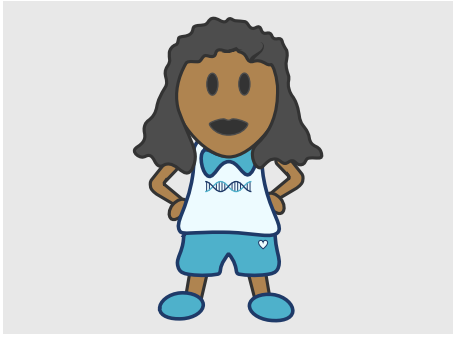


# About genetic health care



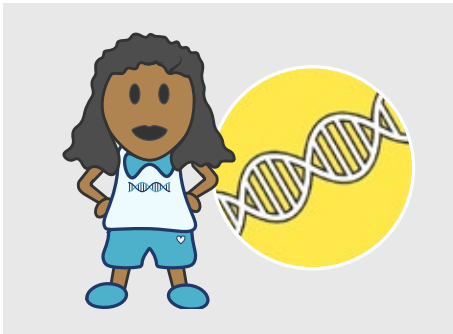
**Easy Read**

[www.geneequal.com](http://www.geneequal.com)



This is Gene.

Gene is on all of our booklets and our website.



When you see Gene you know this is information about genetic health care.



We made 5 booklets to help you learn about genetic health care.

1. About genetic health care
2. Genes and genetic conditions
3. How to make a genetic appointment
4. Get ready to go to the genetic clinic
5. Tips about genetic health care



Some things in the booklets might

- Be hard to understand
- Make you feel sad.

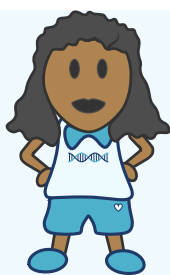


You can read them with someone you trust.



This might be

- Someone from your family
- A friend
- Your support worker.



## About this booklet



This booklet is about genetic health care.



It will help you learn what genetic health care is.



Some things in this booklet might be hard to understand.



You might want to read it together with your support person.



## What is genetic health care

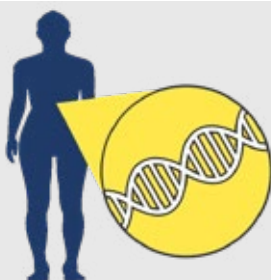


**Genetic health care** is health care for people who

- Have a **genetic condition**
- Might have a genetic condition
- Want to know more about genetic conditions and tests.



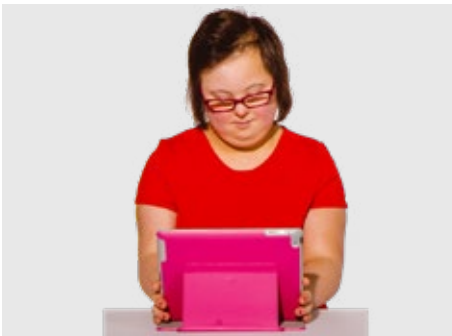
A genetic condition happens if a **gene** changes.



**Genes** are things in your body that make you the way you are.



A **genetic condition** can mean that your health is different from other people.



It can also mean that you learn in a different way to others.

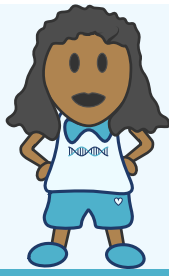


Other words that people use for genetic conditions are

- Genetic disease
- Genetic disorder
- Genetic syndrome.



You can read more about genes in our booklet **Genes and genetic conditions**.



## Learn more about genetic conditions



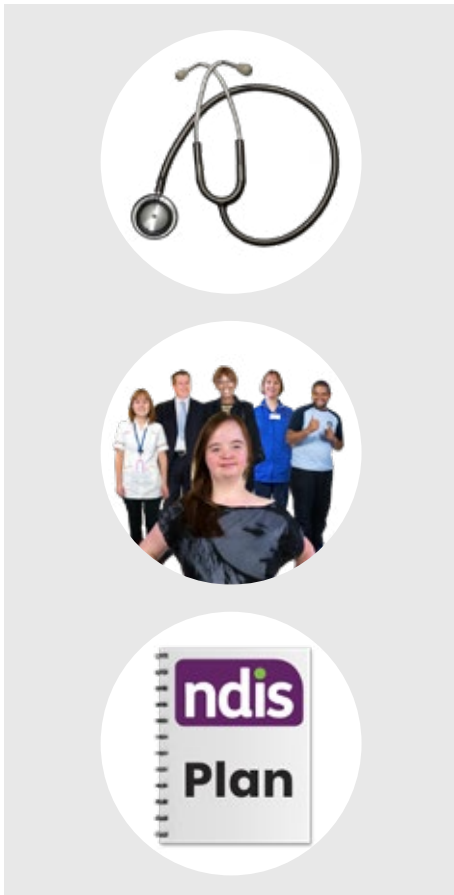
Many people with intellectual disability have a genetic condition.



Sometimes only 1 person in a family has a genetic condition.



Sometimes more people in a family have the same genetic condition.



If you know that you have a genetic condition it can help you

- Get the right health care
- Get the right supports
- Try to get an NDIS plan.



It can also be good to know if you have a genetic condition if you want to have a family.



This is because if you have a genetic condition your children can get the same one.



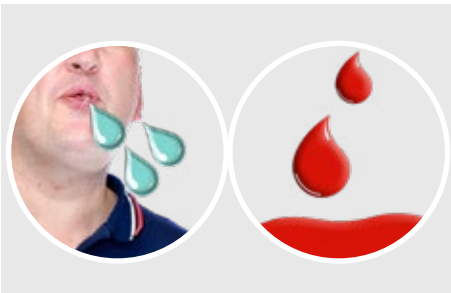


## Genetic test



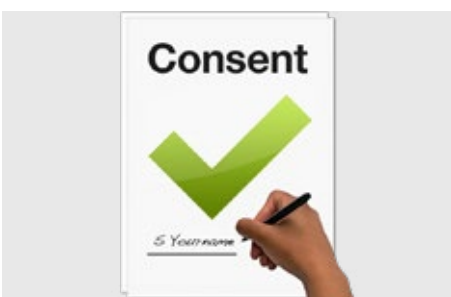
You can do a test to find out if you have a genetic condition.

This is called a **genetic test**.



The test can be done with your

- Spit
- Blood.



If you want to do a genetic or genomic test you need to give **informed consent**.



**Informed consent** means you have information and support to make a choice.



## Your rights with genetic health care



Everyone has the right to good health care.



This also means the right to good genetic health care.



Your rights are in the **Australian Charter of Healthcare Rights**.

We will say **charter** for short.

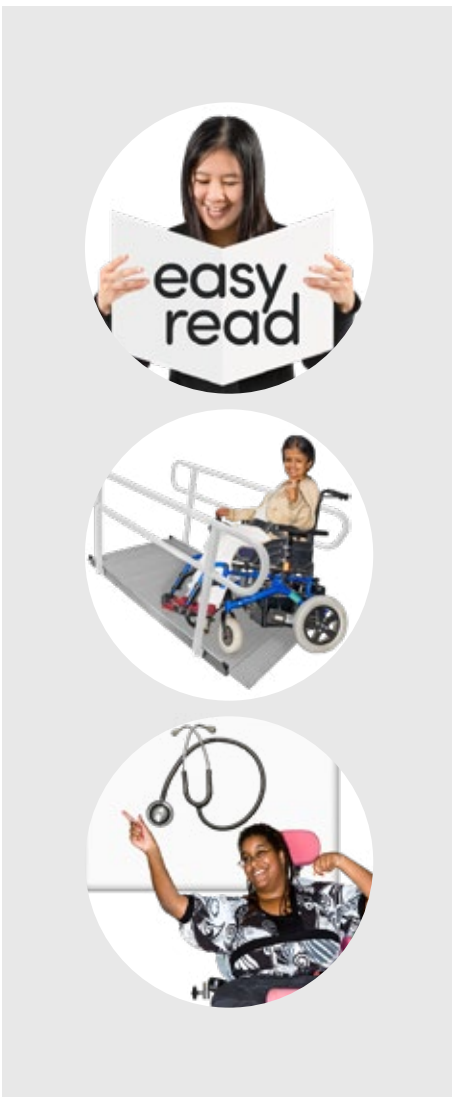


To read the charter go to

**[www.bit.ly/read-the-charter](http://www.bit.ly/read-the-charter)**

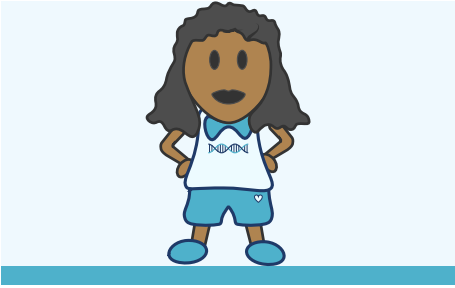


The charter says that you have the right to **accessible health care**.



**Accessible health care** means things like

- Information that is easy to understand
- Health care places that you can easily get into
- Support to make your own choices.

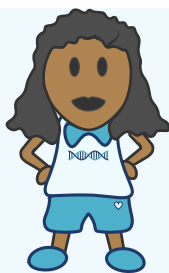


## Notes



You can use this page to write things down.

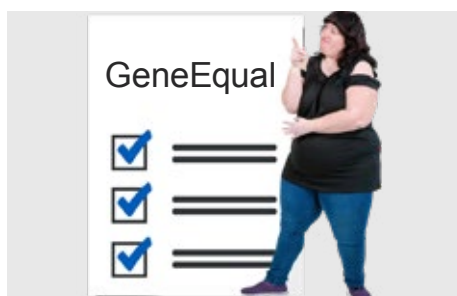
This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



## Who made this booklet



The **GeneEQUAL** team made this booklet.



**GeneEQUAL** is a program to help people with intellectual disability get better health care.

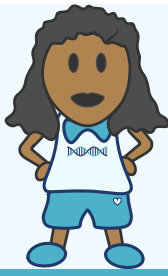


We got money from the **NSW Ministry of Health** to write this booklet.



**NSW Health**

The **NSW Ministry of Health** is the part of government that looks after people's health.



## More information



GeneEQUAL made other booklets about genetic health care.



To get our booklets you can

- Go to our website  
**[www.geneequal.com](http://www.geneequal.com)**

or



- Email the GeneEQUAL team on  
**[geneequal@unsw.edu.au](mailto:geneequal@unsw.edu.au)**

or



- Send us a letter with your address to

GeneEQUAL  
c/o Emma Palmer  
Centre for Clinical Genetics, Sydney  
Children's Hospital, Level 9  
The Bright Alliance Building  
NSW 2052, Australia

You can go to our website for more information



- Go to **[www.geneequal.com](http://www.geneequal.com)**

or

- Scan this QR code with your phone



NSW Council for Intellectual Disability has lots of health information in Easy Read.

To look at them go to

**[www.cid.org.au/resource-tag/easy-read](http://www.cid.org.au/resource-tag/easy-read)**

Council for Intellectual Disability made this document Easy Read. **CID** for short. You need to ask CID if you want to use any pictures in this document. You can contact CID at **[business@cid.org.au](mailto:business@cid.org.au)**.

GeneEQUAL acknowledges the financial support from the NSW Health 'Transforming healthcare through genomic technologies' initiative, funded by the Australian Government through Stage One of the Health Innovation Fund.