

Making Informed Choices About Using DNA

A Resource for People with Experience of Adoption and/or Out-of-Home Care

This resource will help you understand what to expect from DNA testing, consider some of the issues and risks, know your options, and get you to think about whether you want to access support services that might be helpful to you.

ACKNOWLEDGEMENTS

This Resource is an outcome of the research project, “The use and impacts of direct-to-consumer genetic testing and data platforms for family tracing after adoption or out of home care: A Victorian pilot study” (2023-2024).

The project was funded by the Melbourne Social Equity Institute at the University of Melbourne.

You can read more about the project at go.unimelb.edu.au/5rq8

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Thank you to everyone who participated in the workshops and survey which led to the development of this resource.



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OPEN PLACE
Support Service for Forgotten Australians

THE PURPOSE OF THIS RESOURCE

This resource can help you make an informed decision about whether you want to do DNA testing in your search for family information as well as what to consider if you have been found through this technology. You might also see DNA testing called ‘direct-to-consumer genetic testing’ (DTC-GT) and ‘genetic genealogy’ but we’re just going to call it DNA testing (they all mean the same thing).

DNA testing is very popular in family history research, but the DNA companies can present a lop-sided picture of the ease and benefits. If you have an experience of adoption or out-of-home care (OOHC), searching for family information is much more than a hobby or a pastime. You might not have any alternative sources of information available, and so DNA testing may be your only option.

DNA testing can be a powerful tool for people with an adoption or OOHC experience, who search, who are found and who are considering using this technology, so it is important to understand the risks and limitations. It is almost impossible to predict what will come out of your DNA testing - whether the outcome is positive or negative, it can be a very emotional experience. It can have unexpected outcomes and impacts. Coming to terms with new knowledge about your family members or cultural background can be challenging.

We have talked with people from the adoption and OOHC communities to find out what they think about DNA testing to learn more about their experiences, good, bad or bittersweet. We share some of their contributions in this resource.

This resource will help you understand what to expect from DNA testing, consider some of the issues and risks, know your options, and decide whether you want to access support services that might be helpful to you.

This resource provides information about the resources available to people from the adoption or OOHC communities if they need help to do DNA testing or need support at any point during the process.

Four stories

The stories have been created to illustrate some of the issues that can arise when you are thinking about using DNA or when you have been found by others who have used DNA testing. **All scenarios and people presented are composites.** Alongside each story, we have also included quotes about experiences from those with an adoption or OOHC experience who have used DNA and completed the project survey (this has been with participant permission). Each story is then followed by information that might help on your DNA journey.

JASON

MY STORY

I spent a fair few years of my childhood in children's homes because my mother wasn't coping. My father was off the scene by the time I turned one, I never knew him. Mum tried to keep me with her, but it was hard for her to pay the rent - we lived in a country town in rural Victoria and didn't have any family or people who could help look after me when Mum was working.

She put me in a babies' home when I was about one and a half. I remember her coming to visit me sometimes when they let parents come on Sundays. When I turned 4, I went to an orphanage and stayed there until I was 15 and went out to work on farms around Victoria. Me and Mum kept in touch after that, but it was difficult. Then she died when she was only 49.

Later on, I had my own son, and I got more curious about my family and who my father was, but it was hard to find anything out. I knew his name because Mum had told me, but I had no idea how to find him. Then in the late 1990s I found out that I could ask for my state ward file, so I did that - it had my Dad's name, but I still had no idea how to find him. I asked people in the town and eventually found out that he had died. Someone told me that Dad had another family, he took off on them too.

So now I'm in my 60s and hoping I'll be a grandfather soon. I want to know about my parents and my family so I can pass that information on. Also, I wonder if I have half-siblings somewhere.

I've seen the ads about DNA testing, and I've seen stories on the TV about people finding their family. But I'm still not sure about it - what about my privacy? And who knows what they'll do with my DNA down the track - will I be part of an experiment, or will they use it to catch a criminal?

WHAT PEOPLE SAID

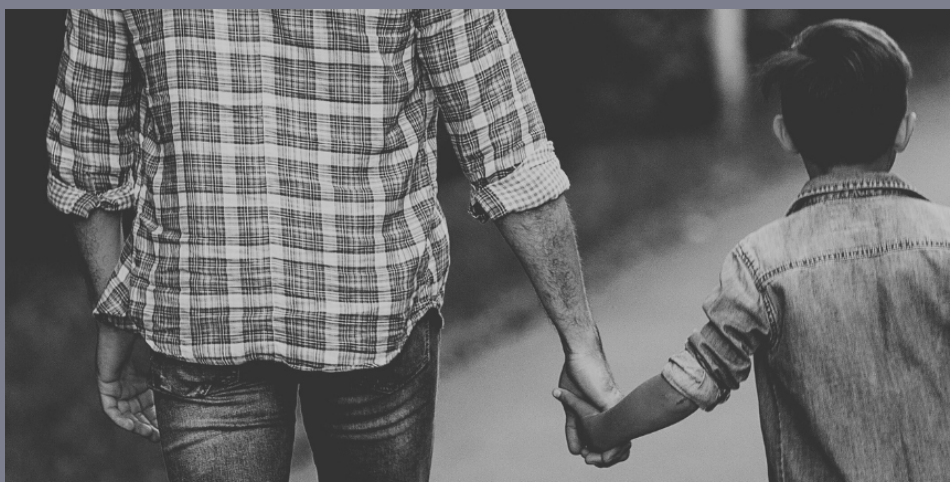
I'm curious about potential half-siblings.

My records were totally inadequate and raised more questions than they answered.

I'm thinking of doing a DNA test as I've hit a dead-end searching for my father.

I didn't find any members of immediate family which was very disappointing, only 2nd and 3rd cousins. Did find ethnic information which was interesting.

What do companies do with your DNA?



BEFORE YOU DO A DNA TEST

People with an adoption and/or OOHC experience have lots of reasons for wanting to do a test including:

- Wondering about family history
- Finding specific family members
- Verifying information from official files
- Filling information gaps from records
- Discovering family for health information purposes
- Searching for cultural identity
- Dissatisfaction with access to records including the waiting time
- Being empowered to find information without involving government departments or past providers

People also have lots of valid concerns about DNA testing including about:

- The unknown and unexpected outcomes for the person and their family members
- The cost of testing and DNA database membership, upfront and over time
- The privacy of personal information
- The ownership, security, storage and future use of DNA samples and data
- Not finding what they are looking for
- DNA companies' terms and conditions
- Whether test results will affect the ability to obtain life insurance
- The possibility of being contacted by unknown people

Only you can make the decision about DNA testing. But it can be helpful to:

- Get as much information as you can – “preparation is key” (VANISH Voice, Autumn 2019, p.6)
- Think about the possible outcomes and how you might respond to them
- Know about steps you can take to protect your privacy
- Know about the support services available

MELISSA

MY STORY

I always knew I was adopted. I grew up with a supportive and close adoptive family, but wanted to know more about where I came from. Even though I knew I could search for my birth parents and get my files, I held off because I was worried about how it might affect my adoptive parents. It wasn't until my adoptive mother passed away that I went to the Adoption Information Service.

I went through the process and finally got my records. I found out the name of my birth mother, but there was no information at all about my father in the file, and not even a name on my birth certificate.

VANISH helped me to search for my mother and we reunited in 2021 after some emails and phone calls. She lives interstate so it all took a bit longer, maybe that was a good thing ... I have a good relationship with her now, but she finds it difficult to talk about the past and my adoption.

She said she doesn't know who my father is, so I felt like using DNA was my only option. I didn't really have any concerns about doing the test and people having my DNA – everything's online already now. I did worry a bit about what matches might turn up – I'm used to not having a large family, what if I suddenly had to deal with cousins and aunties and uncles everywhere?

I did a test through Ancestry and my results came back really quickly – much quicker than getting my files. And, amazingly, I found out who my father was pretty much straight away.

It said that my father had a daughter and a son, so they are my half-siblings. I emailed them through Ancestry's messaging system, and they got back to me pretty quickly.

At first, they didn't believe me – my father had been happily married for two years at the time I was born! But DNA doesn't lie. Then they just blocked me out of the blue and I haven't heard from them since. I'd love to get a photo of my father and know about any health issues on that side of the family.

Since all that happened, I've been dealing with a whole range of emotions – anger, rejection, grief. I didn't realise how upset I'd be after getting my DNA results. I thought I had dealt with a lot of stuff already when I reunited with my mother, but this was a whole new Pandora's box. My partner told me that he was really worried about me, he'd never seen me this bad before.

I ended up contacting VANISH again, and they said I could get counselling through their Counselling Brokerage Program. I'm going to see them next week.

WHAT PEOPLE SAID

I found people I looked like, sounded like.

After a quite enthusiastic connection period, about a year, the enthusiasm has waned as we found that, apart from kinship, we didn't have a lot in common. The gap in relationships has been too long, I think.

With being adopted I have strong abandonment issues so it can be difficult when matching family do not acknowledge you, but I have had help from psychologists and my supportive husband and children.

For me it gave me the factual answers, but it doesn't help or have you ready for the emotions I went through.

Because I have no information and I was born in Vietnam but adopted via the Victorian adoption process, DNA is my best option.

GETTING YOUR RESULTS

Managing expectations is one of the biggest things when using DNA testing.

For some people, DNA provides answers, information, and connections that they've wanted for a long time. It can be immensely satisfying to have uncertainties resolved or stories confirmed, or to discover new information about your cultural background. For others it can be a disappointing experience.

Some connections have provided key medical information enabling people to identify problems and participate in early intervention strategies to manage health conditions. It is important to note that health information returned through this type of DNA testing will need to be discussed with your GP in the first instance to seek further guidance.

Whatever the outcome, the emotional impact of DNA testing can be significant. Many people experience difficult emotions even when they have found what they were looking for. It can be a time of soul searching and adjustment to their sense of identity and place in the world.

When you use DNA testing to search for people, it also opens up the possibility of other people finding you and getting in touch unexpectedly.

Adding your DNA information to genealogical websites can lead to unanticipated outcomes for other people too.

“For me it is reassuring to know where I came from ... especially when having only one son who I could not even tell ... where his maternal gene pool originally came from.”

“I have had an ongoing email relationship with my aunt and cousin ... they have been warm and welcoming.”

“My immediate family have been very supportive and interested in my discoveries.”

ANDREW

MY STORY

I am 53 years old and 5 years ago I was given a DNA test as a present, so I did it because I was curious about my ethnic identity. The results had absolutely no surprises for me, I was basically 40% Irish and 60% Greek heritage.

Then one day when I was out to lunch, I got an email saying that there was DNA news about someone who might be my brother. At first, I disregarded it because I was always getting junk emails from 23 and Me about there being new information. But this email had very specific information about my paternal family. Then I got an email from my cousin who said he had seen a result on the DNA website, and he wanted to know if I had also seen it.

This was an enormous shock as I had not known that my father had another child. I always thought I was the only one. It shook me up and took me time to comprehend and understand.

The next week I had an email from my half-brother, and we arranged a phone call. I got to hear his story. He had been adopted as a baby and had spent much of his adult life searching for his dad as there was no information in his adoption records. It's sad that he never got to meet him as he passed away over a decade ago.

I sought counselling to help me process this news. Our biological relationship was confirmed through a further clinical DNA test, as I wasn't sure about the first DNA result. It took my brother and I some time to test each other's feelings and see how we felt about this new relationship, and we have now been able to establish a strong bond.

WHAT PEOPLE SAID

My aunt reached out to me via the Ancestry DNA platform ... confused as to who I was. Because she reached out to me in the first instance, I felt that it was ok to reveal who I was.

I contacted a nephew, and I was then contacted by my sister.

I worry that my DNA may get another family member into trouble ...

My main concern for people who get a completely unexpected DNA test result is that they have ready access to expert support for the duration that they need it, to help them navigate and deal with the inevitable disruption to their lives.



IF YOU ARE FOUND BY SOMEONE WHO HAS USED A DNA TEST

Some people are contacted unexpectedly by relatives who they may or may not know about. This can happen when a relative uses DNA for fun, curiosity or family history and suddenly finds an unexpected connection to someone who has an adoption and/or OOHC experience. Others may be contacted by a relative who has been contacted by another person who used DNA.

Being contacted out of the blue can be a surprise and a shock, and it is not unusual to feel unsure if the connection is correct. There can be awkwardness about previously hidden information; a feeling of the world being turned upside down; and concern about what the information or connection might mean in the long term. Some people can feel the connection explains the puzzling behaviour of a family member, provides positive connections to family or is a legacy for their children.

Those who are contacted in this way have to decide what they should do next. Some respond quickly; others might speak to friends or family; or consult records to look for links and take time to craft their response. Others then use the DNA platforms to look for familiar family links that might confirm a connection. Some may respond initially and then feel they can't continue the connection, and others may not respond at all. Some people seek counselling support. These decisions can be hard and may take time. Only you can decide on your next steps.

CONFUSING TERMS AND CONDITIONS

DNA companies' terms of service are complex, long, legalistic and sometimes unclear. When you tick a box to indicate your acceptance of 'terms of service', 'terms and conditions', or 'privacy policies', you are entering into a legal contract.

The ownership of DNA samples and data remains a problematic topic in Australian law.

Even though many people use DNA testing to find family after adoption or OOHC, the DNA companies almost never consider the needs of these people specifically. The same terms and conditions apply to people whether they are testing for 'fun' or searching for a parent.

Many companies say that people might receive unexpected results and unanticipated contact from relatives. They note that this might be distressing. However, they take no responsibility for these consequences and do not help people access support.

Some companies offer opt-in or opt-out choices about matters like DNA sample storage, and future use of samples and data by researchers or law enforcement agencies.

Some people may also be concerned that insurance companies can ask for the disclosure of health-related genetic test results, to refuse or increase the cost of life insurance. Take heart! In September 2024 the Australian government announced it will introduce a bill to ban insurance companies from discriminating based on *adverse predictive genetic test* results.

BETTINA

MY STORY

I was 14 when I realised I was going to have a baby. The last three months of my pregnancy were spent in a home for single mothers, and I was told that my daughter had to be given up for adoption. I had no choice. I was made to feel ashamed.

My baby was born in a large hospital, and I then went back home to live with my Mum. My experiences and the baby were never discussed. It was all a secret. I later found out my daughter had been in care for a year and a half before she was placed for adoption. I felt grief stricken.

In my early 20s I left Victoria as I had to get away from the place where everything had happened to me. I later married and had four more children. I'm now in my 70's and a widow. Since my teens I have suffered periods of anxiety and depression, and it has affected my health and how I raised my other children.

I have thought about my first daughter every day. I did look for her but without success. A few years ago, my husband paid for me to do a DNA test and I had hoped my daughter, and I might find each other, and we did.

Our relationship continues and has been both positive and negative. It has been wonderful to be reunited, like a honeymoon. But there are also deep regrets. We are both committed to making it work, however.

WHAT PEOPLE SAID

It has been a complicated experience.

I would have liked to have a better understanding of what I was looking at (DNA results).

It can be costly to remain a member (of a DNA company).

DNA has opened so many doors and has also been the source of many surprises but, as long as the parties involved agree ... I don't see a problem.



TIPS TO PROTECT YOUR PRIVACY

Some companies offer stronger privacy protections than others. Some say they won't ever sell your data. But you might need to weigh up the risks and benefits of different platforms – including cost, the size of the 'family tree' database and privacy protections.

Most companies allow you to set preferences to restrict your visibility and the possibility of others contacting you.

If you are concerned about privacy, consider using an email address or username that doesn't reveal your real name, or using an alias for your account. Take time to look for and adjust privacy settings that might be available once you set up your account. Think twice before uploading things like photos or the details of your social media accounts.

You can also use a web browser that helps to protect your privacy by default, such as Brave, Firefox, Librewolf or DuckDuckGo.

YOU DON'T HAVE TO GO IT ALONE

The International Society of Genetic Genealogy, "highly recommends that adoptees, orphans, donor conceived individuals and others with sensitive matters work with experienced search organisations prior to making contact with biological families".

(https://isogg.org/wiki/DNA_testing_for_adoptees)

There are organisations that can help people with an adoption and/or OOHC experience through the process of DNA testing to find family. These support services can talk to you about your concerns and provide advice. Their staff may have experience in interpreting the results of DNA tests and making contact with matches. Some organisations provide funding or subsidies to help cover the cost of DNA testing.

Some people have also found support from private search providers.

You can find a list of organisations and their contact details on the last page.

Even if you decide to do it by yourself, you have the option of seeking support later if you need it.

SUPPORTS

This page has contact details of organisations that can offer information and support. Our community partners can help you with support using DNA to search for family:

ARMS (Victoria)

Ph: 0400 701 621

Email: arms@armsvic.org.au
armsvic.org.au

Open Place

Ph: 1800 779 379

Email: info@openplace.org.au
openplace.org.au

VANISH

Ph: 1300 826 474

Email: info@vanish.org.au
vanish.org.au

Find & Connect

Many organisations that arranged adoptions and ran children's institutions have their own heritage and information services that can help you with DNA testing. Contact details for the relevant organisations are on the Find & Connect website: findandconnect.gov.au

Department of Social Services

The DSS website has contact details of other organisations for people affected by past forced adoption policies and practices:
dss.gov.au/forced-adoption

CLAN (Care Leavers Australasia Network)

CLAN offers support to people who have grown up in orphanages, children's homes, missions, foster care and other child welfare institutions in Australia and New Zealand. They also support close family members of Care Leavers:

Ph: 1800 008 774

Email: support@clan.org.au
clan.org.au

Other Supports for Searching

There are also people with knowledge and experience about DNA and searching, either paid (professional genetic genealogists) or unpaid (sometimes known as 'Search Angels') who help people with testing and interpreting the results. There are a number of Facebook groups and websites where you can find out more.