



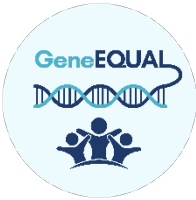
UNSW
SYDNEY



Your own booklet about genetic tests



Easy Read



About this booklet



This booklet is about

- my genetic health care journey.



It can help me decide if I

- want to get a genetic test
- do not want to get it.



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

- my health is different from other people
- I learn in a different way
- and might need support.



My rights

The Australian Charter of Healthcare Rights



The Australian Charter of Health Care Rights says what my health rights are.



I have the right to

- good genetic health care
- to choose if I want a genetic test.



I have a responsibility

- to find out information about genetic tests.



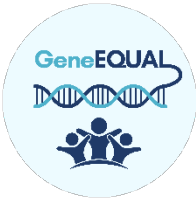
Health care workers have the responsibility

- to give me information that I can understand.



The result is that

- I make a choice that is right for me.



Consent



Consent means saying yes to something

- that I understand.



I can ask questions before I decide.



I can take time to think about it.



Nobody can make me say yes.

It has to be my choice.



I can change my mind anytime.



Sometimes people cannot consent alone

- and someone does it for them.

This person is called a **legal guardian**.



The **legal guardian** making the decision

- is not always the same as the support person.



- ☐ I have a legal guardian making decisions for me.

Their name is



Or

- ☐ I do not have a legal guardian.



My support person



I have the right to decide who I want
involve in the

- planning
- and decision making of your health.



My support person is



I want my support person to

- ☐ be with me during the appointment
- ☐ wait outside during the appointment
- ☐ explain things so I can make a decision
- ☐ make the decision for me.



Getting a genetic test



To get a genetic test I need to do

- a mouth swab
- or
- a blood test.

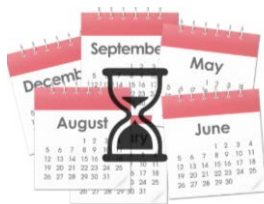


The test

- does not hurt
- it is quick.



I will get the result later.



It can take a long time for the results to be ready.



My doctor or a genetic counsellor

- will explain the results.



About me



My name is _____

I am _____ years old.



The reason why

- I have this appointment today is



A genetic test might help me

- find out more about health conditions.



A genetic test might help me find out more
about this health condition:



I have some questions about getting a genetic test.

Some of my questions about genetic testing are:



- ☐ what is a genetic test?
- ☐ how much will it cost?
- ☐ what does a genetic test look for?
- ☐ will it change my health care?



My other questions are:



I want a genetic test

Here I can write down



- why **I want** a genetic test.



The reasons why I want a genetic test are:

- ☐ I want to find out more
 - about my health condition.
- ☐ It might help to get the right treatment.
- ☐ I want to know the chance my children will have this condition.



My other reasons are:



I do not want a genetic test



Here I can write down

- why **I do not want** a genetic test.



The reasons that are important for me are:

- ☐ It would not change my health condition.
- ☐ I do not want to find out about
 - a health condition I might have later.
- ☐ I do not want to get the test.



My other reasons are:



I need more information to make a choice



Here I can write down

- what I need to make a choice.



Things that would help me make a choice are:

- ☐ More information to help me understand.
- ☐ A chance to ask more questions.
- ☐ Talking to
 - ☐ my support person
 - ☐ my specialist
- ☐ More time to think about it.



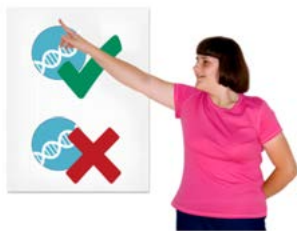
Other things that would help me are:



My choice is



Getting a genetic test is my choice.



I can also decide

- how I want to make a choice.



I want to make a choice about genetic testing

- ☐ by myself
- ☐ with support.

If I choose with support I want:



- ☐ my doctor
- ☐ my family
- ☐ my friend
- ☐ my specialist
- ☐ my carer
- ☐ someone else.



I have made a choice about genetic testing:

- ☐ Yes, I want a genetic test
- ☐ No, I do not want a genetic test
- ☐ I am not sure right now
- ☐ I might get a genetic test later.



If I choose to get a genetic test, I prefer

- ☐ A mouth swab
- ☐ A blood test
- ☐ Either of them.



I would like to get my results

- ☐ In person
- ☐ By video call
- ☐ By telephone.



When I get the result, I want to be

- ☐ By myself
- ☐ With this person:



I will need to wait for my test result.

My test result will be back in

While I am waiting, if I have questions



- I can call _____
- or
- Email



We will meet again in _____

If I need an earlier appointment I can



If I am worried while I wait, I can:

- ☐ Speak to my doctor
- ☐ Make another appointment
- ☐ Talk to someone I trust
- ☐ Talk to a counsellor.



Other things that can help me if I am worried:



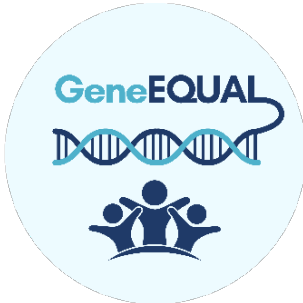
Notes



You can use this page to write things down.



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 **NSW Health** to write this booklet.

Proudly funded by



NSW Health is the part of the
NSW Government that looks after our health.



More information



The **GeneEQUAL** team made other booklets



About genetic health care.



Genes and genetic conditions.



Making a genetic appointment.



Get ready to go to the genetic clinic.



Tips about genetic health care.



Millie's genetic health care journey:
Before a genetic test.



Millie's genetic health care journey:
Getting a genetic test.



Making a choice about a genetic test.



To get our booklets you can

- go to our website www.geneequal.com



- email the GeneEQUAL team on geneequal@unsw.edu.au



- send us a letter with your address to

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NSW 2052, Australia.



You can go to our website for more information

- go to www.geneequal.com



- scan this QR code with your phone



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



To look at them go to

www.cid.org.au/resource-tag/easy-read



- scan this QR code with your phone.