

# Why, when and how to tell children about donor conception

A review of the literature



This document presents what the research literature tells us about disclosure patterns around the world, the reasons for telling children about the way they were conceived, the best age to tell, and strategies and practical tips for having this conversation with donor-conceived children.

## Parents disclosing donor conception

Assisted Reproductive Technology (ART) treatment can help couples who experience fertility difficulties have a family. It can also be a path to parenthood for single people and same-sex couples. In 2011, almost 4% of births in Australia were a result of ART [1].

Approximately 5% of ART procedures in Australia involve the use of donor sperm, eggs or embryos. The use of donor sperm to conceive has a long history, dating at least as far back as the 1800s [2]. Using donor eggs and embryos in ART has been possible since the early 1980s [3].

Historically, and mirroring adoption practices, secrecy surrounded the use of donor gametes; children born as a result were not informed about the way they were conceived, and donor anonymity was expected [4]. The 1980s saw a shift in attitudes towards more openness in the field of adoption as the view that adopted children have a right to know their biological origins began to gain acceptance [5].

Subsequently, the idea that donor-conceived people should be told about the way they were conceived and have access to information about the gamete donor was increasingly supported and counselling practice moved from advocating secrecy to promoting openness [6].

This shift has resulted in an increasing number of parents telling or intending to tell their children of their donor-conception [7-9]. However, for a range of reasons, some parents find it difficult to disclose the use of a donor to conceive to their children and wish they had more professional support and guidance, strategies, and tools for sharing this information with them [10-12].

Here we present what the research literature tells us about disclosure patterns around the world, the reasons for telling children about the way they were conceived, the best age to tell, and strategies and practical tips for having this conversation with donor-conceived children.

### Disclosure patterns around the world

A number of jurisdictions around the world, have introduced laws to enable donor-conceived people to find out the identity of their donor [13] and this increases the likelihood of parents telling their children about their donor origins [9, 14, 15].

#### Australia and New Zealand

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In Australia and New Zealand anonymous gamete donation is banned [13]. The Australian National Health and Medical Research Council (NHMRC) guidelines state that donor-conceived people have a right to access identifying information about their donor and fertility clinics are required to maintain records of all parties involved in donor procedures [16].

To date however, only three Australian states (Victoria, New South Wales and Western Australia) have established central state-administered registers with identifying information about donors,

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recipients, and children born as a result of donor procedures to allow the parties to seek information about each other.

In 1988 Victoria was the first Australian state, and indeed the first jurisdiction in the world, to establish a Central Register where information about ART procedures, including identifying information about all parties involved in donor conception is recorded [17]. In 2001, a Voluntary Register for information exchange between people who were involved in donor conception before donor anonymity was removed became operational. In New South Wales, a Central Register which holds information relating to donors and donor-conceived persons was established in 2010. A Central Register was introduced in Western Australia in 1993 and a Voluntary Register is also operating there [13]. In South Australia, a law was passed in 2010 outlining information to be included in a Central Register. This register is yet to be established. Across Australia, fertility clinics are bound by NHMRC guidelines to record information about donors, recipients and children born as a result of gamete donation. [16].

In 2010 a law was passed in Victoria requiring that donor-conceived people born after 1 January 2010 who apply for a copy of their birth certificate as an adult receive an addendum, which states that additional information about their birth is available. This is intended to be an added incentive for parents to inform their donor-conceived children about their donor origins. There is no evidence yet whether this has resulted in more parents telling their children of their donor origins.

The increasing acceptance of the use of donor gametes to conceive among the Australian community suggests that barriers for disclosure are diminishing [18]. In Victoria, the Victorian Assisted Reproductive Treatment Authority (VARTA), a statutory authority, runs public awareness campaigns such as the three year 'Time to Tell' campaign and annual public seminars where donors, parents and donor-conceived people share their experience of disclosure; offer resources about disclosing donor conception to children in print and electronically. The VARTA website also promotes openness and provides strategies for achieving this [18, 19].

### Europe

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Some European countries, including Sweden, Austria, Switzerland, the Netherlands, Norway, the United Kingdom (UK) and Finland, have also banned anonymous gamete donation. Sweden was the first country in the world to abolish anonymous sperm donation in 1985 [13]. Since then, the proportion of Swedish parents who tell or intend to tell their children of their donor origins has increased [15]. Swedish law also allows donor-conceived people born after 1 March 1985 access to identifying information about their donor when they reach the age of 18 [13].

Studies from Finland where donor anonymity was banned in 2007 suggest that those who use donor oocytes are more likely than those who use donor sperm to disclose this to their children [9, 19].

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In the UK donor anonymity was removed in 2005 [20]. Parents in the UK appear to have become more open with their children in recent years; the proportion of donor-conceived persons aged from seven years to adulthood who know about their conception is now about 50% [7, 14, 21].

In some other European countries, for example Spain, France and Belgium anonymous gamete donation is mandated and donor-conceived people have no legal right to information about their donor. While this means that donor-conceived children are unable to find information about their genetic origin, it appears that parents increasingly disclose to their children that they are donor-conceived and share with them what non-identifying information they have about the donor [22, 23].

### USA & Canada

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In the USA, about 12% of ART cycles involve donor eggs or embryos [24]. An unknown number of donor insemination cycles are also performed. In 2004, the American Society for Reproductive Medicine (ASRM) formally stated its support for parental disclosure of donor conception [25]. While most prospective parents use anonymous donors, some clinics also offer what are referred to as 'identity release' or 'open ID' donors who allow children born as a result of their donation access to identifying about them when they reach adulthood.

Since most donors in the USA are anonymous and information about them often is not kept by the clinic, donor-conceived people are unlikely to be able to trace their origins through fertility clinic records [26].

Existing voluntary, non-government registers, such as the Donor-Sibling Registry allow donors, parents and donor-conceived persons to register their information and search for and be connected with others who may be genetically related to them. In 2013 approximately 42 000 donor-conceived people, parents and donors from around the world had joined the Donor-Sibling Registry [27].

In Canada, although the number of clinics using identifiable donors is increasing, anonymous sperm donation is still permitted. In 2004, the Assisted Human Reproduction Act (AHRA) was introduced, outlawing the release of donors' identity without their consent. The AHRA also mandates that non-identifying information about the donor, such as family medical history and physical characteristics, be made available to parents and donor-conceived persons [28].

### Why tell?

Parents' decision to disclose, or not, their donor origins to their children is influenced by a range of intrapersonal, interpersonal, social and family life cycle factors [29, 30]. Parents, who tell their children about the way they were conceived, may do this because they feel that their child has the right to know and they want to maintain an open and honest relationship with them [9, 31].

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Other reasons parents give for telling their children they are donor-conceived are the importance of family medical history and genetic information in the prevention and management of health problems [28, 32-34] and to prevent them from finding this out from someone else [7, 9, 28, 31-37].

Accidental discovery is a real possibility, as most people using fertility treatment tell someone other than their child about this. Some donor-conceived people report being told by someone outside the family that they were donor-conceived; finding out after asking their parents a direct question or during an argument with them; or having worked it out for themselves [9, 28, 33-39]. Finding out about their conception in these ways can make donor-conceived people feel betrayed and let down by their parents [33].

Some parents fear that knowing about the donor will create emotional distance between them and their child; that it may be distressing for the child to be told that they were donor-conceived; or that the child might reject their non-biological parent if they find out [12, 36, 37]. However, research shows that keeping something like a child's donor origins a secret, either by leaving out information or changing the topic when questions are asked, can create a barrier between those in the family who know the truth and those who do not. This may result in less trust and increased emotional distance between family members [33, 40]. Also, secrets may be harder to keep as the child enters adolescence and is more likely to discover the truth for themselves [8, 33].

Despite parents' fears, donor-conceived persons report feeling more positively towards their parents, especially the non-biological parent, as a result of finding out about their conception [37]. Furthermore, studies of donor-conceived children aged from four to twelve years show that they are similar to their non-donor conceived peers in terms of their psychological adjustment and relationship with their parents [41, 42].

Commonly, parents avoid telling their child about their conception because they worry that they will feel different and want to protect them from social stigma [12, 31, 43]. However there is evidence of growing community acceptance of ART, including with the use of donor gametes, as single parent and same-sex families become more common [9, 44]. In Australia, public approval of the use of ART by heterosexual couples, single parents and lesbian couples has increased significantly over the last three decades [18].

Some donor-conceived people want to find out more about their donor when they learn about their conception and others do not. In contrast to worries of many parents, when donor-conceived persons search for information about their donor, they are not searching for a replacement parent but for a missing part of themselves [45, 46]. Often this reflects a desire for information about inherited physical characteristics or personality traits, and their family medical history [37, 46].

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Single mothers and lesbian couples are more likely than parents in heterosexual couples to tell their child they were conceived using donor gametes and more willing to find out information about and meet their child's donor [45, 47]. This may in part be explained by the need to explain where the child came from in the absence of a male parent [43, 48].

### When to tell?

Parents may wish to tell their child about their conception but be unsure about the most appropriate age to do so [31]. There appears to be two main approaches parents take when beginning to tell their child they were donor-conceived. Some tell their child at a very young age, to ensure the information becomes part of the child's life story [12, 32]. This approach also gives parents the opportunity to practise and gain confidence in telling the story of their child's conception. Parents who take this approach usually begin to tell their children when they are three to four years old or even younger [12].

Other parents think the best time to tell their children of their donor origins is when they commence sex education at school [12]. This is based on the belief that telling children before they are old enough to understand could confuse them and that the right time is when the child is about ten to twelve years old. In practice however, these parents often start the conversation with their children a lot earlier [7, 12]. Sometimes parents begin the process of disclosure in response to questions from their child like 'where do babies come from?' [12].

After the initial conversation with their children, most parents realise that telling their child about their conception requires an ongoing dialogue [12]. While parents may fear that telling a young child about their conception, young children can grasp simplified concepts and be given more complex information as they grow older and it becomes increasingly important to their psychological wellbeing to know about how they were conceived [31].

Regardless of which approach parents take to telling, donor-conceived people who are told before they reach puberty do not appear to be negatively affected. Most report being curious to know more about their donor, but not feeling differently about their parents [36].

There is a paucity of research into the experience of finding out about being donor-conceived as a teenager and findings from the few existing studies of those who find out about their donor origins in adolescence or adulthood are inconsistent. While they may feel sympathetic towards their mother and appreciate her honesty, they may also react negatively to the discovery that their parents have withheld information from them about their biological origins [8, 36]. When asked for their views about the information needs of donor-conceived people their age, secondary school students emphasised the importance of openness and honesty when disclosing donor conception to teenagers [49].

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### How to tell?

There is no right or wrong way to talk to children about their donor origins but it may be helpful to consider some of the strategies suggested by experts in the field. In addition to making sure that the tone of the story is positive, framing it around 'how we built our family' rather than 'how you were conceived' may help to reinforce the donor-conceived person's place in the family [50]. A narrative of donor conception based on the idea of 'family building' or 'love makes a family' can also be useful for different types of families, such as heterosexual couples, single mothers or lesbian and gay couples [12].

Practicing by telling children about how they came to be from when they are too young to understand can help parents become comfortable with telling the story when the child is older [51]. In the last ten years numerous story books to help parents tell children of different ages about their donor-conception have been published. Story books can also help parents develop their own story to tell their child [7]. The use of simple and age appropriate language is important to reduce confusion and help the child comprehend the story of how they were conceived [7, 12, 49]. The 'seed planting' or 'drip feeding' approach of telling a child about its conception emphasises the importance of beginning with a simple story and adding more detail as the child matures and can understand more [12, 50].

From the age of about seven, children can understand more complicated details about bodies and reproduction. From that age parents can use a 'spare parts' narrative to explain donor conception, where one parent had a 'missing' or 'broken' part of their body which needed to be replaced to have a baby [12, 52]. For single, lesbian and gay parents using the 'families are different' approach, may be helpful [50]

The information needs of adolescent and adult donor-conceived people are different from those of younger people. When telling teenagers and adults more technical information about reproduction can be included than when telling children, providing the donor-conceived person with the 'nuts and bolts' of donor-conception [12]. Donor-conceived adults are likely to want to know more about the motivations and decision making processes behind the use of donor gametes. Feedback from donor-conceived people who found out in adulthood emphasises the importance of full disclosure in conversations about their conception, including how parents made the decision to use donor gametes [8].

In addition to knowing that a donor was involved in their conception, donor-conceived adults emphasise the importance of having information about the donor in the management of their physical and mental health as well as the development of their identity [28, 32-34, 45, 46].

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Access to identifying information about the donor is generally not available to those who were born before donor anonymity was banned or in jurisdiction where donor anonymity is mandated. However, increasingly the right of donor-conceived people to know where they come from is recognised. Worldwide voluntary and government instigated initiatives are implemented to facilitate access to information about the donor. At the forefront of these efforts is the state of Victoria where the rights of children to be able to access information about the donor is enshrined in law and a statutory authority registers ART providers and monitors adherence to the law; provides public education and a range of resources to support parents telling their children about their donor conception; and offers specialist counselling services to help in the sometimes delicate process of linking donors and their donor-conceived offspring.

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